THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME FOR ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA

By

RIRHANDZU AUSTICE MABASA

THESIS

Submitted in fulfilment of the requirements for the degree of
DOCTOR OF PHILOSOPHY
In
PUBLIC HEALTH

In the
FACULTY OF HEALTH SCIENCES
(School of Health Care Sciences)
At the

UNIVERSITY OF LIMPOPO

SUPERVISOR: Prof L Skaal
CO-SUPERVISORS: Prof T Mothiba
Prof S. F Matlala

DECLARATION

I **Rirhandzu Austice Mabasa** declare that this thesis **THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME FOR ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA** submitted to the University of Limpopo for the degree of Doctor of Philosophy in Public Health is my own work, has never been submitted by me for any degree at this or any other institution, and all the materials used in the thesis have been acknowledged both in the text (thesis) and reference list.

29/07/2022

Mabasa RA Date

DEDICATION

This work is dedicated to my parents, Mrs Maxawu Grace Bilankulu (Khosa) and Mr Mbazima Daniel Khosa. Most of all, this work is dedicated to my children Utshembhekile, Ndzhaka and Lonene Mabasa, and all adolescents and children who are living with HIV infection in the Vhembe District.

ACKNOWLEDGEMENTS

- All the praise and honour I give to Jehovah who is the Almighty God, for the life, power and zeal to do all this work. All glory to Him.
- My supervisor Prof L. Skaal, for your unmeasurable dedication and support. I always thank God for having you as my supervisor. Your sense of humour and simplicity made this journey manageable.
- My supervisor Prof T. Mothiba. I would not have made it without your support and encouragement. The sleepless nights you spent cannot go unnoticed.
- Prof SF Matlala, your contribution is highly appreciated.
- My beautiful children, Utshembhekile, Ndzhaka and Lonene, for enduring all the time that I was not available for them when they needed me.
- My husband, Mabasa Christopher, for your timeless encouragement and support.
- My two handsome brothers and pastors, Pastor Khosa V.M and Buti Themba for the emotional and spiritual support. You were always there when I need you.
- My mom, Grace Bilankulu, for all the times you had to take care of my kids when I was away, and the much-needed support.
- Adolescents living with vertical HIV infection in Vhembe District, for your simplicity and cooperation.
- Research Assistants Hlekani Evey and Patricia. Your work is appreciated.
- All the operational managers of the health facilities of Vhembe District, for allowing me in your facilities.
- The Limpopo Department of Health, for granting me the permission to conduct this study.
- The University of Limpopo, Turfloop Research Ethics Committee, for the ethical clearance.
- The Vhembe District Department of Health, for granting me permission to access their health facilities and speak to patients.
- Facility staff members in the Vhembe District health facilities, for your friendly welcome and welcome.
- Sister Pashy from Mhinga Clinic, much appreciation for the dedication and support.
- My friend Dr Tracy Masebe, for being my undocumented supervisor and computer mogul.
- My friend Vidah Thangwane, for all the support and encouragement.
- My brother, Buti Bomba, this project would not have materialised without you. Your availability and willingness to assist made this work possible.

- My helper, Mhani Magreth Ndlovu, for taking care of my kids and the house when I was not there.
- My extended children Vongani, Hlawulani, Rendzo and Shelter, for all your support.

ABSTRACT

There has a significant rise in the number of HIV-infected adolescents who were missed as children and are diagnosed with perinatally acquired HIV as teenagers. In 2013, perinatally acquired HIV was estimated at around 10 000 infections globally, a figure which ballooned to 38 000 by 2017. Adolescents living with perinatal HIV experience emotional upheaval as a result of their positive HIV diagnosis, which is exacerbated by real or perceived negative effects on their relationships, career, and family aspirations. They face the same challenges as other adolescents, along with the added complexity of personal decisions relating to their sexual conduct having a direct impact on the global cause to eradicate HIV/AIDS. An extensive body of literature indicates a need for emotional and psychosocial support as existing management focuses mainly on the physical aspects of infection and treatment.

Aim of the study

The aim of the study was to explore the challenges faced by adolescents living with perinatal HIV infection and to evaluate the designed user-friendly support programme in response to formative findings of the research in selected clinics and community health centres in the Vhembe District of the Limpopo Province in South Africa.

Methodology

A mixed-methods sequential exploratory design was employed to fulfil the purpose of the study. Data was collected in two phases. In qualitative phase- a total of 21 participants were interviewed using a semi-structured interview guide. The sample was purposefully selected from adolescents living with HIV/AIDS. In quantitative phase a total of 213 people participated in data collection using a questionnaire. Thematic approach was used to analyse qualitative data using Tesch’s eight steps of qualitative data analysis. Quantitative data was analysed using SPSS version 25. Descriptive statistics was used to explain and summarize data. Fischer’s test was done to establish significance of association between alcohol used, condom use and between age and gender.

The results

The results revealed that adolescents with perinatally acquired HIV face more challenges. They had psychosocial, emotional and economic challenges more than their peers. The current HIV/AIDS management and care has not yet recognised the specific needs these adolescents have related to their care. They have been incorporated into the general adulthood HIV/AIDS making their transition from childhood adolescence difficult. Suggestions for a mentor, and ARV modification were made and a need for a support programme emerged as one of the major themes.

***Keywords**: Adolescents, perinatal, support, programme, Human-immuno-deficiency Viru*

Table of contents

Contents

List of tables

List of figures

List of appendices

Definition of concepts

Adolescence

The World Health Organisation (WHO) defines adolescence as the stage between the ages of 10 and 19 years (WHO, 2012). Adolescence is defined by behaviours such as the search for one's identity, group behaviour, the need to intellectualise and fantasise, religious crises, temporal displacement, sexual development, assertive social attitudes, successive contradictions, and progressive detachment from parents. As a result of the above-mentioned factors, adolescents engage in self-destructive behaviours such as alcohol consumption and unprotected sexual activities. They should be encouraged by caregivers to maintain appropriate self-care activities such as the use of condoms, the adoption of harm reduction measures, and proper use of medications (Cruz & Cardoso, 2015).

The United Nations Convention on the Rights of the Child defines adolescents as persons under the age of 18 years (WHO, 2014). In the HIV/AIDS context, WHO classifies people between the ages of 10 and 19 years born with HIV as adolescents. According to Armstrong *et al. (2018)*, adolescents are a critical and distinct age group with different health requirements from children and adults. For the purpose of this study, adolescents are persons between the ages of 10 and 19 years who are born with HIV, as classified by the WHO in the context of HIV/AIDS.

Perinatal

Perinatal refers to the time that begins at the end of the 22nd week of pregnancy and concludes seven days after the baby is born (WHO, 2018). The Centre for Disease Control (CDC) (2007) refers to perinatal HIV as the Human Immunodeficiency Virus acquired by children either during pregnancy, labour and delivery or during breastfeeding. In this study, perinatal refers to the period in which adolescents living with HIV infection acquired the disease, which could be during birth or infancy through breastfeeding.

Vertical transmission

The WHO (2018) defines vertical transmission as HIV transmission from an HIV-positive woman to her child during pregnancy, childbirth, and nursing. This accounts for the vast majority of HIV cases in children aged 0 to 14 years old. Furthermore, it has been defined as the acquisition of HIV infection in children either in utero, intrapartum, postnatally and/or during breastfeeding (Myburg & Dramowski, 2020). This study adopts the WHO definition of vertical transmission, which is HIV transmitted from an HIV-positive woman to her child during pregnancy, childbirth and breastfeeding.

Horizontal transmission

Horizontal transmission, also called secondary transmission, is when HIV is passed from one person to the next by vaginal fluid or sperm during sexual contact or through the blood of someone who is already infected with HIV (WHO, 2014).

User-friendly support program

A support program refers to a plan for people to improve their knowledge, skills and attitude according to their needs (Hamric, Hanson, Tracy & O'Grady, 2014). In this study, a user-friendly support program refers to a planned series of activities that will help in improving knowledge, practices and the attitude of adolescents who are living with perinatally acquired HIV in the Vhembe District.

Infection

Infection is described as the invasion of disease-causing pathogens into an organism's bodily tissues, their multiplication, the host tissues' reaction to the infectious agents and the toxins they create (WHO, 2017). In this study, infection refers to the presence of the human immunodeficiency virus (HIV) in the body.

LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ALHIV	Adolescents Living with HIV
APHIV	Adolescents with Perinatal HIV
ART	Anti Retroviral Therapy
ARV	Anti-Retroviral Drugs
AYFS	Adolescents and Youth Friendly Service
CDC	Centers for Disease Prevention and Control
CIPHER	Collaborative Initiative for Paediatric HIV Education and Research
CHC	Community Health Centre
DoH	Department of Health
FMP	Fames Matter Programme
HAART	Highly Active Antiretroirval Therapy
HIV	Human Immunodeficiency Virus
HRH	Human Resources for Health
LTFU	Loss to Follow-up
MMR	Mixed Methods Research
MTCT	Mother-to –Child Transmission
MSF	Medecins Sans Frontieres
NMAC	National AIDS Minority Council
NDoH	National Department of Health
NGO	Non-Governmental Organisation
NIMART	Nurse-Intiated Management of Anti-Retroviral Therapy
PHC	Primary Health Care
PHIV	Perinatal HIV

RSA	Republic of South Africa
SSA	Sub-Saharan Africa
SASSA	South African Social Security Agency
SPSS	Statistical Package for Social Sciences
TREC	Turfloop Research Ethics Committee
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children Emergency Fund
VL	Viral Load
YFS	Youth Friendly Services
WHO	World Health Organization

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

HIV is a major public health problem worldwide. Global projections of people living with HIV in 2015 were 36.9 million, with 1.8 million new infections (UNAIDS, 2018). In 2019, an estimated 1.7 million people were newly infected with HIV, 150 000 of them being young people below the age of 15 years (UNAIDS, 2020). The majority of these new infections among teenagers aged between 10 and 19 years were thought to be perinatally acquired (CDC, 2016).

Children with perinatally acquired human immunodeficiency virus (HIV) infection around the globe are reaching adolescence in large numbers due to the introduction of the Highly Active Antiretroviral Treatment (HAART) and the Prevention of Mother-To-Child Transmission (PMTCT) (Mellinse & Malee, 2011). In 2013, perinatally acquired HIV was estimated at around 10 000 infections globally (Macdonelle, Naar-King, Huszti & Belzer, 2013), a figure which ballooned to 38 000 by 2017. Amongst the 38 000 infections, 36 860 (79%) were from Sub-Saharan Africa. It has also been noted that HIV-associated mortality and loss to follow-up (LTFU) were higher during the adolescence stage (UNAIDS, 2018). Sub-Saharan Africa has higher rates of loss to follow-up than higher-income countries like the United States of America (Slogrove, Scholmake, Davies, Williams & Balkan, 2018).

According to Folayan, Odetoyinbo, Harrison, and Brown (2014), adolescents with perinatal HIV experience emotional upheaval as a result of a positive HIV diagnosis. It is made worse when the adolescent experiences a real or perceived negative effect on their relationships, schooling, work, and family ambitions. Their development is complicated by the difficulties of coping with HIV as a stigmatising, sexually-transmitted chronic illness, managing medical treatment, and, in some cases, adjusting to family loss or the death of their parents (Mellins & Malee, 2013). HIV-positive people are socially classified as “*other people*” and they are also seen as people who are different and threatening to the public (Conroy, Teatman & Dovel, 2013). Zanoni, Archary, Subramony, Sibaya, Psaros & Haberer (2021) assert that due to the complex cognitive, social and physical issues faced by adolescents living with perinatally acquired HIV, additional emotional, medical, educational, and psychosocial care is required to assist them.

Folayan *et al.* (2014) also identified the need for support programmes to respond to the complex psychological and physical needs of adolescents living with perinatally acquired HIV. In response to the call for support programmes for adolescents, the Families Matter Program

(FMP) in United States of America (USA) developed an intervention with the intention of promoting positive parenting practices and effective parent-child communication regarding sexuality and sexual risk reduction. The developed programme showed a significant contribution to multi-level efforts to address the needs of Adolescents Living with HIV (ALHIV). It also improved parent-child relationships and communication about difficult sex-related topics. The programme reached over half a million families and is currently available in 15 languages (Winskell, Miller & Allen, 2017).

In South Africa, Tshuma (2015) identified a need for local support programmes and recommended that they be developed in order to address the psychosocial challenges encountered by adolescents living with HIV.

Although the South African government has developed guidelines on the management of adolescents living with HIV, these guidelines are overly generalised; they concentrated on all HIV-positive adolescents and do not recognise the specific needs of adolescents who acquired HIV perinatally (WHO, 2016). Despite current intervention among adolescents living with HIV, there are continued reports of a rise in the rate of HIV-associated mortality and loss to follow-up in the adolescent population of Sub-Saharan Africa (Slogrove *et al*., 2018).

This study seeks to develop a user-friendly support programme for adolescents living with perinatally acquired HIV in the Vhembe District of the Limpopo Province, to address their daily challenges. The developed programme aims to assist in retaining them in HIV care, equipping them with knowledge about HIV and its management, and teaching them skills to cope with HIV as a chronic illness (Mellins, 2013).

1.2. RESEARCH PROBLEM

The introduction of the HAART and the Prevention of Mother-to-Child Transmission (PMTCT) have changed the face of HIV, which is no longer an inherently fatal disease but a manageable chronic condition. HIV-infected children reach adolescence but are then confronted with a lifetime of stigma and the lifelong management of a disease that can be fatal if not managed properly (Mofenson & Cotton, 2017).

The Vhembe District of the Limpopo Province has seen a rise in the number of HIV-infected adolescents who were missed as children and are diagnosed with perinatally acquired HIV as teenagers. They face the same challenges as other adolescents, along with the added complexity of personal decisions relating to their sexual conduct having a direct impact on the global cause to eradicate HIV/AIDS.

The researcher, a nurse working with adolescents on a daily basis, found that the guidelines for the management of adolescents living with perinatally acquired HIV are similar to those for horizontally infected persons (WHO, 2016). These guidelines fail to recognise the unique needs of this population. Consequently, there is a significant loss to follow-up among adolescents and eventual absconding from HIV care and management. The absence of proper guidelines and a support system to help these patients transition safely throughout adolescence often leads to poor decision-making and negative consequences.

The adolescent stage is characterised by exploration and experimentation, leading to risky behaviours (Woollett, 2021). Among these risky behaviours is unprotected sex, resulting in unwanted and unplanned pregnancies (Ramakuela, Lebese, Maputle & Mulaudzi, 2016). There has been a rise in teenage pregnancies, including in adolescents living with perinatal HIV, in the Vhembe District of Limpopo (Limpopo statistics, 2021). Studies have shown that adolescents exhibit virological failure due to low adherence rates (CIPHER, 2018), which poses a risk to the eradication of HIV.

The National Department of Health (NDoH) introduced measures such as the roll-out of the Youth Friendly Services (YFS) and establishing partnerships with NGOs in the Limpopo Province in order to curb the rate of new HIV infections amongst adolescents (WHO, 2014). These programs were effective to an extent, but the overwhelming burden of pregnancies amongst adolescents living with perinatal HIV infection proved that existing programs are not enough to curb the rate of new HIV infections as adolescent struggle with a fear of disclosure due to the stigma attached to their diagnosis.

Tshuma (2015) asserted the need for an emotional support program along with psychosocial management and care for adolescents living with perinatally acquired HIV, with the aim to provide clear strategies for well-structured, continuous support and the provision of HIV/AIDS-related education. The circumstances experienced by adolescents with perinatally acquired HIV are a cause for concern, leading the research to investigate the unique challenges faced by these adolescents with the aim to develop a user-friendly support package for them.

1.3 PURPOSE OF THE STUDY

The goal of this research was**:**

- To explore the challenges faced by adolescents living with perinatal HIV infection and to evaluate the designed user-friendly support programme in response to formative findings of the research in selected clinics and community health centres in the Vhembe District of the Limpopo Province in South Africa.

1.4 RESEARCH QUESTIONS

The research questions which guided this study were:

- What are the experiences of adolescents living with perinatally acquired HIV as well as their families, communities, schools, and health care facilities—selected Community Health Centres (CHCs) and clinics—in the Vhembe District?
- How much information do adolescents who have been infected with HIV perinatally have about their illness, and what are the knowledge gaps regarding perinatal HIV infection in selected CHCs and clinics in the Vhembe District?
- What are the support needs for adolescents living with perinatally acquired HIV in selected clinics and CHCs in the Vhembe District?
- Which user-friendly support program can be developed for adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District?

1.5 OBJECTIVES

The objectives of this study were:

- To explore and describe the experiences of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.
- To identify the support needs of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.
- To identify and describe gaps in the current management and care of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.
- To evaluate the designed user-friendly support programme in response to formative findings of the thesis.

1.6 THEORETICAL FRAMEWORK

The life course theory was adopted for this study (Elder, Johnson & Crosnoe, 2003). The theory is useful in studying how young people shape their lives, how they fit into the modern world's complexity, and how they deal with new threats, uncertainties, and the opportunities they encounter (Policy Research Initiative, 2004). Developmental psychology looks for universal, predictable events and pathways, whereas the life course perspective emphasises how historical time, social location, and culture affect the individual experience of each life stage. According to Elder, Johnson and Crosnoe (2003), principles guide the outcome of an individual life course. This study followed life course theories as outlined by Elder *et al.* (2003), using principles of the theory to develop a conceptual framework. Chapter 2 will provide more insight into the theoretical framework.

1.7 OVERVIEW OF THE RESEARCH METHODOLOGY

A mixed method, sequential exploratory design was followed to fulfil the purpose of this study**.** The study aimed to develop a user-friendly support programme for adolescents in the Vhembe District of Limpopo Province**.** The population of the study comprised 2117 adolescents. The pilot study was done on 5 participants who did not form part of the main study group for both qualitative and quantitative strands. For the qualitative strand, purposeful sampling was used to select adolescents living with perinatal HIV infection, while for the quantitative strand, simple random selection was used. Qualitative data was collected through one-on-one interviews and a questionnaire for the quantitative strand. A semi-structured interview guide, using a voice recorder and field notes, was used to collect data. A questionnaire with structured questions was used to collect data. Tesch's eight steps of qualitative data analysis were used for qualitative data, while quantitative data was analysed using SPSS version 25. The detailed methodology is discussed in Chapter 3.

1.8 PARADIGMATIC PERSPECTIVE

A paradigm is a pattern, structure, framework or system of scientific or academic ideas, values and assumptions. It is viewed as the ability of researchers to understand and articulate beliefs about the nature of reality, what can be known about it, and how they go about attaining this knowledge (Abulaziz, 2016). In social research, a paradigm refers to the philosophical assumptions or the basic set of beliefs and values of a community of specialists regarding the nature of reality and knowledge (Kaushik & Walsh, 2019).

Components of the research paradigm

- Pragmatism

  Pragmatism refers to the proposition that researchers should use the philosophical and/or methodological approach that works best for the particular research problem being investigated (Kaushik & Walsh, 2019). In this research, pragmatism was used through the employing of mixed methods, based on the belief that it will answer the research questions of this study most effectively.

- Axiology

  Axiology in research is about the role of values and morals in the research process between paradigm, methodology and methods (Zareen, 2018). It focuses on the way people respond to situations and is subjected to their values. In this research, axiology was ensured through the first phase (qualitative) which explored the actions and experiences of adolescents living with perinatally acquired HIV.

- Ontology

  Ontology is defined as the nature of our beliefs about reality (Chongwe, 2018). In this study, the reality of the experiences of adolescents living with perinatally acquired HIV was explored and described through one-on-one interviews.

- Epistemology

  Epistemology refers to assumptions on the nature of reality. It is described as the nature and scope of knowledge and justified belief. It analyses the nature of knowledge and how it relates to similar notions such as truth beliefs and justification (Zarren, 2018). In this study, it was achieved through employing the sequential exploratory design to assist in analysing the knowledge gained in the first phase (Kant, 2008-2021). The branches of epistemology include essentialism, historical perspective, perennialism, constuctism and empiricism. Empiricism accepts personal experiences associated with feelings and senses as a valid source of knowledge.

- Methodology

Methodology in research is determined by the research paradigm and the researcher's understanding of the research problem (Choongwa, 2018). Methodology lead researchers to ask certain questions and use appropriate approaches to systemic enquiry (Chilisa and Kawulich, 2012). The quantitative approach to scientific inquiry emerged from a branch of philosophy or paradigm called logical positivism that operates on strict rules of logic, truth, laws, axioms and predictions (Grove, Burns and Gray, 2013). The underpinning beliefs of quantitative research are that all human behaviour is objective, purposeful 40 and measurable, hence quantitative studies assume rigour, precision, logical reasoning and attention to evidence (Levers, 2013). As a result, researchers aim to find the rightful objective tools for measuring behaviour. Some of the quantitative research methods are descriptive research, correlational research, and experimental research

1.9 SIGNIFICANCE OF THE PROPOSED RESEARCH

The researcher hopes that the findings of this study may be of benefit to the following:

Adolescents living with perinatally acquired HIV

- To provide meaningful insight into the daily challenges and issues confronting these adolescents, and to seek solutions.
- To encourage engagement from the government, researchers, and other significant stakeholders with regard to personalising the challenges faced by these adolescents, especially in rural areas such as the Vhembe District.
- To empower adolescents living with perinatally acquired HIV with knowledge about HIV in order to reduce transmission to their peers.

Health Professionals

- The development of a user-friendly support programme for adolescents living with perinatally acquired HIV will enhance the health fraternity with knowledge on the management of perinatal HIV infection in adolescents.
- Health professionals will know how, when and what to do when managing and caring for adolescents living with perinatally acquired HIV, besides giving treatment.

Research

- This study may be useful in formulating the basis for further research either to confirm or object to the findings of the present study.
- The findings may prompt other researchers to further explore the development of a programme for adolescents living with perinatally acquired HIV.
- Researchers may conduct follow-up studies post-implementation of this user-friendly support programme to establish its effectiveness, as well as for the provision of new knowledge to enhance the lives of adolescents.

1.10 CONCLUSION

This chapter provided an overview of this study, introducing and discussing background information on perinatally acquired HIV globally and the challenges encountered by adolescents living with perinatally acquired HIV. The problem statement, purpose, objectives, research questions and theoretical framework were outlined. A brief description of the research methodology with the research design, population and sampling procedures were presented. Chapter 2 will discuss the literature review. The division of other chapters are presented in the table below:

1.11 DIVISION OF CHAPTERS

The thesis comprises six (6) chapters as follows

Chapter 1	Overview of the Study
Chapter 2	Literature Review
Chapter 3	Research Methodology
Chapter 4	Discussion of Findings and Literature Review
Chapter 5	The Development of a User-friendly Support Programme for Adolescents Living with Perinatally Acquired HIV Infection
Chapter 6	Conclusions, Limitations and Recommendations of the Study

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter presented an overview of the study, while this chapter presents the literature review. A literature review is defined as a critical summary of all the published works on a particular topic (Hayward, 2017). This section reviews published research on the development of a user-friendly support programme for adolescents who are living with perinatally acquired HIV infection. The literature review in this study was conducted by examining previous studies to gain knowledge on the challenges faced by adolescents living with perinatally acquired HIV. The knowledge gained assisted in developing and building the current study. Literature was reviewed globally, nationally and locally to get the bigger picture on adolescents living with perinatally acquired HIV.

2.2 LITERATURE REVIEW METHODOLOGY

A narrative literature review, which is a systematic way of collecting, critically evaluating, integrating and presenting findings from across multiple research studies on a research question or topic of interest (Pati & Lorusso, 2018), was conducted. This methodology assisted the researcher to summarise and critique existing literature, which gave a background of the scientific information available regarding the research problem. The body of literature about a thesis topic is critiqued and summarised in narrative or traditional literature reviews. It also assists to accumulate and synthesise the information found in literature. The primary goal of a narrative literature review is to provide the researcher and reader with a comprehensive overview of the topic, to highlight significant areas of research, and to assist the researcher to identify gaps in research. In this case, it is in the management of adolescents living with perinatal HIV infection, as well as redefining the research questions (Griffith, 2019). Cronin (2008) has outlined the following steps when conducting a literature review:

- Selecting a review topic
- Searching the literature
- Gathering, reading, and analysing the literature
- Writing the review
- References

2.2.1 Selecting a review topic

The researcher developed a topic related to adolescents living with perinatal HIV infection. A list of all possible topics related to adolescents with perinatal HIV infection was compiled and researcher then read everything she could access on adolescents living with perinatal HIV infection. The researcher then searched for a theoretical basis to support the topic and for a niche in which the topic could make a difference. The researcher looked at current interventions used to support adolescents with perinatal HIV infection, both nationally and internationally. The research topic was then developed and presented to the supervisor for input and was then fine-tuned based on inputs from the supervisor. The selected topic was "*The development of a user-friendly support programme for adolescents living with perinatally acquired HIV infection in the Vhembe District"*.

2.2.2 Searching the literature

A structured literature search for relevant information was conducted on the selected topic. Search techniques included the following:

1. Conventional (electronic) subject searching on the internet database. These databases included the following: PubMed, Bio-Med Central, 'Human Resources for Health' online journals, Google Scholar, the HRH database, and peer-reviewed journal articles.

2. Reference harvesting where references identified on the retrieved articles were also used to access other relevant articles for review. Grey literature from government sources such as The WHO, UNAIDS and UNICEF was also searched and reviewed.

3. Hand search, where printed articles and relevant articles and reports were searched and reviewed. The following list of search terms was generated to assist to retrieve articles published in English: perinatal, HIV infection, adolescents, horizontal HIV infection. The articles were grouped and summarised into Q-cards, in order to easily access them when needed.

2.2.3 Gathering, reading, and analysing the literature

Relevant articles not older than five years were selected, reviewed, and analysed. Relevant information was extracted from abstracts and full papers. A total of 150 articles were selected and 83 were reviewed, analysed, and cited.

2.2.4 Writing the review

The review of the literature was divided into topics and sub-themes linked to the topic, followed by a discussion of theoretical literature and an investigation of the research methodologies used. The topics and sub-themes that arose are listed below.

- Overview of perinatal HIV infection, global perinatal HIV/AIDS in adolescents
- The African perspective on perinatal HIV/AIDS
- Perinatally acquired HIV/AIDS in South Africa
- Challenges associated with perinatally acquired HIV in adolescents
- Existing interventions on the management of perinatally acquired HIV infected adolescents
- The interaction of adolescents living with perinatally acquired HIV infection with society, families and peers
- Perceptions of adolescents living with perinatal HIV on ART

2.3 Overview of perinatal HIV infection

Studies show that most HIV-positive adolescents contracted the virus from their mothers through mother-to-child transmission (MTCT), either during pregnancy, childbirth, or breastfeeding. The introduction of HAART brought about a change in the prognosis of HIV-infected children and mothers, as HIV is now a manageable chronic disease with most children who were perinatally infected having grown to become adolescents. Studies estimate that new HIV infections amongst currently uninfected adolescents could rise by 13% by the year 2030 (Comley-White *et al*., 2020). The burden of HIV/AIDS amongst adolescents weighs more on the African region as studies shows that about 1 400 000 (66.7%) were from Eastern and Southern Africa (UNICEF, 2017). Figure 2.1 shows an overview of HIV-infected children worldwide and the percentage of those who are on treatment.

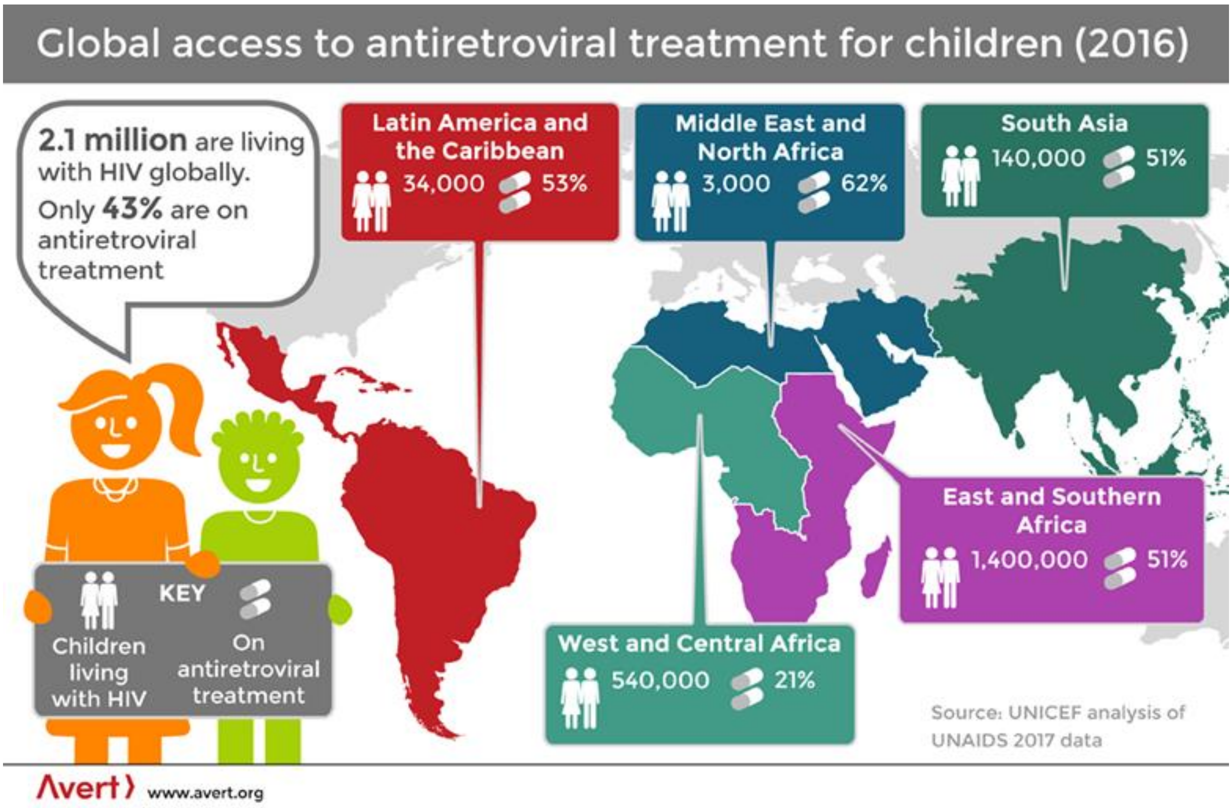


Figure 2.1. Global access to antiretroviral treatment for children.

Slogrove (2017) reported that before 2005, children with perinatal HIV infection in most parts of the world had limited access to antiretroviral therapy, leading to significant mortality during infancy and low long-term survival. However, Cardoso and Cruz (2015) indicated that adolescents with perinatal HIV (APHIV) and young adults may present with specific clinical, behavioural and social characteristics and demands due to prolonged use of ARVs and the stigma attached to HIV infection.

A study conducted by the Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) on the epidemiology of adolescents living with perinatally acquired HIV revealed that 58% of the adolescents were born in the year 2000 or later. According to Slogrove (2018), the percentages range from 0.3% in North America and 2.8% in high-income countries to 86.9% in sub-Saharan Africa and 73.6% in low-income countries. 76.7% of APHIV born before 1995 lived in Europe or North America (Slogrove, 2018).

2.3.1 Global perinatal HIV/AIDS in adolescents

The population of adolescents living with perinatal HIV infection continues to grow every day as most children on ART are surviving into adolescence. The global estimate of adolescents living with perinatally acquired HIV is at 2.1 million, with most of them being from Sub-Saharan Africa (SSA) (Frigati *et al*., 2019). Tshuma (2015) warned that despite the effectiveness of ART, there is still a greater fight ahead for adolescents living with perinatal HIV as they go through different stages in life. A report from an international AIDS commission warned of a resurgence of HIV/AIDS if the world's adolescent population is not protected and monitored (Mhairi, 2019).

CIPHER (2018) reported that, in comparison to other regions, adolescents living with perinatal HIV in North America and Europe, as well as other high-income regions, presented to care facilities and started antiretroviral therapy at a younger age, with higher CD4 counts, and less impaired height. In contrast, it was reported that in Sub-Saharan Africa (SSA), children presented to care and started ART late, which had an impact on the mortality rate of these children. HIV-related mortality during adolescence was therefore significantly higher in Sub-Saharan Africa, South and Southeast Asia, South America and the Caribbean.

Despite global challenges in the roll-out of ARVs, especially in SSA, there has been a significant reduction in AIDS-related fatalities. Mhairi (2019) revealed that global AIDS mortality has decreased significantly since the epidemic's peak in the early 2000s. In 2018, global HIV/AIDS data indicated an overall decline in both AIDS-related deaths and new HIV infections worldwide, demonstrating impressive gains towards the global 90 90 90 strategies (JIAS, 2018).

According to the World Health Organisation (WHO), the recent emergence of the global Covid-19 pandemic has impacted the fight against HIV. In 2020, there was a rise in global AIDS mortality from 120 000 to 680 000, and around 1.5 million new HIV infections were reported worldwide (WHO, 2021). The increase in new HIV infections and AIDS mortalities was attributed to disruptions in the provision of HIV services due to Covid-19. The reported AIDS-related deaths were highest amongst adolescents (WHO, 2021).

2.3.2 The African perspective on perinatal HIV/ AIDS

Africa carries the largest burden of HIV/AIDS infection (WHO, 2018). Armstrong and colleagues (2018) conducted a study on inequality in the outcomes for adolescents living with perinatally acquired HIV in Sub-Saharan Africa (SSA) and found that 80% of adolescents living with HIV infection worldwide are from SSA. They also found new HIV infections among adolescents to be on the rise (15-19 years old). Their findings also discovered that a total of 920 000 children on ART survived into adolescence (Armstrong *et al.* (2018), and that SSA was a home to 80% of the 1.8 million adolescents aged 10 to 19 years who are living with perinatal or horizontally acquired HIV. Furthermore, UNICEF (2018) reported that 1.74 million adolescents with vertical HIV infection live in Eastern and Southern Africa, accounting for 60% of the global total. SSA has also been rated 14th out of 15 regions with the highest HIV burden among adolescents. Adolescent-specific HIV prevalence estimates in SSA countries ranges from 0.6 percent in Kenya, to nearly 3 percent in Zimbabwe for younger adolescents aged 10 to 14 years; and from 0.5 percent in Ivory Coast to 5 percent in Mozambique for older adolescents aged 15 to 19 years (Slogrove *et al.*, 2018).

According to Adejumo and colleagues, adolescents make up large proportions of the population in many SSA countries, meaning that HIV/AIDS is a direct threat to the subcontinent's societies and economies (Adejumo *et al, 2015*). Adolescents in SSA exhibited a higher mortality rate and more significant rate of loss to follow-up when compared to their European counterparts. A study conducted by Slogrove in Malawi showed that out of 201 (79%) adolescents living with perinatally acquired HIV, 11% died and 25% were alive but were no longer on ART (Slogrove *et al.*, 2018).

2.3.3 Perinatally acquired HIV/AIDS in South Africa

The HIV prevalence amongst adolescents in South Africa has been fluctuating over the years. According to Statistics South Africa (Stats SA, 2021), approximately 8.2 million people between the ages 15-49 years are living with HIV in South Africa, constituting 13,6% of the global population living with HIV. According to a recent comprehensive study by Mhairi (2019), the number of young people in South Africa receiving HIV treatment has surged ten-fold in the last decade (Mhairi, 2019).

Access to ART in South Africa began in 2004, while HIV was discovered in 1981. In the late 1990s and early 2000s, lack of access to ART contributed to a high proportion of perinatal HIV infections. Due to political, cultural, infrastructural, geographic and economic challenges, enrolment in the South African National Antiretroviral Treatment Programme was slow, resulting in a large proportion of perinatal HIV infections (Meyersfeld, Vijovic & Struthers, 2011).

Slogrove *et al.* (2018) assert that the exact number of adolescents vertically or perinatally infected with HIV in South Africa is not known. According to UNICEF (2018), an estimated 510 000 young people aged between 10 and 24 years were newly infected with HIV globally. From the 510 000, 190 000 are adolescents aged between 10 and 19 years living in the Eastern and Southern Africa (UNICEF, 2018). In countries such as South Africa, Sierra Leone and Gabon, girls represent more than 80% of new HIV infections. A vast majority of adolescents, including those who are HIV infected, do not know their HIV status (Sam-Agudu *et al.*, 2016).

A study by Tsondai and colleagues (2020) reveals that Southern Africa is home to nearly 40% of the 1.6 million adolescents aged 10-19 years living with HIV globally. Tsondai *et al*. (2020) further report that among the 40% are adolescents who were both perinatally and horizontally infected with HIV. The Human Sciences Research Council (2016) discovered that Kwazulu-Natal has the highest HIV infections in South Africa, with a quarter of the region’s population testing HIV positive. The study also revealed an upward gradient in new infections across all provinces, especially between the ages of 15 and 49 years.

2.4 Challenges associated with perinatally acquired HIV among adolescents

Adolescents living with perinatal HIV have a long-standing HIV infection which they acquired when their immune systems were not fully developed, and they transitioned from childhood to adolescence while living with this chronic condition. This, along with the physical, emotional, psychosocial and mental changes of adolescence, rendered their lives very challenging. A study conducted by Tsondai *et al*. (2020) found poorer outcomes relating to HIV/AIDS management among adolescents. Global mortality due to HIV/AIDS has decreased amongst all other groups but has doubled in the adolescent population, with 120 000 adolescents dying from AIDS in 2013 (Right to Care, 2016).

Adolescents living with HIV exhibit similar transitioning behaviours to those who are HIV negative. These behaviours, in combination with concerns associated with the youth's social vulnerability, contribute to the high number of HIV infections that occur during this stage of life, as well as poor treatment adherence and eventual treatment cessation in adolescents living with perinatally acquired HIV (Cruz & Cardoso, 2015).

The rollout of antiretroviral treatment in SSA has resulted in growing coverage amongst adolescents who are living with HIV. However, less than half of adolescents under the age of 15 years are reported to be on ART. The figure among older adolescents is even less (van Schalkwyk, 2021). Studies also show that there are adolescents who have lived with HIV since birth (slow progressors) who have not yet accessed treatment, and some who are newly infected yet remain unidentified and disconnected from the health system (Toska *et al.*, 2019; van Wyk, 2020; Slogrove, 2018). According to research from SSA, "slow progressors" are young people who can survive until late adolescence without the use of antiretroviral therapy (ART) and account for a third of HIV-positive adolescents (Toska *et al.*, 2019).

Globally, adolescents living with perinatal HIV infection are labelled as a difficult subpopulation in the HIV community because of their complex treatment regimens, socio-economic pressures related to orphanhood, neuro-cognitive deficits due to chronic HIV infection, stigma and discrimination (Le Roux *et al,* 2017). A study in Kenya categorised challenges faced by adolescents who are living with perinatally acquired HIV into six major themes: poverty, poor mental and physical health, lack of school system that is responsive to their needs, challenges on how to disclose to their peers and families, high levels of stigma on various levels and challenges of medical adherence leading to the need for close monitoring (Abubakar, 2016).

Studies on cohort and programmatic analyses show that adolescents aged between 15 and 19 years, and young adults between 20 and 24 years of age, had higher loss to follow-up rates both before and after ART introduction. Compared to HIV-infected adult mothers, HIV-infected pregnant and breastfeeding adolescents have a lower service uptake, higher LTFU, and higher mother-to-child transmission (MTCT) rates (Armstrong *et al*, 2018).

Sexual challenges

A study conducted by Mellins discovered that adolescents engage in early sexual experimentation, leading to gender-based violence among young adult females aged 15 to 24 years. Girls are found to have a higher rate of new HIV infections than boys (Mellins, 2013). A study conducted in New Jersey on sexual behaviour and knowledge among adolescents with perinatally acquired human immunodeficiency virus infection compared to HIV-uninfected adolescents also concurred that adolescents living with perinatally acquired HIV had higher rates of engaging in unprotected sexual activities than HIV-uninfected adolescents (Kest, Pineda & Kaushik, 2016).

A study conducted in Sub-Saharan Africa on health risk behaviour among adolescents living with HIV (Ssewanyana *et al.,* 2018) revealed that adolescents living with perinatal HIV infection have high incidences of risky sexual behaviour compared to uninfected adolescents. 32.9% of the adolescents living with perinatally acquired HIV reported engaging in sexual activities without using a condom, compared to 30.4% of the uninfected adolescents. The study also revealed that adolescents with perinatal HIV infection have their sexual debut at a mean age of 14.7 years, significantly earlier than uninfected adolescents.

A study conducted by Kest and colleagues (2016) noted that teenage pregnancy among adolescents living with perinatal HIV infection was high as a result of risky sexual behaviour, a key risk factor for HIV and drug-resistant virus strains transmission. The study also found a low frequency of substance and drug use in this population (Kest *et al.,* 2016).

Mental and behavioural challenges

According to a study on the prevalence of mental health challenges among adolescents living with perinatal HIV infection, mental health challenges amongst adolescents are a major concern in both developed and developing countries (Mellins, 2013). Woollett (2018) and Dessauvagie et al., (2020) revealed the prevalence of mental health problems in adolescents living in Sub-Saharan Africa: 24-27% had psychiatric disorder whilst 30-50% displayed emotional and behavioural challenges or significant psychological challenges.

Mellins (2013) asserted that HIV as a cause of mental health problems remains unclear, meaning that further studies on the effect of HIV on the mental health of these adolescents need to be conducted. A study on understanding the mental health of youth with perinatal HIV infection found that emotional and behavioural problems, including psychiatric disorders in adolescents, were at higher than expected rates, often exceeding those of the general population and other high-risk groups (Mellins & Malee, 2013). In another study, it was reported that HIV infection affects sub-cortical, white matter and fronto-striatal circuits or systems (neural pathways that connect frontal lobe regions with the basal ganglia or stratum) involved in the regulation of emotion and behaviour (Mellins & Mallee (2013). Louthreno *et al*. (2014) discovered that adolescents reported having more somatic complaints without medical explanations than the general population.

Abram (2018) found that adolescents had high rates of psychiatric, substance use disorders and behavioural disorders which could jeopardise long-term health and adult functioning, particularly in the context of HIV. In a study by Vreeman, McCoy and Lee (2017) adolescents living with perinatal HIV displayed similar or less severe behavioural health problems compared to their uninfected peers, and also reported relatively low rates of substance use. Vreeman *et al*. reported that uninfected youths and adolescents displayed a similar or higher prevalence of emotional and behavioural problems, including psychiatric disorders.

Opportunistic infections

Opportunistic infections are a major challenge in HIV-positive patients, exacerbated by the advancement of the disease and poor treatment adherence. Comley-White *et al*. (2020) found that global studies have insufficient data on the incidences of co-infection amongst adolescents living with perinatal HIV infection, but the limited data available shows similar trends of co-infection among adolescents living with perinatal HIV infection and the general HIV adult population. The incidences of co-infections, especially tuberculosis (TB), were also linked to poor adherence to ARVs and the advancement of HIV.

Substance abuse

In a study conducted by Mutumba *et al*. (2017), it was revealed that adolescents' HIV-positive status was associated with increased drug use and that the influence of other significant contextual factors such as unpleasant life experiences bring about significant change in substance use on adolescents. Few adolescents with perinatal HIV reported the use of substances at baseline, with the number of onsets of substance use increasing at a faster rate as individuals transitioned through adolescence, compared to uninfected adolescents.

2.4.1 Adherence challenges to ART in adolescents living with perinatally acquired HIV

Poor adherence to ART is one of the most significant challenges in ensuring that patients achieve and maintain viral load (VL) suppression (van Wyk & Davids, 2019). Globally, adolescents living with perinatal HIV infection are struggling with daily medication. A study by Ssewanyana, Mwangala, van Baar, Newton & Abubakar (2018) reported varied inferior outcomes of adherence and virologic reviews, which was attributable to the complex ARV challenges experienced by these adolescents. It was highlighted in a study on the perceived challenges of perinatal HIV in adolescents that 36% of them reported treatment fatigue due to complex ART challenges (Comley, 2020).

Studies reveal that adolescents living with HIV have lower rates of viral suppression than adults, as well as higher rates of virological rebound and loss to follow-up (AIDS info, 2019). Because of their emotional and cognitive developmental trajectories, they are vulnerable to specific adherence issues.

Reasons that adolescents with HIV have difficulty adhering to medical regimens include the following:

Denial and fear of being diagnosed with HIV

According to Maseko (2020), the behaviour of adolescents living with prenatal HIV infection to the declaration of their status varies, ranging from denial to living in continual fear of others learning their HIV positive status. This is because of the stigma still attached to HIV/AIDS.

Misinformation

Previous studies reported that adolescents living with perinatal HIV were misinformed about their diagnosis. The misinformation ranged from misdiagnosis, lack of knowledge of their diagnosis and a general lack of information about HIV/AIDS.

Mistrust of the medical profession

Maskew (2019) reveals that adolescents do not trust the medical profession, particularly nurses, and they raised concerns about being stigmatised in health facilities and a pervasive sense that clinics cannot guarantee patient confidentiality. Furthermore, findings by van Wyk and Davids (2019) reveal that adolescents cite poor service delivery, missing or misplaced files and long waiting times as some of the barriers to adherence.

A lack of self-confidence

Previous studies conducted by Jena (2014) and Woollett (2021) reveal that adolescents living with perinatal HIV display low self-esteem as compared to their peers. This is a result of the stigma and discrimination around HIV.

Unstructured and chaotic lifestyles

HIV infection has left many adolescents without parents as they died of HIV, and some were left to care for their siblings and heading the homes. Consequently, they depend on extended families and other relatives for their welfare. A study by Mellins (2013) found that adolescents living with perinatal HIV infection start abusing substances and alcohol earlier than their peers who are HIV negative.

Mood disorders and other mental illnesses

Mellins *et al*. (2013) found that adolescents living with perinatal HIV infection displayed more mental health problems than their HIV-negative peers and other adolescents who were infected with HIV horizontally.

Lack of familial and social support

According to Willies *et al.* (2018) adolescents reported feeling rejected by their families and those they consider valuable in their lives. They reported being deprived of social support.

Lack of or inconsistent access to care or health insurance.

According to Tshuma (2015), adolescents living with perinatal HIV report being dissatisfied with the healthcare they receive in some health facilities. Lack of psychosocial support was reported as one of the major problems. If they use their parents' health insurance, they run the risk of inadvertently disclosing their HIV status (AIDS info, 2019).

A study on the factors associated with suboptimal adherence to antiretroviral therapy in adolescents living with HIV infection reported factors which include (1) the possible impact of gender and knowledge of sero-positive status (2) the influence of the family structure, (3) the impact of burdensome ART regimens, route of administration, and attitudes about medication, and (4) healthcare and environmental factors, such as rural versus urban location and missing clinic appointments (Cluver & Hudelson,2015).

Emotional and psychosocial challenges

In South Africa, a study on the psychosocial experiences of adolescents living with perinatally acquired HIV who resided in youth and childcare centres reported that children and youth living with perinatally acquired HIV experienced a lot of psychosocial challenges such as isolation (Mavangira & Raniga, 2015). However, this study focused on adolescents living with perinatally acquired HIV who were in closed and protected institutions, where almost everyone amongst the people residing in the institutions is HIV-positive. Children who are institutionalised are not exposed to stigma and face challenges of the outside world.

2.4.2 Stigma in relation to perinatally acquired HIV

HIV-related stigma and discrimination continues to do harm by obstructing people from acquiring information and making use of available services (UNAIDS, 2020) Stigma has been defined in different ways by different authors. Scambler (2009) defined stigma as a social process characterised by a person or group's rejection, devaluation, or social judgment. Goffman (1968) defined stigma as discrediting characteristics, and the stigmatised individual is viewed as a person who possesses "an undesirable difference" that leads to "a spoiled identity." (Mpofu & Jacobs, 2017).

Mpofu and Jacobs (2017) report that stigma has been one of the biggest challenges since the emergence of HIV infection. The fact that HIV infection is still a stigmatised condition three decades later is a cause for concern for both those living with HIV and policymakers, as it has a detrimental impact on HIV-infected people's outcomes. (Kaushik, Kineda & Kest, 2016). The findings of a study conducted in Thailand reveal that HIV-related stigmatisation may mediate the negative effect of HIV-infection on school life (Merville *et al.*, 2021).

Surveys conducted around the world have shown that HIV/AIDS has begun to be perceived in a less negative light in numerous African communities. The survey report also indicated that this could be due to the increased availability of life-saving antiretroviral treatment, improved HIV survival across age groups, and broad stigma-reduction initiatives. However, recent research in this region shows that significant rates of stigma persist. (Global AIDS, 2019). The findings of a study conducted in Sub-Saharan Africa on changing forms of HIV-related stigma along the HIV care and treatment continuum confirmed the existence of stigma in the form of gossip and the relative absence of interpersonal discourse following judicious disclosure (Merville *et al.,* 2021)

Initiatives to eradicate stigma have been initiated in certain parts of the world, which has facilitated a slight improvement, especially in Sub-Saharan Africa. A study conducted in Kenya found that overt forms of stigma were less common due to raised awareness. However, covert forms of stigma were still prevalent. From a social cognitive perspective, the study categorised four forms of stigma: vicarious, perceived, enacted, and internalised (Abubakar *et al.*, 2016).

2.4.3 Societal attitude and educational demands towards perinatally acquired HIV

Myths and societal preconceptions regarding HIV create a major challenge for adolescents who have been infected perinatally. Together with the HIV positive community at large, they live with a fear of rejection and isolation due to stigma spurred by society’s ignorance and lack of knowledge regarding HIV/AIDS issues and the presumptive relation of HIV/AIDS to promiscuity (Mpofu, 2016).

According to a study conducted in South Africa, adolescents living with perinatally acquired HIV had the same access to school enrolment, fee-free schools, and free food programs as their HIV-uninfected peers. However, they experience absenteeism and educational delays, potential co-factors which they can’t control. Adolescents reported more chronic illnesses, cognitive difficulties, and the mental health challenges of depression ad stigma (Toska *et al.,* 2019).

Abubakar *et al*. (2016) revealed that adolescents who are living with perinatally acquired HIV are inclined to developmental and educational challenges. This warrants attention by the relevant authorities as those adolescents seem to have their educational experience curtailed following a period of illness. According to a study by Mavaringa and Raniga, ART changed their experiences as the majority of them have never experienced severe illness or been hospitalised due to an HIV-related illness. They experience educational distress indirectly from their HIV positive status (many are orphans), the chronicity of the disease and strict schedules of their treatment (Mavaringa & Raniga, 2015). A study by Abubakar *et al.* (2016) showed that adolescents living with perinatally acquired HIV are subjected to an education system that is not responsive to their specific medical and developmental needs. Participants expressed serious challenges in their schooling, which included lagging in education, discrimination, and isolation at school. Another study proved that adolescents struggled to maintain HIV care and school due to frequent clinic visits which were associated with reduced school attendance and educational delay (Toska *et al., 2019*).

2.4.4. Interaction of adolescents who are living with perinatally acquired HIV with families and their peers

Interpersonal relationships with loved ones are important in everyone's lives, but they are especially important in the lives of teenagers living with HIV. Sometimes these interpersonal relationship with loved ones only exist as a dream to these adolescents. Evidence from previous studies proved that the majority of these adolescents live in difficult conditions due to the loss of their parents. Some are heading families or living with relatives, institutions or foster parents, and living in severe poverty (Bana, Mellins, Small, Nestadt, Leu, Peterson, Machanyangwa & McKay, 2016).

Every human being, including adolescents who are living with perinatal HIV infection, belongs to a certain family or needs a family as a support structure. A good, supportive, and functional family structure affords these adolescents a good transition from childhood to adolescence while living with perinatal HIV infection. Previous studies reveal that the family structures of the adolescents define their life trajectories. Some children reach adolescence being fully aware of their condition, while others learn their HIV status during adolescence (Slogrove, 2018). The knowledge of their HIV positive status had been proven to empower them emotionally and psychosocially. Additionally, it has also been noted that in some families, adolescents were the only ones living with HIV. According to a study conducted in Zimbabwe, adolescents who live in families where another family member had HIV and has good treatment adherence, benefited from the full advantages of combination antiretroviral therapy viral suppression, appropriate growth, and good quality of life throughout childhood (Zwalongo, 2016).

Some adolescents live with relatives and foster parents due to orphanhood. Several studies reported numerous challenges on adolescents living with relatives and foster parents such as abuse, stigmatisation, exploitation, and ill-treatment (Slogrove, 2018; Kimera, Vindevogel, DE Maeyer *et a*l, 2019). A study conducted on understanding the experience and manifestation of depression in adolescents living with HIV in Harare concurred with the above findings as participants reported feeling sad as a result of their interactions and relationships with important people in their lives, like family members and peers. They reported that they felt different to others, both because of their HIV status and because of the impact HIV has had on their lives. Participants expressed a desire to matter or be relevant to the people in their lives (Willis *et al*., 2018).

Comley-White, Potterton & Ntsiea (2020) found that because of bullying and stigmatisation by classmates and teachers, teenagers living with perinatal HIV infection view schools as a highly stigmatised environment. As a result of their recurrent daily/chronic medication, they always internalise the stigma at school. Furthermore, the results of the study conducted in Thailand discovered that adolescents had fewer friends than their peers, and a quarter of these adolescents reported to have experienced stigmatisation at school in the form of bullying, violent or humiliating behaviours or exclusion (Merville, Puangmala, Suksawas *et al.*, 2021).

2.5 Response of perinatally acquired HIV infected adolescents on antiretroviral therapy

Successful ART management in adolescents is often complicated by a high rate of loss to follow-up and viral relapse (Zanoni & Haberer, 2019). Adolescents who are perinatally HIV infected usually are heavily ART-experienced and may have a unique clinical course that differs from that of adolescents who acquire HIV later in life. They were often started on ART early in life with mono- or dual-therapy regimens, resulting in incomplete viral suppression and the emergence of viral resistance. They are likely to have a longer history of disease, complications and chronicity, less functional autonomy, and a greater need for ART as they are at a higher risk of mortality.

Adolescence is characterised by rapid changes in physical maturation, cognitive processes, and lifestyle. Predicting long-term adherence during the adolescent stage can be challenging. Compared with adults, the youth have lower rates of viral suppression and higher rates of virologic rebound and loss to follow-up (Palmer, 2018).

Studies of adolescents who acquired HIV during their teen years and adolescents with perinatal acquisition demonstrate that many adolescents in both groups face numerous barriers to adherence (Maskew, 2016; MacCarthy, 2018). Prolonged HAART seems to have cardioprotective effects in HIV-infected children and adolescents. However, many youths develop severe metabolic complications including lipodystrophy, dyslipidaemia, insulin resistance, lactic acidosis, and bone mass loss. Dyslipidaemia, which is mainly associated with the use of protease inhibitors, may increase the risk of cardiovascular disease in adulthood. Studies have discovered that recent lines of ART have fewer toxicities (Baker, 2017).

Adolescents living with perinatally acquired HIV are frequently put on ART at a young age, with mono- or dual-therapy regimens. This results in insufficient viral suppression and the formation of viral resistance. Several studies have shown that some of these heavily ART-experienced adolescents might harbour a resistant form of the virus (AIDS info, 2019). This poses a serious problem as research conducted in the United States on a cohort of adolescents with recent HIV infection who were naïve to ARV treatment and had acquired HIV via behaviour revealed significant multiclass resistance. According to the detuned antibody testing assay approach, which defined recent infection as occurring within 180 youngsters who were naïve to all ARV medicines and represents a transmission of resistant virus, primary genotypic resistance mutations were found in 18% of the samples. As a result of this transmission dynamic, a significant fraction of the research participants' sexual partners was likely to be older and ART-experienced; consequently, employing baseline resistance testing to guide first therapy in children who have been exposed to ART is a good idea (AIDS info, 2019).

2.6 Disclosure of HIV status in perinatally acquired HIV infected adolescents

Learning about HIV and its implications for adolescents who live with HIV daily is an important aspect of care related to HIV sero-status disclosure (Okawa, Mwanza-Kabaghe, Mwiya, Kikuchi, Jimba, Kankasa & Ishikawa, 2017). However, it is influenced by fears of backlash from the adolescents and the fear of exposing adolescents to psychological trauma, and the perceived level of the stigma in the social context (Mweemba, 2015). Kidman (2020) has indicated that it was not clear whether HIV disclosure alone has a positive impact on adolescents, but the findings of his study found a negative association between social support from the family and disclosure. In contrast, the findings of the study conducted by Kaukish and colleagues discovered that early disclosure of HIV-positive status demonstrated benefits for adolescents who are living with HIV. It was discovered that infected adolescents start sexual activities at the similar age as uninfected adolescents, so they are in a better position to make informed choices on the use of protection during sexual encounter when they have been disclosed of their HIV status earlier (Kaushik, Kineda & Keist, 2016). Another longitudinal study also discovered that disclosure has significantly increased adherence to ART, which promotes viral suppression, safer sex practices (as they would have disclosed to their intimate partners), HIV knowledge, self-care, and responsibility for HIV treatment.

Gitahi (2020) asserts that little data is available on the long-term psychosocial effects of disclosure of HIV status that may occur in late adolescence or when disclosure is timely, but the WHO recommended that as part of the long-term management of children of school-going age, children living with HIV infection should be told their HIV status incrementally to accommodate the cognitive skills and emotional maturity in preparation for full disclosure (Gyamfi, Appiah-Brempong & Ench, 2017). The American Academy of Paediatrics (AAP) concur with the WHO's recommendation and emphasises the importance of an individualised approach in the disclosure process. However, the academy also suggests that younger children should not be informed of their diagnosis but should have their illness discussed with them. (Gyamfi, Appiah-Brempong & Enoch, 2017).

The South African National Guideline on Disclosure Guidelines for children and adolescents in the context of HIV, TB and non-communicable disease provides the processes and legal framework of HIV disclosure (The National Department of Health South Africa, 2016). WHO also provided guidelines on disclosure and developed a manual for health care workers to support caregivers with the disclosure of the HIV status (Doat, Negarandeh & Mazieh, 2019). The WHO has indicated that low rates of disclosure of HIV positive status among adolescents was a result of lack of skills to render a competent work following the process of disclosure (WHO, 2016). Moreover, the findings of the study by Mhairi also concur that the processes and guidelines provided by WHO and The South African National Guideline on Disclosure Guidelines for children were not followed as many health care providers were either not competent or not willing to disclose adolescents' status to them (Mhairi, 2019).

Literature by Dahourou, Raynaud and Leroy (2018) shows that HIV full disclosure rates have increased, but this remains insufficient and occurs at a late age with the median age being 13 years. This has resulted in many discrepancies as the process of disclosure to adolescents depends entirely on the people involved in the care of the adolescent or child, mostly caregivers and health care workers. The results of another study found that most caregivers, especially mothers, have difficulty in disclosing their HIV status to their children (Dahourou *et al.*, 2018). Some barriers to disclosure by parents and caregivers as outlined by Gyamfi and colleagues are:

i. The age of the child. Many caregivers consider children 13 years and below to be too young to understand issues of HIV.

ii. The aftermath of disclosure. Caregivers or parents generally fears the possibility of undesirable consequences of disclosure that include the relationship between the mother and the child. Psychosocial wellbeing and the perception that children will see their parents as having led an irresponsible life which led to them contracting HIV infection (Gyamfi, Appiah-Brempong & Enoch, 2017).

Maladzi, Bandawe and Umar, (2014) also reported that guardians, especially biological parents of children perinatally infected with HIV, find it difficult to inform their children about their HIV status as they view HIV disclosure to their children as a psychosocial process that has the potential to disturb a family's previously established equilibrium with threats of stigmatisation, marginalisation, and parent-child conflict.

2.6.1 The importance of Self-Disclosure

Mpofu and Jacobs (2017) alluded that adolescents perceive self-disclosure of their status as an opportunity to receive the support they need from the people they perceive to be important in their lives. However, despite the opportunity to receive support, there is also the chance that if they self-disclose, their status might not be treated as confidential, which may in turn lead to moral judgement from the community. They are therefore not only confronted with the decision to self-disclose or not, but also with the fear of being alienated by their peers.

According to Mpofu and Jacobs' research, social beliefs and assumptions regarding HIV provide a significant barrier to self-disclosure for adolescents living with HIV infection. Most adolescents believe that disclosing their HIV status is helpful to their well-being, but they are also afraid of the consequences and do not want to risk estrangement from their classmates and community (Mpofu & Jacobs, 2017).

Kidman (2020) pointed out that several factors which facilitated self-disclosure to peers were: being older, being a paternal orphan, contributing to family income, regular visits to the HIV clinic, and greater social support through peers.

Zgambo, Kalembo and Mbakaya (2018) assert that HIV-positive status self-disclosure is associated with a healthy lifestyle and the improvement of the quality of life. The study recommends that it be prioritised and encouraged by healthcare workers, policymakers and parents and be included as an essential part of the management for adolescents. This will equip them with skills and knowledge on how to disclose their status to important people outside their family members, such as teachers and close friends who are likely to support them with their daily living with the HIV infection (Zgambo *et al.,* 2018*).* The findings of a study conducted by Kest *et al*. (2016) reported that only 25% of adolescents disclosed their HIV-positive status to their sexual partners.

2.7 Perceptions of adolescents about ARVs

A common barrier on the management of HIV among adolescents was poor adherence to HIV treatment by some adolescents (Mpofu & Jacobs, 2017) (AIDS info, 2019). In a qualitative study by Mweemba (2015), interviews with caregivers showed that some adolescents did not regularly take their medication and at times threatened to stop taking medication. However, Vreeman and colleagues indicated both psychological and cognitive developmental factors may contribute to adherence challenges and should be assessed regularly. Moreover, many are at risk of mental health issues, including psychiatric, behavioural and substance use disorder that may interfere with adherence (Vreeman *et al.*, 2017).

According to the findings of a study on factors influencing antiretroviral treatment, suboptimal adherence among perinatal HIV-infected adolescents in Thailand, most adolescents had good knowledge about HIV/AIDS and ART, including the consequences of developing resistance to suboptimal adherence (XU, 2017). Xu further found that many people reported getting training from a variety of places, including health care providers, support groups, and community health educators. As a result of treatment, these teenagers reported improved skin conditions (no rashes), strength, and overall health. However, there were concerns raised about side-effects such as lipodystrophy and interference with daily activities (headaches and gastrointestinal issues). They also voiced weariness and the belief that "the condition is incurable" when describing their long-term therapy (XU, 2017). Another study conducted in South Africa among adolescents and caregivers reported that the responsibility for adolescent ART adherence and the relationships with VL suppression among perinatal HIV-infected corroborates the findings of the previous study. The study's findings revealed high levels of increased viral load, particularly among older, male participants. Frequent reports of missing ART doses in the previous 30 days. Furthermore, the findings revealed a significant proportion of adherence issues among younger children who were under the care of caretakers, which was backed up by high levels of viral load (Brittain *et al.*, 2018).

2.8 Existing interventions on the management of perinatally acquired HIV infected adolescents

There is currently no comprehensive global strategy for transitioning to adult HIV care. However, according to UNAIDS (2021), several preventive approaches which include continuous health education on the consistent use of condoms and other behavioural adjustments, universal testing and treatment, and voluntary male circumcision, were initiated worldwide. According to AIDS Info Report, new HIV infections were declining, however, children who transitioned into adolescents' care settings showed higher rates of attrition than those who stayed in paediatric care (AIDS info, 2019). During the transition to adult care, many teenagers drop out of therapeutic interventions, leaving them vulnerable to HIV progression and transmission to partners.

A study of health professionals' perceptions on the care management of young people with perinatally acquired HIV during transition found that there was a shortage of formal training among health professionals, particularly nurses. This was of great concern as they are the primary health care providers for these adolescents and were incompetent regarding issues affecting adolescents, especially those living with perinatal HIV infection. Adaptive practices were unofficially implemented on adolescents using available resources and experiences (Le Roux *et al.*, 2017). Armstrong *et al.* (2018) believe that there is still a lot of work to be done to figure out what works best for this population. To inform innovative and targeted initiatives that guide adolescent HIV policy, more rigorous data is required. Guidelines on the management of HIV in adolescents have been outlined, but they do not specifically address adolescents who are living with perinatal HIV infection (WHO, 2014).

Adherence to antiretroviral medication has been identified as one of the key challenges to adolescents' HIV management. (Brittain *et al.*, 2018; Xu *et al.*, 2019). Armstrong *et al*. (2018) asserted that monitoring adherence in adolescence is a critical step in recognising problems before therapy failure. Objective adherence monitoring remains problematic for the programs as monitoring and evaluation of these adolescents depends on self-reporting adherence or pill-counting, as well as restricted access to routine viral-load monitoring. The use of efficient monitoring technologies was suggested. More suggestions on drug-related techniques were made to maximise treatment options and to ensure long-term adherence through the simplification of antiretroviral regimens, the harmonization with adult regimens, and the identification of optimum antiretroviral sequencing to protect future therapy options (Armstrong *et al.*, 2018).

The Medecins Sans Frontieres (MSF) initiated an intervention in the form of adherence club model. This model focuses on patient participation and peer support, for improved treatment adherence. It aims on the provision of non-interrupted supply of drugs by providing a more supportive environment (Mills, Lester & Ford, 2012).

2.8.1 Existing interventions in South Africa

WHO, together with the NDoH in South Africa developed several strategies to assist adolescents with transitioning from childhood through to adolescence and adulthood. However, as the community of these adolescents have recently emerged or transitioned from paediatric care, much has not been done as far individualising their care. They rely on the umbrella guidelines provided by the WHO for overall management of adolescents (WHO, 2016). One of the strategies provided in the ART management of adults and adolescents (WHO, 2016) advocates for the establishment and integration of adolescents in peer support group structures in health facilities. According to Stangi, Mwangala, Mwale, Sebanyi, Mackworth-Young, *et al*., (2021), a structured support groups is aimed at assisting participants to safely navigate through their lives and also offers critical support gaps. A study conducted by Gitahi (2020) also highlighted the importance of peer support in late adolescents as a strong key in the acceptance of HIV status and also coping with living with HIV. A lack of attendance of support group means that adolescents must find social support elsewhere. Another strategy developed to assist adolescents was the VUKA family program. This program was aimed at facilitating family- based psychosocial intervention to promote health and mental health among HIV infected in early adolescents in South Africa. Report on the implementation of this program showed great improvement on mental health and behaviour in early adolescents (between the ages 10-13 years) (Bhana, Mellins, Petersen, Alicea, Myeza *et al*, 2014).

2.9 The theoretical framework: Life course theory

One aspect of a literature review is the review of the theory that guides the study. The theoretical framework explains the path of a research and grounds it firmly in theoretical constructs. The overall aim of the two frameworks is to make research findings more meaningful and acceptable to the theoretical constructs in the research field.

Ravitch and Carl (2016), concur that the theoretical framework assists researchers in situating and contextualising formal theories into their studies as a guide. During the search for the appropriate theory to guide this research, the researcher identified the life course theory. The theoretical framework has assisted the researcher to contextualise and position the findings of this study into a life course theory as a guidance into developing a user-friendly support programme.

The life course theory, also known as the life course perspective, refers to an approach developed in the 1960s for analysing people's lives within the structural, social, and cultural context. This theory or perspective has assisted the researcher to explore and understands the challenges faced by adolescents living with perinatally acquired HIV within a structural, social, and cultural context and contextualise them into a theory for the development of a user-friendly support programme for adolescents living with perinatally acquired HIV.

Elder *et al.* (2003) indicated that the life course perspective deems persons capable of making choices if they are provided with information. WHO (2018) states that the life course approach takes a temporal societal perspective on the health of individuals and generations. They recognise that all the stages of a person's life are intricately intertwined with each other, with the lives of others born in the same period, with the lives of the past and the future generations. It further states that adopting the life course approach requires taking an action early in the life of a person. They view life course approach as the cornerstone of the policy framework focus on improving health and health equity.

Key principles and concepts of the life course theory

The life course theory is characterised by several fundamental principles including socio-historical life, timing of lives, linked lives or social ties to others, and human agency (Black, Holditch-Davis & Miles, 2009)

- **Time and place**

Sociologists and social historians discovered that historical time may produce group effects which occur when social change affects one group differently than it affects other groups (UK Essays, 2018). Lifespan development is characterised by the view that humans develop biologically, socially and psychologically in meaningful ways and that earlier experiences and attachments shape a person's adulthood. In a study on children and the great depression in 1974, Elder discovered that the life course of young children at the time of economic crisis was more affected by the hardships their parents went through than that of young adults and adolescents. The current study discovered that the life course of the older adolescents was affected more by the historic moments of their HIV infection than the younger adolescents (UK Essays, 2018).

- **Agency**

Elder, Johnson and Crosnoe (2003) believes that individuals construct their lives through the choices and actions they take within the opportunities and constraints of history and social circumstances. George (1996) indicated that childhood events sometimes shape people's lives 40 to 50 years later. The opportunities and the constraints which an individual encounter in their life course determine the choices their make. Scholars have suggested that it is not simply the timing, sequencing, spacing and duration of hardships that affect young people as they the transition into adulthood, hence they have borrowed the concept of cumulative advantage and cumulative disadvantage from sociologist Robert Mertob to explain inequality within groups across the life course (Bartley *et al*., 1997; O'Rand, 1996).

- **Principle of timing**

A life course approach to chronic disease epidemiology uses a multidisciplinary framework to understand the importance of time and timing in associations between exposures and outcomes at the individual and population levels. Such an approach to chronic diseases is enriched by specification of the way that time and timing in relation to physical growth, reproduction, infection, social mobility, and behavioural transitions, etc., influence various adult chronic diseases in different ways, and more ambitiously, by how these temporal processes are interconnected and manifested in population-level disease trend (Lynch & Smith, 2005).

This study explored the importance of timing of HIV infection amongst adolescents with perinatally acquired HIV. The results of the study showed that adolescents viewed the timing of their HIV infection (at an early age) as "off time" as it affects their relationships with others according to sexuality and reproduction. It has been discovered by the findings of the study that participants who are aware of their HIV status find it difficult to divulge their HIV positive status to their sexual partners with the fear of being stigmatised. It has also been noted that participants verbalised that HIV infection later in life would be relevant and make transition from childhood to adolescence much easier in terms of sexuality and reproduction as the study findings discovered that transitioning from childhood to adolescence of these individuals is not easy as they encounter many challenges compared to the adolescents of their age group without perinatally acquired HIV.

UK Essays (2015) reckon that chronological age is not the only a factor involved in the timing of lives because the timing of transitions is based on social norms. The study explored childbearing of adolescents with perinatally acquired HIV, and it was discovered that they give birth at early adolescence like their HIV negative counterparts.

- Linked lives

Elder (1998) reiterates that lives that are lived interdependently and social historical influences are expressed through this network of shared relationships (Elder, 1998). The current study explored the challenge these adolescents face at home, in the community and at school. This study further paid attention to family as the source of support and control, as well as community and financial support systems.

Chase-Lansdale (1997) reckons that a family seems to have more influence on child and adolescents than the neighbour does. Links between families, the findings of the current study found that adolescents' dependent entirely on their families for support in its totality. The results of the study also discovered that most adolescents who either one parent or both were dead faced more challenges especially on support. About 0.8% of respondents in quantitative study who verbalised the wish to die were orphans living with either grandparents or relatives. The pattern of mutual support between older adults and their children is formed by life events and transition across the life course. It is also changed when families go through historical disruptions such as wars or major economic downturns.

The study also It was also explored by the relationship with peers and availability of friends to determine the social influences.

2.9.1 Intention

Ajzen and Madden (1986) described intentions as the immediate determinants that influence the performance of any behaviour of interest. The life course theory assume that intentions determine and shape outcome of individuals and they live in a reasonably ordered manner. (Elder & Johnson, 2003). Life course epidemiology investigates the long-term effects of physical and social exposure during gestation, childhood, adolescence, young adulthood to late adult life on health and disease risk in later life. It also encompasses pathways (biological, behavioural and psychosocial) influencing the development of chronic diseases and operating across individual‘s life course and across generations (Jacob, Baird, Barker, Cooper & Hanson, 2015). This theory assisted the research develop an in-depth interview guide which sought to explore these adolescents holistically. This study has adopted the WHO essentials of the life course approach

2.10 Contextual factors affecting the health and well-being throughout the life course

Jacobs *et al.*, 2015 classified these factors into Behavioural (smoking, alcohol abuse, physical activity and diet and nutrition), environmental factors, and psychosocial factors.

Developmental risk and protection

Developmental experiences have serious impact in the life course of an individual (UK Essays, 2018). The findings of this study also concur with the above statement. The findings of the study found that the life course of adolescents whose parents died due to HIV/AIDS were different from those whom their parents were still alive or died late in their adolescence. The latter experienced more unsteady and more hardships than the former. It was also discovered that most adolescents without parents, no procedure was followed in disclosing their HIV status.

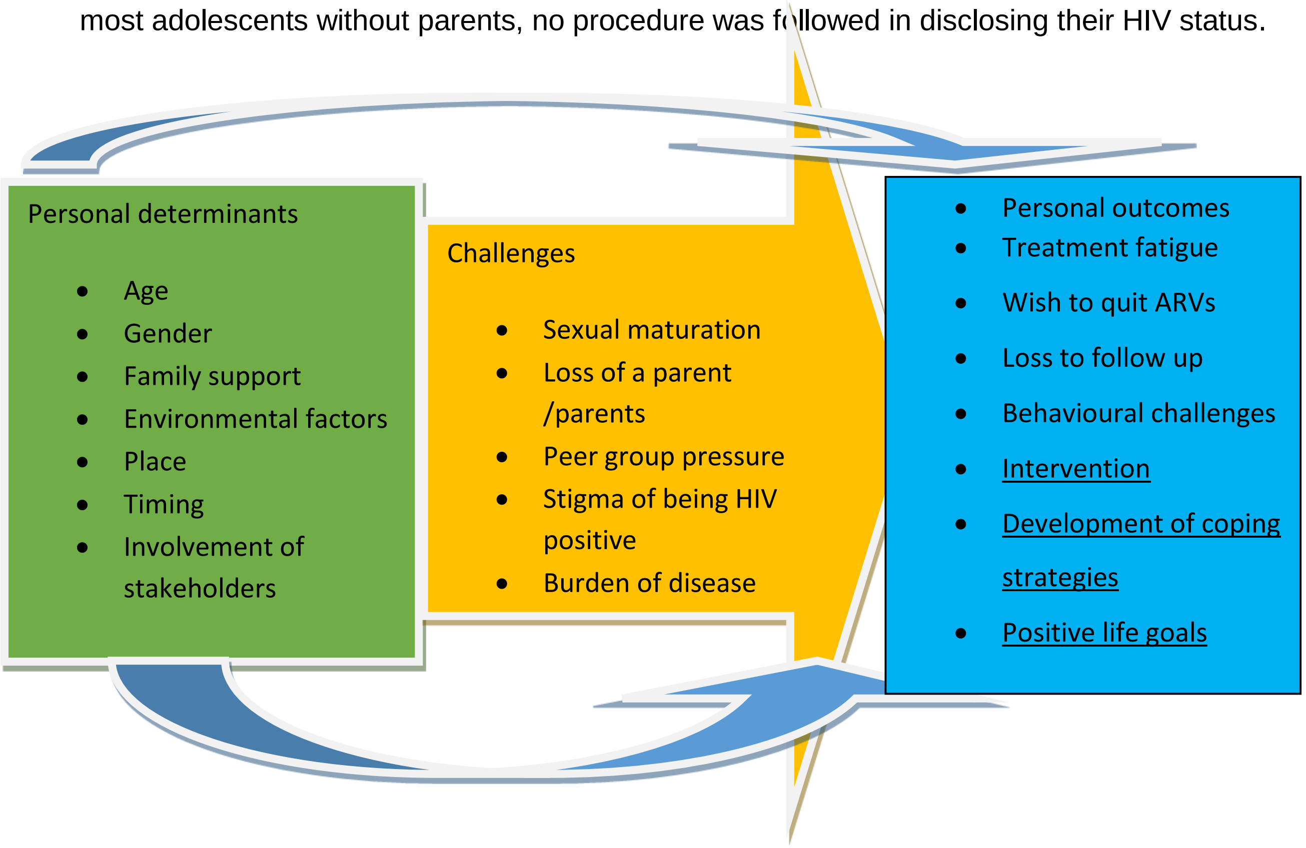


Figure 2.2. Schematic representation of the life course theory

The figure above presents the schematic life course theory. The researcher utilised the collected data from adolescents to explore their experiences and challenges to develop a user-friendly support programme**.** The following personal determinants were explored using qualitative and quantitative measures to rigorously explore the challenges, determine the support needs for these adolescents**.** The researcher explored the challenges and the support need through semi-structured interviews and responses to a structured questionnaire.

Personal determinants

- **Age**
  Age differences were explored between 12-15 and 16-19 years. The results of the study identified no association of significance however, it revealed that the younger adolescents lead riskier life than the older ones. This has subsequently indicated that the older adolescents were coping much better living with vertical HIV than the younger group.
- **Gender**
  To develop a relevant user-friendly support programme, the researcher sought knowledge on the gender that was coping more than the other. The findings revealed that there were more girls with adolescents than boys, but boy adolescents proved to be coping much better than girls. Girls were riskier in sexual relationship than boys.
- **Family support**
  Adolescents lacked much-needed social, emotional, and financial support from their families. This was aggravated by a loss of parents due to HIV as adolescents had to stay with relatives or extended families. Adolescents reported to lack money for transport to fetch their medication.
- **Place**

  The findings of the study revealed that most of the adolescents were residing in rural areas that was characterised by poverty.
- Timing
  All adolescents in the current study were vertically infected and had been on ARVs for a long time. Most adolescents expressed medication-fatigue and their wish to quit ARVs.
- **Involvement of other stake holders**
  The findings revealed that all adolescents verbalised not to be supported by their community structures because they had not disclosed their HIV status to other people due to fear of being stigmatised and discriminated.

Challenges

Secondly, the researcher then collected qualitative data in Phase 1 conducting individual interviews with adolescents explore challenges faced in due to living with HIV. This was followed by collecting quantitative data in second phase with adolescents using a questionnaire. The results also guided the development of a user-friendly support programme. Some of the challenges expressed by the adolescents were discussed below and they gave direction to the researcher on the content of the user-friendly support programme

- **Fear of being stigmatised and discrimination**
  The findings of the study revealed that adolescents were living in fear of being ridiculed and stigmatised by the community because they were living with HIV. Hence, they did not disclose the HIV status to others and to sexual partners due to perceived stigma and discrimination that surrounds living with HIV.
- **Peer group pressure**
  Adolescents verbalised being burdened by the pressure they experience from their peers and friends.
- Loss of parent/s due to HIV
  The findings revealed that above quarter of the adolescents have lost either, one or both parents due to HIV. It was also noted that adolescents recounted a lot of challenges because they were forced to live with relatives.

Negative outcomes of the challenges faced by adolescents

The researcher then analysed the findings of the study and generated results that guided the development of the user-friendly support programme. The results revealed several negative behaviours that lead by adolescents due to the challenges the encounter in their daily lives. The ultimate behaviours reported by adolescents also guided the direction which the support programme had to follow.

- **Treatment fatigue**

The findings of the study revealed that adolescents were tired of taking daily ARVs. Treatment fatigue was linked to several factors like the size, taste and medication curfews.

- **Wish to quit medication**
  Adolescents expressed the wish to quit medication, but factors such as fear of death and side-effects were mentioned as some reasons adolescents did not quit their ARVs.
- **Behaviour challenges**
  Adolescents exhibit risky behaviour which poses a danger to them and others they are associated with. The study findings proved that adolescents engaged in risky sexual behaviours, and some were also risky drinkers. Unprotected sexual intercourse and the use of substance had been proven by yesterday’s studies as detrimental to their health and the health of their sexual partners as risker as they could infect their HIV negative sexual partners and running a risk of becoming pregnant.

In response to the challenges discovered in this study. The researcher embarked on the goal of this study which was to develop a user-friendly support programme for adolescent in the Vhembe District. A user-friendly support programme was developed to address needs and the challenges of the adolescents. SA Specific Learning Objectives (SLO) were developed based on the integrated results from qualitative and quantitative study. The user-friendly support programme for adolescents was implemented on these adolescents which was the fifth objective of the study. A short-term goal that are according to logic model were assessed in the form of evaluation. Which was the last objective of the study. Evaluation of the programme is discussed more on the next chapter.

2.11 Conclusion

This chapter outlined the literature review. A narrative or a traditional review of literature was conducted. The overview of the literature conducted on adolescents who are living with perinatally acquired HIV was critiqued. Themes and sub-themes were developed. A review and analysis of studies on adolescents living with perinatally acquired HIV from around the world, on the African continent, and locally was undertaken. Several studies focused on the rising number of teenagers living with perinatally acquired HIV while others looked at the issues these adolescents face on a daily basis. This chapter further reviewed theoretical and conceptual framework to guide the course of the study. However, there is a paucity of literature on the specific treatment or programs that are designed to address the issues that these teenagers encounter. As a result, the current study, as well as future studies, should delve deeper into these issues and propose solutions to address them. The next chapter goes into the research technique.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The literature review was discussed in the preceding chapter. This chapter outlines the research methodology which guided the whole research. The main purpose of this study was to develop a user-friendly support programme for adolescents living with perinatally acquired HIV in the Vhembe District by exploring their lived experiences, challenges and determining their support needs. Owing to the complexity of this and the limited studies done on these adolescents, this study employed both qualitative and quantitative approaches sequentially to get a full picture to develop a comprehensive user-friendly support programme. This chapter outlined the research design, data collection methods, population and sample selection, qualitative and quantitative strand, data analysis, ethical considerations, reliability and validity and measures to ensure trustworthiness**.**

3.2 METHODOLOGY

Methodology has been described by (Chongwa, 2018) as the process of data collection in research. Furthermore, it is determined by the research problem and the understanding of research. On the other continuum, research methodology is defined as the practicality of a research. Furthermore, it is described as how the researcher systematically designs a study to ensure validity and reliability of research to address the aim and objectives thereof. A good research methodology determines the quality of the results which is scientifically sound, valid, and reliable (Jansen & Warren, 2020).

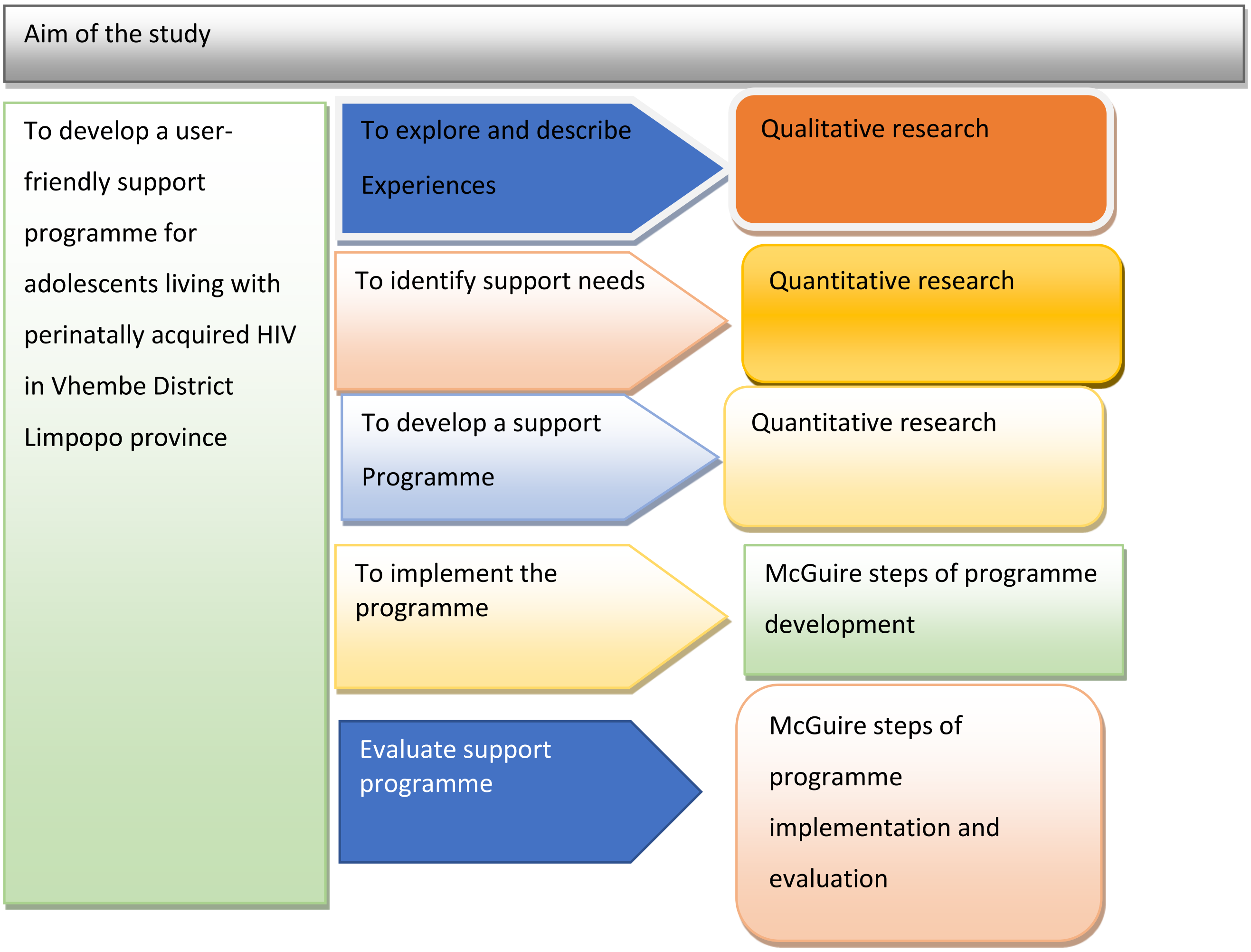


Figure 3.1. The overview of the research methodology

Figure 3.1 above presents the overall research methodology used in this study. Esquivel (2014) defines methodology as the route to perform actions pertaining to research, either to solve the problem regarding an object of the study or to solve a necessity. Dilcha (2019), presents research methodology as a path or steps through which researchers conduct their research. To achieve study objectives, the study adopted Mixed Methods Research (MMR) approach to collect and analyse data.

3.2.1 Research approach

The MMR is an approach that involves collecting and analysing qualitative and quantitative data in the same study (Mahmood, 2012; Creswell, 2008). The use of MMR has become so common in recent years because it provides a detailed and comprehensive data to achieve research objectives because both qualitative and quantitative data are collected and analysed and produces the results of greater strength than those of qualitative or quantitative alone (Creswell & Clark, 2007).

DeCuir-Gunby & Schutz (2016) outlined the benefits of using MMR include: providing strengths that offset the weaknesses of both quantitative and qualitative research. Providing a more comprehensive understanding of the research problem than either quantitative or qualitative approaches alone, and providing an approach for developing better and more context-specific instruments, thus helping to explain findings on how causal processes work. This phase, the researcher spent more time on exploring adolescents to get an in-depth information on the experiences, challenges and the support needs of adolescents and produced the results, then the results of the qualitative study to was used to develop a content – a specific quantitative tool which in this case is a questionnaire. The questionnaire developed from a qualitative result was used to collect quantitative data.

3.2.2 The research design

This study adopted sequential exploratory design. Sequential exploratory design is, according to Creswell and Clark (2018) a method for collecting and analysing both qualitative and quantitative data in a sequential manner. This design comprises two sets of individual and complete studies. Thus, that is according to (Dilcha, 2019) the first phase, qualitative data is collected and analysed to produce the results and the results of the qualitative study informs the development of a quantitative data collection tool. Figure 4.2 below summarises sequential exploratory design.

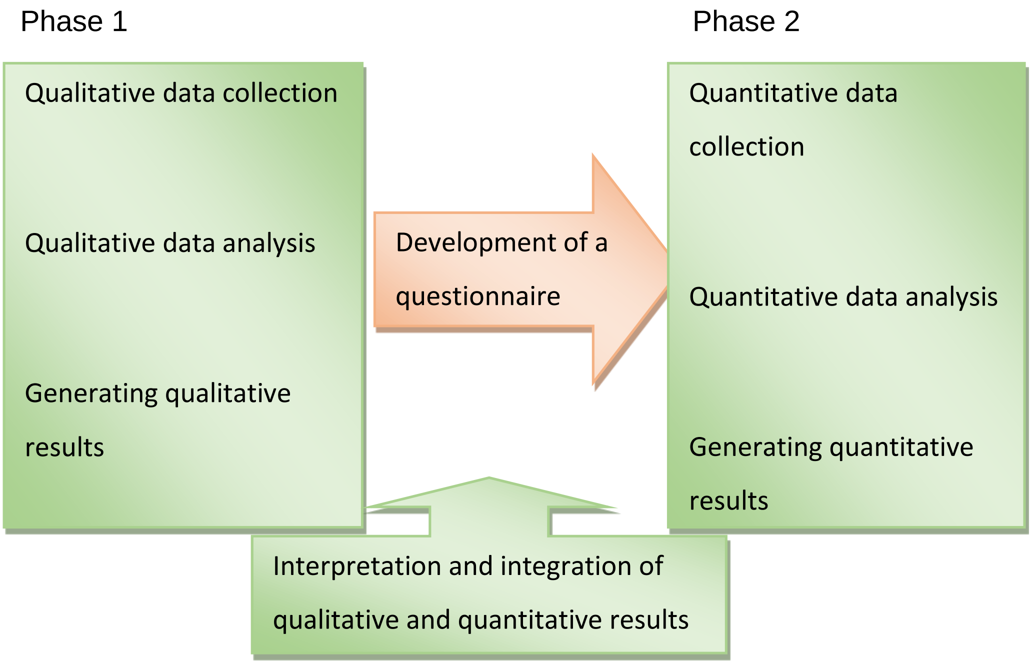


Figure 3.2. Summary of the sequential exploratory mixed-methods design. Source: adapted from Creswell and Clark (2018).

Figure 3.2 above presents the summary of the sequential exploratory design. It implies that the first phase of the study which is the qualitative phase, data collection focused more on exploring experiences, challenges and the support needs of adolescents living with perinatal HIV infection in the Vhembe District. The researcher used qualitative research methods to collect, analyse and produce results. Using the first qualitative phase results, the researcher embarked on the second quantitative data collection. The results of the qualitative phase, which included in-depth interviews with adolescents, were utilised to create a quantitative data collecting tool, a questionnaire, which was used to gather the second quantitative data from adolescents with prenatal HIV infection. A user-friendly support programme was developed and using the formative findings of the study and evaluated using an evaluation tool (appendix 15).

3.2.3 The philosophical underpinning of mixed method research

Doyle, Brandy and Byme (2009) indicated that the main purpose of underpinning Mixed Methods Research is for concretisation and coding. They further described coding as the convergence and corroboration of two research methods in one study provide the factors serving as a basis for underpinning Mixed Methods Research which are the following:

- Triangulation: It enhances corroboration and or convergence of two research methods in one study, hence it allows greater validity.
- The Complementary: It enhance elaboration of the results from both qualitative and quantitative study. It allows the researcher to get a complete picture of the phenomenon from both qualitative and quantitative studies respectively (Pilot and Beck, 2012).
- Development: The use of MMR assists the researcher with developing a better data collection tool by either using the results of the previous study to develop a detailed data collection instrument (UK Essays, 2018).
- Initiation: The use of MMR assists to iron with the restructuring of the questions with the replica from the other method (UK Essays, 2018).
- Expansion: MMR allows the span and expand on exploring a variety of different research method resulting in the expansion of the scope of the study (Doyle, Brandy and Byme, 2009).

Triangulation

The triangulation design is commonly used to obtain different but complementary data on the same topic to best understand the topic (Creswell & Clark, 2003). Moule and Goodman (2014) Defined triangulation defined as the application of two or more research procedures, data collection methods, or analysis techniques in a single study. Furthermore, Naeem (2019) echo the definition of triangulation above by describing triangulation also describe it as cross examination as the use of two or more research methods for the verification of the findings and results. In addition, the adoption of the MMR sequential exploratory design was to allow triangulation as alluded by Doyle, Brady and Byme (2009) which in turn allows greater validity. In consistent with the previous researchers, Naeem (2019) corroborated that the rationale behind using triangulation is for more confidence and increased credibility and reliability of the study findings when using different methods to produce similar results.

In this study, the researcher collected data in different sub-districts in the Vhembe District (space triangulation) to people who speak different languages (Xitsonga and Tshivenda)
(Person triangulation). The researcher used different methods to collect data. For example, when collecting qualitative data, interviews using semi-structured questions were used; field notes where non-verbal communication and other cues were noted; a questionnaire was used to collect data and obtain quantitative (data triangulation) to develop a user-friendly support program for adolescents living with perinatally acquired HIV in the Vhembe District.
Furthermore, it allowed the researcher to gain an understanding on the experiences and challenges of adolescents living with perinatally acquired HIV in the first or initial phase by using a qualitative data collection tool which is a semi-structured interview guide. The use of this approach ultimately gave the researcher a balanced and more detailed picture of adolescents living with perinatally acquired HIV in the Vhembe District.

3.3 STUDY SITE

Figure 3.3. Limpopo health care map

The study was conducted in the Vhembe District in three municipalities or sub-districts which are Collins Chabane, Thulamela and Musina in selected at CHCs and clinics. These facilities were chosen because they provide HIV/AIDS care and management, including the distribution of antiretroviral therapy (ARVs) to adolescents with perinatal HIV. Since the rollout of ARVs in South Africa, almost all primary health care facilities offer HIV/AIDS care and management. The Vhembe District is situated in the far east of Limpopo Province in South Africa. This District has health care facilities which provide HIV/AIDS care and management to adolescents living with perinatally acquired HIV in urban, semi-urban and rural areas. Most primary health care facilities are found in the deep rural areas of Vhembe District. HIV/AIDS management in these facilities is primarily run by Nurse-Initiated and Management of Anti-Retroviral Therapy (NIMART) trained nurses. Where they do not have a site doctor only a visiting doctor once a week, which makes management of ARV sites difficult. Vhembe District is dominated mostly by unemployed people who depend entirely on the government for financial assistance (Limpopo stats, 2021). The primary health care facilities are situated far apart, far more than the 10kms stipulated by the World Health Organization which worsens the situation for this poverty-stricken District (WHO, 2000).

The District has four sub districts, which are Musina, Makhado, Thulamela and Collins Chabane. Xitsonga and Tshivhenda speaking people dominate the district. The Vhembe District has 112 clinics, 8 community health centres, 1 regional hospital, 6 District hospitals and 22 mobile clinics (Limpopo statistics, 2011). The map of the study site is shown below.

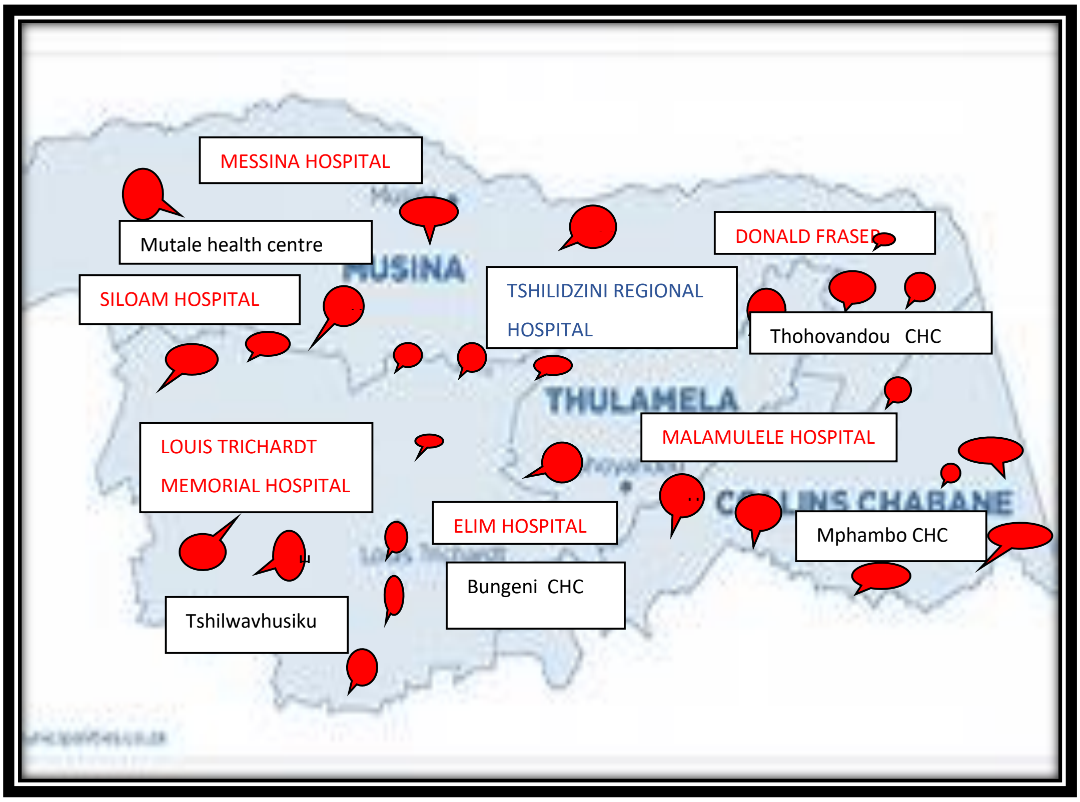


Figure 3.4 Vhembe District clinics and primary health care centres

Key: Vhembe clinics = ●

3.4 STUDY POPULATION

Lapan, Quartaroli and Riemar (2012) defined the study population as people who are the focus of the study. The total population adolescents' registered as living with perinatally acquired HIV in the Vhembe District was 2117. These included all adolescents in public primary health care centres and clinics in urban and rural areas in the four municipalities of the District, which are Thulamela, Collins Chabane, Makhado and Musina. Therefore, the study was conducted in only three municipalities which are Thulamela, Collins Chabane and Musina due to demarcation issues at the time of the commencement of the study. The population size also included Makhado municipality. Adolescents living with the perinatally acquired HIV aged 10 to 19 years in the Vhembe District of Limpopo Province were included. The study targeted all perinatally acquired HIV adolescents, who have enrolled in the HIV care and management in the Vhembe District, and they are on ARV. Only adolescents who started medication before the age of 10 years as indicated on the inclusion criteria as the data in the District includes all adolescents taking ARVs who are these ages. The figure above shows the map of health centres and primary health care clinics offering HIV/AIDS management and treatment (Figure 3. 4).

Table 3. 1 Summary of adolescents in municipalities

Municipality	Number	Proportion
Collins Chabane	823	38.9%
Thulamela	720	34.0%
Musina	574	27.1%
Total	2117	100%

3.5 PHASE 1- QUALITATIVE STRAND OF THE STUDY

The initial phase of this study was qualitative data collection and analysis followed by a second quantitative phase.

3.5.1 The sampling method

A Sample is described as the specific group of individuals a researcher wants to collect data from (McCombes, 2021). Sampling in the study was done in multi stages. Stage 1 sampled facilities using stratified random sampling and stage 2 sampled participants using purposive sampling.

Stage 1.

- The Facility sampling

This stage used stratified random sampling for sampling of the facilities. Stratified random sampling also known as stratification is the process of dividing members or population of into subpopulations or subgroups called strata based on specific characteristics such as race, gender, location. McCombes (2021) indicated that these sub-populations may differ in important ways. Therefore, the sub-divisions allow the researcher to draw precise conclusions through ensuring that every subgroup is properly represented. According to (Saksena, 2020) stratification entails dividing the entire population into several non-overlapping classes or stratum and drawing random samples from each stratum and the concluded by combining all units together. Stratified random sampling is used in populations with different characteristics, for example, different mean values (Thomas, 2020). Goel (2014 emphasise that stratified sampling allows one to draw a sample with any desired degree of representation of various parts of the population by using strata). Additionally, facilities were classified using stratified random sampling was used to stratify Primary Healthcare (PHC) clinics into: sub districts, then further into: urban, semi urban and rural. Three sub-districts were identified which are Thulamela, Collins Chabane and Musina. From the three sub-districts in the Vhembe District, PHC facilities were stratified into rural, semi-urban and urban. Each stratum comprised of 2 facilities and 1 community health centre were selected randomly as part of the study sites.

Randomisation of facilities per strata was done by compiling a list with all the names of the clinics was compiled per strata. Put inside a basket and 2 clinics were randomly picked up for example, a list of all clinics in situated in rural communities in one sub-district was compiled and put inside, reshuffled and the researcher picked 2 names randomly.

Table 3. 2 Summary of adolescents' selection for qualitative interviews per sub-district

Name of the sub-district	**Name of the facility**	**Strata**	**Number of participant/facilities**
Collins Chabane	Mphambo CHC	Semi-urban	2
	Mhinga clinic	Semi-urban	3
	Ntlhaveni C clinic	Rural	2
	Ntlhaveni D clinic	Rural	1
	Malamulele clinic	Urban	1
Thulamela	Thoyandou CHC	Urban	2
	Sibasa clinic		
	Duvhuledza clinic	urban	2
	Lwamondo clinic	Rural	1
	Tshakhuma clinic	Semi-urban	1
	Muledane clinic	Rural	
	Vhuruvhuri clinic		

Musina	Mutale CHC Nancefield clinic Musina gateway Tshipise clinic	Semi-urban Urban Semi-urban Rural	1 2 1 2
Total number interviewed			21

- Participants sampling

Adolescents on HIV care and management in selected clinics and community health centres in the Vhembe District were purposefully selected to participate in the study using homogenous purposive sampling. Homogenous sampling focuses on candidates who share similar characteristics or traits like age, cultures, or life experiences (Etikan, Musa & Alkassim, 2016). McCombes (2021) elaborated the use of purposive sampling to gain more knowledge about specific phenomenon rather than making statistical inferences. Adolescents living with perinatally acquired HIV were recruited to participate in the study.

Inclusion criteria

- Clinics and CHCs which offered HIV services and management of children and adolescents living with perinatally acquired HIV.
- Adolescents enrolled in HIV care and management with HIV infection in selected PHC clinics and community health centres in the 3 sub-Districts of Vhembe District.
- Teenagers and adolescents who have been on HIV care and management prior the age of 10
- They must be between the ages of 10 to 19 years
- They must have collected treatment for at least 6 months on their own without a caregiver or a parent

Exclusion criteria

- Adolescents who were diagnosed and started HIV care and management after the age of 10
- Adolescents who were living with perinatally acquired HIV and were also living with a chronic mental illness that was not controlled as their response could be influenced by their state of the mind.
- Perinatally acquired HIV adolescents were between the age of 10 and 19 but were not collecting ARVs on their own from the health care facilities.

3.5.2. Phase 1- Data collection process

For the purpose of this study, 21 in depth one-on-one interviews were conducted with participants attached to selected CHCs and clinics whereby challenges faced by adolescents living with perinatally acquired HIV were explored over a period of three months until data saturation was reached. The number of participants varied per facility with the mean of 2 per facility. The number of participants depended on the number and availability of adolescents who honoured the appointments with the researcher. Facilities that have more adolescents had more than 2 depending on data saturation.

- *Gaining access to the facilities*

Vuban, (2018) stated that localising access, which is a general ethical concept, is a viable strategy for approaching qualitative research participants and dealing with institutional norms in order to obtain meaningful data. In this study, the researcher went to the identified facilities to introduce the study and request permission to conduct it in their facilities. Operational managers as the gate keepers of the facilities were contacted in each facility to gain access to the facility and to assist with identifying of the adolescents included in the study. In each facility the researcher requested a staff member working directly with adolescents as a point of contact and to assist with the contacts of adolescents,

- *The Research Assistants*

Two research assistants were hired to assist in the data collection process. They were: 1. A nurse and a 2. Master of Public Health (MPH) student. The researcher trained both research assistants for two days on data collection process, verbal and non-verbal communication skills, ethics in data collection which includes confidentiality and maintaining privacy for the participants. Their roles differed, the first research assistant who an MPH student assisted with data collection, conducting interviews with adolescents when the researcher was exhausted in case of more participants per facility. She also checked adolescents' files for verification of some information said by adolescents during interviews and assisted with writing field notes. The second RA's (nurse) role was also to assist with field notes and assist with the urgent needs of adolescents during interviews like providing water and /tissue paper and also to liaise with the clinic staff for assistance in case a need arises during interview sessions. Accompanying the researcher when visiting facilities for introduction of the study to recruit volunteers and obtain permission to perform the study in the facilities.

- *Recruitment*

The researcher made appointments and conducted the interviews with participants using the interview guide with the assistance of the research assistants. Appointments were made with the assistance of the nurse who usually works with adolescents for easy access. The researcher requested a list and contact numbers of all adolescents meeting the criteria of the study. They were then contacted telephonically to make appointments. The researcher introduced herself on the phone and stated the purpose of the call and made appointments with adolescents. Appointments were made based to the adolescents' availability and preference. Some contact numbers provided by the health facility were no longer in use as they were not updated in the files, so the researcher checked the return dates for those adolescents to make personal arrangements. Transport money was made available for those who were staying far from the health facility. Participants under the age of 18 years were requested to come with the guardians/parents for signing of the consent form. The researcher requested permission from participants or guardians for participants under the age of 18 years and the facility managers to use the health facilities and they (parents/ guardians) were requested to accompany these adolescents for the purpose of signing the consent form). Due to the sensitivity of the topic, in facilities where there were more than two interviews one of the research assistants assisted with conducting the interview while the researcher takes field notes and observe the procession of the interview to avoid mental fatigue.

- *Preparation of an interview room*

One-on-one interviews were conducted in a consultation room which was not frequently used to maintain privacy and confidentiality in all facilities. In certain facilities, interviews were delayed, especially those which appointments were scheduled for mornings as some facilities were full and sometimes the room allocated was occupied due to a shortage of consultation rooms in those facilities. Therefore, an alternative venue which was also secured and within the facility premise were provided by staff members. A sign written "no noise, interview in progress" was placed outside the door to avoid interference during interview sessions.

Furniture in the allocated interview rooms were either shifted or temporarily placed outside in a secured place (with the permission of the Operational Manager or manager of the day) to create more space. Windows were opened for ventilation and curtains were opened for light, leaving the lace to avoid peeping through by passer-by's, to maintain privacy for adolescents. Two chairs were positioned in a squarely position at the centre of the room without a table in between for the researcher and adolescents. This was to avoid the feeling of supremacy and inferiority between the researcher and adolescents and to allow non-verbal communication like rubbing of the adolescents' back for comfort and provide a clear view for the RAs to collect non-verbal communication. Two more chairs were positioned at the different opposite corners of the room each RAs. The chair for the nurse RA was placed at the corner closer to the interview station for easy access and assistance. Although the researcher is a nurse by profession, the researcher together with the RAs were dressed casually to avoid influencing the way in which the adolescents responded (researcher bias).

- *Consent process*

Guardians or participants received a letter of information outlining the study's specifics. The interview guide was written in English, then translated into the two local languages spoken in the research area, Xitsonga and Tshivenda. Finally, back into English by a language specialist to ensure consistency (back to back translation). The researcher read and clarified concerns and misunderstandings on the letter of information to the adolescents and/guardians. A signed written consent was sought from adolescents and their parent/guardians by issuing out a detailed written consent form for adolescents and their parents/ guardians to read and make an informed choice. For those who could not read, the researcher, along with the assistant, read the consent form for them and gave it to them for signing. In this study, however, all adolescents together with their parents/guardians were able to sign and there was no need for a stamp pad for thumb signing. In the case where the participant was below the age of 18 years, she or he was considered a minor according to the South African constitution of 1994 (RSA, 1994). In this case, consent was sought from the participants' parents/guardians, with adolescents' assent given in their presence.

One-to-one interview was conducted with participants using an interview guide with open-ended questions. This allowed the interviewer to probe and get insight on the experiences of adolescents living with perinatal HIV. All interviews were audio taped as participants had given a written consent as it was one of the details of the study provided on the consent form.

The central question was **"how has living with HIV affected your life, kindly describe**?" One of the advantages of the using one-on-one interviews as indicated by Langkos (2014) is that it involves personal and direct encounter with the participants which is an advantage and it also reduces low response rates. Furthermore, interviewers should have the necessary interview skills to carry successful interviews to elicit more information from participants.

The researcher personally conducted the interviews in the presence of both research assistants. Interviews lasted between 25 and 60 minutes per session. Interviews were conducted using the language of the participant where in this case was either Xitsonga or Tshivenda. Non-verbal communication was also jotted down. Interviews were recorded using a voice recorder and the recordings were encrypted with a code which was only known by the researcher. RAs also noted body cues of adolescents, facial expressions and all non-verbal actions displayed by adolescents. Adolescents' files were also checked for verification of verbal information by adolescents. The researcher applied all communication skills to conduct the interviews which are outlined by Doyle (2021) which are listening, reflections, nodding summarising and paraphrasing, friendliness, clarity and concision, confidence, respect and giving feedback. Due to the sensitivity of the topic, some adolescents were emotional, which was displayed by crying. The researcher allowed them to vent out the emotions by allowing them to cry while giving a soft touch at the back as a form of comfort. They were also offered a glass of water to calm them. The researcher assessed them and enquired if they would continue with the interview or needed to reschedule the interview. After each interview, the researcher and the RAs debriefed for 30 minutes before embarking on another interview session. All those who needed counselling were referred for professional counselling by the psychologist. All the audio-taped interviews were listened to at the end of each day for completeness and transferred to researchers 'personal laptop and protected by a secured password for backup. The audio tapes and the field notes were stored and locked in a cupboard and the key remained with the researcher. These data collection tools are described below.

3.5.3. Data collection tools

i). Semi-structured interviews

The semi-structured interviews (appendix 17) use an open framework to allow for focused, conversational two-way dialogue. It entails a conversation between the researcher and the participant, which is directed by a customisable interview technique and augmented by follow-up questions, probes, and comments (Dejonckheere & Vaughn, 2019**).** Back –to-back translation of the interview guide was done. It was prepared in English and translated to Xitsonga and Tshivhenda respectively and back to English. The translation was done to allow all participants to express themselves in their own languages**.** It consisted of a series of pre-set questions, open-ended questions, supplemented by follow up questions, clarification, probing, and comments were asked.

ii) Voice recorder

The use of a voice recorder is necessary to 'counter criticism' that qualitative research is prone to systematic bias (Rutakumwa, Mugisha, Bernays, Kabunga, Mbonye & Seeley, 2019). During data collection, participants were informed about the use of a voice recorder and consent was sought from participants. Interviews were voice-recorded during one-on-one interview sessions. Voice-recorded interviews were transferred to the researcher's personal laptop which was protected by a password only known by the researcher for backup.

iii) Field notes

Field notes were used to capture non-verbal cues which were not recorded by a voice recorder. These cues included all events relating to the participants which happened during one-on-one interview by either the researcher or research assistant who was not conducting the interview to minimise interruptions and maximise the interviewer’s concentration. Field notes were incorporated and reflected with the voice recorded data during transcribing. Field notes in this study, were used to describe and capture adolescents living with perinatally acquired HIV, emotion, attitude, and physical appearance of participants to provide full insight of the participants.

3.5.4 Data analysis

Data was collected until saturation. In this study, data saturation was reached after Twenty-one (21) one-on-one interviews were conducted by the researcher. Raw data were obtained from participants through one-on-one interviews. Interviews were audio- taped, simultaneously translated to English and transcribed to get raw data in a paper for thematic analysis of data. according to (Warren, 2020) thematic data analysis takes large bodies of data and group them according to similarities (themes) to assist the researcher in making sense of the data and derive meaning out data. The researcher carefully read all twenty-one transcripts, line by line to make a meaning of the interviews. The researcher then noted all inputs on the transcripts which related to each other. They were then grouped together in a separate sheet and given a topic or a theme. After reading through all 21 transcripts, the researcher then extracted themes and sub-themes by giving them unique codes. These codes allowed the researcher to easily group them into themes and sub themes. An independent coder qualified in qualitative research coding was approached for analysis of all verbatim transcripts and an agreement with regard to the final themes and sub-themes which were independently identified by the researcher. The independent coder re-coded all 21 transcripts for comparison of the themes and sub-themes. The researcher and the independent coder agreed on the final themes and sub themes. Below is the summary of how data was analysed using Tesch’s eight steps of qualitative data analysis.

Tesch’s (Creswell, 2009) eight steps of data analysis were used to analyse qualitative data and it involved the following steps:

The procedure

- Step 1: the researcher and the research assistants transcribed all voice recordings translating them from Tshivenda and Xitsonga to English for analysis.
- After transcribing the audio voices, manual thematic analysis of the transcripts was conducted by the research through the reading of all transcripts and jotting down ideas on the margins as they came to the mind on each transcript to make sense of the whole idea. All 21 transcripts were read through, and ideas were jotted down on each of the scripts.
- Step 2: The most interesting of the transcript (script no 1) was carefully read by the researcher to make sense of the meaning of the information collect and jotted down these meanings on the margins of the transcript.
- Step 3: The researcher then wrote down a list of all topics based on the collected data and grouped similar topics and organise such topics into columns of either major topic, unique topics and those that were classified as leftover.
- Step 4: The researcher went back to the verbatim transcripts with topics written in columns to organise them into codes and wrote the codes next segment of the transcribed text. The researcher also checked if there were new codes that emerged as codes are allocated to the data collected.
- Step 5: The researcher identified the best wording of the topic and reduced a total list of topics and turned them into categories by grouping the topics that related to each other.
- Step 6. The researcher made abbreviations for each category and arranged the codes in alphabetic order.
- Step 7: The researcher then made an introductory analysis by collecting data material belonging to each category in one.
- Step 8. Existing data was then re-recorded. Themes and sub-themes were summarised and sent to the independent coder concerning the final themes and sub-themes which were independently identified by the reached and the independent coder was reached.

3. 6. MEASURES TO ENSURE TRUSTWORTHINESS

Lincon and Guba (1985) described trustworthiness as the extent to which a research study is worth paying attention to, worth taking note of, and the extent to which other researchers are convinced that the findings are to be trusted. Furthermore, is referred to as the degree of confidence in qualitative data interpretation and methods used in the study (Shenton, 2004). Trustworthiness is how the qualitative researchers make sure that their studies are transferable, credible, dependable, and confirmable (Lincoln & Guba, 1985. In pursuit of trustworthiness in this study, the researcher employed the above four criteria as outlined by Shenton.

3.6.1. Credibility

Credibility is described as the confidence that can be placed in the truth of the research findings. It reflects the value of research findings (Anney, 2014). The following criteria were made in this study to ensure credibility.1. Adoption of well-established research methods. The study employed sequential exploratory method to collect data. Tesch's eight steps of qualitative data analysis were adopted to analyse data which many researchers such as Theron, 2015; Mia, 2014 & Samuel & Madlala, 2020 have used in qualitative data analysis with success. To ensure that the study was credible, the following were observed:

i. Triangulation: Two data collection methods were used to collect data to maintain triangulation. The semi-structured, one-on-one interviews conducted with participants were audio recorded with an audio-recorder and was triangulated with participants' observations of the non-verbal actions done by the participants were noted as field notes. Field notes were recorded for accuracy of the data as Rutakumwa, Mugisha, Bernays, Kabunga, Tumwekwase *et al.,* (2019), stated that the disadvantage of audio recording interview processes is that researchers focus on audio taping the process and not the broader experience of the research.

ii. Examination of the previous research findings

A total of 101 articles and 56 studies on adolescents living with perinatally acquired HIV globally, published no earlier than 5 years ago, were sourced, reviewed, analysed and cited. Studies were reviewed to compare the findings and that of the current study to relate this study with the existing body of knowledge.

iii. Scrutiny of the research project

The research proposal was presented to the Department of Public Health, School of Health Sciences and Turfloop Research Ethics Committee (TREC) for scrutiny. Feedback and comments received from each presentation were welcomed and allowed the researcher to refine this study.

iv. Member checks

An audio recorder was used to capture actual articulations from participants to maintain the accuracy of data collected as Shenton recommends (Shenton, 2004). After each interview, the researcher summarised the entire discussion with each participant to ensure that they agreed with what was discussed.

3.6.2. Dependability

Frambach, Vleuten and Durning (2013) describe dependability as the extent to which the findings are consistent with the contexts in which they were generated. It involves appropriateness of inquiry, decision and methodological changes. Dependability in this study was ensured by collecting data until no new themes emerged (data saturation). Data was continuously analysed to inform further data collection (iterative data analysis). The study's research methodologies were described in detail, allowing a future researcher to replicate the work (Shenton, 2004). An independent coder did an inquiry audit by structuring the data and using supporting documents like field notes and voice recordings. A code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing and/or evocative attribute for a portion of language-based or visual data (Strauss, 1987). An independent coder identifies a passage in the text or other data items such as photographs and images, searching and identifying concepts and finding relations between them (CESSDA, 2020).

3.6.3. Transferability

The transferability of this study was verified using a full description of the qualitative research methodology employed, which included the research design, population, sampling method, data collection method, and data analysis. Adolescents who were HIV-positive perinatally were chosen for the study using a method called purposive sampling. (Trochim, 2006). Findings from the study were discussed alongside existing literature from different studies to relate this study with the existing body of knowledge (Frambach *et al.*, 2013).

3.6.4. Confirmability

Confirmability is defined as the extent to which the findings are based on the study’s participants and settings instead of researchers’ biases (Frambach *et al*., *2013*). Shenton (2004) described the role of triangulation as one of the steps to ensure confirmability. The researcher in this study used a variety of sources in data collection to maintain triangulation. An interview guide with open-ended questions was used during one-on-one interview to explore the depth and effects of perinatal HIV infection on adolescents in the Vhembe District. Observations were also made to record non-verbal communication. Interviews were recorded and transcribed to help ensure that the results are based on the views and experiences of the informants rather than those of the researcher.

The researcher detailed the process of data collection, data analysis and the interpretation of data by recording the topics that were unique and interesting during data collection, writing down the thoughts about coding, provision of the rationale for merging the codes and explaining what the themes meant (audit trail) (Shenton, 2004). Themes that emerged from data analysis were used to formulate the questionnaire as a quantitative data collection tool. Themes that emerged from qualitative data analysis formed the basis for the development of the questionnaire.

3.7. PHASE 2: QUANTITATIVE STRAND OF THE STUDY

The quantitative strand of the study was based on the results of the qualitative results as the study employed the sequential explorative design (Creswell, 2018).

3.7.1 Sampling procedure

To determine the final sample size for the quantitative strand, the researcher used stratified random sampling to select adolescents living with perinatally acquired HIV to participate in the study. In random sampling, everyone in the target population has an equal chance of being selected (Mcleod, 2014). Health facilities were stratified into rural and urban. Five (5) facilities were randomly selected from urban areas and 20 facilities were randomly selected from rural areas. Limpopo is a predominantly rural province dominated by villages, so most health facilities are located in villages compared to town. From the selected facilities, a list of adolescents living with perinatally acquired HIV was requested from the facilities' operational managers. The sample size was calculated using the Taro Yamane formula outlined by the Department of Sociology and Criminal Justice (Saxena, 2017) and is as follows:

$$n = \frac{N}{1 + N(e)^2}$$

Where *N*= Population size, n= sample size, and *e*= error margin 5%. Based on the formula above, the sample size was 213. An additional 10% was added to cater for non-response and spoiled questionnaires. 213 questionnaires were distributed and of these, 186 were suitable for analysis.

Table 3. 3 Sampling of participants per sub-district

District	**Total no of PIP**	**Total recruited**	**Sample size 45% per District using random sapling**
Collins Chabane	172	160	72
Thulamela	132	129	58
Musina	196	182	83
Total	-	-	213

Inclusion and exclusion criteria

The researcher retained the same criteria used in the qualitative study for the survey.

3.7.2 Data collection

A questionnaire

A questionnaire (Appendix 6) was used to collect data on adolescents living with perinatally acquired HIV. The questionnaires were written in English and translated to Xitsonga and Tshivhenda by both language experts respectively as the dominant languages in the Vhembe District. Questions of the questionnaire were formulated based on the research objective's themes and outcomes of qualitative research soon after finishing data analysis of Phase 1. A written consent form with details of the study was issued out to participants and guardians of participants under the age of 18years to seek consent.

Questionnaires were self/ hand-delivered to participants at places chosen by participants for completion and collection. They were self-administered by the adolescents and completed in the presence of the researcher, research assistant (RA) and /or guardian. Those who were not able to write, for reasons such as age, were assisted by either the researcher, RAs or the guardian (depending on the adolescent's preference), who filled in the questionnaire based on the adolescent's responses. Clarity was provided by the researcher and research assistants as questions arose during completion of the questionnaire. The details and formulation of the questionnaire included the following: it was developed immediately after the data analysis of qualitative data. The developed questionnaire for adolescents living with perinatal HIV infection was informed by the findings of the themes and sub-themes of qualitative data collected. The questionnaire comprised of 3 sections: section A Demographic information of the participants, section B: Assessment of the challenges faced by adolescents living with perinatally acquired HIV and section C: Assessment of the coping strategies of adolescents living with perinatally acquired HIV infected adolescents.

3.7.3 Pilot study

A pilot study asks whether something can be done, whether researchers proceed with it and if so, how to go about it. However, it has a specific design feature: it is conducted on a smaller scale than the main study. A pilot study is performed to reflect all the procedures of the main study and validates its feasibility by assessing the inclusion and exclusion criteria of the participants and testing of instruments used for measurements in the study (Anesthesiol, 2017).

A pilot study was conducted on a sample of 20 respondents for the quantitative part of the study, to pre-test the questionnaire at selected clinics and health centres of the Vhembe District in Limpopo, as advised by the university's statistician. A pilot study was done in Madimbo Clinic as their clinic sample constituted almost 10% of the whole sample, which was 20 participants. Participants in that clinic did not form part of the main study. Piloting of the questionnaire ensured that ambiguous questions were rectified before the main study data collection sessions started. It also clarified if the questionnaire was language-appropriate. Respondents involved during the pilot study were not included in the main study. Adjustments and modifications were done by removing questions that were not clear to participants, before using it in the main study

3.7.4 Data Quality Control and management

The questionnaire was prepared in English and translated to Xitsonga and Tshivenda, the two local languages commonly spoken in the study area, and then translated back to English by a language expert to check for consistency. Data preparation and cleaning was conducted. Data was analysed using Statistical Package for the Social Sciences (SPSS) Version 25 with the assistance of the university bio-statistician.The questionnaire was pre-tested on 20 adolescents who were not part of the actual study. Orientation was given to the data collectors on the objectives of the study, techniques of making a good interview and possible errors, obtaining and maintaining quality data, and the measurement tools used. The completed questionnaires were checked for inconsistencies and missed values during data collection, timely communication with data collectors was done and feedback was obtained. Questionnaires with significant problems were excluded from the analysis. Questionnaires were stored in a locked cabinet for safe-keeping and only the researcher had access for the key of the cabinet.

3.7.5 Quantitative data analysis

Descriptive statistics were used to explain and summarise data. A Fischer' test was done to establish a significance difference between the age and the dropout rate from the antiretroviral program to establish if age played a significant role in the dropout of an adolescent living with perinatally acquired HIV from HIV management and care. Multiple linear regression analyses were applied to determine whether there is a significant difference in the use of alcohol, disclosure of HIV status to partner and coping strategies by controlling the demographic variable. Data was presented using a range, mean, mode and graphs (Saunders, Lewis & Thornhill, 2012).

3.7.6 Validity and Reliability

Validity and reliability concepts are used to evaluate the quality of research. Validity is about the consistency of a measure while reliability is about the accuracy of a measure (Middleton, 2019).

(i) Validity

It is concerned with whether our research is believable and true and whether it is evaluating what it is supposed to evaluate (Zohrabi, 2013). Fraenkel and Wallen (2003) state that the quality of the research instrument is critical as the outcome of the research will be obtained out of the instrument. The following procedure was used to measure validity. Three types of validity were observed in this study.

Face validity, also called logical validity, is a superficial and subjective assessment of whether or not a study or test measures what it is supposed to measure (Stephanie, 2015). A pilot study of the questionnaire was conducted on a sample of 20 adolescents who are living with perinatal HIV infection to assess its relevance to the objectives of the study. Content that was not relevant to the objectives was removed from the questionnaire. The pilot study group of adolescents who are living with perinatal HIV infection did not form part of the main study.

Content validity has been defined as the type of validity in which elements of skills and behaviour are adequately and effectively measured (Zohrabi, 2013). In this study, the questionnaire was reviewed by the supervisor and co-supervisors and has been presented to the Department of Public Health panel, the School of Health Science panel, the Faculty of Health Sciences and the TREC. Readjustment of the questionnaire was made based on comments received. Unclear and obscure questions were revised, and complex items reworded. Ineffective and non-functioning questions were discarded (Zohrabi, 2013).

Zohrabi (2013) indicates that internal validity is concerned with congruence of the research findings with reality. It also deals with the degree to which the researcher observes and measures what is supposed to be measured. To prevent researcher’s bias, the researcher created data analysis plan before the survey. The researcher used a questionnaire with multiple choice questions to collect data from adolescents who are living with perinatally acquired HIV in order to quantify the results.

(ii) Reliability

Reliability deals with the consistency, dependability and replicability of results obtained from a piece of research (Zohrabi, 2013). It is measured by producing consistent results over repeated testing under stable conditions. The above-mentioned implies that the instrument used to collect data should be replicable by an independent researcher, reproduce the study and obtain similar results.

Internal reliability deals with the consistency of collecting, analysing and interpreting the data. Internal reliability might be obtained when an independent researcher on reanalysing the data obtains similar findings as to the original researcher (Zohrabi, 2013). Internal reliability was ensured by piloting the questionnaire. The quantitative questionnaire was piloted to 20 adolescents (nearly 10 percent of main sample total) who did not form part of the main study to see if participants understood the content. The results of the piloting are discussed under 3.6.2.

3.8 ETHICAL CONSIDERATION

A proposal was submitted to the TREC to obtain ethical clearance (Appendix 11) to conduct the study. Permission to conduct (Appendix 8) the study in the Vhembe District health facilities was obtained from the Department of Health Provincial office. Presentation of the permission from the Provincial Health Department was done to the district office to obtain permission to conduct the study (Appendix 9) in the facilities. A letter of information or informed consent (Appendix 2) was made available to all potential participants. Permission was sought from the facility operational managers to conduct the study.

3.8.1 Informed consent and voluntary participation

Written consent was obtained and signed by participants before conducting the study. For those who were under the age of 18, written consent was sought from and signed by the legal guardian or parents of the participants. All consent forms were written in English and translated to Xitsonga and Tshivenda to afford participants and/guardians a chance to read and understand the content of the consent form in their preferred language. They were also informed that participation is voluntary and that they had the right to terminate any time during the study should they wished not to participate further in the study despite their initial consent.

3.8.2. Anonymity

Due to the sensitivity and stigma attached to HIV infection, participants were reassured of remaining anonymous in this study. Their names and addresses were not disclosed in any research documents; instead, their names were substituted by numbers, e.g. participant 001, participant 002, and so on until participant 021. When transcribing the narration of the interviews, these numbers were given anonymously by the sequence of their interviews and the researcher knew to avoid linking participants to any conversation in the study.

3.8.3. Protection from harm

Participants were protected from physical and psychological harm at all times. They were guaranteed freedom to withdraw from the study at any time should they feel emotionally or physically exhausted as they participate in the study. Due to the nature of the study, some participants were emotional as they relived some experiences which they had encountered. The researcher constantly enquired from them if they still wanted to continue with the interviews in a simple and compassionate way. Those who expressed or showed emotional and/or psychological fatigue, were assured of a referral to a psychologist should they require one. No one was referred to a psychologist as participants assured the researcher that they were fine and would continue with the interviews. One-on-one interviews were conducted in a secured cubicle free from noise in selected health facilities to maintain privacy. To maintain professional honesty, findings of the study were reported in a complete and honest manner, without misrepresenting the actual findings of the study.

3.8.4. Confidentiality

HIV information may not be disclosed based on the general release of medical information. Specific authorisation for the release of HIV related information must be obtained (Wolf, 2001). HIV information of adolescents living with perinatally acquired HIV who participated in the study were disclosed on the general release of medical information. Specific authorisation from the relevant authorities for the release of HIV-related information was obtained. Participants were assured that confidentiality would be maintained at all times. All information and their identities was kept confidential. Recorded data was kept in a computer protected by a secure password only known by the researcher, and all transcripts collected during one-on-one interviews was kept in a lockable cupboard.

3.8.5 Refusal to participate in the study

Shenton (2004) advocates for the right of refusal of people who are approached to participate in studies, to ensure that data collection only involves participants who are genuinely willing to take part and are free to give data willingly. An informed written consent form with a refusal clause was issued to every person who was approached to participate in this study. The researcher further explained to each participant that participation in the study was voluntary and they had the right to withdraw from the study anytime without explanation should they wish not to continue being part of the study.

3.8.6 Bias

Simundic (2013) described bias in research as any trend or deviation from the truth in data collection, data analysis, interpretation and publication which can cause false conclusions. This writer further indicates that bias can either be intentional or unintentional.

3.8.6.1 Researcher bias

Researcher bias is a process where the researcher influences the systematic investigation to arrive at certain outcomes (Simundic, 2013). All 21 transcripts were fully and carefully read through and thoroughly analysed to prevent interpreting data in the researcher’s understanding.

An independent coder was employed to verify the results and concur with the researcher on the final themes and sub-themes. The researcher is a nurse by profession. Thus, she did not put on her uniform when conducting interviews as it would have affected the way adolescents viewed and responded in the interviews as a means of preventing researcher bias.

3.8.6.2 Bias in data collection

Data collection bias is also known as measurement bias happens when the researcher‘s personal preferences or beliefs affect how data samples are gathered in the systematic investigation (Bell, 2015) Bias in data collection was prevented by using the same semi-structured interview guide and questionnaire respectively. Similar questions were asked, however, probing sometimes differed depending on the response from participants all participants the use of purposive sampling which afforded all adolescents who perinatal HIV were infected an equal and fair chance of participating in the study. Adolescence in this study, were defined according to the South African Constitution that gave an age cut of 10-19 years of age. However, no preference of age or gender was done as Simundic (2013), stated that it can be done by choosing particularly vulnerable group amongst participants to prove the researcher’s hypothesis or over-report the truth (Simundic, 2013).

3.8.6.3 Bias in data analysis

Data analysis bias often happens when the researcher focuses on data samples that confirm his or her thoughts, expectations, or personal experiences, that is, data that favours the research hypothesis (Bell, 2015). Several strategies were employed to avoid data analysis bias. During data analysis, more than one person coded raw data. Themes and sub-themes were sent to an independent coder for coding. Both the researcher and the independent coder agreed on the final themes and sub-themes. Bias was also prevented by retrieving data from different sources (triangulation). Voice recorded data was supplemented and verified by the field notes which recorded all non-verbal actions which could not be audio-recorded.

3.9 CONCLUSION

This chapter outlined the research methodology that was used to collect and analyse data in this study. This study employed mixed methods research; a sequential exploratory design which is a well-established method. The transparency of the research methodology employed in this study supports the reader’s evaluation of the actions of the primary research team throughout the research process. The researcher and the research team observed and avoided biases throughout the research process to ensure the validity of the results. The final description and the findings of the research study are discussed in the next chapter.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF THE QUALITATIVE FINDINGS

4.1 INTRODUCTION

The previous chapter discussed the research design and method which guided the study. The chapter included an explanation of the study site, population and sampling, research methods and design, data collection method and analysis. This chapter presents and discusses the research findings from the individual semi-structured interviews conducted with adolescents living with perinatally acquired HIV in the Vhembe District. The results are presented in a narrative format and after, the descriptions of the findings are presented, verbatim excerpts from the participants. Relevant literature to support the findings is then described. The findings of this study are discussed based on the themes and sub-themes which have emerged during data analysis, based on the individual semi-structured interviews conducted with adolescents living with perinatally acquired HIV in the Vhembe District. The main objective of the chapter is to provide critical reasoning and presentation of the results to provide a foundation for how participants viewed perinatal HIV infection and the challenges thereof.

4.2 RESEARCH METHODOLOGY APPROACH

Phase 1 of the study addressed objectives 1, 2 and 3 where the first objective was to explore and describe the experiences of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District, the second objective was to identify support needs of perinatally acquired HIV infected adolescents in selected CHCs and clinics in Vhembe District and the third objective was to identify and describe gaps on the current management and care of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District. A mixed method sequential approach was used.

4.3 DISCUSSION OF THE FINDINGS OF QUALITATIVE STRAND

4.4.1. Demographic profile of the participants

This section presents the report of the demographic information of the participants used in this study. The demographic information of the participants comprised of the age, gender, location was rural, semi-urban or urban, highest educational level. The population of the study comprised of 21 adolescents living with perinatally acquired HIV from all clinics and CHCs in the Vhembe District, South Africa.

Table 4.1 Demographic profile of the participants

Demographic characteristics	**Number**	
Gender	**Female**	**17**
	Male	**4**
Age	**12-15**	**4**
	16-19	**17**
Location	**Rural**	12
	Semi-rural	5
	urban	4
Highest grade	Secondary school	17
	Primary school	4
Years on ART	**Below 5years**	**8**
	8 years	**13**

Demographic characteristics of the participants showed that a majority of the participants were females 17 females and most resided in rural area. Majority were between the ages of 16-19 and were in secondary school. Most have been on ART for more than 5 years.

4.4.2. Themes and sub-themes emerged during data analysis

Themes and sub-themes reflecting the experiences of adolescents living with perinatally acquired HIV on their day to day lives are presented as follows: Five themes and sub-themes emerged during data analysis of the research. Main themes and sub-themes summarised in table 4.2 and they will each be discussed.

Table 4.2 Themes and sub-themes reflecting the experiences of perinatally acquired HIV positive Adolescents on their day to day lives.

Themes	Sub-themes
1. **HIV/ AIDS knowledge**	**1.1 knowledge related to HIV/AIDS and self-HIV positive status** **1.2 knowledge on ARVs and related side effects** **1.3 Knowledge on contra-indications of mixing he herbs a pills** **1.4 HIV positive status disclosure to adolescents** **1.5 Knowledge on dangers of unprotected sex and dangers**
2. **Expectations**	**2.1 Importance of diet** **2.2 ARVs and HIV-positive diagnosis kept a secret** **2.3 Alcohol and substance abuse**
3. **Support systems**	**3.1 Clinic nurses support.** **3.2 Family and community support** **3.3 Teachers and friends support**
4. **Challenges faced by adolescents**	**4.1 Lack of adherence and thoughts to quit treatment (ARVs** **4.2 Stigma and discrimination associated with taking ARVs experienced** **4.3 Different types of abuse experienced by adolescents** **4.4 Psychosocial and emotional needs**
5. **Suggestions**	**5.1 Treatment modification** **5.2 HIV -positive status must be disclosed** **5.3 Request for mentors and supporters**

4.4.2.1 Sub-theme 1: HIV/AIDS knowledge

The findings of the study pointed out vast issues related to the knowledge of and description of HIV held by adolescents living with acquired HIV infection. Although, some participants had some knowledge of HIV had challenges. The following sub-themes emerged which was the evidence of these challenges

Sub-themes

1.1 Knowledge on HIV/AIDS and self- HIV positive status
1.2 Knowledge ARVs and related to side effects
1.3 Knowledge related to contra-indications of mixing herbs and pills
1.4 HIV positive status disclosure to adolescents
1.5 Knowledge on dangers of unprotected sex and dangers

Sub-theme 1.1: knowledge on HIV/AIDS, self HIV-positive status,

The findings of the current study found that more adolescents knew about HIV transmission and prevention and were able to describe what HIV is. However, most participants who had knowledge on HIV were in age of adolescence (16-19 years) and advanced grades of secondary school level as compared to the ones in a lower grade. A quantitative study conducted in South Africa also found that only a quarter of the youths have accurate knowledge about HIV transmission and prevention with females scored higher than male adolescents (Miller, Nkala, Closson, Chia, Ccui, Palmer *et al*, 2017). They further reported that majority of these adolescents lacked correct information about HIV. Knowledge on HIV/AIDS varied from having some information on the mode of transmission and knowing what HIV is. The study conducted by Galea and colleagues identified lack or incorrect information about HIV and the treatment as one of the contributing factors to poor adherence to ART (Galea, Won, Muñoz, Valle, Leon, Perez, Kolevic & Franke, 2018). Further discovery of adolescents having incorrect HIV/AIDS knowledge of HIV was made by another study which discovered that a majority of their participants (17) mean age 15.2 demonstrated gaps in critical areas of HIV knowledge, including routes of transmission, STI prevention, medication-taking skills and chronic disease management among ALWH in western Kenya (Chory, Nyandiko, Martin, Akioch, Scanlon, Ashimosi, Njoroge, McAteer, Apondi & Vreeman, 2021).

Participant 002 said:

> *"HIV is a disease that is caused by mixing of two types of blood where one person is infected by HI virus. e.g., when someone who is infected with HIV is injured and someone without HIV assists him/her without protection; he or she can be infected. It*

> *can also be transmitted from the mother to an unborn child and when people have sexual intercourse without protection".*

Some adolescents described HIV as either a disease or a virus that lives in humans which is deadly but also a manageable chronic condition and can only be controlled by constant taking of medication. Some participants knew the prevention of HIV but did not know what it is. A study conducted in Abidjan also revealed that a majority of the adolescents knew at least one mode of HIV transmission and one preventive measure (Azagoh, Yeboua, Yao, Kouassi- Koudiao, Aholi *et al*., 2019). These findings were confirmed when Participant 004 said:

> *"HIV is a virus which lives in a human body but when you take your medication it can be controlled".*
>
> Participant 006 further explained *"I was told it is a disease which is transmitted through unprotected sexual intercourse, and it is deadly. It is incurable but a person will not die if he or she takes medication and follow instructions"*.
>
> Participant 009 explained the prevention of HIV but had no idea of what HIV is when he said" "*I don't know anything about HIV, but I have heard that when I sleep with a man, I must use condoms and also that I must take my pills every day*".

The study results further revealed that adolescents lead risky behaviours like having unprotected sex as a result of a lack of knowledge of HIV. According to (UNAIDS, 2020), the high new HIV infections amongst adolescents are a result of incorrect knowledge of HIV transmission and prevention. The results of the study conducted on characteristics of adolescents living with HIV receiving care and treatment services in antiretroviral therapy clinics in Cambodia also revealed that adolescents had suboptimal knowledge of HIV (Yi *et al,* 2018*).*

The current study further explored the knowledge of self HIV-positive status from adolescents. The findings of the study revealed that just over half of the adolescents living with perinatal HIV infection knew their HIV status. However, it was also noted that majority of those who knew their HIV positive status, were the same people who had some information of HIV, but there were few in the lower grades who also knew their HIV status. This was confirmed by 11 of the adolescents in the current study who when asked if they knew their HIV status, said:

> *"Yes,"* another one added by saying that "*I know that I am HIV positive.*
>
> *Another participant added by saying "I know that when you are HIV positive, you should not touch other people's blood and that you must not play in dirty wate*r".

The findings of the study also revealed that some adolescents seemed to know their HIV positive status, but they did not want to disclose because of the stigma attached to HIV. They regarded

HIV as a shameful disease which they were not supposed to have, participant confirmed this by saying:

"*HIV is "that disease (vuvabyi lebyiya), it is not like any other disease".*

Participant 008 further said:

"*I just don't want to have HIV; I would rather take my medication without knowing what it is for than to be told that I have HIV"*

Participant 001 indicated that she was not comfortable saying that she has HIV because of fear of what people will say about her. She said:

"*This sickness of HIV that I have, I only heard people talking, saying HIV, HIV'*.

The study findings also revealed that 10 out of 21 adolescents were not aware of their HIV status. When asked if they knew their HIV status they responded

"*I do not know*"

Consistent with the findings of the study by Vranda and Mothi (2019) which revealed that few children were aware of their HIV status while 43/50 were unaware as reported by their guardians/parents. They reported that majority of caregivers felt mid-teenage was the appropriate age for disclosing the HIV infection and the parents were the appropriate persons to reveal the infection status. Congruent to this study are the findings of a study by Gitahi and partners which revealed that a majority of the adolescents had their HIV status disclosed to them between the ages of 13 and 16 (Gitahi et al, 2020).

Sub-theme 1. 2 Knowledge on ARVs and related side effects

Knowledge on treatment has not been established since most adolescents did not know the medication they were taking. They only knew the medication they were taking was to control the disease or illness they were suffering from or living with. To confirm this one participant said:

"I don't know what the treatment is for, I was told by my father that I need to collect treatment every month and I must take them every day, or I will die". This was confirmed by participant 001 who said:

> " *My father told me that if I don't take my pills, I will get sick and go to the hospital, they will finish me off, they will give me an injection that will kill me".*

Contrary findings were discovered by another study on Anti-retroviral treatment Adherence: knowledge and experiences amongst adolescents and young adults. The study found that most participants had basic knowledge about how to take their ARVs properly (Hornschuh, Dietrich, Tshabalala & Laher, 2017). The findings of the study also revealed that some adolescents living with perinatally acquired HIV lived in fear, as they were only threatened to take their medication. They were told by their guardians that they will die should they not take their medication daily, however, there was neither disclosure of the diagnosis nor the knowledge of the medication, hence

More findings of the study revealed that most adolescents living with perinatal HIV infection started medication while they were still young, so they just continued to take the medication with instructions when they are adults without the knowledge of what the medication is for.

This is confirmed by participant 003 who said:

> *"I don't know; I was given only given medication with the instructions only".*

The findings of the study revealed adolescents who knew about their treatment were the ones who know their HIV status and also knew what HIV was.

Participant 005 confirmed by saying

> *"HIV is a virus which lives in a human body but when you take your medication it can be controlled"*

Gitahi (2020) also concurred that adolescents reported that they preferred to be told of their status as it enhanced the known knowledge on HIV and adherence. The findings of the study further discovered that most children trust their parents enough to know that they will not harm them in any way. The above statement emanated from the fact that the findings of the study revealed that some adolescents did not know their HIV status because since they were given medication by their parents while they were still children. The findings further revealed that adolescents did not ask what the medication was for because they trusted their parents that they had good intentions for them. This was confirmed by participant 007 who said:

> *"I never saw a reason to ask my mother, I trust that my mother will not give me something which will harm me; I believe that whatever medication she (mother) and the nurses are giving me is for the benefit of my health. I am going to ask her just for the sake of my curiosity now that you have raised it".*

Participant 016 also supported this by saying

> "*I feel fine, I trust my father, I don't believe he can give me something that kills*".

The findings of the study on exploring side effects on adolescents discovered that majority of participants verbalised to have never experienced side effects, but some reported to know and have experienced side effects. Foster, Ayers & Fidler (2020) alluded that despite two decades of marked improvement in both access to ART and pill burden, frequency, toxicity and tolerability, some patients continue to struggle daily on oral medication. Similar findings were revealed in this study that adolescents living with perinatally acquired HIV have a problem with the frequency of ARVs. According to Sabin *et al*. (2020) adolescents reported medication-related challenges such as pill size and taste, tiredness, nausea and vomiting as a major barrier to adherence.*"*

"My treatment is fine; I don't have side effects. I only have a problem with time in most cases, I forget because I am busy or studying. I feel like I am in jail because I must mind time always. It is also tiring as there is no end to taking this medication and one will never get used to it"

Meanwhile participant no 005, when asked if she ever experienced side effects, she mentioned that "*I get dizzy after taking my pills"*

Another one supported by saying "Whenever I take my medication, I feel sick and I am always sick, like every month I have to consult I think it is because of the ARVs".

Similar results were reported by (Nsibandze *et al.*, 2021) when adolescents pointed out the unbearable side effects of taking ARVs as a barrier to adherence. The results of the study conducted in South Africa revealed that adolescents desired healthy and normal lives, hence they took their medication daily (Madiba & Mokgatle, 2016).

Findings of the study show that adolescents cited treatment fatigue. Another one said: *"Sometimes I get tired of taking treatment because of the strict schedule, at times I just forget that I have to take my medication. The thought of taking treatment on daily basis for the rest of my life sometimes scares me as I don't know what the future holds for me".*

Participant 002 said *"Our lives are in danger as we have to take treatment every day and follow up instructions and of which failed to do that could mean the end of our lives".*

Sub-theme1.3. Knowledge related to contra-indication to mixing herbs and pills

The findings of the study revealed that participants had knowledge on contra-indications related to mixing herbs and pills. No one amongst the adolescents has verbalised the use of herbs or traditional medicine with their pills. One participant has however mentioned when asked if she knew the dangers of mixing traditional medication with ARVs, the participant indicated that she knew that there is indeed danger in using traditional medicine with ARVs, but she did not have details of what the dangers were except that she would die if she mixed them.

> "*Yes, nurses told me that if I mix traditional medicine with my pills, I will get sick that the father promised to buy medication to cure them*". Another one confirmed and said *"I*

> *know that I must not mix my medication with any medication that is not from the clinic or the doctor".*

The findings of the study revealed that adolescents living with perinatally acquired HIV possess knowledge on the dangers of mixing traditional medicine with herbs.

Sub-themes1.4. HIV positive status disclosure to adolescents

The study results revealed that less than half of the adolescents were disclosed to by either guardians, parents or professionals, while others discovered their own status, and more were not aware of their HIV status. It has also been noted that disclosure of the HIV status was mostly done by caregivers and relatives than biological parents or by professionals like nurses or social workers in health facilities. Congruent results were reported in another study where more than half of the caregivers reported to have disclosed the HIV status to the adolescents compared to one fourth of the parents and one third were disclosed to by the doctor (Sabin, 2020). Vranda and Mothi (2019) alluded that disclosure of HIV/AIDS to self and parents has multifaceted challenges. This could be because parents were afraid of disclosing their status to their children compared to caregivers, who did not have to explain why and how adolescents acquired HIV. According to the WHO (2020), adolescents are an emotionally vulnerable age group, and how they will respond to their disease status can never be predicted. Perinatally acquired HIV infected adolescents can blame their parents for their situation, while horizontally infected adolescents may be angry and have self-blame. The above statement is supported by the findings of the study conducted in Zambia which discovered variations on their experiences regarding HIV disclosure process. Participants verbalised mixed feelings after the HIV status disclosure. Reactions ranged from feeling good after disclosure, to feeling sad after being told about their HIV positive status, and others were not pleased by the disclosure of their status without their consent (Zulu, 2017). Furthermore, the results of the study conducted in Zambia revealed that primary caregivers were scared of inflicting emotional pain to the adolescents by disclosing their HIV status (Okawa *et al*. 2017).

The study findings have however discovered that adolescents who were disclosed by professionals had more knowledge of HIV than the ones informed by relatives. This is confirmed by Participant 015 saying:

> *"I grew up taking treatment but I did not ask what the medication was for, because I was given by my grandmother until in 2017 when I fell pregnant, that is when the nurses told me that I was born with HIV that is why I have been taking this treatment since birth, so I had to continue taking my medication to prevent my child also from being born with HIV*".

Meanwhile, participant 006 said:

> *"I found out in 2016, my sister told me. My parents passed away, so I am staying with her in her home. I asked her why I am taking this medication, then she explained to me that I was born with HIV, and I must take my medication daily for the rest of my life*.

The findings of the study also discovered that some adolescents discovered their HIV status on their own, Participant 002 said:

"No one told me, I have just discovered it along the way that I am HIV positive as I was taking treatment. I do a lot of reading about HIV". Another one supported by saying*" I was never told what the medication is for but when I read my file its written RVD".*

Consistent with the findings are Gitahi (2020) which also discovered that some adolescents reported having discovered their own HIV status through posters, reading books and through the internet.

The findings of the study discovered that some participants were told a wrong diagnosis by relatives to continue taking their medication. This could be that caregivers did not know the process of disclosure, or they were not ready to disclose. As participant 010 said:

> "*My father told me that the medication that I am taking were for the tonsils"*

Consistent with the findings of a study conducted by Gitahi (2020) which narrated that caregiver lacked knowledge of the disclosure process or were not ready to disclose their status, with the fear that adolescents were going to ask how they became HIV infected. Hayfron-Benjamin, Obri-Yeboah, Ayisi-Addo, Siakwa & Mupepi (2017) Concurrent with the findings of this study, they also discovered that caregiver lack of knowledge on the disclosure process was identified as one of the barriers to adolescents not knowing their HIV positive status. Caregivers did not know how and when to disclose to their children. Most adolescents' HIV status was only known by close biological relatives or legal guardians as their statuses were not disclosed to other family members or relatives. This was supported by some participants who alluded that only immediate family members knew their HIV status. Participant 002, 007, 009, 011, 018, 019 & 020 when asked about who knew their HIV status besides immediate family members, they replied
"N*o one*"

The findings of the study revealed that the majority of the parents of adolescents living with perinatally acquired HIV are scared to disclose their HIV status, which is evidenced by most adolescents not being disclosed to. This leads to frustration in these adolescents who are taking medication while they do not know what it is for. This, together with the side effects, makes adolescents living with perinatally acquired HIV want to quit taking their medication. However, it was also pointed out that disclosing HIV status to these adolescents empowers them. Consistent to that of Madiba (2020), which discovered that delay in disclosing HIV status contributes to children's refusal to take their medication, leading to accidental disclosure, give rise to anger and resentment towards the caregiver. Thus, increasing the risk of secondary transmitting of HIV and poor health outcomes. However, the study by Madiba & Mokgatle, (2016) revealed that some adolescents reacted emotionally to the disclosure of the status, which left them angry and hurt. Furthermore, A study by Dietrich *et al.* (2017) among perinatally acquired HIV infected adolescents whose HIV status was disclosed to them at an early age, demonstrated correct basic knowledge about medication adherence and its benefits as well as the consequences of non- adherence.

The above paragraph was supported by the findings which discovered that some parents have disclosed HIV status to their adolescents living with perinatally acquired HIV. It was also observed that adolescents whose HIV status was disclosed by their parents, felt empowered and felt that HIV is a disease like any other disease. Participant 011 confirmed by saying that

> *"I was told by mother that I am living with the HI virus in my body that I was born with, but it doesn't mean that I am different from other people, it just that I was born with the disease which I must take medication for the rest of my life. She also told me that she is also living with the HI virus and since I have never seen her sick, I understood that it was just a disease like any other".* Participant 012 supported by saying that *"2 years back, my mother told me when I was sick that I am living with HIV, and I have to take treatment daily for me to be cured".*

This proves that disclosure at an early stage is a contributory factor to good adherence. The findings of the study therefore, revealed that disclosure of HIV status to adolescents was not properly done and no processes were followed. Caregivers and parents should be taught the correct processes of disclosure. A gradual process of disclosure should be implemented to empower adolescents.

Sub-theme 1.5. Knowledge on the dangers of unprotected sexual intercourse

The findings of the study revealed that adolescents living with perinatally acquired HIV knew the dangers of unprotected sexual intercourse. Contrasting findings were reported by (Woollett *et al.*, 2021) that sexual reproductive health matters were considered taboo and not communicated with adolescents in families. Participant 002 confirmed when asked about the dangers of having unprotected sexual intercourse, saying:

> *"Yes, but I intend to use condoms every time I have sex to protect the girl from getting HIV or/and unwanted pregnancy"*. This is supported by participant 004 who said that "*Yes, they protect us from unwanted pregnancies and sexually-transmitted diseases like HIV/AIDS*". Another participant added by saying that "*Through reading, I understood that if I had unprotected sexual intercourse, I could pass the virus to my partner and weaken my Immune system in the process. So, I have decided to wait to avoid unnecessary risks"*.

The findings of the study therefore imply that adolescents living with perinatally acquired HIV infection are aware of the dangers and risks of having unprotected sexual intercourse and they take necessary precautionary measures such as using condoms and abstaining.

4.4.2.2 THEME 2: Expectations

Adolescents living with perinatally acquired HIV, like other adolescents, their families or people living around or with them, have certain expectations about their lives, hence the findings of the study revealed expectations that families of these adolescents had on them. The following sub-themes then emerged.

Sub-themes

2.1. Eating well -balanced diet
2.2. ARVs and HIV positive status kept a secret
2.3. Alcohol and substance abuse

Sub-theme 2.1. Eating well-balanced diet

The findings revealed that adolescents experienced challenges eating a well-balanced diet. Some adolescents knew the type of nutritious diet they should consume but their families were not able to provide the food due to a variety of reasons, such as ignorance and lack of knowledge. Previous studies also discovered that a well-balanced diet amongst adolescents with perinatal HIV was a challenge as there have was a high prevalence of stunting and overweight in HIV-infected children (Canavate, Sonego, Sagrado, Escobar, Rivas *et al.,* 2019). Additionally, a study conducted by Audi, Jahanpour, Antelman, Guay, Rutaihwa *et al.* (2021) pointed out that adolescents lacked basic socio-economic needs such as food and money for transport to fetch their medication, resulting in poor adherence to ARV. The findings of the study revealed that most families were living in poverty, and it was reported to be one of the contributory factors to adolescents not eating a well-balanced diet. This is supported by Participants 016 and 020, who said, respectively:

"*That I must not eat meat every day, I must eat vegetables for my body to be healthy and strong, but my mother does not have money to buy all the food that I need".* Participant 001 further elaborated by saying that "*I don't eat sometimes because my father always busy meat and I end up losing appetite, so I sometimes do not take my pills as I don't want to take them on an empty stomach".*

"I don't go to school trips because my mother does not work, we depend solely on child support grant for survival and food. She is saving money for me to go to university".

The findings of the study therefore imply that adolescents living with perinatally acquired HIV know the importance of consuming a well-balanced diet.

Sub-theme 2.2. ARVs and HIV-positive diagnosis kept a secret

The findings revealed that families did not want adolescents to tell other people their HIV status and that they were taking ARVs; it was supposed to be kept a secret within the family. Results of a study on the secret lives of young adolescents living with HIV in Northern Mozambique show that adolescents were told about the secrecy of their HIV-positive status by their parents and caregivers (Falcao, 2021). Woollett *et al*. (2021) also narrated that adolescents reported the burden of secrecy in HIV diagnosis. The study findings also discovered that HIV status was kept a secret from adolescents themselves, with some were taking medication without the knowledge of the diagnosis. Another participant said:

"No one knows my HIV status except my mother and grandmother"

"My *father told me not to tell anyone because people will laugh at me*

The study also discovered that adolescents living with perinatal HIV infection chose to keep their HIV-positive status a secret from other people for various reasons. Amongst these reasons was the fear of being stigmatised. The findings have confirmed that HIV is still a stigmatised condition:

Participant 001 confirmed this by saying

"Because people will laugh at me".

Meanwhile, participant 007 said

> "I *have a good relationship with them but I think if they knew about my HIV status, they would treat me badly. They would treat me differently and not only my friends even the community at large.* She further explained the reasons why she keeps her HIV status a

> secret: *"People who are living with HIV are not treated well by the community, they are treated as if they are not human, like they have done something wrong to be sick. I don't know maybe it is transmitted through sexual intercourse, so it is believed that when you are HIV positive, it's because you are sleeping around. So that is why I don't anyone to know".*

A study conducted on the psychosocial issues of children affected by HIV/AIDS concurs with the above findings. Vranda and Mothi (2019) indicated that HIV-infected children and their families live in a "conspiracy of silence" and shame as HIV infection is kept as a secret. The consequences of the "conspiracy silence" is that the families may be withdrawn, become socially isolated and become emotionally cut off from traditional support systems. The study also noted that parents delayed disclosing the children's as well as their own HIV status due to stigma and the fear of social consequences.

The findings of this current study imply therefore that HIV is still regarded as a secret disease or infection due to several factors.

Sub-theme 2.3. Alcohol and substance abuse

Adolescents demonstrated knowledge of the dangers of abusing substances including alcohol, with most reporting alcohol use. The results further revealed that alcohol use was linked to peer pressure. A study on the prevalence of alcohol use disorders among people living with HIV/AIDS: a systematic review and meta-analysis, also revealed a remarkably high prevalence of alcohol use among adolescents. It was also found that the use of alcohol among adolescents in developed countries was remarkably higher than that of adolescents in developing countries (Duko, Ayalew & Ayano, 2019). Participant 002 said:

> ***"****I don't do either of them although one day I have felt like drinking when we were attending a friend's party, but I didn't drink as I had to think about my life or alcohol".* He mentioned peer group pressure as a major reason for him to like drinking alcohol, he said *"It was peer pressure because my friends were drinking, that's why I have decided to choose new friends who do not drink so that I don't get tempted again".*

Another participant supported the issue of drinking due to peer group pressure as he said:

> "*I do drink sometimes, like on New Year's Eve, but I have never smoked cigarette or dagga*", and when he asked why he drinks alcohol he said "*When I am with my friends and they are drinking, I also feel like drinking".*

Another participant added by saying:

> *"All of my friends' drink and I didn't want them to think I was stupid if I don't drink, I started while we were attending a friend's party".*

Some adolescents living with perinatal HIV infection have expressed the desire to change the lifestyle they have adopted by staying away from bad friends,

Participant 017 said:

> *"I'll stop hanging around with them (friends) to that I can save my life."*

The findings of the study revealed that a majority of the participants are aware of the dangers of smoking cigarettes and other substances, which is supported by a participant who said*:*

> *"Smoking is bad for my health, it damages the lungs and people who smoke dagga, and they act "mad" so I don't want to be like them. I have not heard anyone telling me the dangers of drinking alcohol".* Another participant supported by saying *"I do drink, but I don't smoke, because smoking is bad for my lungs"*

The findings of the study therefore show that adolescents living with acquired HIV infection have knowledge on the dangers of abusing alcohol and substances.

4.4.2.3 THEME 3: Support systems

The findings of the study showed a variety of issues related to support experienced by adolescents living with perinatally acquired HIV. These challenges are discussed in detail in the following sub-themes**.**

Sub-themes
Sub theme 3.1 Support from clinic nurses **Sub-theme 3.2 Parental and community support** **Sub-theme 3.3 Support at school from friends and teachers**

Sub-theme 3.1 Support from clinic nurses

The findings of the study identified that only a quarter of adolescents reported getting emotional support from clinic nurses. The majority of adolescents only verbalise being given treatment and being treated well, participant 019 said**:**

> **“***Nurses are treating me well, there was a time when I wanted to stop my medication, and they advise me not to give up because it might mean the end of my life, it would be dangerous”.*
>
> Another one supported by adding” *nurses treat me well, I have never experienced any problem, when I am sick and they check everything and give me advice on how to take care of myself as an adolescent who is living with HIV infection”.*
>
> Meanwhile, another participant alluded that *“I feel at home when I am at the clinic, they treat me well”.*

Similarly, the findings of the study by Woollett *et al*., 2021 also reported a lack of skilled mental health professionals to assist in the emotional support of the adolescents as one of the major challenges in the management of adolescents living with HIV. However, other participants do not share similar sentiments. Some have verbalised to have a good relationship with nurses. Participant 010 said:

> “*I can say my relationship with the nurses is fine, but I am not used to them as I am a shy person. I have questions that I would like to ask them sometimes, but I am afraid to ask. Like I would want to know as to why I am taking treatment daily”.* Another participant supported by saying *“I do not get any emotional support from the nurses”*

However, participants reported that they were not taught anything related to their diagnosis and/or ARVs and when asked what he is taught when collecting his medication by saying:

> *“No, nurses don’t teach me anything related to my disease they only tell me to come early if I am due for blood collection”.*

The findings of the study denote that there is a need for the incorporation of services by the nurses when attending to adolescents living with perinatally acquired HIV for holistic intervention.

Sub-theme 3.2 Parental and community support

The findings of the study noted that more of the adolescents indicated that they remained adherent to medication as a result of the social support they receive from their parents. However, a majority of those who lost one or both parents received negative emotional support from either relatives or the one parent who is left behind, especially their fathers. In a study conducted by van Vyk and Davids (2019), adolescents reported negative relationships with non-biological parents as one major reason they defaulted on the medication. Another study showed that adolescents who received emotional support from their immediate family members were encouraged to remain adherent to their medication (Shiferaw & Gebremedhin, 2020).

Another participant said:
"My *sister supports me emotionally and financially; she also reminds me my treatment"*
Another one also said "my *mother works far, and I am staying with my granny. She is very supportive; she prepares food for me before taking my medication*"

The findings show that some relatives knew adolescents' HIV status but did not provide emotional support, especially non-biological caregivers/ guardians. Participant 005 narrated that she was abused emotionally by her aunt (sister to her mother who passed away and who knew her HIV status) and made fun of her positive HIV status:

> "*I was constantly sick, sometimes I would not go to school because I was not well, my aunt would say I was not sick, I was lazy to do household chores. Sometimes she would tell her friends that she is not the one who killed my mother, AIDS killed her".*

Death of one parent, especially mothers, or the separation of parents, was another barrier depriving adolescents from getting support in any form. Participants narrated that they felt angry as fights between their parents deprived them of getting the emotional support of one parent as the other would not allow them to have a relationship.

> "*I feel angry like I am a real orphan, I sometimes wish they were both dead, the pain would be less knowing that they are both dead unlike now that my father is alive and doing well but he does not mind if I am dead or alive. My aunt is taking good care of me though"*.
>
> *Sometimes I cry and refuse to do household chores and go to play with my friends and come home late after 19h00 for my pills"*. When asked what is it that makes her cry, she replied "*When I think about my mom, sometimes I wish she was around so that she will do beautiful things for me, not that my dad doesn't, it's just that he doesn't buy me clothes. He also brings different women in the house and gives them money, but he doesn't buy me clothes".*

Consistent with the findings, are the findings of the study by van Wyk & Davids (2019) which revealed that adolescents cited negative relationships with non-biological caregivers/guardians, which contributed to poor adherence among adolescents.

The findings of the study prove that adolescents with perinatal HIV infection lack emotional support from people close to them.

Sub-theme 3.3 Support experienced at school from friends and teachers

The findings of the study revealed that adolescents had civil relationships with peers and teachers but did not get support from them on their HIV positive status, as most of them do not know their status. They relate to one another normally, with participants saying:

> "*I have a good relationship with everyone at school".*

The study also revealed that adolescents did not trust their peers with their HIV-positive status due to perceived stigma related to HIV infection. Participants believe that their friends would treat them in a bad way if they knew their HIV status. Others were afraid of being laughed at the by their friends. They responded as follows:

> "*No, they would treat me differently, they would also gossip about me*".
>
> Another participant "*Yes, I think so, some people when they know your HIV status laugh at you forgetting that no one chooses to be sick".*

Other participants reckoned that they did not think their friends would treat them differently if they knew their HIV-positive status, but they did not feel comfortable telling them. Participant 005 said:

> "*They will play with me well".* When asked how he would feel if this friend knew that he was HIV positive he responded that *"I would not feel well".*

The findings of the study revealed that some adolescents living with perinatal HIV infection have friends who know that they are taking medication daily and they get support. Participant 015 said:

> *"No, my best friend knows that I have to take my pills every day, sometimes when I am late, he reminds me".* Participant 002 confirmed by saying *"my friend knows that I collect treatment monthly at the clinic".*

The findings of the study revealed that friends did not know their diagnosis or have the wrong diagnosis. Participant 015, when asked how the friend found out that he was taking medication, said:

> *"We were playing, and I was nearing my medication time, so I had to tell him that I am going to take my medication for the tonsils". Participant 002 confirmed by saying that "He doesn't but he knows that I collect treatment every month from the clinic".*

It has also been noted that some adolescents living with perinatal HIV infection have not accepted their own HIV-positive status, hence they were unable to disclose to their friends. A study conducted by Nsibandze *et al.*, (2021) shows that adolescents related their HIV diagnosis to psychological stress, hence they were unable it. A participant in this study confirmed this by saying:

> *"I feel bad, I don't accept it, because I am always sick and sometimes, I vomit the medication*".

This study reveals that most adolescents living with perinatally acquired HIV have not disclosed their HIV positive status to their peers because they do not trust them with their secrets.

*T*he findings of the study prove that adolescents living with perinatal HIV infection do not get support from their peers, friends, and teachers, because these people do not know their HIV status.

4.2.2.4 THEME 4: Challenges experienced by adolescents living with Perinatal HIV infection

Sub-themes

4.1 Lack of adherence and thoughts to quit treatment (ARVs
4.2 Stigma and discrimination associated with taking ARTs experienced
4.3 Different types of abuse experienced by adolescents
4. 4 Psychosocial and emotional needs

Sub-theme 4.1 Lack of adherence and thoughts to quit treatment (ARVs)

The findings of the current study that pointed out that some adolescents with perinatally acquired HIV lack adherence to ARV. WHO (2020) stated that great care should be exercised when initiating or changing medication for adolescents with perinatally acquired HIV as they are at risk of neurocognitive impairment which can interfere with their ARV adherence. UNICEF (2017) also mentioned that adherence on ARVs is poorer amongst adolescents linked to several factors like structural barriers in fitting into complex patterns in their daily life, low expectancy for outcomes of the ARVs and mental health/substance abuse. The participant also mentioned that she does not take her medication regularly by saying that

> *"I sometimes do not take my pills as I don't want to take them on an empty stomach".*
>
> Participant 003 also said, *"Yes, I do skip doses, sometimes 3 times a month but most of the time I just miss time and take them late".*
>
> Another adolescent supported by saying that "*I do skip taking my medication, not more than 10 days, but I don't have exact days".*

The findings of the results have also confirmed that adolescents with perinatally acquired HIV are tired of taking ARVs and have or think of quitting medication several times. Several reasons were mentioned as the reasons for the thoughts. Amongst the few mentioned reasons were pill fatigue and a strict schedule of the medication. Several participants confirmed by saying.

> *"Yes, several times. I wish I could stop taking this medication, but my aunt told me that I must take this medication for the rest of my life as I might die if I quit".*
>
> Another participant supported by saying that "*Yes I want to quit, because it makes me sick all the time, what is the use of taking medication which makes you sick than to heal you",*
>
> Participant 001 also echoed that she wishes to quit her ARVs by saying that *"Yes, several times I don't know what the pills are for, because there are pills that I can't tolerate and those that I can tolerate, so I change my medication frequently".*

Poor adherence to ARVs has been reported as a common problem amongst adolescents with perinatally acquired HIV. The study therefore, has learnt that most adolescents living with perinatally acquired HIV have adherence problem to their medication and they think of quitting medication.

Sub-theme 4.1 Stigma and discrimination associated with taking ARVs

The findings of the study recognised that most adolescents living with perinatally acquired HIV have never been stigmatised, but they live with the fear of being stigmatised because of living with HIV infection. Participant 008, when asked why she doesn't want people to know that she is living with HIV, said:

> "*HIV is "that illness" (vuvabyi lebyiya), it is not like any other disease".* When asked what does "that" illness means? She responded, *"It is a disease which cannot be cured, and people look at you as if you are not human enough when you have it"*.

Evidence from a study conducted by Dietrch *et al*. on adolescents and young adults shows that caregiver fear of stigma and discrimination are major barriers to adherence. Dietrich and colleagues (2017) also reported that social reasons for suboptimal adherence were heavily clustered around stigma and discrimination. Study findings by Hayfron-Yeboah, Ayisi-Addo, Siakwe & Mupepi (2017) also proved that caregivers' fear of disclosure associated with stigmatisation and consequences such as social rejection was identified as the major barriers of disclosure. The results are consistent with that of (Nsibandze *et al*., 2021). It was reported that adolescents were scared of disclosing their own HIV status to friends and relatives due to the fear of stigma and discrimination expressed by the community towards people living with HIV. The findings of the study conducted by McHenry, Nyandiko, Scanlon, Fischer, McAteer, Aluoch, Naanyu & Freeman (2016) further revealed that adolescents showed increased knowledge regarding HIV. However, there were still more misconceptions and negative beliefs about HIV. It has been reported that HIV diagnosis was associated with sexual immorality. The findings of the current study concur with the above findings as it was proved that parents and caregivers kept their adolescents' HIV status a secret due to the fear of stigma and discrimination.

> Participant 001 said, "*No one else knows that I am taking this medication because my father told me not to tell anyone because they will laugh at me".*

Participants verbalised that they were not free to take ARVs in front of their friends as the friends would know that they have HIV. However, the study has pointed out that adolescents living with perinatally acquired HIV also face stigma and discrimination from their relatives or guardians they live with, hence participant 005 said:

> *"I was constantly sick; sometimes I would not go to school because I was not well, my aunt would say I was not sick, I was lazy to do household chores. Sometimes she would tell her friends that she is not the one who killed my mother, AIDS killed her".*

Similarly, the findings of the study conducted in Uganda revealed that adolescents usually reported enacted stigma which is described as the unfair and harsh treatment they experience at home compared to the HIV negative children in the same household (Ashaba, Cooper-Vince, Vorechovska, Rukundo, Maling et al, 2019). The study, therefore, revealed that most adolescents live with perceived stigma but they have not experienced the stigma.

Sub-theme 4.2 Abuse experienced by adolescents

The study pointed out that adolescents living with perinatally acquired HIV experience different types of abuse. They are abused by their immediate families or relatives who adopt them. One form of abuse that dominated amongst most of the participants was emotional. It was revealed by the findings of the study that some adolescents were ill-treated by their guardians. The results revealed that only adolescents living with relatives or guardians suffered this abuse, and not those living with their parents. Previous studies revealed that adolescents suffer emotional, psychosocial and financial abuse. The WHO (2020) indicated that adolescents encounter many forms of abuse linked to their immediate family members. A global study revealed that a third of adolescents reported experiencing physical /sexual violence (Kidman & Violari, 2018). Participant 005 reported to emotionally abused when she said,

> "*My aunt whom I was staying with was ill-treating me".* When probed how she was ill-treating her she said, "*She used to talk about my illness in public*".

Another form of psychosocial abuse observed in this study is a denial of the right to have a relationship with one parent by the other one due to the parents' conflict as participant 001 mentioned. A study conducted revealed that most adolescents reported psychosocial abuse especially from their immediate family members (Merrill, Campbell, Kennedy, Burke, Miti *et al.,* 2020)

> "*I miss my mother, but I am afraid of my father*.

When asked if the father has a problem with you having a relationship with her mother, she replied

> "*Yes, he does, he also told me that my mother told her relatives that she wants to kill me". Another participant added by saying that "He (the father) also brings different women in the house and give them money*"

Merrill *et al*. (2020) revealed that several youths reported to having experienced physical violence which they considered unjustified from their family members. Similarly, the findings of the current study revealed that adolescents reported physical violence from their immediate family members,' participant 001 said*:*

> *"No, I fear him. He does not listen to anyone else, sometimes he threatens to chase me away and he used to beat me a lot but since I started having this sickness he has stopped".*

The findings of the study also revealed economic abuse where the parent of the adolescent living with perinatally acquired HIV would refuse to buy the basic things which they need to survive, participant 001 said:

> *"When I think about my mom, sometimes I wish she was around so that she will do beautiful things for me, not that my dad is doesn't, it's just that he doesn't buy me clothes. He also brings different women in the house and gives them money, but he doesn't buy me clothes".*

It has been noted by the findings of the study that adolescents living with perinatally acquired HIV suffer all types of abuse, particularly, those adolescents whose parents have passed away on are not staying with them.

Sub-theme: 4.3 Psychosocial and emotional needs

The findings of the study pointed out that the majority of adolescents living with perinatally acquired HIV do not have any support from the social development agencies. It was also noted that most adolescents are only cared for by the Department of health by giving them medication., consistent with the findings, Toth *et al.* (2018) revealed that social protection from social development agencies was only received by some adolescents and their families. Participant 001 when asked if she receive any sort of assistance from the social development agencies she replied "*no".* The findings of the study also noted that only a few participants receive food parcels from the Department of Social Development and some few receive foster care grant. Almost half of the adolescents and their families reported being getting social support ranging from food parcels, transport money and school allowance from social development agencies (Toth *et al., 2018).* The rest of the adolescents reported either get a child support grant or depend on family members for financial support. Participant 011 said:

> "*I only get my child support grant".* Another participant further supported that she was supported financially by her relatives, and she said *"I have a good relationship with my sister since she is the only person I stay with, she is my support system financially and emotionally. I have never had any problems since my mother passed away*".

The findings of the study also recognised the need for psychological support for some participants. It has been noted regarding that adolescent living with perinatal HIV infection do not receive any form of counselling regarding their condition. This has led to some of them feeling angry and having emotional problems and other behavioural problems. Participant 001 said:

> "*Nothing, I just wish to change my savage lifestyle. The other day I wanted to kill another girl at school who locked us in the class, my friends just held me up"*.

When probed more on another lifestyles she classifies as savage lifestyle, she said:

> *"Adolescent stage, sometimes I cry and refuse to do household chores and go to play with my friends and come home late after 19h00 for my pills*.

The study also observed behaviours that were narrated by participants supported the need for emotional and psychological support in the form of counselling. Participant 004 said

> *" I feel angry like I am a real orphan; I sometimes wish they were both dead, the pain would be less knowing that they are both dead unlike now that my father is alive and doing well but he does not mind if I am dead or alive. My aunt is taking good care of me though*".

Other adolescents expressed the need for emotional and psychological support to deal with their HIV positive status. The study conducted by Toth *et al.* (2018) also revealed that adolescents had significant support needs including lack of access to the peer support groups, stigma, discrimination and inability to cover medical bills. Participant 008 said:

> *"I only started having problems when I discovered that I am HIV positive. I imagined myself sick like my mother and it felt really like I was physically sick; I would sometimes lock myself in the room and cry. I started isolating myself from people, felt like I had no use living. My performance at school dropped that I have failed that year as I was also suffering from morning sicknesses. In the community, there have not been any problems. Since I have accepted my HIV status, I don't have any problem, and I am so happy because my son is HIV negative".*

The findings of the study also discovered that adolescents did not attend any existing support groups because of a variety of reasons. It has also been noted that others did not have an idea what a support group is. Participant 002 and 012 confirmed not knowing of any support group by saying:

> "*No, I have never heard of a support group*".
>
> "*What is a support group, I have never heard of it"*

Another participant said:

"*No, I have not attended because I am a shy person*".

Other participants have however, verbalised not to have attended a support group but can be interested in attending if invited. Participants 008 and 009 said:

"*No, I have never attended a support group, but I would like to attend".*

The findings of the study denote that adolescents were in dire need of emotional and psychosocial support.

4.2.2.5THEME 5: Suggestions made by adolescents living with Perinatally Acquired HIV

Adolescents living with perinatally acquired HIV have made several suggestions that might assist in making their lives better during this journey of taking ARVs. These suggestions are outlined in following the sub-themes.

Sub-themes

5.1 Treatment modification
5.2 HIV -positive status must be disclosed
5.3 Request for mentors and supporters

Sub-theme 5.1 Treatment modification

Few adolescents living with perinatally acquired HIV suggested that if their medication could be modified to smaller tablets, it might ease their lives. Some alluded that some of the current pill sizes choke them, and it is attributable to them not adhering to their treatment schedule. Consistently, the findings Slogrove (2018) study mentioned the size of the pills as one the factors affecting adherence among adolescents. Participant 001 said:

> "*I want the big pills changed; they choke me".* Another participant supported that the pills are too big for them and said that *"these pills are too big"*

The findings of the study, however, noted that most of the adolescents also complained of the treatment schedule that was too strict for them as it has a curfew, and it makes them feel tired. They further suggested that the treatment schedule be flexible like other medication and be taken in the morning, afternoon and evening. The findings by van Wyk & Davids (2019) reported that adolescents made a suggestion for treatment modification to enhance adherence. Furthermore, Foster *et al*. (2020) suggested the use of single-tablet regimens with high genetic barriers which would tolerate intermitted adherence would enhance adherence and reduce mortality amongst adolescents. Participants said:

> "*I am not free to go as I wish as I have to take medication on time and sometimes when I am studying, I have to stop for treatment*".

> "*Sometimes I get tired of taking treatment because of the strict schedule, at times I just forget that I must take my medication".*

> "*I only have a problem with time because in most cases, I forget because I am busy or studying. I feel like I am in jail because I must mind time always. It is also tiring as there is no end to taking this medication and one will never get used to it".*

The findings of the study therefore recognised that adolescents were not coping well with the current regimen and the current form of their treatment.

Sub-theme 5.2. HIV positive status must be disclosed to people living with perinatally acquired HIV

Adolescents living with perinatally acquired HIV suggested that they should be told about their HIV status. However, no one mentioned who, how and when the status must be disclosed. The results of the study discovered that most adolescents living with perinatally acquired HIV do not know their HIV status and amongst those who know their HIV status few have been disclosed to by either nurses, parents or relatives but most have discovered their HIV status on their own**.**

Sub-theme 5.3 Request for mentors and supporters to perinatally acquired HIV positive adolescents will be valuable

The adolescents living with perinatally acquired HIV raised concerns about having questions and uncertainties, and not having someone to talk to. They verbalised their desire to have a mentor who would always be available for them. One participant pointed out the need for someone to talk to, as she sometimes felt overwhelmed by taking daily medication and living with a chronic and stigmatised illness. They also pointed out that it is not easy for them to ask the nurses some of the questions they have. Participant 002 said:

> *“Can we please have a mentor who will always be available in case we have questions or uncertainties*”.
>
> *“I can say it is fine, but I am not used to them (nurses) as I am a shy person. I have questions that I would like to ask them sometimes, but I am afraid to ask. Like I want to know as to why I am taking treatment daily.”*

The findings of the study therefore illuminated the adolescents’ need for a mentor as it was noted that participants do not have access to health education. The nurse did not teach them about their illness, and this left them with questions and uncertainties. The adolescents requested that information on HIV be made universally available for those who are vertically infected with HIV (Woollett, 2021).

4.4.3. Summary

This chapter presented qualitative result findings. Themes and sub-themes that emerged from data analysis were discussed in detail. The five major themes were: description of the knowledge of HIV/AIDS amongst adolescents living with perinatally acquired HIV infected adolescents, expectations placed on these adolescents, support systems/needs for adolescents living with perinatally acquired HIV, challenges faced by adolescents living with perinatally acquired HIV, coping strategies, and recommendations made by adolescents living with perinatally acquired HIV. Sub-themes were discussed in detail.

4.5. PRESENTATION AND INTERPRETATION OF QUANTITATIVE RESULTS

This section provides information and presents the results of the quantitative strand of the study on how adolescents living with perinatally acquired HIV in the Vhembe District are coping with the disease, their challenges and support needs. The findings are presented using tables and other graphic formats like graphs, charts, and histograms. The results are presented in numerical scores and percentages according to related categories. The results of the study are presented according to the five sections of the questionnaire, starting with the socio-demographic profiles of the participants. The following objectives were addressed:

- *To identify support needs of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.*
- *To identify and describe gaps in the current management and care of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.*

Table 4.3 The response rate

Descriptive information	**Number of questionnaires**	**Percentages**
Number of questionnaires distributed	213	100%
Number of questionnaires returned	213	100%
Total number of usable questionnaires	186	87.3%

Table 4.3 above presents the summary of the response rate of the participants. The questionnaires were checked by research assistants once the participants were done with filling them. This ensured that all questionnaires do not have unfilled gaps, which could be spoilt and affect the sample size. A total of 213 questionnaires were distributed to the adolescents, 213 (100%) were collected and 27 were not usable due to major errors. The response rate was high as 186 (87.3%). All 186 questionnaires were analysed, and data is presented below.

Table 4.4. Socio-demographic characteristics of the adolescents; n=186, % in column

VARIABLES		FREQUENCIES	PERCENTAGES
Age	12-15years	91	48.9%
	16-19years	95	51.1%
GENDER	FEMALE	100	53.8%
	MALE	86	46.2%
EDUCATION	PRIMARY	64	34.4%
	SECONDARY	116	62.4%
	TERTIARY	6	3.2%
RESIDENCE TYPE	RURAL	106	57.0%
	SEMI-RURAL	62	33.8%
	URBAN	18	9.7%
STAYING WITH PARENTS	YES	104	56.5%
	NO	82	43.5%
LOST A PARENT/PARENT DUE TO HIV INFECTION	YES	54	(29.0%)
	NO	132	(71%)

Table 4.4 above shows that 95 (51.1%) of adolescents were above 15years of age, over half were females and most resided in rural areas and only 54(29%) lost their parents.

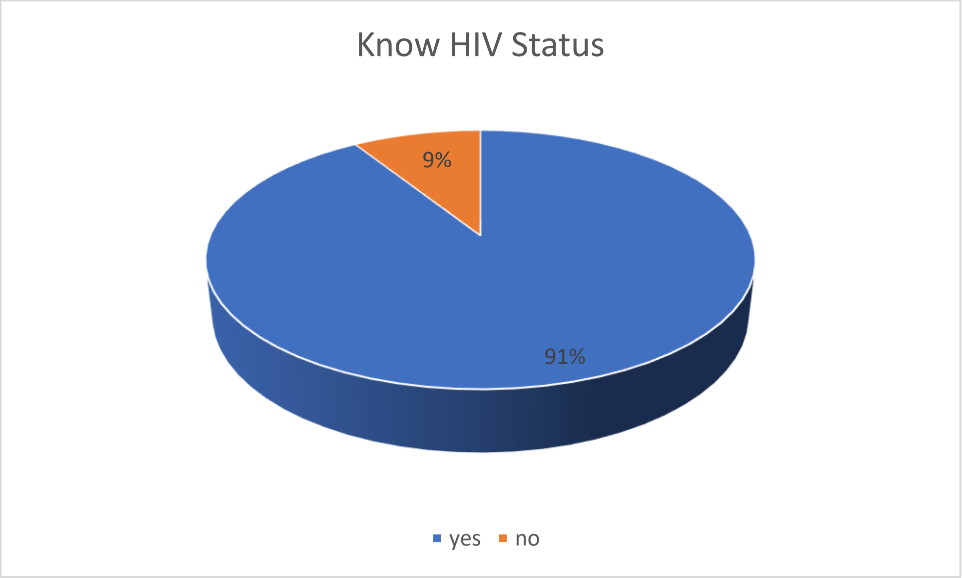


Figure 4.1 Adolescents who know their HIV status.

Figure 4.1above shows that the majority 170 (91.4%) of adolescents knew their HIV status.

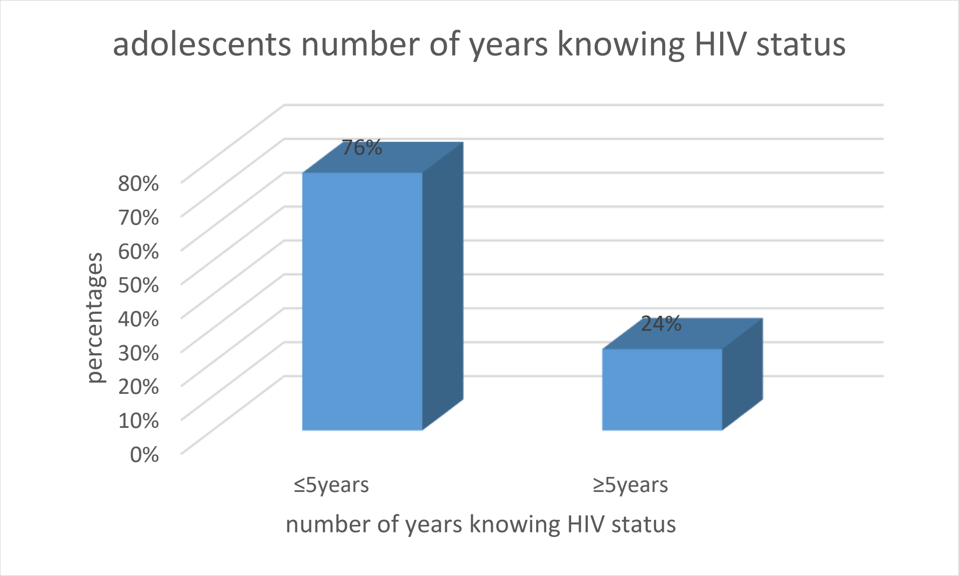


Figure 4.2 Adolescents' number of years knowing HIV status (n=170)

Figure 4.2 above shows that the majority of adolescents 130(76.0%) knew their HIV status for ≤5 years.

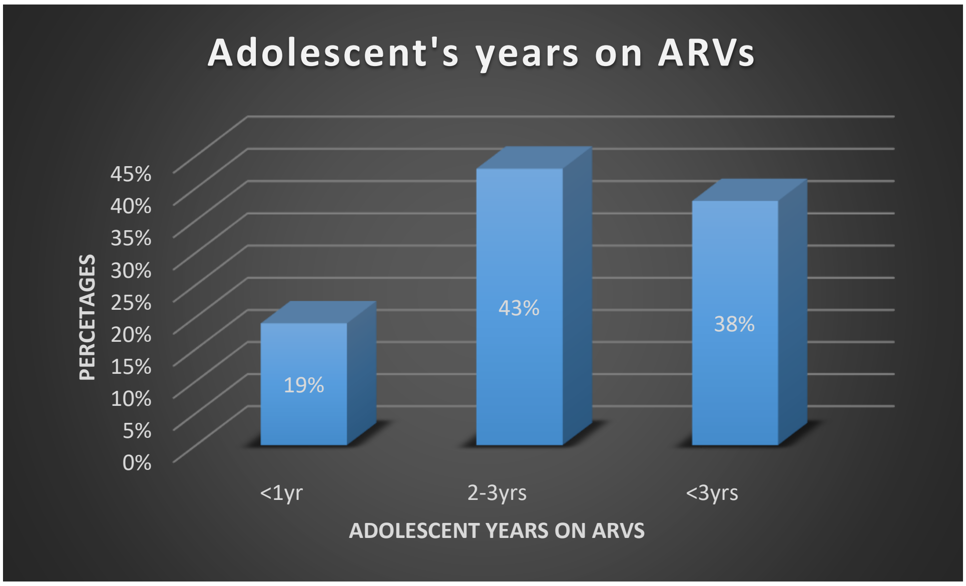


Figure 4.3 Adolescents' number of years on ARVs (n=186)

Figure 4.3 above shows that the majority 150 (81.0%) of the adolescents were on ARVs for more than 1 year.

Table 4.5. Adolescents' emotional assessment n=170 % in rows: n (%)

Emotional Aspects	YES n (%)	NO n (%)
Have been admitted or bedridden due to HIV	26 (15.3)	144 (84.7.1)
Have ever got help regarding your problem	57(33.5)	113 (66.5)
Support		
HIV positive status caused problems with other family members	29 (17.1)	141(82.9)
lost friends because of your condition	30 (17.6)	140 (82.4)
Daily Activities		
condition disturbed you with your school activities	40(23.5)	130 (76.5)
feel guilty about your HIV positive status	56(32.9)	114(67.1)
Have lost interest in the things you used to enjoy before knowing your HIV status	30(17.6)	140(82.4)
Have attended any support group for adolescents living with perinatal HIV infection	38(22.4)	132(77.6)

Table 4.5 above shows the emotional status of the adolescents**.** Below a quarter 29 (17.1%) of adolescents have had problems with other family members due to their positive HIV status. Also close a quarter of adolescents 40 (23.5%) once experienced challenges with their schooling due to HIV infection and above quarter 56 (32.9%) reported feeling guilty about their HIV positive status.

Table 4.6 Assessment of adolescents coping status n=186 % in rows: n(%)

Statements	**Agree**	**Neutral**	**Disagree**
Need more knowledge regarding HIV/AIDS	102 (54.8)	66 (35.5)	18 (9.7)

Feel helpless about my HIV positive status(n=170)	22(12.9)	37(21.8)	111 (65.3)
Feel like I am not coping with taking medication every day	66 (35.5)	80 (43)	40 (21.5)
Don't know how to get out of this situation	56 (30.1)	75 (40.3)	55 (29.6)
The health professional attend to me when I come for a consultation	74 (39.8)	53 (28.5)	59 (31.7)
Wish nurses can also give attention when I come for my consultation and medication	100 (53.8)	43 (23.1)	43 (23.1)
Wish the nurses can talk to me about my HIV status when I come for my consultation	95 (51.1)	46 (24.7)	45 (24.2)
Feel sometimes I need clinical counselling regarding my condition	72(38.7)	57(30.6)	57(30.6)
Family is supportive of my situation	83(44.6)	54(29.0)	49(26.3)
Feel like I am losing control of my situation	71(38.2)	66(35.5)	49(26.3)
Have fear about my future	68 (36.6)	55 (29.6)	49 (26,3)
My lifestyle has changed since I started taking my ARVs	37(19.9)	4 (26.3)	100(53.8)
Family do not treat me like other children at home	53 (28.5)	51(27.4)	82 (44.1)
Sometimes feel useless and wish I was dead	49 (26.3)	45 (24.2)	92 (49.5)

Table 4.6 above shows that over 50% of adolescents required more knowledge regarding HIV/AIDS, emotional and psychosocial support from health care providers and other professionals dealing with emotional support. About 53.4%, of the adolescents indicated that their lifestyle has not changed since they have started taking ARV. Data tabled above also

shows that 44.6%% of the adolescents received emotional support from home. Over a quarter of the participants, 66 (35.5%) were not coping well taking ARVs every day. The above table further shows that above a quarter of the adolescents expressed great distress when agreeing with a statement that sometimes they feel like they want to die.

Table 4.7 Adolescents behavioural assessment n=170 %in rows: n(%)

Statement	**Agree**	**Disagree**
I use condoms every time I have sex(n=154)	72(46.8)	82(53.2)
I understand the importance of using a condom (n=162)	108(66.7)	54 (33.3)
I know the danger of having unprotected sex(n=138)	87(63.0)	51 (37.0)
I share my HIV status with my partner (n=151)	112 (74.1)	39 (25.9)
I care about what people say about my HIV status(n=127)	82 (64.6)	45 (35.4)
I use alcohol/drugs(n=142)	42(29.6)	100(70.4)
I understand the dangers of using alcohol/drugs(n=132)	49(37.1)	83(62.9)
I understand the danger of mixing herbal medication with ARVs (n=135)	43 (31.9)	92(68.1)

*Neutral responses were excluded from analysis

Table 4.7 above shows that most (74.1%) adolescents shared their HIV status with their sexual partners and 64.6% (82) cared about what people say about their HIV status. above half (82) 53.2% did not use condoms, and over half (108) 66.7% indicated to have an understanding of the importance of using condoms. The table also shows that most 87(63.0%) knew the danger of having unprotected sex and meanwhile over a quarter 42(29.6) agreed to the use of alcohol/drugs.

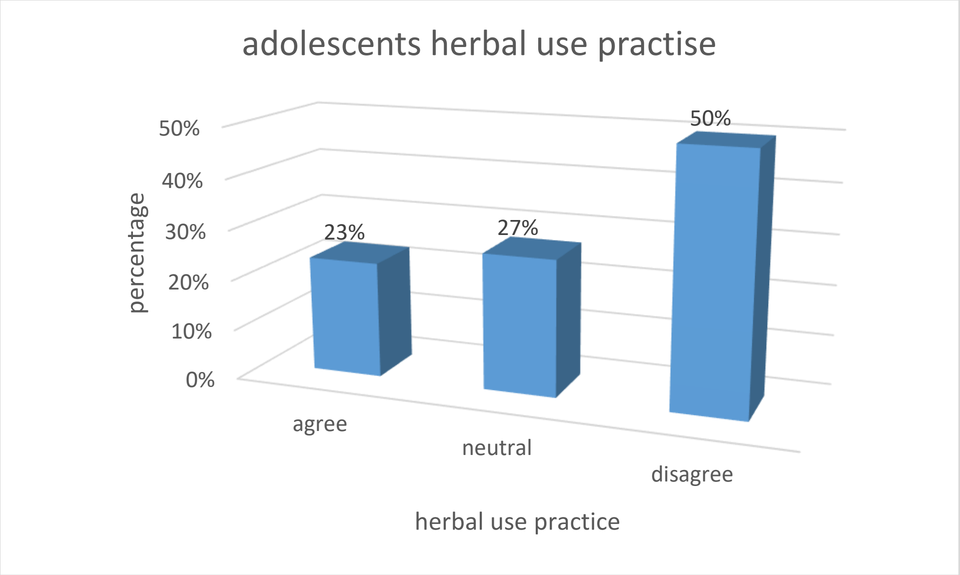


Figure 4.4. Adolescents herbal use practise

Figure 4.4 above shows that that half (50%) of the adolescents did not use herbal medication

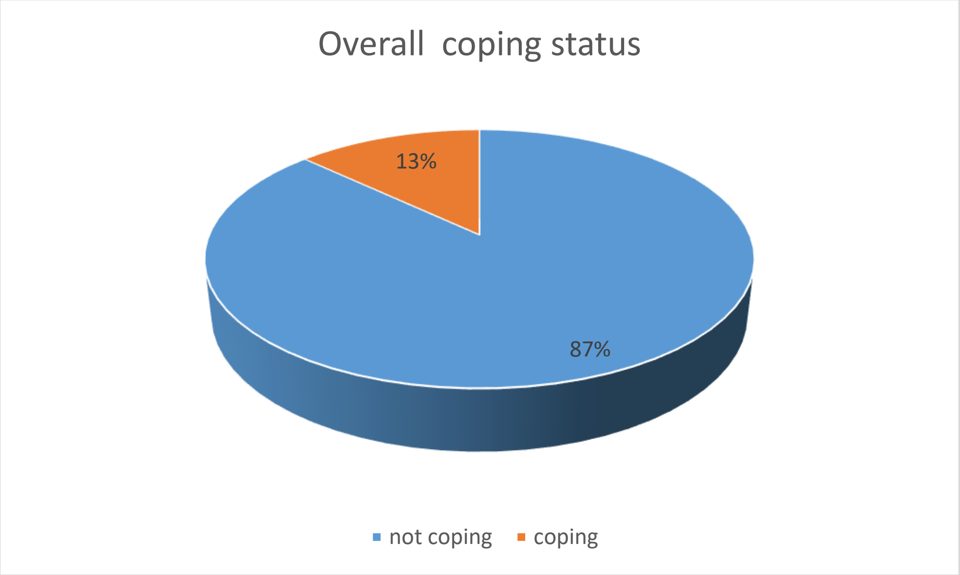


Figure 4.5. Overall coping status

Figure 4.5 above shows that overall, only 13% of the adolescents are coping living with HIV status.

Table 4.8. Coping status by Socio-Demographic Properties (SDP)

Socio-demographic Profile		Not coping	Coping	Fischer's exact
Age	12-15years (n=91)	79 (86.8%)	12 (13.2%)	P=0.546
	16-19years (n=95)	82 (86.3%)	13 (13.7%)	
Gender	Female (n=100)	85 (85%)	15 (15%)	P=0.325
	Male(n=86)	76 (88.3%)	10 (11.6%)	
Education level	Primary (n=64)	55 (85.9%)	9 (14.1%)	P=0.934
	Secondary (n=116)	101(87.1%)	15(12.9%)	
	Tertiary (n=6)	5 (83.4%)	1(16.6%)	
Residence	Rural (n=90)	88 (97.7%)	2(2.3%)	P=0.96
	Semi-rural n=58()	56 (96.6%)	2(3.4%)	
	Urban (n=18)	17(94.0%)	1(6.0%)	
Years on ARVs	<1year (n=36)	30(83.3%)	6(16.7%)	P=0.452
	1-2 years(n=80)	69 (86.3%)	11(13.7%)	
	>2years(n=70)	62 (88.6%)	8(11.4%)	

**=P<0.05 show level of significance @95% CI*

Table 4.8 above shows the association of SDP and coping status by adolescents at P<0.05@ 95%CI.

Table 4.9. Adolescents coping status by selected variables (n=186)

Variable		Not coping	Coping	Fischer's exact
Know HIV status	No (n=16)	9	7	P=0.080
	Yes (n=170)	138	32	
I use alcohol/drugs				*P=0.004**
	yes	39	3	
	no	80	20	

**=P<0.05 show level of significance @95% CI*

Table 4.9 above shows there was no significant association between coping status and knowing of HIV status where P<0.05 @95%CI. Those using drugs/alcohol were significantly less likely to report they were coping hence an association of significance was revealed between the coping status of adolescents and drug/drinking alcohol (P=0.004).

Table 4.10 Alcohol/drug; condom use and HIV disclosure by age and gender

Variables		Yes to alcohol /drug use	No to alcohol /drug use		P-value
Age	12-15years(n=70)	24(34.3%)	46(65.7%)		X2=1,503
	16-19years(n=72)	18(25.0%)	54(75.0%)		P=0.472
Gender	Male(n=64)	20(31.3%)	44(68.7%)		X2=0.484
	Female(n=78)	22(28.2%)	56(71.8%)		P=0.490
Variables		Do you use always condoms?			
		Yes	No		P-value
Gender	Male(n=71)	38	33		X2=02.708
	Female(n=82)	33	49		P=0.258
Age	12-15years(n=91)	34	38		X2=1.238
	16-19years(n=95)	37	44		P=0.539
Variables		Disclose HIV status to Partner			
		Yes	No		P-value
Gender	Male(n=73)	56	17		X2=1.912
	Female (n=78)	56	22		P=0.384
Age	12-15years (n=79)	61	18		X2=4.497
	16-19years(n=72)	51	21		P=0.106

Table 4.10 above shows no significant association on alcohol/drug use and condom use and disclosure according to age and gender@ P> 0.05 @ 95%CI.

4.6. DISCUSSION OF THE QUANTITATIVE RESULTS

4.6.1 Introduction

This section presents the discussion of quantitative results. The results of the study were discussed according to the five sections of the questionnaire starting with socio-demographic profile of the participants. Results were discussed in relation to the following objectives:

- To identify support needs of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.
    - To identify and describe gaps in the current management and care of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.

Socio-demographic factors

Section A, socio-demographic characteristics of adolescents, a descriptive statistic were conducted on the responses to assess the coping status on each item. The level of significance was presented on each item. P<0.05 was considered significant @ 95%CI.

Age of adolescents

The results of the study revealed that most adolescents were between the ages of 16 and 19years, meaning that they were in mid to late adolescence. According to WHO (2020), adolescents are facing a lot of challenges linked to peer pressure, such as their risky sexual behaviours, at risk of substance use as found in the current study. Late adolescents in general have high rate of alcohol and drug use. Interestingly, this current study found that most adolescents who reported that they use alcohol/drugs were in the lower age group (12-15yrs), though not statistically significant. A study conducted in Limpopo Province, South Africa, by Maserumule *et al.* (2019), found that a quarter of adolescents (15-16yrs) were risky drinkers and almost dependent on alcohol. Gamarel *et al.* (2016) further reported that 21.3% of youth living with HIV consumed alcohol and used drugs. These studies show a concerning picture of adolescents who are already abusing alcohol, which could be a way of coping with their HIV status, and could be at risk of being dependent on alcohol at an early age. The limitation in this section was using “neutral” as one of responses, which could have made those who drink to opt not to report, or the environment where data was collected could have influenced a biased response.

At adolescence, sexual activities are common, with some having their sexual debut at this stage. Studies show that the majority of adolescents engage in unprotected sexual activities, posing a huge risk of unplanned pregnancy and HIV infection (Schimelpfining, 2020). The current study reveals that close to half (47%) of adolescents at all age groups always used condoms during coitus, and most were older adolescents. This is a concern because of their pre-existing HIV status, as there is a chance of adolescents who engage in unprotected sexual activities infecting their partners of unknown status. Ssewanyana (2018), alludes to this fact and warns sexually active adolescents of this threat, coupling that with excessive alcohol and drug use.

The results of this study further revealed that most adolescents in this age group reported that they engage in unprotected sexual activity, alcohol and substance use and other risky behaviours. These can be risky for their quality of life, given their HIV status. It was revealed that adolescents in this study take ARVs every day and of concern is the fact that a third of them reported that they are not coping with taking their treatment every day. Most adolescents in the current study reported that they have been taking ARVs for more than 3 years, which could indicate treatment fatigue, as supported by studies by Sabin *et al*. (2020) and van Wyk (2019), where adolescents on ARVs reported that they were tired of taking pills.

The results of the current study further revealed that over a third of the adolescents reported feeling helpless and needing a way out of their situation, which shows that they are indeed not coping with their HIV status and the routine it presents when it comes to medication and how they should prevent spread. Adolescents are already undergoing physical changes, which presents with episodes of mood swings and massive cognitive development (Markova & Nikitskaya, 2017).That being said, it can be imagined that those who are already HIV positive would feel helpless, as found in the current study and supported by the WHO (2020).

Adolescents with perinatal HIV infection also encounter transition trajectories like all other adolescents. However, their transition also encompasses the realisation that they are living with a highly stigmatised, chronic disease which requires advanced coping strategies than their HIV negative peers. Moreover, it was noted that sexual and romantic relationships in mid to late adolescence become the centre of their focus as they move towards adulthood (Markova & Nikitskaya, 2017). The WHO concurs by indicating that some adolescents are vulnerable to mental health conditions due to stigma, discrimination and exclusion (WHO, 2020). The findings of the study by Amal and Pandin (2021) noted that age plays a significant role in coping strategies. Contrary, to the results of the current study, are the results on a coping mechanism by deprived adolescents that noted that adolescents in their advanced age (16-19 years) have better-coping status than those in early adolescence (NAS, 2019). However, WHO noted that suicide is the third leading cause of death among adolescents between the ages of 15-19 and that 10-19years account for 16% of mental conditions globally. Interestingly, the results of the current study further revealed that there was no significant association between age and coping status by adolescents at p<0.05, meaning there was no significant difference in coping status whether one is a younger or older adolescent. The current study found that the majority of adolescents were not coping, irrespective of age. Adolescents with perinatal HIV infection are vulnerable as they live their daily lives with most of the factors leading to suicide outlined by the WHO, like living with stigmatised diseases and barriers to accessing care due to ill health. (WHO, 2020).

Gender of adolescents

The results of this study revealed that just over half of the adolescents were females compared to 46% of males. Furthermore, most adolescents were from poor communities and families and over a quarter reported that they engaged in unprotected sexual activities, which exposes them to the risk of pregnancy or infecting their negative partners. This is no different to global trends, where it was reported that adolescents are engaging in unprotected sexual activities resulting in unplanned pregnancies in girl adolescents, which is a major concern, especially in middle and low-income countries (WHO, 2020).

Proven by recent studies is the significant reduction of children born with HIV, attributable to the scaling up of the PMTCT programme (van Wyk & Davids, 2020). The engagement of adolescents in risky sexual activities increases their viral load and further lowers the immune system, putting them at risk of MTCT (Woollett, 2020). A global study conducted by Ssewanyana *et al*. (2018) revealed that 36% of adolescents living with perinatal HIV reported that they engage in risky sexual behaviour, compared to 30% of HIV uninfected adolescents, leaving their sexual partners vulnerable to acquiring HIV. It is therefore an alarming concern that the results of this study revealed that over half of adolescents (53%) reported that they do not use condoms when engaging in sexual activities.

The current study further revealed that a quarter of adolescents reported that they do not disclose their HIV status to their sexual partners. This is a concern in that it may contribute to them engaging in risky sexual behaviours, as they have been found to be vulnerable, as alluded to earlier. The issues of pros and cons of self-disclosure have been well-documented, even though benefits outweigh disadvantages, there is still a large number of adolescents who do not disclose, including in this current study behaviour (Mpofu & Jacobs, 2017; Sabharwal, Mitchell & Fan, 2018).

The results of this study further revealed a difference in disclosure status by gender. It revealed that a majority of males reported that they disclosed their HIV status though there was no statistical significance in their disclosure status by gender. Of concern is that girls were less likely to disclose their HIV status to their sexual partners and that may also affect condom use and increases the possibilities of the consequences of risky sexual activities which are re-infection Supporting these findings, the results studies show that that a most males disclosed their HIV status to their sexual partner than women and fear of stigmatisation has been alluded to as a major factor to girls' no-disclosure (Odiachi, Erekaha, Cornellius, Isah, Ramadhani, Rapoport & Agudu, 2018; YI *et al*., 2018; Nabunya, Byansi, Bahar, MCkay, Ssewamala & Damulira, 2020;). The results of this study, just findings by Mpofu & Jacobs, (2017)and Sabharwal, Mitchell & Fan, (2018) showed a positive relationship between condom use and disclosure of the HIV status where most males who disclosed reported that they use condoms every time they have sexual intercourse compared to females, though not statistically significant. This calls for more vigilance in empowering females to be assertive and freely disclose their HIV status to partners, hence the development of the user-friendly support programme was born to assist them to disclose among other things.

The current study results further revealed that there was just a slight difference in the coping status between boys and girls though not statistically significant. Interestingly, different studies reported that girls cope better than boys, whilst boys are likely to discuss their health problems with their health care providers and friends than girls, which indicate that boys are likely to cope much better than girls (Toth *et al*. 2018; Breik and Zaza, 2019; Atraro, Mengesha, Abrham & Digafe, 2020 & Neogi, 2020).

Adolescents' level of education and Residence

Education-based data indicated that most of the adolescents' highest education level was secondary school. The study results contrast with the initial anticipation that the higher the level of education, the more adolescents will have more coping status. In this study, adolescents even in a higher level of education, meaning the older ones were not coping living with HIV. Contrary to the results of a study conducted by Rzeszutek (2017) which discovered that higher education was a personal resource in coping with HIV-related distress among PLWHIV and also protected them from depression. Furthermore, education has been associated with exerting a positive influence on adolescents assists with improved mental health outcomes, reduction of risky sexual behaviour and substance/alcohol use (Toth *et al.*, 2018).

The results of this study reveal that over half of the adolescents reside in rural areas and are from poor families, and a majority still live with and are dependent on their biological parents. According to Woollett, most adolescents living with vertically transmitted HIV are from poverty-stricken families (Woollett, 2021). This study also revealed that over a quarter of the adolescents are orphaned due to HIV and live with grandparents and relatives, which is an indication that of harsh socio-economic conditions. According to Woollett (2020), orphaned adolescents have a heightened risk of exposure to physical, emotional and sexual violence in South Africa, leading to higher probable rates of secondary transmission and potential reinfection and resistance to ART. Kimera *et al.*, (2019) indicated that orphaned adolescents reported experiencing financial stress, which is a major challenge attributable to the loss of one or both parents, or parents who are too sick to fend for them. The implication of financial stress is that adolescents will not have money for transport to attend clinic appointments, leading to poor adherence to therapy. In line with this, a study conducted among South African adolescents reported a lack of funds for transportation to attend their clinic appointments, which contributed to adherence challenges (van Wyk & Davids, 2019; Madiba, Josiah, 2019).

The results of the current study also revealed that over a quarter of the adolescents reported being involved in risky sexual behaviour and alcohol/substance use, which is associated with low socio-economic status. Woollett (2021), posit that adolescents exposed to harsh living conditions have a high tendency of risky behaviour such as risky sexual behaviour, alcohol and substance use. Vhembe district is one of the districts characterized by high levels of poverty in South Africa, even those who stay in urban areas in this study could be living in poverty, and in the researcher experience as a nurse directly working in the HIV clinic, there is indeed a high level of default on treatment.

4.6.2 Knowledge of HIV status

The current study reveals that the majority of the adolescents knew their HIV status i.e. 80%. Even with them knowing of their status, less than a quarter were coping with their diagnosis. More than half of the adolescents reported that they still needed information regarding HIV, denoting a gap in their knowledge of HIV. From the results, it was of concern that over a third of adolescents reported that they needed counselling regarding their HIV status, meaning that they had not accepted their condition.

Study results also revealed that nearly a quarter of the adolescents who had been taking medication (ARVs) since birth did not know their diagnosis. This implies that caregiver-to-child disclosure is not happening as it should. Madiba and Josiah (2019), warn that non-disclosure of HIV status to children leads to poor adherence to therapy.

Timely disclosure of HIV status to adolescents has been recommended by many studies as it was shown to improve the mental health of the adolescents, as well as adherence to ART. However, it has also been discovered that adolescents who have been informed of their HIV status earlier in life had a re-emergence of negative feelings towards themselves due to the comprehension of the repercussions of living with a lifelong disease (Githahi, 2020).

The results of the study showed that the majority had known their HIV status for a while. The longer adolescents had known of their positive HIV status, the more informed choices they make regarding their lifestyle engagements like substance use and engaging in risky sexual activities (Sabin *et al*., 2020). Fear of stigma surrounding HIV did not make it easy for adolescents to feel empowered by the period of knowing their HIV status. HIV is still the most stigmatised disease, as reported by the WHO (2020), so the longer adolescents know of their HIV status, the longer they live in fear of being stigmatised and discriminated against.

4.6.3 Adolescent psychosocial challenges and emotional support

UNICEF (2017) reiterates that living with HIV, and the social situation adolescents live in, can present difficult psychosocial issues which impact how they care for themselves and engage with others. Studies show that adolescents who are facing psychosocial and emotional challenges are in dire need of support (Vreeman, 2017; Githahi, 2021, Kimera, 2021 & Woollett, 2021). As shown in the current study, over half of the adolescents reported that they had never attended a support group, despite not coping with their condition.

A third of the adolescents in this study admitted to feeling guilty about their positive HIV status in this. This was also an indication that these adolescents were struggling to cope with their HIV status and it affects their mental health. Dessauvagie *et al*. (2020) as well as Madiba and Mohlabane (2021) argue that social support and good parenting are major factors in improving mental health and adherence to ART in adolescents.

The results of this current study also revealed that most of the adolescents reported a disturbance in their school activities due to HIV infection. These disturbances were not quantified in this study and could have been due to ill health. Evidence shows that school attendance by adolescents serves as a source of hope for the future and also assists in the reduction of girls' vulnerability (Van Wyk & Davids (2019). It is for this reason that efforts have to be in place to ensure that these adolescents adhere to treatment and are embracing a good quality of life.

This study shows that over a quarter of the adolescents reported being treated differently by family members. This was more common with children who live with relatives than those who live with their biological parents, leaving them feeling discriminated against. This can be demonstrated through them being made to use separate utensils, showers and basins to the rest of the children in their families (Kimera *et al*., 2019). This discrimination often leads to depression and makes these adolescents to resort to alcohol and drug use as a coping mechanism.

The results of the study also revealed that adolescents were not coping with taking their medication, half of them reported that they did not see the importance of ARVs in their lives as they have reported, no change since they started taking ARVs, which poses a threat to adherence to ART. There are a number of reasons for this, HIV is classified as a chronic illness, therefore, adolescents who are perinatally HIV infected have been on treatment for the longest time and yet, they show no signs of ill-health. Issues of non-disclosure will also apply in this case, though not a significant issue in this study as only a few didn’t know their HIV status. .

Studies show that mental health disorders are common and prevalent among adolescents. It has been documented that most adolescents display one or more symptom/s of mental health challenge at a point in their life, which could either be behavioural, anxiety or mood disorder (WHO, 2021). Another study noted that most adolescents have mental challenges, while also recognising that the mental health needs of adolescents differ globally, with poor mental health being prevalent in low- and middle-income countries, which has a negative impact on adherence to medication (Woollett, 2021). The current study reveals that that a third of adolescents reported suffering from mental problems like forgetfulness, confusion and difficulties in their thought process. Dessauvagie *et al*. (2020) indicated that the ability to control the future and having dreams are a sign of mental soundness. This is felt by about a third of the adolescents in the current study, and it is sad that no programme is currently being implemented in Vhembe District, which is a rural area in South Africa. This is not unique to South Africa, as many studies allude to the fact that the mental health of adolescents is neglected globally and have used the phrase “severely underserved” to emphasise the severity of the negligence in low- and middle-income countries (Woollett *et al*., 2021)

4.6.4 Sexual Behaviour and Substance Use

This study reveals that most adolescents are sexually active and do not use condoms despite knowing the dangers of having unprotected sex. The researcher believes that fear could be the driver of this behaviour, along with the desire to live like other adolescents transitioning from childhood to adolescence. Studies around the globe have shown in different scenarios that sexual activity and substance use by adolescents are some of the risky behaviours displayed by adolescents in sub-Saharan Africa and that these pose the potential danger of suboptimal adherence and other health-related challenges (Zgambo, Chingatichifwe & Mbakanya, 2018; Woollett, 2021 & Zerbe, Mellins *et al.,* 2021).

Study results revealed that over a quarter of adolescents reported consuming alcohol. This is a concern as the level of alcohol use is high among adolescents, which is one of the risky behaviours associated with poor adherence to medication, especially in SSA (Duko, Ayalew & Ayano, 2019; WHO, 2021). Global trends report similar statistics of alcohol use by adolescents, which is around 20-25% (WHO, 2021)

This study revealed that two-thirds of adolescents did not know the dangers of using alcohol, which leaves them vulnerable to alcohol abuse in the near future. This is an indication that alcohol consumption amongst adolescent is a major challenge and poses major setbacks to the health system (Mutumba, Elkington, Bauermeister, Bucek, Dolezal, Lue *et al.,* 2017). Other studies further link alcohol use to adolescents not coping with living with perinatally acquired HIV (Mutumba *et al*., 2017).

4.6. SUMMARY

This section discussed the results obtained from the questionnaire, quantitative phase 2 of the study that was conducted with adolescents living with perinatally acquired HIV in the Vhembe District. The results were presented according to the sequence on the questionnaire. Data was analysed using both descriptive and inferential statistics. The next section presents the integration of qualitative and quantitative results.

4.7. INTERGRATION OF QUANTITATIVE AND QUALITATIVE DATA AND DISCUSSION

The integration or linking of results of the two strands of data (qualitative and quantitative) defines mixed methods research and highlights its value. The mixed methods sequential exploratory design consists of 2 distinct phases. Integration can happen at the design level, method level and interpretation level, and can happen in variety of different ways, namely connecting, binding and merging or embedding (Berman, 2017; Creswell & Clark, 2011). In this study, integration or linking of data happened at the design level by using an exploratory sequential design. The results of the qualitative data informed the development and design of the questionnaire that was used to collect quantitative data.

Interpretation level integration has been utilised to fully address the research questions connecting qualitative data from Phase 1 of the study and quantitative data from Phase 2 of the study using a joint display (table). The main aim of a visual joint display is to represent the integration of the results for better understanding by the reader. On the joint display on Table 4.11, qualitative interview results and statistical analysis results were compared and contrasted, and areas of convergence were discussed in order to develop an overall understanding through integration of both data strands.

Table 4.11. Joint display of data from qualitative and quantitative strands

Responses from qualitative strand		**Quantitative and qualitative data**	**Mixed methods interpretation**
1. **HIV/AIDS knowledge amongst**	-lack of knowledge on HIV/AIDS	Quantitative-54% needs HIV information	Vast lack of knowledge on HIV/AIDS
		Qualitative- more than half lacked valuable HIV information	
	-lack of knowledge of self HIV positive status	9% did not know their HIV positive status	Delay in disclosing HIV status by parents.
		Were not aware of their HIV positive status	
2. **Support systems**	families as their only emotional	54% lacked family support	Family support is needed.

-non-attendance of support groups	and support system		
	lacked emotional support from health care providers		
	psychosocial support		
challenges	**ARV challenges**	Challenges in prolonged use of ARVs.	Life-long ARVs is the major challenge.
	Stigma and discrimination	Family members and friends stigmatizing adolescents.	
	Sexual	Risky sexual behaviours.	
suggestions	Support programme	Few attending support groups	Greater need for an individualised programme and a counsellor recommended
	Mentorship	A need for mentorship on life skills	

4.8. SUMMARY INTERPRETATION OF THE INTERGRATED FINDINGS

The results of both strands were merged and interpreted to make sense of data collected from both strands and to draw out conclusions emanating from both strands. Data was then compared and contrasted with the results of previous studies to draw out associations. Frequency distributions and percentages of the results were presented to quantify the findings. Interpretation of data was conducted in relation to the research questions.

RQ1.

***What are the challenges of adolescents living with perinatally acquired HIV in relation to their families, community, schools and health care facilities in selected CHCs and clinics in Vhembe District*?**

Findings from both qualitative strands and quantitative strands of this current study provide a clearer understanding of the challenges faced by adolescents living with perinatally acquired HIV as summarized below. Major findings under this question:

Not coping with daily medication with medication was mention several times during in depth interviews. The “strict” schedule of the medication and the pill size were mostly cited as major factors to non- coping. For example during interviews most adolescents cited that they were taking their medication once daily but they had to adhere to time. Statistical findings from the questionnaire discovered that above half (53.8%) of the respondents were not coping with their daily medication.

There were contradicting results on the psychosocial and emotional challenges. During phase 1 data collection emotional and psychosocial challenges were experienced differently by adolescents. For instance those who were staying with their parents narrated to less of emotional and psychosocial challenges than their HIV negative peers, unlike those living with other people. Phase 2 however, revealed that over a quarter of the adolescents were experiencing emotional and psychosocial challenges. Additionally, 36.6% of the quantitative respondents reported to feel useless and they were dead.

Adolescents indicated to use condoms inconsistently which lead to risky sexual behaviour during phase 1 data collection. In support only below half (46.5%) only of the survey respondents agreed to be consistent with condom use during sexual activities. Furthermore, all qualitative respondents revealed that they were not comfortable with disclosing their HIV status to other people due to fear of the stigma surrounding HIV diagnosis. Supporting are the findings of the quantitative respondents that showed that 64.6% cared about what people say about people with HIV.

RQ2

How much information do adolescents living with perinatally acquired HIV have about their illness and what are the knowledge gaps regarding perinatal HIV infection in selected CHCs and clinics in the Vhembe District?

During one-one interviews, responses on the question “what is HIV” varied significantly from “I do not know” to HIV as a disease and one mode of transmission mostly through blood. Similarly, during the quantitative Phase 2, the need for basic HIV/AIDS knowledge was vast as revealed by high score of those who agreed that they need more knowledge (n=186, 54.8%)

During phase 1 data collection, it was revealed that adolescents were taking medication but others were not aware of their HIV positive status. Since most of them have been on ARVs since birth, they did not enquire or felt the need to enquire of their diagnosis from either, their parents or health care workers. In addition statistically from the quantitative survey n=186, 9% did not know their HIV status.

A need for a personal mentor was mentioned several times during interviews which indicated that adolescents were in need of information. It was also noted by the high number of adolescents who indicated a need for health professionals to talk to them about their disease from the surveys. Similar sentiments were shared by above half (53.8%) of the survey respondents indicated to be in need of the nurses’ attention.

RQ3

What are the support needs for adolescents living with perinatally acquired HIV in selected clinics and PHC facilities in the Vhembe District?

Most qualitative respondents reported a need for clinical counselling, which may highlight the inner feeling of seeking help. Furthermore, contrasting results came up as others reported to receive social support from their families meanwhile others were abused by their family members. Similarly, statistical findings discovered that adolescents reported to be fearful about their future and felt like they were losing control over the whole situation above quarter and the need for support by adolescents living with perinatally acquired HIV.

Adolescents living with acquired HIV infection indicated that they don’t have support from their families, supported by 45% of quantitative respondents who did not receive family support.

4.9. DISCUSSION OF THE RESULTS

This section discusses the mixed findings from Phase 1 and Phase 2, qualitative and quantitative. The discussion is based on the main purpose or aim of this study, the objectives, and the life course theory which acted as a guide in this study. It is important to discuss the pragmatic findings of the study. HIV/AIDS has been around for decades, but the community of adolescents living with perinatal HIV infection is relatively new as they have recently transitioned from childhood. It was essential for this study to be conducted, and the methodology employed was necessary as it provided a holistic view of the adolescents to facilitate effective and proper intervention.

The WHO (2014) supports a holistic approach to the management of adolescents. The discussion that follows provided insight into the challenges faced by adolescents, and their support needs. The discussion is presented under each objective.

4.10 DESCRIPTION OF CURRENT EXPERIENCES OF ADOLESCENTS LIVING WITH PERINATAL HIV INFECTION

Objective 1. To explore and describe the experiences of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.

Under this objective, the study explored adolescents' experiences of living with HIV and found that they face numerous challenges due to living with HIV. The extent of the challenges differed from person to person depending on social and familial factors. Adolescents who experienced greater familial challenges were those living with people other than their biological parents. Adolescents living with biological parents experienced fewer challenges as their parents tried to protect them from pain. The findings of the study established that parents had to give their children a wrong diagnosis or not disclose their HIV status at all, in order to protect them from emotional trauma. The study discovered that most adolescents who knew their positive HIV status were orphans. Orphans and those who stayed with relatives or other caregivers experienced more emotional pain as there was no one to protect them, and sometimes their challenges were caused by living with these people. The researcher is not against the disclosure of a positive HIV status to adolescents, but the manner in which the disclosure of the status is made can be traumatising. In many cases, the HIV status was divulged by caregivers/relatives unintentionally or accidentally following an argument with these adolescents.

4.10.1 Challenges associated with ARVs and treatment adherence

The study found that adolescents were not coping well with their ARV drugs, which had a negative impact on adherence. Factors linked to struggles with ARV drugs included treatment fatigue, the curfew attached to taking ARVs, side effects, the size of the pill and the fear of being stigmatised. Coping with treatment was further complicated by adolescents managing their school activities and their time for medication simultaneously. Adolescents are in the process of self-discovery, which often leads to poor adherence to treatment. A study conducted by van Wyk & Davids (2019) revealed that adolescents reported treatment fatigue as a barrier to adherence. They grew tired of taking medication daily due to the rigidity of the treatment regimen and a lack of leniency.

A review report from the CDC (2017) showed poor adherence to ARV drugs among children and adolescents due to medication formulation, the frequency of dosing, drug toxicities and side effects, children’s age and developmental stage, as well as psychosocial, behavioural, and socio-demographic characteristics of children and caregivers. Woollett (2016) also indicated that adolescents are expected to negotiate the complexity of treatment, social pressures and vulnerable health without the necessary skills to manage these circumstances.

Adherence is a significant determinant of treatment success and an indicator of healthcare transition readiness as part of self-help health management (Yi *et al.*, 2018). Foster, Ayers and Fidler (2020) indicated that adolescence is a challenging time for adherence to ARV drugs. The inclusion criteria in this study comprised of adolescents who have collected their medication on their own without being accompanied by a guardian, implying a level of independence.

A study conducted by van Wyk and Davids (2019) found that adolescents living with perinatally acquired HIV experienced challenges associated with transitioning from childhood to adolescence, such as a lack of adherence and loss to follow-up. The results of this study confirmed through verbal utterances from the qualitative strand that the adolescents lacked information on HIV/AIDS, admitted to not coping with taking their medication daily, and verbalised the need to quit their medication. Adolescents in low-income households were associated with higher rates of non-adherence.

It was further established that lack of adherence to ARVs was not voluntary but due to the poor socio-economic conditions and financial constraints, resulting in them not getting their medication and thus defaulting. Adolescents defaulted due to lack of food and refused to take medication on empty stomachs, leading to non-adherence. Vreeman, Britanny and Lee (2017) reported that adolescents defaulted ARVs due to food insecurity.

4.10.2 Challenges in social support

The findings of this study revealed a significant gap in social support for adolescents. More than half of the adolescents reported a lack of family support and were in families that were not able to cater to their essential needs due to poverty. Financial challenges also had a negative impact on their adherence as they had to miss clinic appointments due to poverty. Vreeman, McCoy and Lee (2017) discovered that access to social support has an impact on an adolescent's ability to cope. The CDC reported that limited social support amongst adolescents may jeopardise treatment adherence (WHO, 2021).

4.10.3 Challenges related to HIV-related stigma and discrimination

Adolescents reported that their positive HIV status was known only by their immediate family members, meaning that there was no direct stigma from outside. The confidentiality surrounding living with HIV/AIDS created an internalised stigma based on what they heard or saw happening to others. The stigma surrounding HIV infection creates fear among adolescents, who would rather take ARVs without the knowledge of their diagnosis than to be told that they have HIV. Adolescents pointed out that they cared about negative attitudes and what people said about people living with HIV, resulting in adolescents refusing to disclose their HIV status to anyone, including sexual partners.

Adolescents were found to be afraid rejection and alienation, so they preferred to keep their HIV status to themselves and their loved ones, believing that they will be laughed at should people know the truth. Some adolescents preferred to be alone rather than being stigmatised. The fear of being stigmatised also caused adolescents to lie to their friends about their diagnosis when asked what the daily pills were for.

The scaling up of HIV/AIDS management and care, which include PMTCT and rolling out ARVs, brought hope to the lives of those living with HIV/AIDS. The stigma surrounding the disease is still remarkable. Living with a stigmatised and chronic disease excludes adolescents from leading a normal social life and transitioning well from childhood to adulthood. The current guidelines and policies directed towards improving the lives of these adolescents are insufficient and cannot satisfy their daily support needs.

Four decades since its initial discovery, the stigma and discrimination associated with HIV still exist, increasing the vulnerability of those living with it, especially adolescents who acquired it vertically (Boushab, Fall-Malick, Melainine, Milak & Busco, 2017). HIV is erroneously linked with promiscuity, and adolescents in this study reported that people who are HIV-positive are labelled as "those" people. As the product of parents who were HIV-positive, adolescents still suffer the fear of being stigmatised, regardless of their mode of infection.

Findings revealed that adolescents suffer perceived and internalised stigma related to living with HIV, affecting their adherence to treatment. Pantelic, Sprauue and Stang (2019) described internalised stigma in HIV as when a person living with HIV endorses people's utterances and attitudes and accepts them as applicable to them. A study conducted by Kimera *et al.* (2020) revealed that adolescents reported a pattern of enacted, anticipated, and internalized stigma in their day-to-day lives and felt devalued. They feared a lack of future perspectives, experiencing injustice and feeling lonely. The results of a study on perceived stigma and the fear of unintended disclosure as a barrier to medication adherence in adolescents with perinatal HIV in Botswana revealed that adolescents were afraid of perceived stigma and discrimination, which affected their adherence as they feared taking medication in front of their roommates (Madiba & Unaswi, 2019).

Results also revealed that a positive HIV status made adolescents feel "useless" and that they wished they were dead. The narrative of feeling useless coupled with the wish to die was a significant finding as it meant that they were not mentally well and were at risk of self-harm. A study conducted by Woollett (2021) shows that HIV-infected adolescents who have lost their father or mother to AIDS reported feeling less valuable than other children and consequently withdrew from health services and social activities to avoid being insulted, rejected or being gossiped about, experiencing both internalised and perceived stigma (Oladunni, Sina-Odunsi, Nuga, Adebisi, Bolarinwa, Adeola & Lucero-Prisno, 2021). Unlike the adolescents in the study conducted by Oladunni *et al.* (2021), none of the respondents in the current study reported experiences of actual discrimination or being stigmatised.

Woollett (2016) asserted that stigma is a result of poor knowledge regarding a certain disease. HIV-related stigma is a key issue among adolescents living with HIV as it affects the quality of life, health access and health outcomes (Vreeman, McCoy & Lee, 2017). Boushab et al. (2017) indicated that stigma and its forms are a source of discrimination. They discovered that most adolescents living with perinatally acquired HIV did not disclose their HIV status to their family members and that they suffered from self-stigma. Corrigan's progressive model of self-stigma (Gopfert, Dressing, van Heydendorff & Bailer, 2019) reiterates that individuals who suffer from self-stigma internalise the shame of living with HIV/AIDS. They are ashamed of their HIV positive status and are not free to disclose it to others due to the fear of being stigmatised. The three stages of Corrigan's progressive model of self-stigma are the perception of public stigma (awareness of stereotypes), personal agreement (where a person believe the public stereotypes), and self-concurrence (internalisation and self-application of stereotypes).

4.10.4 Lack of HIV disclosure

The findings of the study show that most adolescents were not disclosed to and were taking HIV medication without knowledge of their diagnosis. The decision of when and how to disclose therefore depended on the caregiver, together with health care workers. It was also noted that sometimes disclosure was circumstantial, such as the development of opportunistic infections such as TB or when adolescents started to display risky behaviour such as substance and alcohol abuse. Findings revealed that disclosure was done by anyone from primary caregivers to healthcare providers and social workers, but the WHO step-by step process of disclosure was not followed in any of these instances (WHO, 2020). The step-by-step guide to disclosure of HIV status emphasises the importance of age-appropriateness, but the results of the current study did not gather enough information on whether certain processes were followed as caregivers were not included in the study. It appeared that parents feared disclosing adolescents' HIV status due to the "secretness" of HIV diagnosis.

HIV remains the most stigmatised condition, so it is not surprising that only a third of adolescents are disclosed to (Li, Morano, Khoshnood *et al.*, 2018; UNAIDS, 2017). According to the WHO (2020), disclosure of HIV status to adolescents should be timely and facilitated by a healthcare practitioner. The WHO (2016) outlined a step-by-step process of HIV status disclosure, but the results of the current study revealed that these guidelines were not properly followed. The findings of both strands have noted that age played a role in the disclosure of HIV status. The majority of those who were disclosed to were older than 15 years, meaning that parents or caregivers were age-cautious. A lack of disclosure was also caused by healthcare providers, who were either not well-equipped or were not following the step-by–step process of HIV disclosure. Nurses are expected to facilitate disclosure between the adolescent and the primary caregiver.

Reflection

The researcher acknowledged that the study might have accidentally disclosed HIV positive status to those who were not aware of their HIV positive status. Questions about HIV could have triggered curiosity and despair noticed during data collection. The researcher took an opportunity to explain the situation to them, and referred those who needed professional counselling after disclosure.

4.10.5 Challenges with self- disclosure of HIV status

Adolescents in the study did not disclose their HIV status to anyone other than their close family members, citing fear of being stigmatised and discriminated due to their positive HIV status. The study established that adolescents did not disclose their HIV positive status to their sexual partners, even after they had babies with them. They had a fear of being alone and labelled as an HIV-positive adolescent, consequently suffering loneliness. Lack of disclosure was associated with the need to be a 'normal' adolescent who does what other adolescents do, and they engaged in unprotected sexual activities with their partners and felt no sense of guilt about the possibility of infecting others. Some adolescents demonstrated an understanding of the importance of self-disclosure to their sexual partners following the establishment of a stable sexual relationship.

The American Psychiatric Association (APA) indicated that stigma is fear-based and can be attributable to inaccurate or misleading information (APA, 2017).

4.10.6 Lack of knowledge about HIV/AIDS

- **Lack of knowledge about the aetiology of HIV/AIDS**

The findings indicate that adolescents lacked valuable information about HIV/AIDS. The older (16 to 19 years) adolescents were able to give some information on HIV and displayed an understanding that they got the disease from their mothers. However, few could explain ARVs and their side effects. They understood that they needed to take their ARVs to be well, but did not know what it meant to be virally suppressed. It should be noted that the inclusion criteria included 10-year-olds, which could have contributed to the lack knowledge on HIV/AIDS. Adolescents lacked general knowledge about HIV and its mode of transmission. However, they seemed to have some knowledge on the management of HIV, and most of them knew that HIV can be controlled by taking daily medication.

The findings noted that knowledge on HIV was limited to the causes of HIV/AIDS, which was also limited to knowing that HIV was caused by unprotected sexual intercourse. The younger ones (10 to 14 years) explained that HIV was caused by touching someone’s blood. This meant that they were not aware of other modes of transmission of HIV, including how they got infected. They reported to be in need of more information about HIV. Qualitative results by Woollett (2021) showed adolescents’ lack of understanding of PMTCT and future reproductive health options, as well as poor comprehension of how they contracted HIV and pathways to vertical transmission. The findings of a study conducted in India revealed that the majority of adolescents had accurate information on HIV but had a lot of misconceptions about its mode of transmission (Lal. Onam, & Sidhu. 2019).

The study findings show a knowledge gap among adolescents living with perinatally acquired HIV. Saying “we need our own clinics”, adolescents living with HIV requested a responsive health system and reliable and comprehensive information regarding vertical HIV transmission (Tooth *et al*., 2021).

4.11 NEEDS PERCEIVED BY ADOLESCENTS TO BE ESSENTIAL IN THEIR LIVES

Objective 2. To establish support needs for adolescents living with perinatal HIV

The findings of this study established that some adolescents received enough support from their families in order to help them cope with and manage this disease well, but others were on their own as they did not have enough support. Orphaned adolescents living with HIV struggle to find other sources of support, due to the stigma attached to HIIV infection.

Some adolescents in this study reported that they felt like outcasts in their own homes due to living with HIV, evidenced by them expressing a need to be treated like other children in their families. Findings from a study by Damulira *et al.* (2019) showed a significant association between positive family support and treatment adherence. Adolescents reported that they valued the social from their families more than others such as friends, peers, and teachers as they did not disclose their HIV status or even discuss their HIV issues with them.

In some instances, adolescents' family members caused emotional pain by reminding them that they lived with a shameful disease instead of offering support.

4.11.1 Social support needs

Social support is described as a belief that others understand your needs and will try to help you. It can be found through friend and families, clubs, or support groups. Social support was categorised into two types: i. Instrumental support, which is helping in a tangible way and ii. Emotional support, being some whom a person can confide in (Kort-Butler, 2018).

i. Instrumental support

- financial support

The results of this study show that most adolescents depend on their families for financial support, and most of these families live in poverty without assistance or intervention from the Department of Social Development. This study also revealed that some adolescents were orphans who were in need of financial assistance. Even those staying with their parents had financial needs as their parents were not working and depended on social and child-support grants. These challenges impede adolescent development, especially the cognitive, socio-emotional, and behavioural capacities that support health and well-being. According to Van Wyk and Davids (2019), adolescents reported that a lack of financial support had a negative impact on their ART adherence, as they often did not have money to pay for public transport to the clinic. Yi *et al*. (2018) indicated that the availability or lack of social and financial protection affects treatment adherence.

The findings of the study conducted by Mabaso (2018) also indicated that low socio-economic status is a major driver for new HIV infections, especially among girls as most adolescent girls who were from poor families adopted risky behaviours for survival and put their sexual partners at risk of HIV infection in the process. The findings of the study by Woollett (2021) also revealed that most adolescents who were vertically infected with HIV were from poor families and were mostly exposed to violent circumstances. The findings, therefore, revealed a relationship between non-adherence to treatment and poverty, where some adolescents indicated that they sometimes lacked money for transport to fetch their medication. Further investigations on the cause of the discrepancy between adherence rates and financial status could be conducted in future studies.

ii. Emotional support

Feelings of uselessness and wishing to die, as reported by adolescents, indicate the need for emotional support for young people living with HIV/AIDS. The findings of this study show that most adolescents do not attend support groups, which are meant to supplement their existing support systems and provide platforms for debriefing, sharing and learning from others without fear of stigma or what others will say. Toth *et al*. (2019) discovered that two-thirds of adolescents living with perinatally acquired HIV have never attended a support group with their peers

4.12 CURRENT INTERVENTIONS ON MANAGEMENT OF ADOLESCENTS LIVING WITH PERINATAL HIN INFECTION

Objective 3. To identify and describe gaps in the current management and care of adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.

The NDoH established guidelines to manage people living with HIV/AIDS. These guidelines provide an umbrella-type of management to all HIV positive adolescents and adults. The findings of this study and previous studies highlight the uniqueness of adolescents living with perinatal HIV and the need for equally unique and specific interventions. The government of the Republic of South Africa (RSA), together with NGOs, established support groups for people living with HIV as part of management and care. These support groups were meant for debriefing without the fear of being stigmatised, and sharing experiences and coping strategies. Support groups are established in health care facilities offering HIV/AIDS care and management. According to Audi *et al*. (2021), support groups have been identified as a method to improve adherence amongst people living with HIV, although their effectiveness is still to be established.

The findings of the study revealed that there was a gap in supporting the needs of adolescents living with perinatally acquired HIV. Some adolescents were interested in attending support groups but had no information on the existence of such groups in their health facilities, while others reported not being interested in attending as they feared disclosure of their HIV status. Mark, Hrapack, Ameyan, Lovich, Ronan *et al*. (2019) indicated that while peer support programs have not been consistently effective for adolescents and youth prevention or sexual health education, some peer support programs have demonstrated an impact on health-seeking behaviour and treatment outcomes for adolescents living with perinatally acquired HIV, such as linkages, adherence to ART, retention in care and viral suppression. Additionally, Woollett (2021) established the effectiveness of support groups for the provision of emotional support as part of HIV management and care.

4.12.1 The need for a user-friendly support programme

The findings of the study indicate the need for a specific user-friendly support programme as well as additional interventions suggested by the adolescents: a mentor who will always be available as a support system, as well as a psychologist. The results also showed that there was no specific programme available for adolescents, meaning that their management and care was incorporated into adult HIV care and management without considering their period of infection and other trajectories they encountered while transitioning from childhood to adolescence. The gaps in HIV knowledge among these adolescents point to the need for a specific user-friendly support programme which will assist in empowering them to cope better with HIV. It is worth noting that some of the findings actually suggest different types of interventions. For instance low levels of advice from health workers might be addressed through training of HCWs and the problem with the size of the pill might be addressed through reformulation by pharmaceuticals. A review report conducted by UNICEF highlighted the need for a support programme for adolescents, pointing out that a number of countries were implementing service delivery packages but that the evidence on reach, coverage and impact is limited (UNICEF, 2021). Findings by Woollett (2021) reveal that adolescents require age-appropriate ways of expressing themselves and acquiring more knowledge on HIV/AIDS.

Content for a user-friendly support programme outlined

Study results suggest that the content of the user-friendly support programme should address strategies to cope with challenges related to HIV and general information on HIV including treatment side effects, adherence strategies and support needs.

4.10. SUMMARY

The WHO, together with the NDoH, have developed guidelines for the management of adolescents living with HIV, including those with perinatally acquired HIV. These guideline cover psycho-social and sexual health, HIV status disclosure and general physical health. However, the findings of this study show that adolescents living with perinatally acquired HIV still experience challenges in those areas, highlighting the need for further research and intervention.

CHAPTER FIVE

THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME FOR ADOLESCENTS LIVING WITH PERINATAL HIV INFECTION IN VHEMBE DISTRICT

5.1. INTRODUCTION

Chapter 4 presented the findings and literature review. This chapter intends to describe the development of a user-friendly programme for adolescents living with perinatally acquired HIV infection. The aim of the user-friendly support programme is to improve knowledge, retain adolescents in HIV care, and improve HIV treatment adherence.

5.2 THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME

To evaluate the developed user-friendly support programme in response to formative findings of the thesis for adolescents living with perinatally acquired HIV in selected CHCs and clinics in the Vhembe District.

5.2.1 Steps for programme design planning

The McGuire steps for programme development have been adopted to develop the user-friendly support programme (McGuire, 2016). The following 8 steps as outlined by McGuire were undertaken to develop the programme: 1. Identification of a potential need, 2. Conducting a needs assessment, 3. Researching on the existing literature through literature review, 4. Selection of an evidence-based design, 5. Development of the programme, 6. Roll out the programme, 7. Piloting of the programme and 8. Monitoring and evaluation. This phase has utilised all steps to develop the programme as they build on each other. Below is the schematic diagram of the steps used in this phase.

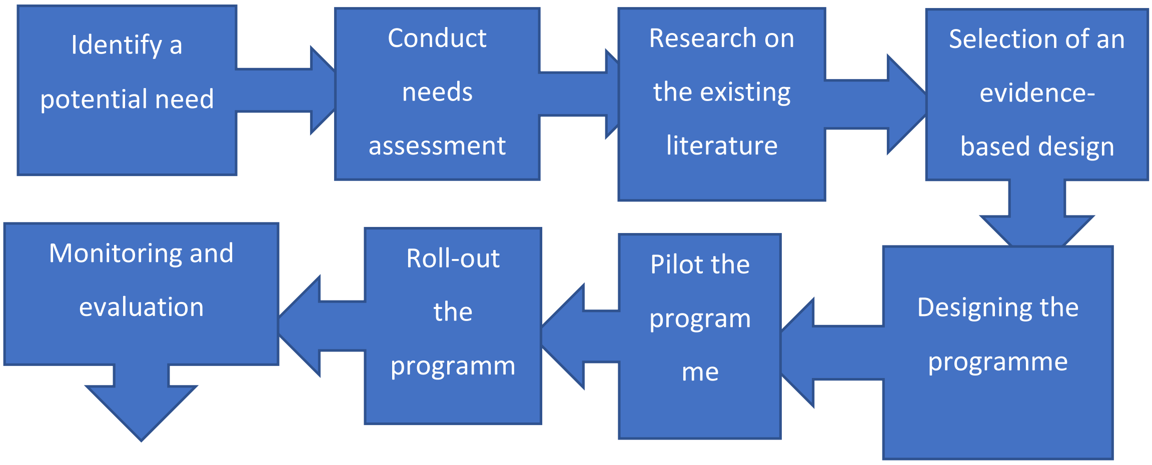


Figure 5.1. McGuire steps of programme development *(adapted from: McGuire, 2016)*

Step 1: Identification of a potential need

The findings of the study revealed a gap amongst adolescents living with perinatally acquired HIV which could be filled by a specific user-friendly support programme focusing on their needs holistically. Adolescents have been incorporated into HIV/AIDS management and care, but there is growing evidence of virologic failure, defaulting, quitting of ARVs as well as high mortality. This has prompted the development of this user-friendly support programme.

Step 2: Conducting a needs assessment

McGuire reiterates that a needs assessment is conducted to ascertain the need for a particular programme, to ascertain where needs are or have not been addressed, and to provide and determine the content of the programme. The findings of the study identified a need for a user-friendly support programme for adolescents with perinatally acquired HIV. There is also a growing body of evidence regarding the impact of good adherence to ARVs in reducing virological failure, morbidity and fatalities and reducing the spreading of the HIV infection to other adolescents. Virological suppression has been defined as viral copies of less than 400 after six months of taking prescribed ARVs (WHO 2017,) Through one-on-one interviews, surveys and questionnaires completed by adolescents living with perinatal HIV infection, the findings of the study identified that these adolescents lack knowledge on HIV/AIDS and consequently default and quit medication. The researcher found no existing programmes addressing these issue for adolescents, especially those living in rural areas.

Step 3: Research potential programs to address the need

Potential programs were researched using PubMed, Google, Google Scholar, grey literature, and peer-reviewed journals. Contextual issues related to the demographic population, location and the magnitude of the need were considered before selecting the existing program.

Step 4: Select an evidence-based program

After a thorough review of existing programs, a program is selected based on its components.

Step 5: The development of a user-friendly support programme for adolescents living with perinatally acquired HIV in the Vhembe District.

The researcher used the logic model framework (see appendix 16).

Step 6: Piloting the program

The programme was piloted in the local facilities where the study was conducted. A few facilities were selected to determine if the programme was implementable and understandable.

Step 7: Roll out the program

The programme was not rolled out as the study programme was short.

Step 8: Evaluation of the program

The evaluation of the programme was conducted on participants' post-implementation. Evidenced from the formative research findings of the study, most adolescents reported a lack of knowledge on HIV/AIDS, ARVs, coping skills, and attitude on ARV. The evaluation tool was developed based on that, with the aim to assess the knowledge gained from the implementation of the user-friendly support programme. The evaluation tool had a score rating of 1-10 points, 1 being unsatisfactory and 10 excellent.

5.2.2. Application of the logic model for the development of a user-friendly support programme

The development of a user-friendly support programme is based on the findings of both qualitative and quantitative results. It is designed for primary healthcare (PHC) facilities to improve their management, care and support for adolescents living with perinatally acquired HIV. The findings of the Phase 1 results revealed that the user-friendly support programme must address the challenges faced by these adolescents and must be structured according to the logic model structure with a needs assessment, inputs, activities, short-term goals, and intermediate goals and long-term goals (figure 5.2).

5.2 Application of logic model in the development of a user-friendly support programme

Assessment of the user-friendly support programme

6.14.1.8 Unit standard or programme assessment

The programme assessment was supposed to be in the form of a summative assessment or test which was to be marked to evaluate the impact of the programme. Participants were informed of the assessment from the beginning of the course so that they can prepare. Pre-course test or assessment was not issued out to participant to assess the level of impact of the programme due to Covid 19 restrictions. A post implementation questionnaire was issued for evaluation (appendix 17)

The critical cross-field outcomes (CCFOs)

CCFOs as defined by SAQA (SAQA website- glossary of terms) are those critical generic outcomes for the development of the capacity of lifelong learning that inform all teaching and learning. This programme has adopted the CCFOs by SAQA which relate to the study specific outcomes as shown in appendix 12.

6.4.2. The learning content of the user-friendly support programme

The learning content of the user-friendly support programme has been divided into different study units. These study units aim to address the findings of the study. Sources consulted for information on each study units have been outlined at the end of each unit. The study units are**:**

Learning outcomes	Study units and content	Assessment criteria
Demonstrate correct knowledge and understanding on HIV	Study unit 1: the description and background of HIV/AIDS Study unit 1.1: definition of HIV/AIDS and brief background Study unit 1.2: different modes of spread	Define HIV/AIDS Outline a brief background of HIV/AIDS Describe different modes of transmission and prevention Explain the concept perinatal acquired HIV
Explain different types of ARVs and their side-effects	Study unit 2: antiretroviral treatment Study unit 2.1: different types of ARVS and their uses Study unit 2.2: coping strategies with ARV pill burden	Describe different types of ARVs and the use ARV side effects and the management Develop personal coping mechanism
Describe the importance of adherence in ARV context	Study unit 3: adherence in ARVs Study unit 3.1: definition and description of the concept adherence Study unit3.2: barriers to adherence and strategies to overcome them	Demonstrate willingness to adhere and comply to ARVS Describe barriers to ARV Develop personal strategies for adherence to ARVs
Describe the importance of self -disclosure	Study unit 4: Disclosure of HIV positive status	Acknowledge the importance of self-disclosure

	Study units 4.1: Definition of the concept disclosure Study unit 4.2: importance of self-disclosure study unit4.3: step-by-step guidance for disclosure of HIV	Understand and explain the importance of disclosure in HIV
Stigma and discrimination And the coping mechanisms	Study units 5. Stigma and discrimination. Study unit 5.1: define the concepts stigma and discrimination Study units 5.2: forms and types of stigma and discrimination Study units 5.3: coping strategies	Develop strategies to deal with stigma and discrimination Identify and prevent self-discrimination and stigmatisation
Referral and support systems	Study units 6: referral and support system Study unit 6.1: types and uses of referral institutions Study unit 6.2: types and importance of support systems 6.3: importance of support groups	Knowledge on different types of support institutions for emotional, psychosocial and financial Acknowledge

The designed user- friendly support programme see (appendix 13)

5.3.1. The purpose of the programme

The main aim of the programme is to equip adolescents living with perinatally acquired HIV with knowledge and coping skills. Study findings showed a gap in knowledge and coping skills, especially with regard to taking ARVs daily. It was also discovered that there was no user-friendly support programme to address those gaps. The purpose of this study was achieved through developing a much-needed user-friendly support programme for adolescents living with perinatal HIV, to empower them with knowledge and skills to cope with HIV and ARVs. Diaz, Gusto and Diehl (undated) asserted that an educational program should deliver targeted and measurable outcomes in order to distinguish itself from a mere sets of activities. They further stated that an effective program plan must have an outcome-focused orientation to measure, track and responds to the needs of the community.

5.3.2. Outcomes of the programme

In line with the objectives of the study, the outcomes of the user-friendly programme are to cultivate empowered, knowledgeable and well-skilled adolescents living with perinatally acquired HIV; adolescents who are empowered to cope with the challenges that come with living with perinatally acquired HIV and are skilled enough to adhere to ARVs. A study discovered that secondary school students demonstrated an increased positive social behaviour and improved social skills after mindful or social and emotional skills-based interventions (Van Loon, Creemers, Vogelaar, Saab, Miers, Westernberg *et al.,* 2019).

5.3.3. Strategies to implement the user-friendly programme

A variety of strategies were used to implement the user-friendly support programme. This was done to ensure that all participants were accommodated despite age. Effective teaching strategies for adolescents were used. (Kidwell, Dunham, Bacho & Pastorino, 1995). The strategies included the following:

- Supporting adolescents by engaging them in planning for their future, offering assistance to those who need help, being a positive influence, reaching out to adolescents in need and allowing them to open up if problems are suspected.
- Encouraging peer interaction by implementing peer review/tutoring, getting all adolescents involved in discussions by creating activities that require them to rely on each other and promoting extracurricular activities like clubs and teams.
- Creating a pleasant learning environment by engaging adolescents to help design in its design. Being patient with adolescents, making them feel valued and respected and safe enough to share ideas, encouraging respect amongst themselves. Being interested in adolescents outside the facility environment by asking them about their time outside the facility environment, learning every patient's name and using it often, providing opportunities for adolescents to talk about themselves.
- Keeping adolescents engaged by including fun activities to keep them from getting bored. Making sure that adolescents understand before moving to the next chapter, varying instructional methods to reach all adolescents.
- Being effective in management by encouraging respectful communication even when viewpoints differ, and communication of clear expectations of behaviour.

- The facilitator set an example by modelling appropriate behaviour, correcting inaccurate perceptions about normal behaviour, respecting adolescents, having patience, having a positive attitude, and being encouraging to others.

5.3.4. Prerequisite for attending the training programme

Attendants of the user-friendly support programme training were all adolescents who met the criteria to participate as the study group.

The experimental learning cycle

The trainer used the experimental learning cycle to facilitate implementation of the user-friendly support programme. Experimental learning is a popular way to provide students with the opportunity to learn how to apply knowledge gained in the classroom (Sisselman- Borgia, 2017). In this learning cycle, participants are encouraging to experiment with or try new ways of thinking and behaving, thereby exploring more effective ways of solving problems and applying solutions. The experimental learning cycle has 4 stages: direct experience, reflection on the experience, generalisation of the experience and application (Gormly & NcCaffery, 1982)

The four stages of the experimental learning cycle

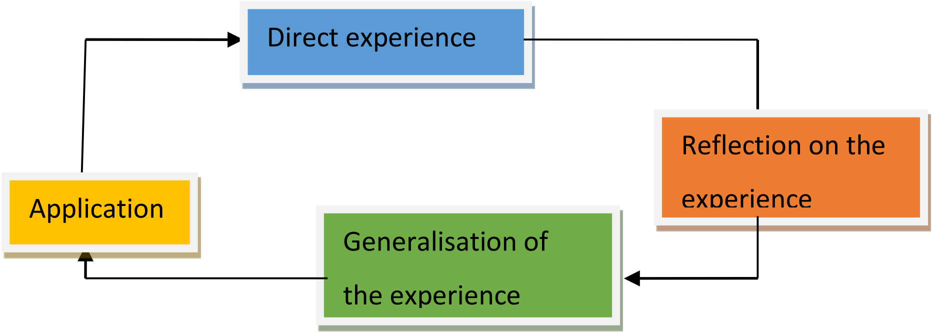


Figure 5.3 Design components of experimental training session. *Adapted from:* Gormly. W & NcCaffery. J (1982).

Direct experience

During this training, direct experience is provided by activities including exercises and small group activities. Adolescents were given topics to prepare in small groups to present to the whole group. Participants were encouraged to divide into groups of four and were tasked with sharing their individual experiences regarding ARVs, and summarising their experiences in a chart to present to the whole group. The aim was to involve all participants in talking and learning new ways of solving their problems by hearing about each other's experiences.

Reflection on the experience

They were asked to reflect on one person’s journey and share their thought on how they feel about the whole experience and the behaviour of that person.

Generalisation about the experience

During this stage the facilitator asked participants to reflect on their experience and share what they have learnt from each other’s journey individually. They were also asked what could be transferred to their own situations.

Application

Participants were assisted to identify areas in their lives where they could apply knowledge. They were requested to pick one person’s journey and identify solutions which they could apply in their own situations, and discuss how they were going to apply them.

The learning environment

The learning environment for the user-support programme was the primary healthcare (PHC) facilities in the Vhembe District of the Limpopo Province, where adolescents with perinatally acquired HIV collect their medication. Facilities were assessed for the characteristics of a conducive learning environment as conducive attributes in a physical learning environment play a dominant role in the successful delivery of lessons for adolescents.

For effective delivery of the programme, the physical learning environment of the programme was centrally located for the convenience of the majority of learners, to minimise transport issues. The venues chosen in this study had to have appointed groundsmen for the security of the learners and have easily accessible washrooms that are cleaned regularly with an adequate amount of toilet paper and soap. Three hospitals which are centrally located in each sub-district were chosen as they met the above criteria. Malamulele Hospital, Tshilidzini Hospital and Selome Hospital were selected as learning areas.

5.4. Guidelines for effective implementation of the user-friendly support programme

Three principles to guide the implementation of the user-friendly support programme (National Minority Aids Council, undated) are training of staff, implementation of sound management practices, and supervision of staff and volunteers.

5.4.1. Training of staff

A user-friendly support team will be offered training for two-and-a-half days to promote their sense of confidence, dedication and professionalism. The researcher will provide training supplies, instructions and other support needed to implement the user-friendly support programme. They will be offered training on their specific duties; the training program has been attached. As the researcher works at the clinic, the training of the staff will be conducted during weekends and in the afternoons when the facilities are less busy, to avoid contravening the daily routines of the PHC facilities.

5.4.2. Implementation of sound management practices

Implementation of the programme will be done based on the following basic management principles:

- Strengthening of systems and processes: There should be appropriate staffing, equipment and funding for the provision of quality work.
- There should be good management and supervision to ensure the delivery of a good programme.
- Encouragement of active participation and team work: every team member should be empowered towards the success of the programme and the solving of problems.
- Improving communication and coordination: all team members should be encouraged to work together to improve the quality of the programme by sharing information freely and coordinating activities.
- Demonstrating leadership commitment: leaders must be and show commitment at all times to the provision of good quality.

5.4.3. Supervision of team members

- Leaders must always provide supervision to ensure provision of quality work.
- Hold meetings monthly to give feedback of the progress of the programme
- Have individual follow-ups with team members in activities which require follow-up.

5.4. Conclusion

Chapter 5 discussed the development of the user-friendly support programme for adolescents with perinatally acquired HIV based on the findings of the study. Guidelines for the implementation of the programme were provided based on the National Minority Aids Council (NMAC).

5.5. PROGRAMME IMPLEMENTATION

Implementation workshop was conducted in one sub-district with seven participants due to enforcement of level 3 Covid-19 restrictions and the other training were conducted telephonically as individual sessions to eleven participants in other sub-districts. The workshop and individual teachings were voice-recorded.

Table 5.1 Characteristics of adolescents participated on the programme implementation

Name of sub-district	**Name of the clinic**	**Gender**		**Total**
		Female	Male	
Collins Chabane	Ntlhaveni C clinic	4	3	7
Thulamela	Muledane clinic	3	3	6
Musina	Tshipise clinic	4	1	5

Table 5.1. Presents the characteristics of adolescents with perinatally acquired HIV who participated in the implementation of the user-friendly support programme. The table shows the distribution by the sub-district and per clinic. 11 females and 7 males participated.

The process

The researcher requested clinic managers' permission to implement the programme. A list of contact details was obtained during Phase 1 data collection to recruit adolescents to participate in the implementation of the programme. Consent to implement from participants and caregivers of minors was obtained. A letter of information was read out to participants telephonically and audio-recorded verbatim (see appendix 14). Adolescents and guardians were briefed telephonically about the implementation of the programme and arrangements for participants to avail themselves for group and individual sessions were made. A separate room was prepared for group sessions and those who preferred a one-on-one session presented themselves at their respective facilities. Other sessions were delivered telephonically.

Delivering the programme

Training sessions were conducted for three groups, and one-on-one training sessions were conducted telephonically or individually as some adolescents were not comfortable in a group setting. Some could not go to the clinic due to the Covid-19 lockdown restrictions. Some adolescents cited that they were not ready for the unintended or accidental disclosure of their HIV status to others. Some training were conducted telephonically as the country moved to Covid-19 lockdown levels 3 and 4 respectively. Implementation was conducted mostly through presentations of different topics. Training was conducted as outlined in the programme (see appendix 13) and was facilitated using the language preferred by the participant. Group sessions lasted for 1 hour and 40 minutes and individual sessions ranged from 40 to 60 minutes. It was interactive, with the facilitator occasionally asking questions. Participants also asked questions and reflected on themselves. A lecture method with question-and-answer sessions and role plays was used, especially in group sessions. Participants were advised to ask questions and seek clarity before moving to the next topic or item. The researcher asked knowledge questions to assess the knowledge gained from different participants and after presenting each aspect. After each session, the researcher asked recall questions.

5.6. EVALUATION OF THE PROGRAMME

The final objective of this project was to evaluate the user-friendly support programme. The evaluation of the programme was incorporated at the end of the implementation. Participants were asked to give verbal feedback on the sessions which included the following: knowledge gained, skills gained from the programme, attitude changes towards perinatally acquired HIV and ARVs, the level of motivation gained. The user-friendly support programme was evaluated using the logic model. Below is the summary of the outcome's evaluation elements according to the logic model *(*Mccawley, 2001*)*. According to the logic model, program outcomes can be short-, medium- or long-term. This project has short-term items as medium- and long-term evaluation is a longer process needing more time.

Table 5.2. Evaluated logic model elements. (Adapted from Mccawley, 2001)

Outcomes

Short term	Medium	Long
Change in **Knowledge** **Skills** **Attitude** **motivation**	Change in behaviour practices	Change in situation social conditions economic conditions

Table 5.3. Summary of the evaluated elements

Element	Average Rating In %
Knowledge	88.8%
Skills	87%
Attitude	88%
Motivation	92.7%

The programme received an overwhelming positive response from participants. All participants have verbalised to have gained is 18 participants have verbalised to have gained a lot from the programme.

- Knowledge
  6 participants rated this element 10 which is 100% knowledge gained from the programme, 2 = 9, 8=8 and 2=7. This element received an average of 88.8% response, which indicates that participants have benefitted knowledge on HIV and related matters.
- Skills
  This element evaluated coping skills gained from the programme. This element adolescents verbalised to have gained from the knowledge on how to cope with challenges. 7 rated 10, 11=8. An average of 87% on coping skills was attained in this element.
- Attitude
  Participant were evaluated on their attitude change towards perinatal acquired HIV and ARVs. 5 rated 10, 7=9, 4=8 and 2, 7 which is an average of 88%. This demonstrated a good attitude change towards HIV and ARVs.
- Motivation
  All 18 participants were evaluated on the level of motivation to continue and adhere to HIV management and care programme. 15 rated 10, 1=9 and 2 =8 which is a total of 167=92.7% participated verbalised to be motivated to continue with HIV/AIDS management and care program after the implementation of the user-friendly support programme.

5.7. SUMMARY

The processes of implementing and evaluating the user-friendly support programme were discussed in this chapter. Four elements were evaluated: knowledge, skills, attitude and motivation. The next chapter discusses limitations, conclusions and recommendations

CHAPTER SIX

LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS

6.1. INTRODUCTION

The previous chapter discussed the development and implementation of the user-friendly support programme for adolescents to assists with the management and retention of these adolescents in HIV/AIDS management and care. This chapter discusses the limitations, conclusions and recommendations of the study, which emanate from the integrated findings of the quantitative and qualitative research conducted.

Reflection

The researcher is a nurse by profession who has been working for more that fifteen years. Through the years in the profession, she gained vast experience in professional ethics and code of conduct. She also attended different HIV courses management and NIMART. She works with adolescents who acquired HIV perinatally on daily basis. The researcher undertook this study fully aware that she had to swap roles from being a nurse to a researcher. As she entered the facilities to collect data, she always reminded herself that she was a learner and a researcher not a nurse and her role was to collect data not to try to solve the adolescent's problems.

During one-on-one interviews, sometimes it was hard for the researcher to control her emotions as some adolescents became emotional and distraught. She had debriefing sessions in between the interviews to calm down.

6.2. LIMITATIONS

Limitations related to participants

Some of the participants were young and were not able to articulate themselves well. Other interviews with younger adolescents were conducted in the presence of the caregiver which in some cases was not the biological parent/s and this could have prevented adolescents from expressing themselves well. There were instances where the researcher and the adolescents scheduled appointments failed to take place or were postponed as adolescents did not honour their appointments due to various reasons.

The study did not explore the challenges faced by caregivers, especially non-biological parents. They could have given an insight on their experiences living with adolescents who acquired HIV perinatally. They could have shared light on the issues of HIV positive status disclosure and their challenges.

Limitations related to the study design

The sequential exploratory MMR comprises of two set of qualitative and quantitative study, therefore, it requires a lot of time to complete a detailed analysis of both studies. The processes of each study requires a lot of time, reading and thoroughness on the part of the researcher. Although this design requires more than the qualitative or quantitative respectively, it provides the reader with completeness of the study.

Data collection

During data collection in Phase 1, some of the participants included in the study did not know their HIV status but were taking ARVs on their own. Some had an incorrect diagnosis, which was told to them by either their parents or guardians. One-on-one interviews were often difficult as the researcher had to probe deeper in order to get more information from participants. The duration of the interviews varied significantly between participants who were aged between 10 and 14, and those aged between 15 and 19 years. The adolescents in their late teens were more informed about their condition than the younger ones.

The study relied on the ages of the participants when initially accessing HIV management and care as the only measure to differentiate between vertical and horizontal HIV infection among adolescents, which could have left out adolescents who were tested after the age of 10 years but were vertically infected with HIV.

Programme implementation

The implementation workshops were scheduled to occur in each sub-district where data was collected (i.e. 3 workshops), but due to the enforcement of level 3 Covid-19 restrictions, only one workshop was conducted.

For those adolescents who were trained telephonically, it is worth noting that the researcher wouldn’t know whether they were attentive or could not read their body language on information shared, it was therefore difficult to establish if deeper learning occurred.

Programme evaluation

There was no pre-implementation test for adolescents, but evaluation tool was developed from the programme. Evaluation was done at the end of implementation which to some participants were voice recorded. Participants could not express themselves well as the evaluation tool was only read out to them and they rated the programme verbally (telephonically) and this could have prevented participants to rate the programme truthfully due to social desirability bias.

Generalising the results

The study was conducted in one deeply rural district of the Limpopo province and did not cover the ARV sites in hospitals, therefore, it cannot be generalised to the urban-part of Limpopo Province. However, some lessons can be drawn for adoption in areas outside the study area for the improvement of the management of adolescents living with perinatally acquired HIV.

6.3. CONCLUSIONS

The following conclusions are made based on the findings of the whole study, which is Phase 1 of qualitative data collection, Phase 2 of quantitative data collection and the integrated findings of both qualitative and quantitative findings. Understanding the challenges of adolescents living with perinatal HIV is critical in the attainment of the 90 90 90 strategies and designing a user-friendly support programme for them. The findings of the study gave rise to the following conclusions:

Adolescents living with perinatally acquired HIV experience more challenges transitioning from childhood into adolescents than their peers. There are various challenges faced by adolescents living with perinatal HIV, including a gap in knowledge on HIV/AIDS. There is a challenge of adherence, which is attributable to factors such as pill-fatigue, medication curfews, stigma and discrimination attached to living with HIV/AIDS.

The nursing staff managing HIV programmes minimally provided psychosocial support to adolescents, highlighting the need for a psychosocial counsellor. The management and care of adolescents living with perinatally acquired HIV in disadvantaged rural clinics and primary healthcare facilities is undertaken by the nursing staff, who are not fully equipped in dealing with the emotional and psycho-social aspects of the adolescents.

Adolescents with perinatally acquired HIV are not linked to any social development service, support system or support group as shown by all of them not attending existing support groups and most not having knowledge on the financial support systems available through the Department of Social Development.

The majority of adolescents living with perinatally acquired HIV (APHIV) have a desire to quit ARVs, which emphasises the need for a user-friendly support programme to supplement the WHO guidelines on the management of HIV. There is a lack of involvement by other stakeholders, which weakens the overall management of APHIV and makes their lives unbearable.

The user-friendly support programme will empower adolescents living with perinatally acquired HIV to be familiar with general information on HIV, the mode of transmission, treatment interventions and side effects.

The maintenance and sustainability of the user-friendly support programme will require support from the National Department of Health (NDoH), health personnel (especially nurses) who are working with these adolescents, and the private sector to provide funding.

6.4. RECOMMENDATIONS

The following recommendations are made towards policy makers, nursing practice, and future research and studies:

Recommendations to policymakers

Amendment and new policies on HIV/AIDS care are urgently needed. These policies must be evidence-based and focus primarily on adolescents living with perinatally acquired HIV. They should be precise on their directives to all stakeholders, a key focus being the holistic management and care of adolescents living with perinatal HIV (APHIV).

Re-implementation of this program as COVID 19 restrictions have been lifted to improve evaluation component and to minimise social desirability bias. Re-implementation to include pre and post evaluation tools.

The re-introduction of collaboration between the Department of Health and the Department of Social Development is recommended to aid the management of APHIV.

Study findings implore the government to urgently invest in adolescents living with perinatally acquired HIV infection by permanently employing young non-nursing personnel who will assist in managing psychosocial issues. Interventions will include the establishment of support groups and support clubs for adolescents to prevent a surge of new HIV infections amongst their peers.

All nursing personnel must undergo compulsory training on the holistic management of adolescents living with perinatally acquired HIV, especially the psychosocial aspects, in order to retain them in care. Effectively managing social and psychological issues has proven to play a major role in the management of APHIV.

To attain uniformity in the disclosure of HIV status, there should be an amendment to current guidelines. Clear written guidelines on when, how and who must disclose the HIV status to these adolescents must be available. All personnel assisting adolescents and caregivers must be trained on the proper disclosure process.

All nursing personnel who do not have the necessary skills on HIV/AIDS must be trained on Nurse-Initiated Management of Anti-Retroviral Therapy (NIMART) and basic HIV/AIDS counselling and training. Each facility must delegate a daily overseer who is responsible for adolescents. Youth Care Club managers must have the necessary skills and training in the management and care of adolescents living with perinatal HIV. Youth Care Club meetings should incorporate HIV/AIDS issues to address stigma and discrimination.

Recommendations for the nursing practise

Training and utilisation of the user-friendly support programme by the nursing personnel is recommended to facilitate the on-going teaching of adolescents about their condition and providing continued emotional support. Teamwork and collaboration with different stakeholders and support staff in all operational health facilities are recommended in order to create opportunities and benefits for adolescents with perinatally acquired HIV.

Recommendations for further studies

Further research is recommended in order to improve the designed user-friendly support programme for adolescents living with perinatally acquired HIV, as well as the post-implementation of the user-friendly support programme. Future research should include health care worker perspective. Additional research will assist in a range of recommendations which the local staff (nursing personell) NDoH and the Government of the Republic of South Africa can implement. More investigations is needed on how to respond to adolescents requests beyond support groups e.g. reformulation of pills.

REFFERENCES

Abrahams, E. J., Mellins, C.A., Bucek. A, Dolezal. C., Raymond, J. Wiznia, A. J., Bamji, M., Leu, C. and Warren Ng.Y. 2018. Behavioural Health and Adult Milestones in Young Adults with Perinatal HIV Infection or Exposure. Pediatrics. 2018 Sep, 142(3): e20180938. Aug 10. PMID: 30097528; PMCID: PM6317560.

Abubakar, A., Fons J. R. Van de Vijver, R., Fischer, A. S., Hassan, J. K., Gona, J., Tumaini, D., Grace, B., Khamis, K and Charles, R. N. 2016. Everyone has a secret they keep close to their hearts': challenges faced by adolescents living with HIV infection at the Kenyan coast. United Kingdom.

Abulaziz, A. 2016. Chromatographic analysis and survey studies to evaluate the emerging drugs of synthetic cannabinoids in Scotland and Saudi arabia available at http://theses.gla.ac.uk/7579/

Adams, L. and Crowley, T. 2020. Adolescents' human immunodeficiency virus self-management: needs of adolescents in the Eastern Cape. *PHCFM*. Vol 13 NO 1(2021)

Adejumo, O.A., Malee, K.M., Ryscavage, K., hunter, S.J. and Talwo, B.O. 2015. Contemporary issues on the epidemiology and Antiretroviral Adherence of HIV- infected adolescents in Sub-Saharan Africa: A Narrative review. Journal of the International AIDS Society, 18, Artcile ID: 20049. https://doi.org/19.7448/IAS.18.1. 20049.

Aderemi-Williams,R. I., Razaq,R., Abah,I. O., Opanuga, O.O. and Akanmu, A.S. 2021. Adolescents and Young Adults Knowledge, Adherence and Experiences While on Antiretroviral Therapy in a Tertiary Hospital in Lagos, Nigeria: A Mixed-Method Study. Vol. 20. Pubmed. Available at https://doi.org/10.1177%2F23259582211062754 accessed on the 7/02/2022

Alexander, G. E., DeLong, M. R. and Strick. P. L. 1986. Parallel Organization of functionally Segregated Circuits Linking Basal Ganglia and Cortex. Annual review of Neuroscience. 9(1): 375-381. Doi: 10.1146/annurev.ne.09.030186.002041. PMID 3085570

Amal, A.I., Pandin, M.G.R. 2021. Stressor and coping strategies of people living with HIV/AIDS (PLWHA): a literature review Surabaya City, East Java, Indonesia. medicine and pharmacology other doi: 10.20944/preprints2 02104.0149.v1

Anesthesiol, K. J. 2017. Introduction to pilot study. Korean journal of anaesthesiology 70(6): 601.vol.70. NO.6: United Kingdom.

Anney, V. N. 2014. Methods and meanings: Credibility and Trustworthiness of qualitative Research. Oncology Nursing Forum 41 (1): 89-91 DOI: 10.1188/14.ONF.89-91

Ataro, Z., Mengesha, M.M., Abrham, A. and Digaffe, T.2020. Gender Differences in Perceived Stigma and Coping Strategies among People Living with HIV/AIDS at Jugal Hospital, Harar, Ethiopia. Psychol Research and Behav Management. 2020; 13: 1191–1200.

Published online 2020 Dec 14. Doi: 10.2147/PRBM.S283969

Armstrong, A., Magata, T., Viary, M., Irvin, C., Cluver, N., Sonh, A., Ferguson, T., Caswell, G., Njenga, L, W., Alweras, C., Rose, D., Puthanaka, T., Baggalel, R and Ross, D. 2018. A global Research Agenda for Adolescents living with HIV. JAIDS. Volume 78 suppleme1 (s16-s21). Wolters Kluwer Health, Inc.

Ashaba, S., Cooper-Vince, C., Vorechovska, D., Rukundo, G.Z., Maling, S., Akena, D. and Tsai, A.C. 2019. Childhood trauma, major depressive disorder, suicidality, and the modifying role of social support among adolescents living with HIV in rural Uganda- Afri J AIDs Res. PMCID: PMC6774805. Doi:10.2989/16085906.2019.1637912.

Audi, C., Jahanpour, O., Antelman, G., Guay, L., Rutaihwa, M., van de Ven, R., Woelk G. and Baird, S.J. 2021. Facilitators and barriers to anti-retroviral therapy adherence among HIV-positive adolescents living in Tanzania. BMC *Public Health 21,* 2274(2021) https://doi.org/10.1186/s12889-021-12323-1

AVERT. 2020. Global information and education on HIV/AIDS. Available at info@AVERT. Accessed on the 26/06/2021

Ayer, S. and Fidler. S. 2020. *Antiretroviral adherence for adolescents growing up with HIV: understanding real life, drug delivery and forgiveness*. Vol7: 1-12 DOI: 10.1177/2049936120920177

Azago-Kouadio, R., Yeboua, K. R., Yao, K, C., Kouassi-Kouadio, A, C., Aholi, J. M., Cisse, L. and Asse, K, V. 2019. *Knowledge, Attitude and Practices of HIV Positive Adolescents Related to HIV/AIDS prevention in Abidjan* (Cote d'Ívore). International Journal of Paediatrics. Vol. 2020. Article ID 8176501availsbe at https: //doi.org/10. 1155/2020/8176501

Bhana, A., Mellins, C.A., Petersen, I., Alicea, S., Myeza, N., Holst, H., Abrams, E., John, S., Chhagan, M., Nestadt, D.F., Leu, C.S., McKay, M. 2014. *The VUKA family program: piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa.* AIDS Care. 2014 Jan;26(1):1-11. doi: 10.1080/09540121.2013.806770. Epub 2013 Jun 14. PMID: 23767772; PMCID: PMC3838445.

Berman, L. 2017. An Exploratory Sequential Mixed Methods Approach to Understanding Researchers' Data Management Practices at UVM: Integrated Findings to Develop Research Data Services. *Journal of eScience Librarianship.* ISSN 2161-3974. JeSLIB 2017; 6(1): e1104 doi:10.7191/jeslib.2017.1104

Black, B. P., Holditch. –Davis, D and Miles, M, S. 2009. Life Course Theory as a Framework to Examine Becoming a mother of a medical fragile preterm infant. Research in nursing and health.

Borenstein, J. 2020. Stigma, Prejudice and Discrimination Against People with Mental Illness

Brain and Behavior Research Foundation. American Psychiatric Association.

Boushab, B. M., Fall-Malick, F. Z., Ould Cheikh Melaïnine, M. L. and Basco, L. K. 2017. Forms of Stigma and Discrimination in the Daily Lives of HIV-Positive Individuals in Mauritania. *The open AIDS journal*, *11*, 12–17. https://doi.org/10.2174/1874613601711010012

Brittain, K., Asafu-Agyei, N.A., Hoare,J., Bekker, L.,Rabie, H., Nuttall, J., Roux, P., Stein, D.J., Zar H.J and Myer, L. 2016. Association of adolescent- and caregiver-reported antiretroviral therapy adherence with HIV viral load among perinatal-infected South African adolescents. J Int AIDS Soc. (Suppl 3): 21497.

CESSDA, Training Team. 2017-2020. CESSDA. *Data Management Expert Guide*. Bergen, Norway: CESSDA ERIC. Retrieved from://www.cessda.eu/DMGuide.

Chory, A., Nyandisi, W., Wartin., Akioch, J., Scalonlon, M., Ashimosi, C., Njoroge, T., McAteer, C., Apondi, E. and Vreeman. 2021. HIV-Related Knowledge, Attitudes, Behaviors and Experiences of Kenyan Adolescents Living with HIV Revealed in WhatsApp Group Chats. Journal of the International Association of Providers of AIDS Care Volume 20: 1-11: sagepub.com/journals-permissions DOI: 10.1177/2325958221999579 journals.sagepub.com/home/jia.

CIPHER Global Cohort Collaboration. 2018. Inequality in outcomes for adolescents living with perinatally acquired HIV in sub-Saharan Africa: A Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) Cohort Collaboration analysis. *Journal of the International AIDS Society*, *21 Suppl 1*(Suppl 1), e25044. doi:10.1002/jia2.25044

Choongwa, G.H. 2018. Fundamentals of applied research methodology: A complete guide to scholar and researchers in social sciences. Mbabane 262 Swaziland: Southern Africa Research Foundation for Economic Development (SAFRED).

Colton, T., Allread, V., Abrams. E., Schoeneborn. A., Thome, B and Fayorsey. R. 2012. A training curriculum for health Workers. ICAP. Columbia.

Comely-White, Pottrton and Ntsiea, 2020. The perceived challenges of perinatal HIV in adolescents: a qualitative study. An International Interdisciplinary Journal for Research, Policy articles. 2021 https://doi.org/10.1080/17450128.2

Conroy, A., Yeatman, S. and Dovel, K. 2013. Cult Health Sex. PMC. Doi: 10.1080/13691058.2013.791057 PMCID: PMC3821758 NIHNSID: NIHMS24772 PMID: 23705846.

Cruz, M. L. S. and Cardoso, C. A. 2015. Perinatally infected adolescents living with human immunodeficiency virus (perinatally human immunodeficiency virus). World J Virol. 2015 Aug 12, 4(3): 277-284. Doi: 10.5501/wjv. v4. I3.277. PMCID: PMC4534818 PMID: 26279988

Dahourou, D., Raynaud, J.P. and Leroy, V. 2018. The challenges of timely and safe HIV disclosure among perinatally HIV-infected adolescents in sub-Saharan Africa. Curr Opin HIV AIDS. 2018 May; 13 (3):220-229. Doi: 10.1097/COH.0000000000000462. PMID: 29461328.

Damulira,C., Mukasa, M.N., Nabunya, P., Kivumbi, A., Namatovu, P., Namuwonge, F., Dvalishvili, D., Bahar, S.O. and Ssewamala, F.M. 2019. ART adherence among HIV-positive adolescents in southern Uganda: baseline findings. Vulnerable Children and Youth Studies. An International Interdisciplinary Journal for Research, Policy and care Volume 14, 2019 - Issue 2 doi: 10.1080/17450128.2019.1576960. Available at PMC

DeCuir-Gunby. J, T. and Schutz. P, A. 2016. Social science. SAGE Publication

Dejonckheere, M. and Vaughn, L. M. 2019. Semi- structured interviewing in primary care research: a balance of relationship and rigour. Family Medicine and Community Health Vol. 7 Issue 2

Dessauvagie, A, S., Jorns-Presentati, A., Napp, A, K., Stein, D, J., Jonker, D., Breet, E., Charles, W., Swart, R, L., Lahti, M., Suliman, S., Jansen, R., van den Heuvel, L. L., Seedat, S. and Groen, G. 2020. The prevalence of mental health problems in sub-Saharan adolescents living with HIV: a systematic review. *Global Mental Health*, 7, E29. Doi:10.1017/gmh.2020.18

Dey, A. and Neogi, S. 2020. A study on coping mechanism of deprived adolescents. International Journal of social science. Volume 2(5and6) DOI: 10.13140/RG.2.2.24478.97609.article ID ISSN: 2394-1405.

Diaz, J., Gusto, C. and Diehl, D. undated. Developing a program plan Based on the program planning cycle. IFAS Extension. Florida.

Doat, A., Negarandeh and Hasanpour. 2018. Disclosure of HIV status to Children in sub Saharan Africa: a systemic review. Medicina (Kaunas). Doi: 10.3390/medicina55080433. PMCID: PMC6722600.

Doyle, A. 2021. Communication skills for workplace success. The balance careers.

Duko, B., Ayalew, M. and Ayano, G. 2019. The prevalence of alcohol use disorders among people living with HIV/AIDS: a systemic review and meta-analysis. *Substance Abuse Treat Previous Policy* 14, 52. Available at *https://doi.org/10.1186/s13011-019-0240-3.*

Elder Jr, G. H., Johnson, M.K and Crosnoe, R. 2003. The emergence and development of Life Course Theory. Handbook of the Life Course. ISBN: 978-0-306-47498-9

Elizabeth, D. and Lowenthal, M. D. 2014. *Perinatally acquired HIV infection in adolescents from sub Saharan Africa*. A review of emerging challenges. The lancet infectious Diseases, vol. 14. Issue 7: 533

Elliot, V. 2018. Thinking about Coding process in Qualitative Data Analysis. *The Qualitative Report, 23*(1), 2850-2861. Retrieved from *http//nsuworks.edu/tqr/vol23/iss11*/14

Gitahi, N. 2020.psychological needs among older adolescents perinatally infected adolescents living with HIV and transitioning to adult care in Kenya. Plos one. Kenya.

Goel, B. 2014. Sampling Methods for producing core data items for Agricultural and Rural Statistics. Jakarta. Indonesia.

Gormly, W and NcCaffery. J.1982. Design components of experimental training session. Available at: *http://www.icarzcu3.gov.in/kvk/technical/4.pdf*

Gopfert, N. C. 2019. Applying Corrigan's progressive model of self-stigma to people with depression. *Plos one. doi: 10.1371/journal.pone.0224418.*

Griffith, 2019. (Available on *http://librayguides.griffith.edu.au/systematic-literature-review-for-education)* retrieved on the 06/09/2019

Grove, S.K., Burns, N. and Gray, J.R. 2013. *The practice of nursing research: appraisal, synthesis, and generation of evidence*. 7th edition. St Louis: Missouri: Elsevier. Inc.

Gyamfi, E., Okyere, P., Enoch, A. and Appiah-Brempong. 2017. Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. BMC Int Health Human Rights. 2017; 17:8. Doi: 10.1186/s12914-017-0114-6. PMCID: PMC5385066 PMID: 28388947

Folayan, M., Odetoyinbo, O., Harrison, A. and Brown, B. 2014. Addressing the socio-Developmental needs of adolescents living with HIV/AIDS in Nigeria. A call for action. African Journal of Reproductive Health.

FoodRisc Resource Centre. 2016. Mixed methods research. Sourcecentre.foodrisc.org. retrieved on the 26/ 01/2020.

Foster, C., Ayers, S. and Fidler, S. 2020. Antiretroviral adherence for adolescents growing up with HIV: understanding real life, drug delivery and forgiveness. SAGE journals. Available at https://doi.org/10.1177/2049936120920177. Retrieved on the 29/03/2021.

Frambach, J.M., van der Vleuten, C.P. and Durning, S.J. 2013. *AM last page. Quality criteria in qualitative and quantitative research*. Academic med journal. 88(4):552

Hayfron-Benjamin, A., Obiri-Yeboah, D., Ayisi-Addo, S., Mate, S. PandMupepi, S. 2018. HIV diagnosis disclosure to infected children and adolescents; challenges of caregivers in the central region of Ghana. BMC Pediatrics, 18(1), 365. Available at https://doi.org/10.1186/s12887-018-1330-5.

Hayward, A. 2017. 5 Tips to write literature review. Accessed on https://doi.org/10.34193/EI-A_5563

HIV clinical info. 2021. Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection. Adherence to Antiretroviral Therapy in Children and Adolescents with HIV. CDC.

Hodgson, J., Ross, J. and Haamujompa, C.A. 2012. *Living as an adolescent with HIV in Zambia.* Lived experiences sexual health and reproductive needs. 1204- 1210

Hornschuh.S,. Dietrich. J.J., Tshabalala. C. and Laher. F. 2017. Antiretroviral treatment Adherence: Knowledge and Experiences among Adolescents and Young Adults in Soweto, South Africa. Volume 2017. AIDS research and Treatment Article ID 5192516.

Jansen, D. and Warren, K. 2020. What exactly is research methodology. GRADCOACH. Available at gradcoach.com.

Jerome, T. Galea, J.M., Wong, M., Muñoz, M., Valle, M., Leon, S.R., Perez, D. D., Kolevic, L. and Franke, M. 2018. Barriers and facilitators to antiretroviral therapy adherence among Peruvian adolescents living with HIV: A qualitative study. Plos One. Available at https://doi.org/10.1371/journal.pone.0192791

Kant, I. 2008-2021. *Philosophy basics. Available at philosophybasics.com.* retrieved on the 23/06/2021

Kaushik, A., Pineda, C. and Kest, H. 2016. Sexual Behavior and Knowledge among Adolescents with Perinatally Acquired Human Immunodeficiency Virus Infection Compared to HIV-Uninfected Adolescents at an Urban Tertiary Center in New Jersey. USA.

Kaushik, V. and Walsh, C, A. 2019. Pragmatism as a Research Paradigm and Its implications for Social Work Research. *MDPI journal of social science*, 255.

Kidwell. J.S., Dunham.R. M., Bach. R.A and Pastorino. E. 1995. Adolescent Identity Exploration: A test of Erikson's Theory of Transitional Crisis.'Rpt. In Adolescence. Vol. 30. Libra. Web.

Kort-Butler, L, A. 2018. The theory of social support. University of Nebraska. Lincoln.

Kresina, F. T. and Lubran, R.2017. The linkage of illicit drug use / alcohol use and HIV infection in young adults. Int J High Risk Behaviour Addic. 2017 March; 6(1): e32129. Doi: 10.5812/ijhrba.32129.

Lal, Onam. and Sidhu. 2019. A Study of Knowledge Attitude and Practice Regarding HIV/AIDS among Adolescents. Indian Journal of Youth and Adolescent Health. 4. 10.24321/2349.2880.201716.

Li, Z., Morano., J P., Khoshnood, K. et al. 2018. HIV- related stigma among people living with HIV/AIDS in rural central China. BMC Health Serv Res 18, 453(2018) available at https://doi.org/10.1186/s12913-018-3245-0. Accessed on the 04 May 2022.

South Africa Limpopo statistics. 2011. South Africa

South Africa Limpopo statistics. 2021. South Africa

Louthrenoo, O., Aurpibul, L., Oberdorfer, Pand Sirisanthana, V.2018. Family functioning in Adolescents with perinatal HIV infection. Journal of the International Association of Providers of AIDS Care (JIAPAC). Sage publications. Available at https://doi.org/10.1177/2325958218774782.

Lowenthal, E, D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K. and Ferrand R, A. 2014. Perinatally Acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. Lancent Infect Dis. 2014 Jul; 14(7): 6727-39.doi. 10.1016/s1473-3099(13)70363-3. Epub 2014 Jan 7. PMID: 24406145; PMCID: PMC4074242.

Mabaso, M., Sokhela, Z., Mohlabane, N. Zuma, K. and Simbayi, L. 2018. Determinants of HIV infection among adolescent girls and young women aged 15–24 years in South Africa: a 2012 population-based national household survey. *BMC Public Health* **18,** 183 (2018). https://doi.org/10.1186/s12889-018-5051-3

Madiba, S. and Mohlabane, N. 2021. Attendance of psychosocial clubs and self-reported anti-retroviral medication adherence: a cross section study of adolescents with perinatal HIV in the Kingdom of Lesotho. *AIMS Public Health*. Doi: 10.3934/publichealth.2021044.

Madiba, S. 2020. The consequences of Delaying Telling Children with Perinatal HIV About their Diagnosis as perceived by Healthcare Workers in the Eastern Cape, A Qualitative study. National Library of Medicine. Pubmed.org

Madiba, S. and Unaswi, J. 2019. Perceived Stigma and Fear of Unintended Disclosure are the Barriers in Medication Adherence in adolescents with Perinatal HIV in Botswana: A Qualitative Study. Biomed Research international, vol. Article ID 9623159, 9 pages, 2019. https://doi.org/10.1155/2019/9623159

Madiba, S. and Unaswi, J. 2019. Perceived Stigma and Fear of Unintended Disclosure are Barriers in medication Adherence in adolescents with Perinatal HIV in Botswana: a Qualitative study *"Bio Med Research International,* vol. 2019. Article ID 9623159, 9 pages. https://doi.org/10.1155/2019/9623159

Madiba, S. and Mokgatle, M. 2016. Perceptions and experiences about Self-Disclosure of HIV status among Adolescents with Perinatally Acquired HIV in Poor-Resourced Communities in South Africa. AIDS Research and Treatment, vol. article ID2607249, 10 pages. https://doi.org/10.1155/2016/2607249. retrieved on the 29/03/2021.

Mandalazi, P., Bandawe, C. and Umar, E. 2018. HIV Disclosure: Parental dilemma in informing HIV infected Children about their HIV Status in Malawi. Malawi Med J. 2014 Dec; 26(4):101-4. PMID: 26167257; PMCID: PMC4325342.

Marike, A., Saedi, B., Byron, B., Chahine, de Beer, I., Jacobson, T., Jagals, D., Kamanga, E. M., Mackey, T. P., Olivier, J., Reyneke, M. and van Tonder, D. 2021. Learning through assessment: an approach towards self-Directed learning. Doi: 10.4102/aosis. 2021. B280.

Mark, D., Hrapack, S., Ameyan, W., lovich, R., Ronan, A., Schmitz K. and Hatane L. 2019. Peer Support for Adolescents and Young People Living with HIV in sub-Saharan Africa: Engaging insights and Methodological agenda. Current HIV/AIDS Rep. PMC

Martin-Canavate, R., Sonega, M., Sogrado, M, J., Escobar, G., Rivas, E., Ayala, S., Castaneda, L., Aparicio, P. and Custodio, E. 2018. Dietary patterns and nutritional status of HIV-infected children and adolescents in El Salvador. A cross-sectional study. PLOS ONE.13 (5) e0196380. Available at https://doi.org/10.1371/journal.pone.0196380.

Maseko, Y. and Madiba, S. 2020. Pain, anger, and fear of being discovered persist long after the disclosure of HIV sero-status among adolescents with perinatal HIV in rural communities in South Africa. Global and Public health. Available at https://doi.org/10.3390/children7120261 accessed on the 20 June 2021.

Maskew, M., Fox, M, M., Evans, D., Govindasamy, D., Jamieson, L., Malete, G., Mongwenyana, C. and Technau, K. 2016. Insight into Adherence among a cohort of adolescents aged 12-20 years in South Africa: reported barriers to Antiretroviral Treatment. AIDS Res Treat. 2016; 2016: 4161738. Doi:10.1155/2016/4161738. PMCID: PMC5102702 PMID: 27867661

Mavangira, V. and Raniga, T. 2015. Psycho-social experiences of perinatally HIV-infected adolescents residing in child and youth care centres in South Africa. Online version ISSN 2312-7198 vol. 51 n.3 Stellenbosch available at http://dx.doi.org/51-1-456

Mccawley, P. 2001. The Logic Model for program planning and evaluation. University of Idaho Extension. Vietnam

McHenry, M.S., Nyandiko, W.M., Scalon, M. L., Fiscer, L.J., McAteer, C.I., Aluoch, J., Naanyu, V and Vreeman, R. C.2016. HIV stigma: perceptions from Kenyan Child caregivers and Adolescents Living with HIV. Journal of the International Association of Providers of AIDS care (JIAPAC). SAGE journals. PubMed. Available at https://doi.org.10.1177/2325957416668995

Mellins, C.A and Malee, K.M. 2013. Understanding the Mental Health of Youth Living with Perinatal HIV Infection: Lessons Learned and Current Challenges. Journal for the International AIDS Society. 16(1): 1-3. Available: http://www.jiasociety.org/index.php/jias/article/view/18650 (Accessed 10/05/2018).

Merril, K.G., Campbell, J.C., Kennedy, C.E., Burke, V.M., Miti, M., Rimpong, C., Decker, M. R., Abrams, E.A., Mwansa,J. K and Denison, J. A. 2021. So hurt and broken': A qualitative study of experiences of violence and HIV outcomes among Zambian youth living with HIV. https://doi.org/10.1080/17441692.2020.1864749

Merville, O., Puangmala, P., Suksawas, P. *et al.* 2021. School trajectory disruption among adolescents living with perinatal HIV receiving antiretroviral treatments: a case-control study in Thailand. *BMC Public Health* 21**,** 189 (2021). https://doi.org/10.1186/s12889-021-10189-x

Miller, Nkala, Closson, Chia, Cui, Palmer, Hogg, Kaida, Gray and Dietrich. 2017. The Botsha Bophelo adolescent Health study: A profile of adolescents in Soweto, South Africa. Southern Africa journal of HIV Medicine. Vol 18, no1 (2017)

Mills, E.J., Lester, R. and Ford, N. 2012. Promoting long term adherence to antiretroviral treatment Patient support and community interventions are probably the best interventions. British Medical Journal. Geneva. Switzerland.

Mhairi, M. 2019. South Africa needs to get more young people living with HIV on treatment. University of the Witwatersrand Johannesburg. South Africa.

Mofenson, L, M and Cotton, M. 2013. The challenges of success: adolescents with perinatal HIV infection. Journal of the International AIDS Society 16(1): 18650 DOI: 10. 7448/IAS.16.1.18650. PubMed.

Mpofu, C and Jacobs, I. 2016. Perceptions of adolescents perinatal infected with HIV regarding the self-disclosure of their status. South Africa.

Mutumba, M., Elkington, J.A., Bauermeister, A., Bucek, C. Dolezal, C., Leu, C, S and Mellins C.A. 2017. Changes in Substance Use Symptoms Across adolescence in Youth Perinatally infected with HIV. *AIDS Behav.*doi 10.1007/s10461-016-1468-9. PMC

Myburg, D and Dramowski. 2020. Horizontal transmission to children of HIV-uninfected mothers: A case and review of the global literature. International Journal of Infectious Diseases. Volume 98, pages 315-320

Mweemba. M, Musheke M.M, Michelo. C, Halwiindi. H, Mweemba. O and Zulu. J.M. 2015. When am I going to stop taking the drug?" Enablers, barriers, and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia. BMC Public health. Zambia.

National Minority Aids Council. Undated. Programme Development. Washington DC. Available at info@nmac.org. (Accessed 04/05/2021)

National Academics of sciences, engineering, and Medicine; Health and Medicine division; Division of behavioural sciences and Education, Board on Children, Youth and Families; committee of Neurobiological and Socio-behavioural science of Adolescent development and its Applications, Backes, E, P and Bonnie R, J editors. 2019. The promise of Adolescence: realising opportunity for all Youth. Washington DC. National Academics Press. Adolescents Development.

Nsibandze B. S., Downing. C., Poggenpoel, M. and Myburgh C. P. H. 2021.

"I have been rejected so many times" experiences of female adolescents living with HIV in rural Manzini, Eswatini: A case study. International Journal of Africa Nursing Sciences. Volume 14, 2021, 100307

Okawa, S., Mwanza-Kabaghe, S., Mwiya, M., Kikuchi, K., Kankasa, C and Ishikawa, N. 2017. Adolescents, experiences, and their suggestions for HIV Serostatus disclosure in Zambia: A mixed Methods study. Public Health. https://doi.org/10.3389./fpubh.2017.00326. Accessed on the 30th of November 2021

Oladunni, A. A., Sina-Odunsi, A. B., Nuga, B. B., Adebisi, Y. A., Bolarinwa, O. A., Adeola, A. A and Lucero-Prisno, D. E. Psychosocial factors of stigma and relationship to healthcare services among adolescents living with HIV/AIDS in Kano state, Nigeria, Heliyon, Volume 7, Issue 4,2021, e06687, ISSN 2405-8440,https://doi.org/10.1016/j.heliyon.2021.e06687.

(https://www.sciencedirect.com/science/article/pii/S2405844021007908)

Ramakuela. N, J, Lebese. T.R, Maputle. S.M and Mulaudzi. 2016. Views on termination of pregnancy at Muyexe high school in Mopani District, Limpopo Province, South Africa. African Journal of primary health care and family medicine8(2)1-6. South Africa

Relf, M, V., Holzemer, W, L., Holt, L, Nyblade, L and Caiola, C. 2021. A Review of the State of the Science of HIV and Stigma: Context, Conceptualization, Measurement, Interventions, Gaps, and Future Priorities. The Journal of the Association of Nurses in AIDS Care: JANAC Publish Ahead of Print (3) DOI:10.1097/JNC.0000000000000023

Roth, M. J.S. 2014. Logic Models. A tool for Telling Your Programme's Performance story*. Evaluation and program planning.*

Rutakumwa, Mugisha, Bernays, Kabunga, Tumwekwase, Mbonye and Seeley. 2019. Conducting in-depth interviews with and without voice recorders: a comparative analysis. Sage journals. Pubmed. https://doi.org/10.1177/1468794119884806

Rzeszutek, M. 2018.Health-related quality of life and coping strategies among people living with HIV: the moderating role of gender. *Archives of Women's Mental Health* 21:247–257. Available at https://.org/10.1007/s00737-017-0801-2

Saksena, R. 2020. Stratified random sampling. Lucknow. Uttar Pradesh. India.

Salomans, M. S. 2019. Youth born with HIV face unique challenges. Contagion Live resources.

Sam-Agudu, N. A, Folayan, M and Ezeanoule, E (2016) Seeking wider access to HIV testing for adolescents in Sub-Saharan Africa. International paediatric Research foundation Inc.). Retrieved on the 26/01/2020.

Schimelpfening, N. 2020. How self-esteem influence risky sexual behaviours in teens. Childhood depression. Dotdash publishers. Incl

Sexana, V. 2017. What is Yamane sample calculation? Available at https://www.quora. com. Retrieved on the 30th August 2020.

Sisselman-borgia., Amanda, G and Torino-Gina, C. 2017. Innovations in Experimental Learning for Adult Learning. Journal of Applied Learning in Higher education v7 p3-13.

Shenton, A, K. 2004. *Strategies for ensuring trustworthiness in qualitative projects*. Northumbria University, Newcastle upon Tyne, NE1 8ST, UK.

Shiferaw, H and Gebremedhin, S. 2020. Undernutrition among HIV-Positive Adolescents on Antiretroviral Therapy in Southern Ethiopia. Adolesc Health Med Ther. 2020 Aug 19; 11:101-111. Doi: 10.2147/AHMT.S264311. PMID: 32903856; PMCID: PMC7445507.

Slogrove, A, L., Esser, M, M., Cotton, M, F., Speert, D, P., Kollmann, T, R., Singer, J., Bettinger, J, A. 2017. A Prospective Cohort Study of Common Childhood Infections in South African HIV-exposed Uninfected and HIV-unexposed Infants. Pediatr Infect Dis J. 2017 Feb; 36(2): e38-e44. Doi: 10.1097/INF.0000000000001391. PMID: 28081048; PMCID: PMC5242219.

Slogrove, A. L., Schomaker, M., Davies, M. A., Williams, P., Balkan, S. and Leroy, V. 2018. The epidemiology of adolescents living with perinatally acquired HIV: A cross-region global cohort analysis. *PLoS medicine*, *15*(3), e1002514. doi: 10.1371/journal.pmed.1002514

Ssewanyana, Mwangala, van Baar, Newton and Abubakar. 2018. Health Risk Behaviour among Adolescents living with HIV in sub-Saharan Africa. A systemic review and Meta-analysis. *Biomed Research International*. Vol 2018. ID 73756831 18 pages.2018 https://doi.org/10/10.1155/2018/7375831.

Stangi, A.L., Mwangala, M., Sebanyi, M., Mackworth-Young, C. R.S., Chiiya, C., Chonta, M., Clay, S., Siewright, K and Bond. 2021. Feasilibty, Acceptability and Preliminary Efficacy of. Tikambisane ("let's Talk to Each Other'): a pilot Support Group intervention for Adolescent Girls living with HIV in Zambia. Journal of the International Association of Providers of AIDS Care (JIAPAC) SAGE Journals.

Strauss, A.L. 1987. An introduction to codes and coding. P27.

South African Qualification Authority. 2004. Criteria and Guidelines for short Courses and Skills Programmes: South Africa

South Africa South African National Department of Health. 2020. National Consolidated Guidelines for the management of HIV in adults, Adolescents, Children and infants and prevention of Mother-to- child Transmission. South Africa.

Sohn, A.H and Hazra, R. 2013. The changing epidemiology of the global paediatric HIV epidemic: keeping track of perinatally HIV infected adolescents. Journal of International AIDS society, 16, 18555. Httpa://doi.org/10.7448/IAS.16.1.1.18555

Thomas, L. 2020. How to use stratified sampling. Available at scribbr.com. Accessed on the 15th/11/2021.

Toska, E., Cluver, L., Orkin, M. 2019. Screening and supporting through schools: educational supporting needs of adolescents living with HIV in a South African cohort. *BMC Public Health* 19, 272 (2019). https://doi.org/10.1186/s12889-019-6580-0.

Toth, G., Mburu. G., Sovannary, T., Khol, V., Ngin, C., Chhoun, P and Yi, S. 2018. Social support

Needs among adolescents living with HIV in transition from pediatric to adult care in Cambodia: findings from cross-sectional study. AIDS research and Therapy! 5 Article number:8(2018).

Tshuma, S. 2015. Challenges faced by adolescents living with perinatal HIV/AIDS. University of Pretoria. South Africa

Tsondai, P, R., Braithwaite, K., Fatti, G., Bolton Moore, C., Chimbetete, C., Rabie, H., Phiri, S., Sawry, S., Eley, B., Hobbins, M, A., Boulle, A., Taghavi, K., Sohn, A, H and Davies, M, A. 2020. Characteristics and outcomes of adolescents living with perinatally acquired HIV within Southern Africa. AIDS. 2020 Dec 1; 34(15):2275-2284. Doi: 10.1097/QAD.0000000000002683. PMID: 32910063; PMCID: PMC7674245.

UK Essay. 2018. The pros and cons of qualitative, quantitative and Mixed Methods Research. Retrieved from hhttps://www.ukessays.com/essays/psy.

UNAIDS. 2018. Global HIV & AIDS statistics-2018 fact sheet. Retrieved from https://www.unaids.org/en/resources/fact-sheet

UNAIDS. 2020. Global HIV & AIDS statistics- 2020 fact sheet. Retrieved from https://www.unaids.org/en/resources/fact-shet

UNICEF. 2021. HIV and AIDS in adolescents. UNICEF DATA. Retrieved at www.https://data.unicef.org

UNICEF. 2021. HIV treatment, care, and support for adolescents living with HIV in Eastern and Southern Africa: A review of interventions for scale 2021. UNICEF/UN0147076/Noorani.

UNICEF. 2016. Adolescents Living With HIV. Developing and Strengthening Care and Support Services. GENEVA. UNICEF Regional office for central and Eastern Europe and the Commonwealth of the Independent states (CEECIS).

Van Wyk B.E and Davids, L.C. 2019. Challenges on HIV Treatment adherence amongst adolescents in a low socio-economic setting in Cape Town. Southern African Journal of HIV medicine. Vol. 2.

Vreeman, R.C, MacCoy, B.M. and Lee, S. 2017. *Mental health challenges amongst adolescents living with HIV.* Journal of international AIDS society. USA.

Van Loon, A. W.G., Creemers H, E., Vogelaar. S., Saab. N., Miers. A, C., Westernberg P,M and Asscher. J, J. 2019. The effectiveness of the school based skills-training programs promoting mental health I adolescents: a study protocol for a randomized controlled study. *BMC Public Health* **19**, 712

Van Wyk and Davids. 2019. Challenges to HIV adherence amongst adolescents in low socio-economic Durban.

Vuban, J, A and Eta, A, E. 2018. Negotiating access to research sites and participants within an African context: the case of Cameroon. SAGE journals. Available at https://doi.org/10.1177/1747016118798874.

Warren, K. 2020. Qualitative data Analysis Methods 101. Available at gradcoach.com. Retrieved on the 23/07/2021.

Willis, N., Mavhu, W., Wogrin, C., Mutsinze, A and Kagee, A. 2018. Understanding the experience and manifestation of depression in adolescents living with HIV in Harare, Zimbabwe. Available at:https://doi.org/10.1371/journal.pone.0190423. Retrieved on the 26/01/2020.

Winskell, K., Miller, K., Allen, K. A and Obong'o. 2016. Guiding and supporting adolescents living with HIV in sub-Saharan Africa: the development of curriculum for family and community members. Child and youth review, 61 (2016), pp. 253-260. 10.1016/j.childyouth.2015.12.017

Woollett, N., Pahad, S and Black, V. 2021. "We need our own clinics": Adolescents living with HIV recommendations for a responsive health system. PLos ONE 16(7): e0253984. Doi: 10.1371/journal.pone.0253984

World Health Organisation. 2013. HIV and adolescents: guidelines for HIV testing and counselling and care for adolescents living with HIV. Retrieved from https://www.who.hiv/aids adolescents

World Health Organisation. 2014. Consolidated guidelines on prevention, diagnosis, treatment and care for the key populations – includes section on adolescents and young people from the key populations. Retrieved from https://www.who.hiv/aids adolescents

World Health Organisation. 2021. HIV/AIDS. Retrieved from who.int.

XU, L., Munir, K., Kanabkaew, C and Le Coeur. 2017. Factors influencing antiretroviral treatment suboptimal adherence among perinatally HIV-infected adolescents in Thailand. PLos One. 20176; 12(2): e0172392. Doi: 10.1371/journal.pone.0172392 PMCID: PMC5312953 PMID: 28207891

Zanoni, B.C., Archary, M., Subramony, T., Sibaya, T., Psaros, C and Haberer, J, E. 2021. Disclosure, Social support and Mental Health Are Modifiable Factors Affecting engagement in care of Perinatally-HIV infected adolescents: A Qualitative Dyadic Analysis. AIDSBehav. Jan;25(1): 237-248. Doi: 10.1007/s10461-020-02968-1. PMID: 3238220; PMCID: PMC7790871.

Zareen, Z. 2018. Commentary: Paradigms, axiology. And praxeology in Medical Education Research. Vol. 93-issue 11s-pS1-S7. Article doi: 10.109/ACM.000000000000002384

Zgambo, M., Kalembo, F, W and Mbakaya, B, C. 2018.risky behaviours and their correlates among adolescents living with HIV in sub-Saharan Africa: a systemic review. Reproductive Health. 2018Oct 24, 15(1): 180.doi: 10.1186/s12978-0614-4. PMID: 30355344; PMCID: PMCID: 6201550

Zohrabi, M. 2013. Theory and Practice in language studies. Vol 3. No. 2 pp254-262. Academy publishers. Finland.

Zulu. J, M. (2017). Experiences and coping strategies of adolescents living with HIV at community level in Zambia. Edorium J Public Health. 4.48-57.10.5348/P16-2017-15-OA-7

APPENDICES

Appendix 1: Letter to the department of health

P.O BOX 2314

MALAMULELE

0982

24 October 2019

Department of Health

Private bag X908

POLOKWANE

0700

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN SELECTED CLINICS AND COMMUNITY HEALTH CENTRES OF VHEMBE DISTRICT

Dear Sir/Madam

I, Rirhandzu Austice Mabasa, a PhD candidate in Department of Public Health at the University of Limpopo, hereby request permission to conduct my study at the selected public hospitals mentioned above. The research I wish to conduct is entitled: **THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME FOR ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA.** This project will be conducted under the supervision of Prof. T. M. Mothiba and Co-supervisor Prof L Skaal of the University of Limpopo.

All information received from the respondents will be treated confidentially and will be used solely for purposes of the research. Attached receive a copy of my thesis proposal, which includes a copy of the consent form and an interview guide to be used in the research process.

The study will be conducted in the following facilities in Vhembe District of Limpopo Province: Collins Chabane Sub-District: Mphambo CHC, Mhinga Clinic, Ntlhaveni C Clinic, Ntlhaveni D Clinic, Xikundu Clinic, Tlangelani Clinic. Thulamela Subdistrict: Thoyandou CHC, Sibasa Clinic, Duvhuledza Clinic, Lwamondo Clinic, Tshakhuma Clinic Muledane Clinic, Vhuruvhuri Clinic. Musina sub District: Mutale CHC, Nancefield Clinic, Madimbo Clinic, Matswale Clinic, Musina Gateway, Tshipise Clinic and Musina Mobile.

My NHRD registration number is LP-201910018

If you require any further information, please do not hesitate to contact me on:

Cell: 082 9396 492/ 0786961861

Email address: rhandzuk0@gmail.com

Thanking you in advance for your cooperation.

Yours sincerely

Mabasa RA

Appendix 2: Consent form

UNIVERSITY OF LIMPOPO

Statement concerning participation in a Research Project

Name of Study: THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME FOR ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA

Information box:

Thank you for agreeing to participate in this study. My name is **Rirhandzu Austice Mabasa** and I am a researcher from the University of Limpopo. The aim of this study is to develop and implement a programme for adolescents living with perinatally acquired HIV in Vhembe District. The study is non-invasive. Interviews will be conducted and voice-recorded and questionnaires will be distributed to collect data.

Participation in this study is voluntary and you may withdraw from it at any time and without giving reasons. This will have no influence on the way I am treated at my treatment point.

Should you have any queries, kindly contact:
Mabasa RA (082 9396492)

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

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without giving reasons. This will have no influence on the way I am treated at my treatment point.

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

I hereby give consent myself/ child to participate in this study.

....

Name of volunteer/ parent or guardian Signature of volunteer/ parent or guardian

....

Place Date Witness

Appendix 3: Fomo ya mpfumelelano

YUNIVHESITI YA LIMPOPO

Xitatimende mayelana na vutinghenelerisi eka vulavisisi lebyi bya xisayese

Vito ra ndzaviviso: ku humelerisa na ku endla phirogireme ya vantshwa lava nga beburiwa na xitsongwa- tsongwana xa HIV a Disitrikitini ya Vhembe e ka Xifundzha xa Limpopo a South Afirika.

Bokisi ra vuxokoxoko: Ndzi khensa ku va mi pfumerile ku teka xiave eka ndzavisiso lowu. Vito ra mina hi mina **Rirhandzu Austice Mabasa** naswona ndzi mulavisisi ku suka a Yunivhesiti ya Limpopo. Xikongomelo xa ndzavisiso lowu I ku humelerisa na ku endla progireme ya vantshwa lava nga beburiwa na xitsongwa-tsongwana xa HIV a Distrikitini ya Vhembe. Ndzavisiso lowu a wu na ku tlhaviwa. Hi ta vutisa vutiso leswi nga ta kandziyisiwa hi tlhela hi nyika phepha ra swivutiso e ka lava nga ta ti nghenelerisa ku endla vulavisisi. Ku nghenelela a ka ndzavisiso lowu I ku ti twela, a swi boheleriwi munhu na swona u pfumeleriwa ku tshika nkarhi wunwani na wunwani loko u nga ha swi lavi u nga nyikangi na swivangelo. Leswi a swi nga vi na nkucetelo e ka makhomeriwelo ya wena eka ndhawu leyi u tekaka ka yona maphilisi. Loko mi ri na swivutiso, mi nga khumba: Mabasa RA (082 9396492)

Ndzi twile swikongomelo na ndzavisiso lowu naswona ndzi nyikiwile na nkarhi wo vutisa swivutiso ndzi tlhela ndzi nyikiwa nkarhi wa ku hleketa hi yona mhaka leyi. Swikongomelo swa ndzavisiso lowu swa twala swinene e ka mina. A ndzi fositeriwangi ku nghenelela eka ndzavisiso lowu.

Ndzi twisisa leswaku ku nghenelela eka ndzavisiso lowu I ku titwela na swona ndzi nga tshika nkarhi wunwani na wunwani ndzi nga vulangi swivangelo. Leswi a swi nga vi na nkucetelo eka ma khomiwele ya mina ya laha ndzi tekaka kona maphilisi.

Ndza swi tiva leswaku ndzavisiso lowu wu pfumeleriwile hi va vulavisisi na matikhomelo ya Turfloop (TCREC), Yunivhesiti ya Limpopo na Ndzawulo ya rihanyu ya Limpopo.ndzi tlhela ndzi swi twisisa hi vutalo leswaku mbuyelo wa ndzavisiso lowu wu ta titrhisiwa ka sayese ntsena, naswona wu ta humesiwa hi ku kandziyisiwa ntsena. Ndza pfumela, ntsena loko swihundla swa mina swi ta tiyisisiwa ku hlayiseka

Ndzi nyika mpfumelelo wo tinghenelerisa eka ndzavisiso

....

Vito ra mupfumeri/ mutswari Nsayino wa mupfumeri/ mutswari

....

ndhawu siku Mbhoni

Appendix 4: Interview guide

Interview guide

What do you know about HIV?

Do you know your HI V status?

How did you know your HIV status?

How do you feel being born with HIV?

In your opinion, how different are you with your friends who are “supposedly” HIV negative?

Have you ever been sick and bedridden?

When did you find out about your HIV status?

Who else know about your HIV status besides your family?

How do you relate to your friends and teachers at school?

Do you think they would treat you treat you differently if they knew your HIV status?

Do you have a girlfriend or a sexual partner?

How do you feel about the treatment the nurses give you?

How do you feel about your treatment (pills) schedules?

Do you smoke*?*

Do you drink*?*

Have you ever wished or felt like drinking or smoking? *No*

Is there any sort of assistance you get from stakeholders like social workers or ward councillor? *No*

What do you think can be done to improve your life*?*

Appendix 5: Nongonoko wa swivutiso

1. Xana u tiva yini hi HIV?
2. Xana wa xi tiva xiyimo xa wena xa HIV?
3. U titwa njan ku va u beburiwe/ Tswariwa na xitsongwa- tsongwana xa HIV?
4. Swi vula yini e ka wena ku va na xitsongwa-tsongwana xa HIV?
5. Hi swihi swiphiqo leswi u nga hlangana/ hlanganaka na swona hi kuva u ri na hanya na xitsongwa- tsongwana xa HIV?
6. Xana u xi tive rini xiyimo xa wena xa HIV na swona u xi tive njan?
7. I mani unwani a tivaka xiyimo xa wena xa HIV handle ka va ndyangu wa wena?
8. U na munghana loyi mi hlanganaka hi swa masangu?
9. Munghana wa wena wa masangu wa xi tiva xiyimo xa wena xa HIV?
10. Xana mati sirhelela loko mi endla masangu?
11. U nga byi hlamusela njani vuxaka bya wena na tintangha ta wena, ndyangu na tiko hinkwaro?
12. U ti twa njani hi makhomiwele ya wena hi vaongori?
13. Xana u nga navela leswaku ku cinciwa yini hi mayelana na makhomeriwe ya wena hi vaongori?
14. U titwa njani hi mayelo ya wena aya ku ya teka mirhi ya wena ya vutshunguri
15. Xana wa nwa byalwa naa?
16. Xana wa dzaha fole kumbe swidzidziharisi?
17. Loko ku ri hi wa nwa kumbe ku dzaha, xana u sungule rini?
18. Xana kun a mpfuneto lowu u wu kumaka a handle ku suka eka vahlaysi va vanhu, kumbe vurhangeri bya tiko?
19. U nga navela ku endleka yini ku antswisa vukorhokeni bya vantshwa lava hanyaka na xitsongwatsongwana xa HIV

Appendix 6: Questionnaire

English

SECTION A

Demographic data of the adolescent living with perinatally acquired HIV infection.

A1. Age

12-15	
16-19	

A2. Gender

Female	
Male	

A3. Highest level of education

Primary school	
Secondary school	
Tertiary	

A4. Residence

Rural	
Semi-rural	
Urban	

SECTION B

Information about the years in ARVs

Instructions: Please choose the appropriate response to each statement**.**

Years knowing HIV status

0-1 year	
1-5years	
Above 5 years	

.

Years in ARVs

Less than 1 year	
1-2 years	
3-4 years	
5 years and above	

SECTION C

Assessment of HIV/AIDS on the adolescents living with perinatally HIV infection

Instructions: Please choose the appropriate response to each statement**.**

No.		YES	NO
C1.	Do you know your HIV status		
C2.	Do you stay with your parents		
C3.	Have you lost a parent/parents due to HIV infection		
C4	Have you lost interest on the things you used to do before due to your condition		
C5.	Has your HIV positive status caused problems with other family members		
C6.	Have you lost friends because of your condition		
C7.	Has your condition ever disturbed you with your school activities		
C8.	Have you ever got help regarding your problem		
C9.	Do you feel guilty about your HIV positive status		
C10.	Have you been admitted or bedridden due to HIV		
C11.	Have you had memory problems (forgetfulness, confusion, difficulty thinking…)due to your condition		

C13.	Have you ever had financial problems to attend your medical issues		
C14	Have you ever attended any support group for adolescents living with perinatally HIV infection		

SECTION D

Assessment of adolescents living with perinatally HIV infection‘coping mechanisms and the practices

Instructions: Please choose the appropriate response to each statement**.**

		Agree	neutral	Disagree
D1.	I need more knowledge regarding HIV/AIDS			
D2.	I feel helpless about my HIV positive status			
D3.	I feel like I am not coping taking medication everyday			
D4.	I don’t know how to get out of this situation			
D5.	The health professional attend to me when I come for consultation			
D6.	I wish nurses can also give attention when I come for my for consultation and medication			
D7.	I wish the nurses can talk to me about my HIV status when I come for my consultation			
D8.	I feel sometimes I need clinical counselling regarding my condition			
D9.	My family is supportive to my situation			
D10	I feel like I am losing control on my situation			
D11	I have fear about my future			
D12	My lifestyle has changed since I started taking my ARVs			

D13	My family do not treat me like other children at home			
D14	I sometimes feel useless and wish I was dead			

SECTION E

Assessment sexuality and substance use

		I agree	neutral	I disagree
E1	I share my HIV status with my sexual partner			
E2	I care about what people say about my HIV status			
E3	I use condom every time I have sex			
E4	I understand the importance of using condom			
E5	I understand the danger of having unprotected sex with my HIV status			
E6	I use alcohol / drugs			
E7	I understand the danger of using drugs/ alcohol with ARVs			
E8	I understand the danger of mixing herbal medication with ARVs			

Appendix 7: Example of an interview

Interview 1
15 years
Female

What do you know about HIV?

Some I know, some I don’t know but nurses help me understand.

Mhh… do you mind sharing with me what you know?

That I must not eat meat every day, I must eat vegetables for my body to be healthy and strong.

What do you understand about HIV/AIDS?

I don’t really remember what they told me, but they told me something about HIV.

According to your clinic file, you are taking daily medication, do you mind sharing what the treatment is for?

Yah, I don’t remember anyone telling me but they told me to take my medication every day

Do you know your HIV status?

No I don’t.

Do you know if you are living with the HI Virus or not?

I don’t know, I just know that I have to take my medication daily so that I don’t fall sick.

Who collects your medication from the clinic?

I do

I come to the clinic and tell the nurses.

Will you please share with me what you tell the nurses?

I tell them what pills they must give me and which ones they are not supposed to give?

Which ones are they not supposed to give you?

The big pills

Have you ever thought of quitting treatment?

Yes, several times I don't know what the pills are for, because there are pills that I can't tolerate and those that I can tolerate, so I change my medication frequently mostly the bigger ones which chokes me.

You mentioned earlier that nurses explained to you about HIV/AIDS, what was the reason?

(Silence*)…….i don't know because some information they told my father, I was only told about the food that I should eat so that I don't fall sick.*

Have you ever thought of asking nurses what is the treatment for?

No I have not.

Do you mind sharing why not?

I really don't see the necessity of asking them.

Why were nurses talking to you about diet?

So that I don't get drowsy after taking my pills.

Besides your father who else knows that you are taking these pills?

My neighbour by the name of Linah.

Anyone else?

No one else because my father told me not to tell anyone, because they will laugh at me.

Ok…….

Do people laugh at each other when one is taking medication?

Ehhhh…….those ones at my place they do laugh at you when you are taking pills.

Tell me more about that….have you ever seen or heard anyone being laughed at because she/he was taking pills?

No I have not seen or heard anyone, I just know that they do, and besides, I don't tell people my issues.

I hear you talking about your father, where is your mother?

She left us in 2014, she is staying in Mpumalanga.

Why did she leave?

She left because she doesn't love me, she wanted to kill me when I was in her stomach.

..Ohhh… ok… but these things happened before you were you were born, who told you this?

My dad, he also told me that she left me when I was still a baby, she gave birth to my younger sister and then she came back.

Do you have a relationship with your mother? E.g. do you visit each other?

No, I don't, she doesn't visit me because she doesn't love me that is why she wanted to abort me.

How do you feel about this whole information your father gave you?

I feel fine, I don't have a problem.

Don't you sometimes wish that she was around?

I do, but I am scared of my father.

Does your father have a problem with you having a relationship with your mother?

Yes, he does, he also told me that my mother told her relatives that she wants to kill me.

Do you know where your mother stays?

No. I once went there with her, but I can't recall the place.

What other challenges do you encounter when taking your medication?

I don't eat sometimes because my father always buy meat and I end up losing appetite, so I sometimes not take my pills as I don't want to take them on an empty stomach.

How many times in a month can you say you don't take your medication?

3- 4 times a month

Have you ever thought of quitting taking your pills due to this drowsiness?

Yes, several times.

Do you know the importance of taking your medication daily?

Yes, my father told me that if I don't take my pills I will get sick and go to the hospital, they will finish me off, they will give me an injection that will kill me.

Has anyone told you how long you are going to take this medication?

No one told me and I am afraid to ask my father.

You seem to be scared of your father, do you mind sharing why?

Yes, I am scared of him because he used to beat me up a lot

Do you mind sharing more on that?

He would beat me up when I did not do the household chores.

Who else are you staying within your house besides your father?

It's only me and my dad, so I cook and do all the household chores. Sometimes I don't cook when I'm tired of eating meat.

Do you have a boyfriend or a sexual partner?

No I don't, I am scared of my dad, if he can find out that I am having an affair, he will kill me.

How can you describe your relationship with your peers?

It's fine, although we fight at times.

Do you mind sharing what causes the fights?

They turn against me when I tell them not to get involved in sexual relationship with many boys.

Why do you hang out with them when they have many boyfriends and you don't?

I also used to have many boyfriends and when I tell my friends that it is not good, they turn against me.

You say you used to have many boyfriends but you have never had sexual intercourse, how so?

I used to date them on face book, there was no physical contact.

How is your relationship with the nurses where you collect your medication?

I feel at home when I am at the clinic, they treat me well.

Are you free to ask them anything? *Yes.*

If yes, why have you not asked them what are the pills that you are taking for?

I just forget when I am with them.

Do you think you will ever ask them?

Yes I will

What do you think can be changed on your treatment schedule to make it easier for you?

I want the big pills changed; they choke me….

Since they are part of your pills, how do you handle them?

I don't take them.

Do you know the effects of not taking your treatment well?

Yes, one of the sisters in the clinic told me that if I don't take my pills I will get sick and develop sores.

Have you ever discussed the "big pills" with this sister?

Yes I have, they told me to take them with lots of water but sometimes I get tired, like yesterday, I didn't take them and I don't feel like taking them even today.

Do you attend support group?

No, I don't want people to know my issues.

Do you drink alcohol or smoke?

I used to drink alcohol when mom and dad were drinking, I have stopped now since I knew that I am sick. I have never smoked.

Tell me more about the drinking of your mother and father.

They used to drink with their friends and home and they will be dancing, but they would fight after that, which is why my mother left me

Do you get any other assistance from other institutions like social services etc.?

No

What do you think can be done to improve the service you are getting from the clinic?

Nothing, I just wish to change my savage lifestyle. The other day I wanted to kill another girl at school who locked us in the class, my friends just held me up.

What other lifestyle can you classify as savage lifestyle?

Adolescent stage

Tell me more on that?

Sometimes I cry and refuse to do household chores and go to play with my friends and come home late after 19h00 for my pills.

What makes you cry?

When I think about my mom, sometimes I wish she was around so that she will do beautiful things for me, not that my dad is not doesn't, it's just that he doesn't buy me clothes. He also brings different women in the house and give them money, but he doesn't buy me clothes.

How that does makes you feel?

I feel angry

Do these girlfriends sleep over?

Yes, he also gives them food.

Who cooks this food?

He buys them takeaways.

Have you ever discussed your feelings with your dad?

No, I am scared of him. He does not listen to anyone else, sometimes he threatens to chase me away and he used to beat me a lot but since I started having this sickness he has stopped.

Okay, do you mind telling me more about the sickness you are referring to?

This sickness of HIV that I have, I only heard people talking, saying HIV, HIV.

Who are these people who saying HIV, HIV?

It's a certain woman who said the nurses are going to replace the pills that I am taking now to monthly injection and my father said he is going to buy me treatment to cure my disease.

Meaning that this woman knows your HIV status?

Yes she does….

Who is she to you?

She is a relative. She is the woman who told my father to stop beating me.

Has your father ever taken you to a Sangoma for a cure for HIV?

No, I only have an ancestral calling; I have an ancestral name called Nwa-Bekwani.

What do you do with this ancestral calling?

I help people who are sick, I once initiated (ku tlhavela) my father.

Are you initiated to be a sangoma?

No

Have you ever used traditional medication for your condition?

No, I only use pills.

Has your father bought the cure he promised to buy for you?

No

Have you ever been told about the dangers of mixing traditional medication with your pills?

Yes, nurses told me that if I mix traditional medicine with my pills I will get sick.

Is there anything that you want to share with me concerning treatment or about HIV that we have not discussed?

No

Do you have any other question?

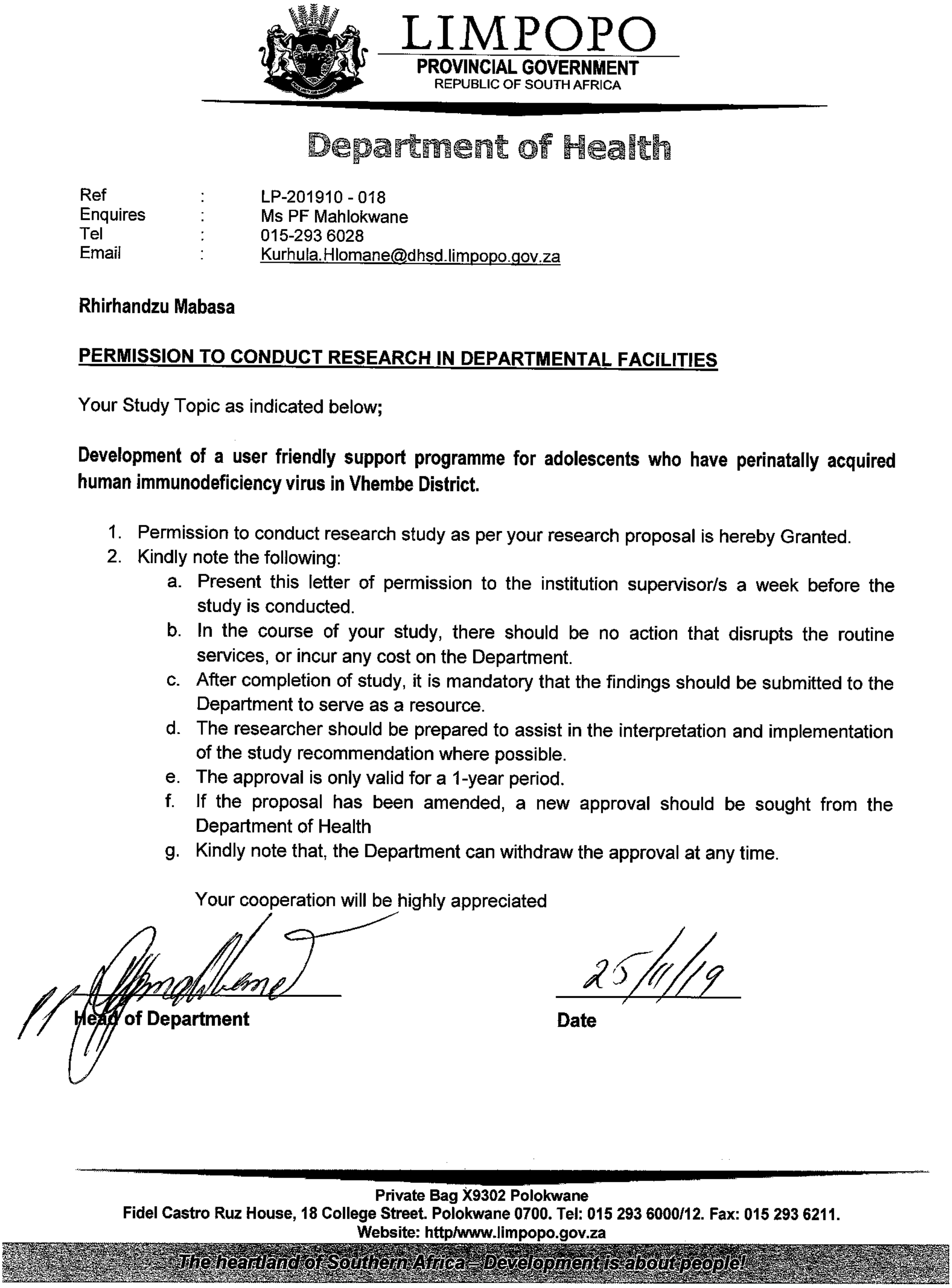
May you please ask my father to buy me clothes?

Will it be possible for you to ask your father to accompany you to the collect on your next visit so that nurses can ask him?

I will try, although I don’t know how.

Thank you.

Appendix 8: Permission to conduct research from the department of health (provincial)



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

Ref : LP-201910 - 018
Enquires : Ms PF Mahlokwane
Tel : 015-293 6028
Email : Kurhula.Hlomane@dhsd.limpopo.gov.za

Rhirhandzu Mabasa

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

Development of a user friendly support programme for adolescents who have perinatally acquired human immunodeficiency virus in Vhembe District.

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

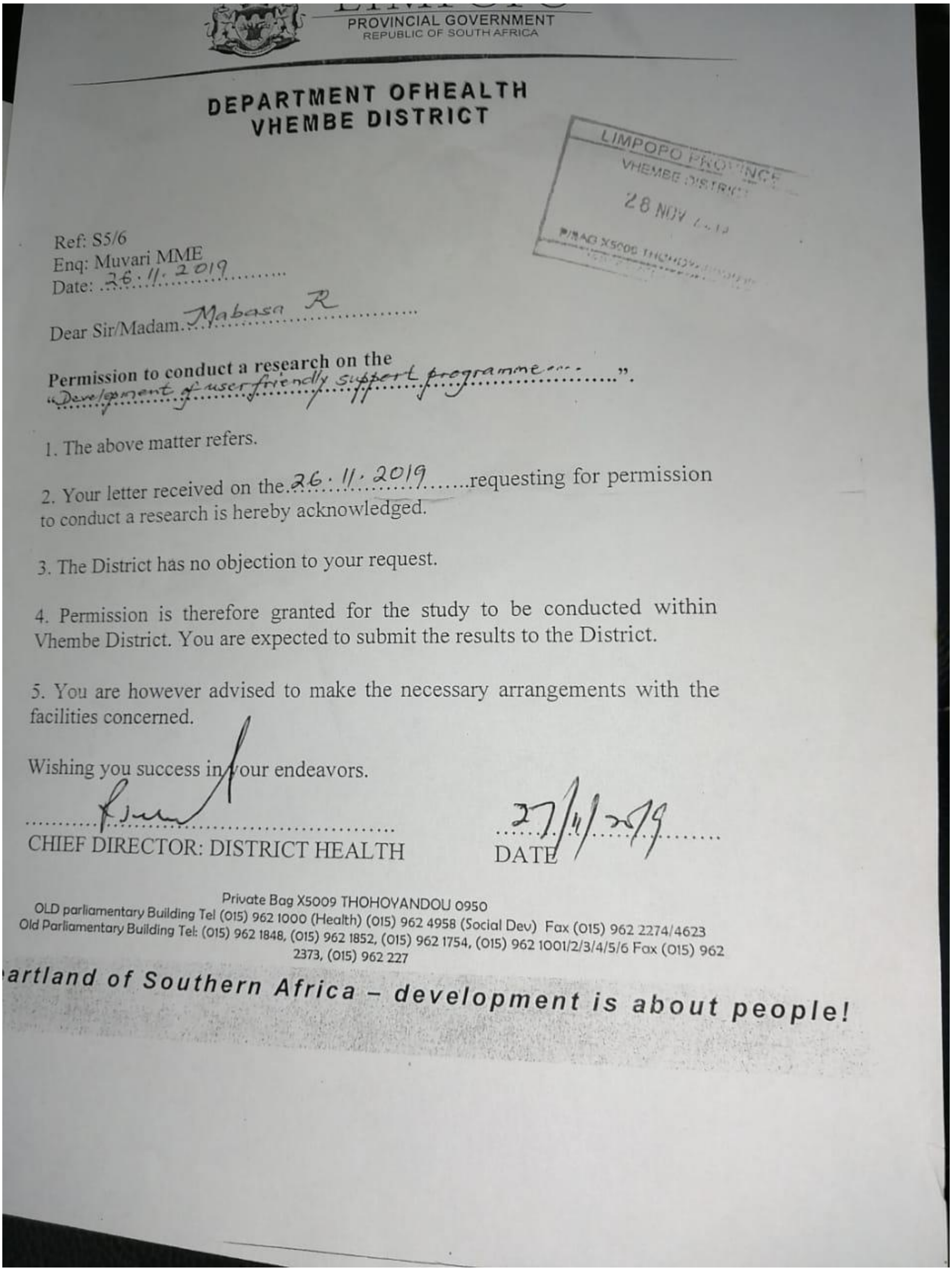
Your cooperation will be highly appreciated

Head of Department

25/11/19
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za
The heartland of Southern Africa – Development is about people!

Appendix 9: Permission to conduct research (district)



PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OFHEALTH
VHEMBE DISTRICT

LIMPOPO PROVINCE
VHEMBE DISTRICT
28 NOV 2019
P/BAG X5009 THOHOYANDOU

Ref: S5/6
Enq: Muvari MME
Date: 26.11.2019

Dear Sir/Madam. Mabasa R

Permission to conduct a research on the
"Development of user friendly support programme…"

1. The above matter refers.

2. Your letter received on the 26.11.2019 requesting for permission to conduct a research is hereby acknowledged.

3. The District has no objection to your request.

4. Permission is therefore granted for the study to be conducted within Vhembe District. You are expected to submit the results to the District.

5. You are however advised to make the necessary arrangements with the facilities concerned.

Wishing you success in your endeavors.

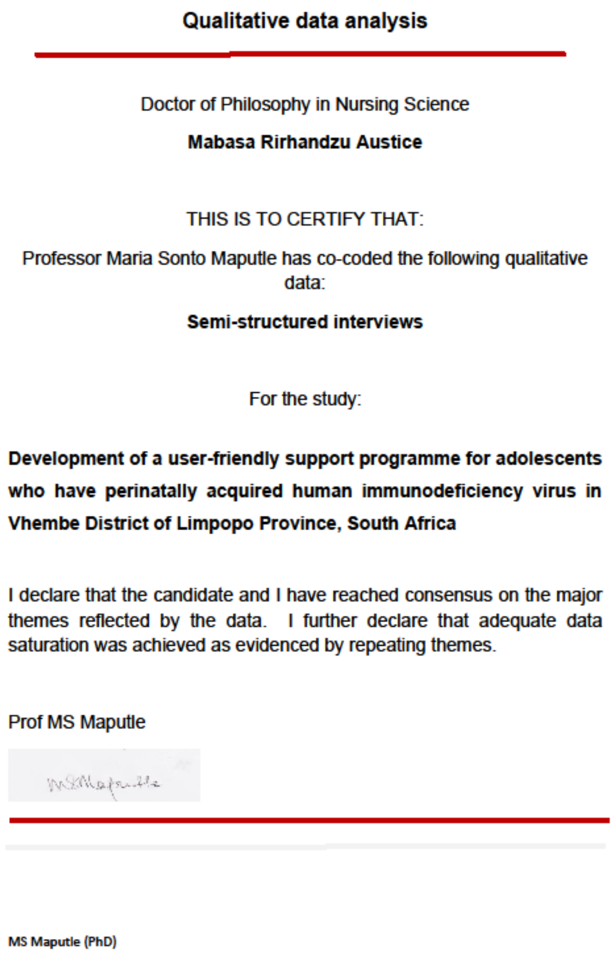
CHIEF DIRECTOR: DISTRICT HEALTH

27/11/2019
DATE

Private Bag X5009 THOHOYANDOU 0950
OLD parliamentary Building Tel (015) 962 1000 (Health) (015) 962 4958 (Social Dev) Fax (015) 962 2274/4623
Old Parliamentary Building Tel: (015) 962 1848, (015) 962 1852, (015) 962 1754, (015) 962 1001/2/3/4/5/6 Fax (015) 962 2373, (015) 962 227

artland of Southern Africa – development is about people!

Appendix 10: Coding certificate



Qualitative data analysis

Doctor of Philosophy in Nursing Science

Mabasa Rirhandzu Austice

THIS IS TO CERTIFY THAT:

Professor Maria Sonto Maputle has co-coded the following qualitative data:

Semi-structured interviews

For the study:

Development of a user-friendly support programme for adolescents who have perinatally acquired human immunodeficiency virus in Vhembe District of Limpopo Province, South Africa

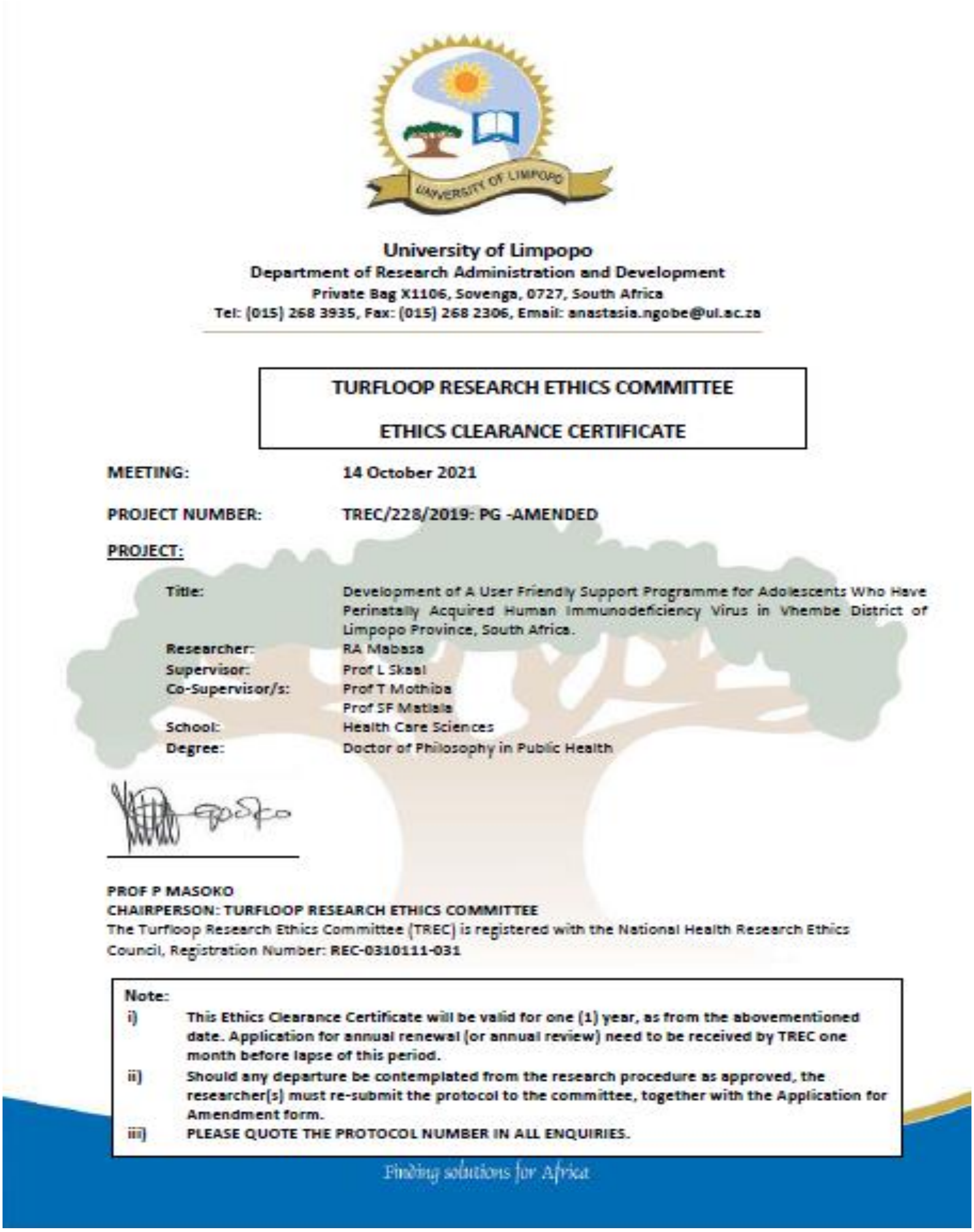
I declare that the candidate and I have reached consensus on the major themes reflected by the data. I further declare that adequate data saturation was achieved as evidenced by repeating themes.

Prof MS Maputle

MSMaputle

MS Maputle (PhD)

Appendix 11: TREC certificate



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

TURFLOOP RESEARCH ETHICS COMMITTEE

ETHICS CLEARANCE CERTIFICATE

MEETING: **14 October 2021**

PROJECT NUMBER: **TREC/228/2019: PG -AMENDED**

PROJECT:

Title: Development of A User Friendly Support Programme for Adolescents Who Have Perinatally Acquired Human Immunodeficiency Virus in Vhembe District of Limpopo Province, South Africa.
Researcher: RA Mabasa
Supervisor: Prof L Skaal
Co-Supervisor/s: Prof T Mothiba
Prof SF Matlala
School: Health Care Sciences
Degree: Doctor of Philosophy in Public Health

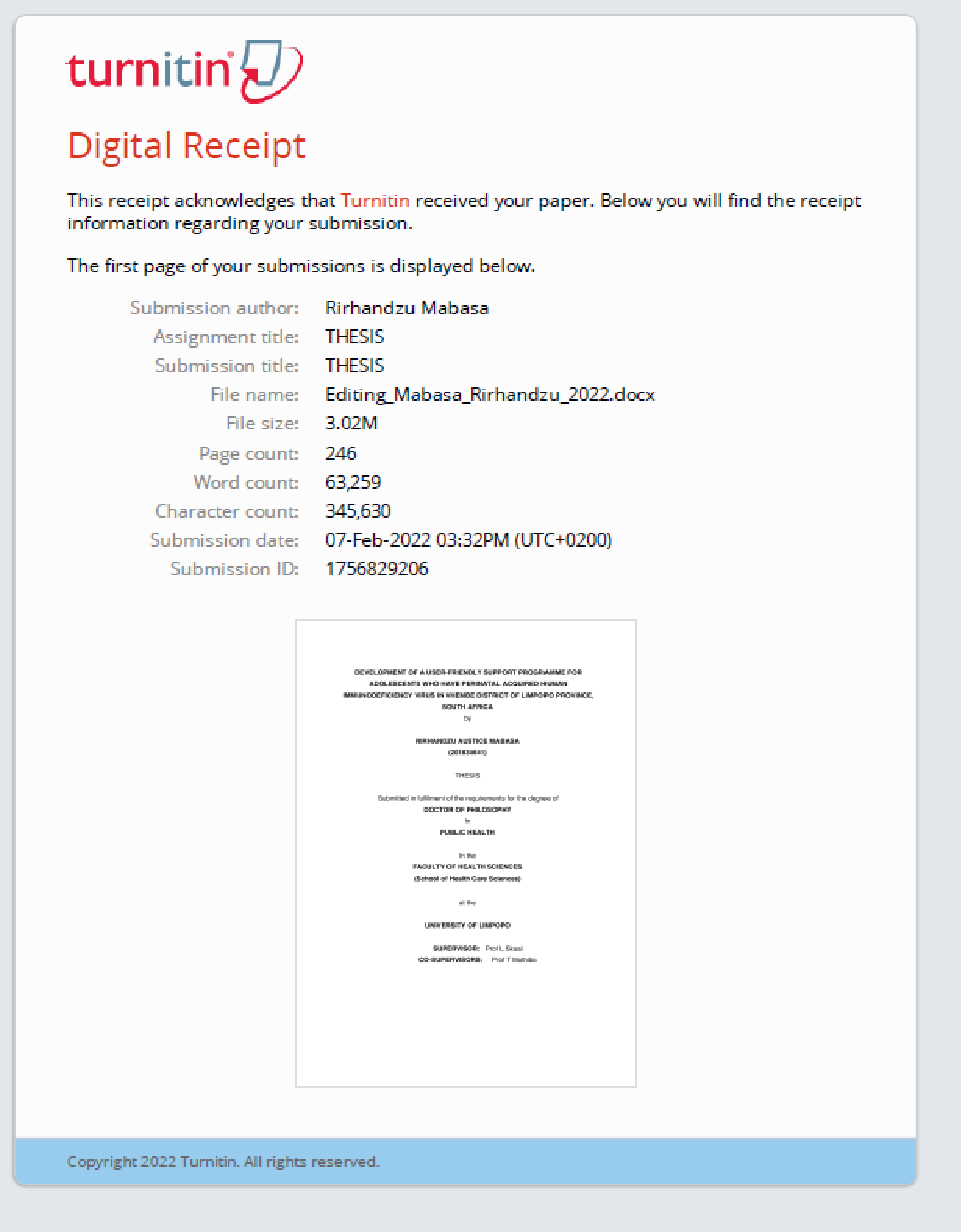
PROF P MASOKO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE
The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:
- i) **This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.**
- ii) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.**
- iii) **PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.**

Finding solutions for Africa

:

Appendix 12: turn it in report



turnitin

Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

Submission author: Rirhandzu Mabasa
Assignment title: THESIS
Submission title: THESIS
File name: Editing_Mabasa_Rirhandzu_2022.docx
File size: 3.02M
Page count: 246
Word count: 63,259
Character count: 345,630
Submission date: 07-Feb-2022 03:32PM (UTC+0200)
Submission ID: 1756829206

Appendix 13: The designed user- friendly support programme

User-friendly support programme for adolescents living with perinatally acquired HIV

By

MABASA RA

Course:	**Training course on the user-friendly support programme for adolescents with perinatally acquired HIV**
Duration of the training sessions	**8hours**
Pre-requisites **Learning assumed to be in place**	**Adolescent living with perinatally acquired HIV collecting ARV in public health facilities of Vhembe District**
Co-requisites **Units of learning during the course**	**Basic literacy skills** **Able to communicate in English, Tshivhenda or Xitsonga** **Adolescents living with perinatally acquired HIV**
Course facilitator	**MABASA RA- PhD student**
Purpose of the course	**To capacitate adolescents with perinatally acquired HIV with knowledge of HIV/AIDS and its management and to equip them with coping strategies**

Critical cross-field outcomes

Participants will be able to:

Define HIV/AIDS

- **Have correct knowledge of ARVs and management of side effects**
- **Have knowledge on the importance adherence to ARVs and dangers of defaulting or quitting**
- **Importance of self-disclosure**
- **Deal with stigma and discrimination related to living with the HIV**
- **Develop and use problem- solving skills related to living with perinatally acquired HIV**
- **Know different types of the referral institutions**

Course outline:

On completion of this training course, NINART trained nurses will be able to:

- **SO1. Define and differentiate HIV/ AIDS**
- **SO2. Discuss historic background of HIV**
- **SO3. Outline Anti Retro Viral Treatment and the management of side effects**
- **SO4. Outline step by step and appropriate guidelines for disclosure**
- **SO5. Overview of stigma and discrimination and strategies to deal with them**

- **SO6. Explain, sexual health, positive lifestyle and copying strategies**
- **SO7. Referral and support systems for adolescents living with perinatally acquired**

Specific learning outcome 1: Overview of HIV/AIDS

1.1 Learning outcomes

At the end of the session participants should be able:

- to define and differentiate HIV/AIDS

Activity: 1.1 individual activities

By raising hands, using personal knowledge, participants

- Define HIV/AIDS
- Discuss different modes of transmission of HIV
- Differentiate between HIV and AIDS
- The facilitator sums up by giving s brief lecture on the definition and background of HIV/AIDS

Specific objective 2: Historical background of HIV/AIDS

Learning outcomes

At the end of the session participants should be able:

Activity: 2 face to face lecture

Give a historical background of HIV/AIDS

HIV statistics globally, continentally and in South Africa

Impact of HIV globally and locally

Specific learning outcome 3: antiretroviral treatment

Group activity

Learning outcomes

At the end of the session participants should be able to know:

- The specific ARVs they are taking individually
- Know the purpose of antiretroviral treatment
- Pharmaco-dynamics and pharmacokinetics of ARV
- ARV side effects
- Management of side effects

Scenario

Group activity: 1

Rirhandzu, a 39-year-old female tested positive for HIV, she was given ARVs to take everyday. After 2 days she started complaining of generalised itchy rash, diarrhoea and dizziness.

She started thinking of quitting ARVs because the dizziness was severe and was interfering with her job as a till packer in a local shop. She then decided to come to you for advice before she quits.

In 2 groups, write your findings in a piece of paper

- What do you think is the course of the dizziness and the rash?
- Write down side- effects which Rirhandzu experienced
- What advice would you give to Rirhandzu?
- The facilitator raps up the session by giving a lecture on the ARVs

Ref> Ayers. S and Fidler. S. 2020. Antiretroviral adherence for adolescents growing up with HIV: understanding real life, drug delivery and forgiveness. Vol7: 1-12 DOI: 10.1177/2049936120920177

Specific Learning Objective 4: HIV disclosure

Learning outcomes:

At the end of the session participants should be able to know:

- the definition of disclosure
- the importance of disclosure in HIV context
- step by step guide to disclosure to children regarding their HIV status
- importance of self- disclosure

Activity: group activity

The facilitator gives a task to the participants

Each participant must share her secret which has been bothering her with a friend.

The friend must just listen and not answer anything but show that she/he is listening

Each participant must then report to the entire group how they felt when they were talking to the friend?

Their feelings after talking to the friend

The facilitator gives a presentation on step by step disclosure of HIV status to children

In a piece of paper, participants must write:

How they relate their experience with disclosing their HIV status to someone

The facilitator sums the session.

(Ref> South African National Department of Health (2020). National Consolidated Guidelines for the management of HIV in adults, Adolescents, Children and infants and prevention of Mother-to- child Transmission)

Specific Learning outcome 5: stigma and discrimination

Learning outcomes

At the end of the session participants should be able to:

- define stigma and discrimination
- forms and types of stigma
- develop personal strategies to deal with stigma and discrimination

Activity: facilitator lecture

Define stigma and discrimination

Forms and types of stigma

Coping strategies

Specific learning outcome 6: adherence counselling

Learning outcomes

At the end of the session participants should be able to:

- importance of adhering to ARVs
- barriers to adherence to ARVs

Activity: role play

Rendzo, a 15-year-old girl in grade 10, has been taking ARVs since birth. She was given treatment by her mother hence she has been taking her ARVs well. Her mother found a job in Johannesburg, and she is leaving Rendzo to remain at home. She comes to the clinic for assistance with adherence counselling of her daughter

Divide participants into 2 groups

Two people to volunteer to be the counsellor and the adolescent and the other group members observe.

Write comments on a chart about the counselling session and the group chooses one person to present

Specific outcome 7: sexual health, positive lifestyle and coping strategies

Learning outcome

After completing this model, participants should be able to:

- explain the concept ‘positive living’ and describe concepts of positive life style
- identify ways to adopt positive lifestyle
- explain sexual health and different types of contraceptives
- develop and utilise coping strategies when dealing with HIV issues

Activity: facilitator lecture

Facilitator asks participants to explain the concepts positive living and positive lifestyle with examples, using common knowledge

Facilitator the gives a lecture on the following topics

Define and differentiate the concepts positive living and positive lifestyle

Identifying and management of substance abuse

Supporting adolescents to maintain healthy minds and body

Adopting healthy sexual behaviour and the use of contraceptives

Developing life skills and coping strategies

Specific learning outcomes 8: referral and support systems

At the end of the session participants should be able to:

- have knowledge on different referral institutions for emotional and financial support

Activity: face to face lecture

Outline different institutions for referral of adolescents with perinatally acquired HIV and the reasons for referrals

Identify the use and need for a support group

THE END

Appendix 14: consent for participation in the implementation of the programme

UNIVERSITY OF LIMPOPO

Statement concerning participation in a Research Project

Name of Study: THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME FOR ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA

Information box:

Thank you for agreeing to participate in this study. My name is **Rirhandzu Austice Mabasa** and I am a researcher from the University of Limpopo. The aim of this study is to implement the user-friendly support programme for adolescents living with perinatally acquired HIV in the Vhembe District. The study is non-invasive. Training on the content of the programme will be conducted, and Voice recorded, and questionnaires will be distributed to collect data.

Participation in this study is voluntary and that you may withdraw from it at any time and without giving reasons. This will have no influence on the way you are treated at any treatment point.

Should you have any queries, kindly contact:
Mabasa RA (082 9396492)

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

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without giving reasons. This will have no influence on the way I am treated at my treatment point.

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

I hereby give consent myself/ child to participate in this study.

....

Name of volunteer/ parent or guardian Signature of volunteer/ parent or guardian

....

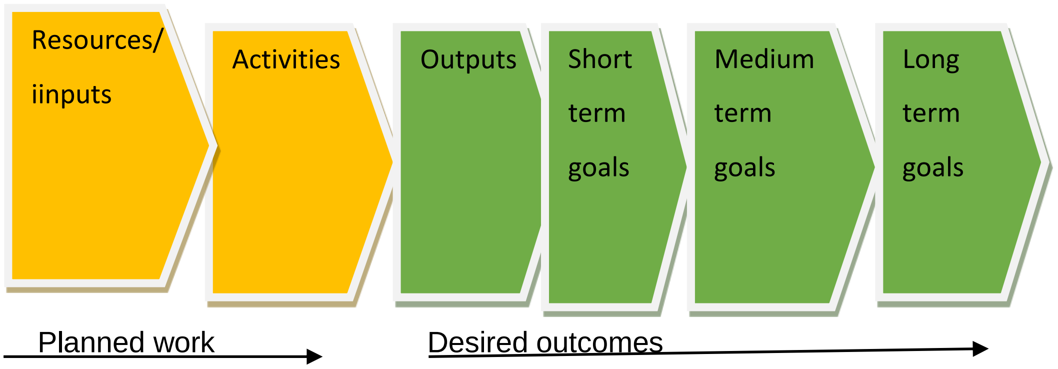
Place Date Witness

Appendix 15: Evaluation tool for the user-friendly support program

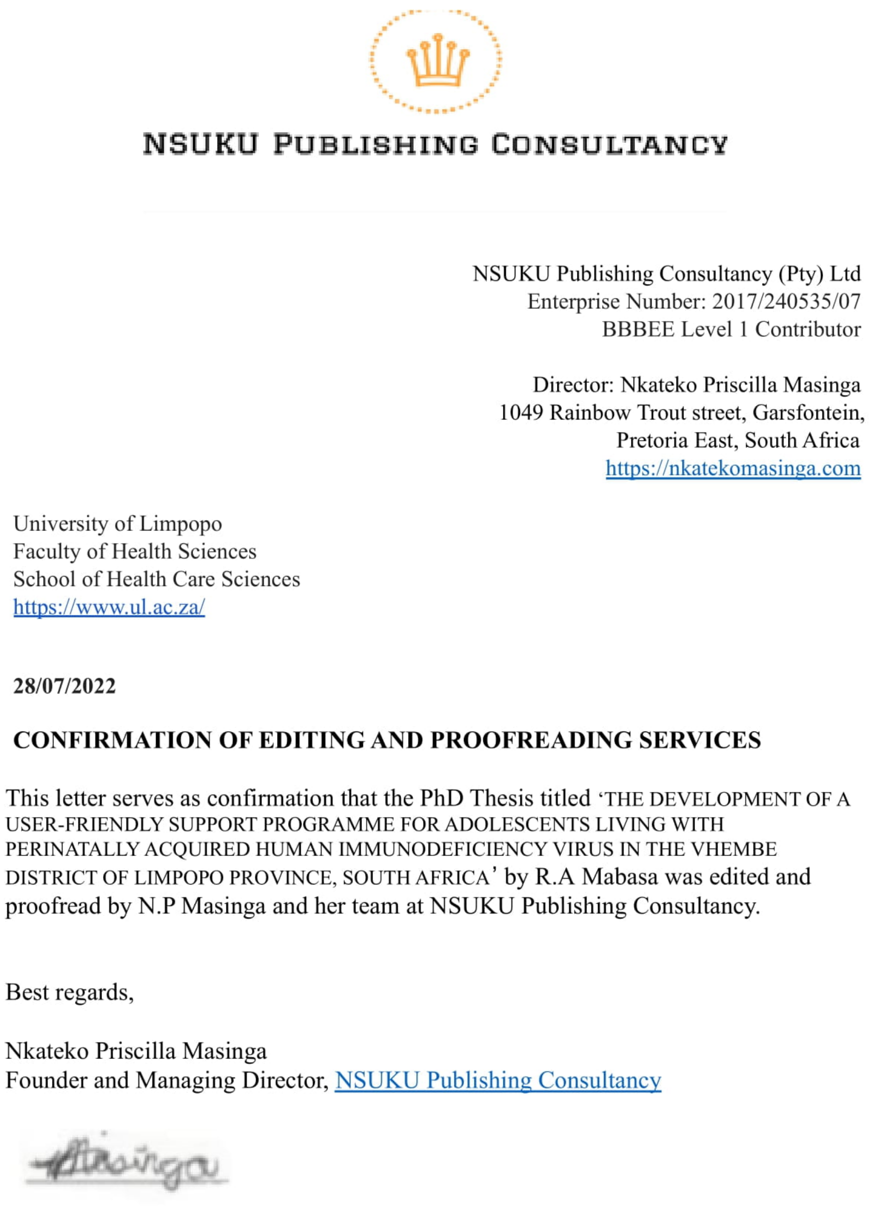
Please on a scale of 1-10 kindly rate the level of satisfaction you received.

	1-5	**6-10**
I gained more knowledge on HIV/AIDS and ARVs		
I have developed coping skills		
I now have a positive attitude towards HIV and ARVs		
I am motivated to continue the HIV/AIDS management and care		
Total score		
Comments --- -- -- --		

Appendix 16: logic model



Appendix 17: Editing certificate



NSUKU PUBLISHING CONSULTANCY

NSUKU Publishing Consultancy (Pty) Ltd
Enterprise Number: 2017/240535/07
BBBEE Level 1 Contributor

Director: Nkateko Priscilla Masinga
1049 Rainbow Trout street, Garsfontein,
Pretoria East, South Africa
https://nkatekomasinga.com

University of Limpopo
Faculty of Health Sciences
School of Health Care Sciences
https://www.ul.ac.za/

28/07/2022

CONFIRMATION OF EDITING AND PROOFREADING SERVICES

This letter serves as confirmation that the PhD Thesis titled 'THE DEVELOPMENT OF A USER-FRIENDLY SUPPORT PROGRAMME FOR ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA' by R.A Mabasa was edited and proofread by N.P Masinga and her team at NSUKU Publishing Consultancy.

Best regards,

Nkateko Priscilla Masinga
Founder and Managing Director, NSUKU Publishing Consultancy

Masinga