



Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa

Samkelo Bhekinkosi Sithole

Student Number: 2605265

A dissertation submitted as a prerequisite requirement for the fulfilment of Master of Public Health degree programme at the School of Public Health

University of Witwatersrand, Johannesburg.

Supervisor: Dr Pumla Pamella Sodo (Lecturer, Department of Family Medicine and Primary Care, School of Clinical Medicine, University of Witwatersrand).

31st of July 2025.

ABSTRACT

Background: South Africa's antiretroviral therapy (ART) programme is regarded as one of the biggest in the world, to combat the effects of Human Immunodeficiency Virus (HIV) and Acquired Immuno-deficiency Syndrome (Aids) among infected and affected rural communities. The notable challenge on the programme was related to the sub-optimal adherence to ART among vulnerable groups including adolescents and young adults (AYA), who remained viral unsuppressed despite being on ART. The available literature has made recommendations for future research studies to explore factors hindering adherence to ART to adolescents and young adults living in rural areas.

Aims: To explore multi-level facilitators and barriers to ART adherence among AYA living with HIV/Aids in rural South Africa.

Methodology: A cross-sectional study using a qualitative approach was used to explore the phenomenon. A convenient sampling method was employed to recruit a maximum of 20 participants or until data saturation was reached. Data was collected through in-depth interviews using audio recorder tape lasting about 25-45 minutes per session, which were transcribed verbatim. Thematic analysis using deductive and inductive approaches was used to analyse data and interpret the research study findings or results. As an Operational Manager at Othobothini Community Health Centre, I approached this study with insider knowledge of the healthcare system, while using reflexive and participant-centred strategies to minimise bias and ensure that the voices of adolescents and young adults living with HIV/AIDS remained central to the research.

Findings: The most evident experiences explored in the study relating to ART adherence barriers from intrapersonal to structural level were medication related side effects and lack of autonomy, non-disclosure of HIV status, stigma and discrimination, overarching priorities, and lastly, adolescence stage largely influenced the ability to efficiently adhere to ART among targeted groups. The common facilitators explored among AYA from intrapersonal to structural level were fear of getting sick or death, family support system, normalisation and shared experiences, positive attitude of healthcare workers, and lastly, technology innovation such as manual and digital reminders played a significant role in promoting optimal ART adherence.

Conclusion: Facilitators and barriers to ART adherence have several sources of origin, some are health system and process induced. Therefore, creating an environment enabling full disclosure, maintaining healthcare worker professionalism, and demand creation for HIV information can help eradicate stigma related factors. Furthermore, multisectoral stakeholders need collaboration to strengthen adherence counselling, family support, education, and continuous supervision at homes.

KEYWORDS: Adherence, Antiretroviral therapy, Adolescents and young adults, Rural.

DECLARATION

I declare that this research study titled “Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa” is my own work, submitted for the degree of Master of Public Health in the School of Public Health, Faculty of Health Science, University of Witwatersrand, Johannesburg. It has not been submitted for any other degree at the University of the Witwatersrand, nor at any other university before.

I have not fabricated data or falsified results, and no portion or elements of another person’s work have been taken as my own credit. Credits accurately reflect the individuals, organisations and/or institutions concerned.

Signature:



Date: 31st of July 2025.

ACKNOWLEDGEMENT

I am compelled to express my profound gratitude to all individuals who have contributed significantly to the successful completion of my Master's degree program in Public Health at the University of Witwatersrand.

Firstly, I would like to extend my sincerest appreciation to my supervisor, Dr. Pumla Sodo, whose expert guidance, constructive feedback, and unwavering support have been instrumental in facilitating my academic and professional development throughout the research process.

Furthermore, I acknowledge the invaluable contributions of my fellow esteem research students, Nkgomelang Lekodeba and Dzunisani Chabalala, whose collaborative efforts and insightful perspectives have substantially enriched my research experience and contributed meaningfully to the success of our shared academic endeavours.

To the District Research Committee at uMkhanyakude and Jozini Health Sub-District led by Mr Fakude, as well as the Othobothini Community Healthcare Centre CEO Mrs DS Mkhwanazi and Deputy Manager Nursing Mr SR Dlamini, and all healthcare facilities that were involved, particularly the operational nursing managers, namely: Mr Sibisi, Ms Myeni, Mrs Dlamini, Mrs Mathenjwa and Ms Gunya, I extend my sincere appreciation for their cooperation, support, and priceless assistance. Their input and partnership were integral to the execution and completion of my research study.

I truthfully feel privileged to have a family with undivided, unwavering support and encouragement throughout my graduate studies. Their unconditional love, patience, and faith in my abilities have served as a constant source of motivation and resilience, enabling me to navigate the challenges of this academic journey.

In addition, I am indebted to my broader support network, comprising individuals who have generously offered guidance, reassurance, and leadership throughout my master's degree program. Their collective contributions have had a profoundly positive impact on my academic experience, and I am truly grateful for their unwavering support and encouragement.

With deepest appreciation and warm regards,

A handwritten signature in black ink, appearing to read 'Samkelo B Sithole', is written over a grid of small dots. The signature is fluid and cursive, with a long, sweeping flourish extending upwards and to the right.

Mr Samkelo B Sithole

TABLE OF CONTENTS

ABSTRACT.....	ii
DECLARATION.....	iv
ACKNOWLEDGEMENT.....	v
CHAPTER ONE: Introduction and Background	1
1, Introduction to the research study	1
1.2 Background	1
1.2.1 Global perspective on Antiretroviral Therapy (ART) and adherence.	1
1.2.2 The Sub-Saharan Africa perspective on ART and adherence.	2
1.2.3 South African perspective on ART and adherence.....	2
1.3 Problem Statement	3
1.4 Justification of the research study.....	4
1.5 Research Question.....	4
1.6 Research Aim.	4
1.7 Research Objectives.....	4
1. 8 Structure of the thesis.....	5
1.9 Summary of the chapter	5
CHAPTER TWO – LITERATURE REVIEW	6
2,1 Introduction to the literature review	6
2.2 Conceptual Framework – Bronfenbrenner Socio-Ecological Model.....	7
2.3 Rationale for the employed conceptual framework in the study	8
2.3.1 Micro – System	8
2.3.2 Meso – System	9
2.3.3 Exo – System.....	9
2.3.4 Macro – System	9
2.3.5 Chrono – System	10
2.4 Summary of the chapter	10
CHAPTER THREE – RESEARCH METHODOLOGY	11
3.1 Introduction to the research methodology	11
3.1.1 Positionality Statement	11
3.2 Study Design	11
3.2.1 Study Setting.....	12
3.2.2 Research Study Population	12
3.2.3 Study Sample and Sampling Method	12
3.2.4 Inclusion criteria	13

3.2.5 Exclusion criteria	13
3.4 Data Collection	13
3.4.1 Data collection tool.....	13
3.4.2 Recruitment process	14
3.4.3 Data collection process	14
3.5 Data Management and Analysis	15
3.6 Ethical considerations.....	16
3.6.1 Informed consent and voluntary participation	16
3.6.2 Confidentiality and Anonymity	16
3.6.3 Protection of the participants from harm	17
3.6.4 Distress Protocol	17
3.7 Summary of the chapter	18
CHAPTER FOUR: RESEARCH RESULTS	19
4.1 Introduction to the research results.....	19
4.2 Participants' demographic characteristics	19
4.3 Themes emerging from the data	20
4.4 Multilevel Barriers to ART Adherence.....	24
4.4.1 Theme 1: Intrapersonal level barriers.	24
<i>Lack of autonomy or dependence on others:</i>	24
<i>Medication-related side effects:</i>	24
<i>Treatment regimen/ pill burden:</i>	25
<i>Knowledge deficit related to HIV:</i>	25
<i>Denial or reluctance to accept HIV status:</i>	26
<i>Forgetfulness and irregular timing</i>	26
4.4.2 Theme 2: Interpersonal level barriers	26
<i>Non-disclosure to partner/ family:</i>	27
<i>Non-disclosure to adolescents and young adults:</i>	27
<i>Peer/ family members' HIV knowledge deficit:</i>	27
<i>No food to eat:</i>	28
4.4.3 Theme 3: Community-level barriers:.....	28
<i>Stigma and discrimination:</i>	28
4.4.4 Theme 4: Structural/ Organisational level barriers	29
<i>School versus clinic commitments:</i>	29
<i>Hostile clinical environment:</i>	30
<i>Long waiting times at clinics:</i>	30
<i>Inadequate education on HIV infection and treatment:</i>	30

4.4.5 Theme 5: Other related ART adherence barriers	31
<i>Adolescence hood stage:</i>	31
4.5. Multi-Level Facilitators to ART Adherence	31
4.5.1 Theme 1: Intrapersonal level facilitators:	35
Acceptance of the condition and ARVs:	35
Fear of getting sick & death	35
Self-efficacy and determination.....	36
4.5.2 Theme 2: Interpersonal level facilitators	36
Peer/ friend support:	36
Parent/ guardian HIV disclosure to AYA:	36
AYA discloses HIV status:	37
Other family members taking ART:	37
Family support system:.....	37
Companion; someone to talk to:	38
Medication collected by others:	38
4.5.3 Theme 3: Community-level facilitators:	39
Normalization and shared experiences:.....	39
4.5.4 Theme 4: Structural/ Organisational Level Facilitators.....	39
Provision of HIV-related information:	39
Positive attitude of the healthcare workers:	40
Multidisciplinary team member collaboration:	40
Multi – month ART supply:	40
Youth friendly approach for learners:	40
Availability of Reliable Healthcare Services	41
4.5.5 Theme 5: Other related ART adherence facilitators	41
Technology: Manual and digital device reminders.....	41
4.6 Summary of the chapter	42
CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS	43
5.1 Introduction to Discussions, Conclusion and Recommendations	43
5.2 Demographic of the study population.....	43
5.3 Multilevel Barriers to ART Adherence.....	44
5.3.1 Intrapersonal Level Barriers:	44
5.3.2 Interpersonal Level Barriers:	45
5.3.3 Community-Level Barriers:	46
5.3.4 Structural Level Barriers:	46
5.3.5 Other related ART adherence barriers.....	47

5.4 Multilevel Facilitators to ART Adherence	48
5.4.1 Intrapersonal Level Facilitators:.....	48
5.4.2 Interpersonal Level Facilitators:.....	48
5.4.3 Community-Level Facilitators:	50
5.4.4 Structural Level Facilitators:	50
5.4.5 Theme 5: Other related ART adherence facilitators	51
5.5 Limitation of The Study	52
5.6 Reflexivity in the research study	52
5.7 Implications and Recommendations for Policy and Practice	53
5.8 Conclusion.....	55
5.9 Disclosure:.....	55
REFERENCES	56
APPENDICES.....	63
Appendix A ₁ : Plagiarism Declaration Report.	65
Appendix A ₂ : Turnitin Research Report Signed by Supervisor.	66
Appendix A ₃ : Human Research Ethics Committee (Medical) Clearance Certificate No. M231014.	67
Appendix B: National & Provincial Health Research Committee Approval.	69
Appendix B ₁ : uMkhanyakude Health Research Committee Approval.....	70
Appendix B ₂ : Othobothini Community Healthcare Centre CEO Approval.....	71
Appendix C: Interview Guide (English)	72
Appendix D: Uhlelo lwemibuzo (isiZulu).....	73
Appendix E: Demographic Questionnaire.	74
Appendix F: Participants Information Sheet for young adults aged 18-24 years.	75
Appendix G: Participants Information Sheet for Parent/Guardian of a Minor* aged 16-17 years.	77
Appendix H: Participants Information Sheet for Minor* aged 16-17 years.....	79
Appendix I: Consent for participation for young adults aged 18-24 years.....	81
Appendix J: Consent Participation for Parent/Guardian of a Minor* aged 16-17 years.....	83
Appendix K: Participant Assent for Minors aged 16 -17 years*	85
Appendix L: Consent for Audio Recording of Study Participation for young adults aged 18-24 years.	87
Appendix M: Consent Form for Audio Recording for Parent/Guardian of a Minor* aged 16-17 years.	88
Appendix N: Consent Form for Audio Recording for Minors* aged 16-17 years.....	89

ACRONYMS AND ABBREVIATIONS

ART	Antiretroviral Therapy.
AYA	Adolescents and Young Adults.
CHC	Community Healthcare Centre.
DALYs	Disability Adjusted Life Years.
DHIS	District Health Information System
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome.
IDI	In-depth Interviews
LTFU	Lost to Follow Up.
NDOH	National Department of Health.
PHC	Primary Healthcare Clinic.
PLHIV	People Living with HIV.
PMTCT	Prevention of Mother to Child Transmission.
SA	South Africa.
uLTFU	Unconfirmed Lost to Follow Up.
UNAIDS	Joint United Nations Programme on HIV/AIDS.
TIER, Net	Three Interlinked Electronic Register for HIV/Aids & TB
WHO	World Health Organization.

CHAPTER ONE: Introduction and Background

1, Introduction to the research study

As a permanent Department of Health employee at Othobothini Community Health Centre (CHC). The researcher decided to conduct this research study because of the willingness to contribute positively to the body of knowledge on issues affecting the community servicing, however, researcher's current facility was excluded from the main study to eliminate the positionality factor. The available literature has revealed that the Jozini area under the uMkhanyakude district, is one of the rural areas with a high volume of HIV prevalence and incidences at 35% with a notable proportion of clients experiencing poor adherence to antiretroviral therapy especially adolescents and young adults(AYA) (1–3), therefore, the research study would seek to explore facilitators and barriers to ART adherence in the rural setting.

1.2 Background

1.2.1 Global perspective on Antiretroviral Therapy (ART) and adherence.

The HIV/Aids pandemic globally has reached newfound altitudes, with more than 84.2 million individuals affected since the beginning of the epidemic(4). Universally about 38.4 million people live with HIV, with an estimated 1.5 million becoming infected and 0.65 million succumbing to HIV/Aids related deaths on an annual basis (4). World Health Organisation (WHO) and United Nations Programme on HIV/Aids (UNAIDS) collaborating with other stakeholders devised mechanisms to combat the epidemic such as the 95-95-95 strategy, which resulted in 85% of individuals infected with HIV knowing their status, 75% receiving antiretroviral therapy (ART) and 68% of them virologically suppressed as of 2021 (4,5). The performance was below compared to the targets that were pre-set by Joint United Nations to eradicate HIV/Aids by 2030 (6). Additionally, it is estimated that approximately 1.75 million individuals between the ages of 15 – 24 years around the globe are currently living with HIV infections (7). Poor adherence to antiretroviral therapy is believed to be a significant factor contributing to an annual HIV/Aids related mortality rate of 45%, this impact is most pronounced among adolescent girls and young women, with a mortality rate of 54%, these statistical findings are aligned other with research studies conducted in the African region (6).

The existing literature has embraced the World Health Organization's definition of adherence, which pertains to how closely an individual's behaviour aligns with the recommendations provided by healthcare professionals, encompassing lifestyle adjustments, dietary modifications, and adhering to prescribed treatments(5). In the context of the HIV/ Aids pandemic, adherence is paramount for people living with HIV in achieving viral suppression

and mitigating drug resistance, indirectly curbing high transmission, morbidity, and mortality rate. Meanwhile, adolescence signifies the transitional phase from childhood to adulthood, marked by an array of unique challenges, inquiries, and vulnerabilities (6). In contrast, young adults are characterized as individuals in the process of self-discovery and identity formation (6). Consequently, it is imperative to pay particular attention to the development and growth of adolescents and young adults (6).

1.2.2 The Sub-Saharan Africa perspective on ART and adherence.

The African region's effort to respond to HIV/Aids epidemic encountered utmost challenge during delivery of HIV services in the context or background of corona virus pandemic, which distorted distribution of resources, healthcare services and resilience of health system away from HIV/Aids prevention and management cascades(6). The African continent has more than 25.6 million people infected with HIV, this is expected to be two folds of world's epidemic in the near future (8), with Sub-Saharan Africa at 82% of total HIV infections, 40% of them are adolescents and young adults (9,10). The transmission and mortality rates of HIV infection among adolescents and young adults are on the rise, and the anticipated health outcomes fall below the expected indicators. This is primarily attributed to insufficient levels of adherence to antiretroviral therapy. (10). Scholars have attributed poor adherence to different categorised influencers that forms an interacting complex web inducing an individual's behavioural patterns towards antiretroviral therapy adherence (10,11). Moreover, AYA adherence practices to ART are disproportionately poorer compared to adults, with high rate of unconfirmed lost to follow up cases (uLTFU), lost to follow up (LTFU), low virological suppression and increased mortality rate (7,12).

1.2.3 South African perspective on ART and adherence.

South Africa has the largest programme that is dealing with burden of HIV infection transmissions and management(13,14), Currently about 7.8million people are living with HIV, new infections amounts to 230 000 yearly, deaths related to HIV estimated to 83 000, and 1.6 million orphans were reported in the year 2020 due to mortality associated with HIV/Aids(4). In 2014, government adopted an implementation of 90-90-90 strategy as articulated by Joint United Nations Programme on HIV/Aids to monitor progress of HIV prevention and management cascades(15). The abovementioned programme yielded some positive outcomes, though element of poor adherence has been evident as 35% of individuals on ART are virological unsuppressed(13). According to most released National Department of health guidelines on ART, within the South African context, unsuppressed viral load refers to number

of viruses per millilitre above 50 copies, and below 50 copies is interpreted as a suppressed viral load (16). The guidelines further emphasized that a minimum of two consecutive suppressed or unsuppressed viral load results is needed to conclude whether client is stable or not on ART for their differentiated model of care(16,17).

Literature states that disability-adjusted life years (DALYs) are reduced due to poor adherence to ART, as this may affect the replication of the virus, progression of the disease, and virological failure (3,7). Scholars have noted that adherence to ART is mainly impeded and facilitated by disclosure, stigmatization and discrimination, support system, socio-cultural belief, and the health system of the country (7,12,18). The susceptible group to ART non-adherence are AYA aged 15-24 years sitting at 67% away from 100% adherence to continuum of ART(6,9). The evidence of antiretroviral therapy adherence challenges is demonstrated in 3.5% of vertical transmission rate among adolescents and young women who are breastfeeding, along with new reported incidences of HIV infections on yearly basis in South Africa (6,17).

1.3 Problem Statement.

There are five primary healthcare clinics under Othobothini CHC situated in poorly resourced area governed by Jozini Local Municipality, serving more than 95000 populaces (2,19). According to STATSSA, leading cause of death among AYA aged 16-24 years is attributed to HIV/Aids under Jozini Municipality with mortality rate of 41% (2,3). In the research carried out by Hlophe et al., it was found that HIV-related mortality and morbidity were linked to inadequate adherence to antiretroviral therapy in many regions of sub-Saharan countries, including South Africa (17). According to reports from uMkhanyakude District Health Plan and the District Health Information System (DHIS), the age group that is most affected by poor adherence to ART is 16-24 years, as indicated by a high rate of virological non-suppression within the district (15,18). Some studies have attributed adherence enablers and challenges to multilevel intrinsic and extrinsic factors in semi and urban areas (12,20). The vision of 2030 Agenda for Sustainable Development(21) will be highly compromised in relation to combating HIV/Aids pandemic if issues pertaining ART adherence are not properly addressed. To contribute on the conundrum of ART adherence, the researcher has explored the facilitators and barriers of adherence to ART among AYA aged 16-24 years within the rurality context.

1.4 Justification of the research study.

The researcher's selection of age group between 16-24 years was informed by uMkhanyakude Health District Plan, DHIS and STATSSA recent reports relating to the most affected group to HIV/Aids with high mortality and poor adherence in Jozini area, and uMkhanyakude district as a whole (3,22,23). The available literature focuses on factors influencing non-adherence in AYA aged 15-49 years(9) in the context of semi and urban settings(7,12), furthermore, qualitative studies' findings on ART adherence facilitators and barriers cannot be extrapolated to rural or resource poor environment due to limited literature (10). Scholars have highlighted the need for future research studies on the above-mentioned gap (10). The recent literature has revealed that Jozini area under uMkhanyakude district, is one of rural areas with high volume of HIV incidences and prevalence at 10.3% and 35% respectively (2,22,24), therefore, the research study intends to explore and contextualize the experiences of ART adherence among AYA aged between 16-24 years in poor resourced or rural environment, whether their lived experiences are like what is known from the available literature on semi and urban areas. Data from this study will add to the available literature on antiretroviral therapy adherence among adolescents and young adults, furthermore, the data shall inform public health policies for future intervention programme on adherence to ensure viral suppression and reduce HIV/Aids related morbidity and mortality in rural South Africa.

1.5 Research Question.

What are the facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults aged 16-24 years living with HIV in rural South Africa?

1.6 Research Aim.

To explore facilitators and barriers to ART adherence among AYA aged 16-24 years living with HIV in rural South Africa.

1.7 Research Objectives.

1.7.1 To explore multi-level barriers to ART adherence among AYA aged 16-24 years in rural South Africa.

1.7.2 To explore multi-level facilitators to ART adherence among AYA aged 16-24 years in rural South Africa.

1. 8 Structure of the thesis.

The research study report is categorized into five chapters:

- Chapter one provides the introduction and background of the study from different hierarchical perspectives, problem statement, study aim, and objectives.
- Chapter two draws from the available literature about the questioned phenomenon that is yet to be explored.
- Chapter three outlines in detail the methodologies adopted by the principal investigator to safeguard research ethical principles and while ensuring the quality, credibility, and trustworthiness of the research findings.
- Chapter four presents the research study outcomes or findings, emerging themes, and sub-themes relating to facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults.
- Chapter five presents a discussion of the study's key findings while incorporating the existing or available literature, afterwards, draw conclusion, highlights the limitations of the study and provides recommendations that may inform the current healthcare framework or model to improve health behaviour relating to adherence to antiretroviral therapy.

1.9 Summary of the chapter

This chapter has summarised up the purpose and structure of the research study. Also, highlighted the problem statement, aim and objectives to be explored in the research study to understand the phenomenon to be undertaken, and all the ethical processes to be considered. Below is chapter two with literature review relating to research topic and conceptual framework employed by the researcher.

CHAPTER TWO – LITERATURE REVIEW

2,1 Introduction to the literature review

The chapter reviews existing literature and research related to the facilitators and barriers to ART adherence among adolescents and young adults to establish connections between the current study and previous research findings. This thorough review aims to encompass all critical aspects of the issue, providing readers with comprehensive information to enhance their understanding of the topic and its background. Additionally, the review seeks to streamline the intricate process that impacts antiretroviral therapy adherence among adolescents and young adults, ensuring that key elements of this process are highlighted.

The existing literature have highlighted several sources that facilitate adherence to antiretroviral therapy among adolescents and young adults. A South African study by Knight et al, revealed that social support from family, caregivers and peers play a significant role, as this system provides a platform for emotional, practical and financial support to enabling ART adherence among abovementioned group(25). Hlophe et al, in their study highlighted the informative continuous counselling and education provide clients with a clear HIV/Aids information and antiretroviral therapy, articulate explicitly clients' responsibilities and the benefits of proper ART adherence(11) In the study conducted by Maskew et al, their found community based interventions including support groups or clubs, direct observed treatment programme by community healthcare workers plays a crucial role in monitoring, guiding and supporting clients to adhere to ART(26). Moreover, the professional secrecy or confidentiality, an ethical conduct expected from healthcare providers has demonstrated a positive influence in ensuring that people living with HIV/Aids adheres to ART(27)

The current research study seeks not only to explore facilitators but also the barriers to ART adherence among adolescents and young adults. Several scholars have highlighted barriers that may lead to non-adherence to ART from multi-level determinants of health. The social related ART adherence barriers as stated in the study of Ammon et al, included stigma, lack of social support and societal expectations have played a significant influence in hindering optimal ART adherence among the adolescents and young adults(10). Ketzi et al, further highlighted the role economic ART adherence barriers such as poverty, unemployment and limited access to healthcare services may negatively impact adherence to ART, as some clients may struggle to afford transportation to healthcare facilities or access to healthy balanced diet(28).

According to Hennessey et al, there health system induced ART adherence barriers among others includes prolonged waiting times, medicine stockouts, rigid appointment system and

poor patient experience of care discourages clients from adhering to ART(29). The study conducted by Croome et al, revealed that there are therapy related ART adherence barriers including side effects, pill burden or fatigue, and complex regimens can result to non-adherence to ART(30). Adeniyi et al, patient related ART adherence barriers such as forgetfulness, lack of motivation, denial, negative perceptions and lack of knowledge about their illness and treatment do influences their non-adherence behaviour to ART(18). And lastly, Natukunda et al, highlighted how certain cultural beliefs system negatively affect ART adherence as some of clients still relies on traditional medicine, seen as a supplemental alternative in dealing with HIV/Aids(31).

To accomplish the main objectives of the research study, the researcher did not only reviewed literature on the phenomenon in question but also, the models utilized in prior studies on the subject and identified the most appropriate one. The most relevant conceptual framework the researcher found for the study was Bronfenbrenner's Socio-Ecological Model to guide the selection of literature and determined the specific topics to be examined to address the research questions, with the researcher focusing on literature that directly pertained to these topics. Given the significance of a literature review in research, only credible and scholarly sources were considered. The literature primarily comprised articles from peer-reviewed journals and books authored by subject matter experts. After a thorough review of the literature, the researcher gathered the explored multi-level facilitators and barriers influencing antiretroviral therapy adherence among adolescents and young adults across the universe in particularly South Africa and aligned them as per chosen conceptual framework.

2.2 Conceptual Framework – Bronfenbrenner Socio-Ecological Model

The conceptual framework used in the research study is adopted from Bronfenbrenner's social ecological paradigm developed in 1979(32). The researcher chose this framework because of its popularity in explaining and providing clear understanding on influences and interactions of the environment where an individual resides and their behavioural actions(25). On inception of the framework(32), the Bronfenbrenner model was used to understand childhood developmental milestones, then later it was applied in adult studies to explain the relationship or interaction between an individual's behaviour and environment(33). The framework is divided into five multilevel systems, namely micro-system, meso-system, exo-system, macro-system, and chrono-system. Coetzee et al used the model in their study successfully to explore facilitators and barriers to ART adherence among paediatrics who are below the age of five years in rural South Africa(34).

This model helps to bring about an understanding of the interrelationship or interdependency between an individual and the socioecological environment, and whether their interactions may lead to certain behaviour in a particular individual (33). Erie Bronfenbrenner developed a social-ecological model to comprehensively comprehend influencers of an individual's behaviour during interaction with different socioecological factors such as the individual's level of education, family support system, healthcare system, stigmatization, and cultural beliefs (35). There are various variables in each level or system which directly or indirectly influence an individual's behaviour at the centre of the model. Kurl Lewin's classic opinion expressed in an equation form upholds that behaviour changes as a result of the interrelationship involving an individual and the natural environment (36). Furthermore, several scholars have accentuated the importance of exploring adherence barriers and facilitators to ART in different viewpoints of an environment where an individual lives (7,10).

2.3 Rationale for the employed conceptual framework in the study

The model assisted the researcher in choosing literature that would answer the research question and lengthily gain insight into multilevel adherence barriers and facilitators to antiretroviral therapy. This model provides an understanding of and considers multilevel influencers and barriers in an environment that may influence one's behaviour to ART adherence, multi-level systems are categorised as micro-system(individual), meso-system (interpersonal), exo-system (community/ health system) and macro-system (sociocultural belief system) within the social system (13,35). As the Ottawa Charter for Health Promotion articulated that healthy behaviours are enhanced or promoted provided an environment and public policies are designed to facilitate healthy choices amongst individuals (37). Like any other model, limitations are inevitable. The degree of importance of variables within each system is unmeasurable when using this model(32), therefore, to eliminate this limitation, the researcher will account for and be responsible for sorting the variable in each system/level as per available literature and results of data analysis of the research study. Below are the components of the conceptual framework by Bronfenbrenner's socio-ecological model.

2.3.1 Micro – System

The available literature defines the micro-system as sociobiological effects of an individual in a specific environment, including knowledge, perceptions, preferred social networks and so forth(35,38). Scholars have acknowledged several individual factors contributing to poor adherence to ART among adolescents and young adults. The most prevailing includes minors since adherence entirely depended on guardians(7), knowledge about the disease and

preparation of treatment(39), forgetfulness(10), mental health issues – denial (30), disclosure(7), motivation associated with life desired goals(39). The above-mentioned factors may either promote or impede adherence to ART among AYA. The available literature has revealed that age and gender are associated with barriers to ART adherence, that is, younger age and males are at higher risks of non or poor adherence to antiretroviral therapy(14,24)

2.3.2 Meso – System

Scholars have described meso-systems as interrelations among different environment or settings where an individual spend most of time of experiences(38), this system is directly linked with microsystem(32). The literature revealed that sociodynamic factors that are proximal to adolescents and young adults' survival such as family, peer groups, school, and church may direct or indirect play a role in facilitating adherence to ART (35).

2.3.3 Exo – System

Bronfenbrenner described exo-systems as structures or forces within the whole social system where an individual is entrenched and is directly or indirectly influenced by their behavioural pattern within an environment(32,38). Literature has uttered constituents of the exo-system that can influence an individual's behaviour, this includes unemployment, mass media, health system, and public health policies(13,32,38). Eyassu et al, expressed that the health system may contribute to poor adherence (40).

2.3.4 Macro – System

Scholars have described macro-system as the broad system made up of a cultural belief system, constantly influencing and impacting on micro-, meso-, and exo- system on an individual level(32,34). Available literature has associated cultural make-up of the society where adolescents and young adults with ART adherence barriers to factors like stigmatization and discrimination(35), furthermore, other societies still believe that taking ART is the result of unsafe sex practices and such brings shame to AYA group (41). Natukunda et al, further demonstrated the role played by religious customs and cultural beliefs among AYA on ART adherence, for example, some AYA stopped taking ART with a belief that God will heal their sickness (31). Moreover, Bongfen et al, in their study revealed that some of AYA complemented ART with other traditional medicines with a belief that HIV/Aids will be cured, this led to unsuppressed viral load, and later recorded as the poor adherence to ART (42).

2.3.5 Chrono – System

Bronfenbrenner described chronosystem as the occurred processes or changes over a specific time-period in micro-, meso-, exo-, and macro-system(43). Changes may include individual growth and development, support structures, socioeconomic status, political landscape, public health policies, and the epidemiological profile of the community and country. The researcher excluded chronosystem in this study because of cross-sectional design n adopted in the study. The importance of this system may be fully recognised in future longitudinal studies.

2.4 Summary of the chapter

This chapter revealed in detailed the literature review relating to research topic, multi-level facilitators and barriers to ART adherence among adolescents and young adults. Further explained in depth the employed conceptual framework and the justification around the chosen framework. Below is the commencement of chapter three, disserting the methodology of the research study.

CHAPTER THREE – RESEARCH METHODOLOGY

3.1 Introduction to the research methodology

This chapter details the procedures and methods utilized by the researcher to achieve the research project's objectives. It outlines the researcher's positionality towards the study, geographical scope of the study, research procedures, and analysis plan that were part of the study's implementation. The success of the project was contingent on the provision of pertinent information consistent with the research questions and objectives to ascertain the impact of socio-ecological factors on antiretroviral therapy adherence among adolescents and young adults in a rural area of South Africa. Below is a review of the research design outlining the study setting, population demographics, specifics regarding the study area, and a concise introduction to the key components of the study.

3.1.1 Positionality Statement

As an Operational Manager at Othobothini Community Health Centre (CHC), I bring insider knowledge of the healthcare system, including its operational structures, resource constraints, and policy environment, to this study on facilitators and barriers to antiretroviral therapy (ART) adherence among adolescents and young adults aged 16–24 years in five primary healthcare clinics under Othobothini CHC. While this perspective offers valuable contextual insight, it also carries the risk of shaping the research through my own assumptions and institutional viewpoint. I am mindful of the potential power imbalance between myself as a healthcare provider and participants, many of whom may be in vulnerable situations due to their health status.

To address these influences, I adopted a reflexive, participant-centred approach that prioritised the voices and lived experiences of adolescents and young adults living with HIV/AIDS. This included bracketing my preconceptions, using open-ended questioning, and maintaining transparency about my role throughout the research process. By engaging in ongoing reflexivity and critically examining how my position could affect data collection and interpretation, I aimed to ensure that the findings are credible, ethically grounded, and reflective of the realities of ART adherence in a rural South African context.

3.2 Study Design

The study employed cross-sectional research using a qualitative approach. The qualitative approach defined as exploring subjective experiences and understanding about certain

phenomenon using non numerical data(44). Researcher's study process was guided by conceptual framework of Bronfenbrenner's Socio-Ecological Model(32), which helped to explore in-depth the understanding and experiences (45) in relation to facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults.

3.2.1 Study Setting

The study was executed at five primary healthcare (PHC) clinics under Othobothini Community Health Centre (CHC), rural Jozini, uMkhanyakude district, KwaZulu Natal, South Africa (namely, Jozini, Makhathini, Nondabuya, Ophondweni and Gwaliweni). The CHC together with feeder clinics serve an estimated population of 198 000 (23). The CHC & clinics operate 24 hours a day, offering preventive, emergency and curative services during the day, and only emergency services including gynaecology & obstetric after hours. According to District Health Information System (DHIS) as of 2020, CHC & five feeder clinics had an estimated 12000 clients on ART, of which 32% are virological unsuppressed attributed to poor adherence(2). The district is regarded as one of the poorest socio-economical among districts in the KwaZulu Natal province, and the leading cause of death among AYA is attributed to HIV/AIDS at 42% as the result of poor adherence to ART and delay in linkage to healthcare services (1,2,46).

3.2.2 Research Study Population

The study included people living with HIV aged 16-24 years receiving antiretroviral therapy at five provincial primary healthcare clinics under the Othobothini Community Healthcare Centre.

3.2.3 Study Sample and Sampling Method

The researcher employed convenience sampling to recruit participants for the study. Convenience sampling is defined as a non-probability technique employed where participants are selected based on their availability and accessibility(47). The goal was to select 20 participants who met the inclusion criteria or continue until data saturation is reached. Depending on the availability of participants, the researcher tried to ensure inclusiveness and representativeness by selecting four participants per facility, the researcher ensured that the sample was inclusive in terms of gender. The choice of sample was intended to achieve data adequacy that would unfold rich textured information, enhancing the research study's credibility and validity (48). By employing convenience sampling, the researcher's aim was to select participants who could provide rich information and facilitate in-depth insights and

explanations of the unknown being studied in rural or poor-resourced environments(49), and lastly increase the chances of recruiting the most used study population for ART research studies such as adolescents and young adults(50).

3.2.4 Inclusion criteria

- Adolescents and young adults aged 16 – 24 years on antiretroviral therapy, regardless of duration, in rural primary healthcare clinics under Othobothini CHC and be able to consent.

3.2.5 Exclusion criteria

- All adolescents and young adults on antiretroviral therapy, regardless of duration, in rural primary healthcare clinics under Othobothini CHC aged outside the age group of 16-24 years,

3.4 Data Collection

3.4.1 Data collection tool

A semi-structured interview schedule was developed for data collection. The conceptual framework served as the foundation for formulating the interview guide. Questions were designed based on Bronfenbrenner's Socio-Ecological Model, which highlights multilevel factors influencing individual behavioural systems. This approach facilitated a comprehensive exploration of adherence barriers and facilitators among adolescents and young adults (AYA) aged 16-24 years receiving antiretroviral therapy (ART) at rural healthcare facilities under Othobothini CHC, Jozini, KwaZulu-Natal, South Africa. In-depth interviews (IDIs) were conducted in private consultation rooms at each primary healthcare (PHC) clinic to ensure confidentiality and comfort. Detailed field notes captured key events, conversations, observed behaviours, and the researcher's reflections.

The interview questions were written in both isiZulu and English to accommodate participants' preferred languages. Open-ended questions and probing techniques were employed to elicit rich, comprehensive responses. Given the sensitivity of the research topic, in-depth interviews were deemed the most suitable method, allowing participants to express themselves openly and flexibly. To enhance the depth and reliability of the collected data, method triangulation was employed. This involved integrating data from in-depth interviews, detailed field notes, and the researcher's reflective observations. This multi-source approach strengthened the validity and contextual richness of the findings.

3.4.2 Recruitment process

Participants who met the inclusion criteria were recruited through the facility manager, filtered through a reporting system called Tier.Net by data capture, then phoned to enquire about their potential participation. For participants below age of 18 years, parents or guardians were requested telephonically and if agreed for potential participation, were requested to present with the minor on the scheduled clinic visit to sign consent. Those who consented to participate were thoroughly informed about the purpose of the study before scheduling a convenient date for data collection. Interviews were conducted either during participants scheduled antiretroviral therapy (ART) clinic visits or on mutually agreed dates at the facility. For participants under the age of 18, parental consent forms, accompanied by detailed information sheets, were provided. Parents were required to review the documents, provide written consent, and submit them on the designated data collection day. During the recruitment process, participants were reassured that the study was entirely voluntary, and their information would be kept confidential.

3.4.3 Data collection process

After obtaining ethical clearance and all necessary permissions, the researcher coordinated data collection dates with facility managers and participants. On the scheduled day, participants were approached during their clinic visits, and the study's purpose was clearly explained. For participants under 18 years of age, a consent form and an information sheet were provided for review with their parents or guardians at home. If parents or guardians approved participation, they signed the consent form, while minor participants provided assent if they agreed to participate. Participants aged 18 and above signed an informed consent form independently. The researcher requested a private room from the facility manager to conduct the interviews. Participants who agreed to participate were directed to the interview room after completing their clinic consultations. Those unable to attend interviews on the same day were given the option to reschedule at a more convenient time. Each interview lasted approximately 25-45 minutes and was audio-recorded with the participant's consent.

The in-depth interviews were conducted by the researcher using interview guide (**Appendix C & D**), who had been trained and calibrated by the supervisor prior to data collection. The pilot study was conducted at Othobothini CHC, using two participants that were not included in the actual study, to test whether questions answer the research question, and add modifications. The interviews were conducted in isiZulu, the participants' native language, to ensure clarity and comfort. The questions focused on participants' experiences with antiretroviral therapy (ART), exploring both facilitators and barriers to adherence. To ensure

trustworthiness, the researcher employed reflexivity throughout the study, acknowledging the subjective nature of qualitative research. Personal, methodological, and theoretical reflections were documented and incorporated into the research analysis, enhancing the study's credibility and depth.

3.5 Data Management and Analysis

The audio files were transcribed verbatim by the researcher, who then carefully reviewed the transcripts while listening to the recordings to ensure accuracy and completeness. The transcripts were subsequently translated from isiZulu to English to facilitate analysis by the researcher, a Zulu speaking language person and fluent in English. The translation of transcripts was double-checked and confirmed by the research supervisor, who is also, a Zulu speaker and fluent in English language. To ensure data security, all research data were stored on an encrypted, password-protected external drive. Access was restricted to the researcher and supervisor.

Thematic analysis was conducted using both deductive and inductive approaches. Thematic analysis is described as the method used to identify, analyse and report on found patterns of themes from the raw data(51). An inductive approach identified themes emerging directly from the data, while a deductive approach was applied to align findings with Bronfenbrenner's Socio-Ecological Model. The team conducted thematic analysis following the six-phase process by Braun and Clarke, 2006, which includes familiarization with the data, generating initial codes, identifying key themes, reviewing and refining themes, categorizing themes, and producing the final thematic report. Coding of data was conducted using MAXQDA 2024 software. To enhance reliability and validity, an intercoder agreement was established through collaboration with the researcher and the study supervisor, ensuring consensus on codes and themes from multiple perspectives. This process broadened the exploration of the phenomenon, enabling the identification of new insights and interpretations.

Upon familiarizations with the data, the team, including the researcher, the other co-coder, and the supervisor identified the initial codes to create the initial codes to guide the development of the coding template that was used for identifying the rest of the codes. Coding was conducted until no further codes were identified and the research team felt that the ideas from the interviews were fully covered. Indexing and information mapping were employed to organize codes into thematic networks, highlighting similarities, variations, and sub-themes. To ensure the dependability of the findings, the supervisor cross-checked the entire analysis process; any discrepancies were resolved by the team while reviewing the final document.

3.6 Ethical considerations

Ethical approval was obtained from the Wits Human Research Ethics Committee (HREC) – Clearance Certificate No. M231014 Ref No R14/49 (**Appendix A₃**) and permission to conduct the study was received from the KwaZulu Natal Department of Health (**Appendix B**) and uMkhanyakude Health District Research Ethics Committee before data collection (Ref No; KZ_2023_021) (**Appendix B1**). The researcher strictly adhered to established ethical research principles involving human participants. The study posed a minimal risk of harm while addressing research questions pertinent to minors. Including participants aged 16-24 years was crucial, as this demographic has been identified as the most affected by antiretroviral therapy (ART) adherence challenges in the uMkhanyakude district. Excluding this age group would have compromised the study's relevance, depth, and overall impact on understanding ART adherence in the targeted population.(2,52)The researcher did not provide any financial incentives or rewards to the participants for their involvement in the study, as it was self-funded, which ensured the elimination of bias.

3.6.1 Informed consent and voluntary participation

Participants were provided with an information sheet (**Appendix F & K**) detailing the research topic, procedures, and ethical considerations, written in their preferred home language before the interviews commenced. Participation in the study was entirely voluntary, with participants retaining the right to withdraw at any point without fear of penalty or loss of their rights and privileges as patients. Written informed consent was obtained for conducting in-depth interviews (**Appendix G, I & L**), audio recordings (**Appendix H & J**), and potential follow-up for clarification if needed. For minors aged 16-17 years, informed assent procedures adhered strictly to the legal provisions outlined in the National Health Act No.61 (51) and the Children's Act No.38 (52), ensuring their constitutional rights were respected throughout the study. Parental or guardian permission was sought before approaching minors for their assent. The researcher ensured consistency in decision-making between the parent/guardian and the minor, with the minor's decision being final (54). These comprehensive ethical measures ensured that minors' constitutional rights to dignity, autonomy, and informed decision-making were upheld, prioritizing their best interests throughout the study process (50,53,54).

3.6.2 Confidentiality and Anonymity

Confidentiality was strictly maintained throughout the research process. Only the principal investigator conducted IDIs in a private and quiet consultation room within each clinic to ensure privacy and minimize external disruptions. Research findings are presented in a non-

identifiable manner, safeguarding participants' personal information. Anonymity was consistently upheld using pseudonyms during both the IDIs and data analysis processes. This approach ensured that participants' identities remained protected, fostering a safe and secure environment for open and honest sharing of experiences.

3.6.3 Protection of the participants from harm.

Available literature on the investigated phenomenon highlights the sensitive nature of the research topic, with the potential for participants to become emotionally overwhelmed (7,55). To address this, the researcher took proactive measures to preserve participants' dignity, demonstrate empathy, and offer psychosocial support when needed. Participants' comfort levels were continually assessed throughout the interviews, ensuring that they felt safe and respected though providing autonomy to withdraw anytime during the study and ask their willingness to continue with IDI.

The researcher also maintained regular communication with the supervisor during the data collection process, providing continuous updates for constructive feedback, support, and guidance. This collaborative approach strengthened the research process while ensuring ethical and compassionate engagement with participants.

3.6.4 Distress Protocol

The sensitive nature of the research topic had the potential to trigger emotional distress, particularly among participants from child-headed households, where survival responsibilities often rest on their shoulders (56), as well as those experiencing stigmatization and discrimination in their social environments (57). To mitigate this risk, voluntary participation was emphasized, with participants retaining the autonomy to refuse or withdraw from the study at any time without penalty.

To ensure adequate preparation for handling emotional distress, the first five interviews were conducted under the supervision of a senior researcher for training and capacity-building purposes. During interviews, if a participant became emotionally triggered, the session was paused immediately. Participants were offered tissues, water, and a supportive, empathetic listening environment, ensuring a non-judgmental approach. Their emotional and psychological state was assessed by asking about their current feelings and thoughts. If participants expressed readiness to continue, the interview resumed; otherwise, a follow-up session was scheduled with their consent.

Participants requiring professional psychological support were referred on the spot to a registered counsellor based at Othobothini CHC. Arrangements for such services were made prior to data collection. Additionally, alternative counselling services, social support, and empowerment programs were available through the Solid Foundation for Rural Development (SORD), a non-profit organization in the Jozini area specializing in psychosocial and detoxification services, as stipulated by the Mental Healthcare Act No. 17 of 2003 (58).

Follow-up courtesy calls were made to consenting participants to ensure their well-being and address any unresolved distress related to the research. The same distress protocol was extended to the transcriber, and continuous debriefing sessions were conducted with research team members, as recommended by Haigh et al. (59). This comprehensive distress management plan ensured a supportive, ethical, and emotionally safe research environment.

3.7 Summary of the chapter

Chapter three have articulated all methods that would be utilized throughout the research process, ensuring that the research findings can be replicable in the future. The ethical considerations to protect participants from harm were clear demonstrated as per good clinical practice guidelines. Below follows chapter four with current research findings.

CHAPTER FOUR: RESEARCH RESULTS

4.1 Introduction to the research results

This chapter presents the results of lived experiences collected among adolescents and young adults taking antiretroviral therapy in rural areas, collected through in-depth interviews. The following section describes the study participants followed by themes that emerged from qualitative analysis.

4.2 Participants' demographic characteristics

A total of 20 IDIs were conducted with AYA, 80% were females, and 90% were between the ages of 18 and 24 years. Just above half (55%) of participants were Christians, all of them were single, 90% were in secondary school, most of them were unemployed (60%) and remaining portion were students, one consumed alcohol, and 55% resided with parents as demonstrated below in **Table 1**.

Table 1 Participants Demographics of the study sample

Variables	Categories	Frequency	Percentage
Age group	16-17 years	2	10%
	18-24 years	18	90%
Sex	Females	16	80%
	Males	4	20%
Religion	Christians	11	55%
	Nazareth	6	30%
	Traditional	1	5%
	Other	2	10%
Marital Status	Single	20	100%
	Married	0	0%
Educational Level	Secondary	18	90%
	Tertiary	2	10%
Employment Status	Unemployed	12	60%
	Student	8	40%
Lifestyle Assessment	Drinks alcohol	1	5%
	None	19	95%
Participants reside with	Parents	11	55%
	Partner	1	5%
	Guardian	6	30%
	Siblings	2	10%

4.3 Themes emerging from the data

The themes emerging from the data are presented in Table 2 and Table 3, with multilevel barriers and facilitators, respectively, to ART adherence among adolescents and young adults in rural areas. These themes were categorized into four organizing themes which were part of the conceptual framework employed by the researcher, namely, intrapersonal, interpersonal, community, and structural level barriers or facilitators. The application of inductive data analysis in the study further revealed an additional data-driven theme outside of the deductive data analysis which complimented the worthiness and credibility of the study in exploring broadly the multilevel facilitators and barriers to ART adherence. The researcher tabled a descriptive theme with a broad, overarching concept that emerged from the data, representing key ideas or phenomena of the study. The subthemes identified helped to clarify, contextualize, and provide detailed insights into the main themes.

Below is **Table 2** with detail multilevel barriers to ART adherence, addressing the second research study objective of the research question. Categorised according to employed conceptual framework, that is, micro – system (intrapersonal level barriers), meso – system (interpersonal level barriers), exo – system (community level barriers), macro- system (organisational/ system level barriers). and lastly, other related ART adherence barriers emerged from the data that were outside of the conceptual framework.

Table 2 Multi-Level Barriers to ART Adherence; Conceptual Framework of Bronfenbrenner's Socio-Ecological Model

Systems	Themes	Sub-themes	Description	Examples
Micro-System	Intrapersonal level barriers	Lack of autonomy or dependence on others	Heavy reliance on others for reminders hindered adherence.	“At my younger age it was difficult because my mother died when I was young, I lived with my grandmother, and she didn't know how to give me medicine” (Thembi* female 19 years)
		Medication-related side effects	Adverse effects like nausea related to medication hindered ART adherence.	“When you drink it in the afternoon, you will feel it wanting to come back, the one you drank in the morning, and it always happened in the morning. This ended up making me to hesitate to take the pills” (Luzu* male 23 years)
		Treatment regimen/ pill burden	Complex older regimens or side effects reduced trust & sense of pill burden in ART.	“Sometimes when I drink the medication, it comes back to the throat and wants me to throw them up, this happened a lot when I was drinking the pills that I had to take twice a day, it got better when they changed and gave me the one that I should drink once a day.” (Duzo* male 19 years)
		Knowledge deficit related to HIV	Lack of information provision to AYA promoted non-adherence to ART	“There were some medicines that were given to me at the clinic, and they didn't understand it at home, and they told me not to take it.” (Thembi* female 19 years)
		Denial or Reluctance to Accept HIV Status	State of emotional denial led to delays in starting or maintaining ART.	“I was saddened to know that I have this disease, and I find it difficult to accepted it” (Kholi* female 20 years)
		Forgetfulness and Irregular Timing	Disrupted routines or lack of reminders caused missed doses.	“I used to forget to take the pills, and that made me miss some days.” (Lizzy* male 23 years)

Meso-System	Interpersonal level barriers	Non-disclosure to partner/family	Reluctance to disclose HIV status hindered support-seeking.	<i>“I never told him (boyfriend) because I once heard him talking badly about infected people, and I finally decided not to tell him because he will end up talking bad about me too. They talked about infected people and made jokes.” (Phiwe* male 20 years)</i>
		Non-disclosure to AYA	Non-disclosure of HIV diagnosis to AYA led them not realising the importance of ART	<i>“when I asked at home, they told me that I had TB “ (Thembi* female 19 years)</i> <i>“but she did not tell me what the disease was,” (Duzo* male 19 years)</i>
		Peer/ family members’ HIV knowledge deficit	Limited access & availability of HIV information to the public act as the barrier to adherence	<i>“My brother did not know how he was going to explain to me what this virus was.” (Thembi* female 19 years)</i>
		No food to eat	Lack of food at home led to poor ART adherence	<i>“There are times when we don’t have food because there is not enough money at home, so I drink it without eating, but I feel uncomfortable in my stomach and sometimes I don’t drink it.” (Zipho* female 24 years).</i>
Exo-System	Community level barriers	Stigma and discrimination	Fear of judgment and distress discouraged adherence.	<i>“It is not easy because of people’s eyes; they judge others and pay attention to the person going to the clinic.” (Luzu* male 23 years)</i>
Macro-System	Structural/ Organisational level barriers	School versus Clinic commitments	Clashing of school & clinic commitments led to missed ART doses	<i>“It happened that I didn’t drink them because I was at school, in the afternoon when we attended 6 pm and I would come back maybe around 9 pm and it would too late, and I ended up not drinking anymore” (Khali* female 20 years)</i>
		Hostile clinical environment	Rude or judgmental staff reduced trust and clinic visits.	<i>“They also scolded me that I came before my due date to ask for pills, and they thought I was selling pills when I was just pretending that I was not ready if I missed my due date because of school or the fare” (Xolo* female 22 years)</i>

		Long waiting times at clinics	Extended clinic queues created logistical challenges.	<i>“What happened was that the queues were long until I got help and left sometimes.” (Phiwe* male 20years)</i>
		Inadequate education on HIV infection and treatment	Health workers shared limited information relating HIV	<i>“The doctors could see that my blood results were not going well, they asked me why I explained my problem with the pills, but in the end, they did not explain to me how to solve the problem” (Luzu* male 23 years)</i>
Other related ART adherence barriers	Adolescence hood’ stage	Social, emotional & physical transition/ changes influenced negatively ART adherence for no valid reason.	<i>“I stopped taking the pills for a whole year, I lied to the clinic that I take them, but I used to take them when I feel like I’m sick,” (Hero* female 17 years)</i>	

4.4 Multilevel Barriers to ART Adherence

The thematic data analysis identified four main themes that fall in each system under the socio-ecological conceptual framework of Bronfenbrenner, which played an influential role in poor ART adherence among adolescents and young adults. Inductive analysis revealed other related ART adherence barriers among adolescents and young adults living in rural areas. The below data presents the main themes and their sub-themes: intrapersonal level barriers, interpersonal level barriers, community-level barriers, structural/ organisational level barriers, and other ART adherence-related barriers emerged from the data that were outside of the conceptual framework.

4.4.1 Theme 1: Intrapersonal level barriers.

Participants identified several internal and personal barriers that hinder their thoughts, emotions, and behaviours, ultimately affecting their ability to adhere to antiretroviral therapy (ART). The following sub-themes emerged as significant contributors: lack of autonomy or dependence on others, medication-related side effects, treatment regimen and pill burden, deficits in HIV-related knowledge, as well as denial and anger. These shared experiences highlight factors leading to poor ART adherence, and each sub-theme is elaborated upon below.

Lack of autonomy or dependence on others:

Participants, particularly younger individuals, frequently depended on family members or caregivers for medication reminders and assistance with attending clinic appointments(53). This reliance occasionally resulted in missed doses when such support was unavailable.

A 19-year-old female participant indicated that the age factor during their childhood era played a significant role in poor adherence to ART.

“At my younger age, it was difficult because my mother died when I was young, I lived with my grandmother, and she didn't know how to give me medicine”.

This signifies the importance of parental or guardian presence in ensuring optimal ART adherence.

Medication-related side effects:

Participants reported that adverse effects, such as nausea, vomiting, and dizziness, were common barriers to ART adherence. These side effects often led to hesitation in taking

medication or skipping doses altogether, significantly impairing their compliance with the prescribed treatment regimen.

“When you drink it in the afternoon, you will feel it wanting to come back, this ended up making me to hesitate to take the pills, male 23-year-old”.

Another 19-year-old female participant reported experiencing side effects, although they differed from those described by the first participant.

“I felt sleepy as if I was drunk, when I had to go somewhere or do something I would feel dizzy”.

Treatment regimen/ pill burden:

Previous challenges with ART, such as being prescribed older regimens involving multiple pills or experiencing significant side effects, negatively influenced participants' perceptions and adherence. A 19-year-old male specifically highlighted pill burden and the unpalatable nature of certain treatment regimens as major obstacles that contributed to poor ART adherence. After transitioning to a more user-friendly treatment regimen involving a single pill, adherence to ART became significantly easier and more manageable for participants. This adjustment improved their overall experience with treatment and facilitated better adherence.

“Sometimes when I drink the medication, it comes back to the throat and wants me to throw them up, this happened a lot when I was drinking the pills that I had to take twice a day, it got better when they changed and gave me the one that I should drink once a day.”

Knowledge deficit related to HIV:

A 23-year-old male participant acknowledged having an insufficient understanding of the medication and its significance, which can hinder adherence. Reflecting on this, the participant stated: *“I told them, I don't know.”*

Another participant shared that no formal educational information was provided at the clinic regarding the treatment. As a result, they did not fully understand its importance and chose not to adhere to the prescribed regimen. This highlights an insufficient understanding of the medication and its importance, which can hinder adherence. This gap in understanding can be attributed to poor communication on the part of healthcare workers, as well as the participant's failure to seek clarification about her treatment. The lack of a sense of ownership over her healthcare further contributed to this challenge.

“The doctors could see that my blood results were not going well, they asked me why I explained my problem with the pills, but in the end, they did not explain to me how to solve the problem, male aged 23 years”

Denial or reluctance to accept HIV status:

Some participants struggled with accepting their diagnosis, which led to resistance to initiating or maintaining ART. This denial or non-acceptance was often linked to factors such as the mode of HIV acquisition, the experience of learning about their HIV status, and the fear of societal judgment. For instance, a 20-year-old female expressed a deep sense of anger toward her mother, a family member whom she held responsible for not being honest with her and for transmitting the HIV infection to her.

“I was saddened to know that I have this disease, and I find it difficult to accepted it”

Forgetfulness and irregular timing

Forgetting to take pills on time or missing doses due to disrupted routines or a lack of reminders hindered adherence. This issue was especially prevalent among younger participants and those with busy schedules. A male participant aged 23 years old shared an experience led to missing ART doses

“I used to forget to take the pills, and that made me miss some days”

Similar sentiments were shared by a 20-year-old female, who sometimes missed her ART doses due forgetfulness as the results of competing activities.

“It happened that I didn't drink them because I was at school, in the afternoon when we attended 6pm and I would come back maybe around 9pm and it would too late, forget and I ended up not drinking anymore”

4.4.2 Theme 2: Interpersonal level barriers

Participants identified several obstacles arising from their interactions and relationships with individuals close to them, which negatively impacted effective communication, social support, and compliance with ART adherence. The sub-themes that emerged under this category include nondisclosure to partners or family members, nondisclosure to adolescents and young adults (AYA), knowledge deficits among peers or family members regarding HIV, and a lack of food to accompany medication. Each sub-theme is elaborated upon below.

Non-disclosure to partner/ family:

Participants reported that they avoided disclosing their HIV status to friends, partners, or even family members due to fears of stigma and judgment. This secrecy often created challenges in adhering to ART, particularly in social settings or shared living environments where discretion was difficult to maintain. This highlights the role of mistrust, social stigma, and nondisclosure as key factors contributing to poor adherence among adolescents and young adults.

“I never told him (boyfriend) because I once heard him talking badly about infected people, and I finally decided not to tell him because he will end up talking badly about me too. They talked about infected people and made jokes, male 20 years”

Non-disclosure to adolescents and young adults:

Participants reported that delayed or non-disclosure of their HIV status had profound negative impacts on their physical, emotional, and social well-being. Their lack of awareness about their condition often led to poor medication adherence, as they did not fully understand the importance of treatment. For instance, a 19-year-old female and female participants respectively, revealed that she was never informed about her diagnosis or the necessity of taking ART.

“when I asked at home, they told me that I had TB, female aged 19 years.”

“but she (mother) did not tell me what the disease was, male 19 years.”

Peer/ family members’ HIV knowledge deficit:

The data revealed that low levels of literacy regarding HIV infection and its treatment among family members and peers negatively impacted ART adherence among adolescents and young adults (AYA). For instance, a 19-year-old female participant noted that her family’s lack of understanding about HIV and antiretroviral therapy significantly affected her ability to adhere to treatment.

“My brother didn’t know how he was going to explain to me what this virus was.”

Her second experience shared was relating to HIV knowledge deficit on ART

“There were some medicines that were given to me at the clinic, and they didn’t understand it at home, and they told me not to take it”

No food to eat:

Some participants revealed distressing experiences related to ART adherence, particularly due to the impact of poor socioeconomic conditions. They reported having no food to accompany their medication, which hindered adherence and often resulted in discomfort. For example, a 20-year-old female participant shared that she frequently had to take her medication on an empty stomach, underscoring the challenges posed by food insecurity and poverty in maintaining adherence to ART.

“If it happens that we don't have enough food before the month is over when we come across that situation, I try to get a piece job at my nearest store and get some money to buy bread so that I can be able to drink my medication.”

A similar situation was experienced by a 24-year-old female, who also faced challenges adhering to ART due to a lack of food and the impact of poor socioeconomic conditions.

“There are times when we don't have food because there is not enough money at home, so I drink it without eating, but I feel uncomfortable in my stomach and sometimes I don't drink it.”

4.4.3 Theme 3: Community-level barriers:

Participants identified several external factors within the community and social environment that hindered their access to healthcare services. The overarching theme highlights social and environmental barriers, with stigma and discrimination emerging as significant deterrents to seeking care and maintaining treatment adherence. Each sub-theme is detailed below.

Stigma and discrimination:

Participants stated that fear of judgment or gossip from community members discouraged them from seeking ART services or openly discussing their HIV status. Concerns about becoming the subject of gossip created significant stress and reluctance, ultimately leading to non-adherence to treatment. This fear often resulted in nondisclosure of their status and missed doses, as participants sought to avoid societal judgment. A 23-year-old male participant emphasized this issue, noting that stigma and discrimination directed toward people living with HIV/AIDS made it especially difficult for adolescents and young adults to freely access healthcare facilities and collect their medication.

“It is not easy because of people's eyes; they judge others and pay attention to the person going to the clinic.”

Another participant reported a similar experience, expressing fear of discrimination as a significant barrier to accessing healthcare services and adhering to ART.

“I'm afraid to tell my friends that I'm taking pills because I have a fear, that they'll discriminate me, thinking that I'm going to transmit the disease I have to them. female 20 years.”

4.4.4 Theme 4: Structural/ Organisational level barriers

Participants reported systemic and institutional obstacles that hindered access to healthcare services related to antiretroviral therapy, indirectly impacting ART adherence among adolescents and young adults in rural areas. The main theme comprises four sub-themes: school versus clinic commitments, a hostile clinical environment, long waiting times, and insufficient education on HIV infection and treatment. Each of these sub-themes, which emerged from the data analysis, is elaborated upon below.

School versus clinic commitments:

Some participants expressed concerns about the challenge of balancing school commitments with clinic appointments, which often became an overwhelming task. The conflict between these priorities made it difficult to manage both effectively, leading to missed clinic appointments and skipped ART doses. A 20-year-old female participant stated:

“It happened that I didn't drink them because I was at school, in the afternoon when we attended 6 pm and I would come back maybe around 9 pm and it would be too late, forget and I ended up not drinking anymore.”

This concern was affirmed by one of the participants, who highlighted the difficulty of balancing school responsibilities with attending clinic appointments, which often resulted in missed doses of ART.

“I was studying and sometimes I didn't take the pills, because I was doing my matric and sometimes at school, they refused to let me go to the clinic because it was too far, female 22 years.”

Hostile clinical environment:

Participants reported that rude or judgmental behaviour from healthcare providers discouraged them from seeking timely medical care, which negatively affected their ART adherence. The fear of being reprimanded for missing doses or clinic visits further worsened the situation, leading to the avoidance of healthcare services. A 22-year-old female participant highlighted instances of unprofessional and unethical conduct by healthcare workers providing services to adolescents and young adults, which further strained their willingness to seek care.

“They also scolded me that I came before my due date to ask for pills, and they thought I was selling pills when I was just pretending that I was not ready if I missed my due date because of school or the fare.”

Some participants even expressed strong resentment toward healthcare workers due to the ill-treatment they received after missing their clinic appointments. This negative experience further discouraged them from returning to the clinic and negatively impacted their adherence to ART.

“There was a doctor that I hated because of the way he used to yell at me, male 23 years”.

Long waiting times at clinics:

Participants reported long queues and extended waiting times at clinics as significant barriers to ART adherence. These delays were particularly burdensome for students and individuals juggling multiple responsibilities, making clinic visits increasingly challenging. A 23-year-old male participant shared that the prolonged waiting hours at the clinic before receiving services diminished his motivation to attend appointments and collect his medication.

“What happened was that the queues were very long until I got no help and left sometimes.”

Inadequate education on HIV infection and treatment:

Inadequate health education on HIV infection and treatment contributed to poor adherence to ART. A male participant aged 23 years old responses suggests that initial communication from healthcare providers might not have been thorough or timely enough to address all concerns.

“The doctors could see that my blood results were not going well, they asked me why I explained my problem with the pills, but in the end, they did not explain to me how to solve the problem.”

4.4.5 Theme 5: Other related ART adherence barriers

Additional themes emerged from the data that were not aligned with the initially employed conceptual framework but were revealed through inductive data analysis. These themes provide deeper insights into the factors influencing ART adherence.

Adolescence hood stage:

Participants admitted to discontinuing their antiretroviral therapy without providing any specific or valid reasons. This behaviour underscores the complexity of adherence challenges, as it suggests underlying factors that may not have been explicitly communicated or identified.

“I stopped taking the pills because, for a whole year, I lied to the clinic that I take them, but I used to take them when I felt like I was sick female 17 years”

4.5. Multi-Level Facilitators to ART Adherence

The study identified detailed multilevel facilitators of ART adherence, addressing the second research objective, and categorized them based on the employed conceptual framework. These facilitators were organized into four levels: the micro-system (intrapersonal-level barriers), meso-system (interpersonal-level barriers), exo-system (community-level barriers), and macro-system (organizational/system-level barriers). Additionally, the data revealed other ART adherence facilitators that fell outside the scope of the conceptual framework.

Below is **Table 3** with detail multilevel facilitators to ART adherence, addressing the second research study objective of the research question. Categorised according to employed conceptual framework, that is, micro – system (intrapersonal level barriers), meso – system (interpersonal level barriers), exo – system (community level barriers), macro- system (organisational/ system level barriers). and lastly, other related ART adherence barriers emerged from the data that were outside of the conceptual framework.

Table 3 Multi-Level Facilitators to ART Adherence; Conceptual Framework of Bronfenbrenner's Socio-Ecological Model

System	Themes	Sub-themes	Short definitions	Examples
Micro-system	Intrapersonal level facilitators	Acceptance of the HIV diagnosis	Acceptance promoted psychological readiness for lifelong treatment.	<i>"I was afraid of what people would say if they saw me in the clinic, and I finally told myself that it will not help me to be afraid because this will ruin my life, and I will end up not taking any more pills. (Xolo* female 22 years)"</i>
		Fear of getting sick and death	Awareness of health risks from missing doses reinforced commitment.	<i>"It always comes to my mind that if I don't take the pills, I will lose my life, but I know that if you take them, you will be fine, and you won't get sick. (Sabi* female 22 years)"</i>
		Self-Efficacy and Determination	Belief in one's ability to manage treatment ensured persistence.	<i>"It was not easy, but I finally accepted that I have to take care of my health. (Phiwe* Male 20 years)"</i>
Meso-system	Interpersonal level facilitators	Peer/ friend support	Interaction with peers living with HIV created a sense of belonging.	<i>"Three of my friends know that I am living with this virus, the one I live with has no problem because we have been friends since we were in primary school, she reminds me that it is time for me to take pills. (Thembi* female 19 years)"</i>
		Parent/ guardian disclosure to AYA	Disclosure of HIV diagnosis promoted sense acceptance and facilitated adherence	<i>"My mother explained to me when we were at home because I was sick and had sores all over my body until we were examined at the clinic. The nurses asked me if I knew what was going on, and I told them that my mother had explained it to me. (Bongi* female 19 years)"</i>
		AYA discloses HIV status	Disclosure of HIV diagnosis reduce fear and improved adherence	<i>"I didn't face too many problems because after I found out I told my mother, the family and the child's father, they never had a problem, but they supported me (Sabi* female 22 years)"</i>
		Other family members taking ART	Source of encouragement emanated from seeing other taking ART	<i>"I remember to drink them when my mother drinks them because she also drinks them, and I sometimes remind her. (Wendi* female 23 years)"</i>

		Family support system	Encouragement and reminders from family facilitated adherence.	<i>"When I started taking them, my mother always told me or reminded me until I got used to taking the pills, and I ensure that I drink the pills very well. (Wendi* female 23 years)"</i>
				<i>"I have an older brother who was watching over me, making sure that I take the pills or if I have to go to the hospital, he was helping me. (Luzu* male 23 years)"</i>
		Companion; someone to talk to	Individual in a form of family, friends providing	<i>"I told my younger sister; I told my mother later. I was able to talk to my sister first because we talk about a lot of things; she is the one I can talk to. (Yise* female 22 years)"</i>
		Medication collected by others	Medication collected on behalf of participants	<i>"When I'm at school, my mother fetches the medicine for me, but when the schools are closed, I go to pick them up or if the blood will be taken (Bongi* female 19 years)"</i>
Exo - system	Community level facilitators	Normalisation and shared experiences	Common experiences fostered support and inclusivity	<i>"I was saddened to know that I have this disease, but I accepted it because I know that there are many people with this disease (Khali* female 20 years)"</i>
Macro-system	Structural/ Organisational level facilitators	Provision of HIV related information	Easily available & accessible promoted better understanding HIV & medication	<i>"it was as if I was dreaming that the house was spinning, as if I was dizzy and it ended there, but it didn't scare me because I had already been told about its effects on the body. (Sabi* female 22 years)."</i>
		Positive attitude of the healthcare workers	Compassionate communication from providers enhanced adherence.	<i>"Then one day I gave up and tried to go to the clinic and found Dr. X, I was lucky and happy that I found someone who helped me, who spoke to me well, and gave me the motivation to go to the clinic (Luzu* male 23 years)"</i>
		Multidisciplinary team member collaboration	Coordination of services and shared responsibility among clinicians facilitated adherence	<i>"I used to see a lot of social workers in Clinic Z, there is one I just saw a few days ago, Dr. They are so beautiful that I wish to thank him again for the way he helped me (Luzu* male 23 years)"</i>

		Multi-month ART supply	Three-month supplies reduced logistical barriers.	<i>It doesn't bother me; at the clinic they give me three months of treatment which makes it take longer to go back to the clinic and that makes me able to set good times to go to the clinic. (Zipho* female 24 years)</i>
		Youth friendly approach for learners	Reduced waiting times for students minimized disruptions.	<i>"If it was 3 o'clock in the afternoon, there was no time that you were still a student, they would treat you like everyone else, if it was early in the morning they would pass you on because they saw that you still had to go back to school. (Yise* female 22 years)"</i>
		Availability of Reliable Healthcare Services	Dependable clinic services ensured access to ART.	<i>"I always get the pills from the clinic, and they explain everything I need to know (Thembi* female 19 years."</i>
Other related ART adherence facilitators	Technology; manual & digital device reminders	Structured routines supported consistent adherence.	<i>"I am reminded by the carrier with the dates written on it, I will see when my" pills are about to be finished and then go to the clinic (Zipho* female 24 years)</i>	
			<i>"I set the alarm so that when it is 5:40 it goes off, I know that at 6:00 I will take the pill. (Luzu* male 23 years)"</i>	

4.5.1 Theme 1: Intrapersonal level facilitators:

Participants identified three sub-themes within this main theme that were pivotal in promoting optimal adherence to ART among adolescents and young adults (AYA): acceptance of their condition, fear of illness and death, lastly, self-efficacy and determination.

Acceptance of the condition and ARVs:

Participants emphasized that acceptance of one's HIV status was a crucial factor in promoting consistent ART adherence. Participants who adopted a positive mindset often bolstered by the support of family members or healthcare professionals exhibited improved adherence. This acceptance involved acknowledging the significance of ART for survival and embracing lifelong treatment as essential for sustaining their health and well-being. As one 22-year-old female participant noted, this internal process of acceptance empowered her to adhere to ART independently, without reliance on external pressures or influences.

"I finally told myself that it will not help me to be afraid because this will ruin my life, and I will end up not taking any more pills"

The shared sentiments were reaffirmed by another participant.

"I accepted them because they explained to me that I must not stop them because if I stop them, I will not be good in life, female 20 years"

Fear of getting sick & death

Participants reported that awareness of the health risks associated with missing or discontinuing ART was a key motivator for adherence. They recognized that skipping medication could result in severe illness, health deterioration, or even death, reinforcing the importance of consistently following their treatment regimen. According to a 22-year-old female participant, fear of illness and death were significant factors driving her commitment to ART adherence.

"It always comes to my mind that if I don't take the pills, I will lose my life, but I know that if you take them, you will be fine, and you won't get sick"

This was also acknowledged by a 19-year-old male participant.

"When I find out what the disease is I never felt well because it's not fun to take pills; I take them because the situation forces me"

Self-efficacy and determination

Participants' belief in their ability to take control of their health and adhere to ART played a significant role in promoting adherence. This sense of self-efficacy included a determination to overcome challenges and a commitment to maintaining the treatment regimen. A 20-year-old male participant shared an experience that reinforced this point, stating:

"It was not easy, but I finally accepted that I have to take care of my health."

4.5.2 Theme 2: Interpersonal level facilitators

The data highlighted positive interactions and relationships between adolescents and young adults (AYA) and their close relatives or friends, which provided essential social support for promoting adherence to antiretroviral therapy (ART). Seven sub-themes emerged from the data, capturing the experiences of AYA regarding the interactions they encountered throughout their ART journey. Each sub-theme is detailed below.

Peer/ friend support:

Participants mentioned that support from peers or others living with HIV fostered a sense of community and helped reduce feelings of isolation. Sharing experiences with trusted friends or partners not only normalized ART adherence but also provided crucial emotional encouragement. A 19-year-old female participant underscored the pivotal role her friend played in supporting her adherence to ART.

"Three of my friends know that I am living with this virus, the one I live with has no problem because we have been friends since we were in primary school, she reminds me that it is time for me to take pills."

Parent/ guardian HIV disclosure to AYA:

Participants reported that the disclosure of HIV status to adolescents and young adults (AYA) by parents or guardians during childhood played a crucial role in facilitating ART adherence. These sentiments were echoed by a 19-year-old female participant, who shared:

"My mother explained to me when we were at home because I was sick and had sores all over my body until we were examined at the clinic. The nurses asked me if I knew what was going on, and I told them that my mother had explained it to me."

AYA discloses HIV status:

Participants noted that disclosing their HIV status to trusted relatives or friends appeared to have a positive influence on their adherence to antiretroviral therapy (ART). This sentiment was highlighted by a 22-year-old female participant, who shared:

“I didn't face too many problems because after I found out I told my mother, the family, and the child's father, they never had a problem, but they supported me.”

Other family members taking ART:

A 19-year-old male shared his experience of how comforting it was to know and take ART alongside other family members or a partner. He described this as a form of coping mechanism, where they supported each other as “treatment buddies,” helping to maintain good adherence to antiretroviral therapy.

“At home, there are others who take pills like me, they accept me because they know the situation I'm in and they don't discriminate (against) me.”

Another female participant shared her experience on the matter, referencing the support she received from her partner.

“My partner is also the same as me and that makes me brave because I know we both drink medication for the HIV and I'm not ashamed female 23 years”

Family support system:

According to participants, support from family members was identified as a critical facilitator for adherence to ART. Family members encouraged participants to take their medication, reminded them of their schedules, accompanied them to clinics, and provided emotional reassurance. Many participants shared similar experiences, emphasizing the pivotal role of family in ensuring proper adherence to antiretroviral therapy. Family support was widely regarded as the primary source of motivation for maintaining optimal ART adherence. A 23-year-old male participant highlighted the fundamental role his brother played, stating:

“I have an older brother who was watching over me, making sure that I take the pills or if I must go to the hospital, he was helping me.”

A 23-year-old female participant praised her mother's role in consistently reminding her of her scheduled time for taking treatment each day.

“When I started taking them, my mother always told me or reminded me until I got used to taking the pills, and I ensure that I drink the pills very well.”

Furthermore, this role was not limited to close relatives of the participants; extended family members, often acting as guardians, also played a significant part in supporting ART adherence. This was highlighted by a 20-year-old female participant, who stated:

“My grandmother and aunt made sure that they reminded me to take the pills in time, and sometimes I used to remember them.”

Companion; someone to talk to:

A 22-year-old female participant revealed that her strong adherence to ART was facilitated by having a trusted confidant with whom she could share, and offload stressors related to her HIV infection and treatment.

“I told my younger sister; I told my mother later. I was able to talk to my sister first because we talk about a lot of things; she is the one I can talk to.”

Medication collected by others:

A 19-year-old female participant shared her experience of how she managed to cope with competing priorities, such as school commitments while adhering to her ART regimen.

“When I’m at school, my mother fetches the medicine for me, but when the schools are closed, I go to pick them up or if the blood will be taken”

This means that there would be no conflicts between school activities and clinic appointments, as someone close to the participant could assist by managing other commitments on their behalf. Both school and health care were recognized as important aspects of upbringing and future development. A similar experience was shared by a 16-year-old female participant, who noted:

“My mother used to fetch my pills from the clinic when I was at school or sometimes, I would ask my sister.”

4.5.3 Theme 3: Community-level facilitators:

The thematic data analysis revealed facilitators at community level that enables, support and enhance an individual's commitment to, access to and effective utilisation of healthcare services related to antiretroviral therapy among adolescents and young adults in rural areas.

Normalization and shared experiences:

Participants reported that broader public awareness about HIV and ART contributed to normalizing treatment and reducing stigma, thereby encouraging adherence. They expressed reassurance in perceiving HIV as a manageable condition that is increasingly understood and accepted within the community. A 20 and 22-year-old female participants highlighted this, reflecting a sense of belonging, normalization, and reduced stigma within her community. This, in turn, positively reinforced their practice of adhering to antiretroviral therapy.

"I was saddened to know that I have this disease, but I accepted it because I know that there are many people with this disease "

"I came back from the clinic, and they encouraged me to drink them because there are others who drink them, and no one dies".

4.5.4 Theme 4: Structural/ Organisational Level Facilitators

Participants revealed that external facilitators within the healthcare system, such as supportive policies and processes, played a significant role in promoting access to and adherence to antiretroviral therapy (ART) among adolescents and young adults (AYA) in rural areas. Below are participants' shared experiences related to structural-level facilitators, organized into different sub-themes.

Provision of HIV-related information:

According to participants, the provision of comprehensive counselling sessions on ART played a crucial role in helping them develop coping mechanisms and resilience to maintain adherence, even when faced with medication-related side effects. A 22-year-old female participant shared that despite experiencing unbearable side effects, she continued taking her medication because the clinic had explained the potential side effects she might encounter during the initial days of ART.

"It was as if I was dreaming that the house was spinning as if I was dizzy and it ended there, but it didn't scare me because I had already been told about its effects on the body."

Positive attitude of the healthcare workers:

Participants highlighted that respectful, empathetic, and motivational interactions with healthcare providers significantly encouraged their commitment to ART. Healthcare providers who actively listened to their concerns and offered practical solutions were seen as instrumental in fostering adherence. A 23-year-old male participant shared an example of good practices demonstrated by healthcare workers during his ART journey, reinforcing the importance of adhering to treatment.

“One day I gave up and tried to go to the clinic and found Dr. X, I was lucky and happy that I found someone who helped me, who spoke to me well, and gave me the motivation to go to the clinic.”

Multidisciplinary team member collaboration:

A 23-year-old male participant acknowledged the critical role played by various members of the multidisciplinary healthcare team in preventing poor ART adherence. He shared that different healthcare professionals consistently encouraged him to comply with the requirements of ART, highlighting their collective efforts in supporting his treatment journey.

“I used to see a lot of social workers in Clinic Z, there is one I just saw a few days ago, Dr. I wish to thank him again for the way he helped me, male 23 years”

Multi – month ART supply:

Participants reported that the Department of Health implemented several patient-centred strategies to enhance service delivery and support ART adherence. One such strategy involved providing participants with three-month medication supplies, which reduced the frequency of clinic visits. This approach particularly benefited individuals facing transportation challenges or managing busy schedules. A 24-year-old female participant specifically recommended the multi-month ART supply strategy, noting that it helped her avoid frequent visits to the clinic and allowed her to budget effectively for her next trip.

“At the clinic, they give me three months of treatment which makes it take longer to go back to the clinic and that makes me able to set good times to go to the clinic”

Youth friendly approach for learners:

Participants reported that clinics often prioritized students during their visits, enabling them to return to school quickly and minimizing disruptions to their education. This approach was

instrumental in encouraging adherence among younger participants. A 22-year-old female participant shared an example of how the healthcare facility implemented measures to accommodate their needs and make them feel valued, stating:

"If it was 3 o'clock in the afternoon, there was no time that you were still a student, they would treat you like everyone else, if it was early in the morning they would pass you on because they saw that you still had to go back to school."

Availability of Reliable Healthcare Services

According to participants, the consistent availability of ART medication and supportive clinical services played a key role in encouraging adherence among adolescents and young adults (AYA). Participants emphasized the importance of ensuring access to high-quality care and youth-friendly services, noting that such efforts can significantly improve ART adherence and overall health outcomes. This sentiment was echoed by a 19-year-old female and 20-year-old male participants, respectively, who acknowledged the positive impact of these services on their adherence journey.

"I always get the pills from the clinic, and they explain everything I need to know."

"They treated me well like all patients, I was never scolded, and it was impossible for me not to get my pills"

4.5.5 Theme 5: Other related ART adherence facilitators

The data revealed additional ART adherence facilitators among adolescents and young adults that were not part of the employed conceptual framework. These facilitators were linked to current technologies that enhance daily life and play a significant role in promoting adherence to ART.

Technology: Manual and digital device reminders

Participants acknowledged that establishing a routine or habit around taking medication was instrumental in ensuring consistent adherence to ART. Strategies such as setting alarms, following structured timing, or integrating ART into daily activities made adherence more manageable. The data further revealed that participants employed various methods to remind themselves of their next ART appointment at the clinic. For example, a 24-year-old female participant relied on her carrier card and the number of pills remaining in the container. These

experiences highlight the important role technology and practical tools play in facilitating optimal ART adherence among adolescents and young adults (AYA).

“I am reminded by the carrier card with the dates written on it, I will see when my pills are about to be finished and then go to the clinic.”

On the daily intake of ART, a 23-year-old male participant shared that he relies on a digital device for assistance, using an alarm to remind him to take his medication.

“I set the alarm so that when it is 5:40 it goes off, I know that at 6:00 I will take the pill.”

4.6 Summary of the chapter

This chapter has shared all the research findings for the study, categorised shared experiences of adolescents and young adults on ART adherence into facilitators and barriers to ART, all relevant quotes were included in the findings to support emerged themes from the raw data. Below is chapter five with discussion, conclusion and recommendation.

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction to Discussions, Conclusion and Recommendations

This chapter presents a discussion of the research findings in relation to existing literature and draws conclusions based on the study results. Additionally, it reflects on the study's limitations and strengths and provides recommendations for the research topic and future studies. The primary goal of this research was to identify the facilitators and barriers to ART adherence among adolescents and young adults (AYA) living in rural settings. The study explored multilevel barriers and facilitators to ART adherence among adolescents and young adults (AYA) in rural settings. By analysing the perspectives of 20 participants, the findings provided valuable insights into the complex interplay of personal, social, community, and structural factors that influence ART adherence.

5.2 Demographic of the study population

Most participants were female and aged 18–24 years, with the majority attending secondary school and residing with parents. These characteristics reflect the vulnerability of this group to adherence challenges due to their developmental stage, social standing, and reliance on caregivers. Similar demographic trends have been observed in rural contexts where social support systems play a critical role in healthcare outcomes, and further reveal significant proportion of females who are AYA taking ART compared to males, as emphasized by other studies(14,54). The current study showed no experiences of marital status influencing ART adherence among AYA, the finding was in support of an international literature by Carballo et al(55), though a rural Kenyan study found a strong association between marital status and ART adherence(56). The unemployment rate figures concur with existing literature relating to high unemployment rate at 59.7% and 29.9% nationally and provincially respectively, among the South African aged 15 – 24 years(57), in rural areas in particular(58).

The data from this study revealed that, gender played no direct or indirect role in the issue of ART adherence among AYA in rural areas. While other studies found a link between being female and poor adherence to antiretroviral therapy(59,60), contrarily, a study conducted in Uganda reported an optimal ART adherence among female adolescents living with HIV/Aids (61). The study further revealed that patterns of good ART adherence experiences amongst those recently initiated and initiated since birth were equally the same among the adolescents and young adults, this was attributed to support system surrounding them during their upbringing. The above articulated findings were in agreement with the study conducted in Zambia by Mburu et al, which identified younger age pupils more compliant to antiretroviral therapy compared to adults irrespective of ART duration, due to the fact that, majority of them

are still under supervision of parents or caregivers who monitor them taking treatment on regular basis (62,63). Ugandan's research study further maintained similar sentiments that adolescents and young adults with no parental guidance and supervision are likely to miss their ART daily doses and collecting treatment on their scheduled clinic visit(60).

5.3 Multilevel Barriers to ART Adherence

5.3.1 Intrapersonal Level Barriers:

Barriers such as lack of autonomy, medication side effects, pill burden, denial and forgetfulness highlights the significance of personal capacity and understanding in ART adherence. Participants' dependence on others for medication or reminders often resulted in missed doses, especially in the absence of caregivers. For instance, a 19-year-old female highlighted the challenges of living with a caregiver unfamiliar with administering medication. Other studies have shown that dependence on caregivers & healthcare providers can weaken an individual's ability to manage their own treatment(34,64). Several studies indicated that AYA living with HIV rely heavily on others to manage their medication, attend clinic appointments, and monitor their health(11,53). While such support may yield positives, an overreliance may result in diminished autonomy, self-efficacy, and intrinsic motivation, which can ultimately undermine adherence to antiretroviral therapy. Research has indicated that AYA who exhibit greater autonomy in the management of their HIV treatment are more likely to achieve higher rates of adherence (9). Conversely, those who rely heavily on others may experience anxiety and decreased self-esteem, further exacerbating adherence challenges. Therefore, these findings align with existing literature signifies the importance of empowering caregivers to balance supervision and creating an enabling environment for AYA to develop self-efficacy and autonomy.

Medication-related side effects, such as dizziness and nausea, also emerged as deterrents to ART adherence. Previous studies have noted that addressing these side effects through patient education and supportive care is critical for promoting adherence(10,30). Participants' reflections on transitioning to single-pill age-appropriate regimens further highlight the importance of minimizing treatment complexity to enhance adherence among AYA aligned with other studies' findings(60,65). Notably, participants in this study reported ways to mitigate the unpleasant taste of certain medications, these findings reflect on the resilience demonstrated by AYA when they have an insight on the importance of taking ART, indicating a good practice to sustain in the healthcare system to promote optimal adherence experience.

The research findings were consistent with other studies which showed that lack of knowledge about HIV, its transmission, and treatment can lead to misconceptions, stigma, and

subsequently to poor adherence(53,64,66). This suggests the huge role health department and healthcare workers need to play in formulating strategies and policies that would bridge the knowledge deficit gap among adolescents and young adults, as suggested by another South Africa study which found association between HIV knowledge and ART adherence among AYA(67).

This study has noted that denial and anger were common emotional responses experienced by participants diagnosed with HIV, which resulted to impede ART adherence. The findings were in line with an existing literature, that revealed the importance of vigorous counselling sessions before ART initiation especially to AYA as most of them are still in transitional phase, still uncertain and ignorant to some important aspects of their lives(68). Similarly, such emotional responses were experienced in urban context by AYA on ART resulting to suboptimal adherence(67). The most obvious finding to emerge from the analysis was forgetfulness as the results of competing activities, complex regimens or multiple daily doses(18,63). This has highlighted the relevance of directly observed treatment which may be offered by their close relatives and the need to utilise community-based healthcare workers to improve ART adherence.

5.3.2 Interpersonal Level Barriers:

Social stigma and nondisclosure of HIV status to family or partners and AYA, themselves were significant barriers to ART adherence. Fear of judgment often led participants to hide their status, resulting in poor ART adherence. For example, a male participant avoided disclosure due to his partner's negative perceptions about HIV. This finding corroborates research showing that stigma after disclosing HIV diagnosis remains a pervasive barrier to adherence, especially in rural areas with limited HIV awareness campaigns(59,60,63,69), but for the current study, while there may be reported stigma after disclosure, evidence suggested that disclosing ART status to partner/ family members and AYA themselves improves ART adherence within the rurality context.

A study carried in Rwanda, maintained that isolation, fearing that AYA may develop anger towards themselves were main source of non-disclosure(70), and other studies has critiqued the act of non-disclosure as the influencer of poor adherence(59,65). A northern Ethiopia study by Erage (65), noted that when AYA are informed, they comprehend the reasons for needing ART and adhere properly to ART(71). Though Mburu's study contradicted Ethiopians' study findings by noting that disclosing HIV status can lead to negative consequences in terms of how others view one's status, potentially resulting to issues related to poor ART adherence (62). This finding highlights the importance of noting different environmental context when

addressing issue of ART adherence among AYA, for this study suggest that in rural areas disclosure of HIV would likely promotes ART adherence.

The study found that food insecurity and inconsistent mealtimes were significantly barriers to adherence which led to unintentional interruption to ART. These results were coherent with the existing literature, highlighting the critical need to address food insecurity and its effect on ART adherence among adolescents(34,60). These findings signal the importance of actively co-involving close and extended relative in the ART journey to avoid treatment interruption and non-adherence among AYA coexisting with HIV infection, further revealed the importance of integrating all services such as nutritional assessment, and departments such as social development in the management of ART among adolescents and young adults in rural South Africa.

5.3.3 Community-Level Barriers:

Stigma and discrimination within communities were identified as major barriers, discouraging participants from seeking care or attending clinics. Participants reported fears of being judged by others, which often led to missed appointments and interruptions in ART adherence, these similar experiences were noted on the qualitative study conducted in other countries as well including Tanzania(63). Such findings highlight the continued need for public health interventions that address community stigma and foster a supportive environment for individuals living with HIV especially in rural areas where there are limited resources to provide structured and continuous demand creation on HIV/Aids programmes.

5.3.4 Structural Level Barriers:

Long clinic waiting times, hostile clinical environments, and conflicts between school commitments and healthcare appointments emerged as structural barriers to adherence. Several studies have consistently demonstrated that extended waiting periods result in frustration, discontent, and reduced motivation to go to clinic appointments, which ultimately undermines ART adherence(29,72,73) The current study findings are aligned with the earlier work of scholars, that reported negative effects of extended waiting periods on ART compliance, which may cause reduced attendance at clinic visits and missed chances for ART refills, lab tests, and adherence counselling(29,40,74–76)

These findings suggest that greater efforts should be channelled in ensuring that health facilities comply with policies and standard operating procedure detailing strategies intended to reduce long waiting times in the public sector.

Another participant revealed that hostile clinical environment led to decreased motivation to ART adherence and disengagement in care, this finding highlighted the importance of positive interactions between AYA and healthcare providers, upholding good ethical conducts and professionalism to promote optimal adherence to treatment(29,77).

A significant number of participants were still attending school and the data showed that they had challenges in balancing their school schedule and attending their clinic visits often led to them skipping clinic appointments and getting their ART late. These findings were aligned with previous studies, which found that competing activities such as clinic and school schedule were hindrance to adolescents' optimal adherence to ART(60,70,71). All these findings are consistent with prior studies indicating that healthcare system inefficiencies disproportionately affect adolescents and young adults in rural settings, especially in the realisation and implementation of adolescents and youth friendly services to all public health institutions.

5.3.5 Other related ART adherence barriers

One unanticipated result found was the element of negligence associated with adolescents' stage, for instance, one young adult revealed that he lied at the clinic for the whole year that he was taking ART correctly, so to identified himself as normal adolescent or young adult, regardless of counselling provided on the importance of ART. These findings are consistent with that of MacDonell(64) who noted that adolescents and young adults are naturally more focused on peer relationships, identity formation, and independence, which can lead to decreased motivation to adhere to treatment. An Ugandan study defined adolescence as a critical developmental stage characterized by momentous emotional, physical and social evolution(31), that involves the cognitive and emotional changes including impulsivity, risk-taking, and emotional dysregulation, which can impair decision-making and level of adherence(9,11,34). Therefore, these transformations can produce distinctive encounters for adolescents coexisting with HIV, making it challenging for them to comply to antiretroviral therapy. Therefore, the present study raises possibilities that transition process from adolescence stage to adulthood may lead to disruptions in ART care, leading to decreased adherence and disengagement in treatment care. And further highlights the importance of developing strategies that seek to address and support adolescents and young adults during transition phase.

5.4 Multilevel Facilitators to ART Adherence

5.4.1 Intrapersonal Level Facilitators:

Acceptance of HIV status, fear of illness, and a sense of self-efficacy were pivotal in promoting adherence. Participants who acknowledged the importance of ART for survival were more likely to maintain consistent adherence, even in the face of challenges. This results support the work of other research studies which stated that acceptance of HIV status enhances self-efficacy, enabling AYA to take control of their health and informed decisions about their medication(70), reduce symptoms of anxiety and depression(68) and increases motivation to ART compliance(64). Such findings reinforce the role of psychosocial interventions in strengthening individuals' resolve to adhere to treatment.

The findings were also aligned with studies of Hornschuh(39) and Mutwa (71) which asserted that fear of getting sick were a powerful motivator for adolescents and young adults to adhere to their ART regimens. Another study have shown that AYA who fear the consequences of non-adherence, such as illness or death, are more liable to adhere to their antiretroviral therapy (73). These findings highlight the significance of leveraging this fear through education, awareness, risk perception counselling, goal-setting, and positive reinforcement, healthcare providers and caregivers can empower adolescents to prioritize their health and adhere to their ART regimens.

Furthermore, a study conducted by Mugavero(73) indicated that self-efficacy, defined as an AYA's confidence in their ability to perform a specific behaviour, plays a critical role in facilitating ART adherence among adolescents. This was demonstrated by acknowledgement by participant that though it was not easy he accepted and took ART accordingly. Similar to study findings of Mengesha (70) that indicated element of determination, well-defined as an AYA's firm decision to achieve a specific goal, is another critical factor in facilitating ART adherence among adolescents. This study has high pointed the importance of encouraging AYA to set the recommended adherence goals for their ART management, continuous positive reinforcement to AYA who are complying to ART, provide ART educational support and foster active participation in their HIV care, to facilitate AYA self-efficacy and determination for the betterment of ART adherence.

5.4.2 Interpersonal Level Facilitators:

Support from peers, family, and guardians emerged as critical facilitators. Participants who disclosed their status to trusted individuals or had family members also taking ART described a sense of community and mutual accountability. These findings align with literature highlighting the importance of social support networks in improving ART adherence among

young people, as they feel more connected and motivated(73). Several studies have noted the substantial task demonstrated by family members in promoting and improving adherence to ART, including creating an enabling environment, non-judgemental, encouraging, signifying compassion and understanding for optimal ART adherence among AYA(10–12,60). However, unlike previous studies focused on urban populations, this study found a stronger reliance on close and extended family support in rural areas. The current study findings have demonstrated that utilizing peer or partner support through various strategies, including peer support groups, mentorship initiatives, online support networks, and the involvement of family and partners, healthcare professionals and caregivers can enable adolescents to maintain their ART regimens effectively, thereby attaining improved health outcomes.

The emphasis on family support in rural settings may somehow reflect limited access to peer or community support networks, making familial relationships the primary source of encouragement and accountability. However, this reliance on family may limit autonomy and self-efficacy, as noted by other researchers, potentially affecting long term adherence as AYA transition to independent adulthood. These findings suggest the need for targeted interventions to balance familial support with autonomy building strategies, particularly in rural healthcare programs.

The existing literature also indicated that AYA living with HIV adhered to ART following disclosure due to an insight and understanding they gain post disclosure(69,70). Interestingly what stands out in the current study, was that, simply revealing medical information is not enough to ensure compliance with antiretroviral medication, because some of AYA informed of their HIV diagnosis, demonstrated anger and emotional turmoil since the HIV infection was not acquired through their means but of their parents which directly led to poor antiretroviral therapy adherence. Another complementary finding showed by the current study, was the ability of AYA disclosing their HIV status to friends, sexual partners, and other family members, which positively facilitated their adherence to ART, as their levels of fear and anxiety were reduced, and were able to take their ART freely without any hiding. These results validate the findings of the preceding work exploring relationship between disclosure of HIV diagnosis and ART adherence among AYA(70), where the study showed optimal level of ART adherence among AYA who disclosed their HIV status.

One unanticipated result was that other family members taking ART were the source of motivation to ART compliance among some adolescents and young adults, though this finding may be somehow limited because not all guardians or parents takes medication. The existing literature have not yet explored the phenomenon relating association between other members

taking ART and optimal ART adherence of AYA, it only recognises the importance of family system support, in the context of reminding AYA of daily ART doses. Furthermore, the current study findings were in line with that of Bukenya(27) who demonstrated that having companion or someone to talk to during ART journey has assisted adolescents and young adults to cope better and improve significantly on ART adherence(27). Other studies highlighted the importance of companion and it helps improved mental health, boost self-confidence and self-esteem(70,73), directly increasing motivation to ART adherence as they feel more connected and supported to ART(68).

5.4.3 Community-Level Facilitators:

Community normalization of HIV and shared experiences reduced stigma and encouraged adherence. Participants who perceived HIV as a manageable condition within their community were more motivated to stay committed to treatment. According to Naar-King(64), sharing experiences with others who have similar conditions can reduce feelings of stigma and shame, making it easier for adolescents and young adults to adhere to treatment. Moreover, create a sense of community and belonging, which can motivate adolescents and young adults to adhere to treatment(70), can enhance self-efficacy, enabling adolescents and young adults to feel more confident in their ability to manage their treatment(73), with others can improve mental health outcomes, such as reduced anxiety and depression, which are common barriers to ART adherence(68). These results underscore the need for broader public awareness campaigns to normalize HIV and reduce associated stigma.

5.4.4 Structural Level Facilitators:

Supportive healthcare policies, such as the provision of multi-month ART supplies and fast-lane services for students, significantly reduced logistical barriers to adherence. Additionally, respectful and empathetic interactions with healthcare workers were reported as major enablers of adherence, highlighting the value of youth-friendly healthcare services. The findings were consistent with the study results of Maskew (26) which emphasized the importance of multidisciplinary team collaboration for promoting ART adherence among adolescents. The study of Maskew(26) further elaborated on the benefits of multi-month ART supply, a critical constituent in the process of promoting ART adherence among adolescents. Other studies have supported notion of providing adolescents and young adults with multi-month supplies of ART to improve adherence, reduce frequent clinic visits or medication refills and lastly the risk of treatment interruptions(73).

Recent literature highlights the importance of providing AYA with timely and convenient healthcare services, minimizing disruptions to their academic schedules(26). According to Maskew (26) Fast Lane Service can include expedited clinic appointments, priority laboratory testing, and rapid medication refills.

These results were in line with findings of Yehia (78) that showed that healthcare workers with positive attitudes towards AYA living with HIV can improve adherence and health outcomes. Further reiterated that healthcare workers should receive training on adolescent-friendly care, including communication skills, confidentiality, and cultural sensitivity. The results of this study showed that accurate and age-appropriate information about HIV infection, its treatment, and healthy living is critical for promoting ART adherence among adolescents. Recent literature highlights the importance of providing adolescents with comprehensive information about their treatment, including the benefits and side effects of ART (41). This signifies the importance of healthcare providers to continuously afford clear, simple language and opportunities for adolescents to ask questions and seek clarification. Furthermore, the study results reflected to those of Mbebe et al (79) who also found that available and reliable healthcare services are essential for promoting ART adherence among adolescents and young adults(52,70). Consistent with the literature, this research found that participants who receive consistent, high-quality healthcare services are more likely to adhere to their treatment regimens and healthcare services should be tailored to meet the unique needs of adolescents, including flexible clinic hours, confidential services, and youth-friendly healthcare providers(73). This finding suggests the necessity of an integrated strategy to enhance and bolster ART adherence within the abovementioned demographic.

5.4.5 Theme 5: Other related ART adherence facilitators

The current findings are aligned with prior study findings that highlighted the potential of technology, including manual and digital device reminders, to facilitate ART adherence among AYA(73). A study by MacCarthy(80) demonstrated the importance played by manual reminders, such as paper calendars, pill boxes, and alarms, in the promotion of ART adherence. Another study conducted by MacDonell (64) found that AYA who used paper calendars to track their medication adherence had better adherence rates compared to those who did not use calendars. A systematic review study by MacCarthy (80) further found that mobile phone-based interventions, including reminders and adherence tracking, significantly improved ART adherence. These findings of MacCarthy (80) was coherent with the current study findings which noted the role of digital device reminders, such as mobile phone apps, text messages, and alarms, have also been shown to be effective in encouraging ART adherence. These findings suggest that technological innovations such as Mobile Health

interventions have the potential to significantly improve adherence among AYA in rural South Africa, ultimately contributing to optimal ART adherence and generally better health outcomes.

5.5 Limitation of The Study

The research study design chosen covers only the qualitative aspects of facilitators and barriers to ART adherence, some important statistical data to measure adherence and non-adherence to treatment may be missed, such as accessing viral load and CD4 blood results to interrelate it with the experiences of the participants. Furthermore, the research study could not explore relationship between guardians/ parents and ART adherence, which could have shed light on family structure and its impact on adherence.

5.6 Reflexivity in the research study

My positionality in this study is shaped by my role as an Operational Manager at Othobothini CHC, where I oversee healthcare delivery, including services related to HIV/AIDS care. This insider position affords me access to contextual knowledge, professional networks, and institutional resources, but it also carries the risk of shaping the research through my own assumptions, values, and experiences. I am conscious that my professional identity may influence how I interpret participants' narratives and could unintentionally privilege institutional perspectives over lived realities. Furthermore, the inherent power dynamics between a healthcare provider and adolescent or young adult patients, particularly those living with HIV/AIDS, may affect how openly participants share their experiences.

To address these challenges, I engaged in continuous reflexivity throughout the research process, critically examining how my social location, professional responsibilities, and worldview might influence data collection, analysis, and interpretation. I adopted a participant-centred approach that prioritised the voices and lived experiences of adolescents and young adults, ensuring that their perspectives guided the framing of findings. Strategies to reduce bias included using open-ended questioning, actively bracketing my preconceptions, and maintaining transparency about my role and its potential impact on the study. By acknowledging these influences and deliberately working to mitigate them, I aimed to produce a study that is methodologically rigorous, ethically grounded, and authentically reflective of the complexities of ART adherence in rural South Africa.

5.7 Implications and Recommendations for Policy and Practice

The study's findings emphasize the need for a multifaceted approach to improving ART adherence among AYA in rural areas, the recommendations are categorised as per responsibility levels. Interventions should include:

1. Healthcare facility and district level:

- **Education and Empowerment:** Providing comprehensive HIV education to improve knowledge and self-efficacy. Demand creation on HIV information using media platforms; online/ social/ forums/ televisions where adolescents and young adults connect nor spent most of their valuable time, can be used as the tool to educate about HIV infection and antiretroviral therapy, would significantly reduce stigma and discrimination relating to the phenomenon in question.
- **Social Support Networks:** Strengthening family and peer support systems to enhance adherence. Provision of continuous mentorship programmes, peer support group, departmental online forums, school-based support, community-based organisation collaboration and healthcare provider support can play crucial role in mitigating barriers to ART adherence among adolescents and young adults within the rurality context.
- **Community Engagement:** Reducing stigma through targeted awareness campaigns. The department of health should enforce partnerships and collaboration with non-governmental organisation, civil society organisation, community engagement events, activist group against HIV/Aids and local media platforms to conduct on continuous basis vigorous campaigns or awarenesses on HIV/Aids programme and adherence, importance of disclosure and family support as the source of promoting ART adherence among adolescents and young adults in the rural areas.
- **Healthcare providers dealing with adolescents and young adults on ART** play a crucial role in promoting adherence to ART by fostering strategies such as enhance adherence counselling.
- All healthcare providers to facilitate and coordinate multisectoral and multidisciplinary team interventions, that are required to tackle ART adherence gaps to boost ART adherence and enhance current adherence counselling approaches.

2. District/ Provincial/ National Department of Health.:

- **Healthcare System Reforms:** Expanding patient-centred policies, such as multi-month ART supplies and youth-friendly services. The healthcare system to strengthens adolescents and youth friendly services (AYFS) rendered at primary healthcare level,

be aligned with AYA needs in relation to schedules for clinic visits and monitoring investigations.

- The employee performance management and development system's work plan should include adolescents and youth friendly services to monitor implementation and impact of the programme and bring about accountability and co-ownership of the programme.
- Enforce flexibility of working hours and formalisation of weekends to cater for school going AYA.
- Foster and monitor establishment of AYA support adherence group at the primary healthcare facilities, that would closely facilitate and monitor antiretroviral therapy adherence.
- The department of health to foster effective collaboration with other department such social development, develop a policy and standard operating procedure detailing steps on how to deal with adolescents and young adults with difficult social background in the context of HIV/Aids programme to ensure availability of food parcels and facilitate ART adherence among these groups.
- The department of health policy makers to review integrated school health policy to accommodates adolescents and young adults living with HIV on ART to facilitate compliance to ART. The policy healthcare service packages are addressing screening and prevention part of health conundrum, which excludes nor overlooks adolescents and young adults already diagnosed with HIV infection and on ART.
- The department of health policy maker to consider incorporating technology innovations in the ART conundrum to assist improve adherence among AYA. Interventions such as mobile health, electronic medication adherence system, telemedicine etc can play a significant role in promotion of ART adherence.

5.8 Conclusion

This study contributes to the understanding of ART adherence among AYA in rural contexts by identifying complex and multifaceted barriers and facilitators within the socio-ecological framework. Through the eyes of Bronfenbrenner's conceptual framework, broader insight on major barriers to ART adherence were demonstrated, the intricate interplay of intrapersonal and environment in influencing adherence was explored, highlighting medication related side effects, stigma and discrimination as the significant barriers to adherence. Furthermore, the relationship between interpersonal level factors and an adolescent, proved to be a crucial tool in the facilitation of ART adherence among AYA. The interacting revealed that family support was the most effective source of motivator that promoted optimal adherence among adolescents and young adults taking ART in rural areas, this highlights the need to include familial relationship in the strategies employed to facilitate adherence to ART. And lastly, there was no influence of cultural beliefs reported that were associated with ART adherence among adolescents and young adults.

Addressing these factors through targeted interventions can significantly improve adherence rates and health outcomes in this vulnerable population. Healthcare system implications to adapt patient centred approaches in the delivery of quality AYA service. Future research should explore the long-term effectiveness of these interventions and their adaptability across diverse rural settings. Furthermore, add elements of quantitative study to collaborate lived experiences to variables that determines optimal adherence to antiretroviral therapy such as the suppressed viral load and CD4 count in AYA living HIV infection.

5.9 Disclosure:

There are no conflicts of interest in this research study, as they were no external stakeholders responsible for funding the research project or with ulterior motives.

REFERENCES

1. Plazy M, Diallo A, Hlabisa T, Okesola N, Iwuji C, Herbst K, et al. Implementation and effectiveness of a linkage to HIV care intervention in rural South Africa (ANRS 12249 TasP trial). *PLoS One*. 2023;18(1 January):1–17.
2. Kwazulu Natal Department of Health. Umkhanyakude district health plan 2018/19 - 2020/21. 2018;21:1–87.
3. Local Municipality | Statistics South Africa [Internet]. [cited 2022 Jul 8]. Available from: https://www.statssa.gov.za/?page_id=993&id=jozini-municipality
4. Joint United Nations Programme on HIV/AIDS (UNAIDS). Global HIV & AIDS statistics — Fact sheet [Internet]. UNAIDS. 2021 [cited 2023 Apr 27]. p. 2020–2. Available from: <https://www.unaids.org/en/resources/fact-sheet>
5. World Health Organization. HIV Drug Resistance Report 2021. Technical report. 2021. [Internet]. World Health Organization. 2021. 125 p. Available from: <https://www.who.int/publications/i/item/9789240038608>
6. Joint United Nations Programme on HIV/AIDS (UNAIDS). UNAIDS DATA 2022. In: UNAIDS [Internet]. Geneva; 2022. p. 1–446. Available from: https://www.unaids.org/en/resources/documents/2023/2022_unaids_data
7. Villiera JB, Katsabola H, Bvumbwe M, Mhango J, Khosa J, Silverstein A, et al. Factors associated with antiretroviral therapy adherence among adolescents living with HIV in the era of isoniazid preventive therapy as part of HIV care. *PLOS Glob Public Heal*. 2022;2(6):1–12.
8. World Health Organization (WHO). HIV and AIDS Key Facts. World Heal Organ [Internet]. 2021 Apr 19 [cited 2023 Apr 29];(july):1–7. Available from: <https://www.who.int/news-room/fact-sheets/detail/hiv-aids>
9. Kim SH, Gerver SM, Fidler S, Ward H. Adherence to antiretroviral therapy in adolescents living with HIV: Systematic review and meta-analysis. *Aids*. 2014;28(13):1945–56.
10. Ammon N, Mason S, Corkery JM. Factors impacting antiretroviral therapy adherence among human immunodeficiency virus–positive adolescents in Sub-Saharan Africa: a systematic review. *Public Health*. 2018;157(0):20–31.
11. Hlophe LD, Tamuzi JL, Shumba CS, Nyasulu PS. Barriers and facilitators to anti-retroviral therapy adherence among adolescents aged 10 to 19 years living with HIV

- in sub-Saharan Africa: A mixed-methods systematic review and meta-analysis. Vol. 18, PLoS ONE. 2023. 1–40 p.
12. Maskew M, Fox MP, Evans D, Govindasamy D, Jamieson L, Malet G, et al. Insights into Adherence among a Cohort of Adolescents Aged 12-20 Years in South Africa: Reported Barriers to Antiretroviral Treatment. *AIDS Res Treat*. 2016;2016.
 13. National Department of Health. The South African National Welcome Back Campaign Strategy. NDoH. 2021.
 14. Zuma K, Simbayi L, Zungu N, Moyo S, Marinda E, Jooste S, et al. The HIV Epidemic in South Africa: Key Findings from 2017 National Population-Based Survey. *Int J Environ Res Public Health*. 2022;19(13).
 15. United Nations Programme on HIV/aids. UNAIDS. UNAIDS 2021 Conference: UNAIDS Data 2021. 2021.
 16. National Department of Health. 2023 ART Clinical Guidelines for the Management of HIV in Adults, Pregnancy and Breastfeeding, Adolescents, Children, Infants and Neonates. 2023;3(June):1–46.
 17. South African National Department of Health. Guideline for Vertical Transmission Prevention of Communicable Infections. 2023;1(August):1–62.
 18. Adeniyi OV, Ajayi AI, Ter Goon D, Owolabi EO, Eboh A, Lambert J. Factors affecting adherence to antiretroviral therapy among pregnant women in the Eastern Cape, South Africa. *BMC Infect Dis*. 2018;18(1):1–11.
 19. KwaZulu-Natal Department of Health, Health Facilities. [Internet]. [cited 2023 Mar 5]. Available from: <http://www.kznhealth.gov.za/health.asp>
 20. Belus JM, Msimango LI, van Heerden A, Magidson JF, Bradley VD, Mdakane Y, et al. Barriers, Facilitators, and Strategies to Improve Participation of a Couple-Based Intervention to Address Women's Antiretroviral Therapy Adherence in KwaZulu-Natal, South Africa. *Int J Behav Med*. 2023;(0123456789).
 21. Napier D, Depledge M, Knipper M, Lovell R, Ponarin E, Sanabria E, et al. Cultural Contexts of Health and Well-being, Culture Matters: Using a Cultural Contexts of Health Approach to Enhance Policy-Making. *WHO Policy Br* [Internet]. 2017 [cited 2022 Jul 7];(1):54. Available from: http://www.euro.who.int/__data/assets/pdf_file/0009/334269/14780_World-Health-Organisation_Context-of-Health_TEXT-AW-WEB.pdf?ua=1

22. Jozini Local Municipality. Jozini Local Municipality (KZ272) Integrated Development Plan (IDP) 2019/20 Review, ANNEXURE D: ADOPTED LED STRATEGY [Internet]. 2019 [cited 2022 Jul 5]. Available from: www.jozini.gov.za
23. UMkhanyakude District Municipality. Integrated Development Plan Review 4th Generation 2021/2022 [Internet]. Mkhuze; 2022. Available from: <https://www.ukdm.gov.za/>
24. Vandormael A, Cuadros D, Kim HY, Bärnighausen T, Tanser F. The state of the HIV epidemic in rural KwaZulu-Natal, South Africa: A novel application of disease metrics to assess trajectories and highlight areas for intervention. *Int J Epidemiol*. 2021;49(2):666–75.
25. Knight L, Schatz E. Social Support for Improved ART Adherence and Retention in Care among Older People Living with HIV in Urban South Africa: A Complex Balance between Disclosure and Stigma. *Int J Environ Res Public Health*. 2022;19(18).
26. Maskew M, Technau K, Davies MA, Vreeman R, Fox MP. Adolescent retention in HIV care within differentiated service-delivery models in sub-Saharan Africa. *Lancet HIV*. 2022;9(10):e726–34.
27. Bukenya D, Mayanja BN, Nakamanya S, Muhumuza R, Seeley J. What causes non-adherence among some individuals on long term antiretroviral therapy? Experiences of individuals with poor viral suppression in Uganda. *AIDS Res Ther*. 2019;16(1):1–9.
28. Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, et al. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS Soc*. 2013;16(3 Suppl 2).
29. Hennessey CM, Boule A, Stinson K, Smith M. Lost to found: The silent transfer of antiretroviral therapy patients in South Africa. *Top Antivir Med*. 2016;24(E-1):441.
30. Croome N, Ahluwalia M, Hughes LD, Abas M. Patient-reported barriers and facilitators to antiretroviral adherence in sub-Saharan Africa. *Aids*. 2017;31(7):995–1007.
31. Natukunda J, Kirabira P, Ong KIC, Shibanuma A, Jimba M. Virologic failure in HIV-positive adolescents with perfect adherence in Uganda: A cross-sectional study 11 Medical and Health Sciences 1117 Public Health and Health Services. *Trop Med Health*. 2019;47(1):1–10.
32. Bronfenbrenner U. The ecology of human development: Experiments by nature and

- design. Harvard University Press; 1979.
33. Shapiro J, Perez M, Warden M. The importance of family functioning to caregiver adaptation in mothers of child cancer patients: testing a social ecological model. *J Pediatr Oncol Nurs*. 1998;15(1):47–54.
 34. Coetzee B, Kagee A, Bland R. Barriers and facilitators to paediatric adherence to antiretroviral therapy in rural south africa: A multi-stakeholder perspective. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV*. 2015;27(3):315–21.
 35. Glanz K, Barbara K, Rimer K, Viswanath K. *Health Behaviour and Health Education: Theory, Research and Practice*. 4th Editio. Sallis J, Owen N, Fisher E, editors. San Francisco: Jossey-Bass; 2008. 504–591 p.
 36. Kurl Lewin. *A dynamic theory of personality*. New York: McGraw-Hill Book Company. Development, Factor Analysis & Validation; 1935. 1–349 p.
 37. World Health Organization. Ottawa Charter for Health Promotion [Internet]. [cited 2023 Mar 7]. Available from: <https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference>
 38. Mcleroy KR, Bibeau D, Steckler A, Glanz K. An Ecological Perspective on Health Promotion Programs. *Heal Educ Behav*. 1988;15(4):351–77.
 39. Hornschuh S, Dietrich JJ, Tshabalala C, Laher F. Antiretroviral treatment adherence: Knowledge and experiences among adolescents and young adults in Soweto, South Africa. *AIDS Res Treat*. 2017;2017.
 40. Eyassu MA, Mothiba TM, Mbambo-Kekana NP. Adherence to antiretroviral therapy among HIV and AIDS patients at the Kwa-Thema clinic in Gauteng Province, South Africa. *African J Prim Heal Care Fam Med*. 2016;8(2):1–7.
 41. Amuche NJ, Emmanuel EI, Innocent NE. HIV/AIDS in sub-Saharan Africa: Current status, challenges and prospects. *Asian Pacific J Trop Dis*. 2017;7(4):239–56.
 42. Bongfen MC, Torpey K, Ganle J, Ankomah A. Level of adherence and associated factors among HIV-positive adolescents on antiretroviral therapy in Cameroon. *African J AIDS Res*. 2020;19(4):269–75.
 43. Berk L. *Child Development*. 5th Editio. Boston: Allyn and Bacon; 2000. 1–804 p.
 44. Creswell WJ, Creswell JD. *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* [Internet]. Vol. 53, *Journal of Chemical Information and Modeling*. 2018. 1–388 p. Available from: file:///C:/Users/Harrison/Downloads/John W.

Creswell & J. David Creswell - Research Design_ Qualitative, Quantitative, and Mixed Methods Approaches

(2018).pdf%0Afile:///C:/Users/Harrison/AppData/Local/Mendeley Ltd./Mendeley Desktop/Downloaded/Creswell, Cr

45. Hennink M, Hutter I, Bailey A. The nature of qualitative research: In *Qualitative Research Methods*. Los Angeles: Sage Publications; 2011. 8–28 p.
46. Statistics South Africa (Stats SA). Mid-Year population estimates 2021. Stat Release. 2021;P0302(July):35.
47. Creswell JW, Creswell DJ. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Fifth Edit. London: SAGE Publications; 2018. 1–388 p.
48. Carter N, Bryant-Lukosius D, Dicenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. *Oncol Nurs Forum*. 2014;41(5):545–7.
49. Majid U. Research Fundamentals: Study Design, Population, and Sample Size. *Undergrad Res Nat Clin Sci Technol J*. 2018;2(1):1–7.
50. Onwuegbuzie AJ, Leech NL. Sampling Designs in Qualitative Research: Making the Sampling Process More Public. *Qual Rep*. 2007;12(2):19–20.
51. Akinyode BF, Khan TH. Step by step approach for qualitative data analysis. *Int J Built Environ Sustain*. 2018;5(3):163–74.
52. Loveday M, Goga A, Dhali A, Labuschaigne M, Roussouw T, Burgess T, et al. Ethically acceptable consent approaches to adolescent research in South Africa. *South Afr J HIV Med*. 2022;23(1):1–7.
53. Chem ED, Ferry A, Seeley J, Weiss HA, Simms V. Health-related needs reported by adolescents living with HIV and receiving antiretroviral therapy in sub-Saharan Africa: a systematic literature review. *J Int AIDS Soc*. 2022;25(8).
54. Cornell M, Schomaker M, Garone DB, Giddy J, Hoffmann CJ, Lessells R, et al. Gender Differences in Survival among Adult Patients Starting Antiretroviral Therapy in South Africa: A Multicentre Cohort Study. *PLoS Med*. 2012;9(9):1–12.
55. Carballo E, Cadarso-Suarez C, Carrera I, Fraga J, de la Fuente J, Ocampo A, et al. Assessing relationships between health-related quality of life and adherence to antiretroviral therapy. *Qual Life Res Kluwer Acad Publ*. 2004;13:587–99.
56. Kioko MT, Pertet AM. Factors contributing to antiretroviral drug adherence among adults living with HIV or AIDS in a Kenyan rural community. *African J Prim Heal Care*

Fam Med. 2017;9(1):1–7.

57. Statistics South Africa (Stats SA). Quarterly Labour Force Survey (QLFS) Q1:2024 Statistician-General, Risenga Maluleke. Stats SA [Internet]. 2024;(1):1–27. Available from: <https://www.statssa.gov.za>
58. Thurlow J, Gow J, George G. HIV/AIDS, growth and poverty in KwaZulu-Natal and South Africa: An integrated survey, demographic and economy-wide analysis. *J Int AIDS Soc.* 2009;12(1):1–13.
59. Ankrah DNA, Koster ES, Mantel-Teeuwisse AK, Arhinful DK, Agyepong IA, Lartey M. Facilitators and barriers to antiretroviral therapy adherence among adolescents in Ghana. *Patient Prefer Adherence.* 2016;10:329–37.
60. Nabukeera-Barungi N, Elyanu P, Asire B, Katureebe C, Lukabwe I, Namusoke E, et al. Adherence to antiretroviral therapy and retention in care for adolescents living with HIV from 10 districts in Uganda. *BMC Infect Dis.* 2015;15(1):1–10.
61. Bermudez LG, Jennings L, Ssewamala FM, Nabunya P, Mellins C, McKay M. Equity in adherence to antiretroviral therapy among economically vulnerable adolescents living with HIV in Uganda. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV.* 2016;28:83–91.
62. Mburu G, Hodgson I, Kalibala S, Haamujompa C, Cataldo F, Lowenthal ED, et al. Adolescent HIV disclosure in Zambia: Barriers, facilitators and outcomes. *J Int AIDS Soc.* 2014;17:1–9.
63. Nyogea D, Mtenga S, Henning L, Franzeck FC, Glass TR, Letang E, et al. Determinants of antiretroviral adherence among HIV positive children and teenagers in rural Tanzania: A mixed methods study. *BMC Infect Dis.* 2015;15(1):1–13.
64. MacDonell K, Naar-King S, Huszti H, Belzer M. Barriers to medication adherence in behaviorally and perinatally infected youth living with HIV. *AIDS Behav.* 2013;17(Jan):86–93.
65. Arage G, Tessema GA, Kassa H. Adherence to antiretroviral therapy and its associated factors among children at South Wollo Zone Hospitals, Northeast Ethiopia: A cross-sectional study. *BMC Public Health.* 2014;14(1).
66. Muessig K, Manali N, Jose B, Sheana B, Highlo-Weidman L. A systematic review of recent smartphone, Internet and Web 2.0 interventions to address the HIV continuum of care. *Curr HIV/AIDS Rep.* 2015;12(Mar):173–90.

67. Peltzer K. Health-Related Quality of Life and Antiretroviral Therapy in Kwazulu-Natal, South Africa. *Sci J*. 2012;40(2):267–82.
68. Beyeza-Kashesya J, Wanyenze RK, Goggin K, Finocchiaro-Kessler S, Woldetsadik MA, Mindry D, et al. Stigma gets in my way: Factors affecting client-provider communication regarding childbearing among people living with HIV in Uganda. *PLoS One*. 2018;13(2):1–14.
69. Madiba S, Mokgatle M. Perceptions and Experiences about Self-Disclosure of HIV Status among Adolescents with Perinatal Acquired HIV in Poor-Resourced Communities in South Africa. *AIDS Res Treat*. 2016;2016.
70. Mengesha MM, Teshome A, Ajema D, Tura AK, Hallström IK, Jerene D. The association between HIV diagnosis disclosure and adherence to anti-retroviral therapy among adolescents living with HIV in Sub-Saharan Africa: A systematic review and meta-analysis. *PLoS One*. 2023;18(5 MAY):1–20.
71. Mutwa PR, Van Nuil JI, Asiimwe-Kateera B, Kestelyn E, Vyankandondera J, Pool R, et al. Living Situation Affects Adherence to Combination Antiretroviral Therapy in HIV-Infected Adolescents in Rwanda: A Qualitative Study. *PLoS One*. 2013;8(4).
72. Gijo E V., Antony J. Reducing patient waiting time in outpatient department using lean six sigma methodology. *Qual Reliab Eng Int*. 2014;30(8):1481–91.
73. Mugavero M, Westfall A, Cole S, Geng E, Crane H, Kitahata M, et al. Beyond core indicators of retention in HIV care; missed clinic visits are independently associated with all cause mortality. *Clin Infect Dis*. 2014;59(10):1471–9.
74. Mesic A, Halim N, MacLeod W, Hacker C, Mwansa M, Biemba G. Facilitators and barriers to adherence to antiretroviral therapy and retention in care among adolescents living with HIV/AIDs in Zambia: a mixed methods study. *AIDS Behav*. 2019;23(Sep):2618–28.
75. McIntyre D, Chow CK. Waiting Time as an Indicator for Health Services Under Strain: A Narrative Review. *Inq (United States)*. 2020;57.
76. Daniels J, Zweigenthal V, Reagon G. Assessing the impact of a waiting time survey on reducing waiting times in urban primary care clinics in Cape Town, South Africa. *J Public Health Africa*. 2017;8(1):98–101.
77. Umberson D, Karas Montez J. Social Relationships and Health: A Flashpoint for Health Policy. *J Health Soc Behav*. 2010;51(1):S54–66.

78. Yehia BR, Stewart L, Momplaisir F, Mody A, Holtzman CW, Jacobs LM, et al. Barriers and facilitators to patient retention in HIV care. *BMC Infect Dis.* 2015;15(1):1–10.
79. Mbebe S, Rabie S, Coetzee BJ. Factors influencing the transition from paediatric to adult HIV care in the Western Cape, South Africa; perspectives of healthcare providers. *African J AIDS Res.* 2023;22(3):175–84.
80. MacCarthy S, Mendoza-Graf A, Saya U, Samba C, Birungi J, Okoboi S, et al. Lessons learned from a mobile technology-based intervention informed by behavioral economics to improve ART adherence among youth in Uganda. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV.* 2020;32(5):616–22.

APPENDICES

Appendix A₁: Plagiarism Declaration Report.

Appendix A₂: Turnitin Research Report Signed by Supervisor.

Appendix A₃: HREC (Medical) Clearance Certificate No. M231014

Appendix B: National & Provincial Health Research Committee Approval.

Appendix B₁: uMkhanyakude Health Research Committee Approval.

Appendix B₂: Othobothini Community Healthcare Centre CEO Approval.

Appendix C: Interview Guide (English)

Appendix D: Uhlelo lwemibuzo (isiZulu)

Appendix E: Demographic Questionnaire.

Appendix F: Participants Information Sheet for young adults aged 18-24 years.

Appendix G: Participants Information Sheet for Parent/Guardian of a Minor* aged 16-17 years.

Appendix H: Participants Information Sheet for Minor* aged 16-17 years.

Appendix I: Consent for participation for young adults aged 18-24 years.

Appendix J: Consent Participation for Parent/Guardian of a Minor* aged 16-17 years.

Appendix K: Participant Assent for Minors aged 16 – 17 years

Appendix L: Consent for Audio Recording of Study Participation for young adults aged 18-24 years.

Appendix M: Consent Form for Audio Recording for Parent/Guardian of a Minor* aged 16-17 years.

Appendix N: Consent Form for Audio Recording for Minors* aged 16-17 years.

Appendix A1: Plagiarism Declaration Report.



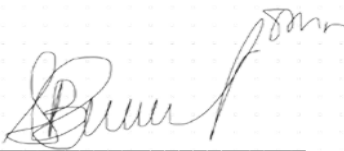
PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Sithole Samkelo Bhekinkosi (Student number: 2506256) am a student registered for the degree of Master of Public Health in the academic year 2025.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: 

Date: 17 March 2025

Appendix A2: Turnitin Research Report Signed by Supervisor.

RESEARCH_REPORT Turnitin 2025-1.docx

ORIGINALITY REPORT

7 %	5 %	5 %	2 %
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Submitted to University of Witwatersrand Student Paper	1 %
2	wiredspace.wits.ac.za Internet Source	<1 %

Exclude quotes	On	Exclude matches	< 8 words
Exclude bibliography	On		

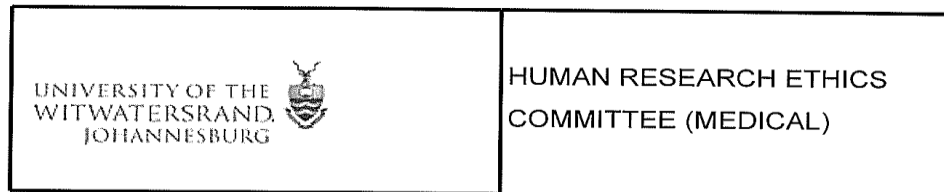
Student Signature: _____



Supervisor Signature: _____



**Appendix A3: Human Research Ethics Committee (Medical) Clearance
Certificate No. M231014.**



Office of the Deputy Vice-Chancellor (Research and Innovation)

TO: Mr SB Sithole
School of Public Health
Medical School
University

E-mail: samkelo.unizulu@gmail.com

CC: Supervisor: Ms P Sodo
Pumla.Sodo@wits.ac.za
and <HREC-Medical Research Office@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 19 March 2024

REF: R14/49

PROTOCOL NO: **M231014** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *Facilitators and barriers to antiretroviral therapy adherence amongst adolescents and young adults in rural South Africa*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

A handwritten signature in black ink, appearing to be 'Iain Burns', is written over a faint, stylized 'B' watermark.

MSWorks2000/Iain0007/Clearscan.wps



R49 Mr SB Sithole

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M231014**

NAME: Mr SB Sithole **DEGREE:** MPH
(Principal and Co-Investigators)

DEPARTMENT: School of Public Health
Medical School
University

PROJECT TITLE: *Facilitators and barriers to antiretroviral therapy adherence amongst adolescents and young adults in rural South Africa*

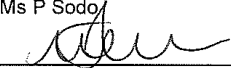
DATE CONSIDERED: 27 October 2023

DECISION: Approved unconditionally

CONDITIONS:

NOTE: If contact information regarding student study participants is required, please contact the Registrar's office <Nicoleen.Potgieter@wits.ac.za>

SUPERVISOR: Ms P Sodo

APPROVED BY: 
Ms M van Niekerk, Co-Chairperson, HREC (Medical)

DATE OF APPROVAL: 19 March 2024 **EXPIRY DATE:** 18 March 2029

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report** in the format available at <https://wits.ac.za/research/researcher-support/research-ethics/ethics-committees/>. This report is due annually, for the duration of the Clearance Certificate, beginning on the first anniversary of Date of Approval above. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

Date

Appendix B: National & Provincial Health Research Committee Approval.



KWAZULU-NATAL PROVINCE

HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: hrkm@kznhealth.gov.za

Health Research & Knowledge
Management

NHRD Ref: KZ_202307_021

Dear Mr S B Sithole
(Wits)

Approval of research

1. The research proposal titled 'Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

The proposal is hereby **approved** for research to be undertaken at Gwaliweni, Jozini, Makhathini, Nondabuya & Ophondweni Clinics.

2. You are requested to take note of the following:

- a. **Kindly liaise with the facility manager BEFORE your research begins.**

This is to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.

- b. All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.
- c. Please ensure that you provide your letter of ethics re-certification to this unit when the current approval expires.
- d. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za
- e. Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.

For any additional information please contact Dr. G Shezi on 033-395 3189.

Yours Sincerely

Dr E Lutge

Chairperson, Provincial Health Research Committee

Date: 07/07/2023

GROWING KWAZULU-NATAL TOGETHER

Appendix B₁: uMkhanyakude Health Research Committee Approval.



KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE: DHS

Postal Address PB X 026, Jozini 3969
Physical Address: 304 Ntsinde Road, Jozini
Tel: 035 572 1390 Fax: 035 5721245
www.kznhealth.gov.za

Umkhanyakude Health District Office

Email address: Bheki.Fakude@kznhealth.gov.za

Enquiries: Mr BP Fakude
Telephone: 035-572 1390 Ext 111

31 October 2023

Dear Mr SB Sithole

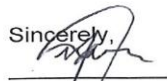
I have pleasure in informing you that permission has been granted to you by the Umkhanyakude Health District Research Committee to conduct research in this district, entitled:

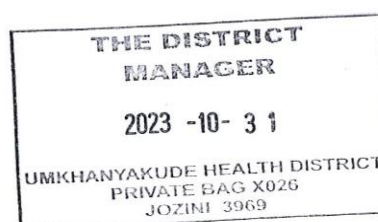
'Facilitators and barriers to Anti-retroviral Therapy adherence among adolescents and young adults in rural South Africa'

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received approval of your study from the Provincial Health Research and Ethics Committee (PHREC) in the KZN Department of Health.
3. Application to PHREC is done online via the National Health Research Database (NHRD): <http://nhrd.hst.org.za>
4. Please ensure this office is informed before you commence your research.
5. The District Office will not provide any resources for this research.
6. Please provide feedback on the progress of your research to the District Research Committee every six months.
7. Please provide the District Office with a copy of your final write-up or publication.

Sincerely,


Mr BP Fakude
Acting District Director
Umkhanyakude Health District Office



GROWING KWAZULU-NATAL TOGETHER

Appendix B2: Othobothini Community Healthcare Centre CEO Approval.



KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE: OTHOBOTHINI COMMUNITY HEALTH CENTRE

Postal Address : Private Bag X12, Jozini, 3969

ADMINISTRATION

Physical Address : D850 Road, Msiyane Reserve next to Msiyane High School

Tel: 035 572 9002 Email: othobothini@kznhealth.gov.za
www.kznhealth.gov.za

Enquires: Mrs. DS Mkhwanazi
Ext #1004

Dear Mr SB Sithole

I have the pleasure to inform you that permission to conduct research study at five provincial clinics namely Jozini, Makhathini, Nondabuya, Ophondweni and Gwaliweni under Othobothini Community Healthcare Centre (CHC) has been granted. This was after consideration made by University of Witwatersrand, Human Research Ethics Committee - Medical's provisional approval of the study and uMkhanyakude District Research Committee's permission or approval to conduct the study in our health district.

Research study titled as "Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa".

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols, and guidelines of the Department of Health with regards to this research.
2. This research will only commence once CHC Facility has received approval of your study from the Provincial Health Research and Ethics Committee (PHREC) in the KZN Department of Health
3. Application to PHREC is done online via the National Health Research Database (NHRD): <https://nhrd.health.gov.za/>
4. Please ensure that the CHC Facility is informed before you commence your research study.
5. The CHC Facility will not provide any resources towards your research study.
6. Please provide feedback on the progress of your research study to District research Committee every six months.
7. Please provide the CHC Facility and District Office with a copy of your final written report or publication.

Yours Sincerely

Mrs. DS Mkhwanazi
Chief Executive Officer
Othobothini CHC

01/12/2023
Date

OTHOBOTHINI COMMUNITY HEALTH CENTRE
CHIEF EXECUTIVE OFFICE
01 DEC 2023
PRIVATE BAG X 12 JOZINI, 3969
PROVINCE OF KWAZULU NATAL
DEPARTMENT OF HEALTH

GROWING KWAZULU-NATAL TOGETHER

Appendix C: Interview Guide (English)



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

Opening Question:

1. Kindly tell me about your antiretroviral therapy journey (Probe easy, difficult).

Key Questions:

2. Reflect on yourself, what things facilitated and or prevented taking of ART?
3. Reflect on family and friends how did they influenced your ART journey? (Probe, how they facilitated or prevented)
4. Reflection on the social support (community, work environment, school, or varsity environment) influenced your ART journey? (Probe, stigma, discrimination)
5. Reflect on the access to healthcare (distance to health facilities, transportation issues, current financial status, availability of medication etc) influenced your ART journey?
6. Lastly, in relation to your culture, and social classes influenced your ART journey. (Probe, facilitators & barriers - myths taboo)

Closing Question:

7. Is there anything you would like to share with us pertaining adherence to ART we have not mentioned?

Appendix D: Uhlelo lwemibuzo (isiZulu)

WITS
UNIVERSITY



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

Umbuzo wokuvula:

1. Ngicela ungitshele, ngohambo lwakho lwemishanguzo (Chaza Bekulula, bekunzima)

Imibuzo eqondene nesihloko:

2. Uma uzibheka siqgu sakho, yini ekusiza noma ikuvimbe ekuthatheni imishanguzo yakho ngendlela efanelekile?
3. Ake ubheke kubantu osondelene nabo, ochitha nabo iskhathi esiningi, bakusiza noma bakuvimbela kanjani ekuthatheni imishanguzo yakho ngendlela efanelekile?
4. Ake ubheke ngokuthinta umphakathi, la uhlala, funde futhi usebenze khona, bakusiza noma bakuvimbela ngayiphi ndlela ekuthatheni imishanguzo yakho ngendlela efanelekile?
5. Uma ubheka ukuthuthuka kwendawo ohlala kuyo, isibonelo ezokuthutha, ukuqhela komtholampilo, izinga lobugebengu nomnotho, kukusiza noma kukuvimbela ngayiphi ndlela ekuthatheni imishanguzo yakho ngendlela efanelekile?
6. Sesiphetha, uma ubheka ngokosiko mpilo yasekhaya, kukhona okukusiza noma vimba uthathe imishanguzo yakho ngendlela efanelekile?

Umbuzo wokuvala:

7. Kukhona ongafisa kukusho mayelana nesihloko sethu obekungabuziwe?

Appendix E: Demographic Questionnaire.

WITS
UNIVERSITY



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

Unique ID Number:

Please mark with a cross "X" where appropriate.

Age:

Sex: Female ☐ Male ☐ Other ☐

Religion: Christianity ☐ Traditional ☐ Islamic ☐ Nazareth ☐ Other ☐

Marital status: Single ☐ Cohabitation ☐ Married ☐ Separated/Divorced ☐

Highest educational level: None ☐ Primary ☐ Secondary ☐ Tertiary ☐

Employment Status: Unemployed ☐ Self-employed ☐ Employed ☐ Student ☐

Lifestyle: Alcoholic ☐ Smoking ☐ Drug User ☐ None ☐

Where do you live? Ophondweni ☐ Gwaliweni ☐ Jozini ☐ Makhathini ☐
Nondabuya ☐ Other ☐

With whom do you live with? Parents ☐ Guardian ☐ Partner ☐ Siblings ☐
Alone ☐

Appendix F: Participants Information Sheet for young adults aged 18-24 years.



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

Warm greetings, I am Samkelo B Sithole, Master of Public Health student from University of Witwatersrand, Johannesburg, South Africa. As part of fulfilment of my degree, I'm undertaking a research study to seek knowledge regarding multilevel facilitators and barriers of antiretroviral therapy adherence among adolescents and young adults aged 18-24 years from five selected provincial primary healthcare clinics under Othobothini CHC. The final findings from this research study may provide insightful knowledge on the phenomenon and provide directive or guidance on the proposed future healthcare intervention for adolescents and young adults living with HIV/Aids in rural areas.

I would like to invite you to partake in my research study. You will be asked to provide us with your demographic data and answer seven open-ended questions during our in-depth interview that would take approximately 25-45 minutes of your time. The interview session (including audio recorder with your permission) will be of high confidentiality and privacy will always be maintained. The face-to-face IDI will be conducted in one of selected consultation rooms within the area of care or health facility in the convenience of participant's time. No names or identifying information will be required, provided information will be held safely and never disclosed to anyone else except the researcher. There will be no personal costs to you incurred as the result of participating in this study. You will receive no preferential treatment from participation but guaranteed that no disadvantages or penalties if you opt not to partake or withdraw during the study.

Benefits of being in the study: All information that is gathered during this process will be used only for research and educational purposes. It is possible that outcomes of this study will benefit you directly or indirectly. It is expected that such outcomes will help us improve the quality of our healthcare service and thereafter, interventions to improve adherence among adolescents and young adults in particular rural areas.

Risks of being involved in the study: Participation in the study bears no more than minimum risks, due to sensitive nature of research topic psychotherapy and counselling session will be provided for all participants in need of such services. Othobothini CHC Registered Counsellor, Mr S Sibiya. Contact No: 035 572 9002/ 079 597 2990.

Solid Foundation for Rural Development (SORD), Program Director: Mr B Mpontshane.
Contact No. 035 572 5590/ 078 738 3948.

The finalised research report will be submitted for assessment at School of Public Health, University of Witwatersrand. The results will be shared with participants, Department of Health policy makers and other academic research network that are developing health models addressing antiretroviral therapy adherence among adolescents and young adults in rural areas. Avenues for publication will be explored. Open channels for communication or any enquire regarding the research study on adherence facilitators and barriers to ART are always maintained throughout the process. Information sheet will be provided prior interviews and allow chance to ask questions of clarity.

Researcher Contact Numbers: 064 682 1696 Email: 2605265@students.wits.ac.za

Ethics Question: Any question about your rights as the participants in the study, kindly contact: Ms Pumla Sodo. contact Number: 011 717 2762 Email: pumla.sodo@wits.ac.za

Complaints: This study has been approved by the Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za

Thank you for your time and consideration.

Yours sincerely

A handwritten signature in black ink, appearing to read 'SB Sithole', written over a horizontal line.

Mr SB Sithole (Researcher)

Appendix G: Participants Information Sheet for Parent/Guardian of a Minor* aged 16-17 years.



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

Warm greetings, I am Samkelo B Sithole, Master of Public Health student from University of Witwatersrand, Johannesburg, South Africa. As part of fulfilment of my degree, I'm undertaking a research study to seek knowledge regarding multilevel facilitators and barriers of antiretroviral therapy adherence amongst adolescents aged 16-17 years from five selected provincial primary healthcare clinics under Othobothini CHC. The final findings from this research study may provide insightful knowledge on the phenomenon and provide directive or guidance on the proposed future healthcare intervention for adolescents living with HIV/Aids in rural areas.

I'm inviting your children/ adolescents aged 16-17 years with your permission to partake in my research study, provided they can consent to participate in the study. They will be asked to provide us with their demographic data and answer seven open-ended questions during our in-depth interview that would take approximately 25-45 minutes of their time. The interview session (including audio recorder with your permission) will be of high confidentiality and privacy will always be maintained. The face-to-face IDI will be conducted in one of selected consultation rooms within the area of care or health facility in the conveniency of minor's time. No names or identifying information will be required, provided information will be held safely and never disclosed to anyone else except the researcher. There will be no personal costs to you and the minor incurred as the result of participating in this study. They will receive no preferential treatment from participation but guaranteed that no disadvantages or penalties if the minor opt not to partake or withdraw during the study.

Benefits of being in the study: All information that is gathered during this process will be used only for research and educational purposes. It is possible that outcomes of this study will benefit you directly or indirectly. It is expected that such outcomes will help us improve the quality of our healthcare service and thereafter, interventions to improve adherence amongst adolescents in particular rural areas.

Risks of being involved in the study: Participation in the study bears no more than minimum risks, due to sensitive nature of research topic, psychotherapy and counselling session will be provided for all participants in need of such services.

Othobothini CHC Registered Counsellor, Mr S Sibiya. Contact No: 035 572 9002/ 079 597 2990. Solid Foundation for Rural Development (SORD), Program Director: Mr B Mpontshane. Contact No. 035 572 5590/ 078 738 3948.

The finalised research report will be submitted for assessment at School of Public Health, University of Witwatersrand. The results will be shared with participants, Department of Health policy makers and other academic research network that are developing health models addressing antiretroviral therapy adherence among adolescents and young adults in rural areas. Avenues for publication will be explored. Open channels for communication or any enquire regarding the research study on adherence facilitators and barriers to ART are always maintained throughout the process. Information sheet will be provided prior interviews and allow chance to ask questions of clarity.

Researcher Contact Numbers: 064 682 1696 Email: 2605265@students.wits.ac.za

Ethics Question: Any question about your rights as the participants in the study, kindly contact: Ms Pumla Sodo. contact Number: 011 717 2762 Email: pumla.sodo@wits.ac.za

Complaints: This study has been approved by the Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za

Thank you for your time and consideration.

Yours sincerely

A handwritten signature in black ink, appearing to read 'SB Sithole', written over a horizontal line.

Mr SB Sithole (Researcher)

Appendix H: Participants Information Sheet for Minor* aged 16-17 years.



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

Warm greetings, I am Samkelo B Sithole, Master of Public Health student from University of Witwatersrand, Johannesburg, South Africa. As part of fulfilment of my degree, I'm undertaking a research study to seek knowledge regarding multilevel facilitators and barriers of antiretroviral therapy adherence amongst adolescents aged 16-17 years from five selected provincial primary healthcare clinics under Othobothini CHC. The final findings from this research study may provide insightful knowledge on the phenomenon and provide directive or guidance on the proposed future healthcare intervention for adolescents living with HIV/Aids in rural areas.

I'm inviting adolescents aged 16-17 years with parent/ guardian's permission to partake in my research study, provided they can consent to participate in the study. You will be asked to provide us with their demographic data and answer seven open-ended questions during our in-depth interview that would take approximately 25-45 minutes of their time. The interview session (including audio recorder with your permission) will be of high confidentiality and privacy will always be maintained. The face-to-face IDI will be conducted in one of selected consultation rooms within the area of care or health facility in the convenience of minor's time. No names or identifying information will be required, provided information will be held safely and never disclosed to anyone else except the researcher. There will be no personal costs to you and the minor incurred as the result of participating in this study. They will receive no preferential treatment from participation but guaranteed that no disadvantages or penalties if the minor opt not to partake or withdraw during the study.

Benefits of being in the study: All information that is gathered during this process will be used only for research and educational purposes. It is possible that outcomes of this study will benefit you directly or indirectly. It is expected that such outcomes will help us improve the quality of our healthcare service and thereafter, interventions to improve adherence amongst adolescents in particular rural areas.

Risks of being involved in the study: Participation in the study bears no more than minimum risks, due to sensitive nature of research topic, psychotherapy and counselling session will be provided for all participants in need of such services.

Othobothini CHC Registered Counsellor, Mr S Sibiya. Contact No: 035 572 9002/ 079 597 2990. Solid Foundation for Rural Development (SORD), Program Director: Mr B Mponshane. Contact No. 035 572 5590/ 078 738 3948.

The finalised research report will be submitted for assessment at School of Public Health, University of Witwatersrand. The results will be shared with participants, Department of Health policy makers and other academic research network that are developing health models addressing antiretroviral therapy adherence among adolescents and young adults in rural areas. Avenues for publication will be explored. Open channels for communication or any enquire regarding the research study on adherence facilitators and barriers to ART are always maintained throughout the process. Information sheet will be provided prior interviews and allow chance to ask questions of clarity.

Researcher Contact Numbers: 064 682 1696 Email: 2605265@students.wits.ac.za

Ethics Question: Any question about your rights as the participants in the study, kindly contact: Ms Pumla Sodo. contact Number: 011 717 2762 Email: pumla.sodo@wits.ac.za

Complaints: This study has been approved by the Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za

Thank you for your time and consideration.

Yours sincerely



Mr SB Sithole (Researcher)

Appendix I: Consent for participation for young adults aged 18-24 years.



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto.
2. I was given time to read it, or had it read to me, in the language I best understand.
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory.
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be.
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time.
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained.
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details: Mr Samkelo B Sithole, Principal Investigator, contact no. 064 682 1596, or by e-mail at 2605265@students.wits.ac.za,

Ms Pumla Sodo, Supervisor, contact no: 011 717 2762 Email: pumla.sodo@wits.ac.za

Professor P Ruff, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Name of Participant: _____

Date: _____ Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____ Date: _____

Appendix J: Consent Participation for Parent/Guardian of a Minor* aged 16-17 years.



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto.
2. I was given time to read it, or had it read to me, in the language I best understand.
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory.
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be.
5. I understand that there will be no immediate benefit to me or my child, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time.
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw my child's participation at any time and would not be required to give any reasons; if that happened, any data collected about my child for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

Mr Samkelo B Sithole, Principal Investigator, contact no. 064 682 1596, or by e-mail at 2605265@students.wits.ac.za, Ms Pumla Sodo, Supervisor, Contact no: 011 717 2762 Email: pumla.sodo@wits.ac.za

Professor P Ruff, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za

Name of Child: _____

Name of Parent or Guardian: _____

Date: _____

Place: _____

Signature or mark of Parent: _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix K: Participant Assent for Minors aged 16 -17 years*



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

1. I have been given a Participant Information Sheet for Minors, which explains what this study is about.
2. The study was explained to me, and I understand what will happen if I take part.
3. I was given time to ask any questions I wanted to and was happy with the answers I was given.
4. I understand that I will not benefit from the study, should I agree to take part. I also understand that I will not be paid to take part in the study; taking part will not cost me anything either.
5. I have been given a range of contact details, repeated below, should I require further information at a later stage, or have any cause for concern over anything which is done to me during the study; and
6. I understand that even if I agree to take part in the study, I can change my mind later and stop being a part of the study.
7. My parent(s) or guardian(s) know that I have been invited to take part in the study. They agree that I may do so, but the decision to take part is also mine.

Contact details:

Mr Samkelo B Sithole, Principal Investigator, contact no. 064 682 1596, or by e-mail at 2605265@students.wits.ac.za, Ms Pumla Sodo, Supervisor, Contact no: 011 717 2762 Email: pumla.sodo@wits.ac.za

Professor P Ruff, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za

Name of child: _____

Name of Parent or Guardian: _____

Date: _____

Place: _____

Signature or mark of parent _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix L: Consent for Audio Recording of Study Participation for young adults aged 18-24 years.



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

I hereby consent to audio recording of the In-depth Interview session.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years if no publications arise from this research.
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____

Date: _____ Place: _____

Signature or mark: _____

Witnessed by:

Name of Witness: _____

Date: _____ Place: _____

Signature or mark: _____

Appendix M: Consent Form for Audio Recording for Parent/Guardian of a Minor* aged 16-17 years.



STUDY TITLE: Facilitators and barriers to antiretroviral therapy adherence among adolescents and young adults in rural South Africa.

I hereby on behalf of my child consent to audio recording of the In-depth Interview session.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years if no publications arise from this research.
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of a child: _____

Name of Parent/ Guardian: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix N: Consent Form for Audio Recording for Minors* aged 16-17 years.



**STUDY TITLE: Facilitators and barriers to
antiretroviral therapy adherence among adolescents
and young adults in rural South Africa.**

I hereby on behalf of my child consent to audio recording of the In-depth Interview session.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years if no publications arise from this research.
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of a child: _____

Name of Parent/ Guardian: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____