

**EXPERIENCES OF HIGHER EDUCATION STUDENTS ON SELF-
MANAGEMENT OF HIV AT A HIGHER EDUCATION INSTITUTION IN
THE WESTERN CAPE AREA**

By

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**Thesis submitted in the fulfilment of the requirements for the Masters
in Nursing degree**

in the Faculty of Health and Wellness

at the Cape Peninsula University of Technology

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Date submitted 08 June 2023

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ABSTRACT

It has been noted that the number of HIV infections among young adults has been on the increase in the last few years. This has prompted the government to strengthen initiatives aimed at both prevention and treatment which include the availability of free condoms in all public facilities and the expansion of the antiretroviral therapy programme. Despite these initiatives, it appears treatment outcomes for the young adults' group are poorer when compared to those of adults. It is also worth noting that HIV is now being identified as a chronic condition like other ailments such as diabetes which means it also requires self-management interventions as part of controlling it. Young adults living with HIV face a myriad of challenges in their efforts to self-manage their condition. University students whose majority falls into the young adults' category have also been affected by the HIV virus in the same manner as young adults elsewhere. The aim of this study was to investigate the HIV self-management experiences among university students living with HIV at a higher education institution in the Western Cape area.

The study employed a qualitative research approach to investigate and analyse the experiences of the university students living with HIV who took part in this study. This study used exploratory, descriptive, and contextual research designs since the objective was to explore the HIV SM experiences of students living with HIV. Professional referral sampling was used to select participants in this study and this method was preferred due to the sensitivity of the matter under investigation. Qualitative approach was used to collect data until data saturation was reached, with a final sample size of eight (8) university students participating in the study. The collected data was analysed through inductive thematic analysis to get the findings and the trustworthiness was ensured. Steps were implemented to ensure adherence to ethical principles.

The major findings of the study showed that the participants of the study only gained a better understanding of HIV after they were diagnosed with the HIV virus, because that is when they began to access true facts about HIV as opposed to the myths they were

exposed to prior to their diagnosis. The findings of the study also showed that living with the HIV virus is a journey that exposes the victims to different experiences that are quite challenging. The evidence also showed that once they devised ways to manage HIV, it became easier for them to strike a balance between their academic studies and managing their HIV status. The study also found that nurses played a key role in the participants' management of the HIV virus both in providing treatment and providing psychosocial support. The participants also indicated that peer support was also a key intervention that allowed them interactions with their peers and share their experiences. A set of recommendations that were formulated based of the analysed data are also listed at the end of the study.

Keywords: Young adults, HIV self-management, Nurse, Experiences, Higher education students, Higher education institution, Western Cape, Qualitative study.

ACKNOWLEDGEMENTS

My immense gratitude goes to God for the salvation of my soul, strength, protection, provision, wisdom, knowledge and understanding throughout this study.

I also wish to express my appreciation to the following people and institutions for the various ways they have contributed to the successful completion of this thesis.

- Great appreciation goes to the study participants, as well as the Institution which granted permission for the students to be approached for completion of the study.
- To my supervisors, Prof RR Marie Modeste and Dr W Phiri; thank you very much for your guidance, motivation, encouragement, counsel, and untiring support. May the good Lord bless you.
- To my dear wife Mrs Phelokazi Tyabazeka and my wonderful son Sithandiwe Tyabazeka – your cooperation, patience, understanding and love made it all possible for me.
- To the church board and the congregation of Word Restoration Bible Church, of which I am the chairperson and the presiding Pastor, thank you very much for bearing with me, praying for me, and supporting me throughout my studies. May the good Lord bless you and keep you.
- To the nursing department at CPUT, thank you for affording me the opportunity to pursue this study.
- To Dr G du Preez, thank you very much for editing this work and make it of a high standard. Your prompt responses to my emails encouraged me to submit the next chapter.

DEDICATION

This thesis is dedicated to my dear wife, Phelokazi Tyabazeka, and my wonderful son Sithandiwe; your support superseded all challenges.

To my father, Zamikaya Tyabazeka and mother, Nonzolo Tyabazeka, my siblings Sixolile, Sivuyile, Khangelani and my dear sister Phelisa 'Phesh' Mbambeni; your teachings and prayers are encouraging me to do more.

To Bishop DJ Mothuko (my spiritual father; who believed in me 13 years ago that I was called by God into the Pastoral ministry and ordained me), thank you for allowing God to use you in my life.

To my spiritual family, Word Restoration Bible Church, you are a blessing.

TABLE OF CONTENTS

DECLARATION.....	i
ABSTRACT	ii
ACKNOWLEDGEMENTS.....	iv
DEDICATION	v
TABLE OF CONTENTS	vi
LIST OF TABLES.....	xi
LIST OF APPENDICES.....	xii
ABBREVIATIONS	xiii
DEFINITION OF TERMS:.....	xv
1 CHAPTER 1 - ORIENTATION TO THE STUDY	1
1.1 Introduction	1
1.2 Background	1
1.3 Problem Statement.....	5
1.4 Research Question.....	6
1.5 Research Purpose.....	6
1.6 Objectives of the Study	6
1.7 Rationale for the Study.....	7
1.8 Significance of the study	7
1.9 Theoretical Departure.....	7
1.10 Preliminary Literature Review	9
1.11 Research Methodology	10

1.11.1	Research Paradigm and approach.....	10
1.11.2	Research Design.....	11
1.11.3	Research Setting.....	11
1.11.4	Population	11
1.11.5	Sampling methods and sample size.....	12
1.11.6	Data collection methods	12
1.11.7	Data analysis.....	13
1.11.8	Academic Rigour	13
1.11.9	Ethical Considerations.....	14
1.12	Structure of the Study	14
1.13	Chapter Summary.....	15
2	CHAPTER 2 - LITERATURE REVIEW AND THEORETICAL FRAMEWORK	16
2.1	Introduction	16
2.2	HIV Burden in Sub-Saharan Africa.....	17
2.2.1	HIV burden in South Africa	18
2.2.2	Prevalence of HIV among young adults.....	19
2.3	The Vulnerability of Young Adults to HIV	21
2.4	The Physical Effects of HIV.....	25
2.4.1	The circulatory system.....	25
2.4.2	The digestive system.....	26
2.4.3	Weight gain and HIV.....	27
2.4.4	The nervous system	28
2.4.5	The respiratory system	29

2.5	The Psychological Effects of HIV	29
2.6	Education and HIV	30
2.7	HIV Prevention Interventions.....	33
2.7.1	Use of condoms.....	33
2.7.2	The use of pre-exposure prophylaxis (PrEP).....	34
2.7.3	Post-exposure prophylaxis (PEP).....	35
2.8	HIV Management Interventions.....	36
2.8.1	Antiretroviral therapy (ART).....	36
2.8.2	HIV self-management.....	39
2.9	Living with HIV	42
2.10	Self-Management of HIV amongst Students Living with HIV	45
2.11	Factors inhibiting HIV prevention and management in young people	46
2.11.1	Substance abuse.....	47
2.11.2	Suboptimal use of condoms	49
2.11.3	HIV Stigma	50
2.12	Knowledge of HIV among University Students.....	51
2.13	Attitudes towards HIV among University Students.....	52
2.14	Chapter Summary.....	53
3	CHAPTER 3 - RESEARCH METHODOLOGY	55
3.1	Introduction	55
3.2	Research Paradigm.....	56
3.3	Research Approach.....	58
3.3.1	Justification for Using a Qualitative Approach	59

3.4	Research Design.....	60
3.4.1	Exploratory Research Design	61
3.4.2	Descriptive Research Design.....	61
3.4.3	Contextual Research Design	62
3.4.4	Rationale for the Adopted Research Design.....	63
3.5	Setting.....	63
3.6	Population	63
3.7	Sampling Method	64
3.8	Sample Size.....	66
3.9	Recruitment.....	66
3.10	Data Collection Process.....	67
3.10.1	Data collection Instrument.....	68
3.10.2	Pilot interview	69
3.11	Data Analysis	70
3.11.1	Familiarisation with the data.....	71
3.11.2	Generating initial codes.....	71
3.11.3	Generating themes.....	72
3.11.4	Reviewing themes	72
3.11.5	Defining and naming themes.....	72
3.11.6	Write up.....	72
3.12	Trustworthiness.....	73
3.12.1	Credibility.....	73
3.12.2	Transferability.....	74

3.12.3	Confirmability.....	75
3.12.4	Dependability.....	75
3.13	Ethical Considerations	76
3.13.1	Respect for the person	77
3.13.2	Beneficence and non-maleficence	78
3.13.3	Justice	79
3.14	Dissemination of Research Findings.....	79
3.15	Chapter Summary	80
4	CHAPTER 4 - STUDY FINDINGS.....	81
4.1	Introduction	81
4.2	Demographic Details of the Participants	81
4.2.1	Age of participants.....	82
4.2.2	Gender of the participants	82
4.2.3	Level of study.....	83
4.2.4	Programmes of study.....	83
4.3	HIV Self-Management (SM) Experiences of University Students in the Western Cape Province of South Africa and Nurses' Supportive Role	83
4.3.1	Understanding of HIV condition by university students.....	85
4.3.2	Experiences of HIV self-management	97
4.3.3	Support from nurses	105
4.4	Chapter Summary	111
5	CHAPTER 5 - DISCUSSION OF FINDINGS, CONCLUSION OF THE STUDY AND RECOMMENDATIONS.	112

5.1	Introduction	112
5.2	Discussion of findings from the study	112
5.2.1	Objective 1: To explore higher education students' understanding of their HIV condition.....	113
5.2.2	Objective 2: To explore the experiences of higher education students on their HIV self-management at a higher education institution	117
5.2.3	Objective 3: To describe the supportive role that nurses can fulfil with regard to the facilitation of the self-management of HIV for higher education students....	121
5.3	Link to the conceptual framework.....	125
5.4	Recommendations	127
5.4.1	Nurses	127
5.4.2	University students	128
5.4.3	Researchers	128
5.4.4	The University.....	129
5.5	Research Limitations.....	130
5.6	Chapter Summary and Study Conclusion	130
	REFERENCES.....	132
	APPENDICES	161

LIST OF TABLES

Table 3-1: Summary of steps taken to ensure trustworthiness.	76
Table 4-1: Demographic details of participants	82
Table 4-2: Themes and Subthemes	84

LIST OF APPENDICES

APPENDIX A: APPROVAL OF ETHICAL CLEARANCE	161
APPENDIX B: APPROVAL OF ETHICAL CLEARANCE - EXTENSION	162
APPENDIX C: PERMISSION LETTER – HIV/AIDS UNIT	163
APPENDIX D: INFORMED CONSENT BY PARTICIPANT	164
APPENDIX E: INTERVIEW GUIDE	165
APPENDIX F: RESEARCH INFORMATION SHEET	167
APPENDIX G: LETTER REQUESTING COUNSELING FOR STUDENTS	170
APPENDIX H: POSTER - INVITATION TO PARTICIPATE IN STUDYS	172
APPENDIX I: STUDENT COUNSELLING REFERRAL FORM	173
APPENDIX J: CERTIFICATE OF EDITING	174
APPENDIX K: TURNITIN RECEIPT	175

ABBREVIATIONS

ADR	Age Desperate Relationships
AIDS	Acquired Immuno Deficiency Syndrome
ANI	Asymptomatic Neurocognitive Impairment
ART	Antiretroviral therapy
ASEAN	Association of East Asian Nations
CPUT	Cape Peninsula University of Technology
CVD	Cardiovascular Disease
DNA	Deribonucleic Acid
ESA	Eastern and Southern Africa
GBD	Global Burden of Disease
GBV	Gender Based Violence
HAART	Highly Active Antiretroviral Therapy
HAD	HIV Associated Dementia
HAND	HIV Associated Neurodisorder
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
ICDM	Integrated Chronic Disease Management
ICHC	Integrated Community /Home Based Care
IFSMT	Individual and Family self-management Theory
INSTIs	Integrase Strand Transfer Inhibitors
MND	Mild Neurocognitive Disorder
NACA	National Agency for the Control of Aids
NHS	National Health Service
NNRTIs	Non-Nucleoside Reverse Transcriptase Inhibitors
NRTIs	Nucleoside/Nucleotide Reverse Transcriptase Inhibitors
PEP	Post Exposure Prophylaxis
PIs	Protease Inhibitors

PLHIV	People living with HIV
PrEP	Pre-Exposure Prophylaxis
SM	Self -Management
STATS SA	Statistics South Africa
STI	Sexually Transmitted Infection
TAF	Tenofovir Alafenamide Fumarate
TDF	Tenofovir Disoproxil Fumerate
UN	United Nations
UNAIDS	United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly
USA	United States of America
USAID	United States Agency for International Aid
VMMC	Voluntary Medical Male Circumcision
WHO	World Health Organisation
YALHIV	Young Adults Living with HIV

DEFINITION OF TERMS:

HIV Self-management: a process of managing chronic illness that is patient centred and it includes factors such as the patients' self-regulation skills, condition specific knowledge and personal beliefs.

HIV Infection: Human immunodeficiency virus (HIV) is an infection that attacks the body's immune system, specifically the white blood cells called CD4 cells (WHO, 2022).

In the context of this study; this refers to the process when the HIV enters the blood stream of a person and it begins to attack and weaken that person's immune system.

Young adults: Young adults is the age group between 18 to 30 years (De Venecia, Lu & Figueredo, 2016). In South Africa, youth consists of those aged 15 to 34 years (StatsSA, 2022).

In the context of this study the term refers to all people who fall into the 18 - 34 age group.

Higher education student: means any person enrolled at a higher education institution, including at short-cycle, bachelor, master or doctoral level or equivalent. It also covers recent graduates (Law Insider, 2023)

In the context of this study this refers to a student enrolled at any institution of tertiary education.

Experience: an event or occurrence that leaves a lasting impression on someone.

In the context of this study this refers to the feelings and emotions which the participants go through as they self-manage their HIV condition.

CHAPTER 1 - ORIENTATION TO THE STUDY

1.1 Introduction

There is an increasing number of Human Immunodeficiency Virus (HIV) infections among young adults (aged 18-30 years) in South Africa (Allinder & Fleischman, 2019). Although the government has increased access to antiretroviral therapy (ART) among this group, they seem to have poorer treatment outcomes when they are compared to other age groups (Adams, 2019:1). HIV is now considered a chronic illness, and young adults who are infected and living with the HIV require the support of their entire families to self-manage their chronic condition (Aneri, Marshall & Harvey, 2020). Among these young adults are University students, a group typically considered healthy and safe from the incidence of disease. Unfortunately, just like other young adults, university students are affected by HIV in the same way, and for those living with HIV, handling, and controlling or self-managing their condition is key (Adams, 2019: 2). There is not much information that is known about the self-management of HIV among university students in South Africa, although self-management programmes, like the integrated chronic disease management (ICDM), do exist. This study aims to investigate the self-management of HIV among university students living with the HIV through a qualitative analysis of the experiences of students from a higher education institution in the Western Cape area. It is hoped that the findings of this research will go a long way in understanding HIV self-management among this group in South Africa and assist health and university authorities in making changes and improvements necessary for HIV self-management interventions for these students.

1.2 Background

The HIV/AIDS pandemic has been around for over four decades, with no permanent solution. The latest statistics presented by the Joint United Nations Program on HIV/AIDS (UNAIDS) show that 38.4 million people were living with HIV worldwide at the end of 2021

(UNAIDS, 2022). The current situation also indicates that the most common mode of HIV transmission remains sexual intercourse (UNAIDS, 2018). It was also noted that young adults aged 15 – 24 years were highly susceptible to HIV infection because they are a highly sexually active group (UNAIDS, 2018). According to global estimates, the total number of young adults (aged 15–24 years) newly infected with HIV in 2017 was 530 000, which accounts for 29% of the overall number of new HIV infections in that year (UNAIDS, 2018). In sub-Saharan Africa, HIV prevalence among young adults varies from region to region, with a rate of one in three newly infected young adults coming from either South Africa or Nigeria (Adejumo, Malee, Ryscavage, Hunter & Taiwo, 2015:10). HIV remains a concern in South Africa. South Africa is home to 20% of the global young adult HIV-infected population (UNICEF, 2016).

Global care for young adults living with HIV (YALHIV) lacks effectiveness, as shown by the increase in Acquired Immune Deficiency Syndrome (AIDS) related deaths among adolescents (Adejumo et al., 2015:11). According to statistics in Africa, AIDS is now the leading cause of death amongst YALHIV in Africa (UNICEF, 2016). South Africa is listed amongst the countries that have failed to significantly reduce HIV-related mortality among its youth (De Wet, Oluwaseyi & Odimegwua, 2014:16). Many reasons account for this negative state of affairs, including the fact that many YALHIV are generally poor, and live in areas where the rates of unemployment, poverty, and violence are high (Cluver, Meinck, Toska, Orkin, Hodes & Sherr, 2018:24). This is exacerbated by the gross lack of social support structures like family and adolescent-friendly healthcare services (Cluver et al., 2018:24).

The discovery and adoption of Antiretroviral therapy (ART) mean that HIV is recognized as a chronic condition that can now be controlled with careful self-management (Adejumo et al., 2015:12). According to Aantjes, Ramerman and Bunders (2014:190), self-management refers to a process of controlling a chronic illness that is patient centred. A broader definition of self-management has been presented, which describes the process as one that includes factors such as the patient's self-regulation skills, condition-specific

knowledge, and personal beliefs (Crowley, Van der Merwe, Kidd, & Skinner, 2019:599). In addition, it has been noted that self-management of any chronic condition is influenced by the kind of family a patient has and the environment within which they live (Rosland, 2009). Moreover, it is essential to note that if self-management is implemented well, it is a very effective approach to care, and evidence supports this position (Suess, 2015).

Self-management requires specific skills and capabilities that differ in terms of how the illness progresses and the developmental stage of the young adult. In addition, several experts have noted that self-management of HIV involves the socio-cultural environment of the affected youth and the relationships they might have with family and close relatives (Crowley et al., 2019:600). Self-management is a process that can be affected by risk and protective factors that include school, family, the health system, and more significant societal factors that include culture and social norms (Crowley et al., 2019: 600).

Many young adults experience several physical, cognitive, and social changes (Chi, Hawk, Winter & Meeus, 2015:3). The prospect of living with a chronic illness for young adults can have such adverse and devastating effects that may hamper their development and affect their "neurocognitive development, prompting behavioural problems, hindering identity-formation or socialization (Crowley et al., 2019:600). The management of YALHIV is made difficult by many shortcomings including encouraging them to adhere to their lifelong treatment and cultivating positive attitudes towards life while managing complications from HIV (Chi et al., 2015:3).

These shortcomings affect the way YALHIV live, and the pursuit of independence as they transition into adulthood becomes complicated (Chi et al., 2015:3). It is important to note that it is not only the young adults who are affected; their families, too, struggle to give the necessary support that YALHIV require at this crucial stage of their lives. As pointed out by Crowley et al. (2019:601) and Kimera et al. (2021), chronic illnesses like HIV/AIDS disrupt the social participation of young adults and negatively impact their quality of life.

On the other hand, much research has been conducted on the treatment and adherence to HIV treatment by YALHIV (van Wyk & Davids, 2019; Audi et al., 2021; Zhou, Toska, Langwenya, Edun, Cluver & Knight, 2023). However, unlike adherence, HIV self-management is a much broader concept that does not solely focus on medical treatment, but it goes beyond and explores actions and emotions as well as role management concerning the HIV infection (Sattoe, Bal, Roelofs, Bal, Miedema & van Staa, 2015:706). Therefore, it is important to constantly monitor and give appropriate advice to YALHIV on issues relating to their care and decision-making, and this should go beyond the simple exercise of advising on adherence to medical instructions (Sattoe et al., 2015:706). Many higher education institutions in South Africa have a clinic and an HIV unit on campus staffed with nurses who support students living with HIV. These students living with HIV are also part of the youth group, which also needs to succeed academically despite some challenges that they face daily due to the HIV infection. Similar to the other groups of people living with HIV, for this group of university students, HIV self-management is critical, as success is highly linked with good health; this is even more important for university students who need to confront academic challenges (Mavhandu-Mudzusi & Sandy, 2015).

Research on self-management interventions for young adults living with chronic conditions has also focused predominantly on medical management, neglecting the psychosocial aspects (Crowley et al., 2019:610). Furthermore, overall, self-management interventions for people living with HIV have not been a research priority in sub-Saharan Africa, and there is little evidence to inform such (Sattoe et al., 2015:708). This has prompted this study to focus on the experiences of higher education students on self-management of HIV because this group falls under the same age group as the rest of other young adults, and yet it also has its own set of unique conditions and academic stressors that might differentiate them from the rest of the young adults in general.

1.3 Problem Statement

Many studies have described HIV-related knowledge, attitudes, and behaviours, as well as HIV testing among university students (Ndongmo, Bertin & Michelo, 2017:71; Barnes, Abramowitz, Lagrange & Chandwani, 2013:320; Reddy & Frantz, 2011:14), while information on the use of HIV prevention services, including HIV prevention education and HIV counselling and testing services is minimal but extremely important (Zhang, Wei, Liu, & Lin, 2018:197). The relationship between academic performance and good health can never be overemphasized. Research on South African universities has consistently shown a high HIV infection and HIV prevalence rate among students, which has hurt the academic performance of those infected with HIV (Hancock, Mikhail, Nguyen & Bright, 1999:34; Kinghorn, 2000:123; HEAIDS, 2008). According to Mavhandu-Mudzusi and Sandy (2015), a decline in academic performance among students living with HIV at South African universities has been noted. There is evidence that students living with HIV face challenges that impact their well-being, including stigma resulting from cultural and socioeconomic norms (Mavhandu-Mudzusi & Sandy, 2015).

Since HIV is considered a chronic illness, students living with HIV should embark on HIV self-management as a way of coping and managing the condition while managing the added burden of fulfilling the demands of academia. In an attempt to provide relief and support to students living with HIV, South African Universities offer voluntary free testing, counselling, and ART to eligible students (Mavhandu-Mudzusi & Sandy, 2015). However, limited research has been conducted on the HIV self-management interventions of young adults in South Africa, as this has not been a priority of many scholars who have often preferred to focus on adherence to medical instructions instead (Sattoe et al., 2015:708). There are very few studies conducted exploring university students' HIV self-management in the Western Cape, despite the high number of HIV infections among young adults and university students in particular (Maskew, Bor, MacLeod, Carmona, Sherman & Fox, 2019). The negative impact of HIV diagnosis on academic performance needs to be mitigated, and the addition of HIV self-management is crucial for university students'

wellbeing and success. Since there is a significant number of students living with HIV at South African universities (Mavhandu-Mudzusi & Sandy, 2015), it is important to explore and describe their HIV self-management experiences and the challenges that affect the self-management of their condition. As the students living with HIV attend the clinic and HIV unit on the campus, it is essential to understand the supportive role nurses from these units can fulfil concerning facilitating HIV self-management for these students; however, such information remains limited.

1.4 Research Question

From the problem statement, one main research question and two additional sub-questions emerged as follows:

- 1) What are the experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area?
 - a) What is the understanding of the HIV condition by the higher education students living with HIV?
 - b) How can nurses support higher education students living with HIV in the students' HIV self-management?

1.5 Research Purpose

This study aimed to explore and describe the experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area and describe how nurses can support these students.

1.6 Objectives of the Study

The objective of this study was accompanied with two follow-up sub-objectives as follows:

- 1) To explore the experiences of higher education students on their HIV self-management at a higher education institution

- a) To explore higher education students' understanding of their HIV condition
- b) To describe the supportive role nurses can fulfil regarding facilitating the self-management of HIV for higher education students.

1.7 Rationale for the Study

There is a dearth of literature about the HIV self-management experiences and needs of university students living with HIV in the South-African context. Several available studies (Reddy & Frantz, 2011; HEAIDS, 2008; Heeren, Mandeya & Jemmott, 2014) focus primarily on other aspects of the disease without explicitly focusing on self-management. Only one study conducted in an urban setting in Cape Town identified the components of adolescent HIV self-management (Crowley, 2017:279). Currently, the available programs to assist students living with HIV have no specific focus on HIV self-management.

1.8 Significance of the study

This study is significant because it seeks to cover a gap in the literature and expand on the prior research, enhancing student well-being and experiences. It is hoped that the findings of this research will go a long way in understanding HIV self-management among the higher education students living with HIV and assist health and university authorities in making changes and improvements necessary for HIV self-management interventions for these students.

1.9 Theoretical Departure

The study used the Individual and family self-management theory (IFSMT) as its theoretical framework. The IFSMT proposes that self-management is an ever-changing and sophisticated concept that consists of three dimensions: context, process, and outcomes (Fawcett, Watson, Neuman, Walker & Fitzpatrick, 2001:116). Elements in the contextual dimension impact individual and family engagement in the self-management

process and directly influence outcomes. Improving the individual's and family's self-management processes lead to more positive outcomes (Meleis, 1997:3). The third dimension of the theory relates specifically to outcomes. Important outcomes are those directly linked to individuals and families yet improving these findings in improved outcomes for healthcare practitioners and systems (Ryan & Sawin, 2009:220). The IFSMT is underpinned by several assumptions listed below:

- Persons engage in behaviours for personally meaningful reasons that may or may not be directly related to optimizing their health status.
- Many factors influence behaviour, including personal preferences, culture, social norms, and family rules and boundaries.
- Numerous contextual factors affect an individual's and family's ability and desire to engage in self-management.
- Individual and family perceptions of resources affect engagement in self-management behaviours.
- Self-management involves dynamic, iterative processes requiring time, repetition, and reflection.
- Social facilitation can direct, encourage, and support engagement in self-management behaviours and achievement of outcomes.
- Person/family-centred interventions are most effective in fostering engagement in self-management behaviours and achieving proximal and distal outcomes.
- The concepts of adherence, alliance and compliance are perceived as contrary to self-management as they dismiss the notion that the primary responsibility and control lie with the individual or family.
- Individuals actively engage in self-managing conditions by collaborating with persons in the health care system to achieve personal health goals.

- Individuals and families engaging in health promotion behaviours may or may not collaborate with persons in the health care system (Ryan & Sawin, 2009:221).

The IFSMT is a descriptive theory that strengthens previous work done on self-management, and it expands risk and protective factors (Meleis, 1997:3). Outcomes have been conceptualized as proximal and distal and formalize the addition of quality of life, well-being, and cost to health status outcomes (Ryan & Sawan, 2009:221). The IFSMT is progressive and innovative. It provides the basis for understanding self-management by the adult or child and their families, including an individual member of a social unit. This theory also “expands the focus from health behaviour change for chronic illness to the potential to include health behaviour change required for health promotion” (Ryan & Sawan, 2009:221). Finally, this theory takes note and utilizes the major contributions made in the field that have emanated from the collaboration of nurses and other health care professionals.

1.10 Preliminary Literature Review

It is known that young adults are vulnerable to HIV and several factors contribute to this, which include their high sexual activity, drugs, and peer pressure, among others (Avert, 2020). Literature has shown that the number of newly infected young adults in South Africa has stabilised at an extremely high rate (Avert, 2020). Among the 15 to 24 years age group, about 4% of men and 16% of women are living with HIV, but according to population-based surveys within this group, only 11% and 19%, respectively, were aware of their HIV-positive status (Closson, Dietrich, Lachowsky, Nkala, Palmer, Cui, Chia, Hogg, Gray & Miller, 2018). Literature has also shown that young adults are very vulnerable to HIV infections for various reasons, such as peer pressure and drug and alcohol abuse (UNAIDS, 2018; StopAids, 2016; Heeren, Mandeya & Jemmott, 2014:440). Furthermore, Literature has noted that HIV is now considered a chronic disease, and

several non-communicable disorders have been noted among people living with HIV (UNAIDS, 2015a). It is, however, concerning that although self-management has proven a very effective way to manage and control chronic ailments such as HIV, (World Health Organization, 2019), not much research has been carried out to ascertain the barriers that might prevent these young people from managing the HIV infection they live with, in addition to sticking to their treatment regimen outside the clinic environment (Bernays, Jarrett, Kranzer & Ferrand, 2014). There have not been many efforts to investigate HIV self-management among university students living with HIV in South Africa, and this study was meant to fill that gap to some extent (Lucero, Frimpong, Fehlberg, Bjarnadottir, Weaver, Cook & Cook, 2017). A more in-depth review of the literature regarding the self-management of HIV among university students is discussed in chapter 2.

1.11 Research Methodology

Research methodology refers to the entire presentation of how researchers conduct the research study and present their findings from the data they have collected during the period of research (Sileyew, 2019). In other words, it describes the strategies adopted by the researcher to answer the research question. A short description of the methods applied in the study is presented in this chapter, and more detailed information is presented in chapter three (3).

1.11.1 Research Paradigm and approach

A research paradigm is a "set of beliefs that guide action which is embedded in all educational research" (Brooke, 2013:15). It reflects the beliefs and perceptions of researchers concerning the way they view the world and its various activities. In this study, the researcher used the constructivism paradigm, fitting the qualitative nature of this study, hence the application of a qualitative research approach. The experiences of students living with HIV were captured and used to shape and construct the outcome of this study. In addition, the researcher's engagement with the participants allowed him to determine meanings and themes that helped to answer the research questions.

1.11.2 Research Design

Research design is a framework that includes the methods and procedures employed by a researcher to gather data, analyze, and draw meaning from it (Creswell, 2015). This research study used an exploratory, descriptive, and contextual qualitative design consistent with a qualitative approach. This research design was also applied to explore and describe the experiences of university students living with HIV at a South African university. A deeper discussion of the research design and methodology used in this study is in chapter 3.

1.11.3 Research Setting

The research setting refers to the physical, social, and cultural environment where research occurs (Snowdon, Brocklehurst & Tasker, 2014). The location from which data for this study was collected is a single University in the Western Cape Province with more than 30 000 students enrolled. The institution is at the heart of technology innovation in Africa. The university has six faculties offering a wide range of accredited undergraduate and postgraduate courses in Applied Sciences, Business, Education and Social Sciences, Engineering, Informatics and Design, as well as Health and Wellness Sciences.

1.11.4 Population

Population refers to all the participants selected for a particular research study or project because they meet the criteria set by the researcher conducting the research or inquiry (Chetty, 2016). The population for this study consisted of university students living with HIV, and are in the 18 to 34 age group. Therefore, the accessible population was university students with HIV enrolled at the selected university. Due to the sensitivity of the subject under investigation, the researcher worked with the university health care workers to recruit participants and set up face-to-face interviews with potential participants.

1.11.5 Sampling methods and sample size

Since the entire population of interest cannot participate in a single research study, a section of that target population is selected through a process known as sampling. Yin (2014:66) defines a sample as a subset of the entire population which is used to represent it. Furthermore, fitting with the qualitative research approach applied in this study, the non-probability sampling technique was used to select participants. The specific sampling method deemed suitable for this study was professional referral sampling, which involves selecting participants through an intermediary who provides professional service to the participants (Hogan, Schulkin, Power & Loft 2009). Professional referral sampling has received less notice as a sampling technique, but it is used in health and mental health research (Hogan et al., 2009). Although the researcher initially planned for snowballing sampling, the researcher reverted to a professional referral sampling technique due to the sensitivity of the topic under investigation, as both sampling techniques share the referral aspect. The researcher worked with the professional nurse from the campus clinic, who assisted in identifying and recruiting the participants. Data saturation was achieved after eight (8) individual in-depth interviews were conducted with university students living with HIV, enrolled in different departments and at different levels of their studies.

1.11.6 Data collection methods

Data collection is collecting information from all the relevant sources to find answers to the research problem, test the hypothesis and/or evaluate the outcomes based on the type of study (Paradis, O'Brien, Nimmon, Bandiera & Martimianakis, 2016). Data used in this study was collected through face-to-face, telephonic, and online individual semi-structured interviews. The specific place at the university where the face-to-face interviews took place was the boardroom in the nursing department, and all Covid 19 protocols were observed. The interviews lasted between 30 and 45 minutes long on average, and they were all conducted in English. Data collection was conducted

concurrently with data analysis, which helped establish when data saturation was achieved.

1.11.7 Data analysis

This study used inductive thematic analysis to analyse the collected data. Inductive thematic analysis is one of the most common methods used in qualitative research. It emphasizes identifying, analysing, and interpreting patterns of meaning (or "themes") within qualitative data (Braun, Clarke, Hayfield & Terry, 2019). The researcher's first process was transcribing all recordings and reproducing them as Microsoft word documents. The researcher also carried out a process of member checking to ensure that all the transcribed data corresponded with what the participants actually said. The information given by the participants was rephrased to ascertain the meaning was actually what the participant had just said. Codes and patterns were then developed through coding, through which the researcher identified items of analytic interest in the data and assigned them coding labels. The inductive thematic analysis involved more than counting phrases or words in the text to decipher meanings from within the collected data (Braun et al., 2019). The identified codes were analysed and combined further into themes and subthemes. A more detailed data analysis process is discussed further in chapter 3.

1.11.8 Academic Rigour

The researcher conducted this study in a manner that maintained the quality of the collected data, authenticity, and truthfulness of the findings by pursuing steps that ensured the study was trustworthy. According to Saunders, Lewis and Thornhill (2019:218), validation is the process of verifying research data, analysis, and interpretation to establish validity, credibility, and authenticity. However, since this study is qualitative, the criteria employed to establish the truth value of this research was through assessing the study's credibility. In order to achieve this, the researcher had to establish the trustworthiness of the study by ensuring transferability, credibility, dependability, and confirmability. More details on this are provided in chapter 3 of this study.

1.11.9 Ethical Considerations

Corbin and Strauss (2015:89) define ethics as "a code of behaviour considered correct". Therefore, all researchers need to be aware of research ethics. Research approval was obtained from the Institution's Research Ethics Committee (Appendix A; Appendix B), and permission was obtained from the public university authorities to carry out the study at their campus (Appendix C). Furthermore, ethical principles like informed consent (Appendix D), privacy and confidentiality were observed and applied. These are discussed further in detail in chapter three (3).

1.12 Structure of the Study

This study is presented in five (5) chapters as follows:

Chapter 1 gives the introduction to the study, background to the study, the rationale for the study, the research problem, research questions and objectives of the study. The chapter also briefly outlines the literature review, research design, methodology and ethical considerations.

Chapter 2 presents a review of available literature on the self-management of HIV among young adults and university students specifically. It also explores the challenges they face due to their condition.

Chapter 3 outlines the research methodology as applied in this study, including population, sampling techniques and method of data collection and analysis. In addition, steps taken to ensure academic rigour and adherence to ethical principles are highlighted.

Chapter 4 provides analyses and interpretation of the findings of the study.

Chapter 5 discusses the study's findings accompanied by literature support, and conclusion and contains recommendations.

1.13 Chapter Summary

This chapter provided an overview of the study. It also included the research problem and reasons for the study. Next, it described the study's purpose, objectives, terminology, and theoretical framework. A brief discussion on the research design, methodology, and ethical principles applicable to the study and data analysis followed. The chapter concluded with an outline of the chapters to follow in the study. The next chapter presents a review of relevant literature to the study.

CHAPTER 2 - LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Introduction

This study aimed to explore and describe the HIV self-management experiences of students at a higher education institution in the Western Cape area. The study had the following objective and sub-objectives:

- 1) To explore the experiences of higher education students on their HIV self-management at a higher education institution
 - a) To explore higher education students' understanding of their HIV condition
 - b) To describe the supportive role nurses can fulfil concerning the facilitation of self-management of HIV for higher education students.

This chapter reviews relevant literature on HIV and its impact on young adults with a specific focus on university students in South Africa. A literature review is a necessary part of research because it gives a comprehensive background of the subject under research, demonstrates an in-depth knowledge of the researcher, and helps identify the areas of the subject that are underexplored.

Various electronic databases, platforms, and journals were used to search for relevant literature, including Google scholar, Scopus, Lancet and Sage journals since they are easily accessible. These databases have an extensive collection of high-quality journals, conference papers, reports, and theses. The search strategy used by the researcher for this review focused on using the following keywords: self-management, HIV infection, young adults, youths living with HIV, and university students. These keywords are all directly connected to the subject at hand, which explores and describes the HIV self-management experiences of students at a higher education institution. As part of the search strategy, the researcher also conducted ancestry searches which allowed the researcher to obtain more sources from the reference lists of relevant articles already

accessed for this literature review. Since there is quite a lot of literature on these databases, only literature published between 2012 and 2021 was used. This was done to restrict the search to recent information relevant to the study. In addition, the search strategy included browsing for articles by discipline, searching by subject (e.g., HIV prevalence among youth) and browsing through abstracts to determine the relevance of articles or journals.

This literature review begins by examining the literature on the prevalence of the HIV epidemic on a broader scale, then specifically reviews the impact of HIV on young adults in South Africa. At the same time, the last part analyses self-management of HIV among young adults with a focus on university students. There is a limited amount of scholarly work available on HIV self-management that focuses explicitly on university students in the Western Cape region, and it is envisaged that this study will add to the limited work that is available currently.

2.2 HIV Burden in Sub-Saharan Africa

By the end of 2021, 38.4 million people were recorded as living with HIV worldwide, with 1.5 million new infections, with women and girls accounting for 54% of the people living with HIV (UNAIDS, 2022). The leading cause of morbidity and mortality in the sub-Saharan region has been documented as HIV/AIDS (Global Burden of Disease [GBD], 2018). Several scientific breakthroughs have occurred since HIV was first identified in the 1980s, and those have changed the once-feared illness to one that can be managed with reasonable success through antiretroviral therapy (ART) (Teeraananchai, Kerr, Amin, Ruxrungtham & Law, 2017:258). There has been a gradual increase in the use of ART since the mid-2000s, but there is still a long way to go for everyone who needs ART to access it. As a result, there are still about 34% of people in eastern and southern Africa and 60% of people in western and central Africa who are living with HIV but are not currently receiving any treatment, and this makes HIV/AIDS the most common cause of death in sub-Saharan Africa (GBD, 2018). The burden of the global HIV epidemic is

unevenly concentrated in sub-Saharan Africa, where about 66% of all people living with HIV reside (Gebremichael, Gurara & Weldehawaryat, 2020:320).

The situation is particularly dire for young adults who are at high risk of contracting the disease. For example, in 2016, the United Nations (UN), through its agency that deals with the HIV pandemic, reported that of the 2.1 million adolescents (10–19 years) living with HIV globally, 84% were in sub-Saharan Africa (UNAIDS, 2018). It was also reported that in this region, there was a gender dimension in terms of infections, with adolescent girls being twice as likely as boys to acquire HIV (UNAIDS, 2018). This difference between adolescent girls and boys is most remarkable in Eastern and Southern Africa (ESA), where girls account for 78% of new infections in adolescents (UNICEF, 2018). Complex biological and behavioural factors have been identified that increase young women's risk of HIV acquisition (Harrison, Colvin, Kuo, Swartz & Lurie, 2015). Some of these factors that have been identified include the increased risk of infection associated with each sexual act for females compared to males, the occurrence of age-disparate and intergenerational sexual relationships, and more distal structural factors related to socio-economic and cultural inequality between genders (Mee, Fearon, Hassan, Hensen, Acharya & Rice, 2018). HIV prevalence remains high in southern Africa. UNAIDS data acquired from the World Bank indicates that the prevalence rate for the 15 to 49 age group was 37% in Eswatini, 25% in Lesotho, 25% in Botswana and 19% in South Africa (World Bank, 2019). Although all countries are affected with HIV, South Africa carries the largest number of people living with HIV (PLHIV), documented at between 7.8 and 8.2 million in 2021 (UNAIDS, 2022).

2.2.1 HIV burden in South Africa

HIV/AIDS is one of the most serious health concerns in South Africa. Recent figures show that South Africa has the highest number of people living with HIV, and in terms of prevalence among adults, the country is ranked fourth in the world (World Bank, 2019; UNAIDS, 2022). According to figures published by Statistics South Africa (StatsSA) by

2021, an estimated 13,7% of the total population were HIV positive (StatsSA, 2021:15). Furthermore, out of the total number of South African women who are still in their reproductive ages (15 - 49), almost a fourth were HIV positive (StatsSA, 2021:15). StatsSA reported that HIV prevalence among the youth aged 15–24 has remained stable over time (StatsSA, 2021:15). The HIV burden has increased over the same period with the total number of PLHIV in South Africa increasing from an estimated 3,8 million in 2002 to between 7.8 million and 8,2 million by 2021 (StatsSA, 2021:15; UNAIDS, 2022). The South African government was concerned about the impact of COVID-19 on PLHIV and testing and treatment programmes because South Africa has the largest number of people enrolled in ART programmes worldwide, at over 5,5 million in 2021. A study by Kim Tanser, Tomita, Vandormael and Cuadros, (2021:2) showed that the province of Gauteng had the highest density for both HIV prevalence and the number of PLHIV. Also, according to this study, 80% of all areas in the country were identified as underserved areas (30-minute threshold, which is the median travel time for PLHIV to access the nearest healthcare facility), which contained more than 16% and 20% of the total men and women living with HIV, respectively. Out of all the provinces, KwaZulu-Natal had the largest number of PLHIV in underserved areas (30-minute threshold) and showed less than one healthcare facility per 1000 PLHIV (Kim et al., 2021:2).

2.2.2 Prevalence of HIV among young adults

The Sub-Saharan region, especially eastern and southern Africa, is the most affected area in the world regarding HIV infections. The region has about 54% of all the people living with HIV globally (UNAIDS, 2022). At the global level, 38.4 million people were living with HIV; and out of this number, 36.7 million were adults, while 1.8 million were children (UNAIDS, 2022). An estimated 1.7 million new infections have been recorded worldwide, signalling a 23% decline in new HIV infections since 2010 (HIV.gov, 2020). As for the Sub-Saharan region, in 2018 alone, there were 800 000 new infections, and South Africa accounted for about a quarter (240 000) of the region's new infections (UNAIDS, 2019). Additionally, it has been established that HIV is now the leading cause of death among

young people (aged 10–24) in sub-Saharan Africa (making it the region with the highest burden of HIV) and the second leading cause of death globally (Ajayi, Ismail, Adeniyi & Akpan, 2018). The situation is equally dire in other parts like Nigeria, with 1.4% HIV prevalence, 1.9 million persons living with HIV and 170,000 new infections, according to the National Agency for the Control of Aids (NACA) (2022). The prevalence of HIV infections in Nigeria among youth in the 15 - 24-year age group has risen by 25% from 2.4% in 2010 to 3.0% in 2017 (Ayodeji et al., 2018). Even though there are no verified records of the proportion of youths in this age group showing estimated annual new HIV infections in Nigeria, there is a postulation that more than half of those currently infected with HIV are between 15 and 24 years old (Ayodeji, Oginni, Adebajo & Ahonsi, 2018).

The number of newly infected young people in South Africa has stabilized at an extremely high rate (Avert, 2020). According to Avert (2020), KwaZulu-Natal (KZN) has the highest HIV prevalence (39.5%), and the Western Cape (WC) has the lowest prevalence (16.9%). The Department of Health also noted that the 30–34-year age group had the highest prevalence rate at 41.5%, even though a rate of 26.6% among the 20–24-year age group is also considered relatively high as well (Muchiri, Odimegwu & De wet, 2017). The 20–24-year age group is interesting because a significant percentage in this group are most likely to be at university or in college (Reddy & Frantz, 2011). According to a survey carried out in the early 2000s among university students, the HIV infection rate among undergraduate students was estimated at 22%, rising to 33% in 2005 (Africa Check, 2018). A recent survey by an organization, Avert, in 2016 established that in South Africa, the infection rate in young women aged between 15 and 24, including university students, was 37%, which is a very high figure (Mogaathle, 2019). According to Pillay & Wassenaar (2018), there is an increasing incidence of HIV among university students, which makes it necessary to raise awareness of preventive measures. In a South African study conducted to assess the willingness of university students to take part in preventive trials, Pillay and Wassenaar (2018) discovered that the number of black African students willing to take part was the lowest among students from other races.

Despite the high-risk behaviour found in young adults, including university students, the use of condoms remains low in this group. Research in the KZN province among university students to assess the level of condom use indicated very low levels of condom use among these students (Haffejee, Koorbanally & Corona, 2018). The findings of the study indicated that less than half of the students who participated used a condom at sexual debut, and only 28.5% used condoms during their recent sexual activity (Haffejee, et al., 2018). This evidence supports the situation at the national level, where condom use among the youth has been seen to decline. The Human Sciences Research Council (HSRC) reported that only 39% of youths aged 15 and above were using condoms in South Africa, which is a worrying trend for a country with one of the highest infection rates in the world (Mogaathle, 2019). In general, the findings showed that there were low levels of condom use among university students, and this also indicated that most students engaged in unprotected sexual behaviour, increasing their chances of getting infected by HIV (Muchiri et al., 2017). Furthermore, the HSRC study revealed that university students in South Africa have low confidence levels in the efficacy of condoms (Mogaathle, 2019).

In contrast, some female students cannot negotiate condom use when they are financially dependent and much younger than their sexual partners (Haffejee, et al., 2018). This increases their risk of contracting HIV because they end up engaging in unprotected sex. High levels of vulnerability expose youths to HIV, which triggers several physical effects that disrupt their normal way of life.

2.3 The Vulnerability of Young Adults to HIV

It is important to understand and get perspective on why young adults seem to have a high HIV incidence rate when compared to other age groups, as evidenced by the figures mentioned earlier (Hitchcock, 2016). There are two stages during which young adults are vulnerable to HIV, and the first one is right at birth, where there is the possibility of mother-to-child transmission, which is often referred to as vertical transmission (StopAids, 2016). The second stage is when they enter their decade of adolescence, where they face an

even higher risk of infection as they get exposed to some new habits like sexual intercourse, drugs, and alcohol (StopAids, 2016). Research conducted in some countries that are part of the Association of Southeast Asian Nations (ASEAN) in 2015 (Thailand, Singapore, Cambodia, Malaysia) has shown that about 70% of young adults living with HIV have, in most cases, acquired the HIV through vertical transmission, and they have lived with the disease since birth (StopAids, 2016; Yi, Te, Pengpid & Peltzer, 2018). It is important to note that mother-to-child transmissions have decreased considerably over time due to programs that prevent these transmissions (UNAIDS, 2015b). For example, vertical transmission rates in the first two months of life in South Africa have been reduced significantly from 23% in 2003 down to 0.7% in 2019, and this success can be directly attributed to improved ART during antenatal care (Wessels, Sherman, Bamford, Makua, Ntloana, Nuttall, Pillay, Goga & Feucht, 2020). On the other hand, reducing infection rates among young adults is more challenging (UNAIDS, 2015b).

There are several reasons why young adults have an increased risk of getting infected with HIV. This group is at a stage where they engage in risky explorative behaviours such as experimenting with drugs and alcohol and unsafe sexual practices, which may increase the risk of contracting HIV (HEAIDS, 2009). It is a well-documented fact that university students tend to engage in risky behaviour as they enjoy their newfound freedom from home (HEAIDS, 2009). Unprotected sex, drug abuse, and alcohol abuse are some of the things that students get involved in without any particular concern for their personal safety and health (Poorolajal, Mohammadi, Soltanian & Ahmadpoor, 2019; Born, Wolvaardt & McIntosh, 2015). In addition, university students' inability to perceive and understand their own risk has been noted even in South Africa (Mthembu, Maharaj & Rademeyer, 2019:248). Such inability has been linked to the continued risky behaviour documented among university students, despite their high level of knowledge (Mthembu et al., 2019:248). There are also many physical and emotional changes that young adults go through during this time of their lives, as this is a critical period that marks their transition into adulthood (Heeren, Mandeya & Jemmott, 2014:440). Adolescents and young adults

have growing personal autonomy and responsibility for their health (StopAids, 2016). The transition from childhood to adulthood is also a time for exploring and navigating peer relationships, gender norms, sexuality, and economic responsibility (Born, Wolvaardt & McIntosh, 2015). This is mainly because most teenagers lack the correct knowledge about HIV and how to prevent it during adolescence, while in some instances, this is due to drug abuse or forced unprotected sex (WHO, 2013).

Young adults are also more vulnerable to HIV because condom use among this group is relatively low. Despite the availability of free condoms in many public spaces, Mthembu and colleagues (2019:249) noted that South African male university students did not trust the efficacy of such condoms and felt that their partners would not appreciate the use of free condoms, in addition to its smell that they did not like. According to Nyembezi et al. (2014), the reasons for low condom use among young men have not yet been fully ascertained, but young women are victims of skewed power dynamics in relationships which leave them without any power to make decisions on condom use. Surveys conducted in sub-Saharan Africa between 2010 and 2015 revealed that less than 60% of young women (aged 15 to 24) with multiple partners used a condom during their last sexual intercourse in 19 of 23 countries (UNAIDS, 2015b). Furthermore, UNAIDS (2016) reports that in 15 out of 23 countries, there were similar findings for young men. It was also reported that the issue of multiple partners among young adults is still a grave concern. Although there has been a decrease in this habit elsewhere, it is still quite high in countries most affected by HIV, including South Africa (UNICEF, 2013). For example, a study conducted at a university in the Eastern Cape Province showed that out of 201 student participants interviewed, 46.3% reported sexual intercourse in the previous three (3) months, and 55.91% of these students reported having sex with more than one partner in the past three months (Heeren et al., 2014:438). The same group of students who reported multiple sexual partners were also much younger when they had their first sexual experience, and their use of condoms was low (Heeren et al., 2014:438).

Furthermore, gender-based violence (GBV) is also a significant factor that increases the vulnerability of women to HIV infection, especially those still in their adolescence. Schools and universities were found to be high-risk areas when it comes to GBV, and the most worrying thing is that this problem is not given much attention in these institutions (Beyene, Chojenta & Roba, 2019). Academic institutions in South Africa have been seen to have an exceedingly high rate of sexual violence, estimated between 24.9% and 26.2% among women aged 18–49 years (Ajayi, Mudefi & Owolabi, 2021:299). These rates are higher than the global prevalence of 7.2% and 17.4% in Southern Africa (Steele et al., 2019). In most cases, the justice system has failed to convict offenders in these cases which only serves to exacerbate an already dire situation for young female students. However, some of these cases receive comprehensive coverage in the media, like the rape and killing of a young university girl in Cape Town, whose funeral was attended by the state president (Ajayi et al., 2021:299). In HIV terms, GBV has several adverse effects that include discouraging infected women from participating in ART programs, preventing them from attending HIV testing and counselling sessions, and reducing uptake and adherence to PrEP, among other things (Colombini, Scorgie & Stangl, 2021). In general, GBV undermines all efforts to prevent and treat HIV among women, especially those still in their youth, thereby making them more vulnerable to HIV.

Another factor that has been known to exacerbate the vulnerability of young adults to HIV is intergenerational sex (García-Moreno, 2015:1685; Stoner et al., 2019:84). This is also a factor that is thought to be a major driver of HIV infections among young adults in sub-Saharan Africa (Idele, Gillespie, Porth, Suzuki, Mahy, Kasedde & Luo, 2014). In most cases, older people who engage in sexual relationships with young people are the ones who expose them to HIV through unprotected sex (ANTHENA, 2013). These relationships are primarily transactional, where there is an exchange of sex for money or a particular favour. This occurs typically between older men and young women, and the power dynamics are biased towards the older male, which leaves the young woman vulnerable (ANTHENA, 2013). In the South African context, a significant number of young adults in

the 15 - 24 age group are at university or in college, and it is inferred here that they are as vulnerable to HIV as any other group of young people (HEAIDS, 2009). With this high burden of HIV, it is important to note its effects on those who live with the infection, as such effects extend to their physical and psychological well-being.

2.4 The Physical Effects of HIV

HIV attacks the immune system, making it harder to fight off microorganisms that can cause sickness. Several signs begin to show when one gets infected, and HIV starts multiplying in the body (Nazario, 2019). The human immune system has many white blood cells fighting infection, one type being CD4. When HIV attacks the body, it destroys these CD4 cells while the body continues to make more of these, but after a while, it cannot keep up with HIV (Kaplan, 2021). This weakens the immune system, affects the different body systems, and makes the body vulnerable to infections.

2.4.1 The circulatory system

This system is affected if the immune system is attacked by HIV, especially the heart, which is the central organ in this system. HIV causes inflammation in the body as it attempts to fight off HIV, which keeps the body on a constant simmer (Nazario, 2019). This kind of inflammation negatively affects the heart and can cause heart disease. Some medications like Abacavir are taken to control HIV, which can also affect the heart. In addition, some drugs like elvitegravir can cause insulin resistance which leads to diabetes, and diabetes, in turn, raises the risk of heart disease (Nazario, 2019).

Furthermore, Msoka et al. (2019) note that cardiovascular disease is becoming increasingly important as PLHIV ages. This was noted as an increased rate of atherosclerosis in PLHIV even after the traditional control of cardiovascular risk factors (Msoka et al., 2019). As much as ART has dramatically improved the survival of PLHIV, the incident rate of premature myocardial infarction and cerebrovascular disease in PLHIV receiving ART has increased (Msoka et al., 2019). A meta-analysis conducted in the

United States of America (USA) showed that HIV infection confers a 61% risk of cardiovascular disease to PLHIV (Triant, 2013). The same analysis also showed that the risk of cardiovascular disease (CVD) is double for patients on ART compared to those who are HIV-negative and is 1.5-fold compared to HIV-infected patients who are not on ART (Islam, Wu, Jansson & Wilson, 2012). The study concluded that ART is related to increased CVD in people who were initially at the highest risk of CVD before they started treatment (Triant, 2013).

2.4.2 The digestive system

HIV affects the digestive system, and many people with HIV experience digestive symptoms because of HIV or opportunistic infections brought on by HIV (Pietrangelo & Cherney, 2021). Diarrhoea is the most common one. Various reports indicate that up to 60% of PLHIV are affected by this ailment, categorized as infectious or non-infectious (Franki, 2018). It has been noted that the causes of infectious bacteria like protozoa, fungi, and bacteria have decreased significantly, and non-infectious causes are on an upward trend. Over time, HIV can change how the digestive tract works and even how it looks (Kaplan, 2021). These changes include, but are not limited to, oral thrush, gastric ulcers, and malignancies such as lymphoma and Kaposi's sarcoma (Kaplan, 2021). If the digestive tract is attacked, the infected person might experience a decline in appetite because this affects their eating. Eating problems cause weight loss, a common side effect of HIV (Pietrangelo & Cherney, 2021). People affected by HIV may also suffer from oral thrush, a fungal infection that causes inflammation and white patches on the tongue and inside the mouth (Kaplan, 2021). It can also cause inflammation of the oesophagus, making it difficult to swallow and eat. Several digestive problems are consequences of HIV infection and can cause severe symptoms if they are not controlled. It has been noted that at least one-third of patients living with HIV before the ART era complained about oesophageal issues; this incident increased with the progression of the disease (Kaplan, 2021). All these can contribute to under nutrition among people living with HIV, which is a common problem whose prevalence among PLHIV has been documented to be as high

as 10.28% in Uganda and 25.2% in Ethiopia (Odwee et al., 2020:128), while a South African study reported 13% of the participants being underweight (Mahlangu, Modjadji & Madiba, 2020). Besides digestive problems, some PLHIV develops problems with their weight.

2.4.3 Weight gain and HIV

People living with HIV/AIDS have a variety of psychological and physiological symptoms associated with HIV itself, related medications, or a combination of both (Areri et al., 2020). It has also been noted that as PLHIV ages, some end up with several health problems, including metabolic abnormalities and increased fat accumulation around the waistline (Jaggers & Hand, 2016). Weight gain in PLHIV has been attributed to some medicines used as part of ART, but not everyone is affected by this (Alcorn, 2019). Sax et al. (2019) noted that of the PLHIV who had just begun their ART, showed that weight gain was associated with newer drugs that have been introduced as part of ART which is better tolerated by most patients' bodies. Hill and colleagues (2019) reported similar findings in two randomized control trials conducted in Cameroon and South Africa to investigate the link between weight gain and ART medicines. The trial in Cameroon investigated 613 male and female adult participants and showed that women were more likely to gain weight at the beginning of their ART programme than their male counterparts (Hill et al., 2019). According to the study's findings, a weight gain greater than 10% of body mass was more likely to occur in women taking Dolutegravir compared to Efavirenz after about 48 weeks, but there was no significant weight gain by regimen in men (Hill et al., 2019). Similar findings were obtained in the randomized trial conducted in South Africa with 1053 adult and adolescent participants. A majority of the participants in the South African trial were women, and the participants were randomized to treatment either by Tenofovir Alafenamide Fumarate (TAF), Emtricitabine and Dolutegravir; Tenofovir Disoproxil fumarate (TDF), Emtricitabine and Dolutegravir or TDF, Emtricitabine and Efavirenz (Hill et al., 2019). Participant weight was measured at baseline, every 12 weeks, week 48 and week 96. After 48 weeks and 96 weeks, the findings from all arms show that

women gained more weight than their male counterparts. For instance, in the TAF arm, 20% of women became clinically obese by week 48 and 23% by week 96, compared to 8% of men at weeks 48 and 96 (Hill et al., 2019). All these studies show that besides other factors that might cause weight gain in PLHIV, the medicines used as part of the ART program also contribute significantly. Obesity and weight gain in PLHIV have been linked to other health problems like diabetes and cardiovascular disease (Alcorn, 2019).

2.4.4 The nervous system

HIV can also affect the central nervous system due to inflammation of the spinal cord, damaging it or the brain and altering how it functions (Nazario, 2019). Globally, problems of the nervous system are estimated to affect about 40% of PLHIV, and HIV infection can affect the peripheral or nervous systems and muscles (Krel & Thomas, 2018). It has, however, not yet been established how HIV affects nerve cells, but experts believe that it infects the cells that support and surround nerves in the brain and throughout the body (Pietrangelo & Cherney, 2021). It has also not been established how HIV is linked to neurological damage, but it is known to affect support cells of the nervous system, and the infections contribute to nerve injury (Pietrangelo & Cherney, 2021).

However, advanced HIV is known to cause nerve damage, also known as neuropathy, and it usually causes pain and numbness in the feet and hands (Nazario, 2019). It was a few decades ago when the ART was introduced, and the increase in the life expectancy of PLHIV, signs, and symptoms indicating a decline of brain function and movement capacity as well as changes in the behaviour and mood were noted, exposing a state known as HIV-associated neurocognitive disorder (HAND) (Rojas-Celis, Valiente-Echeverria, Soto-Rifo & Toro-Ascuy, 2019:1245). HAND is separated into three conditions according to the severity of the clinical manifestations: asymptomatic neurocognitive impairment (ANI), mild neurocognitive disorder (MND), and HIV-associated dementia (HAD) (Rojas-Celis et al., 2019:1245). While ANI and MND are associated with mild cognitive functions of a patient, which adversely affects their daily routine, HAD is a more

severe form of HAND, which is associated with rapid motor slowdown, reduced concentration, and several other adverse behavioural changes that can result in death within a short period (Rojas-Celis et al., 2019:1245).

2.4.5 The respiratory system

HIV infection renders common colds and flu, relatively minor respiratory ailments, more difficult to control (Kaplan, 2021). There is very little data on the numbers of PLHIV affected by respiratory issues. However, a study conducted in Europe showed that about 47% of People living with HIV suffer from respiratory symptoms as compared to just about 23% of HIV-negative people (Brown, Roy, Harris, Filson, Johnson, Abubakar & Lipman, 2017). These common ailments may lead to more severe symptoms like pneumonia, tuberculosis, and a fungal infection known as pneumocystis jiroveci pneumonia (PJP) (Pietrangelo & Cherney, 2021). PJP triggers symptoms like fever, cough, and difficulty in breathing. HIV infection can also weaken the functioning of the lungs and open up the way for more infections like lung cancer. Research has shown that people with HIV are at a higher risk of being affected by lung cancer than people without HIV (Pietrangelo & Cherney, 2021). In addition, a person with a low CD4 count due to HIV infection is vulnerable to tuberculosis (TB), an airborne bacterium that affects the lungs. TB is a leading cause of death among People living with HIV across the globe, with symptoms like chest pains and a severe cough that sometimes contain blood or phlegm (Nazario, 2019). This cough can last a long while and causes extensive damage to the lungs.

2.5 The Psychological Effects of HIV

HIV can also cause psychological problems for inpatients and those responsible for their day-to-day care. These range from depression to feelings of anxiety and trauma (Kinyanda et al., 2018). It has recently been noted that the HIV epidemic exerts an enormous mental health burden on its victims and their families (Yeneabat, Bedaso & Amare, 2017). Mental health problems can both be a cause and a result of hardships and challenges, such as those relating to HIV (Kinyanda et al., 2018). Research has

established that people living with HIV (PLHIV) show high rates of trauma, anxiety, and depression, which result from several factors like stigma and the direct burden of the disease (Lwidiko, Kibusi, Nyundo & Mpondo, 2018). The study by Lwidiko et al. (2018), conducted in Tanzania, revealed that 12.9% overall prevalence of depressive symptoms out of 900 adolescent participants. It was also established that 27% of the participants screened for positive depressive symptoms were HIV positive, while only 5.8% were unaffected by HIV. Another cross-sectional study in Ethiopia identified depression as one of the most common psychiatric disorders, with a prevalence rate of about 60% in PLHIV, while the general population had a prevalence rate ranging from 5% to 10% (Yeneabat et al., 2017). Furthermore, it has also been found that depression in people living with HIV is also associated with poorer health status overall, including low weight gain, low CD4 progression, and suicide but also with faster progression to AIDS and increased mortality (Abas, Ali, Nakimuli-Mpungu, & Chibanda, 2014; Kingori, Haile & Ngatia, 2015).

In South Africa and the Sub-Saharan region, there is a general lack of resources to assist PLHIV in dealing with their psychological issues despite the availability of data on effective interventions (Lwidiko et al., 2018). It has also been established that the connection between HIV and mental health is limited, even though it is known to be acute among the 15 to 24 age group (Asrat, Schneider, Ambaw & Lund, 2020). Therefore, mental health for PLHIV is only considered in terms of providing psychosocial support. The World Health Organisation (WHO) has reiterated that mental health should be a top priority, especially for young adolescents in developing countries (Nagata, Hathi, Ferguson, Hindin, Yoshida & Ross, 2018). Mental health considerations are crucial in understanding both pathways to risk and how emotional support can help ameliorate the mental health burden in adolescents.

2.6 Education and HIV

There has been mixed observational evidence on the association between educational attainment and HIV status across sub-Saharan Africa (De Neve, Fink, Subramanian,

Moyo & Bor, 2015). Several studies that have been conducted on the relationship between education and rates of infection have been mainly mixed with others showing that those young adults who spend more time in school are less likely to get infected (De Neve et al., 2015; Stoner, Pettifor, Edwards, Aiello, Halpern & Julien, 2017). Two cross-sectional studies held in Botswana, Malawi, and Uganda that investigated the effect of changes in national educational policy showed evidence supporting the assertion that spending more time in school helps protect young people against the risk of contracting HIV (Dallabetta, Miotti & Chipangwi, 1993; Kirunga & Ntozi, 1997). The study revealed that every additional year spent by a student at school reduced the cumulative risk of contracting HIV by 8.1 percentage points, and this was relative to a baseline prevalence rate of 25.5% among the research participants. In addition, female participants were found to have a much more reduced cumulative risk with more percentage points (11.6 percentage points) (De Neve et al., 2015).

Other studies conducted in Southern Africa have also shown that increased levels of school attendance reduce the likelihood of HIV infection because it was believed to lower risky sexual behaviour among young adults providing evidence for a pathway that would explain the causal mechanisms for a protective effect (Mee et al., 2018; Stoner et al., 2017). In Malawi, an experiment in which young women were encouraged to attend school showed that the HIV prevalence rate among these young women decreased once they started attending school (Mee et al., 2018). A randomized trial, which also investigated the link between the provision of cash incentives for school attendance and HIV prevalence in South Africa, also showed that young women who had lower school attendance or those who dropped out of school had a higher risk of being HIV positive (Stoner et al., 2017).

There are various ways through which education can assist in the fight against HIV. Mee et al. (2018) point out that if young people spend more time in school, they get more exposure to sexual and reproductive health education. For young women, the benefits of spending more time in school and acquiring further qualifications can improve their socio-

economic conditions, liberating them from an overreliance on sexual partners and empowering them to negotiate safer sexual practices (UNAIDS, 2015c). Furthermore, higher educational qualifications allow young people, especially women, to develop socio-cognitive abilities and better assimilate risk information (Mee et al., 2018). Other researchers have also suggested that education can be protective because school takes a more significant proportion of their time regularly in a social environment where they interact with their peers as opposed to the outside world where the likelihood of meeting sexual partners is higher along with the risk of contracting HIV (Stoner et al., 2017).

The importance of education about the reduction of HIV infection seems to be confirmed by more studies that are taking place in many parts of sub-Saharan Africa (Stoner et al., 2017; De Neve et al., 2015; Mee et al., 2018). For example, in another study on the trends and determinants of HIV knowledge in Nigeria, it was established that in regions where the youths are more informed about HIV, the rates of infection are low (Ayodeji, Oginni, Adebajo & Ahonsi, 2018). This confirms the value of education because it is the way information on reproductive health is conveyed. Globally, evidence has shown that despite the high level of awareness of HIV among young adults, comprehensive knowledge of HIV remains unacceptably low, even in countries most affected by the epidemic, including the sub-Saharan region (UNAIDS, 2015b).

The UN General Assembly on AIDS (UNGASS) notes that it remains essential for young people aged 15–24 to correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission in order to encourage behaviour change among them (Ayodeji et al., 2018). This would go a long way to reduce the prevalence of the disease and allow those already infected to manage their conditions better. All these studies show that school attendance and education, in general, can reduce or even prevent significant numbers of young people from getting infected by HIV. This is because it provides them with something meaningful to do with their time and gives them reading and writing skills, allowing them to stay informed about such vital matters as HIV. This was corroborated by the findings of the studies conducted in Liberia and Kenya,

which showed that education increased HIV knowledge among youths in the two countries (Ayodeji et al., 2018). An increase in HIV knowledge was noticed in Liberia between 2003 and 2013 (Ayodeji et al., 2018). Levels of knowledge rose by more than 50% among the 15 to 24 age group, while in Kenya, there was an increase from 22% to 54% during the same period owing to increased education attainment (Ayodeji et al., 2018). Education also reduces the incidence of stigma because it disseminates enough information about HIV that helps to clear the myths about HIV (Ayodeji et al., 2018).

2.7 HIV Prevention Interventions

As outlined in the previous section, HIV causes many physical and psychological problems that negatively impact the quality of life for patients and their families. It is, therefore, crucial for these problems to be mitigated. Many preventive measures have been designed to achieve success in the fight against HIV and improve the quality of life for those already infected with HIV. These include antiretroviral medicines, male and female condoms, behavioural change, and voluntary medical male circumcision (VMMC).

2.7.1 Use of condoms

Risky behaviour, in this case, refers to having unprotected sex with several partners and sharing needles with others when using drugs. Research has established that the most common way for HIV transfer is through anal or vaginal sex without a condom (Pietrangelo, 2020). It is, therefore, important to practice safe sex, which means people should use condoms consistently whenever they engage in sex. Condoms have proven to be very effective in preventing all forms of sexually transmitted diseases and have a low failure rate (National Health Service (NHS), 2018). It is also important to note that condoms are most effective when used correctly. According to Myhre and Sifris (2020), HIV prevention is not only about just following the rules but a deeper understanding of the dynamics of infection and ways to prevent it from happening. Condoms are not the only preventive measure available against HIV since other methods are being developed.

There are fairly recent methods that have been developed such as PrEP that those who are at high risk can use to prevent HIV infection.

2.7.2 The use of pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis is a method of preventing HIV infection by taking an anti-retroviral pill each time before engaging in sexual activity, and it is known to prevent the risk of getting HIV quite significantly (Myhre & Sifris, 2020; Muessig & Cohen, 2014). PrEP is meant for HIV-negative people but at a higher risk of contracting HIV, including those living with HIV-positive partners or those sharing needles (Cleveland clinic, 2022). PrEP drugs can be taken as a tablet daily for seven days before having planned sex and every day after for as long as one needs to take them, or they can be taken just before intercourse. Typically, a person needs to take the medication 24 hours before a sexual encounter and up to 2 days after the sexual encounter (O'Byrne, Orser, Jacob, Bourgault & Lee, 2019). When taken correctly, the drugs are effective against the risk of contracting HIV after exposure (WHI, 2021).

However, according to the Washington Health Institute (WHI), there are only two drugs, Truvada and Descovy that have been approved for use (WHI, 2021). Truvada is a combination of two compounds, Emtricitabine, and Tenofovir and is available as a pill. PrEP drugs work by stopping HIV from multiplying in the body. Myhre and Sifris (2020) explain that PrEP drugs assist the body in manufacturing antibodies that fight HIV in the body and prevent it from causing disease. In addition, Tenofovir and Emtricitabine, found in the Truvada pill, work by blocking the enzyme HIV needs to multiply, which stops HIV from infecting an individual exposed to it (WHI, 2021).

Pre-exposure prophylaxis has also been an effective preventive measure in serodiscordant partners (couples in which one partner is HIV-negative), where if it is used correctly, it allows for safe pregnancy (Muessig & Cohen, 2014). In addition, PrEP has proven to be quite effective in preventing the transmission of HIV. In a recent study among gay men in the USA, PrEP was found to reduce the risk of infection by 99 % if taken daily

(Anderson, Glidden, Liu, Buchbinder, Lama & Guanira, 2012). A sub-study within the Partners PrEP study analysed adherence to antiretroviral prophylaxis among African HIV-serodiscordant couples and found that the efficacy of PrEP was 100% among highly adherent PrEP users (Haberer, Baeten, Campbell, Wangisi, Katabira & Ronald, 2013). The bottom line is that PrEP is an effective prevention method that gives hope to many partners of People living with HIV of living a normal life. This prevention method is specifically for partners who are HIV-free themselves and have not yet been exposed prior to starting the treatment, and it is different from antiretroviral therapy, which is directly aimed at those who are already infected.

2.7.3 Post-exposure prophylaxis (PEP)

Post-exposure Prophylaxis (PEP) is a method used to prevent the infection of HIV after recent exposure. The word prophylaxis means to prevent or control the spread of an infection or disease (Inciarte et al., 2020). PEP entails taking HIV medicines within 72 hours after being exposed to HIV to prevent infection. According to the Centre for Disease Control and Prevention (CDC), HIV takes only about 24 to 36 hours to establish infection after exposure. Therefore, if one gets exposed to infection, they have a small window period during which they should administer PEP (CDC, 2021). It is further advised that PEP should be prescribed in people whose vagina, rectum, eye, mouth or mucous membrane, non-intact skin, or perforated skin (e.g., needle stick) come into contact with potentially contaminated body fluids from an HIV- infected source, as long as they are still within the 72-hour window period (CDC, 2021).

The effectiveness of PEP in preventing HIV infection has been measured through studies that focused mainly on animals and observational human studies because a randomized controlled trial to compare the effects of PEP without intervention is deemed unethical (Mulka, Annandale, Richardson, Fisher & Richardson, 2016:107). A single case-control study was conducted in 1997 on healthcare workers from France, Italy, the UK, and the USA who had experienced exposure to HIV-infected blood (Cardo, Culver, Ciesielski,

Srivastava, Marcus, Abiteboul, Heptonstall, Ippolito, Lot, McKibben & Bell, 1997). The controls for this study were HIV-negative and remained negative for at least six (6) months after the study, while among the cases with HIV seroconversion were individuals who were temporarily exposed and had no other known exposures to HIV at the time (Cardo et al., 1997:107). The findings of this study revealed that the cases that received PEP after exposure had their HIV seroconversion reduced by 81% compared to those who did not receive PEP (Cardo et al., 1997:107). According to Dominguez et al. (2018), this study represents the strongest example of the effectiveness of PEP to date. Further studies have been conducted recently and have shown that the effectiveness of PEP can only be enhanced if their administration is done soon after exposure and provided sufficient medications are available (Inciarte et al., 2020; Mulka et al., 2016). In addition to medical intervention, education is another intervention for HIV prevention, and when prevention fails, it is crucial to implement effective HIV management interventions.

2.8 HIV Management Interventions

Since the advent of HIV, much research has been done to understand, manage, and bring it under control. The most common form of management of HIV to date is antiretroviral therapy, which is a very effective way of tackling HIV, and the highly active antiretroviral therapy (HAART), a version of the ART program.

2.8.1 Antiretroviral therapy (ART)

The treatment of PLHIV using drugs that reduce the amount of HIV in an infected person's body is known as ART (Centre for Disease Control (CDC), 2021). HIV has no cure, but with appropriate medical care, it can be controlled (Rodger, Cambiano, Bruun, Vernazza, Collins & Degen, 2019). ART is responsible for changing many people's lives and improving the life expectancy of many people living with HIV (CDC, 2021). A recent study in the United Kingdom on HIV-1-serodiscordant couples compared early administration of ART with late initiation, and the findings revealed that early initiation of ART among HIV-positive partners reduced the risk of infecting HIV-negative individuals by 93% (Eshleman,

et al., 2017:114). Furthermore, an observational study of gay men conducted at 75 sites in 14 European countries discovered that “HIV-infected persons who were treated with ART and achieved viral suppression were 94% less likely to transmit HIV compared to persons with undiagnosed HIV” (Rodger et al., 2019). Globally, the effectiveness of ART is beyond doubt, with figures showing an 18% rise in viral suppression among PLHIV between 2015 and 2019 (Damulak, Ismail, Abdul Manaf, Mohd Said & Agbaji, 2021). It is also important to note that ART only works to reduce HIV, and it does not work against other sexually transmitted infections (STIs) (CDC, 2021).

Despite ART being the best intervention available for all PLHIV, many people still cannot access it (United States Agency for International Aid (USAID), 2022). Of all people infected with HIV in the world, 66% are in the Sub-Saharan region, with about 19.5 million found in East Africa, 17 million in Southern Africa, and 7.7 million in South Africa (Gebremichael et al., 2020). According to the World Health Organization (WHO), approximately 15.3 million PLHIV were receiving ART in Africa by the end of 2017, which is 70% of the 21.7 million people accessing antiretroviral (ARV) worldwide (WHO, 2020). However, there are disparities in access to ART within the region. Ethiopia, for example where, of the 610000 people living with HIV, only 480000 (78%) are currently taking ART, even though everyone infected requires ART (UNAIDS, 2022). According to Gonzalez (2022), South Africa has the world’s most extensive ART program, with 5.4 million people (74%) receiving ART treatment. With about 8.2 million PLHIV in 2021 (Statistics South Africa, 2021), South Africa accounts for 21% of the global HIV burden and 14% of new HIV infections (UNAIDS, 2019). As of 2020, the African country with the highest ART uptake was Eswatini with 98% (Statista, 2020).

South Africa launched its ART program in 2004 and has been leading in adopting ART policy recommendations (StatsSA, 2021). The country has become a testing ground for improving the HIV response from a developing country's perspective. Currently, the country has managed to get 70% of PLHIV, who are 15 years old and above, on the ART program, and this is a result of significant investments into AIDS programs and massive

awareness campaigns over the last 15 years (Gonzalez, 2022). Despite these efforts, South Africa's national HIV program fails to achieve the UNAIDS 90–90–90 targets for epidemic control and has the highest number of new HIV infections per year (UNAIDS, 2019). Furthermore, due to the COVID-19 pandemic, there has been a four (4) per cent decline in the number of PLHIV in the ART program (StatsSA, 2022). Data suggests a decline in the annual number of clients remaining on ART by approximately 4% (StatsSA, 2022).

It is clear that the COVID-19 pandemic has, to some extent, interrupted HIV prevention and treatment programs in South Africa as it did globally. Research indicates that the pandemic disturbed up to 75% of HIV services in several places worldwide (Adugna, Azanaw, Sharew & Melaku, 2021). For instance, during the lockdown in Zambia, there was a 35% decline in HIV tests conducted, while in Ethiopia, more than 50% of HIV services were also disrupted (Adugna et al., 2021). Due to the nature of HIV, medical treatment of HIV requires a combination of multiple drugs, hence the adoption of Highly Active Antiretroviral therapy (HAART).

HIV/AIDS is usually managed through the use of multiple antiretroviral drugs in order to control it and deal with barriers that work against the proper treatment of patients, like stigma. This strategy of employing several drugs that act on different viral targets is known as highly active antiretroviral therapy (HAART). Many classes of antiretroviral agents are used at different stages of the HIV life cycle (Eisinger, Dieffenbach & Fauci, 2019:451). These classes include Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs), Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs), Protease inhibitors (PIs), and Integrase Strand Transfer Inhibitors (INSTIs) (Eisinger et al., 2019:451). The NRTIs are nucleoside or nucleotide analogues that enter a growing viral strand, competitively bind, and reverse transcriptase and cause premature deoxyribonucleic acid (DNA) chains as they inhibit 3' to 5' phosphodiester bond formation (Saag et al., 2018). NNRTIs, on the other hand, create a stereochemical change within reverse transcriptase, thus inhibiting nucleoside binding and inhibition of DNA polymerase (Saag et al., 2018). Some examples

of NNRTIS are Nevirapine, delavirdine, efavirenz, and rilpivirine. The antiretroviral drugs referred to as PI are typically applied in patients whose initial HAART regimen does not succeed and are administered together with boosters like Ritonavir (Lennox et al., 2014). Examples of PIs include atazanavir, darunavir, and indinavir. There is also a regimen known as INSTIs, whose examples include raltegravir, dolutegravir, and elvitegravir (Eggleton & Nagalli, 2022). The primary purpose of these integrase inhibitors is to bind viral integrase and stop viral DNA from being incorporated into the host cell chromosome (Eggleton & Nagalli, 2022).

According to Eisinger et al. (2019:451), using different drug combinations as part of HAART lowers an infected person's viral load, keeps the immune system working and forms a barrier against opportunistic infections often cause death. It also stops the transmission of HIV between sero-discordant couples, provided that the HIV-positive partner maintains an undetectable viral load (Lazarus, Safreed-Harmon, Barton, Costagliola, Dedes, Del Amo & Valero, 2016). The management and control of HIV have gained considerable success worldwide to the extent that HIV has become a chronic condition, and progression to full-blown AIDS is becoming increasingly rare. Anthony Fauci, the head of the United States National Institute of Allergy and Infectious Diseases, states, "With collective and resolute action now and a steadfast commitment for years to come, an AIDS-free generation is indeed within reach" (Hoffman, 2019:1). Fauci also explained that ART saved about 700,000 lives in 2010 alone (Ibid). It has been noted that the fight against AIDS has turned into efforts to manage and control HIV as a chronic condition since there is currently no cure, and that highlights the necessity of self-management as part of HIV management (Rodger et al., 2019).

2.8.2 HIV self-management

Self-management (SM) means the management of illness needs (managing medication and daily physical health), activating social support (family, peers, and HIV care providers), and living with chronic illness (Russell, Martin, Zalwango, Namukwaya,

Nalugya, Muhumuza, Katongole & Seeley, 2016). For ART programs to succeed, they must rely on effective and prolonged SM programs to guarantee maximum uptake of “medical, physical, emotional, and psychological recommendations” (WHO, 2020). Usually, the healthcare provider must assist the patient in identifying suitable SM practices that best fit their condition and guide them in a patient-centred approach that allows them to self-manage their health condition (Russell et al., 2016). Healthcare providers can help identify the unique SM needs of patients and guide a patient-centred approach to enable patients to be the self-manager of their health conditions (Kirton, 2014:26). Several studies have concluded that HIV SM in both high and middle-income countries is based on three domains; social support, daily physical health practice, and living with HIV (Russell et al., 2016; Schulman-Green et al., 2012; Webel et al., 2012).

2.8.2.1 Daily physical health practice

This refers to physical exercise, diet management, reducing stress, symptom management, managing drug side effects, and implementing other recommended physical health activities (Aneri, et al., 2020). The use of physical exercise has been seen as an intervention that can help PLHIV who have problems with their weight, their muscular system, and cardiovascular issues, among other issues. Research has shown that physical exercise leads to positive changes across clinical measurements of health, such as body mass index (BMI), waist circumference, muscular strength, and cardiorespiratory fitness (CRF), among others (Jaggers & Hand, 2016). A randomized controlled trial conducted in South Africa to examine the effects of aerobic exercises on cognitive impairment among PLHIV has highlighted that physical exercises have a significant impact on reducing stress and depression (Nweke, Mshunqane, Govender, Akinpelu, Ogunniyi, 2022).

In the trial, a total of 73 participants diagnosed with HAND were randomly selected for the trial, which lasted three months, and the findings showed that physical exercise lowered depression scores consistently for the duration of the study (Nweke et al., 2022). The

participants participated in 20-60-minute exercise sessions per week, and the findings after three months showed that physical exercise improves the quality of life for PLHIV affected by HAND (Nweke et al., 2022). The benefits of physical exercise were also confirmed by a scoping review of studies that focused on people over 50 years of age living with HIV, which was carried out at the school of health sciences at the University of KwaZulu Natal (Chetty, Cobbing & Chetty, 2021). The review showed that physical exercise improves the quality of life for older people just as it does for younger people living with HIV.

According to Chetty et al. (2021), there was a positive correlation between exercise and physical, mental, and functional status in older people living with HIV. Jagers and Hand (2016) also supported the benefits that PLHIV can draw from regular physical exercise against the problems experienced from using HIV medicines and the risks presented by living a sedentary lifestyle. Numerous other studies document the notion that physical exercise is good for PLHIV as it enhances their quality of life (Grinspoon, Corcoran & Parلمان, 2000; Smith et al., 2001; Jagers & Hand, 2016; Chetty et al., 2021; Nweke et al., 2022). In addition to the daily physical health practice, HIV SM includes social support for the people living with the condition.

2.8.2.2 Social support

This term refers to the involvement of families, social networking, and healthcare providers to ensure effective SM (Russell et al., 2016). Research has shown that patients with access to social support can cope with stressful situations compared to those who do not enjoy social support (Khamarko & Myers, 2013). There is an important link between social support, depression, and health for People living with HIV, as social support reduces stress significantly (Wedajo, Degu, Deribew, 2022). This was confirmed by a cross-sectional study conducted in Ethiopia to determine the link between depression, social support, and internal stigma among PLHIV on second-line ART (Wedajo et al., 2022). The

findings of this study show that social support should be strengthened to counter the effects of depression in PLHIV (Wedajo et al., 2022).

Social support is crucial because it allows PLHIV to maintain good physical and mental health (Khamarko & Myers, 2013). One study of HIV-positive adult men conducted in Brazil established that in HIV-positive men, the lower availability of perceived social support was associated with the greater use of avoidance coping strategies and more significant mood disorders, including higher levels of self-reported depression and anxiety and lower levels of vigour (Isoldi, Carvalho & Simpson, 2017). A meta-analysis of 12 studies with 1782 participants from Australia, the USA, China, Belgium, and Canada who were gay men living with HIV was conducted, and the findings showed that social support had significant benefits for gay men living with HIV (*SMD* 2.22, 95% CI 0.24–4.20) (Yu, Wang & Wu, 2022). This emphasizes the importance of social support, and other studies on the benefits of social support on PLWHIV revealed similar findings (Berhe, Godana, Boti, Birgoda, Gebresilassie, Hussien & Gebeyehu, 2022; Brinkley-Rubinstein, Chadwick, Graci, 2013; McDowell & Serovich, 2007).

2.9 Living with HIV

According to Schulman-Green et al. (2012:137), living with HIV refers to “accepting and adjusting to HIV, dealing with stigma, and giving meaning to life with existing conditions.” The “HIV SM” is an all-encompassing process, according to Areri et al. (2020), and it includes knowledge about HIV itself, ways to manage symptoms of HIV, the benefits of ART, and coping with the side effects of ART. The concept of SM is gradually becoming more pronounced as innovative ways of dealing with HIV are discovered, but these developments were accelerated with the development of ART. For almost two (2) decades, there has been increased access to antiretroviral therapy (ART) and other HIV medical services for people living with HIV worldwide. In the period before ART became widespread, HIV medicines were very expensive and out of reach, especially in the developing world. The treatment used at the time was known as zidovudine monotherapy,

which cost US\$8000 per year at the time, and was not affordable in Africa (Ford, Calmy & von Schoen-Angerer, 2007). In the 1990s, a new treatment also became available in the developing world, but this was also deemed too expensive for the developing world due to resource constraints (Creese, Floyd, Alban & Guinness, 2002). It took a global effort to allow access to HIV medicines to less developed countries eventually. The development of ART improved the situation, because treatments have become cheaper with time. With improved access to ART, the focus is now on SM strategies that seek to improve the quality of life for PLHIV.

Self-management requires the support of the patient from family, friends, workmates, and healthcare workers for it to be more effective (Areri et al., 2020). Therefore, PLHIV need to be involved in activities that give them the confidence to deal with their condition, and a supportive environment makes it easier for them to cope. However, it is concerning that the effectiveness of HIV self-management programs has not been ascertained since not much literature has explored this subject, especially among university students (Bernays et al., 2014). One of the few studies that examined the effectiveness of such a program was conducted by Ncama (2007), even though its focus was more on community-based support for self-management. The study examined the effectiveness of an integrated community/home-based care (ICHC) program in a rural community in South Africa and revealed the importance of community support (Ncama, 2007). Two groups of participants were identified, one comprising participants who were part of the ICHC and the other with participants who were not involved in the ICHC (Ncama, 2007). The study's findings revealed that PLHIV who were part of the ICHC had accepted their status and could freely disclose their status beyond just their families as compared to participants who were not members of the ICHC (Ncama, 2007). The findings showed the importance of community support through programs like the ICHC as part of SM interventions to PLHIV.

Living with HIV also exposes PLHIV to symptoms primarily associated with viral load rebound, poor quality lifestyle, distress, and risky behaviours such as alcohol abuse and sexual risky taking (Harding, Clucas, Lampe, Norwood, Date, Fisher, Johnson, Edwards,

Anderson & Sherr, 2012). A review of 19 studies that examined the self-management of pain and symptoms associated with HIV was conducted, and the total number of participants was 2189, drawn from PLHIV and caregivers (Nkhoma, Norton, Sabin, Winston, Merlin, Harding, 2018). Fifteen studies were conducted in the USA, while the remainder were in Europe. The findings indicated that self-management interventions delivered either through face-to-face strategies or in groups positively impacted the self-management of pain and symptoms associated with HIV (Nkhoma et al., 2018).

Further studies have identified HIV as a chronic condition, and it has been established that some of the benefits of SM include improvements in physical, psychosocial, health knowledge, and behaviour outcomes for People living with HIV (Milliard, Elliot & Girdler, 2013; Chrvla, Sherr & Lipman, 2016; O'Connell, Carthy & Savage, 2018). Furthermore, Russell et al. (2016) also supported the benefits of SM and noted that SM outcomes are comprehensive and far-reaching and include daily physical practice, activating social support, and managing medication. Despite these perceived benefits, YALHIV seems to face several challenges in the self-management of their condition (Bernays et al., 2014). This might be attributed to barriers that prevent young adults from strictly adhering to their treatment regimens. However, the extent of these barriers is unknown because not much research has been conducted on what happens outside the clinic. According to Bernays et al. (2014), the stigma that still prevails in communities about HIV forces most YALHIV to take their treatment in secret. They have to take treatment every day, which is aggravated by poverty. For example, they might live in a crowded house with little privacy and access to food (Bernays et al., 2014). Since there is not much literature on the self-management practices of YALHIV and the specific difficulties they encounter in their efforts at SM, it is envisaged that an inquiry into the SM practices of university students might help to provide some insights into the SM practices of YALHIV in general.

2.10 Self-Management of HIV amongst Students Living with HIV

Young people go through many different experiences as they transition from adolescents, and HIV adds an extra burden for young people who are already faced with various other challenging experiences. This makes SM a necessary intervention because it improves the health outcomes and quality of life for all YALHIV (Weiss et al, 2017:169; Milliard et al., 2013:104). Several aspects of self-management have been identified as affecting YALHIV, including stigma, participating in healthcare decisions and community activities, and coping with disclosing their status (Crowley, 2017:269). One study carried out in the Western Cape Province among YALHIV between ages 15 and 24 discovered that those receiving ART tended to have a high loss of follow-up rates and virological failure rates compared to adults (van Wyk, Kriel & Mukumbang, 2020). These realities are worrisome, hence the need to examine and understand young peoples' SM initiatives and identify any shortcomings that need to be addressed.

However, the researcher noted that there is a lack of literature that specifically documents the self-management needs and experiences of university students; hence the decision was to include the experiences of YALHIV in general for this section. According to Milliard et al. (2013:111), targeted SM programs based on the real needs of the patients could provide excellent outcomes for YALHIV. Therefore, it is imperative to identify these needs before any targeted SM interventions can be introduced. The University student population, in particular, has been considered as always in good health, but it has been found that a significant number of the students live with chronic diseases, including HIV, and this means they have additional needs that are different from youths who are HIV negative (Slogrove & Sohn, 2018:2).

Youths who are HIV positive have several SM needs that include access to medicines, a healthy diet, and a strong social support structure (Crowley et al., 2019: E7; Duffy, Bergman & Sharer, 2014:6; Mutumba, Mugerwa, Mussiime, Gautam, Nakyambadde, Matama & Stephenson, 2019:1). In addition, Adams and Crowley (2021:6) reiterated that

YALHIV need to be in an environment that fosters positive feelings and self-esteem, access to sexual health knowledge and self-regulation skills. They also encouraged the provision of youth-friendly services (dedicated areas and time), training healthcare workers to understand the needs of YALHIV better (Adams & Crowley, 2021:8). YALHIV must be reminded to take their medicines consistently. They need to socialize with their peers, make friends and share their experiences with people who share the same experiences (Denison et al., 2015:4). One study that was conducted in Ghana about facilitators and barriers to antiretroviral therapy adherence among adolescents discovered that YALHIV cited forgetfulness as a barrier to adherence and non-compliance to medication (Milliard et al., 2013). Social activities have been found to affect YALHIV to remember their treatment times. Others rely on the alarms on their mobile phones to remind them of their treatment (Ankrah, Koster, Mantel-Teeuwisse, Arhinful, Agyepong & Lartey, 2016). Young adults might, at times, not take their medicines at home because of commitments such as college or other public activities that may overlap with their treatment times or they might want to keep the knowledge of their condition away from their peers, which might mean a unique plan has to be worked out to ensure they keep taking their medicines (Ankrah et al., 2016).

Healthcare workers were also identified as essential role players in the SM initiatives that YALHIV rely upon regularly. They administer ART treatment, provide counselling services, and encourage them to adhere to their treatment regimens (Mutumba et al., 2019:5).

2.11 Factors inhibiting HIV prevention and management in young people

Despite the remarkable progress that has been achieved to date in the prevention and management of HIV, several factors negatively impact this progress, especially in young people. For example, a study by Chimoyi, Lienhardt, Moodley, Shete, Churchyard and Charalambous, (2022) identified many factors that act as barriers to implementing prevention and management initiatives among young people, including substance abuse, suboptimal condom use and HIV stigma.

2.11.1 Substance abuse

Substance abuse has become one of the major issues affecting YALHIV in the sub-Saharan region and beyond (Kasirye, 2015). Even though alcohol is still the primary substance that young adults abuse, there is growing concern over using prescription drugs, whether by injection or not (UN Office on Drugs and Crime [UNODC], 2016). According to UNODC (2016), approximately 500,000 to 3 million individuals reported injecting drugs in sub-Saharan Africa and about one-fifth are estimated to be living with HIV. Non-injection drug use in Africa ranged widely across substances, and it is believed that about 1.6 million people used opiates, 2.8 million persons used cocaine, and 5.5 million persons used amphetamines and prescription stimulants (UNODC, 2016). As Africa assimilates into illicit drug peddling networks, there is a likelihood that both injection and non-injection drug use are expected to expand (Kasirye, 2016). Also, there are striking similarities between substance use and HIV because they are both responsible for hindering optimal physical and mental health, well-being, and quality of life (Groenewald & Bhana, 2018). A study was conducted in Malawi to investigate drug abuse as a risk factor for HIV infection, which drew its sample from self-presenting drug abusers who came to a district hospital in Malawi (Bisika, Konyani, Chamangwana & Khanyizira, 2008). The study found a higher prevalence of HIV among non-injecting drug abusers, with those who abused alcohol being more likely to be HIV positive than cannabis abusers (Bisika et al., 2008).

Like HIV, substance abuse can significantly and negatively alter every part of one's life, creating social and family relationship issues, problems with work production and finances, criminal and legal complications, and poor medical and mental health (Muchiri & dos Santos, 2018). According to Poniek (2021), drug abuse exposes users to many risks, which only get worse when one becomes addicted to them. A somewhat responsible person can take stupid risks they otherwise would not take under normal circumstances. Poniek (2008) further adds that drugs and alcohol tend to lower inhibitions, which could

lead to unsafe (unprotected) sex or other impulsive decisions, thereby putting one at severe risk and being highly susceptible to HIV infection.

It has been noted that YALHIV who use substances and are not in any rehabilitation program or taking any medication for this may run the risk of failing to achieve optimal engagement in HIV care and treatment when they are put in comparison to those who do not use substances (Azar, Wood & Nguyen, 2015). Furthermore, it is interesting to note that individuals who are going through substance abuse treatment generally do not get tested for HIV, and therefore they also miss out on HIV reduction counselling (WHO, 2014). Sub-Saharan Africa has the highest prevalence (7.4 per 1000 people) of both HIV and heavy episodic drinking in the world (WHO, 2014). Youth in most countries in the region supplement sexual encounters with frequent heavy alcohol use, which may ultimately lead to alcohol use disorders (Lancaster, Cernigliaro, Zulliger & Fleming, 2016).

Several effects of alcohol use have been noted to impact the contracting and transmission of HIV, which was the subject of much research. Excessive alcohol is known to impair one's ability to make judgments, leading to risky behaviour like unprotected sex and multiple sexual partners, and even drug use can directly affect cognitive ability and judgment (Nkosi, Rich, Kekwaletswe & Morojele, 2016). As pointed out by Lancaster et al. (2016), excessive consumption of alcohol is also biologically connected with an increase in HIV transmission and genital viral shedding. For YALHIV, excessive alcohol use negatively impacts adherence to ART and reduces the likelihood of plasma viral suppression, which is the main goal of ART (Nkosi et al., 2016).

According to Matlou (2016), students at South African universities engage in all sorts of irresponsible conduct as a result of consuming excessive amounts of alcohol, including indulging in unprotected casual sex, an act most of them regret afterwards. Research on alcohol abuse among South African postgraduate students conducted by Muswede & Roelofse (2018) also supported that students tend to engage in irresponsible behaviour, making them susceptible to HIV. It has also been noted that alcohol use among YALHIV

can cause ART resistance (Degenhardt, Peacock & College, 2017). For young adults, the prevalence of HIV continues to grow unchecked because most of them do not try to find more information and become more knowledgeable about HIV.

2.11.2 Suboptimal use of condoms

Even though condoms are one of the most effective preventive measures if used consistently, it is quite concerning, most young people in the 15 - 24 years age group either do not use them consistently or do not use them at all (Duby, Jonas, Appollis, Maruping, Dietrich & Mathews, 2021). In one study conducted in South Africa by Ntshiqqa, Musekiwa, Mlotshwa, Mangold, Reddy and Williams, (2018:1137), condom use among this particular age group was relatively low at 57.9%. Another study with 741 youth participants of both genders (in the 14 - 19 age group) from Soweto in South Africa revealed that 54.6% of males and 54.2% of females do not use condoms (Closson et al., 2018). This low level of condom use puts young men and women at an increased risk of HIV infection. More education needs to be provided on the protective benefits of condom use, as knowledge about HIV and education have been found to encourage condom use among the same age group (Closson et al., 2018).

One factor that has been identified as affecting condom use especially among young females relates to the power exerted in the type of sexual relationships they engage in. Some studies conducted in South Africa and other parts of the world revealed that gender roles and lower socioeconomic status among young people are linked with lower condom use (Fladseth, Gafos, Newell, & McGrath, 2015; Pinchoff, Boyer, Mutombo, Chowdhuri, & Ngo, 2017). The skewed power dynamics in age-disparate relationships (ADR) have been identified as one of the major factors contributing to lower condom use among young people (Caldwell & Mathews, 2016; Rodger et al., 2016). In South Africa, ADR is a widespread phenomenon motivated by economic factors or the need to attain social status. ADRs are often transactional in nature, characterised by young women seeking out or being sought after by older and wealthier men who can provide the finer things they

desperately yearn for in exchange for sex (George, Beckett, Reddy, Govender, Cawood, Khanyile & Kharsany, 2022:2). Whilst the young women who get involved in ADRs can enjoy material benefits, research has revealed that they lose their agency, and this puts them at a higher risk for contracting HIV because they have limited power to negotiate for protected sex (Sprague, McMahan, Maqsood & George, 2021). Since they become dependent on their 'blesser', younger women are afraid to request condom use due to fear of intimate partner violence or the loss of benefits accrued from the ADR (Duby et al., 2021:41; George et al., 2022:2).

2.11.3 HIV Stigma

HIV-related stigma has a negative impact on HIV prevention, treatment, and care especially among young people (Mendelsohn, Fournier & Caron-Roy, 2022). According to DeCarlo and Ekstrand (2016) HIV-related stigma is the negative beliefs, feelings, and attitudes towards people living with HIV/AIDS, their families, and people who work with them. Stigma dissuades young people from finding out more about HIV because they fear that doing so would expose their status to their peers or family members. In other cases, young people also fear being identified as promiscuous or unfaithful, or are members of populations associated with HIV, if they seek information about HIV (DeCarlo & Ekstrand, 2016). It causes discrimination and creates barriers that negatively impact HIV prevention. The impact of HIV stigma is more pronounced among young women and female adolescents. In the South African context, Stigma triggers fears of being ostracised socially among young women which prevents them from disclosing their status (Armstrong-Mensah, Ramsey-White, Yankey, & Self-Brown, 2019). The fear to disclose their status among young women and girls is a major obstacle in the fight against HIV prevention and management. HIV stigma also forces these young women to live in constant fear of being abused by spouses or community members and given that this is the group with the highest HIV prevalence rates, an integrated approach is thus required to address the stigma they experience on a regular basis (Armstrong-Mensah et al, 2019).

2.12 Knowledge of HIV among University Students

Many campaigns have been held to raise awareness among citizens to enable them to know and understand HIV and how it works (Mahy, Sabin, Feizzadeh & Wanyeki, 2021). These awareness campaigns seek to counter the stigma around HIV, encourage more people to get tested and ensure that all people living with HIV participate in interventions like ART (Joshi, Kaur, Kaur, Grover, Nash & El-Mohandes, 2021). Despite these efforts, researchers have established that there are still grave misconceptions concerning the transmission of HIV in South Africa among university students (Carter, 2016: 55). This points to the fact that although students have acquired basic HIV knowledge, detailed knowledge on the transmission of the disease is still very limited (Khamisa, Maboe & Basera, 2019). It is also important to note that past research shows the same findings relating to a lack of adequate knowledge about HIV among students who still engaged in unprotected sexual practices (Friedland et al., 1991; Galloway, 1999; Heeren et al., 2014; HEAIDS, 2008). Even in cases where students appeared to have sound knowledge about HIV, they still practised unsafe sex (HEAIDS, 2008; Ngidi, Moyo, Zulu, Adam & Krishna, 2016). The study by Ngidi et al. (2016), which was conducted at a University in KwaZulu Natal, identified peer pressure as one of the reasons that contributed to students engaging in high-risk sexual behaviour. Within this context, the findings revealed that university students could not negotiate risk-aware decisions, especially regarding sexual relationships (Ngidi et al., 2016).

Kene, Deribe, Adugna, Tekalegn, Seyoum and Geta, (2021) established that age was not a significant factor when considering the amount of knowledge people had of the HIV pandemic and its effects in general. For example, in a comparative study conducted between university students in the Western Cape (WC) and KZN, Reddy and Frantz (2011) discovered that there was no difference in HIV knowledge among the students even though those from KZN were older than those from WC. The other point noted in this study by Reddy and Frantz (2011) was that students were most likely to have their first sexual encounter without any knowledge of HIV. According to Kene et al. (2021), this

poses a significant risk to the students who might get knowledge about HIV when HIV has already infected them.

A study carried out by De Wet, Akinyemi, and Odimegwu (2019) investigated the accuracy of HIV knowledge among South African youths who were affected by HIV. These youths were in the 15 - 24 age group, and the sample was drawn from a baseline survey carried out in 2012. This study showed that more than a third of all youths in South Africa are affected by HIV. The study also revealed that about a quarter of the affected youths had 75% knowledge of HIV, while only 10% had 100% knowledge of HIV (De Wet et al., 2019). This showed that efforts to combat the spread of HIV could only be effective if there is improved accuracy in HIV knowledge among the youth. Another critical factor that is important in the fight against HIV among the youth is attitude.

2.13 Attitudes towards HIV among University Students

The issue of attitudes towards HIV among university students is still an area that need exploration, as most studies have focused on the prevalence of infection and knowledge of HIV (Haroun, El Saleh, Wood, Mechli, Al Marzouqi, & Anouti, 2016). An assessment of attitudes among university students in the Middle East revealed that even though knowledge of HIV was very high among university students, about 85 per cent of students tended to look down upon those living with the disease (Haroun et al., 2016). This means that in some instances, knowledge had minimal impact in reducing stigma towards PLHIV. In India, however, knowledge of HIV among university students improved their attitudes towards those living with HIV, with an attitude score of 87% (Limaye, Fortwengel, Limaye, Bhasi, Dhule, Dugane, Borkar, Pitani, Sathe & Atul Kapadi, 2019). In addition, university students in Johannesburg, South Africa, had a positive attitude towards people living with HIV (Khamisa et al., 2019). Positive attitudes among university students can help to create an enabling environment, where those living with the disease can get the support they need in their self-management efforts.

Khamisa and colleagues (2020) conducted a study to investigate gender differences in knowledge, attitudes and behaviours towards HIV and AIDS among 542 private higher education students in Johannesburg. The findings show no differences in attitudes towards HIV along gender lines. Another study aimed at determining the level of sexual knowledge and attitudes about risky sexual behaviour among a sample of South African university students was conducted by Fennie and Laas (2014). The participants (164 females and 56 males) were undergraduates with an average age of 20. The main findings showed that 80% of the participants had positive attitudes about HIV/AIDS, while 24% did not support the idea of sex before marriage, and only 33% indicated having unprotected sex (Fennie & Laas, 2014). About 47% of the participants said they would not engage in sex without protection, while 69% reported that they had been tested for HIV before, and 29% admitted that they had never been tested (Fennie & Laas, 2014). When the participants were asked about health education, 48% indicated that there should be more educational and awareness programmes (Fennie & Laas, 2014). This study showed that a significant part of this particular university was aware of the dangers surrounding risky sexual behaviour, and their attitude towards HIV was very positive since most of the participants had tested for HIV (Fennie & Laas, 2014). However, it remains critical to determining university students' self-management experiences on campus since not much is documented. This will go a long way in understanding these experiences with the hope that any challenges they face in their efforts can be identified to design solutions to those challenges. In general, understanding the HIV self-management practices of university students aims to improve the quality of life they live and help them attain their goals.

2.14 Chapter Summary

This chapter presented a literature review of relevant themes and issues that affect young adults concerning HIV. The literature has established that, young adults in the 18 - 30 age group are the most vulnerable to HIV infection, especially in the sub-Saharan region. A few studies conducted in different parts of the region were reviewed to give context to the

subject at hand and present the argument that it is not only in South Africa where young adults are affected by HIV. The reasons contributing to their vulnerability were also explored, and issues like substance abuse were found to contribute much to young adults contracting HIV. Even though factors like exposure to education are seen as having a positive effect on reducing vulnerability among young adults, many drop out of school due to several issues. The prevalence of HIV among young adults also has a gender dimension, which was briefly highlighted. Given the background of HIV infections among young adults and all the factors that contribute to this, it was also established that university students face the same issues that are faced by other young adults elsewhere, with their main difference being the burden of having to battle the disease while trying to build a career. However, not much has been written on how these students engage in HIV self-management. An awareness of how university students experience their HIV self-management is important because it would provide details on the shortcomings of the support programs that are already running in these institutions. The study would offer a chance to identify these weaknesses and allow students' HIV self-management strategies to be enhanced. The next chapter will present the methodology applied in this study.

CHAPTER 3 - RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the methodology that was used in this study. In addition, a description of the research approach, population, sampling techniques, data collection and analysis, and ethical considerations are also described in detail. The research methodology chosen for this study was considered suitable to achieve the aim of the study, which was to explore and describe the HIV self-management experiences of students at a higher education institution in the Western Cape area, with the following objective and sub-objectives:

- 1) To explore the experiences of higher education students on their HIV self-management at a higher education institution
 - a) To explore higher education students' understanding of their HIV condition
 - b) To describe the supportive role nurses can fulfil concerning the facilitation of self-management of HIV for higher education students.

The information presented in this chapter enables readers to understand the research processes followed, such as gathering and analysing data and the conclusions reached. Research methodology is "the path through which researchers conduct their research" (Sileyew, 2019:01). It is the full presentation of a researcher's implemented actions to reach the set objectives and find answers to the study's research questions. In addition, a research methodology describes and analyses the methods used by a researcher and justifies why particular methods were used over others. This chapter explains the research methods employed in this study.

3.2 Research Paradigm

A research paradigm represents a researcher's beliefs and values about the world, how they define it, and how they work within it. Mukherji and Albon (2015:24) describe a research paradigm as a researcher's specific way of looking at the world and making sense of it. These perspectives, thoughts, and beliefs about a subject under study are the key elements that guide the actions of a researcher. In other words, the paradigm adopted directs the researcher's investigation, including data collection and analysis procedures. According to Kivunja and Kuyini (2017:26), a research paradigm carries significant implications for every decision made throughout the research process. There are three common research paradigms, namely positivism, pragmatism, and constructivism.

Positivism is mainly centred on the belief that measuring and understanding a single reality is possible (Kamal, 2019:1389). Because of this, it is usually associated with quantitative methods of research. Conversely, pragmatism is the view that reality is continually interpreted and renegotiated against new and unpredictable situations (Antwi & Hamza, 2015:218). Lastly, constructivists believe there is no single reality or truth but multiple realities (Kamal, 2019:1389). For this reason, constructivists focus on understanding and interpreting the meaning attached to an action. Therefore, the researcher used the constructivist paradigm in this study.

This paradigm enables the researcher to imitate a subject's way of thinking in order to have a deeper understanding of their perspective in the proper context. Hence, the perspective of the study's subject is emphasised as opposed to that of the observer (Kamal, 2019:1389). In other words, this paradigm gives meaning to the subject, their thoughts, and beliefs from their perspective of the world around them and not from how others might interpret those (Kivunja & Kuyini, 2017:26). This gives credence to one of its central tenets which posits that reality is socially constructed (Kamal, 2019:1389).

When this paradigm is employed, one of its key-defining points is that theory guides the research process for it to be grounded on the collected data. According to Kivunja & Kuyini

(2017:26), the constructivist paradigm assumes a “subjectivist epistemology, a relativist ontology, a naturalist methodology, and a balanced axiology.” A subjectivist epistemology means that the researcher concludes and draws meaning from their interactions with the participant or subject. It is envisaged that when the researcher gets deeply immersed in the natural environment and settings of the subject, they can socially construct new knowledge using their personal experiences of that environment (Kamal, 2019:1389). This is premised on the belief that as the researcher interacts with the subject, ideas, thoughts, and realities transfer. These realities are borne out of these interactions and the dialogue that ensues, including questions posed, ideas generated, and shared thoughts (Kamal, 2019:1389). On the other hand, the assumption of a relativist ontology is based on the belief that the situation under study has many realities which can be further explored to give them meaning or redesigned through the interactions between the researcher and the research subjects and among the subjects themselves as well (Kivunja & Kuyini, 2017:27).

A balanced axiology assumes that the researcher's values will define the result of the research as the researcher attempts to present an objective and balanced report. This study revolved around the HIV self-management experiences and initiatives of higher education students living with HIV. These students were taken on board as the research participants because the researcher strongly believed that their experiences in self-managing HIV could be constructed into knowledge through reflecting on them. While the researcher interacted with several participants in understanding HIV self-management from their viewpoints, the personal opinions and judgements of the researcher were also at play and cannot be dismissed totally, which brings in the element of subjectivity. This aligns with how the researcher views the world and perceives how knowledge is constructed. In essence, how the researcher interacted with the participants and acted on the collected data reflects the constructivist paradigm. This also confirms Creswell (2014)'s viewpoint that constructivism deals with the development of subjective meanings

and understandings of one's personal experiences concerning specific topics based on their social and historical background.

3.3 Research Approach

Three main research approaches are used, namely quantitative, qualitative and mixed methods. The research aim and philosophical foundations of the research study guide the choice of the research approach (Bauer, Churchill, Mahendran, Walwyn, Lizotte & Villarueda, 2021). The quantitative research method investigates the links among variables that are calculated and examined using statistics and graphs (Sileyew, 2019). Bauer et al., (2021) maintain that a quantitative research approach could use a “mono method quantitative study” such as a questionnaire and the appropriate data analysis method. On the other hand, qualitative research is described as an “iterative process in which improved understanding of the scientific community is achieved by making new significant distinctions resulting from getting closer to the phenomenon studied” (Aspers & Corte, 2019:140). It is a systematic approach that allows a researcher to draw information and develop a certain level of detail through actual interaction with participants. This relates to the definition given by Mohajan (2018:30), who describes it as a form of “social action” that closely examines people's lived experiences and their understanding of those experiences, fitting this current study. Mixed methods draw on the potential strengths of the two methods, giving researchers the ability to expose their diverse perspectives and the complex relationships that exist beneath the various layers of research questions. The most important step in the mixed methods approach is the ability of the researcher to link the different forms of data collected at the precise time (Fetters & Molina-Azorin, 2020:136). Mixed methods also provide an excellent opportunity to explore the links and contradictions between the two methods, giving deeper insight and analysis. The mixed method research combines qualitative and quantitative methods of collecting and analysing data (Churchill, et al., 2021).

For this study, a qualitative research approach was applied. Qualitative research uses various methods to gather data, including interviews, diaries, journals, observations, and open-ended questionnaires. According to Mohajan (2018:30), qualitative research is usually exploratory because it attempts to answer the how and why questions of any particular social phenomenon or program. It tries to help us understand our social world and why things are the way they are (Aspers & Corte, 2019:141). Qualitative research has also been described as inductive, where a researcher analyses and explores insights into a given situation (Levitt, Motulsky, Wertz, Morrow & Ponterotto, 2017:10).

The importance of qualitative research lies in the fact that it serves several purposes, including improving the design and interpretation of traditional surveys (Mohajan, 2018:31). It helps to create new knowledge because it is also used to examine previously unexplored phenomena. Qualitative research gives a more in-depth analysis of any social phenomenon from the participants' perspective, as opposed to an external view that might not fully grasp all the underlying dynamics and intricate social relations. According to Mohajan (2018:31), qualitative research also helps to understand “complex phenomena that are difficult or impossible to capture using quantitative research.”

3.3.1 Justification for Using a Qualitative Approach

The Qualitative approach was chosen for this study mainly because the researcher wanted to conduct a more in-depth and independent analysis of the subject matter. As noted by Napolitano (2019:01), qualitative research is most appropriate, where the aim is to provide an intricate and deeper insight into the various relationships and cultural values of the subjects under study without the subjective feelings of the researcher. Secondly, the researcher intended to draw out the experiences of students living with HIV at university and their self-management of the condition. Living with HIV is very challenging and exposes students to very unusual circumstances, and they suffer stigma in some cases, negatively affecting their well-being and social lives (Kimera, Vindevogel, De Maeyer, Engelen, Musanje & Bilsen, 2019). The tendency in such situations might be for

the infected students to be secretive about their condition. According to Napolitano (2019:01), the Qualitative approach allows a researcher to draw out deeply personal experiences from a participant's perspective, thereby allowing for a holistic understanding of the human experience in specific settings.

Denzin (2017:12), for example, explained that qualitative research is “an interdisciplinary field which encompasses a wider range of epistemological viewpoints, research methods, and interpretive techniques of understanding human experiences.” For example, language assessment cannot be separated from values, culture, and context. As done in this study, qualitative research allows researchers to discover the participants' inner experiences and interpret the processes that shape meaning in and through culture (Timonen, Foley & Conlon, 2018:04). In the context of this study, the issue of self-management is dependent on conditions specific to a particular student; even though there might be similarities in experiences, the way these students view many factors shape their condition. Therefore, to understand the nuances in the experiences of students living with HIV on campus, the qualitative approach was deemed most suitable for this study.

3.4 Research Design

The study used exploratory, descriptive, and contextual research designs since the objective was to explore the HIV SM experiences of students living with HIV. McCombes (2019:01) defines a research design as a "plan that guides the procedures and methods used to gather and analyse the data". This means that a research design is used as a framework or guide for the researcher to understand what is being studied, how and why it is being studied, and how the observations will be documented and analysed in response to the research questions. This research design is a process of investigation through which a researcher seeks to understand a social or human problem.

3.4.1 Exploratory Research Design

The exploratory design was implemented to meet the purpose of this qualitative research study. Exploratory research aims to discover more about a subject; often, little is known about the phenomenon under question (Swedberg, 2020). Since there is limited information about HIV self-management among university students, this study aimed to make a contribution and add to the little available information. Information on HIV self-management among this group is important because it allows one to investigate the effectiveness of available self-management programs. This has been noted by Nkhoma, Norton, Sabin, Winston, Merlin and Harding (2018:208), who stated that very little research had investigated the effectiveness of self-management programs, and most of the available information mainly focused on adults. Crowley and Rohwer (2021) have also argued that there is very little evidence of effective components of self-management interventions to inform the development of interventions for youths in general, particularly for interventions focusing on enhancing social support, managing risk behaviours, and improving the quality of their lives. Since this area has not been adequately dealt with, an exploration of the self-management of HIV among university students is important. Exploratory research investigates a problem that has not been studied or thoroughly investigated in the past. In the case of this study, investigating how university students are self-managing their HIV condition is key to determining the effectiveness of the various support programs that have been put in place, as well as gaining better understanding of the support needs to be provided.

3.4.2 Descriptive Research Design

According to Surbhi (2017:70), descriptive research is rigorous, very structured, and more focused on describing characteristics and functions. The researcher used a descriptive research design because this study did not require a deeply theoretical context and aimed to stay close to and describe participants' experiences. As observed by Doyle, Brady, and Byrne (2016:624) use of a descriptive design is to provide straightforward descriptions of

experiences and perceptions, particularly in areas where little is known about the topic under investigation. A qualitative, descriptive design was considered the most suitable in this study because it acknowledges the subjective nature of the problem, and the different experiences participants have. In addition, it allowed the researcher to present the findings in a way that directly reflected the research questions posed at the study's beginning. Since the aim of this research was not about deepening the conceptual understanding of HIV self-management among students but rather an attempt to make a small contribution to improving the practice, a descriptive design was the most appropriate design (Chafe, 2017).

3.4.3 Contextual Research Design

This study also applied contextual design. Contextual research design is generally used in cases where a study investigates the context of the subject at hand. According to Duda, Warburton and Black (2020:45), this design is applied to understand the needs of people using a particular service by observing processes that underpin the service. This design is usually used during the early phases of investigations into a previously unexplored area because the collected data is critical in shaping design choices at this stage (Malpass, 2018:01). The contextual design relies mainly on a user's ability to remember and give a detailed account of a process that they are removed from at that moment. People try to give a summary of their processes. However, essential details usually get left out of the account that is given, leaving researchers with only a superficial understanding of the users' approach to the activity (Surbhi, 2017:75). In this study, the participants did not struggle to provide details of their experiences since they go through them daily. HIV affects different groups of people who are both young and old, and their lived experiences are quite varied. This meant that even though people living with HIV might share similar experiences, there are differences that relate to the context that could only be exposed if the specific context of the participants was established. Therefore, the contextual research design was appropriate for establishing the context of students living with HIV.

3.4.4 Rationale for the Adopted Research Design

A descriptive, exploratory, and contextual design was deemed appropriate for this study because it enabled the researcher to explore the participants' self-management experiences and to describe the contexts within which they engage in HIV self-management and get support from healthcare workers. The aim of this study was to understand the experiences of the students living with HIV and how they self-manage their condition every day since their ailment is a chronic condition. Their opinions, perceptions, and experiences were vital to answering the study's research questions because they are the most suitable to explain and describe their condition. It was, therefore, important to employ a design that would enable the researcher to get a more in-depth understanding of different thoughts and perceptions of the subject at hand (Timonen, et al., 2018:07). Hence this study relied on those thoughts, perceptions and narratives instead of numbers for its data, which is characteristic of a qualitative research design (Aspers & Corte, 2019:140).

3.5 Setting

The research setting refers to the social, cultural, and physical site where a research study is conducted (Malpass, 2018:01). The research setting is important in qualitative research since the main focus is mainly on understanding the context within which activities and actions of the participants happen, the researcher studies the participants in their natural setting. This study was conducted at a tertiary education Institution in the Western Cape since the study focuses on higher education students living with HIV. The institution has the largest enrolment in the Western Cape region with a student population of more than 30000 students.

3.6 Population

According to Etikan and Bala (2017:215), a population consists of all elements that meet the characteristics the researcher wishes to examine. For this research, the study

population comprised of higher education students living with HIV and residing on and off campus. A target population refers to a group of people of particular interest to a researcher and one the researcher wishes to investigate (Ackerman, Lesko, Siddique, Susukida & Stuart, 2021). In this respect, the target population for this study was current university students living with HIV both on and off campus at the selected institution. The researcher chose to select the sample from university students who were living with HIV at the selected higher education institution since the purpose of the investigation was to explore and describe the HIV self-management experiences of students at a higher education institution. In addition, it was essential to get the first-hand experiences of the participants since these experiences differ from individual to individual based on their unique circumstances.

3.7 Sampling Method

Sampling in research is a process that allows a researcher to carefully decide and choose participants for a particular study (Cash, Isaksson, Maier & Summers, 2022). Sampling can be defined as selecting a portion of the population in the applicable research area, and this sample population will effectively represent the entire population (Cash et al., 2022). Sampling is a necessary exercise from a practical point of view. Stratton (2021:273) states that collecting data from the entire population is impossible because time, budget and access may hinder the research when attempting to sample the entire population. There are two sampling methods, which are probability and non-probability sampling methods. While probability sampling aims to ensure representativeness and generalisation of results, it is appropriate for a quantitative study.

Non-probability sampling is generally described as a group of sampling techniques that guide researchers to choose samples from a population they are investigating (Pace, 2021:5). This method is usually not representative, less complex, cheaper, and more conveniently conducted with whoever is available. According to Iliyasu and Etikan (2021:25), there is no random selection in non-probability sampling, and they further

postulate that it can be adequate when the researcher does not want to generalise the findings beyond the sample, which is the case for this study. Several non-probability sampling techniques are available such as quota sampling, convenience sampling, purposive sampling, snowball sampling and professional referral sampling (Iliyasu and Etikan, 2021). Quota sampling is a non-probability technique where the researcher identifies a particular characteristic among the target population, which they then use as the basis for selection. The identified characteristic becomes the criteria for selecting participants for a study (Bhardwaj, 2019:157). It is similar to stratified random sampling, with the difference being that elements are not chosen randomly in quota sampling. Convenience sampling is mainly based on the accessibility of participants, and the researcher chooses participants that are easily accessible (Pace, 2021:5). This technique is usually used in pilot testing. The researcher relies on available data with no additional requirements. Purposive sampling is a sampling technique where participants are identified by the researcher based on their capabilities to fulfil the researcher's specific requirements (Bhardawj, 2019:157).

There is also snowball sampling, through which participants are chosen by meeting the set criteria for inclusion (Pace, 2021:5). Snowball sampling is used on hidden populations like criminals and sex workers. It is also used when the subject under study is sensitive, like drugs and HIV in this case (Simkus, 2022). The process continues through referrals from the participants who are initially selected. At first, the researcher chooses the initial sample by picking a few subjects from the target population. The researcher will then ask the initial participants to recruit other participants by encouraging them to come forward on their own (Simkus, 2022). The privacy of these other participants has to be guaranteed for them to participate and still retain the choice to decline participation. Current participants will continue the recruitment exercise until the required sample size has been reached (Simkus, 2022).

Lastly, professional referral sampling that was applied in this study; it involves selecting participants through an intermediary who provides professional service to the subject

(Hogan, et al., 2009). Professional referral sampling has received less notice as a methodology, but it is used in health research (Hogan et al., 2009). Although the researcher initially planned for snowballing sampling, due to the sensitivity of the topic under investigation, the researcher reverted to professional referral as both sampling techniques share the referral aspect.

3.8 Sample Size

In qualitative research, the sample size should be large enough to adequately describe the subject of interest and answer the research question (Shetty, 2022). However, the researcher has to be cautious to avoid repetitive data, known as going beyond data saturation. When data saturation has occurred, adding more participants will not add new or different perspectives (Shetty, 2022). Data saturation in certain instances can occur around 5 to 10 participants (Etiken & Bala, 2017:216). Therefore, in this study, the sample size was guided by data saturation. The point of data saturation is defined as the point in coding when one finds that no new codes occur in the data (Saunders et al., 2019:258). In this study, the data saturation was reached by participant seven, and the eighth interview was conducted to confirm data saturation; hence the final sample size for the study was eight (8).

3.9 Recruitment

Since the subject under investigation was a very sensitive one, the researcher sought permission to conduct interviews and obtained it from the relevant authorities at the campus clinic, who then referred the researcher to the Professional Nurse (PN) at the HIV unit of the clinic, who works directly with students that are living with HIV. After making initial contact with the Professional nurse via email, the researcher then arranged face-to-face meetings with the Professional Nurse to discuss her perceptions on the issue under study. The PN was very willing and helpful, which made the process less challenging. The PN helped identify potential participants and arranged telephonic meetings with them after she explained the study and asked for their consent to participate. Those who agreed to

participate also permitted their contact details to be shared with the researcher, who would contact them to arrange interviews.

A total of six (6) participants' contact details were shared with the researcher to arrange convenient times for the interviews. Five (5) of the six (6) participants identified by the PN agreed to participate in the study. The sixth participant verbalised telephonically to the researcher that she did not feel ready to speak about her condition as she had been recently diagnosed. The researcher reassured the participant that she was free to withdraw from the study even if she had initially agreed to participate and that nothing would be held against her. Data saturation was not reached with the five (5) participants that were interviewed. The researcher then contacted the PN from the campus clinic for more names of participants willing to participate in the study. A total of 10 potential participants were contacted and initially agreed to participate in the study. However, data saturation was reached with eight (8) participants, with two (2) having face-to-face interviews and six being interviewed telephonically. The recruitment process took about eight weeks to complete, mainly due to time constraints and study commitments from potential participants.

3.10 Data Collection Process

Data collection is collecting information from all the relevant sources to find answers to the research problem, test the hypothesis and/or evaluate the outcomes (Jain, 2021:542). It is also described as the gathering of data from a variety of sources by using scientific methods to get a deeper understanding of the subject under investigation (Aguinis, Hill & Bailey, 2021:679). Consistent with a qualitative research approach, this study used individual in-depth interviews as a data collection method. Individual in-depth interviews refer to a qualitative research method that has a combination of both pre-determined questions and open-ended questions so that interviewees can provide more clarity should they desire to; it also allows for further probing from the interviewer to garner more information on the related topic (Adeoye-Olatunde & Olenik, 2021:1358). Additionally,

Adeoye-Olatunde and Olenik (2021:1360) state that a probing question is a follow-up question that is asked in an interview to ensure that all pertinent points mentioned are understood in their full context, discover as much information about the study and allow the participant to add commentary or their point of view. Using individual in-depth interviews as a data collection method allowed the researcher to collect adequate, relevant information to answer the research questions.

Most of the interviews for this study were conducted telephonically due to Covid 19 restrictions. Only two (2) interviews were conducted face-to-face, and for purposes of ensuring privacy, these interviews were conducted in the nursing department boardroom. All Covid-19 precautions were observed, including using face masks, sanitising hands, and maintaining social distance. For the interviews that were conducted telephonically via mobile phones, the participants were requested to choose the most convenient time for them to conduct the interview. The researcher ensured that from his end, there was the utmost privacy (including locking the door to prevent anyone from just budging in) in the room (at home) he used to make the phone calls. All participants had consented to participate in the interviews by signing consent forms sent to them via email. The full details of the study were explained to the participants before they signed the consent forms. All the interviews were recorded with the consent of the participants, and the researcher later transcribed the audio recordings. It was also noted that individual in-depth interviews were more effective because they required personal interaction. The researcher took personal notes during the interviews, which assisted the researcher to record further probing questions that arose as the participants were giving their responses. The interviews were in English, each taking approximately 30-45 minutes.

3.10.1 Data collection Instrument

A research Instrument is a tool used to collect, measure, and analyse data related to one's research interests (Jain, 2021:542). The data collection instrument used in this study was a semi-structured individual interview guide. This instrument was selected because the

researcher wanted to allow the participants to address any issues and ask follow-up questions. Demographic information of the participants was also asked as part of the data collection tool. The researcher designed a semi-structured interview guide that contained a set of open questions that were supported by follow-up questions, probes, and comments (Dejonckheere & Vaughn, 2018:05). A semi-structured interview guide is a guideline that a researcher uses when conducting a semi-structured interview, which has a set of questions and instructions on how the interview would be carried out (Jain, 2021:545).

The interview guide that the researcher used contained some open-ended questions guided by the study's objectives and research questions. The research aimed to collect sufficient relevant data to fulfil the study's requirements. One main question was: 'What are your experiences in your self-management of HIV condition as a higher education student?' Some follow-up questions included: 'What are the symptoms that bother you the most? How do you manage those symptoms?' (See Appendix E). These questions aimed to determine the participant's daily experiences concerning their condition. They ranged from issues like their experiences at the clinic and the kind of support they got from health personnel at the clinic on campus to the impact their condition has had on their academic work. They also prompted the participants to share their self-management efforts and coping measures while drawing out their views on whether they had seen any significant impact of these measures. The method enabled the researcher to gather open-ended data and analyse the participants' experiences in their self-management efforts (Croxon, Ashdown & Hobbs, 2017:139). An added advantage, however, was that the questions were few, which allowed the participants more time to respond without getting tired or bored.

3.10.2 Pilot interview

A pilot interview was conducted to see if the questions were fit to answer the research questions to achieve the purpose of the study. The researcher also wanted to establish if

the questions were clear enough for the participants to understand the phenomenon (Enago Academy, 2020:1). The first two interviews were conducted as pilot interviews, and because they were quite valuable, no changes were made. Therefore, it was decided to include the pilot interviews in the main study, as researchers Ismail, Kinchin and Edwards had previously done (2018). After the pilot was conducted, since the recruitment process of other participants was protracted and challenging, the researcher did not establish that there were significant issues with the questions and made no changes to the questions. As outlined by Fraser, Fahlman, Arscott & Guillot (2018:14), the pilot process is an important step that cannot be excluded as this enables the researcher to gauge whether participants will understand the questions, what they mean, and their level of comfort in answering these questions.

3.11 Data Analysis

Data analysis in research refers to a process through which collected data is interpreted to determine patterns, relationships, or trends within it (Linneberg & Korsgaard, 2019). A thematic data analysis was used for this study since the data collected was qualitative. Therefore, the process of analysing data was done simultaneously with data collection. Thematic data analysis entails describing data and its interpretation through coding selection and constructing themes (Linneberg & Korsgaard, 2019). Since all the interviews were recorded using an audio recorder, they had to be transcribed before any coding could be done. Therefore, the researcher sought an independent coder's help in data analysis. The independent coder who was engaged to assist with data analysis holds a master's degree in humanities and has over five years of experience in assisting students with their writing projects. The researcher and independent coder conducted their thematic analyses separately and later compared the themes upon which they agreed. They then decided which subthemes to combine into main themes and which to discard. This collaborative approach to inductive thematic analysis was preferable mainly because of its flexibility, which allowed the researcher to gain insight into different perceptions and views. During the data analysis, it became apparent that several themes or codes were

derived from patterns that emerged and needed to be categorised. There are six steps that the researcher followed in analysing the collected data (Caulfield, 2019:01), and they are explained below.

3.11.1 Familiarisation with the data

Qualitative data might come in different forms to increase the credibility of the research findings. Regardless of the format in which the data might be recorded, the raw data should provide an audit trail and a benchmark against which the data could be tested for adequacy (Norris, Hecker, Rabatach, Noseworthy & White, 2017:07). Since the collected data was recorded using an audio recorder, it was transcribed by the researcher, stored on a computer and this process was repeated for the duration of the data collection process. It is important to note that there was a regular back-and-forth during data collection, transcription, and analysis. This meant the process was continuous from the first day of data collection until everything was ready to prepare the research report. First, the researcher had to listen to the recordings again and again while transcribing. Then, the researcher listened to the recordings for a second time as he went over the scripts to make corrections and only after all the corrections were done did the process of searching for codes begin. While the process was very involving and tiresome, it gave the researcher ample time to familiarise himself with the data. The idea of familiarisation is supported by other researchers who deem it a crucial process that should occur before analysis is conducted (Nowell, Norris, White & Moules, 2017:09).

3.11.2 Generating initial codes

Caulfield (2019:01) states that coding is a process through which a researcher gives meaning to the data and reflects on the main ideas drawn from the dataset. After the coding was done separately, a comparison of codes was done to reach a consensus between the researcher and the independent coder.

3.11.3 Generating themes

From the codes that were established, fewer categories were established into which the various codes were grouped to create themes. Themes are much broader than codes, so the researcher identified similarities in these codes, which he then used to create broader categories or themes.

3.11.4 Reviewing themes

The themes were then subjected to a thorough review by the researcher and the independent coder, which allowed a further assessment of the themes. This was important because data needs to be correctly classified in order to give a true reflection of the data. Therefore, the themes need to be reviewed to ensure they are related to the data and accurately reflect it. After the review process, a few themes were merged since they carried similar codes.

3.11.5 Defining and naming themes

After all the themes had been identified, created, and listed, they were defined to make the data more understandable.

3.11.6 Write up

The last stage in the inductive thematic analysis was the write-up. The write-up has an introduction, whose main purpose is to orient the reader and introduce them to the chapter write-up. It includes a methodology section, which describes how the data was collected (Nowell et al., 2017:10). The main section presents findings or findings after the data was analysed and describes each theme against the research questions and objectives. The last section is the conclusion to this write-up, which explains whether the research question was answered and summarises the write-up (Caulfield, 2019:01).

3.12 Trustworthiness

Trustworthiness is an important component and indicates logical accuracy, scientifically adequate or trustworthy outcomes concerning strict adherence to the philosophical viewpoint and meticulous data collection (Korstjens & Moser, 2018:122). According to Korstjens and Moser (2018:122), the trustworthiness standards of credibility, dependability, transferability, and conformability are related to validity and reliability in quantitative studies. Therefore, in this study, different activities were implemented to ensure the trustworthiness of the study, covering the standards.

3.12.1 Credibility

Credibility is one of the key factors that establish the trustworthiness of a qualitative research study; it encourages the researcher to link the findings of the study and reality to establish the veracity of the findings (Carlisle, 2017:945). The researcher employed two techniques, triangulation and member checking, to establish the credibility of this study and its findings.

3.12.1.1 *Triangulation*

Triangulation is a technique that every researcher should know and use when called upon to do so. It usually involves the use of several methods, sources of data, or theories and analyst triangulation to get a deeper comprehension of the subject under investigation (Caulfield, 2019:2). The use of different data sources or multiple methods ensures that the research findings are accurate and well developed. Out of these multiple forms of triangulation, the researcher used analyst triangulation, where an independent analyst was engaged to go over the research, analyse the findings and identify vague points that needed clarity. This was done to improve the credibility of the study.

3.12.1.2 Member checking

The researcher also used another technique called member checking. Member checking entails sharing the collected data, findings, and interpretations of the data with the study participants. It is believed that this allows them to verify and clarify certain aspects and make the data and its findings a true reflection of their thoughts and views (Carlisle, 2017:947). The researcher employed member checking to establish the credibility of the findings during and after the interviews. Member checking was used during the interviews to check whether the participants understood the subject. This was done by rephrasing the information given by the participants to ascertain that the meaning of what the participant had said was accurate.

3.12.2 Transferability

Transferability refers to applying the findings of research in one situation to other similar situations (Carlisle, 2017:947). The study findings can be evaluated to determine whether they can be adapted and used in similar contexts. The researcher will avail the findings to other researchers or institutions with similar circumstances to assess whether the data is usable in their context (Korstjens & Moser, 2018:123). For this study, the researcher used thick descriptions to ensure transferability. This entailed giving adequate details about the participants' context, location, and how data was gathered and analysed. The researcher also described the findings and their context vividly to the readers. The findings of the study were discussed in detail, and a comparison of the findings from the empirical data to those from related literature was done. The researcher established that the findings from the gathered data reflected most insights that have also been established by existing literature. Enough details (provided from thick description) about this research and its process will be made available to allow readers and fellow researchers to recreate the research environment and decide on whether it is transferable.

3.12.3 Confirmability

The concept of confirmability is also used to establish and prove the trustworthiness of a particular study. Confirmability is achieved if other reviewers and readers of the study's findings can identify with the characteristics of the data (Sarvimaki, 2017:28). It is important for the findings not to be tainted by the researcher's own biases and for them to be purely a result of the collected data (Korstjens & Moser, 2018:123). The researcher worked with his peers, who assisted him at every stage of the research by going through the drafts and providing insights and suggestions on various aspects of the research process. The researcher also engaged the services of an independent coder in order to have a more balanced data analysis process where comparisons were made of the various themes upon which the two independently agreed. This was mainly done to limit the researcher's biases to distort the outcome of the research (Moser & Korstjens, 2017:123). Some notes on the steps taken in key processes like sampling and data gathering were also made and discussed with peers for them to provide their input. The researcher used an audit trail in documenting data to ensure confirmability. The audit trail contained all field notes the researcher took during the data collection, detailing the observations made about the participants, their environment and things that were seen or encountered in the process.

3.12.4 Dependability

Dependability is how a researcher can explain changing conditions in his/her study and the harmony of internal processes. Dependability also means that if a study were to be repeated under the same conditions, it would yield similar findings. Rose and Johnson (2020:435) refer to dependability as the extent to which the same findings can be replicated by the same methodology when another researcher conducts the same study. Dependability was also ensured by keeping a record of the data and the consensus meetings with the independent coder. Furthermore, the analysis process was continuous and done simultaneously with data gathering. This allowed for a deeper understanding of

the data and the different trends that emerged from identifying various codes and themes. This also assisted the researcher in determining whether or not additional data was needed for further analysis. Below is Table 3.1 with a summary of the steps taken to ensure the trustworthiness of the research.

Table 3-1: Summary of steps taken to ensure trustworthiness.

Steps taken to ensure the trustworthiness of the study	
Credibility	Analyst triangulation - an independent analyst was engaged to review the research, analyse the findings, and identify vague points that needed clarity. Member checking - data from participants was rephrased to ascertain that the meaning was actually what the participant had just said.
Transferability	use of thick descriptions comparisons of findings from empirical data with findings from related literature.
Confirmability	use of peers to check the data and suggest adjustments. use of independent coder to ensure a balanced analysis of the data.
Dependability	kept records of data and consensus meetings with the independent coder data collection and analysis were conducted simultaneously for continuity and a more balanced analysis.

3.13 Ethical Considerations

The researcher applied for ethical clearance and permission from the university, which was granted (HW-REC 2021/H12). The researcher followed the rules and guidelines on research ethics prescribed in the university code of research ethics. In addition, the researcher observed every step of the research process required to uphold the research participants' cultures, anonymity, and confidentiality" (Hoque & Rana, 2018:607). Head (2020:73) defined ethics as "a code of behaviour considered correct". The steps that were

taken to ensure the ethical principles are adhered to, are presented in the sub-sections below:

3.13.1 Respect for the person

When prospective research participants are afforded the opportunity to make choices on what may or may not happen to them within the confines of their own abilities that is considered as respect for the person taking part in a research study (Hoque & Rana, 2018). In the context of this study, this opportunity was provided to the participants because all the required steps to get informed consent from them were implemented.

3.13.1.1 *Autonomy: Information and informed consent.*

According to Hoque and Rana (2018:609), collecting any information without the informed consent of those participating is unethical. This involves researchers giving sufficient information and reassurance about involvement in the study to permit individuals to understand the reason for participating and reach a fully informed decision without pressure or coercion about whether or not to participate. Information is provided to participants to ensure they are aware of the type of material required, what purpose it will be used for, their participation, and the subsequent effect on them either directly or indirectly (Hoque & Rana, 2018:610). Participants in a research study must also be competent, meaning mentally and legally capable. In this study, participants were given comprehensive information (see Appendix F) so that they understood the purpose of the study prior to commencement. Willing participants indicated consent either via the phone or during face-to-face interaction, and it was made clear to them that they would only participate after they had signed consent forms. Informed consent forms were then sent to all the selected participants either by email or handed them personally by the researcher to sign. All the interviews were recorded (including those conducted over the phone) using an audio recorder after each participant granted the requested consent. It was clarified that these recordings were only for academic purposes and would be kept confidential. Participants were informed that they can withdraw without any negative consequence.

3.13.1.2 Confidentiality and Privacy

Confidentiality refers to the steps taken by researchers to protect the identity of research subjects (Showkat & Parveen, 2017:20). Human research subjects are required to consent to participate in a research project by signing consent agreements with the researcher. During this process, the researcher becomes aware of the subject's identity, which must be protected from being discovered by others in the study. Therefore, confidentiality was maintained as all the collected data was kept on one computer with a password only known to the researcher. Furthermore, no names were put on the interview transcripts to protect the participants' identities. The research participants were only identified as participants 1, 2, 3 and so forth to maintain levels of anonymity. Lastly, all recordings and transcripts were saved on a computer with a protective password, and field notes were locked in a drawer in the researcher's office, where they will be kept for at least five years after the research report is released.

3.13.2 Beneficence and non-maleficence

During the course of collecting data from people, the researcher ensured that the study did not expose participants to any information or practices that were harmful to them. According to Showkat and Parveen (2017:17), human participants must be protected from unnecessary stress because of ethical issues. Head (2020:74) stated that "ethical conduct applies to all involved in the research process from the researcher to the participants to the sponsor." The researcher also took steps within reason to ensure that no harm befell the study participants. These steps included allowing the participants to choose venues for face-to-face interviews to guarantee their privacy, following all Covid 19 safety measures (wearing face masks, sanitising hands, keeping the required social distance), and ensuring that the true identity of the participants would remain a secret to protect them from being stigmatised. Before any interviews were conducted, the researcher made it clear to the participants that the interviews would be stopped at any time if the participant felt uncomfortable. Fortunately, no one was harmed or indicated they were uncomfortable

during the data-gathering process. However, there was one case in which the researcher picked up that the participant was suffering from trauma resulting from the fact that they were born with HIV and never got any form of counselling. The researcher inquired whether the participant was willing to go for counselling which the researcher would organise. The participant consented, and the researcher arranged for the said participant to receive counselling from available services on campus. The researcher planned to provide 1 GB mobile data for the online interviews. However, the two online interviews were conducted with participants on campus and were connected to the campus Wi-Fi, so both participants declined the offer as they did not use their mobile data for the interviews.

3.13.3 Justice

In this study, the researcher ensured adherence to the principle of justice. This was achieved by making sure that there was a fair selection of participants through the referral from the health care professional. The population were chosen appropriately as they related to the problem, there were no manipulation of any participant. Data collected will not be shared with other parties without the consent of the participants. Lastly, Discrimination was avoided in the recruitment of the participant, by ensuring all participants are treated fairly and equally.

3.14 Dissemination of Research Findings

Dissemination of research findings, especially in the nursing discipline, is vital because these findings improve healthcare initiatives. In this respect, the researcher has a plan on how the findings of this study will be disseminated for the benefit of the target audience, mainly university students living with HIV. Part of the plan includes creating a poster that can be put at the campus clinic; making presentations to the target audience at conferences or institutional research day and publishing these findings in a peer-reviewed journal.

3.15 Chapter Summary

This chapter covered the research approach used. In addition, the chapter covered the research methodology that was utilised, the sampling strategy, the data collection instruments used, the data analysis technique, and details of the pilot study conducted, and it concluded with ethical considerations. The next chapter will present the findings of this research study.

CHAPTER 4 - STUDY FINDINGS

4.1 Introduction

The previous chapter presented the methodology used in this study and the justification for using the methodology. This chapter presents the findings from the qualitative interview data collected from the sampled population in line with the aim of the study. The chapter first presents the demographic details of the participants, and then the main themes and sub-themes drawn from the collected data in accordance with the study's research objectives are presented. The presentation of the themes and sub-themes describes each theme and related sub-themes. Quotations from the interviews are included to illustrate what is being presented. The last part of the chapter provides the chapter summary, while the discussion of the findings will be presented in chapter 5.

This study aimed to explore and describe the HIV self-management experiences of students at a higher education institution in the Western Cape area, with the following objectives:

- 1) To explore the experiences of higher education students on their HIV self-management at a higher education institution
 - a) To explore higher education students' understanding of their HIV condition
 - b) To describe the supportive role nurses can fulfil concerning the facilitation of self-management of HIV for higher education students.

4.2 Demographic Details of the Participants

In this section, the participants' demographic profiles are presented graphically and include age, gender, program of study, and level of study. Eight participants took part in the study, and they were registered in different programmes, as illustrated in Table 4.1.

Table 4-1: Demographic details of participants

Participant Number	Age	Gender	Level of study	Programme of study
1	27	Female	Fourth year (undergraduate)	Electrical engineering
2	21	Female	Second year (undergraduate)	Nursing Science
3	23	Female	Third year (undergraduate)	Nursing Science
4	32	Female	Fourth year (undergraduate)	Civil engineering
5	24	Female	First year (postgraduate)	Architecture
6	25	Female	First year (postgraduate)	Electrical engineering
7	27	Female	First year (postgraduate)	Mechanical engineering
8	24	Male	Fourth year (undergraduate)	Land and construction architecture

4.2.1 Age of participants

Table 4.1 shows the ages of the participants in this study. The average age of the participants in the study was 25 years, with half of the participants (4) in the 21 -25 age group, which is not surprising since most university students fall within this age group. In addition, three (3) participants were in the 26 - 30 age group, while only one participant was in the 31-34 age group, which is also typical of the age group distribution among university students. Generally, all the participants who took part from all the represented age groups are still considered youths (StatsSA, 2021).

4.2.2 Gender of the participants

The gender distribution of the participants who participated in this study, as reflected in Table 4.1, shows that there were more female participants than males, with seven (7) females and only one (1) male constituting the total number of participants. There was

very little variation in the participants' views even though there were more female participants, with only one (1) male participant.

4.2.3 Level of study

Table 4.1 also shows the different levels of the study of all participants who took part in this study. Three (3) of the participants were in the first year of their postgraduate studies, three (3) were doing the fourth year of their undergraduate studies, while there was one (1) in the second and third years respectively.

4.2.4 Programmes of study

The study participants were enrolled in different programmes; however, they were all located at one campus of the institution. Table 4.1 shows that four (4) of the interviewed participants were from the engineering department, while the others came from the nursing and architecture departments.

4.3 HIV Self-Management (SM) Experiences of University Students in the Western Cape Province of South Africa and Nurses' Supportive Role

This section presents and discusses the main themes and sub-themes that emerged from the analysis of the data collected by the researcher. The three themes that emerged in relation to the first objective were 1) improved understanding of HIV, 2) Living with HIV and 3) Recognition of HIV stigma. Themes 4 (The HIV self-management journey) and 5 (Positive self-management strategies) and their respective subthemes are linked to the second objective, while the third objective is linked to themes 6 (Nurses as the go-to resource in HIV SM) and 7 (Mental health support) and their subthemes. Table 4.2 presents all the themes and sub-themes that emerged from the researcher's analysis of the collected data, showing the relationship to each objective of the study.

Table 4-2: Themes and Subthemes

Objectives	Main themes	Subthemes
1. To explore higher education students' understanding of their HIV condition	1. Improved understanding of HIV	1.1 Demystifying HIV. 1.2. Accepting one's HIV status
	2. Living with HIV	2.1 HIV effects on social life 2.2 Disruption of normal academic routine
	3. Recognition of HIV stigma	3.1 Broken trust and apportioning blame 3.2 Perceived and experienced stigma
2. To explore the experiences of higher education students on their HIV self-management at a higher education institution	4. The HIV self-management journey	4.1 Challenges in SM of HIV 4.2 Support in HIV SM
	5. Positive self-management strategies	5.1 Maintenance of good physical health 5.2 Having a positive mindset
3. To describe the supportive role that nurses can fulfil regarding facilitating the self-management of HIV for higher education students.	6. Nurses as the "go-to" resource in HIV SM	6.1. Available and accessible nurses 6.2. Health education and information sharing
	7. Mental health support	7.1. Provision of counselling services 7.2 Formation of support groups

4.3.1 Understanding of HIV condition by university students

The first objective of the study was to explore the student's understanding of their HIV status. Three main themes emerged from the interviews, which were (1) improved understanding of HIV; (2) living with HIV; and (3) Recognition of HIV stigma. From the interviews, most participants indicated that they had a very low understanding of HIV prior to their diagnosis, and it was only after they became HIV-positive that their knowledge of HIV improved. As they accessed more information about HIV, their understanding of managing it and staying healthy grew. The reports from the participants also showed that living with HIV is challenging because it brings several changes to one's life; in their case, as students, their normal study patterns are adversely affected. They also have to deal with changes to their social lives, such as losing friends when they discover their HIV status and their fear of disclosure because of the stigma it brings them. The participants also indicated that they felt betrayed by their former partners, from whom they contracted HIV.

4.3.1.1 Theme 1: Improved Understanding of HIV

One of the themes that emerged from the data in response to the first objective was understanding HIV. The main idea shown was that a deeper understanding of HIV by the participants was key to how they responded to it. In order to have a good understanding of HIV, the participants had to accept their status and then learn more about how best to manage their condition, which helped to demystify it. Their perception of HIV changed once they better understood how it worked in their bodies. This put them in a situation where they began gaining information from different sources to understand their condition, including their healthcare providers and personal research. This put them in a better position because they could begin the process of self-management from an informed position.

4.3.1.1.1 Subtheme 1.1: Demystifying HIV

A better understanding of HIV went a long way in shifting participants' perceptions. To most of them, HIV was mysterious and only spelt doom to anyone who contracted it. This was mainly motivated by the several myths about HIV they were exposed to, which painted a gloomy picture. Once they contracted HIV, they became more exposed to the right information through counselling and personal research. This helped to demystify HIV and to separate myths from the truth. It became apparent that one could still live a normal life provided they consistently adhered to their treatment regimes. This was revealed by participant 2, who stated that once she gained more knowledge about her HIV status, she realised that HIV was no different from other conditions:

"I have realised that HIV is not like cancer... It's the same as any other condition; there's no difference in it." (Participant 2, f, 21).

A better understanding of HIV also helped the participants to know the difference between being HIV positive and having AIDS, which is the stage when one gets very sick from HIV. Participant 5 mentioned that she now understood that being HIV positive was not the same as having AIDS and that, with medication, it could be controlled:

"You know the problem with people, they think when you are HIV positive, you have AIDS, which is not. HIV is manageable." (Participant 5, f, 24)

The same participant further explained:

"... For me, it is just a virus that you are living with, it is there, but it does not mean that it will kill you; it is just like any other sickness—you just have to manage it. It is just like diabetes and high blood pressure, and you just have to take medication like all other diseases that people live with." (Participant 5, f, 24).

The data from participants also showed that participants understood that a person living with HIV could lead a normal life, have a relationship with an HIV-negative person and even be able to bear HIV-negative children. For example, participant 4 revealed this when she stated:

“I am HIV positive, and my partner is HIV negative. It does not mean he will be positive. I can have children that are HIV-negative because there are pills that you take when you are pregnant to protect your child.” (Participant 4, f, 32).

Participant 3 also echoed similar sentiments about HIV and pointed to the fact that apart from adjusting to taking medicines regularly, very little had changed from the way she lived:

“I just go on with life like before I was diagnosed; I haven’t changed anything. I only adjusted to medication times; otherwise, all is still the same.” (Participant 3, f, 23).

4.3.1.1.2 Subtheme 1.2: Accepting one’s HIV status

A better understanding of HIV led the participants to acceptance, and that helped them to maintain good health. Most participants indicated that after they were diagnosed with HIV, their understanding of HIV improved through counselling and personal research on HIV and how it is managed, which helped them reach acceptance. However, evidence from the analysed data showed that when the participants first knew about their new condition, it was difficult for them due to fear and a lack of knowledge about HIV and previously held misconceptions. This was revealed by Participant 8, who explained his view of HIV prior to his diagnosis, which was shaped by others around him when he was growing up:

“I think I was in grade 4 when I first encountered the story of Nkosi Johnson, the South African boy that was diagnosed with the disease. At the time, the pictures that were projected about the disease were so scary in that I thought

everyone that is HIV positive will certainly look like that and, in a matter of 2 years, be gone. I had so much fear around the term HIV; I only knew that if you have HIV, you will die. I was even afraid to share things with someone confirmed to be positive.” (Participant 8, m, 24).

Gaining a deeper understanding of HIV also allowed them to accept their status. According to Participant 8, being HIV positive was just as good as assuming a new identity that one could not change but which could help one become a better version of themselves. Participant 8 further narrated the positive impact his new status had brought to his life:

“HIV right now, for me, feels like a code that is added to your identity; it’s like your ID number, something that you cannot change. That’s how HIV is to me, just an identification of who I am... HIV formed who I am now, and I found out that I am a better version of myself than I have ever been before.” (Participant 8, m, 24).

Participant 2 was more direct in her response about this, and she stated that acceptance of her status was the first step which then opened the way for self-management of HIV:

“I have accepted my condition... There is nothing that is more than accepting the condition...first, then self-management will just happen automatically.” (Participant 2, f, 21).

Similarly, Participant 5 indicated that accepting her condition was a very positive step, and it made her realise that being HIV positive was a condition like any other chronic sickness that could be managed:

“I have accepted my condition and took it in a positive way...it is just like any other sickness. You just have to manage it.” (Participant 5, f, 24).

Understanding and accepting HIV was also an important response to stress. As stated by Participant 6, she accepted HIV as part of her new lifestyle, and one of the main benefits she drew from this was that her HIV status did not negatively affect her studies. Furthermore, it was noted that this level of understanding and acceptance is a process and was facilitated by attending counselling sessions.

“HIV has now become my lifestyle; I have accepted the condition, and I do get stressed out like any other student but being HIV positive does not affect my studies at all...Well... since I have been attending counselling since 2015, I think it’s getting easier with time.” (Participant 6, f, 25).

A deeper understanding of HIV made it possible for the participants to accept their HIV status because it was the only way they could move forward with their lives. In addition, their understanding of HIV made them realise that there were certain changes they had to make to their way of life in order to avoid compromising their well-being. This understanding came from accessing the real facts about HIV, relevant information and the support they received from nurses. This shifted their mind-set on HIV, as explained by Participant 5:

“...I did a lot of research, and that changed my mind about HIV. Also, the Sister in the clinic has been very supportive and has contributed to the way I think about HIV now.” (Participant 5, f, 24).

Participant 8 also indicated that he became more informed about HIV after his diagnosis, and this enabled him to make the necessary changes that would allow him to enjoy good health and shift his stereotypical views about HIV:

“I had to be faithful to one partner, unlike before when I used to have multiple partners. The plan was to contain HIV and not spread it. I also changed my stereotypical beliefs about HIV as I am now more knowledgeable about HIV.” (Participant 8, m, 24).

Participant 6 also showed that she was more informed about what HIV was and the steps that are required for one to live a normal life:

“HIV and AIDS is the condition that affects your immune system. It is not treated; you live with it, but it is controlled by taking the medication. Having it does not mean you are going to die; if you take your medication well, then you can live a normal life like any other human being.” (Participant 6, f, 25).

4.3.1.2 Theme 2- Living with HIV

This theme is also in response to the first objective of understanding HIV, and participants in this study indicated that after they gained a better understanding of their status and accepted it, they began to make sense of their lives. They realised that they had embarked on a new and difficult journey where they had to navigate the negative effects of HIV on their social and academic lives. They had to deal with such aspects as the disruption of their normal academic routines, losing friends, and curtailing other activities such as smoking and drinking alcohol. Living with HIV is challenging, but it can be managed by adhering to the professional advice nurses offer and taking their medications religiously.

4.3.1.2.1 Subtheme 2.1: HIV effects on social life

As indicated above, living with HIV is a challenging experience that brings with it several complications. Participants discussed that they came to the realisation that HIV diagnosis has effects on their social lives. This was highlighted by participants who indicated that their social lives were disrupted in several ways, such as isolation from close friends and classmates. Some of their close friends' perceptions changed once they disclosed their HIV status. As highlighted by participant 2, some of their friends did not understand HIV to the extent that they (their friends) would make fun of them due to their status:

“So there was this other day at our high school residence that one of my roommates opened my bag and saw the medication that I was taking, and she

showed it to a lot of other learners all over the school. People started looking at me differently ...crying... I felt like I was left out alone; I would cry for no reason.” (Participant 2, f, 21).

Living with HIV has also made it difficult for some participants to maintain or create new relationships with boyfriends or girlfriends, and some relationships broke down after their partners discovered they were HIV positive. For example, participant 3 explained that it has become very difficult for her to have a boyfriend since she contracted HIV, and this was understood as a result of fear and a lack of understanding on the part of the potential boyfriends:

“Ever since I was diagnosed with HIV, it has not been easy to have a boyfriend because you open up to that person about your condition; they just stigmatise you and don’t want to be with you. I don’t blame them; surely, they are scared of their health.” (Participant 3, f, 23).

Participant 4 also experienced difficulties in her relationship until she eventually broke up with her boyfriend, after which she stopped dating for some time:

“It took me a long time to be in a relationship after I broke up with the man I was with for four years. I would date someone and break up as I would realise that he is not mature enough or see that we are too different; we have very different interests. I stopped dating for a while.” (Participant 4, f, 32).

Participant 2 also echoed the same sentiments on the negative impact HIV had on her relationship because, for her, the main challenge was to disclose her status to a new partner:

“The other challenge was when I had to be in a relationship, the difficult part was to have to explain myself to people all the time, and if I break up with this one, I must not start explaining myself to the next person.” (Participant 2, f, 21).

4.3.1.2.2 Subtheme 2.2: Disruption of normal academic routine

As part of living with HIV, another subtheme that emerged in response to the first objective was the disruption of normal academic routine for most participants. Once their normal routine is disrupted, their self-management efforts conflict with their academic pursuit, and sometimes they can be forced to compromise their SM efforts to accommodate their usual routine. In some instances, the participants were overwhelmed by these disruptions to the extent that they lost interest in their studies. This loss of interest in their studies led some participants to get poor findings in their subjects, while others even considered quitting altogether. Participants 4, 2 and 6 went through similar experiences:

“I failed my subjects, and I was excluded, and I went back the following semester, and I passed. At some stage, I lost interest in my studies, and I just dropped out and went to work. I then came back last year to finish my final year.” (Participant 4, f 32).

“Being HIV positive affected my performance in my studies.” (Participant 2, f, 21).

“That year, I failed 50% of my modules because I was not coping emotionally and psychologically, and that was not a good year for me, so I had to redo the modules in 2016.” (Participant 6, f, 25).

Participants also shared how taking their HIV medicines also disrupted their academic lives due to their side effects. Gradually as the participants gained some understanding of the different side effects of their medications and how they impacted their studies, they realised that they had to make some changes to their usual study timetables to accommodate their medication schedules. They realised that a failure to develop new patterns of study would make life more difficult for them; hence they made plans to minimise the disruptions they encountered. Participants 4 and 1 shared their own experiences and how they were coping with the disruptions to their study routines:

“With that, I will oversleep and end up missing the morning classes and only getting the after-tea classes that start at 11 am.” (Participant 4, f, 32).

“It’s quite difficult when you are a student, and you don’t have a certain pattern that you have, so at times you find out that you have to study at 2 am and you take the pills maybe at 9 pm, and the side effects start kicking in. That was my main challenge in taking my medication.” (Participant 1, f, 27).

4.3.1.3 Theme 3: Recognition of HIV stigma

This theme also emerged in response to the first objective, which was about understanding HIV. The data that was collected from the interviews with participants indicated that living with HIV had put them in a position where they were constantly exposed to negative experiences that amounted to stigma because most people around them still lacked an understanding of HIV and its dynamics. The subthemes that emerged under this theme were broken trust, apportioning blame, and perceived and experienced stigma. Participants indicated that even the people who are involved in the campaigns meant to educate others and raise awareness about the prevention and management of HIV for those living with it tend to discriminate against those who are infected.

Some of the participants indicated that before they became infected, they did not understand what stigma was about, and they also took part in isolating those who had HIV. Only after they got infected did they begin to understand what stigma was about and the psychological damage it could cause to those living with HIV. They also developed the ability to identify stigma when it occurred quickly and ways to deal with it. For most participants, stigma negatively impacted their lives, affecting their relationships with friends and sexual partners who did not understand their condition and status.

4.3.1.3.1 Subtheme 3.1: Broken trust and apportioning blame

This is one of the subthemes that emerged from the main theme of recognising stigma in response to the study's first objective. As most participants grappled with understanding their HIV status soon after finding out they were positive, they also had questions about how they came to contract HIV. In cases where they were in relationships, they blamed their partners, who in turn isolated them, and the trust that kept them together was broken. This led to breaking up in most cases as accusations and blaming each other became rife. For example, after participant 3 was diagnosed, she blamed her boyfriend because she believed that he was the one who had infected her, and in that case, she felt betrayed and broke up with him:

“Yes, I have. In 2018, when I got diagnosed, I was having a boyfriend, the one that infected me so I couldn’t be with him anymore, so we broke up.”
(Participant 3, f, 23).

For most participants, sustaining a relationship with the person responsible for infecting them was difficult. The moment a partner infects the other with HIV, trust is broken, and love is lost in most cases. Participant 4 indicated that she confronted her then-boyfriend because she had been faithful to him, but he denied it. However, she ended the relationship because she felt betrayed:

“I knew who I got it from even though he denied it when I confronted him...I told him that I’d been with him only in the past four years, and I knew that every time he went home, he was meeting with his baby’s mom. I then told him that our relationship was not going to work, so I then focused on myself.”
(Participant 4, f, 32).

The lack of trust and realisation of stigma was also noted beyond the intimate partners, as participants indicated the inability to trust their friends who displayed HIV-related stigma. This is illustrated by Participant 7, who highlighted the fact that after she was

diagnosed, her relations with her friends were affected because of the negative things they said about people with HIV when she was around since they were not aware of her condition. As a result, she felt betrayed by them, and she could not trust them enough to disclose her condition to them:

“Yes, because it takes you back to where you started from; you need to be strong around people, which I think is unnecessary. It also makes me feel unsure about myself. Even though I know that they don’t know my status, listening to them saying all those negative comments somehow just brings me down.” (Participant 7, f, 27).

Participant 6 experienced the same challenges in terms of trust because she felt she could no longer trust them owing to their attitude towards people with HIV:

“I had to change friends at that time because I did not trust them enough to tell them about my condition as I feared that they would judge me.” (Participant 6, f, 25).

Participant 2’s case was no different, even though she was born with HIV. She stated that she felt betrayed by her own mother, who did not protect her from HIV by taking the necessary medication even though it was available. This reality traumatised her and drove her to carry the feelings of anger and hatred towards her own mother because she blamed her for the situation in which she was. As a result, she experienced great anger and feelings of loneliness:

“I felt like I was left out alone; I would cry for no reason. It made me blame my parents; it made me view life differently at that point. The question I was asking was; why me? What I hated most was that my mother knew that she was HIV positive when she gave birth to me, and she knew there were pills to take to make sure that I don’t get positive; I have a big brother that passed away due to HIV right after birth. My mother knew that my brother died from HIV, but

when she fell pregnant with me, she did not protect me ...crying... so that created a lot of anger in me.” (Participant 2, f, 21).

4.3.1.3.2 Subtheme 3.2: Perceived and experienced stigma

This is the second subtheme that emerged from the main theme on recognising HIV stigma in relation to the first objective. Since the participants became infected with HIV, they have become more conscious of the stigma around HIV among their peers, and while they experience it personally, some of it is perceived. They quickly recognise it when it occurs and from the things that are said by some of their peers, and it is quite traumatic for them in most cases, as indicated by participant 2:

“It’s just that there is this stigma around it that it kills” (Participant 2, f, 21).

Similarly, participants 6 and 8 also held the perception that stigma was still rife and most people living with HIV were able to recognise it:

“Yes, there is quite a lot of stigma around HIV condition.” (Participant 6, f, 25).

“There is a lot of stigma that is going on around the concept of HIV.” (Participant 8, m, 24).

The other key important point that came from the interviews was that HIV stigma was so rife and had also entered social media platforms like Facebook, where Participant 1 recognised it. This becomes a devastating situation, as one becomes stigmatised even by people they have never met. She stated that people were using social media to post horrible stuff about people living with HIV. Even though she did not experience it face to face in this case, the crude comments still made her feel worthless and alone:

“I got here, and the clinic was about to move from the off-campus clinic to the campus clinic, and there were all these horrible, horrible comments on Facebook about how ... sigh... they refer to people living with the condition as

if we are invalid, as if you do not matter, you're not human" (Participant 1, f, 27).

The participants also recognised that even on campus among their fellow students, there was still a lot of HIV stigma. For example, participant 7 stated that it was easy to pick it up from the nasty things they said about people who had HIV and the names they called them:

"Yes, there is stigma, at university when you get sick, the other student would say "he/she's been shocked by electricity" meaning that the person is HIV positive looking at their lifestyle. I think they don't have enough knowledge about HIV." (Participant 7, f, 27).

The first study objective was to explore the student's understanding of their HIV status and the 3 themes that emerged in relation to this objective revealed different aspects of understanding HIV. The evidence gathered from the participants indicated that there was a link between knowledge of the HIV virus and understanding it. Most of the participants revealed that their understanding of HIV improved after they were diagnosed with HIV, and they began to live with it. This was mainly because they became more concerned about their health, which prompted them to seek more information on how HIV worked and how it could be managed. With the help of healthcare workers and through personal research, they started accessing real facts about HIV which allowed them to separate falsehoods from true facts, thereby improving their understanding. The next section presents themes related to the second objective of the study.

4.3.2 Experiences of HIV self-management

The study's second objective was to explore the experiences of higher education students regarding their HIV self-management at a higher education institution. From the interviews conducted, two themes emerged from the participants, and they related to the HIV self-management journey and Positive self-management strategies. First, the interviews

showed that the participants went through many different experiences in their daily lives as they faced challenges and changes in their ways of life in their efforts to stay healthy while pursuing their studies and other personal goals.

4.3.2.1 Theme 4: The HIV Self-management journey

The experiences the participants have gone through in relation to their HIV management can be likened to a journey in which they encounter different things. Living with HIV and engaging in its self-management is similar to a journey where one goes through different experiences that are both positive and negative, requiring support from family, friends and the whole community. The HIV Self-management journey also requires a positive mind-set and inner strength to deal with bad days and experiences. From the interviews, the following subthemes emerged: challenges in SM of HIV and support in HIV SM.

4.3.2.1.1 Sub-theme 4.1: Challenges in SM of HIV

The HIV Self-management journey exposes one to different challenges that include the uncertainty of disclosing one's status to friends and not knowing how they would react, the constant need to take one's medication in private for fear of stigma, and missing classes due to the effects of the medication they have to take regularly. It emerged from the data that the participants have similar experiences, especially in relation to the lack of disclosure of their HIV status to family and friends. These experiences range from fear of their status being known by their families and their need for privacy when they take their medicines due to the fear of being isolated to more positive experiences they get, like the support they get from their families, friends, or healthcare practitioners. Participant 3 explained that her main challenge related to taking her medicines, which she had to do in private since she did not disclose her status to her roommate. She said that the fortunate part for her was that her room was divided by cupboards, which enabled her to get the privacy that she needed:

“The way our residence is built, it has dividing cupboards in such a way that the other person would not see what is happening on the other side. I then always made sure that my medication was on the side where she would not see it, and when I took it, I made sure that I did not make any noise as I did not want her to hear anything and started questioning me on why I take pills every day.” (Participant 3, f, 23).

Participant 3 also faced challenges when she went away on weekends with her friends because she had to hide her medicines so that they would not find out that she was taking pills. Socially, this made things difficult for her because of the constant worries at the back of her mind:

“Every time when I am not here on campus, I have to worry about having to hide my medication, even when I go out with friends on weekends away.” (Participant 3, f, 23).

The side effects of the medication itself were also cited as a challenge by some participants, which sometimes affected consistency in taking them. This posed a greater risk to their health, but as indicated by participant 6, it was a way to minimise the terrible experiences of the side effects:

“Also, because of the side effects that I had, mostly nausea, I would skip a day purposely just to bypass the side effects. I know exactly that would compromise my health, but the side effects were terrible.” (Participant 6, f, 25).

Disclosing one’s status to close relatives and friends was also highlighted as a major challenge by some participants, mainly because they fear the stigma that is normally associated with it, and that added to their HIV self-management efforts. Other participants also found it challenging to change the lifestyle they were used to before they were diagnosed with HIV. For example, participant 5 indicated it was very difficult for her to change her way of life:

“I must say it was very challenging for me to change the lifestyle that I was used to. When I was diagnosed, I was pregnant, so my other fear was what if my child will be born HIV positive. My other challenge was how I am going to disclose my status to my mother.” (Participant 5, f, 24).

Participant 8 also experienced a similar challenge of failing to disclose his status to his closest family members, including his parents, and it always forced him to lie to them and make excuses when he needed to take his medicines. He understood that things could be easier for him if he disclosed his status to his parents as this would remove the burden of coming up with excuses in order to retire to bed early so he could take his medicines:

“The other thing I want to do is share my status with my parents because only my two brothers know my status, so I wish somehow I can find a way to tell my entire family. If I can do that, I think I can easily manage without always telling them that I am going to bed at 8 pm just to go take medication.” (Participant 8, m, 24).

4.3.2.1.2 Subtheme 4.2: Support in HIV SM

The HIV SM journey can be very lonely and taxing if one does not get the necessary support. However, it also emerged from the data that despite the negative experiences they go through as a result of their HIV statuses, such as isolation, broken relationships and side effects from their medicines, the participants also had good experiences in relation to the self-management of their status. Most participants indicated that they receive much support from their loved ones, especially those who have managed to disclose their status to family, friends, and healthcare workers, and such support was experienced as an enhancer of their HIV self-management. This included getting help to fetch their medicines when they did not have time to do so themselves, as explained by participant 2:

*“My grandmother would go fetch the medication for me and send it to me.”
(Participant 2, f, 21).*

Getting support from close family members is always an advantage to those who receive it because they are able to play their part in making one’s SM experience better. In addition, the fact that one is able to get different forms of support from loved ones creates a positive atmosphere that can boost one’s perspective on their life, as indicated by participant 4:

“I was fortunate enough to get support from my family.” (Participant 4, f, 32).

Support for participants comes not only from their families but from nurses as well. For example, participant 5 stated that she managed to shift her perception of HIV due to the support she got from the nurse at the campus clinic:

“Also, the Sister in the clinic has been very supportive and has contributed to the way I think about HIV now.” (Participant 5, f, 24).

Being HIV-positive requires getting as much support as possible from those around them. This support comes in different forms, be it emotional, psychological, or social. For example, participant 6 joined a group of peer helpers, giving her a chance to meet other people in a similar situation. By supporting her peers, she also got support in return which helped her cope and engage in self-management of her own condition, and this experience had a positive impact on the way she lived:

*“In 2016, I joined the peer helpers at the university, so meeting other people who are living with the same condition made it easier for me to cope with the condition. Right now, I am in a good space, and I am coping very well... I then started attending counselling, and that is when I could cope with everything.”
(Participant 6, f, 25).*

4.3.2.2 Theme 5: Positive Self-management strategies

The second theme that emerged from the interviews in relation to the study's second objective, which was to explore the HIV SM experiences of students living with HIV, captured the day-to-day experiences that these students went through. The subthemes that emerged from the data were the maintenance of good physical health and having a positive attitude.

4.3.2.2.1 Subtheme 5.1: Maintenance of good physical health

Maintaining good physical health emerged as one of the sub-themes under the main theme of positive self-management strategies. From the interviews conducted, participants highlighted that their HIV self-management experiences involved engaging in activities that were aimed at ensuring that they maintained good physical health. That included participating in activities that would enhance their physical fitness and avoiding anything perceived as interfering with their well-being. This was illustrated by participant 7, who stated:

“I joined the gym as well, so I am maintaining my weight, and it’s not out of control” (Participant 7, f, 27).

Participants also highlighted their heightened awareness of their well-being since they got diagnosed. In addition, a deeper understanding of their HIV status prompted them to make changes that would benefit their health. For instance, participant 3 stated:

“With dizziness, I cut on fatty food and made sure in the mornings I don’t just jump off the bed when I wake up, I first rest and then wake up gently.” (Participant 3, f, 23).

This is further confirmed by participant 4, who indicated changes made in her lifestyle due to reduced energy, and participant 2, who highlighted efforts made to ensure adherence to treatment:

“I used to party a lot, I had to change that, and now I don’t have the energy to party anymore, and I stopped drinking alcohol.” (Participant 4, f, 32).

“Every day, I make sure that I take my medication at the same time, and that is how I manage it.” (Participant 2, f, 21).

4.3.2.2.2 Subtheme 5.2: Having a positive mind-set

This sub-theme also emerged as a response to this study's second objective, which was to explore the experiences of higher education students on their HIV self-management at a higher education institution. Most participants realised that the more they understood how HIV worked, the more they were able to focus on adopting measures that improved their well-being. It was out of this understanding that they realised the importance of keeping a positive mind-set which was key to their overall well-being and enabled them in their HIV SM practices and ongoing experiences. They indicated different ways of achieving this, including finding hobbies, keeping themselves busy with work, and engaging in fun activities with close friends. The researcher noted that some of the activities mentioned were not new to them, but what changed was that they now understood the purpose for which they were engaging in them, which was to maintain positive health outcomes and avoid things that could compromise their well-being since their status had changed. Furthermore, ensuring balance in one’s life was also a vital aspect mentioned, which gave participants comfort and stability as they could find themselves ‘juggling’ the condition with their studies, as illustrated by participant 8:

“One thing that helped me is that I never separated my HIV self-management from my studies, and I have been juggling both very well.” (Participant 8, m, 24).

Participant 3 maintained a positive mind-set by focusing on work and other issues to avoid the stress that came with continuously thinking about her status. She chose to keep herself busy as she indicated:

“I just don’t want to think about it because it frustrates me. I just have to keep myself busy.” (Participant 3, f, 23).

Participant 6 on the other hand was able to self-introspect, and she realised that her life and health were more important than HIV she carried. This positive mind-set allowed her to value herself and develop a great sense of self-belief, leading her to concentrate on her studies. She said:

“When I found out about my status, I told myself that I am more important than anything and that I will not let anyone bring any negativity to me because my health is more important. I was not stressed about it...I realised that I am not a failure, so it was self-motivation. I needed to believe in myself. I even told myself that after this qualification, I want to do my masters in Civil engineering. (Participant 4, f, 32).

Similar sentiments were echoed by participant 8, who pointed out that he saw no value in sitting alone at home stressing about a situation that could not be changed. Instead, he decided to keep a positive mentality by going about his normal life and socialising with other people while taking his medication:

“After I was diagnosed, I learned that there is more to life than just sitting at home and being sick. With HIV, you can go back to society and engage and be like any other person, as long as you take your medication.” (Participant 8, m, 24).

The two main themes presented in this section were drawn from the gathered evidence in response to the second objective which was to explore the experiences of higher education students regarding their HIV self-management at a higher education institution. The two themes showed that living with the HIV virus is a journey that exposes the victims to different experiences that are quite challenging. Since the participants in this study were university students, the evidence revealed that HIV impacted their studies in various ways

and it took some effort for them to develop ways to cope with the experiences of living with HIV. The evidence also showed that once they devised ways to manage HIV, it became easier for them to strike a balance between their academic studies and managing their HIV status. Themes related to the third objective of the study are presented in the next section.

4.3.3 Support from nurses

The third objective of the study was to describe the supportive role nurses can fulfil with regard to facilitating the self-management of HIV for higher education students. HIV self-management is strengthened by support from one's network, and nurses as healthcare providers have a crucial role in providing the needed support. From the interviews conducted, two themes emerged from the participants, and the first was nurses as the "go-to" resource in HIV SM, while the second one was mental health support. These two themes and their subsequent subthemes are in response to the third objective of this study.

4.3.3.1 Theme 6: Nurses as the "go-to" resource in HIV SM

This theme is aligned with the third objective on the role played by nurses in the HIV SM of students living with HIV. Nurses play a very important role in assisting students to understand and accept their status and adopt strategies that enhance their SM practices. This puts nurses in a position where they are the "go-to" resource where students living with HIV can access all forms of support, from health education to counselling. The subthemes that emerged under this theme in relation to the third objective are available and accessible nurses and health education and information services. From the interviews, it was quite clear that the role of nurses is very significant and multifaceted. This makes them an indispensable part of the students' HIV self-management efforts.

4.3.3.1.1 Subtheme 6.1: Available and Accessible nurses

This is one of the two sub-themes that emerged in response to the third objective of this study, and it is related to the availability and accessibility of nurses to students living with HIV. The data gathered from the interviews indicates that nurses played a crucial role in the participants' lives. Participants highlighted that as part of their supportive role, nurses should continue to be available and accessible to provide them with the opportunity to get their services when needed. The participants described the nurse at the campus clinic as very understanding, supportive and accessible. As illustrated by participant 3, the participants appreciated the fact that the nurse used an open-door policy where every patient was free to see her at any given time:

“When we go to the clinic, we don’t even make an appointment. She’s always open to seeing us.” (Participant 3, f, 23).

The participants further highlighted the supportive role of nurses in the form of their availability by explaining the atmosphere created by the nurses at the clinic that was agreeable to them. The nurse at the campus clinic created a positive atmosphere, which allowed the participants to feel comfortable enough to approach her at any given time when they needed to see her. She was also available on her phone, and students were also able to contact her through the phone. This was well described by participant 7 when she said:

“The nurse is very supportive, I even have her mobile number for when I need some advice, and she is like a friend to me...The advice that I get and the support is very good from the nurse” (Participant 7, f, 27).

The nurse's important contribution was also confirmed by Participant 1, who also indicated that she was very supportive of her, and she met any appointments in the shortest possible time, which was very convenient for her as a patient:

“I’m really satisfied with the way in which they accommodated us at the clinic; it’s completely different to the way that we used to be accommodated back home because also the experience at the off-campus clinic was good, so I am really satisfied with everything that they do, It’s convenient, you come in, and you just tell the receptionist that you have an appointment with Sister so and so at a certain time and it doesn’t even take up a long time, you get attended to, you get your meds, and you go and the day continues.” (Participant 1, f, 27).

4.3.3.1.2 Subtheme 6.2: Health education and information sharing

This is the second sub-theme that emerged in response to the third objective of this study. Part of a nurse’s responsibility is to provide health education to people living with HIV and to share relevant information that helps them to take better care of themselves. The evidence gathered from the interviews showed that one of the most important duties performed by nurses was the sharing of relevant information with the patients. This was very key in encouraging students living with HIV to shift their perceptions of HIV and develop a commitment to their SM practices. Health education was a very important part of SM, as was acknowledged by participant 2 as one of the aspects that are needed and expected from nurses as part of their support for HIV SM:

“They must also give health education to us.” (Participant 2, f, 21).

Participant 3 and participant 5 also confirmed the importance of the health education they got from the nurse at the campus clinic, which was more than enough:

“She gives a lot of health education.” (Participant 3, f, 23).

“Also, the Sister in the clinic has been very supportive and has contributed to the way I think about HIV now” (Participant 5, f, 24).

4.3.3.2 Theme 7: Mental health support

This theme also emerged in response to the third objective of the study in relation to the supportive role that nurses can fulfil with regard to the facilitation of the self-management of HIV for higher education students. The sub-themes that emerged from this main theme related specifically to the counselling role that is also played by nurses in their efforts to assist students living with HIV and the expectation from the participants to get assistance from nurses to form peer support groups as part of enhancing better mental health. The discovery that one has contracted HIV is a very stressful development that can affect the mental well-being of a patient and prevent them from executing normal, everyday duties. For university students, the burden of being HIV-positive adds to the stress they get from studying. Findings from this study highlighted the disturbances in academic progress. Most participants indicated that they did encounter stressful situations, mostly emanating from being HIV positive, but they also indicated that they developed ways to manage it so that their health would not be negatively impacted. Nurses and other trained counsellors played a very crucial role in helping People living with HIV deal with the initial shock of becoming HIV positive, understand that one can live a relatively normal life with proper self-management, and handle the mental health challenges that come with status disclosure, such as stigma. The two sub-themes that emerged were the provision of counselling services and the formation of support groups.

4.3.3.2.1 Subtheme 7.1: Provision of counselling services

This sub-theme emerged in response to the third objective of this study, and it related to the provision of counselling services by nurses to students living with HIV. Stress and depression are common among People living with HIV, and if these are allowed to continue, they can disrupt any form of progress that is given by counter initiatives such as ART. Therefore, nurses provide counselling services to People living with HIV as part of their supportive role to help them deal with any situations that are stressful to them. It emerged from the participants in this study that some of them had accessed counselling

services, which helped them to accept their status and cope with it. There were some participants who also felt that nurses should also give mental health education as part of their supportive role, as was indicated by Participant 2:

“Some other nurses would take the blood and just tell you after a while that the findings are back and not tell you what the findings are... They must also give mental health education to us.” (Participant 2, f, 21).

Participant 6 highlighted the major benefits she got from counselling sessions after being diagnosed with HIV. She explained that these sessions were good for her mental well-being, and they helped her cope with HIV during a time when she had not gained a good understanding of HIV and how it worked, hence the need and necessity to include such as part of HIV SM support from nurses:

“Well... since I have been attending counselling since 2015, I think it’s getting easier with time. When I found out about this condition, I was struggling; I really struggled academically and emotionally. I was also diagnosed with depression after I found out about my status. I then started attending counselling, and that is when I could cope with everything. I do attend the counselling sessions when it gets too much to handle; otherwise, I am doing fine with both.” (Participant 6, f, 25).

The benefits of these counselling sessions were also confirmed by Participant 4, who said:

“I was attending counselling from the campus, I would call my counsellor when I felt stressed, and she was always willing to listen and give advice.” (Participant 4, f, 32).

4.3.3.2.2 Sub-theme 7.2 Formation of support groups

Another sub-theme that emerged under this theme in response to the third objective was the issue of nurses assisting the students in forming peer support groups. Since nurses

interact with all students living with HIV, the participants felt that nurses were in a better position to initiate the process of forming these groups. These groups are an important platform that allows these participants to interact and share common experiences about their HIV status. The participants felt strongly that facilitating the formation of peer groups is part of the nurse's supportive role since she works with everyone on a regular basis. Participant 3 mentioned that she wanted the nurse at the campus clinic to organise a peer group for them:

"I also think if they can organise a group of all the HIV positive students to sit and share on how we're managing ourselves that could help us just to hear from other people that are living with the same condition." (Participant 3, f, 23).

Participant 5 also shared similar sentiments with regard to this issue by highlighting the need to have nurses taking over such supportive roles in the organisation of support groups and stated that:

"I have said earlier; I would like to attend the support group where there will be people that are living with the same condition as I am. If the nurse can organise that support group." (Participant 5, f, 24).

These sentiments reflect a strong desire for the company among the participants, which shows that the HIV journey is one that requires support and team effort. The sentiments also show that nurses play such a crucial role, and the participants depend on their support in many aspects of their self-management efforts.

The themes presented in this section emerged from the data gathered in response to the third objective which was to describe the supportive role nurses can fulfil with regard to facilitating the self-management of HIV for higher education students. The evidence shows that nurses play a very pivotal role in the lives of their People living with HIV which goes beyond giving medicines and providing treatment. Nurses are a source of

information pertaining to HIV and self-management and they also give emotional support to participants as revealed by the participants.

4.4 Chapter Summary

This chapter presented the findings of the data analysis that was done of the data that was collected for this study. The demographic details of the participants were presented first, followed by the seven main themes that emerged from the process, and these themes responded to the set objectives of the study at the beginning. For the first objective, three themes emerged in response to it. These themes reflected understanding HIV as a process that began with demystifying HIV, acceptance and living with HIV. Access to correct information about HIV was at the centre of shifting the perception that the participants had before they were diagnosed and after. Under the second objective, there were two main themes which focused on the daily experiences of the participants and their self-management efforts. The themes also covered the challenges the participants faced regularly and the strategies they employed to deal with them. The third and final objective presented themes about the supportive role played by nurses, including their accessibility and availability. There were two themes for the second and third objectives respectively. The next chapter presents a discussion of the findings with supporting literature, the conclusion of the study and study recommendations.

CHAPTER 5 - DISCUSSION OF FINDINGS, CONCLUSION OF THE STUDY AND RECOMMENDATIONS.

5.1 Introduction

The findings of this study were presented in the previous chapter. In this chapter, the findings of the study are discussed, followed by the conclusions of the study and recommendations.

The aim of the study was to explore and describe the experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area and describe how nurses can support these students. The objectives of this study were as follows:

- 1) To explore the experiences of higher education students on their HIV self-management at a higher education institution
 - a) To explore higher education students' understanding of their HIV condition
 - b) To describe the supportive role nurses can fulfil concerning the facilitation of self-management of HIV for higher education students.

The following section discusses the findings of the study. The findings are discussed by objectives, highlighting the themes under each objective with supporting literature.

5.2 Discussion of findings from the study

This section presents findings of the primary evidence that was gathered, supported by the available literature, which will be used to compare with evidence already out. The participants in this study were all students at a university in the Western Cape province of South Africa. The participants were drawn from different departments, there were participants enrolled in undergraduate and postgraduate programmes, the average age was 25 years, and ages ranged from 21 to 32, which generally represented the general university population. Other studies on university students in South Africa show roughly a

similar age range to the university population (Haffejee et al., 2018; Bor, Musakwa, Onoya, Evans, 2021; Gumindega & Maharaj, 2022).

5.2.1 Objective 1: To explore higher education students' understanding of their HIV condition

Evidence collected from participants in relation to the first objective shows that their understanding of HIV was very limited and mostly influenced by myths and stereotypical views of their friends and fellow students. This limited understanding is similar to other studies that have reported a lack of knowledge about HIV in a similar population (Visalli, Cosenza, Mazzù, Bertuccio, Spataro, Pellicanò, Di Pietro, Picerno & Facciola, 2019). However, there was a gradual shift in their understanding of HIV after their diagnosis because they started accessing real facts about HIV through various sources such as nurses, professional counsellors and personal research. Three themes emerged from the gathered data in relation to the first objectives.

5.2.1.1 Theme 1: Improved understanding HIV

Prior to the HIV diagnosis, the participants reported that their understanding of HIV was not based on real facts to a very large extent. Instead, the participants relied more on myths and hearsay, even though several awareness campaigns were conducted on campus. These myths created the impression that having HIV was akin to a death sentence; hence there was a lot of fear and stigma around HIV issues. This finding fits the previous risk reported by Kene and colleagues (2021) who highlighted that students might only acquire HIV knowledge after getting infected. This limited knowledge of HIV among youth has also been documented in a South African study by De Wet and colleagues (2019), who noted that only about 10% of youth affected by HIV had 100% of accurate knowledge. In this study, the situation changed once the participants were diagnosed with HIV because they began accessing new information about HIV from counsellors, nurses and their own personal research. This new information brought clarity and helped to break the myths that shaped their previous perceptions of HIV. As the participants became more

knowledgeable about HIV, accepting their status and adopting steps towards managing HIV became easier. This is supported by a study conducted by Stroumpouki, Perrett, Kasdovasilis, Papatheodorou, Papparizos and Stavropoulou, (2020) in Greece, which found that patients experienced shock initially after being diagnosed with HIV. However, after receiving appropriate information about HIV from healthcare professionals, the participants in the study by Stroumpouki et al. (2020) gained a better understanding which helped them to accept their condition. The mention of healthcare professionals being the main source of information about HIV is consistent with other previous studies, for example De Wet et al., (2019) noted that the majority of youth obtained information from AIDS organisations or clinics. The data gathered in this study revealed a relationship between understanding HIV and acceptance among students living with HIV. This is supported by a study conducted by Horter, Thabede, Dlamini, Bernays, Stringer, Mazibuko, Dube, Rusch and Jobanputra (2017) in Swaziland on PLHIV across different age groups revealed that patients who were well-informed about HIV had a better understanding of their condition and were motivated to accept it while they focused more on healthcare initiatives that would help them to stay healthy. This is further corroborated by findings from a study conducted by Owusu (2022) in Ghana which indicated that health education and counselling from healthcare workers were among the factors that helped to facilitate the transitioning of newly diagnosed patients to self-acceptance of their HIV status.

5.2.1.2 Theme 2: Living with HIV

Most of the participants in the study indicated that living with HIV as a university student brought several challenges. They indicated that the most prominent effect of living with HIV was its disruption to their academic and social lives. This experienced disruption has been documented in previous studies. For example, a study by Payan, Derose, Fulcar, Farías and Palar, (2019) in the Dominican Republic on young women diagnosed with HIV revealed that HIV disrupted several aspects of their lives, like their social and work life. Similarly, another study by Wouters and De Wet (2016), which investigated the

experiences of women living with HIV in South Africa, also indicated that some of the participants' lives were disrupted by the side effects they experienced from taking ART medicines. For most participants, developing plans and strategies to make the necessary changes in response to these disruptions took a while. They had to make significant life changes, including stopping certain activities like drinking alcohol and in some cases, they lost friends and partners because of living with HIV. It also took a while for most participants to understand how to deal with the side effects of their medications that impacted their normal study routines. While some participants indicated that they had disclosed their status to family and close friends, those who could not have to grapple with maintaining their friendships while concealing any evidence about their status from these friends. This meant having to conceal medications and other treatments. A study by Ankrah et al. (2016) also confirmed some of these challenges faced by students living with HIV. Similar to this study, Ankrah et al. (2016) noted that students had to grapple with commitments such as college or other public activities that may overlap with their treatment times, or they might just want to keep the knowledge of their condition away from their peers, which might mean a special plan has to be worked out to ensure they keep taking their medicines (Ankrah et al., 2016).

5.2.1.3 Theme 3: Recognition of HIV stigma

HIV stigma is still very rife, and the participants in this study indicated that they also practised it before they were diagnosed. It occurred in several ways, like saying unpleasant things about those living with HIV, posting derogatory messages on social media platforms and direct verbal abuse aimed at HIV participants. This signifies the different manifestations of HIV stigma, and, according to Azhar (2018), it manifests itself in several ways, including in the family, in relationships, in the community, in education, at work, in religion and even in healthcare workers. Participants indicated that, in some cases, they could not disclose their status to their fellow students for fear of stigmatisation. These findings are similar to the findings of a study conducted by Azhar (2018) on people living with HIV in India, which noted that once people are diagnosed with HIV, they

immediately become afraid of discrimination and stigma from relatives, friends and their communities. Another study on young people and adolescents living with HIV in Thailand found that young people strongly believe that once diagnosed with HIV, they will be shunned by their families and friends and discriminated against (Matthew, Boonsuk, Dandu & Sohn, 2019). Such fears are not unfounded, as another study in South Africa noted multiple types of discrimination towards adolescents living with HIV (Pantelic, Casale, Cluver, Toska, & Moshabela, 2020). Discrimination towards people living with HIV interferes with their HIV self-management as it reduces their access to health care services (Pantelic et al., 2020). It has also been shown that in some cases, these beliefs were mainly based on what they had witnessed happening to other people living with HIV (Matthew et al., 2019).

On the other hand, some participants still struggled with the circumstances surrounding how they contracted HIV. Even though they were more knowledgeable about HIV, some participants had lost trust in their partners, whom they blamed for infecting them with HIV. This resulted in broken relationships and an extra emotional burden that was not good for their well-being. In most cases, the participants felt that they were faithful in their relationships, and the fact that their partners infected them meant they had been betrayed. Similar findings have been reported in a study conducted by Fauk, Mwanri, Hawke, Mohammadi and Ward (2022) on women living with HIV in low and middle-income Asian countries. The findings of the study by Fauk et al. (2022) showed that it was common among women to experience fear, self-blame, blaming spouses and feelings of anger for contracting HIV. Self-blame was normally associated with those who felt that they did not heed their parents' advice against engaging in unprotected sex (Fauk et al., 2022). Previous research also supports the findings made in this study which indicated that female victims also tended to lay blame on their spouses in cases where they felt they were the ones who were unfaithful in their relationships. An investigation by Kashif et al. (2021) found that women forced into marriage tended to blame their spouses and families for their infection. Furthermore, Kimera and colleagues (2021:1945) also reported findings

that support the findings of the study, highlighting that children who were infected at birth blamed their parents, similar to what was noted in this study.

5.2.2 Objective 2: To explore the experiences of higher education students on their HIV self-management at a higher education institution

Participants shared their daily experiences as they navigated through life with the extra burden presented by HIV. HIV changed several aspects of their lives, and since they were diagnosed with HIV, their lives have become like a journey filled with obstacles and opportunities to learn new things. As a result, they had to change their ways of life to accommodate their new status; this has been a gradual process filled with some challenges for most of them. Two themes emerged in relation to the second objective, with participants sharing their everyday experiences. The HIV self-management journey and positive management strategies were the two themes that emerged.

5.2.2.1 Theme 4: The HIV self-management journey

Living with HIV is similar to embarking on a journey filled with positive and negative experiences. From the information shared by the participants, their HIV experiences required emotional strength, a positive mind-set, and support from loved ones and their communities. Having HIV meant that they had to be more aware of their health than before they were diagnosed. This heightened awareness of oneself after an HIV diagnosis has been noted in previous studies. For instance, a study by Collins, Kanouse, Gifford, Senterfitt, Schuster, McCaffrey, Shapiro and Wenger (2001) found that a significant number of people diagnosed with HIV made changes to their lifestyle patterns to promote good health. The researchers discovered that their participants adopted health-promoting initiatives like increased physical exercises, improved diet and quitting smoking (Collins et al., 2001). In this study, participants reported that they had to adhere to their treatment schedules and deal with the side effects of medicines which sometimes meant missing some of their classes or study times or even missing submission deadlines for assignments and projects. The other challenge for some participants was the fear of

disclosing their status to friends and fellow students because of the stigma and discrimination it brought. This fear is not unique to the participants of this study, as literature has noted that disclosure is a major challenge for People living with HIV in general (Arrey, Bilsen, Lacor & Deschepper, 2015). A review of both qualitative and quantitative studies conducted by Evangeli and Wroe (2017) revealed that there are perceived interpersonal risks associated with HIV disclosure that are mainly motivated by fear, anxiety and worry. It should also be noted that there are researchers who have argued that fear and anxiety can sometimes encourage status disclosure, and this is because they are thought to positively influence the way individuals cope with health threats (Hult, Wrubel, Branstrom, Acree & Moskowitz, 2012).

The stress associated with keeping their HIV status a secret, taking their medication in private and dealing with the side effects of their medication was also a source of anxiety for some participants. Available literature also supports that HIV brings numerous challenges to young people living with HIV (UNAIDS, 2015b). Systematic reviews of several studies conducted in East Africa, which covered the psychosocial well-being, health and disclosure of HIV status by YLWHA, identified and confirmed that HIV brings with it several challenges to their lives (Bernays, Papparini, Seeley & Rhodes, 2017; Singh & Lata, 2018; Kimera et al., 2019). Some of the challenges identified by the reviews included emotional and cognitive difficulties that impact them, emanating from a wide range of stressors, including HIV stigma (Kimera et al., 2019). It remains unfortunate that stigma and discrimination remain part of the biggest challenges for PLHIV, and they interfere with HIV self-management efforts (Feyissa, Lockwood, Woldie, & Munn, 2019). Furthermore, research has also established that HIV/AIDS has a strong negative impact on individuals' social integration, as their status often evokes stigmatisation and discrimination in their community leading to poor social support (Smith & Wilkins, 2015).

Similarly, research by Lwidiko et al. (2018) established that people living with HIV (PLHIV) show high rates of trauma, anxiety and depression, which result from a number of factors like stigma and the direct burden of the disease. In this study, participants reported

continuous anxiety and fear of others finding out their status, and such reports fit the realisation that HIV stigma remains in their surroundings, as noted from the findings of the first objective of this study. This becomes a concern as it creates an opportunity for more depressive symptoms, common among young people living with HIV. The study by Lwidiko et al. (2018), conducted in Tanzania, revealed that out of the 900 adolescents who participated, 27% of the participants screened for positive depressive symptoms were HIV positive, while only 5.8% with depressive symptoms were unaffected by HIV.

Despite the numerous challenges cited by the participants in relation to their HIV status, they also enjoyed varying levels of support from close relations, friends, fellow students and their partners. In most cases, the participants who indicated that they enjoyed social support were those who had managed to disclose their status to their close friends and loved ones. According to Hogwood, Campbell, and Butler (2012), the benefits of HIV status disclosure outweigh the negatives, including receiving effective treatment and having a higher chance of being supported by loved ones and partners. Despite opening them up to discrimination and stigma, disclosure increased support for those brave enough to disclose their status. Research has shown that patients with access to social support can cope with stressful situations compared to those who do not enjoy social support (Khamarko & Myers, 2013). According to Areri et al. (2020), self-management of HIV is a journey that requires the support of the patient from family, friends, workmates, and healthcare workers for it to be more effective.

5.2.2.2 Theme 5: Positive management strategies

The participants indicated that they had adopted different measures as part of HIV self-management, which assisted them in improving their well-being. From the interviews conducted, participants highlighted that their HIV self-management experiences involved engaging in activities that were aimed at ensuring that they maintained good physical health. This included participating in activities that would enhance their physical fitness and avoiding anything perceived as interfering with their well-being. A study of factors

affecting the quality of life of PLHIV in Uganda showed more benefits in adopting positive changes (Mutabazi-Mwesigire, Katamba, Martin, Seeley & Wu, 2015). The study noted that behavioural factors such as alcohol abuse among PLHIV were associated with risky sexual behaviour, jeopardising their quality of life (Mutabazi-Mwesigire et al., 2015). It was encouraging to note that participants in this study reported avoiding such behaviours. Understanding the relationship between these negative behavioural factors and quality of life is very important because it may also prevent the spread of HIV (Mutabazi-Mwesigire et al., 2015), and avoidance of negative behaviour is an indication of good engagement in HIV self-management.

Furthermore, staying in good physical shape was mentioned by some participants as one of the fundamental changes they had adopted to maintain and enhance their well-being. The benefits of regular physical exercise are well documented, and according to Jagers and Hand (2016), physical activity leads to positive changes across clinical measurements of health such as body mass index (BMI), waist circumference, muscular strength, and cardiorespiratory fitness (CRF), among others for people living with HIV. The benefits of physical exercise were also confirmed by a scoping review of studies that focused on people over 50 living with HIV, carried out at the school of health sciences at the University of KwaZulu Natal (Chetty, et al., 2021). The review showed that physical exercise improves the quality of life for older people just as it does for younger people living with HIV (Chetty et al., 2021).

The participants also revealed that they encountered many stressful situations related their HIV status, especially with the numerous negative effects they had to deal with regularly, like side effects from medicines and stigma. This meant that they had to avoid any factors that increased stress, and having a positive mind-set was the basis for achieving this. As noted by Sikkema, Dennis, Watt, Choi, Yemeke and Joska, (2015), mental disorders and psychological distress compromise overall well-being and quality of life among PLHIV and impact individuals' ability to engage effectively with HIV care, including their adherence to antiretroviral therapy (ART). Therefore, good mental health is key to

achieving success for the participants. Furthermore, it has been found that lots of stress in people living with HIV is associated with poorer health overall, including low weight gain, low CD4 progression, and suicide, but also with faster progression to AIDS and increased mortality (Kingori, Haile & Ngatia, 2015). Similar to this study, literature has noted that PLHIV develop their own coping strategies to deal with the stress they experience as a result of their HIV status (Ahmad, Shah & Nor, 2022). Furthermore, according to Fauk et al., (2022) some PLHIV rely on peer support activities like meeting others who are also living with the condition to share information on how to deal with stress, while others depend on social support from healthcare workers and healthcare services. Other studies on women living with HIV also established that women rely on institutional support they get from the church and family members (Ashaba, Kaida, Burns, O'Neil, Dunkley, Psaros, Kastner, Tsai, Bangsberg & Matthews, 2017; Bhadra, Hershov, Ha, Pence, Mai & Go, 2020).

5.2.3 Objective 3: To describe the supportive role that nurses can fulfil with regard to the facilitation of the self-management of HIV for higher education students.

The evidence gathered also revealed that nurses are very important and their role is indispensable in HIV SM, and this was also in response to the study's third objective. The importance of the role played by nurses in treating and caring for People living with HIV is also supported in the literature (Tunncliff, Piercy, Bowman, Hughes & Goyder, 2013; Dumitru, Irwin & Tailor, 2017). The participants expressed their satisfaction with the supportive role played by their nurse at the campus clinic. They all noted that the nurse was always accessible when they needed assistance, and the nurse went beyond the call of duty by being available to the students even at odd hours, including during the night. Two themes emerged regarding the third objective: nurses are the "go-to" resource, and they provide mental health support.

5.2.3.1 Theme 6: Nurses as the “go-to” resource in HIV SM

Nurses play an indispensable role in the lives of People living with HIV, as evidenced by the evidence shared by the participants in this study. Rouleau, Richard, Côté, Gagnon, and Pelletier (2019) also researched the role played by nurses, and their findings indicated that nurses were indispensable resources in the fight against the HIV epidemic. What makes their role crucial is the fact that they make up the majority of healthcare professionals (Rouleau et al., 2019). The campus nurse was portrayed as a very supportive and understanding individual who went beyond her call of duty to assist them. The participants indicated that they had built close relationships with their nurse, and she was always accessible and available whenever they needed her, which made it easier for them to confide in her when they encountered problems. The nurse also shared with them important information about HIV and always advised them on the importance of taking their medication in accordance with their treatment schedules. The provision of information by nurses is very important and necessary since the findings from the first objective indicated that the participants were exposed to myths and falsehoods before they were diagnosed with HIV.

Available literature also supports the importance of the role played by nurses in their patients' lives. A scoping review of studies focusing on the interactions between nurses and their patients in sub-Saharan Africa conducted by Kwame and Petrucka (2020) revealed that the participation or non-participation of patients in the care process, taking personal control of their health and compliance with medical advice depend on the nature of nurse-patient interaction and communication. The study by Kwame and Petrucka (2020) also noted that poor communication and a lack of empathy for patients are detrimental to the quality of care that patients can receive. According to Bofo (2016), research has revealed that in instances where communication (verbal and non-verbal), including the use of abusive language, use of harsh or rude language and impolite speeches, may cause patients to react negatively towards nurses; this ultimately impacts the care process. In relation to this study, the participants revealed that there was good

communication between them and their nurse which made the care process more effective. This is also confirmed by Campbell et al., (2015), who pointed out that positive relationships between nurses and their patients greatly promoted ART adherence. However, it should also be noted that the relationship between nurses and their patients is not always positive. According to Ondenge Renju, Bonnington, Moshabela, Wamoyi, Nyamukapa, Seeley, Wringe and Skovdal, (2017) some PLHIV suffered abuse from their healthcare providers in the course of their relationship and they felt powerless to do anything about it since they believed that nurses and doctors were the only ones who could help them with their condition.

They further indicated that in some settings, healthcare providers assumed the role of “rule setters” while patients were expected to abide by those rules without question and this only served to create unbalanced relations which compromised proper care (Ondenge et al., 2017). These findings were also confirmed by a study conducted by Campbell et al., (2015) which found that patients strive to live up to the persona of a ‘good patient’ as defined by healthcare providers to avoid being ‘punished’ and to ensure continued access to ART. The good relationship between the participants in this study and their nurses on campus might have been motivated by the fact that there were few nurses at the clinic, which made it easier to forge close relations. The nurse was possibly not overworked, as is the case in public hospitals, a factor that contributes to nurses having bad relations with their patients (Campbell et al., 2015).

5.2.3.2 Theme 7: Mental health support

Findings from this study highlighted the disturbances in academic progress that students living with HIV encounter in relation to their studies. This added to the stress they experience due to other factors, such as HIV stigma and side effects from the medication they take as part of ART. Nurses and other trained counsellors play a very crucial role in helping People living with HIV deal with the initial shock of becoming HIV positive, understand that one can live a relatively normal life with proper HIV self-management,

and handle the mental health challenges that come with status disclosure, such as stigmatisation (Baker & Naidu, 2021). Participants in this study indicated that they wanted the nurse's role in supporting them in their HIV self-management to include mental health support. It is to be noted that mental problems among People living with HIV are a common phenomenon, and these include depression (Clinical Trials Arena [CTA], 2021). South Africa's health care system does not have sufficient mental health specialists to cater for patients who need treatment (Lund, Reider, Whiting & Prichard, 2010). The researcher observed that all the participants who had accessed counselling services did not indicate that they got it from their local nurse on campus but from other sources. Limited time might be the reason why the nurse did not attend to mental health issues since she also had to deal with other students with different ailments or maybe she did not have specialist training in mental healthcare. Baker and Naidu (2021) observed that nurses who are not adequately trained to deal with mental health issues might struggle to diagnose and treat mental health problems.

A probable solution to this would be to ensure that non-mental health nurses also provide mental health services under the guidance of a trained specialist. A study conducted by Andersen et al. (2016) in Cape Town to measure the effectiveness of a nurse-delivered cognitive behavioural therapy intervention for adherence and depression in HIV showed that depressive symptoms were reduced significantly during the three (3) week period when the study was conducted. ART adherence also improved during the period of intervention among the participants. The study by Andersen et al. (2016) also proved that nurses could assume the role of providing mental health support to People living with HIV because of the scarcity of specialists in this area, even though more research is required. It is important to highlight the importance of equipping nurses with competencies in mental healthcare for People living with HIV and Post Graduate Diploma programme in mental health is one of the initiatives that can be expanded to achieve this. Some participants indicated that nurses should facilitate the formation of peer groups to enable them to meet and interact with students in the same situation. These peer interactions can assist the

participants in maintaining their mental health at acceptable levels. Previous research also supports the importance of peer support as a complementary service to general healthcare services (Liu, Wu, Cai, Tang, Coufal, Qian, Luu, Fisher & Jia, 2020). It has been noted that even though access to ART has increased significantly in South Africa and other regions, there are still barriers, such as HIV stigma, that contribute to people falling out of care (Lamb, Fayorsey, Nuwagaba-Biribonwoha, Viola, Mutabaz, Alwar, Casalini & Elul, 2014). This problem can be alleviated through peer support initiatives. Peer support for people living with HIV is the provision of assistance and encouragement by an individual considered equal in taking an active role in the self-management of their chronic health condition.

Four major functions that peer support services serve have been identified: assistance in daily management, social and emotional support, linkage to clinical care and community resources, and ongoing support related to chronic disease (Peers for progress, 2015). These functions are part of what is needed for effective HIV self-management, hence the necessity to ensure the provision of such service to university students living with HIV. A systematic review conducted by Berg, Page and Øgård-Repål (2021) showed that peer support groups with routine medical care are superior to routine clinic follow-up in improving outcomes for people living with HIV. It is a feasible and effective approach for linking and retaining people living with HIV-to-HIV care, which can help shoulder existing services (Berg et al., 2021).

5.3 Link to the conceptual framework

As stated in the first chapter, this study used the IFSMT theoretical framework and some of its underlying assumptions were confirmed in the findings that were made in this study. One of the underlying assumptions of the IFSMT is that persons engage in behaviours for personally meaningful reasons that may or may not be directly related to optimising their health status (Ryan & Sawin, 2009:221). The evidence gathered in this study indicates that the participants changed their ways of life after they were diagnosed with HIV as this

was aimed at promoting their wellbeing. Participants stopped habits like drinking, smoking and changed their diet in order to promote positive health outcomes. They also adopted new habits like taking up regular physical exercises and taking up ART treatment as a way of optimising their health outcomes. In this case, the behaviours that the participants engaged in were meant to improve their personal health outcomes.

The IFSMT also assumed that individuals actively engage in self-managing conditions by collaborating with persons in the healthcare system to achieve personal health goals (Ryan & Sawin, 2009:221). This was revealed in this study by the finding that the participants in this study had managed to develop a strong relationship with their campus nurse. She became their major source of support and information besides the treatment she provided them. This also encouraged them to adopt the necessary changes required to maintain good health.

Another underlying assumption of the IFSMT that was confirmed in the findings of this study is that social facilitation can direct, encourage and support engagement in self-management behaviours and achievement of outcomes (Ryan & Sawin, 2009:221). In the context of this study, the need for social facilitation was identified through the desire of most participants to join peer support groups. They believed that these groups would enable them to connect with their peers and share common experiences. The study also found that PLHIV were constantly exposed to stigma which limited their social interactions and even contributed to some patients' falling-out of care. In this case peer support activities were an appropriate intervention that assisted PLHIV in taking an active role in self-managing their HIV status. As identified by Peers for progress (2015) peer support services included ongoing support to chronic illnesses, assistance in daily management and social support to patients. In this case peer groups played the role of the social facilitator that the participants required.

The IFSMT theory also assumes that person/family centred interventions are the most effective in fostering engagement in self-management behaviours and achieving proximal

and distal outcomes (Ryan & Sawin, 2009:221). In this study person centred interventions were the ones that proved to be more effective. This was mainly because the evidence gathered in the study showed that some participants who took part had still not disclosed their status to their families for fear of being isolated. This meant that most of the self-management initiatives they engaged in were adopted out of their own personal decisions. The decision was different to some extent for participants whose status was known by their families and who provided them with support. In this respect both person and family centred interventions were confirmed as effective interventions in encouraging self-management behaviours.

5.4 Recommendations

After analysing the primary data that was collected, this study has the following recommendations for different stakeholders based on the findings that were made:

5.4.1 Nurses

Mental health services should be strengthened and it should be an important part of nurses' provision of care

Since current registered nurses have done R425 which includes psychiatric nursing, they are able to provide mental healthcare and it should be made a critical part of their care provision when dealing with People living with HIV. Universities can also sponsor the PGDip in mental health for nurses who do not have mental healthcare training.

Nurses should play a role in assisting peer educators to strengthen HIV peer groups and make them more accessible on campus

Participants indicated their desire to participate in peer groups because they are a platform where they can exchange information and different experiences about HIV and self-management initiatives.

5.4.2 University students

Students can form HIV awareness clubs that are open to all for purposes of spreading awareness and tackling HIV stigma

Since students are able to form different social clubs on campus, they can form HIV awareness clubs which can be platforms for organising different activities like plays, quizzes, competitions that are aimed at tackling stigma and spreading positive information to dispel myths about the HIV.

Students living with HIV should join peer groups to access peer support and improve their SM initiatives

Since peer groups provide a platform where students living with HIV can come together and share information, they can also help them to strengthen their SM efforts. In addition, through peer groups, students can create wider networks to benefit them in their fight against HIV.

5.4.3 Researchers

More research is required to investigate the levels of HIV stigma on university campuses and explore ways to reduce it.

The participants in this study agreed that stigma was still rife, and it was quite challenging for them to disclose their HIV status to close friends and classmates. This was quite stressful because they were forced to do normal things like taking their medicines in hiding.

Researchers should also investigate the effectiveness of current HIV SM strategies

This study investigated the HIV SM experiences of students living with HIV, and some HIV SM strategies that the students implement have been presented, although their effectiveness remains to be established. Therefore, their effectiveness must be measured

under different environments and situations to establish key standards that can be recommended for other persons living with HIV.

5.4.4 The University

Universities should provide support (such as funding) for more research in strategies that can enhance current models of HIV education.

This study has established that HIV stigma is still common among HIV-free students, even though there are programmes to teach students about HIV and raise awareness of how it can be managed. It is important to measure the effectiveness of these programmes and establish if more needs to be done to improve them.

More support, such as flexible timelines for the submission of academic assignments, is required for students living with HIV to minimise disruptions to their academic programs

Participants noted that they experience disruptions to their academic programs due to the schedules they are supposed to follow in taking their medicines and the side effects they experience. Therefore, allowing them more time and flexibility to submit their assignments might help them cope with their challenges, which could enhance their HIV SM.

More research is required to investigate the SM initiatives of students living with HIV at more universities

This study was a qualitative one, and it focused on a single institution which means the findings are only limited to this one institution and cannot be generalised. A study with a wider scope to cover more universities and which uses a mixed methods approach would provide more details about the SM initiatives of more students living with HIV while its findings can be generalised. This will also help to add more literature on this subject which is currently very limited.

5.5 Research Limitations

The major limitation of this research was that it was conducted when South Africa was affected by the Covid 19 pandemic, and lockdown measures were still in place. As a result, movement and human interactions were severely limited, and this forced the researcher to conduct some interviews with participants over the phone. This also impacted the selection of participants, which was already difficult due to the sensitivity of the subject under discussion. This resulted in a limited number of accessible participants, and it might also have influenced the perspectives of some participants. However, the use of health care professional in the recruitment of the participants has reduced the negative effect of this limitation, as it provided access to those who were still accessing the services on campus.

5.6 Chapter Summary and Study Conclusion

This chapter presented the study's overall findings from the reviewed literature and the primary evidence collected. A set of recommendations was also presented, along with areas identified for future study. The study was focused on exploring and describing the experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area. The study also made recommendations on how nurses can support these students. A qualitative methodology was employed with individual in-depth interviews as the primary data collection tool to achieve this. The researcher observed the ethical requirements of the University, establishing the trustworthiness of the study through triangulation and member checking. The study's findings revealed that students living with HIV had a much better understanding of HIV than their peers who were not infected with HIV. Even though they went through the normal phases of denial and shock after their initial diagnosis, they eventually accepted their condition due to the information they could access about HIV. This encouraged them to start ART treatments and adopt different strategies to manage their health, including improving their diet, quitting smoking and drinking alcohol, and engaging in regular

physical exercise. Others also joined peer groups to improve their social interactions and learn more about HIV SM from peers who were going through the same experiences. The participants also developed a close relationship with their nurse on campus, which also helped them obtain assistance on matters relating to their health and status. The findings made by this study reflect that the purpose of the study, which was to explore and describe the HIV SM experiences of university students, was achieved to a very large extent.

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APPENDICES

Appendix A: Approval of Ethical Clearance



HEALTH AND WELLNESS SCIENCES RESEARCH ETHICS COMMITTEE (HW-REC)
Registration Number NHREC: REC- 230408-014

P.O. Box 1906 • Bellville 7535 South Africa
Symphony Road Bellville 7535
Tel: +27 21 959 6917
Email: sethn@cput.ac.za

19 April 2021
REC Approval Reference No:
CPUT/HW-REC 2021/H12

Faculty of Health and Wellness Sciences

Dear Mr S Tyabazeka

Re: APPLICATION TO THE HW-REC FOR ETHICS CLEARANCE

Approval was granted by the Health and Wellness Sciences-REC to Mr S Tyabazeka for ethical clearance. This approval is for research activities related to research for Mr S Tyabazeka at Cape Peninsula University of Technology.

TITLE: Experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area

Supervisor: Dr R Modeste

Comment: The ethics permission as set out in this permission letter is conditional on the obtaining of formal site permission to conduct research within the envisaged research site as stipulated in the proposal.

Approval will not extend beyond 20 April 2022. An extension should be applied for 6 weeks before this expiry date should data collection and use/analysis of data, information and/or samples for this study continue beyond this date.

The investigator(s) should understand the ethical conditions under which they are authorized to carry out this study and they should be compliant to these conditions. It is required that the investigator(s) complete an **annual progress report** that should be submitted to the HWS-REC in December of that particular year, for the HWS-REC to be kept informed of the progress and of any problems you may have encountered.

Kind Regards

A handwritten signature in black ink, appearing to read "Carolyn", written in a cursive style.

Carolynn Lackay
Chairperson – Research Ethics Committee
Faculty of Health and Wellness Sciences

Appendix B: Approval of Ethical Clearance – Extension



HEALTH AND WELLNESS SCIENCES RESEARCH ETHICS COMMITTEE (HW-REC)
Registration Number NHREC: REC- 230408-014

P.O. Box 1906 • Bellville 7535 South Africa
Symphony Road Bellville 7535
Tel: +27 21 959 6917
Email: sethn@cput.ac.za

9 March 2022
REC Approval Reference No:
CPUT/HW-REC 2021/H12

Faculty of Health and Wellness Sciences

Dear Mr S Tyabazeka

Re: APPLICATION TO THE HW-REC FOR ETHICS CLEARANCE

Approval was granted by the Health and Wellness Sciences-REC to Mr S Tyabazeka for ethical clearance. This approval is for research activities related to research for Mr S Tyabazeka at Cape Peninsula University of Technology.

TITLE: Experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area

Supervisor: Dr R Modeste

Comment: The ethics permission as set out in this permission letter is conditional on the obtaining of formal site permission to conduct research within the envisaged research site as stipulated in the proposal.

Approval will not extend beyond 10 March 2023. An extension should be applied for 6 weeks before this expiry date should data collection and use/analysis of data, information and/or samples for this study continue beyond this date.

The investigator(s) should understand the ethical conditions under which they are authorized to carry out this study and they should be compliant to these conditions. It is required that the investigator(s) complete an **annual progress report** that should be submitted to the HWS-REC in December of that particular year, for the HWS-REC to be kept informed of the progress and of any problems you may have encountered.

Kind Regards

A handwritten signature in black ink, appearing to read "Carolyn", written in a cursive style.

Carolynn Lackay
Chairperson – Research Ethics Committee
Faculty of Health and Wellness Sciences

Appendix C: Permission Letter – HIV/Aids unit



Office of the Head of HIV/AIDS Unit:
Division of Student Affairs
District Six Campus
Cape Peninsula University of Technology
Corner Tennant & Keisergracht Street
Cape Town
Tel: 021-4604253
Email: maraisme@cput.ac.za

17 April 2021

Dear Mr Siseko Tyabazeka

RE: PERMISSION TO CONDUCT RESEARCH THROUGH THE HIV/AIDS UNIT

The HIV/AIDS Unit received your request for permission to conduct a study titled: **Experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area**

Permission is herewith granted for you to conduct your research through the HIV/AIDS Unit, pending ethical clearance from the relevant Ethical Clearance Committees at the Cape Peninsula University of Technology.

Wishing you the best in your study.

Sincerely

A handwritten signature in blue ink, appearing to read "Melanie Marais".

Ms Melanie Marais
HIV/AIDS Coordinator: Division of Student Affairs
Cape Peninsula University of Technology | #WeAreCPUT

t: +27 (0) 21 460 4253 | e: maraisme@cput.ac.za w: www.cput.ac.za
PO Box 1906 Bellville 7535 | Symphony Way, Bellville, Cape Town, South Africa

Appendix D: Informed consent by participants

INFORMED CONSENT BY PARTICIPANT:

I declare that:

I have read this information and consent form and that it is written in a language with which I am fluent and comfortable with.

I have had a chance to ask questions and all my questions have been sufficiently answered.

I understand that taking part in this study is voluntary and I have not been forced to take part.

I may choose to withdraw from the study at any time and will not be penalized or prejudiced in any way.

I may be asked to leave the study before it has finished if the researcher feels it is in my best interests, or if I do not follow the study plan as agreed to.

I also consent that my information may be:

- Used and kept for future research studies
- Used and discarded

I consent for audio recording of the interview

I do not consent for audio recording of the interview

Signed at (place).....On (date) 202.....

Signature of participant..... Signature of witness.....

Appendix E: Interview Guide

Interview guide

Name:

Gender:

Male	Female
------	--------

Age

18-22	23-26	27-30
-------	-------	-------

Do you stay in university residents?

Yes	No
-----	----

If you do not stay in the university residence, where do you stay?

.....

Do you attend the clinic on campus?

Yes	No
-----	----

Main interview questions:

1. How is it for you to manage your HIV condition as a higher education student?
2. Please describe your understanding of HIV

3. What can the nurses from the campus clinic and the HIV unit do to support you and facilitate your management of HIV?

Further questions asked as part of probing.

What else do you do to manage the condition in addition to you are saying?

What else would you like to do that you are unable to do?

Is there anything that you have changed or would like to change as part of HIV self-management? Please give details.

Is there any stigma attached to being HIV positive? How has it interfered with your ability to self-manage your condition?

What are the challenges you encounter the most with managing HIV?

What are the symptoms that bother you the most?

How do you manage those symptoms?

What are the stressors in your life as a student?

How are you managing those stressors?

Do you know your viral load?

Do you know your CD4 count?

When you were diagnosed where you studying? Did you notice any decline in you academic performance if you were studying?

How do you balance studies with HIV self-management?

Appendix F: Research Information sheet



Research Information sheet

Title: - Experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area

Principal Investigator: Siseko Tyabazeka (210248173)

- Cape Peninsula University of Technology

E-mail: - 210248173@mycput.ac.za

Faculty of Health and Wellness Sciences

Address:

Cape Peninsula University of Technology – Bellville Campus

Symphony Road

Department of Nursing Science

Old Education Building – Block B

Contact Number: 021 959 6183

Dear Participant,

I am **Siseko Tyabazeka** investigator for the research entitled: **Experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area**. I am writing to invite you to take part in this study aimed at explore the HIV self-management experiences of students.

Kindly spend a few minutes to read the information given here, which will describe the details of this project. You can ask me any questions about this project that you do not fully understand. It is very important that you are fully satisfied and that you clearly understand what this research involves and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. There would not be any negative effects, if you refuse to participate. You are also free to withdraw from the study at any point, even if you do initially agree to take part.

This study has been approved by the Research Ethics Committee at Cape University of Technology, and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki.

What this research study is about

The purpose of this study is to explore and describe experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area

Why you have been invited to participate

Since you are a university student 18 years and above living with HIV

What your responsibilities will be

If you agree to participate, after signing the consent form, you will be asked to do an interview with the researcher.

Will you benefit from taking part in this research?

Although there is no personal benefit for you from participating in the study, but your participation will give the researcher the idea of how much you know with regards to HIV self-management and be equipped in better managing your HIV condition.

Are there any risks involved in taking part in this research?

There are no known physical risks from participating in the study, and the researcher will make effort to avoid harm. In case you are emotionally distressed or experience any emotional discomfort, you are encouraged to report to me the researcher and you will be referred to the counsellor at the health care facility for counselling and support.

Will your information be kept confidential?

Your name, contact details and identities will be kept confidential. Information from the study will be kept in a locked cupboard, and electronic information will be password protected. Only those involved in the study will have access to the data, and all identifiers will be removed to protect your identity. Your name and the name of the institution will not be disclosed in the writing of the research report as well as publication of articles. Codes will be used to refer to the institutions, and numerical codes will be allocated to the participants.

Will you be paid to take part in this study and are there any costs involved?

There is no financial reward in participating in this study and no direct cost to you.

You are invited to ask me any question you may have on the study for further clarification

Who else to contact?

Should you need to contact someone else to report any issue about the study, you can contact the head of School: Prof K Jooste at Joosteka@cput.ac.za

Or the chairperson of the research Ethics committee: Mr N Naidoo at Naidoon@cput.ac.za

Or the Dean of the faculty, Prof P Engel-Hills at Engelhillsp@cput.ac.za

Appendix G: Letter requesting counselling for students



Siseko Tyabazeka

210248173@mycput.ac.za

084 265 1482

19/04/2021

Student Counselling unit

Louisa Brits

PIENAARL@cput.ac.za

CPUT

Re: Request to request counselling for students

Dear Louisa Brits

I am Siseko Tyabazeka, Nursing Master's student in the faculty of Health and Wellness. I am conducting a study exploring the experiences of students living with HIV on campus on their HIV self-management. The title of my study is: Experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area. The study will be conducted at this Higher education institution. Participants for the study will be students living with HIV and registered at CPUT. I anticipate starting data collection in the second term of the 2021 academic year, and will continue until data saturation is reached. It is anticipated that it will take no more than two months of data collection.

I am hereby requesting your permission and assistance with counselling services to be rendered to any of the study participants who may feel distressed during or after the interviews.

The study has very minimal risks, however, there might be some exceptional cases of distress that might need the counselling interventions to debrief. I am a professional nurse with psychiatric qualification, and I will be able to establish when participants are stressed as a result of their participation in the study, and I will use my competencies as a psychiatric nurse to counsel them, and would like your approval so that I can refer to your services for further counselling.

I have already received permission from the HIV unit to access the students and the ethics clearance from the faculty of Health and Wellness Sciences Research Ethics committee as attached. I am also attaching the proposal for your information.

The recruitment of participants will be during normal working hours, and interviews will be conducted between 09h00 and 16h00 weekdays, depending on arrangements that suit the participants.

Sincerely



Siseko Tyabazeka

210248173@mycput.ac.za

084 265 1482

Appendix H: Poster - Invitation to Participate in Study

A CALL TO PARTICIPATE IN THE RESEARCH STUDY

Dear Participant,

I am Siseko Tyabazeka investigator for the research entitled: Experiences of higher education students on self-management of HIV at a higher education institution in the Western Cape area. I am writing to invite you to take part in this study aimed at explore the HIV self-management experiences of students.

This study has been approved by the Research Ethics Committee at Cape University of Technology, and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki.

Confidentiality and anonymity will be maintained throughout the study.

It is hoped that the findings of this research would go a long way in understanding the HIV self-management among students in South Africa and assist health and university authorities to make changes and improvements that are necessary for HIV self-management interventions for the students

Contact details of the researcher

Cell: 084 265 1482

Email: 210248173@mycput.ac.za

Appendix I: Student Counselling Referral Form

CONFIDENTIAL

STUDENT COUNSELLING REFERRAL FORM

Referred by:

Name: SISEKO TYABAZEKA Contact details: Ph 084 285 1482 Date: 12/11/2021
 Email 210248173@mycpu.ac.za

Referral information

Referred from: (Please mark appropriately)

Student Counselling	Welfare Officer	Student Health	Student Housing	Student affairs/SRC	Judicial Office	HIV Unit	Disability Unit	Academic Dept. ✓
---------------------	-----------------	----------------	-----------------	---------------------	-----------------	----------	-----------------	------------------

Referred student:

Name & Surname: Student number:
 Course enrolled for: Faculty:
 Contact number: Email:

Reason for Referral

(Please mark appropriately)

Health concerns		Personal/emotional concerns	✓	Career choice	
Study methods		Home circumstances		Welfare	
Financial problems		Academic progress		Other	

Additional information

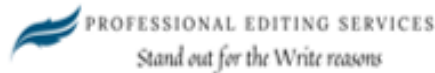
(if any given.)

Signature of referring person:



Date: 12 November 2021

Appendix J: Certificate of editing



Gerald T du Preez
PhD

22 Clivia Avenue
Brantwood, Kuils River, 7580
+27 (21) 903-3145 | +27 (83) 325 1842
gerald9@gmail.com

Certificate of Editing

This serves to confirm that copy-editing and proofreading services were rendered to
for a master's thesis entitled
**Experiences of Higher Education Students on Self-Management of HIV at a Higher Education
Institution in the Western Cape Area**
By Siseko Tyabazeka
with a final word count of 48 419 on 9 March 2023

I am a member of the Professional Editors' Guild (member number DUP015) and commit to the following codes of practice (among others):

- *I have completed the work independently and did not sub-contract it out*
- *I kept to the agreed deadlines and communicated changes within reasonable time frames*
- *I treated all work as confidential and maintained objectivity in editing*
- *I did not accept work that could be considered unlawful, dishonest or contrary to public interest*

I uphold the following editing standards:

- *proofreading for mechanical errors such as spelling, punctuation, grammar*
- *copy-editing that includes commenting on, but not correcting, structure, organisation and logical flow of content, formatting (headings, page numbers, table of contents, etc.), eliminating unnecessary repetition*
- *checking citation style is correct, punctuating as needed and flagging missing or incorrect references*
- *commenting on suspected plagiarism and missing sources*
- *returning the document with track changes for the author to accept*

I confirm I have met the above editing standards and professional, ethical practice. The content of the work edited remains that of the student.

This edit was done to assist the student in paraphrasing significant portions of the thesis due to an initially high similarity index output from Turnitin.

Gerald T du Preez, PhD

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Appendix K: Turnitin receipt



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EXPERIENCES OF WOMEN EDUCATION ETICONS ON SELF-MANAGEMENT OF HIV AT A HIGHER EDUCATION INSTITUTION IN THE WESTERN CAPE AREA

By
SISEKO TYABAZEKA

Thesis submitted in the fulfillment of the requirements for the Masters in Nursing degree

In the Faculty of Health and Wellness

at the Cape Peninsula University of Technology

Supervisor: Prof. BT Mokoabele
Co-supervisor: Dr. W. P. M. M.

Bellville campus, Cape Town
Date submitted: June 2023

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