STRATEGY TO OPTIMIZE THE TRANSITION OF ADOLESCENTS LIVING WITH HIV TO ADULTHOOD AT SELECTED DISTRICTS IN LIMPOPO PROVINCE, SOUTH AFRICA

by

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DECLARATION

I, **Azwinndini Cecilia Mukwevho**, hereby declare that the dissertation titled ‘**Strategy to Optimize the Transition of Adolescents Living with HIV to Adulthood at Selected Districts in Limpopo Province, South Africa**,’ submitted for the **Doctor of Philosophy (PhD)** degree at the **University of Venda (UNIVEN)** is my own work. All the sources that I have used or cited have been indicated and acknowledged by means of complete references. This research project has never been submitted previously for any degree to any other institution.

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DEDICATION

This thesis is dedicated to:

- My loving and supportive father, Makhado Daniel Sadiki, for loving education so dearly.
- My loving and supportive daughter, Unarine, who was also my research assistant. Thank you, my daughter, you were the pillar of my strength in this project.
- To Mutshidzi and Thanyani Junior, my grandson, education is the key to success.

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My God, my Lord, for His unconditional love, which far surpasses my mere knowledge. He gave me the strength, courage and the power to go on with this study. That was far over and above all that I can ask or think, beyond my highest prayers, desires, thoughts, hopes or dreams.

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ABSTRACT

Background: Babies born with Human Immunodeficiency Virus (HIV) in the first decade of the epidemic have reached adolescents stage. As they are growing up, they experience events like all adolescents, irrespective of routines imposed on them by living with the virus. These Adolescents Living with Human Immunodeficiency Virus (ALWHIV) need specialized care to cope with illnesses which could result from the side effects of the medications.

Purpose: This study sought to develop a strategy to optimize the transition of ALWHIV to adulthood at selected districts in Limpopo Province.

The study was conducted in three phases. **Phase 1** was empirical with the following objectives: to explore and describe the knowledge of ALWHIV during transition to adulthood, to describe challenges faced by parents/guardians during the transition to adulthood, to explore the support given to ALWHIV by parents/guardians during the transition to adulthood. **Phase 2** focused on strategy development, i.e., to develop a strategy to optimize the transition of ALWHIV to adulthood and **phase 3** focused on validation strategy, i.e. to conduct validation of the developed strategy.

Methods: The study took a qualitative research approach which involved exploratory, descriptive, and contextual designs. The population comprised of ALWHIV and parents or guardians who live with and care for these children. Non-probability purposive sampling was used to sample ALWHIV and their parents or guardians. The sample size was 27 participants who enrolled for antiretroviral therapy (ART) care and 18 parents or guardians of these children. Measures to ensure trustworthiness articulated in Lincoln and Guba's criteria and ethical considerations were adhered to. Data were collected using in-depth interviews with both groups and analysed through Tesch's open-coding method.

Findings: The following 5 themes emerged from the qualitative data analysis: Descriptions of the experiences of ALWHIV; Challenges experienced from childhood to adolescence period; Descriptions of existing support experiences by ALWHIV and their parents; Knowledge related to HIV+ status and disease progression; and Suggestions made to promote quality of life by ALWHIV. Upon further analysis, these five themes yielded 24 sub-themes. The findings of the empirical (phase 1) were used to develop a strategy using Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis (phase 2). From the SWOT analysis, SWOT matrix emerged and strategy (actionable plans) classified in Building on the strengths, Overcoming weaknesses, Exploring the opportunities and Minimizing the threats (BOEM) was developed. The developed strategy was validated by professional nurses using a qualitative design.

Results of validation: The developed strategy was considered to be good and easy to implement in order to optimize the transition of ALWHIV, but will not be generalized because the study could not cover the whole of Limpopo Province. The strategy will be implemented in the primary health care (PHC) facilities where the study was conducted in the selected districts of Limpopo. The developed strategy could contribute greatly when preparing ALWHIV for transition so that they remain in care until a cure is found.

Recommendations: The study recommendations were made with reference to nursing practice, nursing education and research. The recommendations may contribute and assist NIMART nurses during the preparations for transition of ALWHIV to adulthood and policymakers in the district or province during the updates of adolescents on HIV guidelines or policies.

Keywords: adolescents, living with HIV, optimize, strategy, transition to adulthood.

LIST OF ACRONYMS AND ABREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ALWHIV	Adolescents Living with HIV
ANC	Antenatal Care
ART	Antiretroviral Treatment (Therapy)
ARV(s)	Antiretroviral Drug(s)
BOEM	Building from Strength, Overcoming Weaknesses, Exploring Opportunities and Minimizing Threats
CCMDD	Central Chronic Medicine Dispensing and Distribution
CD4	T-Lymphocyte Cell Bearing CD4 Receptor
CHW	Community Health Worker(s)
DoH	Department of Health
EM	Empowerment Model
FPD	The Foundation for Professional Development
HAART	Highly Active Antiretroviral Treatment/Therapy
HIV+ / HIV-	Human Immunodeficiency Virus Positive / Negative
ILO	International Labour Organization
LTFU	Lost to Follow-Up
MCWH	Maternal, Child and Women’s Health
MTCT	Mother-to-Child Transmission
NGO(s)	Non-Governmental Organization(s)
NIMART	Nurse-Initiated Management of Antiretroviral Therapy

OMN	Operational Managers
PAH	Perinatal Acquired HIV
PESTLE	A mnemonic which in its expanded form denotes **P** for Political, **E** for economic, **S** for social, **T** for technology, **L** for Law/Legal, **E** for environmental factors that give a bird's eye view of the whole environment from many different angles that one wants to check and keep a track of while contemplating on a certain idea/plan.
PHC	Primary Health Care
PMTCT	Prevention of Mother-to-Child Transmission
SANC	South African Nursing Council
SWOT	Strengths, Weaknesses, Opportunities and Threats
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNICEF	United Nation International Children's Emergency Fund
VL	Viral Load
WHO	World Health Organization

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CHAPTER 1

ORIENTATION TO THE STUDY

1. Introduction

Over the last decade, since the arrival of antiretroviral drugs (ARVs) in sub-Saharan Africa, children who were vertically infected with the Human Immunodeficiency Virus (HIV) now survive to adulthood or maturity. Research showed that the life expectancy for this population can increase if they adhere to their treatments and live a healthy lifestyle. Furthermore, these children can represent a population of youth living with HIV and reaching adulthood where everything is possible with their good behaviour (Burgmer, Pharr, Tran *et al.,* 2017). Following treatment and good behaviour, these children are now transiting to adulthood, they would complete degrees/diploma at university/college level, finding a job and getting married and many other inferences one can think of. This formed the premise the researcher was interested in studying, namely, how the transition could be optimized for these ALWHIV (ALWHIV).

1.2 Background to the Study

In 21 of the 22 Global Plan target nations, the proportion of pregnant women living with HIV who are receiving antiretroviral treatment (ART) has increased by more than or doubled, from 36% in 2009 to 80% in 2015. (UNAIDS, 2019). ART and other mother-to-child transmission prevention (PMTCT) therapies can lower the risk of mother-to-child transmission (MTCT) to less than 5%. (WHO, 2016). Since 1995, the use of PMTCT interventions has avoided approximately 1.6 million new HIV infections among children. In the last five years, between 2010 and 2015, an estimated 1.3 million deaths were avoided (UNAIDS, 2019).

Despite this remarkable gain, 23 percent of HIV-positive pregnant women did not have adequate access to ARVs in 2015, and 150 000 children (400 children each day) were infected with the virus. The majority of these youngsters have grown up to be ALWHIV vertically infected adults (Porth, Suzuki, Gillespie, Kasedde and Idele, 2014).

During pregnancy, childbirth, and breastfeeding, HIV can be passed from an HIV-positive mother to her kid (Madiba and Mokgatle 2016; UNAIDS, 2019). PMTCT programs give HIV-positive pregnant mothers antiretroviral therapy (ART) to keep their babies from contracting the virus. This is achieved by suppressing the viral load (VL) through compliance and adherence to medication and the modification of sexual behaviour by using protective sex. The availability of medications (ARVs) in public institutions and the fact that counselling and HIV testing services are free for everybody is making an impact in the day-to-day life of all people across the world. This helps women to know their HIV status earlier (Evangeli and Foster, 2014; Hogwood, Campbell and Buttler 2013).

With the programme of test and treat which was rolled out in 2017, all pregnant women who tested positive are enrolled in the ART programme as soon as possible. They were given thorough education concerning medication, adherence, compliance, and the importance of using condoms during sexual intercourse for the sake of the baby *in utero*. If there were no complications the woman was given the medications, if there are other complications like tuberculosis (TB), ART was delayed for two weeks following clinical investigations (UNAIDS, UNICEF and WHO, 2017). Without treatment, the risk of HIV transmission from mother to kid ranged from 15% to 45 percent (WHO, 2018). ART and other effective PMTCT therapies, on the other hand, can lower this risk to less than 5%. (WHO, 2018).

Six priority nations (Botswana, Mozambique, Namibia, South Africa, eSwatini, and Uganda) achieved the Global Plan's 90 percent MTCT reduction target in 2015. (UNAIDS, 2017). The 90-90-90 method has now been adopted by the majority of countries. The first 90 percent suggests that 90% of the population should be tested for HIV and be aware of their status. The second 90 means that 90% of the population of HIV+ persons should be on treatment. The last 90 means that 90% of those on treatment should have their viral load suppressed (UNAIDS, 2017). According to the most recent data, teenagers in Sub-Saharan African nations account for 12% of new HIV infections worldwide (UNICEF, 2018). While total HIV mortality in all other age groups declined by 32% between 2005 and 2012, with the help of ARVs, ALWHIV mortality increased by 50%, from 71 000 in 2005 to 110 000 in 2012 (Porth, Suzuki, Gillespie, Kasedde and Idele, 2014). Only adolescents are experiencing an increase in HIV-related death (UNAIDS, 2019).

ALWHIV are faced with many more challenges than those without the disease. Many times, they should be involved in decision-making, policies and programmes which involve their needs for them to have a sense of belonging. Extra support was of great value to these adolescents to make sure they can meaningfully engage in these processes (Mweemba, Musheke, Michelo *et al.,* 2015). Adolescents often have lower rates of viral suppression than adults. This might be due to lack of commitment to their care because many parents or guardians fail to disclose to these children as they were growing up (Adejumo, Make, Ryscavage, Hunter and Taiwo, 2015). Therefore, these adolescents might have untold unanswered questions which make them non adherent to their medications. Disclosure for both parents and these adolescents make life so hard and complicated as they both have fear of being stigmatized. Disclosure also affects the achievement of the 90-90-90 strategy in the health care facilities for both adults and children.

As they mature physically, cognitively, and sexually (Lowenthal, Bakeeta, Kitaka, Marukutira, Chapman, Goldrath, and Ferrand, 2014), ALWHIV encounter unique developmental, psychological, and sexuality issues (Lowenthal, Bakeeta, Kitaka, Marukutira, Chapman, Goldrath, and Ferrand, 2014). (Dahourou, Gautier-Lafaye, Teasdale, Renner, Gautier, Yotebieng and Desmonde et al., 2017). The transition to maturity was linked to a deterioration or reversal of immune recovery (Juddy, Sohn and Collins 2016). Transitioned adolescents have a high rate of attrition and loss to follow-up, as well as an unsuppressed viral load (Dahourou et al., 2017). Because there is still no cure for ALWHIV, they live in fear.

Many of them have witnessed the death of their relatives or siblings. Some of these children are orphans and some are heading families as their parents have died. Others are always sick because their immune system is affected. Some fear discrimination and do not participate in activities they know and love either at school, churches or in clinic settings. They also fear being stigmatized by those who know their status or that of their parents (UNICEF, 2016). These ALWHIV are also afraid to visit health facilities when they are sick as they are uncertain of the confidentiality and fear of stigmatization by health providers.

Denison, Banda, and Denis (2015) agreed with the findings above, stating that the increased survival of children with perinatal-acquired HIV (PAH) has been followed with special needs and management for these children. Their needs are more complex and sensitive compared to those of adults. Many ALWHIV, especially those who lost their parents, feel unloved and lack a sense of belonging (Nabukeera-Barungi, Barungi, Elyamu, Asire, Katureebe, Lukabwe, Namugoke, Musinguzi, Ahuyambe, and Tunwesgye 2015; Mburu, Hodgson and Kocibala, 2014).

Marinkovich (2014) pointed out that those born with HIV in the first decade of the epidemic have become adolescents of the same age, irrespective of the routine imposed by coping with the HIV. Some need specialized care as they have illnesses resulting from medication side effects. The study further showed that these ALWHIV also need decent shelter, especially the child-headed families because relatives tend to neglect them. Adolescents should be informed of their health status instead of being stigmatized by health care providers. Therefore, self-disclosure needs to be intensified because children with PAH are becoming adolescents and are faced with sexual life challenges. The need to be informed include family planning, sexually transmitted diseases, condom negotiation and its use (Mutumba, Muslime and Tsai 2015; Villa-Toress and Svanemy, 2015).

Ruria, Mashaba, Kose, Woelke, Mnangi and Matu (2017) concurred with the above notions that sexual and reproductive health needs, the effect of trauma on their HIV status, and their mental health needs and the impact of chronic physical illness among other issues need to be addressed (Puerto Rico (UNICEF, 2016) further revealed that adolescents have questions about bio-psychological changes related to their development as adolescents. Studies showed that the health care and education of adolescent girls is a major determinant of the health of children in the next generation (UNAIDS, 2017; Madiba and Mokgatle, 2016). The health and education requirements of ordinary adolescents are complex, thus necessitating special care for ALWHIV to address inadequate psychosocial support, protection and legal support, sexual education, access to sexual and reproductive health services and access to treatment (UNICEF, 2018).

Another strong priority is the need to reduce unwanted pregnancy among ALWHIV (WHO, 2016; UNICEF, 2018). HIV puts these people at risk for a variety of life-threatening infections, tumours, and illnesses, including pulmonary tuberculosis, Cryptococcal meningitis, Kaposi sarcoma, progressive multifocal leuco-encephalopathy, and many others. (United Nations AIDS Programme, 2017). Other HIV transmission modes in Sub-Saharan Africa include migration, a low risk perception, and several sexual partners at the same time (Mutumba et al., 2015). The availability of ARVs has transformed HIV/AIDS from a lethal disease to a chronic and more manageable condition, improving the quality of life for ALWHIV and all individuals living with HIV/AIDS around the world (Hudelson and Cluver, 2015; Inzaule et al., 2016). Even children from the low-income or poor countries are now surviving infancy, pass adolescence and reach adult maturity. There has been a global success in reducing the impact of HIV in early childhood (Thoth, Tucker, Leahy and Stewart, 2014). The researcher, as a clinical nurse practitioner who provides care to ALWHIV, was motivated to undertake this study to develop a strategy to optimize care for affected adolescents when transiting into adulthood with confidence and to have optimal quality of life until a cure is found.

1.3 Problem Statement

As a clinical nurse practitioner in one of the ARV clinics, in Collins Chabane municipality of Vhembe district, the researcher has noticed that adolescents diagnosed with HIV present with anger and have unanswered questions such as: “Why did this happen to me?” (Russel *et al.,* 2016). Thus, they often default on their appointments for treatment collection once they transit from childhood to adulthood. In 2017/2018, amongst 24.8% youth aged 15 to 19 years who tested positive, 5.5% were pregnant (Limpopo Department of Health Epidemiology Services, 2018).

Some of these sexually active adolescents engage in unprotected sex without disclosing their HIV status to partners. This could increase the rate of HIV transmission and reinfection and they are at risk of premature death. Parents and guardians were not comfortable to disclose the status of their children, especially if there were other siblings in the family who were not infected. Some parents said it would be better for the child to find out on his/her own as s/he grows older. About 1% of these adolescents would know their status for the first time when they book for antenatal visit (Larkian, Amole, Jahun and Abute, 2015). These challenges motivated the researcher with a keen interest in developing a strategy to optimize transition of ALWHIV to adulthood in the selected districts of Vhembe in Limpopo Province.

1.4 Research Purpose

- The goal of the study was to devise a plan for easing the transition of ALWHIV to adulthood in Vhembe, Limpopo Province.

1.5 Research Objectives

- The research was divided into three phases, as indicated by the objectives below:

1.5.1Phase 1: Empirical Phase

- To explore and describe the knowledge of HIV as a condition by

ALWHIV during transition to adulthood.

- To describe challenges faced by parents/guardians during the transition of ALWHIV to adulthood.
- To explore the support given to ALWHIV by parents/guardians during the transition to adulthood.

1.5.2 Phase 2: Strategy Development

- To devise a method for easing ALWHIV's transition to adulthood.

1.5.3Phase 3: Validation Strategy

- To conduct validation of the developed strategy which would be done by NIMART nurses though they will not be part during the process of the study.

1.6 Research question

The question for ALWHIV was:

- Could you share with me the knowledge you have about HIV disease and how is it for you as you transit to adulthood including the support you received from anywhere?

The questions for parents/guardians was:

- Could you describe the challenges you encounter when your child transit to adulthood and the support you need if any providing to ALWHIV during transition to adulthood?

1.7Significance of the Study

The study's findings may aid in the creation of a strategy for ALWHIV transition optimization. It is hoped that the study's recommendations will encourage teens to form social groups or clubs in order to motivate one another and share their experiences on how to live a happy life. Fear and anxiety may be reduced if not completely eliminated as the condition is associated with stigma. Parents or guardians may also benefit because fear of letting their children know of their status could be alleviated if they get supported. The sharing of experiences concerning this condition might strengthen parent–child relationships. Transparency may also lead to cordial family relations with siblings who may not be having the disease. The Department of Health (DoH) has youth programmes which may need to be rescheduled to suit this population group. Affected adolescents may become part of these programmes if they do not fear stigmatization. This may also help the nursing staff in reducing the lost to follow-up (LTFU) and increasing those remaining in care. Policymakers in the DoH could benefit from the recommendations and the strategy and amend other rules such as dealing with confidentiality, and strengthening couple counselling during antenatal care (ANC).

1.8 Theoretical Framework: Empowerment Model

1.8.1 Introduction to the Empowerment Model

The Empowerment Model (EM) is a method for people to obtain more influence over health-related decisions and activities (Vorming, Hansen, Andresdottir, Husted, and Willaing, 2017). The EM was used to facilitate transition of adolescents to adulthood. In this study, empowerment would be achieved by ensuring that ALWHIV understand the importance of adherence and compliance to their medication regimen and to follow appointments as scheduled by health professionals. Among the aims of the National Chronic Disease Strategy (WHO, 2016) are issues that empower patients to reduce the progression of the disease and its complications, to maximize the well-being and quality of life of the individuals living with chronic diseases, their families and or careers and to reduce hospital admissions and health procedures by ensuring that parents and adolescents understand their roles. The adolescents should be the centre of care and manage themselves and take decisions to make a sustainable change in their lives. In this study, the Empowerment Model (Vorming *et al.,* 2017), as illustrated in Figure 1.1, included the following three areas, namely:

- Empowering
- Motivation and
- Medical adherence

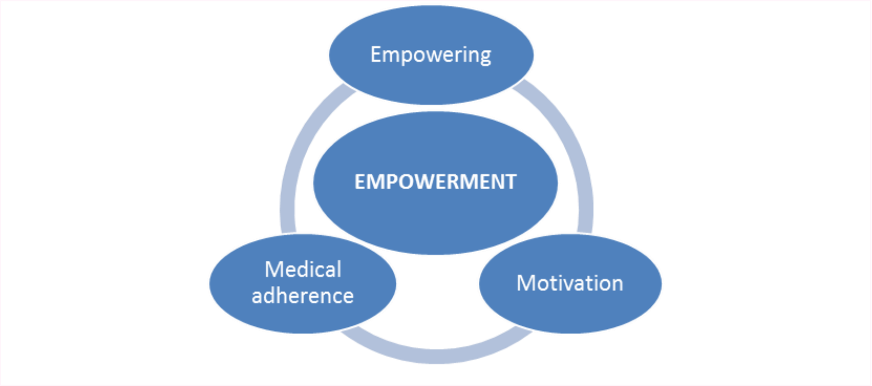


Figure 1.1: Empowerment model (Vorming *et al.* 2017)

1.8.2 Empowering

Empowerment should be a patient-centred and collaborative approach. It should maintain the fundamental reality of HIV/AIDS and transition and help individuals to have positive thinking. The aim is to facilitate the process of supporting the ALWHIV during transition to adulthood. This ensured that patients make informed choices and were organized with the best possible self-management (Vorming *et al.,* 2017). The researcher in this study would build a good rapport with the participants. Empowering strategies would be developed through information giving and health education to the ALWHIV.

1.8.3 Motivation

Motivation is the driving factor behind the desire to alter one's behaviour. Inner motivation is fuelled by one's desires, ideals, and emotions. Other people, monetary items, penalties, and advantages are all examples of external motives. If behaviour change is driven by internal motivation, people are more inclined to work toward the objectives they set for themselves. Empowerment focuses on assessing patients' specific needs, values, and feelings and gives methods to enhance inner motivation (Vorming et al., 2017). This study proposed to achieve motivation by encouraging ALWHIV to go back to their health, enrol in treatment care, adhere and comply with medications, especially those who defaulted or have not yet enrolled in care.

1.8.4 Medical Adherence

The concept of compliance has mostly been supplanted by that of medical adherence. It refers to how closely a person's actions for taking drugs or making lifestyle changes match up with agreed-upon suggestions from a health care practitioner. This seeks to promote compliance by giving assistance and improving patients' perceptions of the treatment's comprehensibility, purpose, and manageability. The term concordance refers to the process of consultation in which a patient and a health care professional collaborate to make a decision (Vorming et al., 2017). In this study, medical adherence means the agreement between the patient and health care professionals reached after negotiations which respect a patient’s beliefs and wishes in determining whether, when and how their medications are taken and follow the appointment as scheduled without defaulting.

1.9 Definitions of Concepts

1.9.1 Strategy Development

Strategy development is the process of planning or designing something new that will be invented or occur as a result of a new phase in changing conditions or the path of change in order to attain a certain goal (Oxford Dictionary, 2015). In this study, strategy development shall mean designing or planning a new method or strategy that will support and empower ALWHIV as they prepare themselves for adulthood.

1.9.2 An Adolescent

According to WHO, an adolescent is an individual between the ages of 10-19 years (WHO 2016). In this study, an adolescent shall mean a person both male and female between 12-19 years who contracted HIV through vertical transmission.

1.9.3 Living with HIV

A retrovirus causes acquired immunodeficiency syndrome (AIDS). HIV compromises the body's ability to resist infection and disease, leading to AIDS (UNAIDS, 2017). In this study, living with HIV shall refer to an HIV+ adolescent who is enrolled in treatment care and is growing into adulthood.

1.9.4 Optimize

Optimize refers to the degree or the amount of something/state that is most favourable to some end, especially in most favourable conditions for the growth and reproduction of an organism (Webster’s Dictionary, 2009). In this study, optimize shall refer to when adolescents are empowered through giving accurate information and support while living with the virus.

1.9.5 Transition to Adulthood

Transition literally means changing or moving from one level to another (Webster’s Dictionary, 2009). In this study, transition to adulthood shall refer to when a baby who was born with HIV reaches the adolescent stage and is progressing into adulthood.

1.10 Research Setting

A research setting is a physical location and or a place where data is collected in a study setting or a place where research is conducted and data is collected (Polit and Beck, 2018; Brink, 2018). This research was carried out in Limpopo Province, which is located in South Africa's north-eastern corner and shares borders with

Botswana, Zimbabwe, and Mozambique. The province is regarded as impoverished (Baron, Day and Monticello, 2007). Mopani, Sekhukhune, Capricorn, Waterberg, and Vhembe are the five districts that make up the province. According to the 2011 census, the province's population is predicted to be 5,693,564. The most rural communities are Mopani and Vhembe (refer to Figure 3.1, Chapter 3). The research was carried out in chosen PHC facilities in the districts of Mopani and Vhembe. In Chapter 3, the detailed research setting will be described.

1.11 Research Methods

The study conducted focused on the mixed approach to achieve the set objectives for phase 1 and 2 hence phase 3 which is validation of strategy followed a quantitative approach. The detailed research methodology will be presented in Chapter 3. Table 1.1 presents the summary of research methodology.

1.12 Summary of Research Approach

The study was divided into three phases. Phase 1 had three objectives and Phase 2 entailed the development of a strategy. In Phase 1, the study population included the ALWHIV and the parents or guardians. Objectives in Phase 1 covered the knowledge and experiences of ALWHIV as they transit to adulthood and the support given to them.

Table 1.1: Summary of the research methodology

Phases	Objectives	Research Design	Population	Sampling Approach	Data Collection	Data Analysis
1	1 and 3	Qualitative Approach (Exploratory, descriptive, and contextual	ALWHIV	Non-probability purposive sampling	In-depth face-to-face unstructured interview	Open-coding method
	2	Qualitative Approach (Exploratory, descriptive, and contextual	Parents/guardians	Non-probability purposive sampling	In-depth face-to-face unstructured interview	Open-coding method
2	4	SWOT analysis and BOEM to develop the strategy	Data collected from ALWHIV and parents/guardians	N/A	Analysed data	SWOT analysis matrix Then BOEM
3	5	Quantitative approach	NIMART nurses	systematic sampling	Checklist	Descriptive data analysis

It also determined the challenges which parents experienced or come across and the support they need when caring for these children. Phase 2 involved the development of a strategy through SWOT analysis, while Phase 3 focused on strategy validation by the Nurse-Initiated Management of Antiretroviral Therapy (NIMART)-trained nurses.

1.13 Organization of the Chapters

1.13.1 Chapter 1: Orientation to the Study

The background, problem statement, goal, objectives, research question, and significance of the study are all included in Chapter 1, as well as the theoretical framework, definition of terms, research setting, research design, summary of research approach, and chapter organization.

1.13.2 Chapter 2: Literature Review

The literature reviewed in this chapter included knowledge of the HIV condition that ALWHIV had during the transition, support system needed by ALWHIV and the parents, transition from primary care service to adulthood care clinic, and disclosure of HIV status.

1.13.3 Chapter 3: Research Methodology

The research technique is summarized in this chapter. A mixed-methods strategy was adopted, which included both qualitative and quantitative methodologies. Both quantitative and qualitative research methods, study design, research setting, population, sampling, data collection methods, and data analysis were discussed. Qualitative design was used to accomplish phase 1 and phase 2 hence quantitative design was used to accomplish phase 3 which was validation strategy.

1.13.4 Chapter 4: Presentation, Interpretation, and Discussion of the Findings

This chapter embodies the discussion of the research findings that describe the strategy to optimize transition of ALWHIV from primary care to adulthood and the support they received from their parents or guardians.

1.13.5 Chapter 5: Strategy Development to Optimize Transition of ALWHIV

This chapter covers the development of the strategy. Strength, Weakness, Opportunities and Threats (SWOT) was used to analyze the data by integrating Political, Economic, Social, Technological, Environmental factors and Laws (PESTLE). The intervention strategy was developed by Building from Strength, Overcoming Weaknesses, Exploring Opportunities and Minimizing Threats (BOEM).

1.13.6 Chapter 6: Validation of the Developed Strategy for ALWHIV

This chapter covered the validation of the developed strategy.

1.13.7 Chapter 7: Limitations, Recommendations, Summary and Conclusions

The study's overview, limitations, recommendations, and conclusion are all included in Chapter 7.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

Literature review is often called the Cinderella of research. This is to show the reader that the researcher has done extensive reading in reviewing academic journals and previous research related to the topic under study. By doing this, the researcher wants to avoid duplication of what has been done in the past on the same topic rather to find gaps which the researcher may try to find closure (Burns and Grove 2020, cited by Brink, van der Walt and van Rensburg, 2018).

2.2. Definition of Literature Review

According to De Vos (2012), a literature review is the process of finding, reading, comprehending, and making conclusions about published research data, methodology, and theories by competent researchers on a certain issue. According to Brink, et al, 2014), a literature review should be organized around the research topic and/or research questions' essential themes. The researcher does not have to repeat work that has already been published when doing a literature review (Brink, et al, 2018). According to (Brink , et al, 2018), evaluating literature is a strategy that entails examining and separating research sources in order to generate a picture of what has already been investigated about a specific condition in order to find any gaps.

Published research data, monographs, and Department of Health publications (guidelines) were employed as sources of literature in this study. As a result, this study's technique was integrative. The researcher was aided in making the study acceptable by the results of previous investigations, particularly in terms of the problem definition, design, and data analysis method. The literature review aided in the discussion of the current study by giving a basis for comparison, as well as supporting and validating the findings (Brink, et al, 2018). The following themes were found in the literature evaluated for this study:

- Knowledge of the HIV condition that ALWHIV had during the transition;
- Transition from primary care service to adulthood care clinic; and
- Support systems needed by ALWHIV and the parents.

2.3. Themes for Literature Review

2.3.1. Knowledge of HIV Condition That ALWHIV Had During Transition

In 2016, an estimated 2,100,000 young people aged 10 to 19 were living with HIV around the world. Sub-Saharan Africa accounted for 80% of the total population. The number of new infections among older adolescents aged 10 to 19 was likewise high. With the help of antiretroviral drugs (ARVs), these children survived to adulthood (UNAIDS, 2017). Adolescents have become increasingly acknowledged as an important age group in HIV programs, although they continue to be neglected by present HIV services (Adejumo, Make, Ryscavage, Hunter and Taiwo, 2015). The research study conducted by Dahourou, Gautier-Lafaye, Teasdale, Renner, Yotebieng, Desmonde (2017) indicated that ALWHIV need to be empowered in all programmes regarding HIV matters. This could assist them to be the owners of their health and be able to make informed decisions.

According to the World Health Organization (WHO, 2016), the number of teenagers dying from HIV-related diseases increased between 2000 and 2015. AIDS is currently Africa's greatest cause of death for young and the world's second leading cause of death for youth. The vast majority of them live in low- and middle-income nations. Juddy, Sohn, and Collins (2016) attested to this by indicating that youth are the future of tomorrow if they are not empowered to take care of themselves despite what they are going through the country will lose its future.

According to UNAIDS (2017), studies revealed that half the number of ALWHIV between 15-19 years in the world are from South Africa, Nigeria, Kenya, Mozambique, India and Tanzania. Figure 2.1 shows the new HIV infections among youth in Limpopo Province South Africa (Department of Health Statistics, 2015).

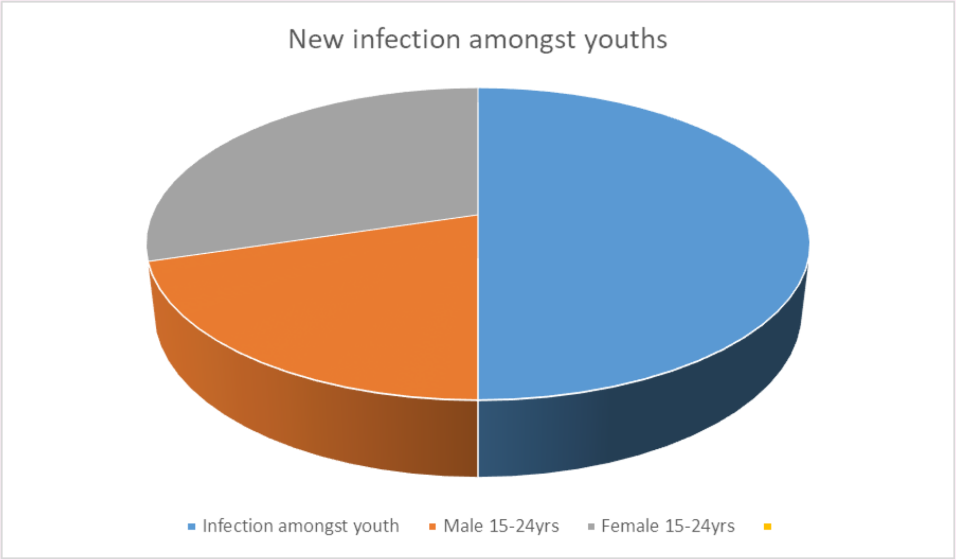


Figure 2.1: New HIV infections among youth (Department of Health Statistics, 2015. Limpopo, South Africa).

By 2060, the number of ALWHIV is predicted to exceed 750 million, meaning that even if current progress is maintained, new HIV diagnoses among young people are likely to increase in the near future. ALWHIV are faced with many more challenges than those without the disease. They should be involved in decision-making, policies and programmes which involve them to make a sense of belonging (Coleman, Tate, Gaddist, and White, 2016). The study further indicated that these adolescents need extra support to make sure they can meaningfully engage in the process.

2.3.1.1. HIV Diseases

HIV is a virus that wreaks havoc on the immune system. HIV is passed from person to person by bodily fluids such as blood, sperm, vaginal and rectal fluids, and breast milk (UNAIDS, 2017). HIV affects the immune system and reduces the body's defence systems against numerous infections that the normal immune system can fight off, according to the WHO (2016). Vaginal or anal sex is the common route for transmission, during pregnancy, labour, or delivery from mother to the baby (MTCT) and breastfeeding. The study continued to show that sharing needles, syringes, and other items for injection of drug use from an infected person to another person is a risk. The study continued that immune functioning is measured by the CD4 cell count. The only prevention because adolescents in this study have contracted the disease already, is to continue taking medications and using condoms to prevent reinfections.

However, according to Roberts (2018), HIV can be transmitted through the exchange of a range of body fluids from infected people, including blood, breast milk, sperm, and vaginal secretions. Moreover, during pregnancy and delivery, HIV can be passed from the mother to the infant. Rath (2021) confirmed the above showing that HIV can be spread when infected blood, semen or other body fluids enter someone’s bloodstream. The study also found that unprotected anal or vaginal sex, as well as sharing needles or syringes with an HIV+ person, are the most common ways of transmission. HIV-positive women can spread the infection to their offspring before, during, and after birth, as well as via nursing. The risk is very low with breastfeeding mothers who are taking treatment and wean their babies at six months before tooth eruption. The study continued to indicate that there is little or no risk to get the infection through oral sex or being beaten by a HIV+ person unless the bite is deep and breaks the skin (Rath, 2021).

The study showed that individuals can reduce the risk of HIV infection by using male or female condoms or to abstain when one is not yet ready for sexual intercourse. Infected pregnant mothers should be taught and motivated to comply with their treatment and to breastfeed their babies for only 6 months before tooth eruption to minimize the risk of infection passing to the babies. Males should be encouraged to go for voluntary medical male circumcision (VMMC) (UNAIDS, 2016; WHO, 2021). According to Rath (2021), taking ARVs can halt or delay the spread of the spread of the virus. The amount of HIV in the body is measured by the Viral Load (VL), which can be decreased with the help of ARVs. The aim of the ARVs is to lower the VL in the body which when taken, the laboratory test will state undetectable on the results. If the VL is undetectable, the health of an individual improves and s/he cannot pass the virus to another person. ALWHIV should be taught to eliminate MTCT of HIV during sexual reproductive education.

2.3.1.2. Knowledge About Medication

Over the past 20 years since the beginning of the HIV pandemic there is no medication for cure. But the arrival of ART has saved many lives, including those who came forward, were counselled, tested, initiated, and complied with their treatment (UNAIDS, 2016). According to WHO (2021), there is currently no cure for HIV infection, but with increased access to effective HIV prevention, diagnosis, treatment, and care, including opportunistic infections, HIV has evolved into a chronic manageable health condition that allows people to live a long and healthy life. The arrival of ARVs improved the life expectancy of many people, including the adolescents who acquired vertical transmission and reduced mortality and morbidity rates. Adolescents have an inferiority complex that is a significant impediment to their accessing HIV services and ARVs. This might be due to fear of stigma and or discrimination because many parents/guardians fail to disclose the status as their children grow. The study continued to indicate that adolescents might have lot of unanswered questions (Bailley, Cruz, Songtweesin, and Phuthanakit, 2017).

According to the 90-90-90 strategy, 90% of the population in a health facility should be HIV tested and 90% of the population should be initiated on treatment and 90% should be cured in case of TB. Research showed that there is high rate of Lost to Follow-Up (LTFU) among these populations who registered in care, poor adherence and increase need of psychosocial support and social reproductive health services (Ruria, Mashaba, Kose, Woelke, Mnangi and Matu, 2017). The study revealed that change of regimen can result in adolescents defaulting treatment or medication. Children should know that drug dosage can be increased with weight as they grow. Therefore, education needs to be strengthened to improve the outcomes for these adolescents and help to reach the global targets for an AIDS-free generation by 2030. Coleman, Tate, Gaddist and White (2016) agreed with the above by showing that adolescents experience self–blame and with suicidal thoughts, some present with anger and denial and start swearing to their parents, disrespecting them. Thorne, Newel, Bore, Bohlin, Ferrazin, Glaquinto, Gomez and Peltier (2015) concurred with the above and said that transition should be managed with full involvement of the youth themselves as changes can be more confusing and disturbing. Studies also showed that changing of drug regimen can be a challenging and more complex issue resulting in adolescents defaulting their medications or not adhering to their treatment. The study continued that adolescents may skip their medications, miss their appointments for taking bloods like VL monitoring as they fear to be seen by friends, relatives and even the community. Therefore, pill counting should be adhered to when they come to collect their medications.

During the preparation for transition, ALWHIV should be taught about medications, how they work and the side effects thereof. The study showed that HIV disease can be managed by treatment regimens comprised of a combination of three drugs or less drugs. ALWHIV should be empowered and motivated to take their treatments at the right time. They should know that if they missed a dose, they increase the chance of raising the VL and the ability to infect others. Rath (2021) indicated that although there is no cure, treatment can slow or stop the progress of diseases or HIV. Many people who tested and took initiative to comply with medications, live longer and never develop AIDS. ARVs do not treat HIV infection; instead, they stop the virus from replicating in the body. Since 2016, WHO (2016) has advised that all persons living with HIV, including children, adolescents, adults, pregnant and breastfeeding women, get lifelong antiretroviral therapy (ARVs), regardless of their clinical state or CD4 cell count.

Like other drugs, ARVs can cause side effects which could differ among individuals and the type of treatment they are taking. HIV drugs have improved over the past years, and serious side effects are less likely to occur than they used to be when HIV started. The most common side effects are nausea and vomiting, diarrhoea, headache, vivid dreams, insomnia, rash, fatigue, loss of weight, lipodystrophy, mood changes and many others (Watson, 2020). Abacavir (ABC) and zidovudine can cause poor appetite. Efavirenz and dolutegravir can cause vivid dreams and fatigue, depression, anxiety, and mood changes. Nevirapine can cause rash. Rath (2021) attested that every time a person misses the dose, the risk of treatment failing to work increases. The study showed that side effects should be treated if severe or the health care professionals should consider switching to alternative ARV drugs.

2.3.1.3. Adherence and Support System

Adherence means sticking to the treatment plan. The importance of adhering to medication is to keep the virus dormant while suppressing the VL until it is not detectable in the body. Adherence will increase the CD4 cell count and keep the body healthy (UNAIDS, 2018). ALHIV should be empowered not to miss their dose of treatment because it gives the virus a chance to recopy itself and could resist to the drugs if done frequently (Juddy, et al, 2016). Research showed that some health workers may have negative attitudes or be judgmental towards those adolescents who are sexually active or may not understand the needs of ALWHIV. Failure to follow good practices and provision of age appropriate care result in retention among the adolescents (Wilson, Beima–Sofie, Mooroe, Wagner, Mugo and Mutiti, 2015). Therefore, health workers should be youth friendly, design youth zone in their facilities with appropriate time for all youth can come freely in their own time.

The study continues to reveal that adolescents were afraid of school mates, colleagues, long waiting queues in the facilities and end up defaulting. Adherence support systems in the form of beepers, peer support should be encouraged to sustain treatment as a form of prevention and to stop onward transmission to others thereby improving the quality of care. According to Mark, et al, (2019) teenage groups' or adolescents' adherence to ART is concerning because it is frequently abandoned when taken into account that many factors are ahead of them at this stage, including fear of disclosure, social stigma, a lack of support, insufficient communication and education, and depression related to having HIV/AIDS. Non-adherence can be prevented by building good rapport with the ALWHIV, giving psychological support during preparation for transition and in the continuity of care. Intentional and unintentional non-adherence were identified as two types of non-adherence in the study. Intentional non-adherence results from denial of diagnosis, lack of trust from health care providers and in the treatment itself, fear of HIV stigma, restraints due to life-long treatment and many others. Unintentional non-adherence arises from misunderstanding or ignoring treatment indications. Drug and alcohol abuse play a role in reducing adherence (Iacob, Jacob, and Jugulete, 2017). Abadiga, Hasen, Mosisa and Abdisa (2020) confirmed the above by showing that poor adherence reduces the effectiveness of ART and increases viral replication.

Research also indicated that lack of support may hinder adherence and adolescents may engage in substance abuse resulting in depression and anxiety (Bailley, Cruz, Songtiweesin and Phuthanakit, 2017). Findings of this study showed that ALWHIV do not get enough mental support from anyone, including health care professionals. ALWHIV are more likely to have mental health issues, which have a negative influence on adherence and retention of care. Support groups are beneficial to education because they facilitate understanding through experiential learning rather than just supplying facts (Woollett, Pahad & Black, 2021). Peer support allows clinicians, programs, and services to be more responsive, acceptable, long-term, and relevant, which encourages ALWHIV to seek treatment and stay in care. Support groups, peer-to-peer counselling, and treatment buddy programs are all examples of peer support activities. ALWHIV could be educated to be peer supports in health institutions and communities, providing care and promoting their peers' health and well-being (Mark et al., 2019).

Good parental support is important for ALWHIV during the transition period. Parents should be taught and understand that their children need their full support and value their guidance at this difficult time of transition and should protect and guide them until they have adjusted to the transition and able to do things alone. Though it is a taboo in other cultures to talk about sex with children, parents should add value at this period to educate their children on physical and reproductive changes adolescents go through and to orientate them on condom use, if possible (UNICEF, 2018). Therefore, parents should provide social, emotional, spiritual, and often material support for their children.

Findings of the study further showed that ALWHIV need to be supported financially, especially girls as they would need to buy girls' stuff every month. Males should be guarded against smoking, substance abuse and alcohol consumption which can influence them to become delinquent and default treatment. Currently, both parents and the adolescents receive a cash grant from the government, but the grant is very little and cannot afford to buy all their basic needs. In their study, Dahourou, Gautier–Lafaye, Teasdale, Renner, Yotebieng, Desmonde *et al.* (2017) agreed with the above indicating that unstable families may cause children to deviate and develop bad behaviours and conduct which could affect adolescents not to comply and adhere to their medications. The study further showed that many ALWHIV, especially those who lost their parents, feel that their need to be loved and to belong is neglected by those closer to them.

2.4. Transition from Pediatric Care to Adult Care

UNAIDS and UNICEF (2016) showed that most countries have no guidelines or protocols that are followed when moving children from primary to adult health services. During this time, ALWHIV are faced with many challenges such as, there is a greater need for adolescents to take responsibility for their own health and the stigma attached to the condition. Madiba and Mokgatle (2016) showed that the risk of ART to stop working is high (virological failure) in the ALWHIV. They also indicated that this is caused by low educational attainment and poor knowledge about HIV. Coleman, Tate, Gaddist and White (2016) attested that transition should be managed with full involvement of the youth themselves as changes at this time can be very confusing, frustrating and destabilizing. Older adolescents should be counselled on the plans to transit to adulthood clinic. According to Woollett, Pahad, and Black (2021), vertically infected children reach adolescence in high numbers and are poorly kept in care. The study found that there are no clear national recommendations or policies on how to transfer ALWHIV from treatment to adulthood when they reach the age of 18. Adolescence is a difficult developmental period characterised by rapid physiological, psychological, social, and health needs, according to the study. Despite the 'treat all plan,' ALWHIV continue to be underserved by the health-care system, assuming full responsibility for their own health.

According to Dahourou et al. (2017), most African countries' health-care systems are not geared to accommodate the needs of ALWHIV. There is a scarcity of health-care professionals with advanced training in adolescent medicine. The infrastructure is shoddy and insufficient, and clinics are overworked. Furthermore, ALWHIV in Sub-Saharan Africa suffer a slew of behavioural and psychological obstacles, on top of dealing with a stigmatized chronic disease. They are more likely to acquire ailments like renal, bone, and neurocognitive problems than HIV-negative people (Dahourou et al., 2017). ALWHIV are prone to skin disorders and malnutrition. Those with HIV-related comorbidities and opportunistic infections face a great deal of stigma. According to Lee and Hazra (2015), these deficiencies obstruct teenagers' transition from childhood to adulthood and may contribute to poor treatment adherence, virological failure, clinical failure, and medication resistance, all of which have negative long-term consequences.

Employing more trained people with experience in adolescent care and having a specific strategy to lead the transition process attached to the health care provider's resources could help improve transition. By creating an updated report of an individual, adolescents could benefit from enhanced communication between health care specialists from paediatric to adult clinics. Other strategies which could be of benefit are the establishment of multidisciplinary committees, peer support groups for transition, transition readiness tools to assess the adolescent before transition and financial support programmes (Jones, Richwood and Taggart, 2019). Another study observed that many ALWHIV started defaulting their medication at this stage (Bailley, Cruz, Songtiweesin and Phuthanakit, 2017). Some started to ask their parents many questions at that stage. The study continued to indicate that sometimes it is caused by low educational attainment in primary level, poor knowledge about HIV because they do not experience pain in their body and thought everything is fine and lack of independence about HIV. Coleman. Tate, Gaddist and White (2016) underscored that transition should be managed with full involvement of the adolescents themselves as changes at this time can be very confusing, frustrating and destabilizing. Older adolescents should be empowered on the plans to transit to adulthood clinic.

ALWHIV are faced with a challenge, to be accountable for their disease progression, and are left alone with the responsibility for managing their disease and health. About 50% of ALWHIV who transit to adulthood clinic remain in care for a year after transition (Adejumo, *et al.,* 2015), because as a researcher and as a clinical nurse in the facility statistic also showed more defaulters of the adolescents living with HIV. Health care professionals allocated at the adult clinic site should be loving and youth-friendly people to welcome these adolescents who are fearful and full of imagination. If health care professionals could show their support at first, retention to care will increase and defaulter rate could be reduced and vice versa.

Inzaule, Harmer, Kibyo, Tobias, Rinke de Wit, and Roura (2016) corroborated the above and said ALWHIV lack support from families, peers and community as they transit to be working and living independently. The study further showed that these adolescents have low knowledge about HIV and sexual issues. They need to be given comprehensive sexual education before they become sexually active. This will enable them to make informed decisions about sexuality and relationships with more confidence like condom use, reduce adolescent pregnancy, adherence clubs and youth friendly services provided in stigma free environment (Ruria, Mashaba, Kose, Woelke, Mangy and Matu, 2017).

Russell, Zalwango, Namukwaya, Katongole, Mahumuza, and Nalugya (2016) showed that ALWHIV who are not enrolled in the care are reluctant to access HIV services due to negative attitudes on their side and from some health care professionals. Those who engaged in same-sex relationships or used drugs feared the most and are annoyed by long queues in the public health facilities. The same study complemented the above that fear of stigma from peers, partners, families and communities result in ALWHIV not willing to take treatment as it may cause isolation or distance between them. They are afraid to reveal their situation because they want to keep their families safe. Juddy, Sohn and Collins 2016 concurred with the above, and revealed that ALWHIV are few in the retention of care, LTFU is very high and VL suppression very low as they default their medications. In the primary stage, parents were controlling everything unlike in adulthood where ALWHIV are learning to take responsibility. The study continued to show that some health care workers are judgmental towards ALWHIV or do not understand their needs resulting in them to default their medications. And that is a challenge to the ALWHIV. Failure to follow good practices and provision of age-appropriate care also contributes to long waiting queues at the clinic. An abrupt transfer with little or no preparation, poor or absent planning, resistance on the part of patients, family members, or paediatric care providers, delays in booking appointments after transfer from paediatric services, poor or absent institutional support, poor or absent communication between paediatric and adult-oriented services, and differences in care between paediatric and adult-oriented services are all technical and behavioural barriers that may obstruct a successful transition (more supportive, family-centred approach to one where individual independence approach is expected).

2.5. Challenges Experienced When Transiting from Adolescent to Adulthood

The issue for ALWHIV is to take responsibility for their health and the stigma-attached illness progression. They are more prone to diseases like of the skin (sores of some kind or rash) because their immune system has already been compromised than their negative adolescent’s counterparts. ALWHIV are generally not satisfied about the plan used during transition because it considers the age and not the maturity and readiness for one to be independent. This is the other contributory factor why they don't remain in care for longer period after transition without defaulting.

Some ALWHIV felt they are left alone with this condition after transition because the support they get is very minimal from the family as part of those who knew their status. Some ALWHIV were tired of taking treatment because it is long overdue that they were drinking (treatment fatigue) and their bodies are healthy. Findings continued and showed that some ALWHIV had a challenge to keep secrets and sometimes isolate themselves or start engaging in smoking and alcohol use to try and forget what they are going through in their lives. Findings of the study showed that the greatest challenge ALWHIV had was a matter of disclosure. Because some parents fail to disclose the true status to their children until late in the adolescent stage, it led ALWHIV to fail in disclosing to their love partners. Both parents and ALWHIV who feared disclosure also fail to join support groups. Non-disclosure could lead to non-compliance with ARVs. It also raises the risk of ALWHIV living away from their mother's home and ending up with other relatives who are unaware of their HIV status or have become rebels after discovering it later in life. Some ALWHIV started to swear at their parents and became uncontrolled when they found out about their true status. This contributed to poor relationship between parents and their adolescents' children. According to Jones, et al, (2019), 33 percent of adults are unaware of their children's HIV status until the child begins to show symptoms of sickness. Their adherence to medication improved as a result of timely and safe disclosure, and their comprehension of HIV disease improved, allowing active participation in self-care and treatment.

2.6. Summary

The goal of the study was to conduct a strategy for maximizing ALWHIV transition to adulthood in selected districts of South Africa's Limpopo Province. The researcher as a clinician noticed that ALWHIV are faced with a challenge as they transit to adulthood. Their good behaviour’s displayed at primary level for adhering to treatment changed, and some defaulted medications for good while some resumed after becoming very sick. The researcher is interested in knowing and helping ALWHIV to grow into adulthood. The next chapter will give an overview of the research methodology used in this study.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

The literature review was covered in the preceding chapter. The current chapter focuses on the study's methodology. The process of getting, collecting, organizing, analysing, and interpreting data is referred to as methodology (Creswell and Creswell, 2018). The study was mixed research in nature, with the goal of describing and evaluating ALWHIV's knowledge of the HIV disease as they transitioned to adulthood. A qualitative research approach was used to achieve objectives 1-4 and quantitative approach was used to achieve objective 5 which is validation of strategy in this study. The study was exploratory, descriptive, and contextual in nature. The following topics are discussed: population and sampling, pilot study, data collection methods, data analysis, validity and reliability, trustworthiness, and ethical considerations.

3.2 Research Methodology

The research methodology chosen is influenced by the topic and nature of the study hypothesis, which has an impact on the design and interpretation of the findings (Brink, et al., 2018). The following goals were set and met in each phase:

3.2.1 Phase 1: Empirical Phase

- To explore and describe the knowledge of ALWHIV during transition to adulthood thus knowledge about medications, adherence and support groups etc.
- To describe challenges (fears) faced by parents/guardians during the

transition to adulthood because ALWHIV are becoming independent during this stage.

- To explore the support given to ALWHIV by parents/guardians during the transition to adulthood.

3.2.2 Phase 2: Strategy Development

- To devise a method for easing ALWHIV's transition to adulthood.

3.2.3 Phase 3: Validation of the Developed Strategy

- To conduct validation of the developed strategy, to be done by NIMART nurses who were chosen because of their knowledge on HIV issues rather than adolescence and parents themselves.

3.3 Study Setting

The study setting refers to the actual location and conditions in which data collecting takes place in a study, as well as the site where research will be conducted and where data will be collected (Polit and Beck, 2018). This research was carried out in Limpopo Province, which is located in South Africa's north-eastern corner and shares borders with Botswana, Zimbabwe, and Mozambique. Furthermore, this study was unique in that it was done among ALWHIV and their parents/guardians in Limpopo's rural communities because the province is regarded as impoverished (WHO, 2016). Mopani, Sekhukhune, Capricorn, Waterberg, and Vhembe are the five districts that make up the province.

The study focused on two municipalities, Mopani and Vhembe, which are located in the most rural areas (Figure 3.1). The research was carried out in chosen PHC facilities in the districts of Mopani and Vhembe. The Limpopo Province has 477 health facilities, including fixed clinics, mobile clinics, community health centres, and hospitals. There are 444 facilities that provide 24-hour call services and 65 health facilities that provide 24-hour night duty services. (Limpopo Department of Health, 2016). The Limpopo Province also has traditional healers and people of many religions. Most people with HIV/AIDS consult the traditional healers and faith-based religions before consulting health institutions. They were told that they will be cured, as they are bewitched and some perform rituals related to their ancestors, however they never became better.

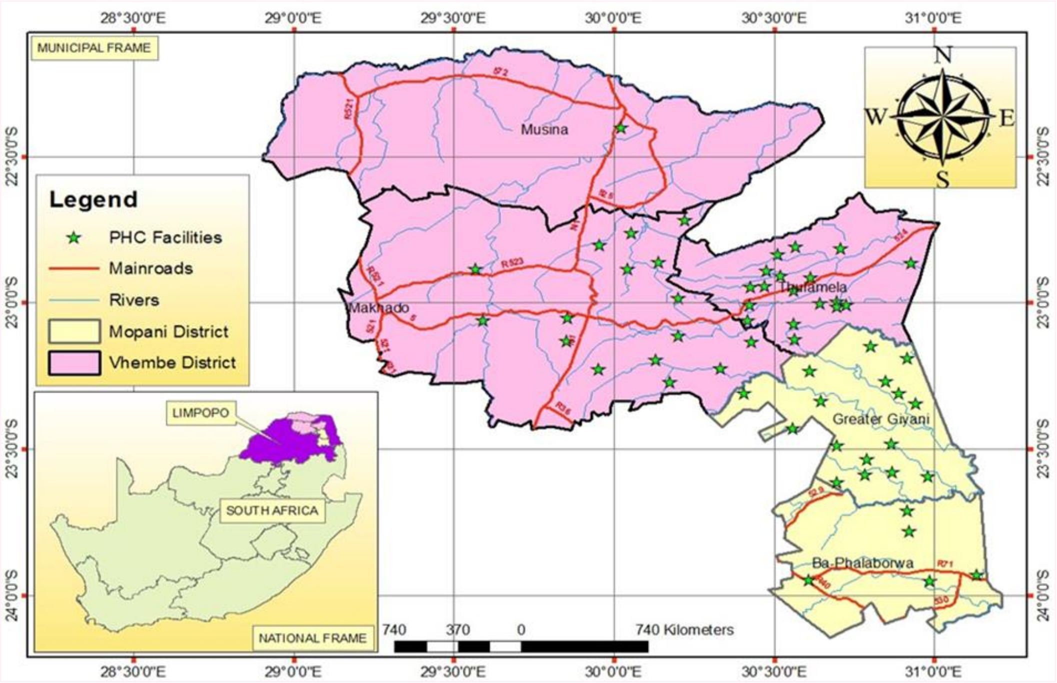


Figure 3.1:Map of the Limpopo Province (Ramavhoya et al, 2018)

The researcher chose Mopani and Vhembe districts as areas of study because in these districts teenage pregnancy is high and most adolescents are living with HIV (Limpopo DoH, 2013). Vhembe district has four municipalities which are Makhado, Thulamela, Musina and Collins Chabane. The chosen municipalities were Thulamela and Makhado. The dominant language and other languages that are spoken are Venda, and Tsonga, Pedi, Shona and English. Mopani district consists of 5 local municipalities which are Greater Letaba, Greater Giyani, Greater Tzaneen, Phalaborwa and Maruleng. It has 223 health facilities-The researcher focused only on the Greater Giyani municipality (Figure 3.1).

3.4 Research Methodology

3.4.1 Research Design

According to Polit et al. (2018), qualitative research methodologies explore participants' thoughts, feelings, behaviours, or linguistic strategies using language as its raw material. The researcher was committed to discovery through numerous methods of knowledge in this design. A qualitative design was chosen because it is adaptable, flexible, and can be taught while collecting data (de Vos, 2013). The qualitative design method is defined by De Vos et al. (2013) as inquiry tactics or tools that can be employed in research. Understanding is more important to the qualitative researcher than explanation (Brink, 2014). In qualitative research, researchers make judgments on how to plan the study and create their own tactics or instruments to help or guide them (de Vos et al., 2012).

The researcher studied the knowledge and experiences of ALWHIV, as well as the support needed by both parents and adolescents, hence a qualitative approach was more suited and beneficial for this research project. Qualitative designs investigate human experiences from the perspective of study participants in the context in which the action takes place, focusing on the qualitative dimensions of meanings, experiences, and understanding (Brink, et al, 2018). The researcher employ actions in a qualitative study and concentrates on interpretative, non-numerical narrative interpretation (Polit and Beck, 2018). This design piqued the researcher's interest because the purpose is to study behavior or activities in the context of HIV programs as they naturally occur. The study employed an exploratory, descriptive, and contextual research design.

3.4.1.1 Exploratory Design

According to De Vos et al. (2014), an exploratory design is used when a researcher comes into an issue that is already well-known and has a description, but is urged to inquire as to why things are the way they are. A casual query is another name for it. As a result, such a study starts with exploratory and descriptive research and then moves on to determining why something happened. An exploratory design aims to gain a basic understanding of occurrences by putting predictions and hypotheses to the test in order to determine the causes of events and the variables or mechanisms that cause them (de Vos et al., 2014). When the problem is unclear or the subject is unfamiliar to the researcher, this strategy is frequently used. The researcher used the initial qualitative phase of an exploratory design to shed light on many ways in which a phenomena manifests itself and is an underlying process (Polit and Beck, 2018).

3.4.1.2 Descriptive Design

The major goal of a descriptive design, according to Polit and Beck (2018), is to accurately reflect the features of people, circumstances, or groups, as well as the frequency with which particular phenomena occur. Descriptive designs paint a picture of the situation's exact facts and concentrate on how and why inquiries.

3.4.1.3 Contextual Design

During data collection, the researcher offered participants enough time to elaborate on their answers. In a contextual study, the researcher is more likely to comprehend the phenomenon in the context of the entire context, which supports the meaning of the occurrence in question (Babbie, 2016). The researcher recounts the experiences of ALWHIV as they transition to adulthood in this study, as well as why some default treatment. The study was conducted in a natural setting where human behaviour and events occur.

3.5 Research Methods

3.5.1 Population

The total aggregation of individuals with some common features that the researcher is interested in examining is referred to as a population (Polit and Beck, 2018). The participants in this study were divided into two groups:

- First group - the ALWHIV; and the

- Second group - the parents or guardians staying with ALWHIV.

- NIMART nurses who would validate the strategy only because of their knowledge in HIV matters as their recommendations could assist the researcher on the applicability and suitability of the strategy.

3.5.2 Sampling

The process of picking a subset of the population to represent the complete population is known as sampling (Polit and Beck, 2014). Burns and Grove (2020) define sampling as the process of selecting participants, events, behaviours, or aspects for inclusion in a study.

3.5.2.1 Sampling of PHC Health Facilities

To choose PHC facilities, the researcher employed the probability systematic sampling method. A list of facilities in the selected districts were made, and every 13th facility was sampled. Thus the strategy gave each facility an equal chance of being chosen for the study (Polit and Beck, 2018; Brink, van der Walt, van Rensburg, 2018). The systematic or interval sampling method requires the researcher to obtain a list of the entire population before formulating a beginning point for selecting the sample at random (Brink et al., 2018). To sample PHC facilities, the researcher utilized a systematic procedure. Each district's Department of Health provided a list of all facilities. Thulamela, Makhado, and Greater Giyani were chosen as the three municipalities to be sampled. The Vhembe district has 101 PHC facilities spread over three municipalities. Because of the vast number of PHC facilities in Vhembe, each thirteen PHC facility was chosen. Because of the smaller number of PHC facilities in Mopani which was 27 the thirteen PHC facility was chosen and two facilities. To get a good representative of the full PHC facility. Two PHC facilities in Greater Giyani's Mopani area were sampled, while seven in Makhado and Thulamela municipality's Vhembe district were randomly selected. The number of PHC facilities sampled is shown in Table 3.1. The sampling of these facilities was sufficient to meet the goals of ALWHIV transition optimization.

Table 3.1: List of sampled primary health care facilities from the sample frame

District	**Municipality**	**Total number of PHC facilities per municipality**	**Number of PHC sampled**
Vhembe	Makhado	49	03
	Thulamela	52	04
Mopani	Greater Giyani	27	02
Total		**128**	**09**
Limpopo Province DoH, 2015			

3.5.2.2 Sampling of Participants

The participants in this study were chosen through purposeful sampling. Purposive sampling, also known as judgmental sampling, is based on the belief that the researcher's knowledge of the population can be used to handpick sampled members, according to Polit and Beck (2018). The researcher used non-probability purposive sampling in this study to select both participants who volunteered to be part of the study and meet the criteria. This exclude the despondence for validation of strategy. The researcher used her own judgment to select participants that represented the phenomena being studied or who are knowledgeable about the question for discussion. Purposive and convenience sampling methods were used to select participants who are ALWHIV (27) and parents/guardians (18) who are staying with these adolescents. Probability sampling was used for sampling NIMART nurses who validated the strategy after the study was conducted. All the NIMART nurses for the facilities where the study was undertaken were allowed to participate if they met the criteria and volunteered to participate.

3.5.2.3 Inclusion Criteria

According to Neuman (2017), inclusion or exclusion criteria are parameters by which a study limits or excludes participants based on pre-defined features, or inclusion criteria are pre-defined traits that qualify people to participate in a research study (Brink, 2014). The study's target audiences are listed in Table 3.2.

Table 3.2: Inclusion criteria of the identified groups:

Adolescents who are living with HIV (ALWHIV)	**Parent/Guardian of ALWHIV**
• Adolescent aged 12-19 years • Tested HIV+ and enrolled on the ART program • On ART long term medications • Has disclosed HIV status • Agree to participate in the study	• Staying and caring for ALWHIV at home • Agree to participate in the study

3.5.2.4 Exclusion Criteria

These were elements or characteristics which were not included in the study. In this study, adolescents who had already given birth in their adolescent stage were not included and those who had contracted the disease sexually as a risk behaviour at their adolescent stage.

3.5.2.5 Sample

A subset of a population chosen by researchers to engage in a research project is referred to as sample size (Polit and Beck, 2018). Purposive sampling would be used in qualitative approach for objective 1 and 2, the researcher does not know how many participants will be needed in advance. The researcher ensured that both groups were recognized for data collection when visiting the sampled health institutions. The expected attendance was 27 ALWHIV and 18 ALWHIV parents/guardians from both districts. Each facility collected three ALWHIV and two parents/guardians. With all of the subjects, data was gathered until saturation was reached (Brink, 2018). When no fresh information was acquired from the participants, data saturation occurred (Brink, 2018). Sampling for NIMART nurses followed a probability systematic sampling. Two NIMART nurses were sampled per facility. The total was 18 respondents. Thus, those who would hand pick a 'yes' piece of paper inside the container and agreed to be part of the study freely without any reward needed as the study is not sponsored.

3.6 Data collection

Data collection is a systemic process of gathering information relevant to answer the research question (De Vos, 2014). In this study, qualitative data were collected by the researcher as the main data collector. Data were collected in all nine facilities in the sample frame (Table 3.1). The researcher communicated with the participants, and face-to-face and in-depth interviews were conducted. Data collection was done with the interest of the participants in mind. The room was free from any destruction. Data were collected during the day when participants came for their appointments. The researcher went to the identified locations and set up an appointment with participants for an interview.

The researcher asked the manager for permission to use an available office or room on the day of data collecting. Following the consultation, the sampled participants were invited to come to the office, where they were given an explanation of the study's details and asked to sign an informed consent form. By paying attention to what the subjects were saying, the researcher created rapport with them. A casual talk in a relaxed conversational style preceded the discussions. Listening and interviewing skills were used by paying close attention to the stories of the participants (Polit and Beck, 2018).

The researcher interrogated the participants to confirm that the objectives were addressed and to get more information on areas that were not addressed in their responses. After receiving informed agreement from the participants, the researcher used a voice recorder during the interview.

The main question for ALWHIV was:

> *Could you share with me the knowledge you have about HIV disease and how is it for you as you transit to adulthood including the support you received from anywhere?*

The questions for parents/guardians was:

> *Could you describe the challenges you encounter when your child transit to adulthood and the support you need if any providing to ALWHIV during transition to adulthood?*

During the interviews, the researcher also made field notes by writing down information communicated that needed clarity and for the purpose of comparison. When performing the interview, the researcher noted the nonverbal communication/gestures and recorded them in the field notes. The researcher aimed for a favourable conclusion to the interview by offering the participants a summary of the conversation and allowing them to clarify, refine, or correct the interviewer's report (Polit and Beck, 2018). The purpose of probing was to urge participants to provide more detailed information about the study. The interview for each participant took 30-45 minutes. Interviews of all the participants were conducted over a period of about four to six weeks.

Participants were reassured that their names will not be known or used and codes would be used as names. Furthermore, the information obtained would be used for the research study and nothing else. The researcher listened to the tape-recorded interview and verified it for audibility and completeness (Polit and Beck, 2018). All taped data was meticulously labelled with unique codes and the date the data was gathered. Data was collected in Venda and Tsonga, then language experts transcribed it into English for study purposes. The researcher took field notes and verified the non- verbal cues made or observed during the interview. The field notes assisted the researcher in remembering and exploring the interview process (de Vos et al., 2014). NIMART nurses were used during the validation of strategy because they have more knowledge on HIV matters than the participants. Self-administered questionnaires would be distributed for the respondents to complete.

3.7 Data Analysis

According to Brink et al. (2018) qualitative researchers explore for patterns and connections. When it comes to assessing and presenting qualitative data, there are no uniform guidelines. Because there are so many pages of story materials, qualitative data processing takes a lot of time (Polit and Beck, 2018). The data's richness and evidentiary were preserved during the reduction process by classifying them into main themes, themes, and sub-themes. If necessary the independent co-coder would confirm the applicability of themes and sub-themes. In the validation of strategy, descriptive statistic s would be used to analyse the responses of the respondents, and would be expressed by frequencies and percentages. Data analysis was a collaborative and active process. Because qualitative researchers begin data analysis early in a research project, while data is still being collected, data analysis began at the time of data collection and not at the end of data collection. The following are the eight steps of Tesch's open-coding data analysis (Creswell, 2018):

1. Getting a Sense of the Whole

The researcher first listened to the audiotapes and then wrote down the interviews word for word on paper. The transcripts were then thoroughly read, with any thoughts noted down in the margin.

2. Picking Up One Document

The researcher chose the most intriguing document from the stack and read it several times, attempting to make sense of it and jotting down notes in the margins.

3. List the Topics

A list of all topics was generated after the researcher completed step 2 for several subjects. Similar subjects were grouped together to form columns, which were then divided into three categories: main topics, unique topics, and leftovers.

4. Going Back to the Data

The researcher drew up a list of possible subjects and compared it to the data. Topics were abbreviated as codes, which were then recorded next to the relevant segments of the notebook to see whether any new categories or codes had arisen.

5. Describing the Topics

The researcher used the most detailed language for each topic and organized it into groups. The total number of categories was then decreased by combining themes that were linked to one another. To show relationships, lists were formed between categories.

6. Abbreviating the Categories

The researcher chose abbreviations for each category and organized the codes alphabetically.

7. Assembling the Data

Data from the same category were gathered in one location and a preliminary analysis was performed.

8. Recoding the Data, if Necessary

Where necessary, the researcher recoded existing data (Creswell, 2018). The independent co- corder would confirm the developed themes and sub- themes if necessary.

3.8 Trustworthiness

Trustworthiness is a means of determining the validity and reliability of qualitative research, and it is attained when the findings accurately reflect the study participants' experiences and it assesses the study's truth value. Credibility, reliability, conformability, and transferability are the four qualities it comprises (de Vos, 2013; Polit and Beck, 2018).

3.8.1 Credibility

The term "credibility" refers to one's belief in the data's accuracy. It entails two steps: first, conducting the inquiry or study in such a way that its credibility is strengthened, and second, demonstrating credibility (Polit, et al, 2018). Credibility was established in this study by:

- **Prolonged engagement**, where the researcher spent as much time as possible with the subjects during their appointments until data saturation was reached Building trust and connection with the participants also ensured that enough time was invested.
- **Referential adequacy,** the use of a voice recorder was ensured.
- **Peer debriefing**- To ensure the accuracy of the views, and analyses, a colleague with a similar status outside the study who understood the nature of the study was asked to review them.
- **Data triangulation**- Various data-collection approaches were used to ensure this. Field notes, and in-depth individual interviews, were used to collect data.
- **Member checks** were carried out in order to ensure the study's reliability. The term "member checks" refers to giving study participants comments on preliminary findings and interpretations, as well as gauging their

emotions. Participants were questioned about their responses both during data collection and after the data had been collected and evaluated to ensure that their responses had been correctly interpreted (Polit and Beck, 2018).

3.8.2 Dependability

This relates to the consistency of data throughout time and under various settings (Polit and Beck, 2018). In this study, dependability was verified by conducting an inquiry audit, in which an external reviewer (co-coder) scrutinized the data and accompanying papers, ensuring confirmability.

3.8.3 Confirmability

The objectivity or neutrality of the data is defined as the ability of two or more people to agree on the data's relevance or meaning (Polit and Beck, 2018). The confirmability audit trail, according to Babbie (2016), is an adequate trial that should be left to allow the auditor to assess if the interpretations, conclusions, and recommendations are traceable to their sources and if they are supported by the inquiry. The researcher guaranteed data consistency by creating an audit trail, which is a systematic collection of documentation, in this case field notes and voice recordings, that allowed an independent auditor to reach conclusions about the data.

3.8.4 Transferability

Transferability is similar to generalizability in that it relates to the extent to which data findings can be applied to other situations or groups (Polit et al., 2018). The term "thick description" refers to a detailed, in-depth explanation of the research setting as well as the transaction processes observed during the investigation (Polit et al., 2018). What happened in the research environment was detailed in detail by the researcher. In addition, the study thoroughly described nonverbal signs detected during the interviews.

3.9 Phase 2: Development of the Strategy

This phase focused on goal 4, which was to establish a strategy to improve ALWHIV transition to adulthood in the Limpopo Province of South Africa. Chinn and Kramer's strategy development approach was adapted by the researcher (2015). Strengths, Weaknesses, Opportunities, and Threats were the focus of the analyses (SWOT). The Strength and Weaknesses (S & W) concentrated on human resources, services, and financial costs, whereas the Opportunities and Threats (O & T) focused on PESTLE analysis (Political, Economic, Social, Technological, Legal, and Environmental). Following that, a SWOT matrix was created and actionable strategies were developed as a strategy using BOEM. When optimizing the appropriate transition of ALWHIV to maturity, a SWOT analysis (alternatively, SWOT matrix) is a systematic planning tool used to examine the strengths, weaknesses, opportunities, and threats involved. Furthermore, a collaborative SWOT analysis should be prepared with a variety of contributions from parents/guardians and ALWHIV as participants. In order to develop the strategy, the following actions were taken:

- The data from the participants' responses were used to create a SWOT and PESTLE analysis matrix.
- PESTLE was a method that helped NIMART nurses have a better knowledge of the large picture of the socio-cultural and environmental context in which ALWHIV should be transitioned to its optimal state.
- PESTLE analysis can help you avoid taking actions that lead to failure due to factors beyond your control.

The PESTLE was studied within the SWOT matrix in this study, and a plan was devised based on the results of the SWOT analysis.

- **Step 1**

The Strengths of PESTLE to impact the ideal ALWHIV transition were determined in this step.

❖ Step 2

Step 2 identified the variables that may obstruct ALWHIV's ideal transition (Weaknesses in PESTLE), and were discovered**.**

❖ Step 3

In this step, participants can use the opportunities in PESTLE to their advantage and help the institution achieve its aim of maximizing the transition of ALWHIV to adulthood.

❖ Step 4

PESTLE threats or actors in the environment that could obstruct ALWHIV's progression to adulthood were identified.

❖ Step 5

The researcher studied the data and noted the strengths before moving on to the flaws, opportunities, and dangers. Strengths, weaknesses, opportunities, and threats were used to create the SWOT matrix. The following are the four questions that have been posed to you:

- How can we make the most of our abilities?
- How can we overcome the threats that have been identified?
- What steps do we need to take to address the identified flaws?
- What can we do to make the most of our opportunities?

The next stage was to turn the results into actionable outcomes, which was done through prioritization. The plan was created using the Build, Overcome, Explore, and Minimize (BOEM) method and using the Chinn and Kramer (2015) as indicated above. Building strengths, overcoming weaknesses, exploring opportunities, and reducing risks were used to construct a strategy to improve ALWHIV's transition to adulthood.

3.10 Validation of the Strategy

The fifth and last goal was to validate the created strategy. According to Ryan and Wheatcraft (2017) validation is the process of correctly constructing a system. Validation had the objective of ensuring that the systems behaved according to their requirements. Validation also assures that the system is free of faults introduced during the implementation phase by developers (Chinn, et al., 2015). Validation was carried out to ensure that the strategy was applicable. The population to validate comprised of NIMART nurses, though they were not part of the study. The researcher saw it suitable to choose them to achieve this goal for their knowledge and competence was relevant. The researcher validated the strategy by giving a brief summary of the study and provide semi structured questions to those who met the criteria above so that they could share their input on the strategy developed, and checked if the strategy was acceptable, applicable and can be used to optimize the transition of ALWHIV to adulthood. Validation was described in detail in Chapter 6.

3.11 Ethical Considerations

Ethics is a set of moral principles proposed by an individual or a group that is commonly accepted and includes rules and behavioural expectations regarding the most appropriate behaviour toward participants, employers, sponsors, other researchers, assistants, and students (Polit and Beck, 2018).

3.11.1 Permission to Conduct the Study

The following structures granted permission to perform the study:

- The following structures granted permission to perform the study:

- Committee of the Department of Health Research (Annexures B and C).
- PHC facility managers at the district level (Annexures D, E and F).

3.11.2 Informed Consent

Informed consent (Annexure G) indicates that participants will be provided with sufficient information about the research, will be able to comprehend the information, and will have the ability to choose whether or not to engage in the research (Polit and Beck, 2018). Before signing the consent papers, the participants were given a full description of what the study comprised. The participants were informed that they were not obligated to take part in the study (Annexures H and I). Children under the age of 18 signed the assent form (Annexure J) and the parent/informed guardian's permission form (Annexure H).

3.11.3 Right to Information

When gaining consent, the researcher was required to give the subjects with relevant and adequate information. Participants should be informed about the study's goal and scope, as well as how the results will be used and how their identity will be safeguarded (de Vos, 2014). The participants were informed that they had the option to leave the study at any time. If a research subject is informed and consents to engage in a study, and voluntarily provides private information with a researcher, the subject's privacy is preserved (Burns and Grove, 2020). The participants were informed that the information on the recording and the field note would be kept private and only shared with individuals involved in the research, and would not be used to harm anyone. By not using names anonymity and secrecy were preserved (Polit and Beck, 2018).

3.11.4 The Principle of Beneficence

In this study, there was minimal effect on mental status such as crying, frowning during the interview because the study is attached to stigma in some of the adolescents. The respondents were debriefed and given the opportunity to ask questions or express grievances. The volunteers were properly informed about the research's benefits, including the fact that there were no direct personal gains. The participants were informed that the study's findings will be published and disseminated internationally (Polit and Beck, 2018).

3.11.5 The Right to Self-Determination

The ethical principle of respect for persons underpins the right to self-determination, which argues that humans are capable of determining or influencing their own fate. As a result, humans should be recognized as independent agents with the freedom to live their life as they wish without the interference of others (Burns and Grove, 2020). Participants in this study were given the right to self-determination by respecting their right to consent to be included in the study and not being forced to participate. The subjects were not duped into participating in the study by the researcher. The participants were informed that they could choose whether or not to participate in the study.

3.11.6 The Right to Fair Treatment

The ethical ideal of justice underpins the right to fair treatment. This idea argues that each individual should be treated fairly and receive what he or she is entitled to (Burns and Grove, 2020). Throughout the course of the study, participants were treated fairly and with respect.

3.11.7 Right to Privacy

People must have the choice to choose when, how, and under what conditions their personal information will be shared with or withheld from others. A person's views, ideas, behaviours, opinions, and records are all considered private information (Burns and Grove, 2020). Participants' privacy was protected in this study by fully notifying them about it. They were also aware that they had to sign a consent form indicating their willingness to participate.

3.11.8 The Right to Anonymity and Confidentiality

When a participant's identity cannot be traced to their responses, even by the researcher, complete anonymity exists (Burns and Grove, 2020). Anonymity was preserved in this study by not putting names. The researcher's management of the participant's private information is referred to as confidentiality (Burns and Grove, 2020). Confidentiality was ensured in this study by explaining to the participants that even though they agreed to participate in the study, they were free not to answer any of the questions with which they were uncomfortable, and that the shared information would only be distributed to those who were involved in the study.

3.12 Summary

The methodology of this study was to explore and describe the knowledge of ALWHIV during transition to adulthood; to describe challenges faced by parents/guardians during the transition to adulthood; to explore the support given to ALWHIV by parents/guardians during the transition to adulthood. The second phase encompasses the development of a strategy to optimize the transition of ALWHIV to adulthood and to conduct validation of the developed strategy. The next chapter covers the results and discussion.

CHAPTER 4

PRESENTATION, INTERPRETATION AND DISCUSSION OF THE FINDINGS

4.1 Introduction

The research methodology, which drove the study and included a description of the study site, population and sample, research design, and procedures, was discussed in the preceding chapter. The mixed approach was used in this research. This study of ALWHIV and their parents/guardians was driven by the Empowerment Model (Vorming, et al., 2015). 27 ALWHIV and 18 parents/guardians who were living with these children participated in face-to-face, in-depth, unstructured interviews, and

The aims of the study were to:

- Discover and describe the knowledge of HIV as a condition by ALWHIV during transition to adulthood.
- Describe challenges (fears) faced by parents/guardians during the transition of ALWHIV to adulthood because the adolescents would be independent at this stage.
- Explore the support given to ALWHIV by parents/guardians during the transition to adulthood.

The main goals of this chapter were to present, interpret, and discuss the findings in order to lay the groundwork for how the participants express themselves in their native tongue, and the information was professionally translated into English. The open-coding method was used to analyse the data. The raw data was analysed, and themes and sub-themes emerged.

To validate the discussion of the topics and sub-themes, verbatim quotations from the participants were given and backed by relevant literature.

4.2 Presentation of the Findings

This chapter present the findings of the as outlined by the participants and supported by literature and direct quotes from them.

4.2.1 Description of the Sample

Below is how sampling was conducted.

4.2.1.1 Profile of Selected PHC Facilities

The sampling of PHC facilities from the two sampled districts, namely Vhembe and Mopani, is summarized in Table 4.1. In Vhembe district, the Thulamela and Makhado municipalities were purposely sampled. In Mopani district, only Greater Giyani municipality was considered. The researcher randomly sampled health facilities from the selected districts. The mobile clinics were not included because mobile clinics are not fixed and they don’t provide ART/ HIV services hence the health centres were tried but the researcher failed to get clients because facilities are always full and the long queues contributed in making clients to be in hurry after consultations. From the list of facilities only 10% were sampled from each municipality. Table 4.1 indicates the sampled facilities: three from Thulamela, four from Makhado and two from Mopani district. The total number of facilities sampled were nine (9).

Table 4.1: Selected PHC facilities

PHC Facilities Sampled	Number of ALWHIV	Number of Parents/Guardian
Makonde Clinic	3	2
Shayandima Clinic	3	2
Madombidzha Clinic	3	2
Muila Clinic	3	2
Tshakhuma Clinic	3	2
Wayeni Clinic	3	2
Makhuva Clinic	3	2
Ntluri Clinic	3	2
Vhurivhuri Clinic	3	2
Total	**27**	**18**

Table 4.2 depicts the keys for the selected PHC facilities.

Table 4.2: Keys for selected PHC facilities

Makonde=Mak	Shayandima=Shayas	Madombidzha=Madom
Muila=Muil	Tshakhuma=Tshak	Wayeni=Way

Makhuva=Makh	Ntluri=Ntlur	Vhurivhuri=Vhuri

4.2.1.2 Demographic Profile of ALWHIV

The demographic profile of ALWHIV who took part in the study is summarized in Table 4.3.

Table 4.3: Profile of ALWHIV

Demographic	Category (Variable)	Number
Age	12-15	4
	16-19	23
Gender	Male	9
	Female	18
Ethnicity	Venda	18
	Tsonga	7
	Sotho	2
Educational level	Primary	0
	Secondary	25
	Tertiary	0
	Drop-out	2
Employment status	Employed	2

	Unemployed	25
Disclosure by gender	Male	0
	Female	1
Not disclosed	Male	27
	Female	26

4.3 Presentation and Interpretation of Themes and Sub-Themes as Reflections of ALWHIV

A total of 27 ALWHIV were used to collect data. As described in Chapter 3, data analysis was carried out utilizing the eight (8) steps of Tesch's qualitative analysis, namely inductive, descriptive open-coding methodologies (Creswell, 2018). The themes and sub-themes as reflections of ALWHIV are shown in Table 4.4.

4.4 Discussion of the Findings

Table 4.4: Themes and sub-themes as reflections of ALWHIV

Themes	Sub-Themes
1. Descriptions of the experiences of ALWHIV	1.1 Paradoxical experiences of living with HIV from childhood to adulthood explained 1.2 Different types of burden (financial, social, psychological etc.) experienced caused by ill-health of ALWHIV endured by parents and guardians explained 1.3 Explanation that memories of living with HIV viewed as traumatic to both

			parents and adolescents
		1.4	An explanation that improvement of physical health experienced is associated with adherence to treatments
		1.5	Health education provided by nurses with peers experienced from childhood to date
2.	**Challenges experienced from childhood to adolescence period**	2.1	The lack of disclosure by parents and guardians to ALWHIV and other children is due to a lack of awareness of the medical state and fear.
		2.2	Challenges in their sexual lives, as well as engaging in activities that may jeopardize their physical health
		2.3	The lack of disclosure of HIV+ status and the manner in which it was transferred to them by their parents and guardians was seen as a difficulty.
		2.4	Lack of HIV+ status disclosure to sexual partners throughout the adolescent stage is seen as a difficulty (leading to telling lies)
3.	**Descriptions of existing support experiences by ALWHIV and their parents**	3.1	The support received from health care professionals by ALWHIV
		3.2	The support received from family members and parents of ALWHIV, and from peers attending sessions at the clinic appreciated
		3.3	Health education content provided to ALWHIV and parents and the importance thereof
		3.4	

Table 4.4: Themes and sub-themes as reflections of ALWHIV (*continued*)

Themes	**Sub-Themes**

		3.5	Medical and health instructions provided by nurses viewed as health support leading to adherence to treatment
4.	**Knowledge related to HIV+ status and disease progression**	4.1	From childhood to the present, there is a disparity between the lack of understanding about the disease and the knowledge that exists.
		4.2	Lack of understanding vs. knowledge of the necessity of treatment adherence and its future repercussions
		4.3	Lack of knowledge vs. having awareness of the ART's disclosed indications
		4.4	Parents and guardians are criticized for not disclosing their children's HIV status.
		4.5	Lack of information versus knowledge about mother-to-child transfer
		4.6	Disclosure of HIV+ status at childhood promotes knowledge which assist in promoting quality of life by ALWHIV
5.	**Suggestions made to promote quality of life by ALWHIV**	5.1	A request for communities to support ALWHIV
		5.2	Request for support from government to provide basic needs to ALWHIV
		5.3	Request for initiation of support groups with consistently scheduled meetings
		5.4	A suggestion that parents be held responsible of not disclosing HIV+ at childhood level and be encouraged to do so.

The information was translated into English by a language expert after participants expressed themselves in their native language (mother tongue). Table 4.4 shows the five (5) themes and 23 sub-themes that evolved. The findings are presented and supported by direct quotations from raw data. Research finding to substantiate the discussion under themes and sub-themes and supported by literature control. The themes are; descriptions of the experiences of ALWHIV; challenges experienced from childhood to adolescence; description of existing support experiences by ALWHIV and their parents; knowledge related to HV+ status and disease progression; and suggestions made to promote quality of life.

4.4.1 Theme 1: Descriptions of the Experiences of ALWHIV

Since the beginning of the pandemic, HIV had been treated secretively in families and highly confidential within the health institutions. Many parents died because of this pandemic, some living behind children who were exposed or born with the virus as orphans, either fatherless or motherless or both. Some grew up heading families. ALWHIV had various life experiences which they came across as they were growing up. Findings of the study revealed that some of the ALWHIV grew up in poverty and life was difficult for them while some families could manage well and some were living with guardians who were able to support their families in all spheres of life. The following sub-themes arose from this theme (Table 4.4):

4.4.1.1 Sub-Theme 1.1: Paradoxical Experiences of Living with HIV from Childhood to Adulthood

ALWHIV had different experiences from childhood to adolescent stage. Due to high unemployment and illiteracy rates in Africa, HIV+ children grew up in poverty. Their childhood life became difficult for those living with them because they are always sick and hospitalized. Parents and guardians' experience financial constraints during this time. However, there were some who grew up in good living conditions where their families earned reasonable living wages and they could sustain better living standards but some of the adolescents grew up in poor families and had tough experiences in childhood life such as sickness and frequent admissions to hospital. Some ALWHIV and parents live in fear and agony as the children were always sick before they could start with ARVs. To some parents, failure to seek medical help for their children was caused by their cultural beliefs and not taking the disease as real. This was supported by ALWHIV participants:

Participant 01 from Makonde clinic said, 'when I heard nurses teaching us about HIV-related issues ***regularly I was so amazed because I never thought I had the disease and*** *never realize the people I'm with also had HIV.'*

Participant 02 from Wayeni, Shayandima 05, Muila 08 and Vhurivhuri 10 added that ***'my childhood was very painful and hard*** *because of poverty. I was always sick and there was no money to visit hospital or clinic regularly, why did this disease come to me?'*

*Participant 13 from Tshakhuma and 17 from Ntluri continued that '****the dying of my parents was very difficult*** *to forget, but also a blessing in disguise because my aunt adopted me and disclose my status very early.' I have peace, love and support in the family. I don't have any problems.'*

According to Roberts, 2018; WHO, 2018 studies showed that people react differently when they heard the name HIV. Some associate it with bad or evil things, mostly because it has a stigma attached to it.

Guardian 05 from Vhurivhuri clinic said, 'after I was told that the child might be *suffering from HIV, **I became scared and fearful that I might have contracted the disease.** I feared to die and live my children suffering. It was not a good experience, but there was nothing I can do because whether good or bad I still have to care for this child.'*

Nyblade, Srini Vasan, Mazur, Raj *et al.* (2018) confirmed the above by showing that the type of burden people may come across differ according to their individual perceptions after being diagnosed with HIV. Furthermore, the study explained that some people can be withdrawn or be depressed, depending on how serious the matters are in their lives. They further showed that the behaviour of individuals can determine the pain that one can come across. Coleman, Tate, Gaddist and White, (2016) attested to the above and revealed that some adolescents live in darkness for quite some time and find out about their true diagnosis or status very late when they transit to adult care. The WHO (2017) added that many of the ALWHIV in sub-Saharan Africa are living in poverty.

4.4.1.2 Sub-Theme 1.2: Different Types of Burden Experienced Caused by Ill-Health of ALWHIV Endured by Parents and Guardians

Research findings showed that some of the ALWHIV and their parents had different experiences depending on their setup or family background. Many poverty-stricken families are physically, financially, emotionally and psychologically distressed because parents or guardians are living in poverty. Seeing both the parents and adolescents struggling due to poverty, it is often asked 'why is HIV a disease of the poor? Seeing both the parents and adolescents struggling due to poverty, it is often asked 'why is HIV a disease of the poor? The above was supported by:

*Participant 10 from Vhurivhuri said, 'the only burden that I get is that sometimes **the food they buy doesn't last for the month** before they get money. If the government can give us food parcels it can help because at the social workers people are many and they don't always get, only once in a while, and money to* *carry to school is also a problem.'*

*Participant 13 from Tshakhuma said, 'at the hospital they **use to give us juice and soft porridge,** saying that our bodies will recover fast.'*

*Participant 15 from Nluri alluded, **'I was very emotionally and psychologically burdened when I first** knew that the condition I was told I'm suffering from is not the true one, but I'm* HIV+*. Again, I was not satisfied by the results, at home I searched in my mother's room everywhere until I found the tablets' same as mine, but mom denied until I told her where the pills are?'*

*Participant 01 from Makonde revealed, **'my childhood was very painful and very demanding** from my mom and grand mom because I was always sick. I had to visit the hospital now and then as I was always admitted until I was stable after starting ARVs. My family depend mostly on grant funds because my mom was not working. The adjustments of my medications during primary care depend on whether the body weight has increased or dropped.'*

Most inhabitants of African countries are living in poverty, especially sub-Saharan Africa, hence, the children are also affected by this pandemic in large numbers (Bailley, Cruz, Songtwenesin and Phuthanakit, 2017). The study further revealed that HIV affected people very badly, especially physically, psychologically and financially, because many people were left unemployed and cannot afford a balanced diet and money for transport to and from hospital. However, at the beginning of this pandemic, HIV+ people, even in South Africa, were given food supplements in the form of milk for babies, soft porridge, juice and grant money in some countries so that they can eat and be able to drink medications and to recover faster (WHO, 2017; Dennison, Banda and Dennis, 2015

The research findings revealed that both ALWHIV and their parents or guardians suffered traumatic pain at some stage after being diagnosed with HIV. Some ALWHIV suffered unbearable physical ill-health while some parents/guardians' experienced psychological, emotional, and financial burden for having to attend hospitals for treatment and follow-up visits, all for the sake of their children to get better. The following quotation supports the burden experienced by parents:

Guardian 07 of Ntluri alluded, 'it was difficult for me to raise these kids because the ***family was poor, and we depend on grant money and the food support from the social workers.*** *Psychologically and financially my spirit was so depressed not hoping that I could do it.'*

Burgamer, Pharr, Batuner (2017) concurred with the above showing that the HIV pandemic brought a disaster and burden in many families because many parents died and left their children orphaned while other children were left to head and care for their families. Many parents also lost their jobs and became frustrated and devastated. Many adolescents are heading families because of this pandemic. The study further showed that ill-health for many adolescents during childhood life became very problematic as they were always admitted to hospitals.

Similarly, Coleman, Tate, Gaddist and White (2016) further showed that many adolescents were traumatized by HIV pandemic as it caused family disorganization and death in some people which impacted negatively on many adolescents. The ill-health during childhood was a burden on many families and posed physical, emotional, financial and psychological constraints. They also stated that these teenagers should be equipped with knowledge about their life so that they may make educated decisions regardless of their circumstances (Ruria, Mashaba, Kose, Woelke, Mangy and Matu, 2017).

4.4.1.3 Sub-Theme 1.3: Explanation That Memories of Living with HIV Viewed as Traumatic to Both Parents and Adolescents

The findings of the study found that women can endure the pains and sufferings caused by their husbands and continue to love and have other children even after they knew their status. Some of the parents knew their status for a long time, yet they kept quite as if nothing happened. They even conceived again, without taking ARVs and continued with their lives. At that time, some parents said they did not believe that HIV is real and that it can affect them. Research findings revealed that some parents and families experienced denial and shock which delayed them in seeking medical help early. As a result, they sought help from spiritual or faith-based institutions, including traditional healers, but all did not produce good results. The sickness continued. Both children and their parents who went there continued to be very sick until late, and this was supported by the following participants:

Parent 01 from Makonde said 'after the funeral, one of the sister's-in-law whom I had a good relationship with told me ***my husband had AIDS long ago and was not taking pills.*** *But he never told me that, but because I was already in the advanced stage of my pregnancy, I went to the clinic a week later and asked the nurse to test me because I refused at first saying I can't get it—the results came back positive, I was deeply hurt and can't forget this a****nd that's how I started medications****.'*

Parent 02 and parent 06 from Madombidzha supported the above saying, 'I realized and found out my status in ***2003 after giving birth to my second born girl.*** *I was afraid to test during ANC when the counselled and nurses gave us information trusting my husband too much and being sure that HIV is for people who are promiscuous.* ***This was my worst memory in life*** *since that day I see my husband as a dog especially when I look at my poor child. Maybe I will forget when the cure medication is found.'*

Whilst participant 15 from Ntluri shared 'as you see I'm very short, people in the village call me shorty because I grew up being sick and was diagnosed very late because ***my family believe in traditional medicines.*** *They were not effective to the virus, but I don't have a problem, I'm used to it now. I knew that I'm* HIV+ *when I was thirteen, understanding* ***how and what HIV means to me.****'*

According to statistics, Sub-Saharan Africa is home to 90% of the world's ALWHIV. HIV stigma and the fear of being identified as HIV positive can jeopardize their survival by preventing them from starting and sticking to antiretroviral therapy (ART) (Pantelic, Boyes, Cluver et. al, 2018). The study also revealed that many patients experienced worry when their HIV status was discovered for the first time. The findings revealed that many women as parents were loyal, faithful, and supportive in their relationships and trusted their partners as people who would not cheat. Some, after they tested positive, realized that it means their spouses were cheating outside their relationships. After finding their HIV status many were bored and felt deceived because their partners never disclosed to them of the relationships they had, neither of their status too. Hence, if they disclosed, first the partners could have blamed them for cheating and transferring the disease to them.

Furthermore, some went to hospital when they were critically ill. After they were tested and found out they were HIV+, parents were started on ARVs and consented even for their children to be tested and started on ARVs. Then their health improved. Some died after few weeks of being diagnosed as they were critically ill. Furthermore, research findings showed that most of the people believe in seeking medical help after they consulted from traditional healers and spiritual or religious faith-based organizations if they don’t get any better from what they felt. Then their last resort would be seeking help from modern or Western medicine, either from hospitals, clinics and private practitioners. And during this time, some would be critically ill or either die at the hospitals.

Roberts (2018) further added that being diagnosed with HIV or knowing that one is HIV+ for the very first time is very frustrating and depressing. People should take it in a positive mind, especially those who are very close to the person. Studies also showed that some people delayed themselves during this time. They were in denial and started to seek traditional help or faith-based help. The families and the community should provide the necessary support and comfort their friends or relatives for them to can continue with treatment. When a person is told about the HIV+ status it is not the end of the world, but help individuals to accept and start treatment early (Roberts, 2018). WHO (2017) concurred with the above showing that bad memories can harm the psychological well-being of a person. Both the ALWHIV and their parents should get the support from those around them. The study further showed that the love and support at all times help them to understand and accept the situation. The community should not mock or label people with HIV. The study continued to show that support shown at first can make the person to live longer and adhering to medications well.

Juddy, Sohn and Collins (2016) in their study revealed that communities, families and children are faced with harsh memories caused by the HIV pandemic and besides all what the countries are faced with, youth are the future of tomorrow and if they are not empowered to take care of themselves despite what they are going through, the country will lose its future leaders. The study further revealed that harsh memories caused by knowing one’s status can cause one to delay starting with the medications due to denial and anxiety. Inzaule, Harmer, Kibyo, Tobias, Rinke de Wit, and Roura (2016) agreed with the above and said some ALWHIV lack support from families, peers and community, as they transit to working and living independently because are referred by their parents’ HIV status or even isolated and these pose bad memories in their lives. However, the study continued to share that when one is diagnosed HIV+ s/he should get a buddy person who will support him/her when starting the medications. Some years back in the 1990s when this pandemic started here in South Africa we knew that our former president Thabo Mbeki and Health Minister Manto Chabalala–Msimang also did not believe that HIV is real and questioned the efficacy of ARVs. This issue had a great impact in the minds of people where some people started to refuse to accept this crisis (Calvin, 2014).

4.4.1.4 Sub-Theme 1.4: An Explanation That Improvement of Physical Health Experienced is Associated with Adherence to Treatments

Research findings showed that since the arrival of ARVs, the life expectancy of many ALWHIV has changed. Their health has improved very much, especially those who are complying with their medications. Hospitalization has also reduced dramatically for those who were following their health programmes correctly. HIV is now controlled, like any other chronic diseases, in those who adhere to their medications without defaulting. Before adulthood, some parents and guardians set their watches and cell phones to ring or beep, reminding them of the time set to take medications.

The researcher as a clinician also concurred with the above as several lines of evidence suggest that health workers should be youth-friendly towards all youth, especially those with chronic diseases. They should design youth zones in their facilities with appropriate time for all youth to enjoy freely in their own time. This could also help ALWHIV to remain in care, hence, the defaulter rate will be lowered in the facility. The study continued to show that ALWHIV at this stage are starting to be more matured and responsible in reaching adult life. They need to be empowered with knowledge, especially adherence to treatment so that they can take informed decisions in future (Dennison, Banda and Denis, 2015).

*Participant 06 from Madombidzha said, 'unfortunately **my body was not taking medications well for a long time (virological failure**). They checked my blood every two months and I ended up changing my medications. The doctor told my aunt that he will switch me off from these medications and **try other anti-retroviral drugs.** Then I was given new medications. From there I started to be well and gain weight.'*

*Participant 20 from Makhuvha added, 'my grandmother always said **don't forget your appointment day and the remaining pills.** Pill counting was always done* *and when I come back I would give her everything, she is very strict so she makes sure I swallow the tablets every time and sometimes she gives me and says, Take, this is your life that your parents applied for, and we would laugh at each other.'*

Participant 25 from Makonde further responded, 'the doctor and nurses told me that my body is resisting to take the medications given on the first line regime which is for most people hence I'm taking the second line medications, not so many people are taking these medications. The doctor told me that ***my body needs to be checked regularly, therefore*** *I don't have to choose what I need about medications, whether I like it or not I have to drink the medications in time and without compromising.'*

*Participant 27 from Tshakhuma also confirmed, '****I must always drink these t****ablets/medications because they are my* ***life whether I like it or not, they have changed my life completely.*** *The way I suffered during my childhood before I started medications was too much.'*

Studies showed that the introduction of ART globally, including Africa, change the lives of many people who adhered and complied with their treatment. Mortality rates caused by HIV infections started to decrease gradually, though the infection rate was increasing very fast in both children and their parents (WHO, 2019). Wilson, Beima–Sofie, Mooran, Wagner, Mugo and Mutiti (2015) also attested to the above by revealing that though many adolescents are affected by the HIV pandemic, they still have a life to live and achieve their dreams. They should be fully empowered with knowledge in all spheres of life for them to be fully accountable to the decisions they take to prevent them from defaulting their medications as priority number one.

4.4.1.5 Sub-Theme 1.5: Health Education Provided by Nurses with Peers Experienced from Childhood to Date

Findings of the study showed that ALWHIV were knowledgeable with some of the topics concerning HIV and their health. Health care professionals were doing their work perfectly by empowering ALWHIV every time when they go for consultation. Transition should be managed with full participation of the adolescents themselves, according to Coleman, Tate, Gaddist, and White (2016), because changes at this time can be exceedingly perplexing, irritating, and disruptive. Older adolescents should be counselled on the plans to transit to adulthood clinic. The researcher observed that health personnel, whether nurses or counsellors and doctors, are doing a good job. Clients don't come and go without being educated on something else concerning their health. They encouraged and motivated clients, both children and adults, to be responsible in their health. This showed the researcher that most of health care workers are dedicated to their work and are user-friendly. Patients can also get the opportunity of asking questions and being clarified during the education sessions. The quotations below support the above:

Participants 01 from Makonde, Wayeni 02, Shayandima 03 and 04 alluded, 'when we arrive there, we go for vital signs check-up. Then comes the teaching sessions. Nurses grouped us, children together and parents together ***and teach us about the HIV related issues*** *like importance of taking medications, sexual behaviour, taking care of blood related issues.'*

Participants from Madombidzha 07, Vhurivhuri 10, Ntluri 17 and Makhuvha 19 further said, 'nurses will teach my mother few things related to the problem. If my blood results are failing or doing well, they would explain to my parents or granny. ***Then comes the teaching session*** *for us as children and also parents aside. Nurses taught us about the HIV-related issues like importance of taking medications, sexual behaviour, taking care of blood-related issues.'*

Adolescent participation is one of the criteria for high-quality adolescent-friendly health services, and adolescent peer support is essential to meeting this criteria. Peer support activities like group support, community support or facility-based activities can be useful and appreciated by many adolescents receiving care (WHO, 2019). They need to be given comprehensive education before they are sexually active. This will allow them to make more confident decisions regarding sexuality and relationships, such as condom use, adolescent pregnancy reduction, adherence clubs, and youth-friendly services given in a stigma-free atmosphere (Ruria, Mashaba, Kose, Woelke, Mangy and Matu, 2017). Madiba and Mokgatle (2016) added that the risk of ART to stop working is high (virological failure). Low educational attainment, inadequate HIV understanding, and a lack of HIV independence, according to the study, may all contribute to this.

4.4.2.1Sub-Theme 2: Challenges Experienced from Childhood to Adolescence

Some ALWHIV uttered a lot of challenges that they have experienced from childhood life until adolescent life. Most of them experienced the ups and downs concerning their health. Before the introduction of ART in their lives, they were always sick and hospitalized. Some, even after being put on ART, experienced serious challenges because their bodies were not responding to the medications taken (treatment failure). The findings of the study showed that these adolescents experience life differently which also depended considerably on the financial background of the family. The grant money of those living in well-to-do families were kept in the bank or post office, whereas those living in poverty were helping their families financially. Some adolescents were told that HIV is a family issue that should not be told to other people. As a result, adolescents are less likely to tell their peers or sexual partners about their sexual orientation. All they did was hide stuff and keep secrets about their personal lives. The following sub-themes (Table 4.4) arose from this theme:

4.4.2.1 Sub-Theme 2.1: Poor Understanding of the Disease Condition and Fear Lead to Lack of Disclosure by Parents and Guardians to ALWHIV and Other Children

Findings of the study revealed that poor understanding of the disease by parents together with lack of disclosure create fear, anger, and instability to the ALWHIV. Findings continued to show that parents felt ashamed and embarrassed when thinking of disclosing to their children. Findings of the study further revealed that the majority of parents were hesitant to tell their HIV+ status to their HIV-positive children or other siblings at home, partners, or family members. They thought they would share the status with other people. Concerning children, they thought they were not secretive, therefore, they would find out late during adolescent stage when they are sexually active. Direct quotes from participants:

Participant 02 of Wayeni said, 'in 2018 I ask my mother about my chronic pneumonia. At this time, I knew I had HIV. I read it on my file. Then she said pneumonia is a very dangerous condition keep on taking your pills. ***I told her she is lying to me I know I had AIDS mom, why are you lying to me. My other siblings are not drinking and is very boring and depressing.****'*

Parent 12 of Vhurivhuri shared, 'my first two children are boys and they are all taking ARVs, but for them to drink it's a fight, they want answers I don't have'. I took them to a social worker so that I disclose to them and that the social worker could help in counselling them, but they are not understanding. My husband said I should leave them they will grow and understand one day. Other siblings also don't know.'

4.4.2.3 Sub-theme 2.3 Lack of Disclosure of HIV+ status and how it was transmitted to them by parents and guardian viewed as a challenge

The research findings further showed that parents and guardians knew that HIV is a condition which needs to be dealt with in secret or in a confidential manner. Some had fear that if people or even relatives knew of their children's status they will bad-mouth them about it, gossip or even isolate the family. Some parents in the family only told the elder siblings who showed a sense of maturity and responsibility. Younger siblings were not told anything as they can just tell anybody. Some adolescents were told not to share their status with anyone because if they do so people will definitely conclude the status of the parents, hence, they saw it as hanging out your dirty laundry for people to see. The quotation below support this notion:

Participant 06 from Makhuva alluded, 'my parents told me that ***having this disease is secretive.*** *Don't share with anyone at school because they will mock me, harass and isolate me.'*

Participant 03 of Shayandima verbalized, 'sometimes adolescents become angry because they find the truth by outsiders that they are HIV+. ***Parents are very secretive, especially fathers.*** *If the government sets a standard time that from this age both parents if still alive should come together for disclosing to their children. And this should be enforced to the child until s/he understand the matter.'*

Tran. Phan, Latkin, Nguyen, Hocing, Ho and Ho (2019) shared that disclosure had stages. When a young person is in the stage of partial disclosure, there is frequently a stage of 'suspicion,' in which the young person suspects their sexual orientation but is denied the opportunity to have it confirmed, either because their parents or guardians refuse to disclose. Similar studies showed it could impact negatively on their adherence to medication or they can think they are not loved in the family, especially if there are other siblings who are not taking medications. Their research also revealed that health care personnel must have an essential instructional and supportive role in the lives of ALWHIV adolescents in order for them to remain in care. Parents and guardians may be anxious about disclosing or telling their children that they are HIV positive, and health care experts should help them overcome such fears (Tran, Phan, Latkin, Nguyen, Hocing, Ho and Ho, 2019).

According to a study, the majority of parents were hesitant to tell their HIV+ status to their HIV-positive children or other siblings at home, partners, or family members. They thought they would share the status with other people. Concerning children, they thought they were not secretive, therefore, they would find out late during adolescent stage when they are sexually active. Some parents did not believe that the disease was real when it started and that influenced many parents refusing voluntary counselling and testing when they visited the health facilities for consultation (Besana, Mafunda and Oliveras, 2017).

Gymfi, Okiyere, Enoch and Brempong (2017) also concurred with the above by revealing that most of people fear to disclose because the parent-child relationship as well as the emotional and psychological well-being of a person can also be affected. For example, an adolescent can run away from home or have suicidal ideation. Many parents had the perception that adolescents or children may see them as being irresponsible to have contracted the infection. Fatoki (2016) went on to say that it's critical to begin the disclosure process early and in a way that takes into account the child's emotional and cognitive maturity. It needs adjustment to learning that one is HIV positive, but late disclosure might have negative consequences for psychological functioning and other behavioural outcomes. Another important consideration is the potential harm to trust in the adolescent-parent connection at a time when help and guidance are most required.

Russell, Zalwango, Namukwaya, Katongole, Mahumuza, and Nalugya (2016) supported that many parents who are diagnosed with the disease don’t understand the importance of disclosure. They see it as something which can cause family feuds and disrespect from children. This might be the reason why disclosure is still challenging throughout the world. There are no strong rules which bind parents to disclose to each other or to their children in many countries.

The research findings revealed that some parents who have children taking medications and others who are not taking don’t experience the whole joy or happiness with their children. Often, they struggle to please the ones who are affected because they might think they are not loved in the family because of being sick. Hence, the unaffected might think the same, if they knew. But the root cause of all this is because they did not disclose their status. Again, the study revealed that parents felt ashamed and embarrassed when thinking of disclosing their status to their children. Some of them said it should be done by health workers in their presence and at a given stage during primary care and also when they transit to adult care.

Furthermore, some said they don’t have sufficient knowledge and the skills to sit down with their children and tell them the truth. The best thing is to tell lies as they will find out themselves as they grow. This issue of having two categories of children brought fear of some sort in the family. The problem of not disclosing posed a challenge to ALWHIV asking themselves questions or wanting to understand why or how HIV was transmitted to them? The research findings, again, revealed that many parents are afraid to disclose to one another as parents and even to their children. This makes them not to speak with one voice to their children.

Men shift the responsibility of disclosure to women and this caused them to tell lies to their children about their diagnosis, saying they will find out as they grow. They do this because they want to protect the family from stigma and family disorganization or disruption. During the childhood stage, parents don’t show any problems because children depend solely on them. When they become adolescents, they become more inquisitive and need answers for things done or to be done. Some ALWHIV showed that disclosure should be a family secret. Both feared to be isolated, to be called by names, and that their privacy will be invaded. The researcher noticed that there is still a great job to do for both parents and ALWHIV to deal with disclosure as it makes one to feel relieved and at peace. Again, one can find support, especially psychologically, because the mind is always stressed. The following quotation supports the above impressions:

Participant 06 of Madombidzha said 'disclosure is not easy, but my parents told me that I should continue taking my medications and do as nurses and doctors said. My father said to me' don't worry my boy one day you will grow up and understand.'

Because some ALWHIV knew the truth, but kept it secret because they feared confronting their parents. Furthermore, research findings indicated that fear to disclose was shown by both adolescents and their parents as something which is very disturbing and depressing, and because of the stigma attached to the disease.

4.4.2.2 Sub-Theme 2.2: Challenges Related to Sexual Life and Engaging in Activities That Might Endanger Their Physical Health

According to UNICEF (2017), everyone should have a comprehensive and correct understanding of HIV in order to create a positive connection with their medical condition if they have it. The study also revealed that it will require a thorough understanding of HIV as a virus, how it multiplies, and how it affects the immune system. A recent study suggests that knowledge will also mean understanding how medications work, how to keep themselves well, taking the control and responsibility over their own health (Madiba and Mokgatle, 2017). If adolescents are not taken care of they end up engaging in drug and substance abuse, sexual activities, and other criminal activities. The researcher found that some ALWHIV were not clear of what was happening at the time they were diagnosed with HIV. Some had no signs or symptoms of the sickness and others were just complaining of flu. They were afraid to confront their partners after knowing their status, especially women as they first blame or accuse their husbands for having the disease. They were also afraid that if they told their husbands they would be blamed for cheating and bringing the disease home. Some of them found out about their status when they were pregnant and decided not to tell their partners. The following participants alluded the following:

Participant 04 from Muila shared, 'I knew about my status when my girlfriend fell pregnant and told me that she tested positive at the clinic when going for ANC. At first, ***I was angry at her and told her she gave me the disease from her previous lovers.*** *She was my first girlfriend and I was not the first to her and I started abusing alcohol.'*

Participant 06 of Madombidzha said, 'at that time I was always demanding, need money to enjoy with friends during weekends. My mom reminded me that the doctor told me not to drink nor smoke. ***Then I answered don't worry I'm not dying here in a loud voice as if I'm fighting.****'*

According to research, the aforementioned revelation is not a one-time occurrence; discussions must continue and be changed as the child progresses through adolescence and early adulthood. This will pave the way to developing a good network of support in many spheres of life (WHO, 2018).

4.4.2.3 Sub-Theme 2.3: Lack of Disclosure of HIV+ Status and How It Was Transmitted to Them by Parents and Guardians Viewed as a Challenge

Adolescents and young adults benefit from solid support systems among family, friends, and partners in general, but it is especially significant in terms of adherence. Adolescents who receive insufficient support may feel alone and ostracized, which might affect their capacity and willingness to stick to ART and achieve life goals (Tran, Phan, Latkin, Nguyen, Hocing, Ho and Ho, 2019). Studies revealed that HIV disclosure may be crucial to HIV prevention and access to health care and treatment. Furthermore, failure to disclose one's HIV+ status may compromise risk reduction and exposes one's spouse or other sexual partners to infection if they are not already infected (Kiranga, Masibo and Musebe, 2018). According to research, HIV-related stigma is still prevalent, and its impacts are debilitating. People living with HIV are denied the opportunity to fully engage in their communities due to stigma and prejudice, which affects all aspects of their lives, including access to treatment and care, as well as employment opportunities (ILO, 2018). Seemingly, the WHO (2017) concurred that health care workers should strongly encourage and strengthen support for disclosure by children and ALWHIV. They demonstrated that disclosure is a vital component of good adherence because it creates a trusting and supportive atmosphere.

Anyone living with HIV may want assistance in deciding who they want to tell about their HIV status and how they will do so, as it may necessitate skills and confidence. UNICEF (2017), in their study, continued to show that stigma devalues people and bring shame and embarrassment. Some people feel punished or blamed and distracted them from the fact that everyone is at risk of getting the virus. The study further showed that stigma attached to HIV is associated with sex, diseases, and death, illegal or cultural taboo practices. Stigma may be harmful to individuals as it leads to guilty feelings or shame. The following quotation supports the above literature:

*Participant 14 from Muila said, ‘**you should have thought long ago that I will not remain a child always, one day I will grow, and the truth will come out.** He said, you can’t control me waya-waya, now I can think and do as I wish. I know that he is talking to me because I did not tell him the truth about being* HIV+, *but I try to give him all the support he needs. Since he started his bad behaviour our communication has been affected badly, even his progress at school is going down and I’m so fearful because he is bossy. Boys are not like girls; he can beat me if I don’t keep quiet.’*

Jonkelowitz, Ronald, Vujovick, and Wilkinson (2017) found that full disclosure allows people to join support groups with other people who have fully reported. As a result, joining support groups will provide ALWHIV with knowledge, support, and a sense of belonging. This also reduces the chance of adolescents asking difficult questions from their parents or guardians.

4.4.2.4 Sub-Theme 2.4: Lack of Disclosure of HIV+ Status to Sexual Partners at Adolescent Stage Viewed as a Challenge (Leading to Telling Lies)

The research findings showed that adolescents who behaved and communicated well with their parents/guardians were orphans or without parents. Those taking care of them found it easy to disclose the status as they were not their biological children, so they won't have questions to ask. Most were told their status very early in life and were very cooperative later in life. Unlike those with parents, some became rude and swore at their parents when they disclose to them. The quotation below supports these views:

*Participant 14 from Muila said, '**you should have thought long ago that I will not remain a child always, one day I will grow, and the truth will come out.** He said, you can't control me waya-waya, now I can think and do as I wish. I know that he is talking to me because I did not tell him the truth about being* HIV+*, but I try to give him all the support he needs. Since he started his bad behaviour our communication has been affected badly, even his progress at school is going down and I'm so fearful because he is bossy. Boys are not like girls; he can beat me if I don't keep quiet.'*

Developing strong support systems among family, friends and partners is valuable for adolescents and young adults generally, but plays an especially important role in strengthening adherence. Inadequate support can leave adolescents feeling isolated and excluded and can impact negatively on their ability and desire to adhere to ART and to achieve life goals (Tran, Phan, Latkin, Nguyen, Hocing, Ho and Ho, 2019). Studies revealed that HIV disclosure may be crucial to HIV prevention and access to health care and treatment. Furthermore, failure to disclose one's HIV+ status may compromise risk reduction and exposes one's spouse or other sexual partners to infection if they are not already infected (Kiranga, Masibo and Musebe, 2018). Research indicated that HIV-related stigma remains pervasive and its effects debilitating. Stigma and discrimination deny people living with HIV the right to fully participate in their communities, affecting all aspects of people's lives, including access to treatment and care, and access to work (ILO, 2018). Seemingly, the WHO (2017) concurred that health care workers should strongly encourage and strengthen support for disclosure by children and ALWHIV. They showed that disclosure is a critical component of successful adherence as it opens an environment of trust and support.

Children do not deal well when they are lied to, according to UNICEF (2017), particularly by persons in positions of trust, such as their parent/guardian, doctors, and health workers. When ALWHIV realized they were being deceived about their HIV status, they felt enraged and resentful. Further research found that in households when a child is unaware that they have HIV, there might be a lot of dread and anxiety. This can cause tension and problems in the connection between parents and their children. They may also be concerned that their children will find out by the time they are required to inform them, and that the children will become increasingly aware that something vital is being withheld from them (Tran, Phan, Latkin, Nguyen, Hocing, Ho and Ho, 2019).

In this study, the researcher noted that adolescents who found their true status by themselves were the ones who were angry and frustrated and wanted their parents to account. Some ALWHIV defaulted their medications for weeks in need of clarity from parents after they became aware of the true diagnosis or their status. Some value themselves as nothing and don't see the value of life anymore. But later they found peace in their lives to forgive their parents and continue with life. Theme 3: Description of Existing Support Experiences by ALWHIV and Their Parents

ALWHIV and their parents expressed immense gratitude for the support they had received from health care staff, according to the researcher. Some ALWHIV experienced a situation they referred to as difficult and traumatic during their primary care life before the initiation of ART. Their health was compromised as they were always sick and admitted to hospitals. These adolescents appreciated their family members like grannies, parents, guardians, health care workers and others. The findings of the study showed that even those whose parents or guardians believed in traditional healers or faith-based healing ended up in hospitals because they were not cured or did not feel better after consultation there. This was also the same to some of the parents or guardians before they started ART or after they were initiated on ART. They showed great appreciation to health care professionals who gave them unconditional love during counselling and when starting ART. Both ALWHIV and their parents showed great appreciation for the support that they have received from either parent, family members and even the health care professionals like nurses, doctors, counsellors and even their peers.

4.4.3 Sub-Theme 3: Description of existing support experiences by ALWHIV and their parents

The researcher found that ALWHIV and their parents showed a great appreciation for the support that they have received from the health care personnel. Some ALWHIV experienced a situation they referred to as difficult and traumatic during their primary care life before the initiation of ART. Their health was compromised as they were always sick and admitted to hospitals. These adolescents appreciated their family members like grannies, parents, guardians, health care workers and others. The findings of the study showed that even those whose parents or guardians believed in traditional healers or faith-based healing ended up in hospitals because they were not cured or did not feel better after consultation there. This was also the same to some of the parents or guardians before they started ART or after they were initiated on ART. They showed great appreciation to health care professionals who gave them unconditional love during counselling and when starting ART. Both ALWHIV and their parents showed great appreciation for the support that they have received from either parent, family members and even the health care professionals like nurses, doctors, counsellors and even their peers.

4.4.3.1Sub-Theme 3.1: The Support Received from Health Care Professionals by ALWHIV

The findings of the study continued on to say that parents and guardians should remember that rules must be adjusted and updated as the child grows older; rules for a child aged 10 will be different than rules for a child aged 16. Instead of a punitive home atmosphere, the focus should be on creating a helpful one. Parents or guardians, as well as other important family members, should be educated and involved in the affected child's adherence support. Moreover, another study added that support is very important to the ALWHIV and their parents or guardians because it plays a major role in them adhering to their medications (Madiba and Mokgatle, 2016).

The study's findings suggested that health professionals' assistance was critical for ALWHIV and their parents beginning with the HIV program at the primary level. Some ALWHIV and parents/guardians appreciated the friendliness of nurses, doctors and counsellors who cared for them when things were still bad in their lives. When they had lost hope not knowing if they will live or die. Findings further showed that ALWHIV opened up and started sharing their things with health care professionals because they build trust with them. Again, they felt that they were not judged nor humiliated as people. Many of the teenagers and their parents or guardians valued the support they received from the health care personnel, which encouraged them to continue taking their prescriptions. It also shows that these health care workers were user-friendly because both adolescents and the parents could ask questions or advice from them. Given support, especially by health care workers, assisted ALWHIV and their parents a lot because they were able to take instructions constructively if things were not going well like when the viral load did not suppress after investigations were done and it was the right thing to better their health. Participants direct quotations were:

*Participant 01 from Makonde said '**most of the health care professionals were friendly and supportive to us.** When I was sick and admitted to hospital nurses comforted me that I will become better and be able to go to school. Later I was* *discharged and* ***my grandmother*** *was given my medicines to drink at home and a paper to take me back following the written dates. That was me starting to take medications (ARVs) continuously at the hospital, but not knowing it is the antiretroviral. I remember the doctor who was discharging me was talking nicely telling me to always remember my medications.'*

Participant 10 from Vhurivhuri shared, 'as time goes on ***'****I was happy with my health and the* ***doctor and nurses were very happy encouraging me to adhere and comply to my medications*** *saying my weight has reached a point were any time soon the doctor will transfer me so I can go and receive my medications at the nearby clinic. At the clinic when entering in the consulting room, the nurses were* ***very friendly and supportive,*** *ask my tablets and count them, ask about my school issues, then she said next appointment you can come alone because now you are an adult and if you go to school on Saturday, come and collect medications on Sunday morning. That was so sweet for me to hear that there is someone who really cares for me.'*

Again, the findings of the study explained that some ALWHIV received support from their peers motivating one another to adhere and comply with their medications. The researcher noticed that these are real friends who are needed when one is going through a rough path of life. Giving advice, motivating to strive and hope to achieve the best is what is needed from a friend.

Research findings further stated that some adolescents were happy to gain friends who shared their experiences with them at the adherence clubs and that pose a very important role in their lives. They were relieved to know that they are not alone in this pandemic and some were relieved from the burden they carried for so long. A quotation in support of the above was:

Adolescent 11 from Tshakhuma said, 'one day I decided to share my status with a friend I got from the support group and I wanted to test her loyalty. I told her about my secret and show her my treatment. Then she was so surprised looking at me. Then she hugged me and whispered in my ears' I'm also like you. We *laughed, and from that day our friendship grew up.'*

Van Wyk and Davids (2019) defined adolescent support as a crucial aspect for adherence. Parents should be encouraged to involve adolescents in the development of regulations, according to Jonkelowitz, Ronald, Vujovick, and Wilkinson (2017). If the rules are broken, the parent/guardian and the adolescent must come to an agreement on the consequences.

4.4.3.2 Sub-Theme 3.2: The Support Received from Family Members and the Parents of ALWHIV, and from Peers Attending Sessions at the Clinic Appreciated

Findings of the study further identified that some of the ALWHIV received a lot of support from family members like their grandparents and nieces. They accompanied each other to the clinic, supported one another when doing their school work and on top of that seeing that the one who is to take medication do so at the right time. Findings of the study further revealed that peer support, played a vital role when facilitated or conducted by a group of people of the same condition, sharing ideas towards a common aim such as ALWHIV." This strategy is founded on the belief that sharing experiences with a group of peers who face the same issues as you does foster empathy and understanding. Peer support can facilitate the sharing of practical measures, such as adherence to medicine, as well as social experiences, such as notifying a spouse or friend about HIV. The support and the availability of peer support is also important. The direct quotation that supported the literature was:

*Adolescent 04 from Shayandima shared, '**when the phone beeps on the wall, I always knew it's time for my meds and if I'm with my** cousins or we are studying they will look at me or bring me water to take my tablets and life continues. Even today I'm with my cousin, he is waiting outside, and the support is great. All my cousins are geniuses at school, but they give me great support in my schoolwork, they don't get angry.'*

Adolescent 11 from Tshakhuma said, ‘one day ***I decided to share my status with a friend I got from the support group a****nd I wanted to test her loyalty. I told her about my secret and show her my treatment. Then she was so surprised looking at me. Then she hugs me and whispered in my ears’ I’m also like you. We laughed, and from that day our friendship grew up.’*

Parents or guardians and relevant family members should be oriented and involved in adherence support for the affected child. Moreover, a study added that support is very important to the ALWHIV and their parents or guardians because it plays a major role in them adhering to their medications (Madiba and Mokgatle, 2016).

However, UNICEF (2017) revealed in their study that adolescents are faced with many challenges, despite their HIV status, therefore, they need more support from family members, parents, or guardians to alleviate stress and anxiety. According to the WHO (2017), support mechanisms are an efficient and successful approach of identifying HIV-positive patients who will stay in care and benefit from treatment. Similarly, the study found that encouraging teenagers to take more control over their health and allowing them to be seen alone while keeping a relationship with their parents/guardians is critical. HIV-positive adolescent support groups provide a valuable opportunity for them to share information, reduce stigma, learn from others, and support one another.

4.4.3.4Sub-Theme 3.3: Health Education Content Provided to ALWHIV and Parents and the Importance Thereof

Findings of the study showed that the overall, participants both adolescents living with HIV and their parents/guardians expressed that when they go for their appointment in the health facilities they were given health information separately meaning that children, adolescents and parents/guardians their age group were considered, as were the levels of understanding and maturity. Everybody was given the information relevant to him/her related to HIV and other health matters. This showed the researcher that truly education is the key to these matters. Therefore, the health care workers know their work and are willing to provide quality care to all people they serve. The quotes confirm:

Participant 08 from Muila said, 'when I go for check-up, ***they first teach us about HIV related issues****, they check our vital signs like weight and temperatures. As time progresses they taught us hygiene, developmental stage and sexual transmitted infection and leaflets to can read at home. Sometimes they gave us packets of soft porridge. The nurse told me that my medications will be adjusted depending on my weight, if the weight increases the dose of medications increases and vice versa. I was also told that there will be time that I will be taken blood to check how medications are working in my body.'*

*Adolescent 15 from Ntluri responded, '****during weekends I could find some youth of my age group*** *at the clinic and nurses first gave us a talk in a room or outside under a tree and teach us on STIs, how to become well and comply with medications given to us and not to miss the appointment date. They told us that if we don't drink our medications our bodies will fail and the pills will be changed to another regimen.'*

Roberts (2018) showed that if people are empowered with knowledge about HIV/AIDS matters the number of those contracting the diseases will be reduced. If people lack the knowledge and understanding about the disease, they will be unable to reject the myth they hear about the disease and these could contribute in them not adhering to medications. The study continued to show that the way to overcome this fight is to strengthen accurate information giving to all the people, children and adults. As outlined in many studies that it is of utmost importance to empower adolescents and their parents or guardians on HIV-related issues so that they develop a sense of responsibility and accountability to their health and medications (UNAIDS, 2017).

4.4.3.4Sub-Theme 3.4: Medical and Health Instructions Provided by Nurses Viewed as Health Support Leading to Adherence to Treatment

The research found out that the instructions that were given to parents for the adolescents contributed to adherence of medications and improve their health status. The health workers demonstrated transparency and information giving to the clients because they use to explain what the results meant after taking blood and by that it shows to ALWHIV and their families was viewed as a continued support to promote quality of life. The research findings also showed that explanations done when the adolescent were there or when procedures were to be undertaken strengthened adherence and compliance to take their food and medications regularly. Like at primary level, medications were adjusted by weight gain or not weight reduction. The following were alluded directly by participants:

Participant 03 from Shayandima said, 'from that time it was check-up every month and there was a time when nurses would collect my blood to check if medications are working correctly. When the results came back, they update my grand mom if they are good or not. What interested me was that my viral load was becoming less and my weight and CD4 count was improving.

Participant 08 from Muila reported, 'at times they will take my blood saying that they want to see how medications are working. Unfortunately, my body was not taking medications ***well for a long time, checking my blood every two months and the doctor ended up changing my medications explaining to my aunt what the problem might be (virological failure).*** *The doctor told my aunt that he will switch me off from these medications and try something else. Then I was given new medications. From there I started to be well and gain weight.'*

Youth-friendly programs can be integrated into mainstream services, according to Roberts (2018). Adolescent-specific sessions and, if possible, separate youth-friendly areas in the clinic are beneficial. Effective adherence support must take place in the context of ALWHIV-specific interventions that are attentive to and responsive to their needs. Ruria, Mashaba, Kose, Woelke, Mangy and Matu

(2017) in their study showed that children should know that drug dosage can be decreased or increased with weight as they grow. The study further showed that they should be explained that at times their blood will be taken to check if medications are working well in their body or not. Therefore, education needs to be strengthened to improve the outcomes for these adolescents to promote the quality of life. According to UNAIDS (2017), young people encounter numerous hurdles to health care, including sexual and reproductive health and HIV services, which are exacerbated by the extra difficulties of being HIV positive. Barriers have a negative influence on service utilization, support, and treatment adherence, and, as a result, on health outcomes.

4.4.4 Theme 4: Knowledge Related to HIV+ Status and Disease Progression

HIV is a serious threat to the health of people all over the world. Lack of knowledge and understanding about the disease also impacts negatively on society. In the treatment of chronic diseases, self-management is critical. It occurs when a person is able to manage his or her own requirements, such as keeping appointment dates and taking medications as recommended, as a result of the disease. Those dealing with chronic illnesses, such as HIV, must adhere to efficient self-management. It has the potential to encourage the development of a healthy lifestyle and safer sexual behaviour, as well as improve medication adherence, anxiety reduction, and overall quality of life for ALWHIV and their parents (Zhang, Yin, Wang, Liu and Chen, 2021).

During the study, the researcher noticed that some parents were ignorant if not fearful during the early years of HIV. When classes or teachings about HIV were given in health institutions, they did not consider the matter seriously until late when the health of their children and themselves deteriorated. Some did not consider testing as important and thought HIV as a disease of some people. Table 4.4 present sub-themes of theme 4, and will be discussed individually.

4.4.4.1Sub-Theme 4.1: Lack versus Existence of Knowledge Related to the Disease from Childhood to Date

Research findings suggest that when HIV started over 20 years ago, testing was not mandatory for pregnant mothers. It was still voluntary. Every person had the right to test or not. According to the findings of the study, some parents who had children at the time had heard about HIV when they went to the clinic for a consultation. Some women shared that when they go for antenatal care, nurses and counsellors started by giving talks in the morning concerning HIV and testing, then allow them to go for testing in the counsellor’s room. Some refused and did not believe that HIV is real. They confirmed this as years went by when they (parents) and their children started to become seriously ill. This was backed up by the following quote:

Participant 01 from Makonde said ‘my mom said that after the funeral, one of the sister’s-in-law whom she had a good relationship with told her my father had AIDS long ago and he was not taking pills. But he never told her that, but because she was already in the advanced stage of pregnancy. She went to the clinic a week later asked the nurse to test her because refused while attending antenatal clinic.’

According to the World Health Organization (WHO), tremendous progress has been made in the prevention of HIV transmission from mother to child (PMTCT). Over the past 20 years, there has been a great reduction in the MTCT. However, problems are still found during breastfeeding (Dong, Guo, Gui, Liu, Yan, Feng and Liang, 2020). Meanwhile Tran, Phan and Nguyen (2019) agreed that while HIV & MTCT is declining, meeting the zero percent elimination target by 2030 remains a challenge, particularly in low-resource countries. According to WHO (2017), all pregnant women should be retested after receiving maternity and child health services. This will aid in the lowering of HIV-related MTCT as well as maternal and child mortality. Antenatal programmes or schedule states that if a woman tested HIV+ anytime during ANC, she should immediately start ART.

Studies showed that prevention of MTCT programmes should be given before conception, throughout pregnancy, labour and breastfeeding. Information should also include early diagnosis after birth which is no longer done within 4-6 weeks, but is done immediately after delivery. According to the study, 1.4 million HIV infections among children were averted between 2010 and 2018 (UNAIDS, 2017). Furthermore, studies explained that during their upbringing some ALWHIV showed lack of knowledge concerning their HIV+ status and how the disease was progressing. For some it was because parents did not tell them the real diagnosis, instead they were told of another medical condition or something else (UNAIDS, 2017). And, as children, they did not have much knowledge to ask why they were always taught matters related to HIV.

4.4.4.2 Sub-Theme 4.2: Lack versus Existence of Knowledge Related to the Importance of Adherence to Treatment and Its Future Implications

Findings of the study indicated that as ALWHIV were continuing with their health care process, some realized they might be suffering from HIV, when doctors explained to their parents or guardians that the body is not responding well to medications. Some started to doubt their status as blood specimens were taken more frequently from them. But, above all, health workers explained everything they do to the children and how medications are working every time they took blood and the results were back during follow-up visits. The quotations below affirm this:

Participant 07 from Madombidzha alluded that 'years come and pass by as I was growing. Medications were also adjusted and changed on the way. When I progressed to secondary school. ***I started to have a problem the day nurses came and teach about HIV/AIDS and the importance of taking medications.*** *I fought with other boys and they tease me swearing about my mother who is* HIV+ *and that I might as well have the disease. That day I was so angry at my mother thinking that I will never ever go to school.'*

*Participant 08 from Muila shared that ‘**it was like my mother tested HIV+ before she died,** because I remember she used to come and see me in the ward sometimes. Early morning the other day nurses came to my bed saying they will come and take me to the other room for collection of blood.’*

Roberts (2018) indicated that being HIV+ does not mean that adolescents should be denied the right to information. ALWHIV deserve to be explained about every step taken or done to their bodies and the results thereof, e.g., analysis of blood specimens. Knowing how the disease is progressing makes them to adhere with the programmes concerning their health. WHO (2017) corroborated that patients have the right to know about the care they receive. Thus, people should be given the information concerning their disease progression because this helps in adherence to medications. The study further showed that if adolescents knew about how medications are working it also would have helped them in decision-making and joining the support groups or adherence clubs

4.4.4.3 Sub-Theme 4.3: Lack versus Existence of Knowledge Related to the Indications of ART Disclosed

Furthermore, the study's findings revealed that ALWHIV were being empowered with knowledge about medication adherence and its implications at the primary care level. Whatever procedure needed to be done, it was explained thoroughly to the parents and to the adolescents themselves. Furthermore, during primary care most of the ALWHIV complied very well with the instructions from the health care professionals. The following quotations confirm the findings:

*Participant 02 from Wayeni shared, ‘Mom took me to my granny’s house. She said, my son**, please forgive me your father and I are HIV+**. I was afraid to talk all these years. My boy please forgive me I was just protecting you.’*

*Participant 04 from Shayandima said, ‘**the doctor said that my weight will determine how much medication am I supposed to take.** Life has to continue* *like that. Some days I had to miss classes because blood is only taken during the week in our clinic by those who collect it.'*

Participant 19 from Makhuva reported, 'at the hospital nurses told me that if I don't listen to my mom and ***take medications in time, my body will go the other way round and resist medications****. They told me that as time goes on the dose of medications will be adjusted following my weight gain or weight loss.'*

The findings of the study also showed that some parents or guardians lacked knowledge regarding HIV. Some believed in doing things culturally or traditionally. Others did not even believe that HIV matters are real when they hear health professionals teaching in health care facilities. This resulted in them seeking medical help very late for their children and even themselves, also denying the opportunity to be tested due to lack of understanding, as explained below:

Participant 05 from Shayandima uttered, 'I was taken to the sangoma's, prophets, traditional healer and doctors, but all in vain. Until you were admitted, and I consented that I be taken blood to check HIV. The results came back positive. ***Then the doctor started giving me the anti-retroviral medications and my health started to improve****.'*

Participant 06 from Madombidzha shared, 'after doing many tests at the hospital, the doctor told her that I'm HIV+. This means that they are starting with antiretroviral medications. Unfortunately, my body was not taking medications well for a long time, checking my blood every two months and I ended up changing my medications. The doctor told my aunt that he will switch me off from these medications and try some ARVs. Then I was given new medications. From there I started to be well and gained weight.'

The confusion in some ALWHIV was that parents or guardians did not tell them about their HIV+ status. Some were told of the other medical diagnoses. Only few whose parents died knew exactly what was happening to them.

Ruria, Mashaba, Kose, Woelke, Mangy and Matu (2017) in their study showed that children should know that drug dosage can be decreased or increased with weight as they grow. The study further showed that they should be explained that at times their blood will be taken to check if medications are working well in their body or not. Therefore, education needs to be strengthened to improve the outcomes for these adolescents to promote the quality of life. While UNAIDS (2017) attested that young people face several barriers in accessing health care, especially sexual and reproductive health and HIV services, and these barriers are exacerbated by the additional complexities of being HIV+. Barriers affect service utilization, support, adherence to treatment, and, ultimately, have a detrimental impact on health outcomes.

4.4.4.4 Sub-Theme 4.4: Lack of Knowledge Related to HIV Status Blamed on Parents and Guardians Who Did Not Disclose

Research findings revealed that some guardians who had custody of these children did not know what the children were suffering from. Due to confidentiality and the stigma attached to HIV many parents, women and men, died without disclosing to their close family members. Findings of the study further showed that some of the ALWHIV blamed their parents or guardians who failed to disclose the HIV status to them. To some parents, they did that to protect the image of their children and family not with the intention to hurt their children. The following quotations supported these notions:

Participant 15 from Ntluri shared, 'the nurse pricked me for the first time and checked the results and then for the second time, then she showed me the results and the two cassettes were having two pink lines saying I'm HIV+. I was so sad, but hiding it from my ***friends, I asked her to show me the medications I should get if she is having. Yooh I was so shocked, some are the same as the ones I'm drinking****, then she asked me if I'm ready to tell anyone and I said not yet as I was so scared. Then she said I should come on Sunday afternoon so that she* *can take the blood for checking how my body is functioning.* ***This was my worst experience ever.*** *At home it was difficult to face my mom and I lived my life as usual, fortunately I was taking my medications from the hospital.'*

Participant 26 from Makhuva shared 'my mom told me that son, I was trying to protect you and my family for not telling you the truth'. I don't hate you my son but ***our image is important.***

*Participant 11 from Tshakhuma verbalized, '****my grand mom said the medications am taking are the vitamins to boost the body as I always suffer from pneumonia.*** *Therefore, I should take them daily, but by that time I saw myself much better and not having flu for the past year. Then years pass by and I was drinking my solutions medications well. Then as my weight increased, because I was weighed monthly as I go for check-up, nurses said my weight is becoming good and soon I will be given pills. Then, I asked the nurse if the pills are also vitamins to boost my body from pneumonia. But she looked at my granny and continued writing.'*

According to WHO (2018), disclosure occurs when a child is helped through the process of transitioning from non-disclosure to health-promoting disclosure within the framework of children's rights. Disclosure of HIV+ status at early childhood promote knowledge and quality of life soon whereas non-disclosure may lead to self-discovery late in life which might be very painful to ALWHIV. Findings of the study revealed that ALWHIV who did not know of their status early blamed parents or guardians for failure to disclose. According to studies, child and adolescent disclosure is the process by which a youngster learns about his or her status. It is a method of gradually providing children with age-appropriate information about their disease, leading to complete disclosure after the child has reached full cognitive and emotional development. The following are disclosure classifications based on the levels mentioned by (WHO, 2018).

4.4.4.5 Sub-Theme 4.5: Lack versus Existence of Knowledge Related to Mother-to-Child Transmission

Findings of the study revealed that some of the ALWHIV showed that illiteracy and ignorance from their parents contributed in them getting the disease. Some ALWHIV verbalized that their parents ignored the health care professionals when they told people to come forth for testing. But because of their little knowledge and faithfulness to their spouse they refuse to be tested. The quotation below supports the above:

*Participant 03 from Shayandima said, '**granny said I was seven months old when my mom died**. Two years later I became very sick. Granny asked the nurses that I be tested for HIV. Results came back being **positive meaning that I was born with the virus.** That's how I knew about my status. From there I'm drinking ARVs till to date.'*

Participant 20 from Muila said 'I loved your father too much and respected him, not knowing that because I'm not learned he can give me the disease and keep this matter secret.'

WHO (2017) has achieved a great success word-wide in the prevention of MTCT. There has been a significant decrease in the prevention of mother-to-child transmission over the last 20 years. The issues, however, are still present throughout breastfeeding (Dong, Guo, Gui, Liu, Yan, Feng and Liang, 2020). Meanwhile,Tran, Phan, Ton and Nguyen (2019) agreed that while HIV MTCT is declining, meeting the zero percent elimination target by 2030 remains a challenge, particularly in low-resource countries.

According to WHO (2017), all pregnant women should be retested after receiving maternity and child health services. This will aid in the lowering of HIV MTCT, as well as maternal and child mortality. Antenatal programmes or schedule state that if a woman tested HIV+ anytime during ANC, she should immediately start ART. Again, studies showed that prevention of MTCT programmes should be given before conception, throughout pregnancy, labour and breastfeeding. Information should also include early diagnosis after birth which is no longer done within 4-6 weeks, but is done immediately after delivery. The study continued to indicate that between 2010 and 2018 about 1.4 million HIV infections among children were prevented (UNAIDS, 2017).

4.4.4.6 Sub-Theme 4.6: Disclosure of HIV+ Status at Childhood Promotes Knowledge Which Assisted in Promoting Quality of Life

The study's findings revealed that ALWHIV who were informed of their status at a young age fared well in life. They got their way of accepting and dealing with grief. Then they develop a trusting relationship with their parents or guardians. This also improved their relationship within the families promoting the quality of their health and life, unlike ALWHIV to whom their parents/guardians did not disclose. The quotation below confirmed the above:

*Participant 02 from Wayeni shared, '**don't worry my boy you will drink medications and be strong.** Look at me, my sugar diabetes and my blood pressure are controlled because I'm taking my pills. Then I told my grannies that even my mom should go to the clinic and register so we can drink together, and she agreed. Now our relationship is good and I'm taking my medications well.'*

Disclosure of HIV status remain one of the major challenges to the effectiveness of the prevention of MTCT (Jones, Richwood, & Taggart, 2019; Roberts, 2018. Coleman, Tate, Gaddist, and White (2016) showed that adolescents experienced self-blame and with suicidal thoughts, some presented with anger and denial and started swearing at their parents, disrespecting them because of lack of knowledge and understanding of the disease from childhood. Furthermore, the study showed that many of the ALWHIV became more hurtful when they found out by themselves about their true status later in life.

According to studies, child and teenage disclosure is a long process in which a kid gains age-appropriate awareness of his or her status, culminating in full disclosure when the child has reached full cognitive and emotional development. The study found that there are different levels of disclosure. Health-promoting disclosure occurs when an adolescent is given the opportunity to learn everything there is to know about an illness in a supportive environment, allowing them to take charge of their own health and improve it (WHO, 2018).

4.4.5 Theme 5: Suggestions Made to Promote Quality of Life by ALWHIV

Findings of the study showed that ALWHIV made suggestions during data collection. Some wished that life could be better if the government could build community centres where they can go and learn different things, including activities and games. Some ALWHIV suggested that support groups or adherence clubs should be moved from the clinics to the communities. Nurses could visit the support centres monthly for the purpose of empowering them with knowledge and giving them, their medications and they can do exercises. However, findings of the study further indicated that some ALWHIV made a plea for the health professionals to move support groups from the clinics to the communities. This can attract many ALWHIV to come and register or enrol in HIV programmes. Health professionals can have schedules to meet us once a month. The next sections explore the sub-themes that arose from this subject (Table 4.4).The quotation below supports the aforementioned:

Participant 18 from Makhuva shared, ‘My transition was easy because I knew from an early age that I had HIV and there is no cure, I should drink my medications daily to boost the soldiers of my body because they are weak and if I fail to do that I will get sick and die.’

Bailley, et al, (2017) showed that adolescents are the cream and future of tomorrow. They cannot be discriminated of their medical conditions, but should be supported by every person living in the country. As such the government is also included. Therefore the ALWHIV are correct in saying that community centres are needed for our adolescents.

4.4.51Sub-Theme 5.1: A Request for Communities to Support ALWHIV

Findings of the study further revealed that some adolescents requested communities to support them in all spheres of life. Communities should also show support to these children as others know their parents died or are having HIV or are living with HIV. They should not discriminate them or call them by names. Findings of the study continued to show that ALWHIV had a plea to raise community awareness on discrimination so they can be accommodated and supported in the community.

*Participant 19 from Makhuva alluded, '****I knew about my status long time ago because people in the village call us by names*** *and the social workers when they visit our house they usually reprimand us not to steal from people because we don't have parents. Though I defaulted many times, the day when it's possible to reach the clinic we used to go and collect our medications.* ***I'm pleading with the community at large to accept us and not discriminate.****'*

Participant 10 from Vhurivhuri shared, 'the only burden that I get is that sometimes the food they buy doesn't last for the month before they get money. ***'If the government can give us food parcels it can help*** *because at the social workers people are many and they don't always get, only once in a while, and money to carry to school is also a problem. The nurses at the clinic are very friendly, they sometimes give us soft porridge and leftovers like bread and juice to eat.'*

Peer support improves the responsiveness, acceptability, and relevance of service providers, programs, and services. They encourage ALWHIV to get medical help and stay involved in HIV therapy. Support groups, peer-to-peer counselling, and treatment buddy programs are examples of peer support activities. Adolescents' ALWHIV linkage, adherence, viral suppression, retention, and psychological well-being can all benefit from peer support (who, 2017).

4.4.5.2Sub-Theme 5.2: Request for Support from Government to Provide Basic Needs to ALWHIV

Findings of the study further showed that some ALWHIV suggested that if the government could supplement them with monthly food packages life would be easy especially those from the needy families. They can go there and be empowered with information and be guided on how to live better. Then provided with something to eat later. Some suggested that most families are poor and depend on grant money for a living. They found the money being too little for their daily living, so if they can be given food parcels to add to the little money they get. The following quotations support the above:

Participant 17 from Ntluri said, 'socially I'm good, not naughty, I like soccer and cooking. I think I will be a chef if not a police. I don't go to church, but believe in God, so that's that. If the government can find a way that all children with chronic conditions can ***meet in community centres and have fun or do activities together, sharing about their life experiences and be given guidance by those who have overcome it was going to be better.****'*

*Participant 22 from Wayeni confirmed, '****other children attend activities at the clinic once a month and are given information regarding sexual reproductive issues****. But I can't because I have a lot of work to do at home, maybe after my father gets an aunty to help us it will be better, however, sometimes our grannies come over during weekends and be with us and go back on Mondays as they also take care of their grandchildren they stay with.'*

The (WHO, 2017; UNICEF, 2016) recommended that no child should sleep without having in the whole world. This is millennium development goal 4 which the world Heal Organization is fighting for zero hunger all over the world.

4.4.5.3 Sub-Theme 5.3: Request for Initiation of Support Groups with Consistently Scheduled Meetings

Findings of the study revealed that some ALWHIV had wished that health care professionals could move support classes or support groups to the communities and be done over weekends. They showed that health care professionals could visit them once a month and give them education and their medications. This could attract others to come and join them. Findings further revealed that some ALWHIV value the support groups convened by heath care professionals when they go for collection of medications. This was also appreciated by the parents. They find it helpful because they are given education important for their daily living including sexual reproductive health matters. The statement confirm:

Participant 20 from Makhuva verbalized, 'I think ***the government can create something outside the clinics where youth can go and do some activities*** *including healthy talks about life or career guidance because we don't have community centres in the villages, they are found in cities. I think we would get a chance to know ourselves there and what we need in life going further. Sports is also something that could help us as youth to divert from drugs, bashes/gigs and alcohol because that's where most teenagers get caught when they are drunk and have unnecessary sex with people they are not in love with.'*

Vorming (2017), in the empowerment model, showed that adolescents or people should be empowered and motivated to take charge of their care. Therefore, if the facility had enough staff, and with the assistance of community-based cadres support groups can be moved to the communities for those who are stable.

4.4.5.4Sub-Theme 5.4: A Suggestion That Parents Be Held Responsible for Not Disclosing HIV+ Status to Their Adolescents

Findings from the study showed that some ALWHIV voiced that parents/ guardians who failed to disclose the true status to their children should be held responsible for their lies. Some further showed that if they were told their right status from the beginning, they would have accepted it better and find their way of dealing with the pressure at an early stage, than finding out when they are grown up. Some ALWHIV further showed that finding out their true status by themselves make them feel angry and hated their parents to the extent that they rebel towards them. Findings of the study also indicated that some adolescents suggested that the Department of Health should set time when parents should disclose to their children without compromising. If possible, it should be by both parents. The quotation below supports the above suggestion:

*Participant 23 from Muila said, '**I wish parents could be held responsible for not telling the truth** because many don't know their HIV status or are playing dump to please their parents while they knew themselves already.'*

*Participant 07 from Makonde said 'I knew about my true status after the nurses who came to our school teaching about sexual transmitted infections invited us to come for HIV test at the clinic.' That day I was so shocked **to find out that the pills am taking for a long time was for HIV.***

According to research, disclosure is the process of informing a person of their HIV-positive diagnosis at a suitable moment when they have attained a sufficient level of emotional and cognitive maturity. The procedure through which an HIV-positive person informs others of their status is known as onward disclosure. The young person's ability to come to grips with and grasp what it means to live with HIV is aided by disclosure (Jonkelowitz, Ronald, Vujovick and Wilkinson, 2017).

4.5 Presentation of Findings from Parents/Guardians of ALWHIV

The researcher interviewed 12 parents and 6 guardians who were staying with

ALWHIV. As they shared their views concerning ALWHIV, the issues that came up were related to HIV, stigma, burdens, and disclosure. Some of the issues and challenges raised were similar to those cited by adolescents. Below is the profile and findings supported by the literature.

4.5.1 Demographic Profile of Parents/Guardians Who Are Staying with ALWHIV

Table 4.5 presents the demographic profile of parents/guardians who are staying with ALWHIV.

4.5.2 Presentation and Discussion of Themes and Sub-Themes Reflecting the Findings of the Parents/Guardians

Data was collected from 18 parents/guardians of ALWHIV.

Table 4.5: Profile of parents/guardians who are staying with ALWHIV

Indicators	Category (Variable)	Number
Parental status	Parent	12
	Guardian	6
Gender	Male	3
	Female	15
Marital status	Married	10
	Single	4
	Widow	4
Ethnicity	Venda	16
	Tsonga	2
	Sotho	0
Employment status	Employed	10
	Unemployed	8
Year HIV diagnosed	Between 2000-2010	10
	After 2010	8
Disclosure of status	Yes	7
	No	11

Years on ART	Less than 5 years	1
	Above 6 years	12
	Not on ART	5
Regimen prescribed	Dolutegravir (TLD)/FDC	11
	Zidovine+Lamivudine+Lopinavir	2
	Not on ART	5

Table 4.6: Themes and sub-themes as reflections of parents/guardians

Themes	Sub-Themes
1. Description of the experiences of parents and guardians of ALWHIV	1.1 Experiences during the initial discovery of HIV+ which was traumatic resulting in feelings of fear
	1.2 Paradoxical experiences of being diagnosed HIV+ which caused suffering at multiple levels of their lives with their children
	1.3 Adherence to treatment leads to a feeling of becoming healthier when days progress
	1.4 Difficulty of disclosing HIV+ status results in feelings of embarrassment and shame
	1.5 Health-seeking behaviour results from fear of testing for HIV and being known by nurses and family
2. Challenges experienced from childhood to adolescence period	2.1 Having one HIV+ child amongst other children is traumatic leading to feelings of guilt
	2.2 Fear of informing other children, partners, and family members about one's HIV status
	2.3 Challenges related to understanding of how HIV was transmitted as they were honest to partners
	2.4 Nurses explanation of every situation encountered by parents and their families viewed as continued support to promote quality of life
3. Description of existing support experiences by ALWHIV and their parents	3.1 The support received from nurses and other health professionals through counselling appreciated
	3.2 Health Education content provided to parents and the importance thereof

Continued/…

Table 4.6: Themes and sub-themes as reflections of parents/guardians (*continued*)

Themes	Sub-Themes
4. Suggestions made to promote quality of life by parents	4.1 A request that nurses assist mothers and guardians to disclose HIV+ status to their children 4.2 Request for initiation of support groups with consistent scheduled meetings (including counselling) 4.3 A suggestion that group counselling be initiated so that adherence could be encouraged 4.4 A suggestion for couple counselling so that care to ALWHIV can be done by all parents

4.5.2.1 Theme 1: Description of the Experiences of Parents and Guardians of Adolescents Living with HIV

Many parents today are living in secrecy with their love partners hiding their status and failing to disclose even to their children. Tran, Phan, Latkin, Nguyen, Hocing, HO and HO (2019) showed that people react differently when they hear shocking or bad news in life. Because HIV is a disease which has a stigma attached to it and that people had another thinking that if a person is affected, it means a person is a prostitute or had multiple sex partners. This was one reason why in South Africa, even today, HIV and confidentiality work hand in glove. Table 4.6 shows the sub-themes that arose under this theme.

4.5.1.1Sub-Theme 1.1: Experiences during the Initial Discovery of HIV+ which was Traumatic Resulting in Feelings of Fear

The findings of the study revealed that health care workers should strongly give support to all people who tested HIV+ to keep them in care as much as possible. Furthermore results showed that some parents were very shocked to hear that they have HIV. Some were frightened and scared of their husbands, while others were frustrated and not knowing how they will tell their partners. Some question the faithfulness and loyalty and the love shown to them by spouses, hence, robbed them of thinking that one day they might get HIV. The study continued to reflect that women showed a big responsibility of going back to the health professionals to seek professional counselling and advises.

This was confirmed by the following quotations: *Parent 01 from Makonde, 'I realized and found out my status in 2003 after giving birth to my second born girl. I was afraid to test during ANC when the counsellor and nurses gave us talks in the morning.* ***I did not think of it coming to me because I'm faithful and loyal to my husband.*** *In my church there are prophets who can tell you if something is not right with you, and I even consulted when I was pregnant and they told me the baby is fine and will be delivered normally.'*

Parent 02 from Shayandima said, 'I was so shocked ***I asked how I am going to breastfeed or if I should give the child a bottle.*** *Our family is an extended one, people will ask me why I am not breastfeeding if I give formula to the child. I was still in shock and refused to be given those milk (formula) for the baby and the medication and even my tablets.'*

WHO (2018) stated that when an individual is told of the shocking news, their psychological, physical and emotional being becomes affected. Some people can start to be rude, depressed and engage themselves in things which they were not doing before like using substances like dagga and alcohol. And socially they can be withdrawn from friends.

4.5.1.2Sub-Theme 1.2: Paradoxical Experiences of Being Diagnosed HIV+ Which Caused Suffering at Multiple Levels of Their Lives with Their Children

Findings of the study revealed that parents / guardians experienced or went through a lot of pressure after they knew of being HIV positive status. Some of the parents were very frustrated and depressed knowing that they were very faithful to their spouses by being loyal to their marriages. Furthermore the study showed that those mothers who were breast feeding, were afraid to disclose in the family so that they can stop from breastfeeding at the stipulated time and they continue to breastfeed their babies. Findings of the study further reflected that parents suffered psychologically when their children stared to be ill. The quote below support that:

Parent 09 from Vhurivhuri said, 'It is hard to have other children not taking medications and others taking, especially if its HIV, it's like the sick one is not loved or is discriminated amongst other children and as a parent ***I can't gather my kids and give them a reason why this one is HIV+ and others not my mind is very disturbed, hence this children should give support to the one who is sick.****'*

Parent 17 from Muila said 'I was ***very ashamed and depressed*** *when I knew that I disobeyed the command of the nurse, as I was told that for the baby to be saved from the virus, I should stop breastfeeding at six months. Though the formula was for free how could I explain that to my husband and the in- laws.*

Parent 12 from Ntluri shared', the mother to this child is no more, I did not know what the child was suffering from. I ***lost lot of money going up and down,*** *from one traditional healer to the other without any cure, until one night when she had fever and shivering then we rushed him to hospital and was admitted. He spend almost a month, thus where he was diagnosed with HIV and started with medications.*

In their study, Nyblade, Srini Vasan, Mazur, Raj *et al.* (2018) attested that the type of burden people may come across differ according to how the individual perceives things after being diagnosed with HIV. Furthermore, the study explained that some people can be withdrawn or be depressed depending on how serious the matters are in their lives. They further showed that the behaviour of individuals can determine the pain that one can come across.

Financial constraints when one is diagnosed HIV+ becomes a challenge and a burden in many people, especially in the first few months if one is not responding to medications. More especially, because many people are poverty stricken because unemployment is also high. Many people in our society depend on social grants, including that for the children. Hospitalization becomes a priority (Maria, Rosario and Maria, 2017).

Roberts (2018) explained that individuals perceive pain differently depending on the seriousness of the problem. Furthermore, some can be in denial for weeks and then recover. Some can start blaming themselves or others and later they may realize and display forgiveness and acceptance of the problem and seek for solutions.

4.5.2.3 Sub-Theme 1.3: Adherence to Treatment Leads to a Feeling of Becoming Healthier When Days Progress

The study findings showed that when people with common problems sit together and share their experiences it helps in finding a way forward or to move on because life is not static. Research findings further showed that all the instructions given by health professionals like nurses were appreciated by parents throughout. Parents took a dignified initiative as they want their children's health and theirs to improve. All these because some knew that medications which they started using failed either from the traditional doctors or faith-based religions. Every instruction given and adhered to lead to better health and quality of life as days progresses.

The quotations supporting this sub-theme were:

Parent 04 of Tshakhuma shred that 'I appreciated ***nurses' explanation of the care provided to us at all levels.*** *As days progressed, going for appointments, I noticed change in my life, gaining weight, diarrhoea stopped and my appetite came back.' Inside my heart I confessed that truly HIV is alive. The majority of the individuals saw a significant difference in their life within a few weeks of starting ARVs. This was noticed by many parents/guardians when they compared their heath and even that of their children.* ***There was great improvement in my health within few months.****'*

Parent 11 of Makonde said, 'during transition to adulthood the counsellor supported us greatly, and she talked about the importance of drinking medications ***and following everything the nurses and doctors might say.****'*

WHO (2017) showed that support groups or adherence clubs are very critical, because that is where patients can quickly find themselves seeing that they are not alone when diagnosed with HIV.

4.5.2.4Sub-theme 1.4: Difficulty of Disclosing HIV+ Status Results in Feelings of Embarrassment and Shame

Findings of the study showed that since the beginning of the HIV pandemic until today people feel ashamed and embarrassed when they tested HIV+. People judge and blame themselves starting to ask the 'why' questions. The research findings showed that many parents or guardians have difficulties in disclosing their status to their closest relatives, children or friends. However, these were indicated by many parents who viewed that they did not disclose their status to their children during childhood. The findings further revealed that some parents as alluded above were affected at various levels, including their physical well-being, psychologically, financially, socially, and spiritually. The interaction with their children and family members were also affected. Moreover, findings indicated that some boosted themselves that they can't get the virus because together with their partners they are faithful in their marriages. Some even think that promiscuous people are the ones getting HIV. While others thought HIV is found only by having unprotected sex as the only mode of transmission. Some thought the mode of transmission for HIV is only through sex. For them it was like HIV is for certain type of people and not for all human beings. The quotes support:

Parent 15 of Wayeni alluded, 'I went to the doctor after the passing of my wife, I ***knew I might have the disease because my life was a mess****. The doctor gave me counselling and offered a test. Within few minutes the results showed up and were positive. He suggested that I went to the public clinic to start medication because I can't afford to take at the surgery or private clinic. I felt guilty and shame because my wife loved and respected me a lot, now she is dead because of me.*

Parent 02 of Shayandima said' the day I was told about my HIV positive at the clinic, I told the nurse very bad things and was very angry'. I called my boss the following day to say I won't come to work I'm sick, then I went to consult at the private doctor, the results were positive again. I visited 5 different places and got ***same results but never took medications nor tell anyone until I was seriously ill.***

Disclosure of HIV+ results is also very difficult in most people across the world in all age categories (Fatoki, 2016, WHO, 2016). Therefore, health-seeking behaviours will lead to fear of being tested and be known by people and not necessarily nurses because they work within confidentiality rules

4.5.2.5 Sub-Theme 1.5: Health-Seeking Behavior Results from Fear of Testing for HIV and Being Known by Nurses and Family

Findings of the study revealed that though some parents delay starting ARVs because of their values and beliefs (culture) they end up seeking modern medications at the hospitals or clinics very late. Some of the parents, like what most Africans do when they are sick, they start their consultation somewhere and finished with modern or Western medicine. Because they heard of HIV several times when the information was cascaded at the clinics or hospitals, they start by seeking traditional help when they thought their health was not okay or having symptoms like diarrhoea, loss of weight or cough. Findings further reflected that they don't become better with the medications given, and some proceed to the spiritual faith-based religions. As days progressed and the sickness continued, they stayed at home in fear of going to the hospital or clinic to be diagnosed medically. At a later stage they rush to medical centres as emergencies. Few weeks after the diagnosis of HIV and the initiation of ARVs most of the people regain their strength and their health improves while some could die of delay. The following statements supported the above:

*Parent 01 from Makonde said, '**I was afraid to test during ANC when the counsellor and nurses gave us talks in the morning.** Before I was discharged the nurse gave me counselling and asked to do a test. I was so excited with my baby girl then I agreed to test. Before the time elapsed, I took the cassette and looked at it and I was very shocked to see the two lines.'*

*Participant 17 from Ntluri said, 'people living with HIV has many challenges in life mostly because **this disease is having a stigma attached to it.** Everything you do you have to hide it to protect yourself, family, and everyone around you.'*

Furthermore, adolescents were told that HIV is a family matter one cannot even share the status with another person. Study revealed that some parents were very fearful to seek medical help for testing because they dreaded to be HIV+. Some feared that nurses and their families or friends could predict their status when they saw them in the queue and know their status.

Russel, et al, 2016 and Bailey, et al, 2017 showed that people are affected with fear differently. Some people could die from fear of unknown and not be killed of the condition they are suffering from. Kiranga, Masibo, et al, 2018, attest with the above showing that testing for HIV positive is very fearful to most of the people because of the heavy weight it carries, from the one performing a test to those living around you if it happened that they could hear the news.

4.5.3 Theme 2: Challenges Experienced from Childhood to Adolescence Period

Findings of the study showed that parents and guardians had various challenges when their children transitioned from adolescence to adulthood. Some of the parents were very happy when their adolescent children transitioned to adulthood care. Some were happy that their children will collect medications alone because they will no longer accompany them. Hence, others felt relieved from transport problems, especially those who started their programme at the hospital when their children were very young. Findings also showed that some parents knew that responsibility and accountability had now increased because their children would be faced with lot of challenges in life like peer pressure in sexual reproductive matters.

Findings further revealed that the biggest challenge some parents had was that they did not disclose their true status to their children. They were afraid that one day their children will find out their true status. When children were still in the primary level, they were told other medical diagnoses and were pleased about it. Findings of the study continued to reflect that some parents had the challenge that their children will start dating, and what if they impregnate the other one and refuse. Some feared that children may be raped. Parents were faced with many problems though most of the guardians had no problem in disclosing the status to their children. For many they thought that disclosing will make these children to behave well and do good as they will fear to misbehave because they don’t have parents. Dahourou, Gautier-Lafaye, Teasdale, Renner, Yotebieng, Desmonde, *et al.* (2017) in their study showed that many people did not understand HIV disease since it started until today. Studies indicate that some parents think it’s a disease from animals and is spread through unprotected sexual intercourse. That showed that lack of understanding from parents and/or guardians impose fear and despair. Furthermore, studies indicated that during the early years of the pandemic, some women who were pregnant by then refused to be tested because they trusted their partners in their marriage. However, the study continued to show that they were shocked when their children started to become sick and were later diagnosed with HIV (Wilson, Beima–Sofie, Mooran, Wagner, Mugo and Mutiti, 2017).

Busza, Besana, Mapunda and Oliveras (2017) in their study continued to share that voluntary testing and fear in the early years result in many women giving birth to HIV+ babies without them knowing anything. The study continued to show that later in life some mothers and their partners started to become ill and were diagnosed with HIV. Many women, as they continued to give birth, some of their children were affected, hence, some were not affected, especially those born after they tested HIV+ and started medications. Gymfi, Okiyere, Enoch and Brempong (2017) in their study concurred with the above revealing that most people fear to disclose because parent-child relationships can be affected, thus, the emotional and psychological well-being of a person can also be altered, e.g., the adolescent can run away from home or develop suicidal ideation. Many parents were concerned that their children or teens would view them as irresponsible for contracting the virus.

UNICEF (2017) in their study continued to show that stigma devalues people and bring shame and embarrassment. Some people feel punished or blamed and distract them from the fact that everyone is at risk of getting the virus. The study also found that HIV stigma is linked to sex, infections, and death, as well as unlawful or culturally forbidden acts. Individuals may be harmed by stigma because it causes feelings of guilt or shame. Studies continued to share that adolescents may ask difficult questions in future in need of answers.

Russell, Zalwango, Namukwaya, Katongole, Muhumuza, and Nalugya (2016) showed that many people who are diagnosed with the disease don’t understand the importance of disclosure. They see it as something which can cause family feuds and disrespect from children. The following sub-themes arose under topic 2, as shown in Table 4.6.

4.5.3.3.1 Sub-Theme 3.1: Having One HIV+ Child Amongst Other Children is Traumatic Leading to Feelings of Guilt

The research findings revealed that many parents felt ashamed and embarrassed when thinking of disclosing the HIV+ status to their children. Some of them said it should be done by health workers in their presence and at a given stage during primary care and when they transit to adult care. Some said that they don't have sufficient knowledge and the skills to sit with their children and tell them the truth. So, the best thing is to tell lies they will find out themselves as they grow. Literature has already been discussed above. The quotation below supports this sub-theme:

Parent 01 from Makonde said, 'it is hard to have other children not taking medications and others taking especially if its HIV, ***it's like the sick one is not loved or is discriminated amongst other children and as a parent I can't gather my kids and give them a reason why this one is HIV+ and others not,*** *hence, these children should give support to the one who is sick. When I know that my daughter is having an affair, I fail to rebuke her, thinking that she might swear at me. I ended up keeping quiet and waiting for anything.'*

UNAIDS (2017) explained that some families with an HIV+ child amongst others feel much traumatized when looking at their own children. Some parents fear that HIV could be transmitted to other children, hence, as parents they were afraid in disclosing for one reason that children might share the status with others and face discrimination. The study also showed that children could weigh the love of parents amongst themselves. Similarly, HIV could have negative impact on family members which can also change family roles causing anger and guilt. The challenge could lead to emotional and behavioural changes in children, especially if they know others in the family don't have the disease. The study continued to show that life-threatening illnesses like HIV negatively impact the quality of life among family relationships which might lead to delinquent behaviours in children (WHO, 2017).

4.5.3.2Sub-Theme 2.2: Feelings of Fear to Disclose the HIV+ Status to Other Children, Partner, and Family Members

The research findings further showed that parents and guardians knew that HIV is a condition which needs to be dealt with in secret or in a confidential manner. Some feared that if people or even relatives knew of their children's status, they will bad-mouth them about it, gossip or even isolate the family. Some parents in the family told the elder siblings who showed a sense of maturity and responsibility. Younger siblings were not told anything as they can just tell anybody. Some adolescents were told not to share their status with anyone because if they do so people will definitely conclude the status of the parents, hence, they saw it as hanging your dirty linen to people. The quotation that emerged from this sub-theme was as follows:

Parent 06 from Makhuva said, 'my husband and I are very supportive towards our son. We make sure he is treated like other children. ***We told him that having this disease does not mean that he is going to die****. He just must do all what the nurses and doctors told him to do. To take his medications in time, we also set the same time so that we can all support one another by drinking at the same time. I even told him that entering into adult care means that he is growing up. He must learn to be responsible,* ***if he tells friends that he is*** HIV+ ***they will mock him at school, isolate him or harass him****. If they are playing whatever he should avoid injury to himself because no one should touch his blood. Teenagers are not easy to manage but as a parent I must be strong. My son is very moody with this thing of attention seeking and rude sometimes.'*

The literature showed that the introduction of ART played a major role in decreasing the incidence and prevalence of HIV-1 worldwide. The WHO has extended the time for countries to reach the set target of 90-90-90 strategy by 2030. People who are unaware that they are infected must be identified and treated (Berg, Olivo. Harris, Rodgers, James, Mampunza et al., 2021). The study further showed that people should feel free and disclose to those they trust and show love to them to take their medications independently.

WHO (2017) indicated that disclosure is not easy and not a matter of one day. It takes time for one to disclose freely meaning that it is a process because one has to build trust with the person s/he will disclose to. Disclosure is like a healing process—it takes time, step-by-step. The study further suggested that health care workers should encourage patients to disclose because it helps a person to find closure and make informed decisions concerning health and medication. People feel relieved from the burden they were carrying after they disclose to someone they trust. Again, it also helps patients to join support groups or adherence clubs freely.

Busza, Besana, Mapunda and Oliveras (2017) showed that most of the parents feel insecure to disclose their HIV status to their children. They feel that children are very irresponsible and immature to be trusted to keep family secrets. The study further showed that the level of understating at an early childhood should be considered because early disclosure helps the child to grow as independent and with responsibility.

Participants lacked disclosure of HIV+ status leading to ALWHIV asking several questions. The findings of the study revealed that parents and guardians showed great support and played a significant role in the lives of their children (ALWHIV). From the time they were diagnosed with HIV they showed a great support making sure they go for monthly appointments, either at the hospital, clinic or private practitioner to get their health checked. The support shown during all this time included financial, psychological and social. Some parents and guardians extended by teaching their children how to choose friends at school. Some participants cited the following:

*Parent 04 from Muila said ‘**I beg her not to leave medications because is life until they find the one to cure the disease.** What I have noticed is that as a parent was not happy inside when talking to her, my guilt conscience was not clean. She never answered me, just nodding the head on everything. But I give all the support mentally, financially, and psychologically and that everybody is happy at home’.*

*Guardian 07 from Ntluri said '**I continue to give support because that is part of my duty as a parent.** The finance is me, psychological, spiritual social and everything'. I told them that if you sleep with boys your blood will stop and you will be pregnant. Every month you must give them money to buy girls staff and see to it that they don't mingle with boys as they will be raped.'*

Studies showed that there are many ways of supporting ALWHIV whereby parents can show or engage themselves with their HIV+ children. These options play a role in reducing the risk of reinfection or transmitting HIV. Encouraging ALWHIV to use their medications and condoms or abstinence could be other ways of showing support (WHO, 2017). UNAIDS (2017) alluded that parents or families can provide the three main forms of support to people living with HIV which are financial protection, access to affordable quality services and knowing their rights or regulations which protect them.

4.5.3.3Sub-Theme 2.3: Challenges Related to Understanding of How HIV Was Transmitted as They Were Honest to Partners

Findings if the study showed that the majority of women were respectful and subservient to their relationships. They respected their marriages too. Some, after being diagnosed with HIV, blamed their partners as the ones who gave the disease to them, saying they were very faithful in their marriages. Furthermore some partners were faithful to themselves accepting that their social behaviour was not right and it was them who got the infection and transmitted to their wives as they had multiple affairs. Again findings revealed that some women were afraid to disclose to their partners because they would be told they had affairs with other men and had brought the disease home, hence, family disorganization can occur. This was confirmed by the following quotations:

*Parent 02 from Shayandima said, '**that day I was very scared** but for my child's sake I did the test and I was HIV+. I followed all the procedures, and my child was also taken blood with my consent and the nurses showed me that he is* HIV+. *I prayed that he be healed and took medications. **I called my husband and he***

***never had questions, he said that the child will be given medication and that he will be ok, I was very shocked**.'*

Parent 18 from Tshakhuma said, 'HIV was still in fashion and very embarrassing if you test positive. I remember when we were given a group talk in the morning. After that we were told to go for testing one by one. It was still voluntary by that time when I arrive in the queue, I ask the counsellor if I can test but not given the results. I was very scared and not want to hear about HIV. ***I did not believe that the disease is real; nor can I be affected or get it.*** *I had a lot of faith in my husband, so I told the counsellor that I didn't want to be tested. The nurse pleaded with me, but I declined.'*

HIV is a virus that wreaks havoc on the immune system. Under specific circumstances, or if in close touch with the infected person's body fluids, an HIV positive person can transmit the virus to another person. This happens when an HIV+ individual injects fluid into the bloodstream or through the mucous membranes, wounds, or open sores of an HIV negative person. People need to understand the facts about HIV transmission. This could prevent both the spread of misinformation and the transmission of HIV (WHO, 2017).

Similarly, UNAIDS (2017) stated that HIV is a virus that damages immune system cells and reduces the body's ability to fight infections and disease on a daily basis. The study showed that there is no cure available presently. But the introduction of ARVs across the globe enabled most of the people who enroled in care to live a longer and healthy life.

Furthermore, Coleman, Tate, Gaddish, and White (2016) shown that early diagnosis and appropriate drug use can prevent HIV+ persons from developing AIDS-related illnesses and allow them to enjoy a near-normal lifespan.

4.5.4.4Sub-Theme 2.4: Nurses Explanation of Every Situation Encountered by Parents and Their Families Viewed as Continued Support to Promote Quality of Life

During the interview, the researcher noted that in both the adolescents and their parents or guardians everything done by health professionals was accompanied by an explanation. Whether it was a counsellor, doctor or nurse, clarity was given to show support and to promote quality of life. The quotations were cited by participants:

Parent 06 from Makhuvha said, 'my husband and I are on treatment. We go for our appointment dates at the clinic though my husband receives through the programme *they call CCMDD where he receives message on his phone to go and collect his medications at the clinic every two months. Unlike me the nurses told me I cannot be moved in this* programme *because* ***I'm receiving the 2nd line regimen,*** *so I need to be monitored strictly here at the clinic****. The nurses are very caring, they inform us of every step they would do and tell us our expectations****.'*

WHO (2017) defined quality of life as an individual's perceptions of their place in life in relation to their objectives, aspirations, expectations, and concerns in the context of the culture and value systems in which they live. Quality of life identified as the most important medical outcome indicator in the evaluation of current preventative and treatment options for patients with HIV infections. Quality of life is determined by physical being, social and psychological well-being, coping strategies, spiritual well-being, and ART. The use of ART increases the survival of people living with HIV which is important in promoting quality of life. The monitoring by health care providers on monthly bases with everything done for the patients from taking of vital signs, cohort checking for CD4 count and viral load and giving medications and monitoring side effects are all done to promote the quality of life (Hipolito, Oliveira, Costa, Marques, Pereira and Gomez, 2017). Surur, Teni, Wale, Ayalew and Tesfaye (2017) concurred with the above that the introduction of ARVs improves longevity of people living with HIV, especially if they follow instructions of health professionals.

4.5.3 Theme 3: Description of Existing Support Experiences by ALWHIV and Their Parents

This theme represents the support which the parents received from all directions. The support may be from friends or family members. Both the parents and the ALWHIV appreciated the support they received from their family members, peers, health care workers and other support structures. When a person is diagnosed with a very debilitating condition, s/he becomes very frustrated and develops fear of the unknown or fear to die. Support during this time becomes very crucial. Though the parents did not disclose to one another, they supported each other after they found out and supported their children. Grandparents who were told of the disease also gave support to both their (children) as parents and their grandchildren and encouraged them to adhere to their medications as instructed by the nurses or doctors.

Madiba and Mokgathle (2017) showed that support is very important to ALWHIV and their parents or guardians because it plays a major role in them adhering to their medications and this will be the sign that they are rendering quality nursing care. Overall, participants (parents or guardians and adolescents themselves) appreciated the support from all levels of life. Similarly, UNICEF (2017) revealed that ALWHIV are faced with many challenges, despite their HIV status. Therefore, as parents they need to be supported by other family members for them, in turn, to support their children to alleviate stress and anxiety. The study continued to show that it is important to encourage parents to take more control over their health so that they can take responsibility for the health of their ALWHIV.

In their study WHO (2017) continued to reveal that their parents are faced with many challenges despite their HIV status. Parents also need more support from other family members. Many parents expressed the love, care and support given by family members after disclosure in a way that they did not expect. However, UNAIDS (2017) continued to share that it is of utmost importance to empower parents/guardians on HIV-related issues so that they can develop a sense of responsibility and accountability. The following sub-themes arose from this subject, as shown in Table 4.6:

4.5.3.1 Sub-Theme 3.1: The Support Received from Nurses and Other Health Professionals through Counselling Appreciated

Research findings showed that health care professionals were very supportive to clients and did their work diligently. Counsellors showed their passion and love to patients or clients. They were very welcoming and provided the necessary counselling and support to clients. They also maintain confidentiality between clients. Direct quotations were:

Parent 08 of Muila said, 'on discharge, grand mom and the nurse took me to another side in the hospital for counselling. There we were welcomed by another nurse (counsellor) who told my grand mom to tell me everything. ***Then she holds my hand and said that my mother died of AIDS that is why she ask nurses that I be checked as I'm always sick****. The doctor said that I might have been born with the disease. This means that I will be given medications to take every day and once in a month I will be given date to come for check up at the hospital.'*

The study's findings revealed that parents who revealed their HIV status to other family members, such as their biological parents, were given complete support and were never judged. Some grannies continued to give support when parents found jobs from afar, and even to their ALWHIV. Research findings continued to show that when they go for their appointments in the health facilities, they were given health information separately, meaning that children, adolescents and parents/guardians were considered according to their respective age groups, level of understanding and maturity level. Everybody was given the information relevant to him/her related to HIV and other health matters. This showed the researcher that truly the health care workers knew their work and were willing to provide quality nursing care to all the people they serve. Findings of the study continued to show that from the time they were diagnosed with HIV, those who disclose to their family members showed enormous support making sure they attended monthly appointments, either at the hospital, clinic, or private practitioner to get their health checked. During all this time financial, psychological and socially support was given. This was confirmed by:

Parent 04 from Muila said, 'one day he accompanied me to the clinic for ANC, I was already on medication but not taking sometimes, ***that day a nurse explained everything to him about HIV, modes of transmission to the child, several behaviour support, adherence to medication, hey a lot of things, when she finished she said can I offer you a test if you don't mind****. My girl looked at me and I nod my head but was very scared. The nurse taught us the importance of using condoms, adherence to medications and keeping appointments.'*

Parent 15 from Wayeni uttered, 'a month later I lost my wife, I was very sad knowing how she lived being faithful to me while I was reckless changing women like old cars and not using protection like condoms. It was very sad and told myself that I failed my wife. After the burial I decided to go for testing at the doctor and my results came back positive. ***The doctor counselled me Again, strengthening the issue of protective sex or to always use a condom to prevent reinfection****.'*

WHO (2018) indicated that HIV affects people in all dimensions of life, either physically, socially, psychologically or spiritually. The study showed that counselling and social support can help parents to cope more effectively and enhance the quality of life. The study further showed that with adequate support given to parents, they can cope with stress and be able to move forward. Roberts (2018) concurred with the above indicating that it is important for people with HIV as individuals, couples and families to get psychological support to cope with their emotions and psychosocial needs.

The support received from family members by parents was very significant to those who managed to disclose their status. Some parents indicated that they never expected the support the way they have seen it. The support for parents living with HIV+ children should be vital in the family. Therefore, disclosure is also important because people or family members cannot give support if they don’t know the matter. According to Glazer (2018), HIV care and support are non-ART clinical services, which include the treatment of HIV-related infections in addition to ART. People who are HIV+ are more likely to develop psychological problems than those who are HIV-. Problems can also start by thinking of the challenges which one can come across in life regarding one’s own health, financial constraints and many more things. Furthermore, some parents worried about their health and feared death, but, above all, stigma and discrimination (Russel, Zalwango, Namukwaya, Katongole, Mahumuza, and Nalugya (2016).

4.5.3,2 Sub-Theme 3.2: Health Education Content Provided to Parents and the Importance Thereof

Research findings showed that when parents attended their appointments in the health facilities they were given health information separately meaning that children, adolescents and parents, their age group, the level of understanding and the maturity level were considered. Findings continued that everybody was given the information relevant to him/her related to HIV and other health matters. This showed the researcher that truly the health care workers knew their work and were willing to provide quality nursing care to all people they serve. Findings continued to show that during the interview parents and guardians showed that health care professionals explained each one what they would do for them or for their ALWIHIV. Like if they want to take blood, they will explain everything to their understanding or if they are increasing medications or changing medications. All these were viewed as a continued support to promote the quality of life. This was confirmed by:

Parent 16 from Makhuvha said, ‘when I was diagnosed some years back nurses taught us many things like importance of taking medication, importance of disclosing, the use of condom together with another method of family planning (dual therapy), other sexual transmitted infections and many other information on HIV.’

Parent 04 from Muila said, 'one day he accompanied me to the clinic for ANC, I was already on medication but not taking sometimes, that day a nurse explained everything to him about HIV, modes of transmission to the child, several behaviour support, adherence to medication, hey a lot of things, when she finished she said can I offer you a test if you don't mind. My partner looked at me and I nod my head but was very scared. The nurse taught us the importance of using condoms, adherence to medications and keeping appointments.'

The risk of ART to stop working is high (virological failure) if adherence is not explained and understood well. Therefore, health care professional has a role to play in empowering parents to be responsible with their health and that of their children (ALWHIV). Adolescents should be empowered very strongly to HIV issues (WHO, 2018; Roberts, 2018). Non-adherence may be caused by low educational attainment, poor knowledge about HIV, and a lack of independence about HIV. As a result, adolescents should be empowered very strongly to HIV issues (WHO, 2018; Roberts, 2018). Coleman, Tate, Gaddist and White (2016) corroborated the above showing that parents need to be given comprehensive education after being diagnosed with HIV. This will enable them to make informed decisions about sexuality and relationships with more confidence in condom use to reduce reinfection. Parents can be recruited to join adherence clubs where they can gain more knowledge to deal with their challenges and that of ALWHIV and services provided in a stigma-free environment (Ruria, Mashaba, Kose, Woelke, Mangy and Matu, 2017). The quotation below confirms the sub-theme:

Parent 07 of Vhurivhuri said,' 'I have good relationships with my family, friends, neighbours, teachers and school mates and nurses are very friendly. ***My medications are working well in my body, my viral load has suppressed and my CD4 count is okay*** *and I no longer go to the clinic during the week to collect medication, I'm being given a date for Sunday because I attend Saturday school. My mom or my elder sister go and collect for me if I'm writing tests or exam and my two elder sister's love and support me with everything that I do. We talk and laugh and they help me with my school work every time.'*

Khamisa, Mokgobi and Basera (2019) explained that people with HIV need to be given education regarding their health. The study rationalized that parents need to be given information concerning reproductive health, including the use of condoms. Those who use family planning as contraceptive measures should be advised to use it in combination with condoms. This will prevent reinfection.

4.5.4 Theme 4: Suggestions Made to Promote Quality of Life by Parents

Some parents during data collection made a plea ‘that they be assisted by health professional to disclose to their children about their HIV status.’ They didn’t have enough skills to face their children because they also had fear to be disrespected by their children. Some indicated that the government should come with a plan or set time where both parents should take a child for disclosure in the health facility as this could also promote adherence for medications. The following sub-themes in emerged Table 4.6:

4.5.4.1.1 Sub-Theme 4.1: A Request That Nurses Assist Mothers and Guardians to Disclose HIV+ Status to their Children

Findings of the study revealed that some of the parents/ guardians manage to disclose the true status to the children, and the children accepted early and adjust themselves in living with the condition. But the majority of the parents, study showed that they did not reveal the true status to them. The study further revealed that disclosing to their children is difficult, and pleaded that they be assisted by professional people while they are present. Parents who lived longer on ART shifted their focus from survival to increasing quality of life, according to the literature. Adherence to medication, stay in treatment, virus suppression, and maintaining physical and mental well-being are all examples (Glazer, 2018).

Parent 01 from Makonde said, ‘I think nurses showed support to us during the transition when children move from childhood entering adult care. It is difficult as a parent to tell a child about this or to disclose. ***If nurses can help us to tell our children or to disclose it will be very great****.’*

Parent 06 from Makhuva uttered, 'I feel more pain sometimes when I look at him. If doctors and nurses could help ***us disclosing early as parents' life could be easy for us and our children.'***

*Parent 09 from Vhurivhuri said '****I asked the nurse to tell them (disclose) but she told me that I should be the one doing it****, she will just be there to give me the support in case the adolescent can be angry then I told her I will see.'*

According to the World Health Organization (WHO), disclosing HIV status to ALWHIV and their families is a vital part of HIV care and treatment. The global prevalence of HIV disclosure among children and adolescents, on the other hand, continues to be low. Health care personnel, according to the study, can play an important role in assisting parents because they should be the ones to tell the child. Peer support is becoming more common in HIV service packages, according to research, and it can be delivered in a variety of ways. Individuals, groups, community or facility-based, and in-person or virtual support methods are all options (Mark, Hrapcak, Ameyan, Lavish, Ronan, Schmitz and Hatane, 2019). The following sources were used

4.5.4.2Sub-Theme 4.2: Request for Initiation of Support Groups with Consistent Scheduled Meetings (Including Counselling)

Findings in this study revealed that some of the parents suggested the idea that the government, through the clinics or health facilities, should create support groups outside the facilities where nurses can go out and support them with knowledge empowerment, activities, career information and many issues related to their health. Again, the researcher as a clinician noted that support groups are present in health facilities, but they are not that much active. They still lack something because of the stigma attached and now because COVID-19 support groups are dominant due to laws of the country. Findings of the study also revealed that some parents and mentioned that counselling of both parents should be done at some stage if they are positive. This could better disclosure to the child by both and when the time is due at an early age of life. Findings of the study showed that some of the parents attributed a great concern for not having the skills to perform the duty of disclosure. Though some voiced that they were just fearful now that their children were grown-ups, some are stubborn because they found the truth outside. But the fact remained that they needed support from health professionals during the process of disclosure. Group support could offer a space in the individual's life where psychosocial issues could be addressed, and more knowledge gained. In addition, HIV programs use support groups as a way for health workers to deliver information to HIV-positive patients.he citation in support of the aforementioned was:

*Parent from Ntluri shared, '**if the support group could be moved to the community many parents could enrol in care.** Many people can come nearby because others are taking in other clinics far from home. They fear to be seen by friends and relatives in the queue. And again, the **government should give us food parcels to compensate the little grant we get**.'*

*Parent 02 from Wayeni uttered, 'I think **both parents should be held responsible and tell their children or disclose everything at an early stage** so that children adjust early knowing that parents are also like them.'*

*Parent 13 from Tshakhuma said 'I also think parents should be **done couple counselling** even when they have been diagnosed already for the sake of **raising the children and disclosing together.'***

The WHO (2017) suggested that support groups be formed to help those who were using ART stay on track. Furthermore, according to the study, support groups can help people share their experiences, encourage disclosure, and reduce stigma and discrimination while also improving self-esteem, patience, coping skills, and psychological functioning, as well as supporting medication adherence and improving retention in care (WHO, 2017). According to UNAIDS (2017), disclosure is an emotionally and socially complicated process. Fears of negative repercussions from disclosure, such as psychological issues, inability to accept and deal with the diagnosis and stigma, and unintended disclosure to others, lead to parental or guardian hesitancy in disclosing an HIV+ status to their children. Adolescents who were aware of their HIV+ status early on had higher self-esteem than those who were unaware of their condition, according to studies.

4.5.4.3Sub-Theme 4.3: A Suggestion That Group Counselling Be Initiated So That Adherence Could Be Encouraged

Findings of the study showed that some of the parents suggested that group counselling is important for adherence to treatment, even though they no longer meet as groups because of the rules of COVID-19.

Parent 12 of Madombidzha verbalized, 'I also suggest that as parents we should meet as groups to discuss the challenges we are facing and to get ideas how others are dealing with those challenges.'

In many pair partnerships, an estimated 50% of people living with HIV have HIV-positive partners. Some HIV-positive people have kept their status a secret from their sexual partners. When one spouse has tested positive for HIV, it's critical to tell the other. This increases the likelihood of social support and encourages long-term HIV prevention and management measures. It will also motivate participants to stick to HIV treatment and support programs (Adetumi, Talofa and Gbalagade, 2018).

According to WHO (2018), being diagnosed with HIV is very isolating and depressing to many individuals. Some think of committing suicide, and blame themselves for their HIV+ diagnosis. Going to a support group for counselling could assist making adherence to treatment possible. Group support or counselling made people realize that they are not alone in the situation.

Roberts (2018) agreed with the above showing that group counselling might help to build confidence and strength. Furthermore, it may be quite inspiring to see people in the very same boat doing well. Some people came to group counselling to see how others were doing and later enrolled for the treatment. Group counselling might also help newcomers to enroll in the care and adhere to HIV programmes. HIV is no longer a life-threatening disease though it is characterized by a high level of sigma. Engaging in group counselling can help individuals adjust with their medications, preventing reinfections and building their relationships with their families (UNAIDS, 2019).

4.5.4.4Sub-Theme 4.4: A Suggestion for Couple Counselling So That Care to ALWHIV Can Be Done by All Parents

During the interview sessions, the researcher found that some parents and adolescents mentioned that counselling of both parents should be done at some stage if they are positive. This could promote better disclosure to the ALWHIV by both and when the time is due at an early age of life. The following quotations were cited:

*Parent 02 of Wayeni uttered, ‘I think **both parents should be held responsible and tell their children or disclose everything at an early stage** so that children adjust early knowing that parents are also like them.’*

*Parent 21 of Wayeni shared, ‘I started to know straight about this disease one day when I came for my appointment with my mother, that day there was a group of parents and adolescents who came for their medications so I asked one who was sitting next to me and he said **it’s Support Group day and that was my first day attending.**’*

Parent 13 of Tshakhuma said, ‘I also think parents should be done couple counselling even when they have been diagnosed already for the sake of raising the children.’

Dessaegn, Hailemichael, Shewa-Amare, Sawleshwarkar, Lodebo, Amberbir *et al.* (2019) explained that couple counselling is vital for parents who are raising children with HIV. The study revealed that couple counselling may prevent HIV transmission and facilitate safer sex practices between couples. Though HIV is still a challenging disease along the entire globe, couple counselling is possible to those who want to live freely and independently. And it may be cost-effective for couples and to start a new life which can aid disclosure to their ALWHIV and families (Glazer, 2018).

4.6 Data Triangulation

Triangulation is a method used to strengthen the credibility and validity of study findings, according to Polit and Beck (2012). Furthermore, credibility refers to the study's dependability and realism. Triangulation could improve the study's dependability and allow it to saturate the data (Fusch and Ness, 2015). Triangulation gave depth to the data acquired, according to the study.

4.7 Summary

The study's goal was to devise a plan for optimizing the transition of ALWHIV from primary care to adulthood in the selected districts of Vhembe, Limpopo Province, South Africa. The study was conducted using qualitative strand. It involved gathering information from ALWHIV and their parents or guardians, as well as analysing the information (Table 4.7). The next chapter will focus on the development of the strategy.

Table 4.7: Summary of findings from raw data of parents/guardians and ALWHIV

• Both the ALWHIV and parents experienced pain and suffering before they were diagnosed with HIV and both had bad memories of the past. • Some ALWHIV were amazed for the first time when realizing they are being taught of HIV-	• Some of the adopted ALWHIV expressed the pain of losing their parents but living a good life in their families. • Most of the guardians were happy that they disclosed the status to their adolescents and they were both comfortable with that and the

related issues, while some parents were shocked when they heard they are HIV+ for the first time after being tested. • Like adolescents who had little knowledge on HIV matters even some parents had little knowledge which contributed in them not taking HIV matters seriously until they became very ill. • Many parents and ALWHIV experienced financial constraints, psychological, spiritual, and social problems after they discovered their status. • Lack of disclosure by parents to their adolescents resulted in them not disclosing to their lovers when entering sexual relationships, some lied when asked while some quit the relationships when asked to taste sweets. • Both parents and ALWHIV appreciated the support and services they received from health care professionals and adhered to the instructions which assisted them to recover fast. • They showed that they were given various information related to HIV/AIDS *en mass* and individually when they went for check-ups. • Both ALWHIV and parents/guardians showed appreciation that health care professionals were transparent in all procedures to be done, and the reasons and way forward explained. Before consultation, their vital signs, blood pressure, pulse, respiration, temperature and weight were measured. • Fear of stigma and discrimination was experienced by both parties. • ALWHIV appreciated the support received from parents and other stakeholders like pastors and *vice versa*. • Both made a plea for the government to support them with food parcels besides the grant they get. • They wanted community support groups	adolescents were cooperative. • Guardians felt at ease to disclose the status because the parents of ALWHIV were dead. • Parents who disclosed to their families received support while those who did not disclose were not fully supported. • Only ALWHIV who disclosed to their peers or friends received support and were encouraged to adhere to their medications by their peers. • ALWHIV blamed their parents for telling lies about their HIV status while they were still young. • Lack of knowledge hindered the parents to explain the existence of the disease to their adolescents. • ALWHIV who knew their true HIV status by themselves were very disappointed and angry with their parents. • Only those ALWHIV who knew their status early were found to be happy and responsible about their health and were adhering better to their treatments. • ALWHIV pleaded with the communities to support them rather than to discriminate and call them names. • ALWHIV requested support groups to be established in the communities to attract more adolescents who are not in the care. • ALWHIV made a plea that both parents should be held accountable to disclose early to their children to better their quality of life and for adolescents to learn to be independent as they grow. • ALWHIV made a plea to the government to support them with basic needs like food parcels and to build community centres where they could be assisted in terms of skills. • Some parents pleaded that health care professionals should assist them with disclosing because they lacked the skills for doing so.

rather than facility-based adherence clubs.	

CHAPTER 5

STRATEGY DEVELOPMENT TO OPTIMIZE TRANSITION OF ALWHIV

5.1 Introduction

The previous chapter dealt with data analysis, presentation, interpretation, and discussion of the findings. The researcher interviewed parents/guardians who were taking care of ALWHIV on the burden they faced as they were transiting to adulthood and the support they needed. Five themes emerged with their sub-themes from the ALWHIV and four themes with their sub-themes emerged from the parents/guardians. The development of a plan to optimize ALWHIV's transition to adulthood is the subject of this chapter. The strategy was developed utilizing the Empowerment Model framework's Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis, followed by concrete plans based on building on strengths, overcoming weaknesses, exploring opportunities, and managing threats (BOEM).

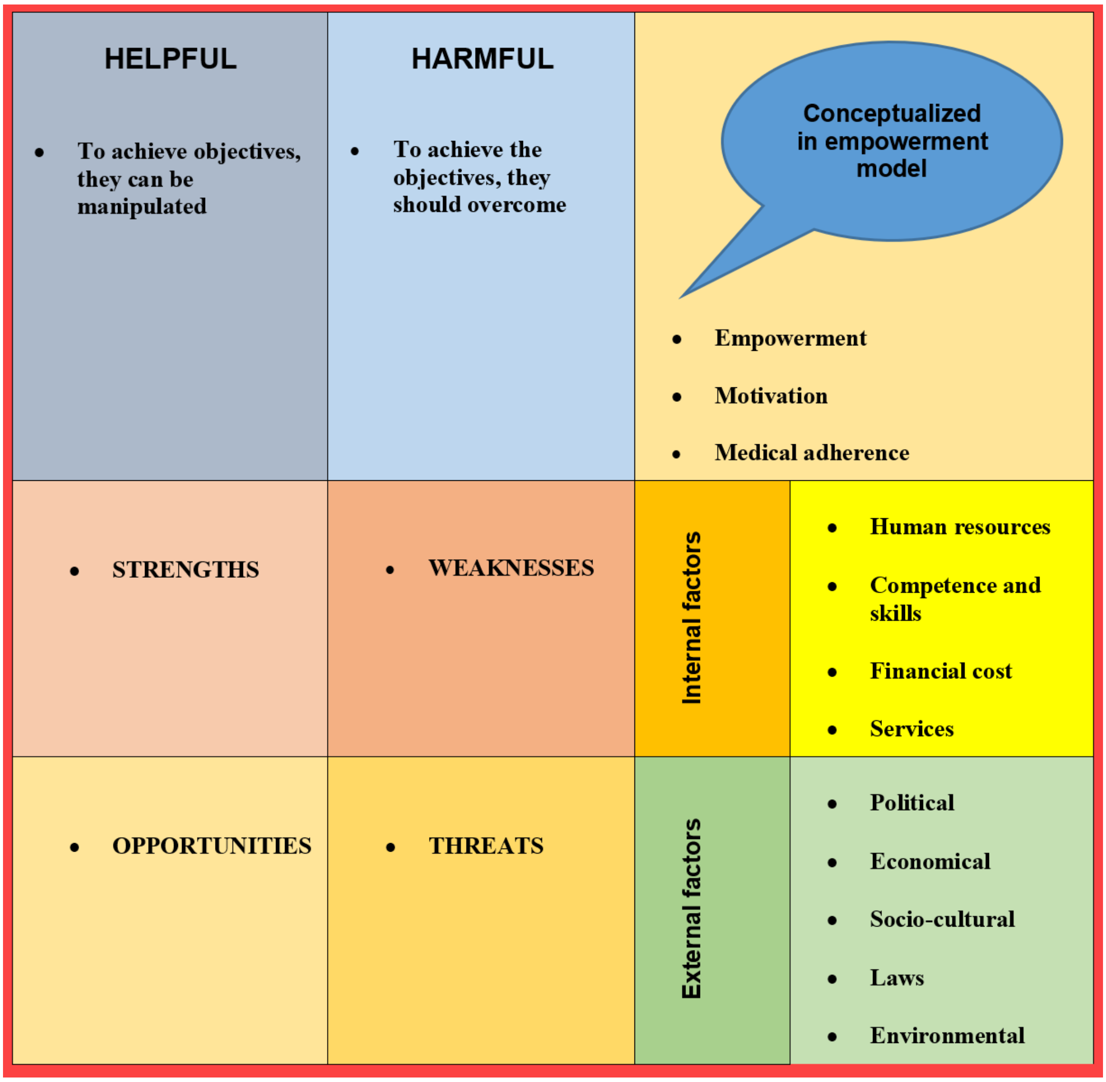
5.2 Approach Used to Develop the Strategy

The strategy's development would be used to optimize ALWHIV's transition to adulthood in the Limpopo Province's designated areas. Chinn and Kramer, 2015 technique was employed by the researcher. The SWOT analysis was employed in this method. The researcher was able to identify the strengths, weaknesses, opportunities, and risks that could obstruct or improve the development of an ideal ALWHIV transition to adulthood using this technique. This was accomplished by creating a SWOT matrix, which is a systematic planning tool for evaluating SWOT (Chinn and Kramer, 2015). Following SWOT analysis, the researcher would focus on Political, Economic, Socio-Cultural, Legal/Law, Technology and

Environmental (PESTLE) analysis.

Furthermore, SWOT analysis (Table 5.1) was developed in collaboration with the Empowerment Model by Vorming *et al.* (2015)—the principles of this framework included empowerment, motivation, and medical adherence.

Table 5.1: SWOT Analysis



HELPFUL To achieve objectives, they can be manipulated	**HARMFUL** To achieve the objectives, they should overcome	Conceptualized in empowerment model Empowerment Motivation Medical adherence	
STRENGTHS	WEAKNESSES	Internal factors	Human resources Competence and skills Financial cost Services
OPPORTUNITIES	THREATS	External factors	Political Economical Socio-cultural Laws Environmental

5.2.1 The Steps Followed in SWOT Analysis

SWOT analysis is defined as an organized process of analysis that discovers and evaluates the Strengths, Weaknesses, Opportunities, and Threats (Bezuidenhout, 2014). Bunn and Conlin (2013) went on to say that instead of seeing strengths and opportunities as minor things, they can be viewed as resources that can be leveraged to overcome weaknesses and threats. The SWOT analysis considers both internal and external influences. These aspects in the SWOT analysis (Table 5.2) deserve special attention because they can have a favourable or negative impact on ALWHIV's optimal transition into health care (Bunn and Conlin, 2013).

Table 5.2: Strengths, weaknesses, opportunities and threats (SWOT) analysis

Strengths	**Weaknesses**	**Opportunities**	**Threats**	
• Availability of staff; trained NIMART nurses. • Empowerment of NIMART nurses (knowledge and skills) • Availability of HIV guidelines/protocols • Friendly health care workers who provide health education and health assessment • Support from health care workers, parents, guardians, peers • Availability of Tier.net programme • Availability of support groups, CCMDD programmes • Given weekend check-up dates if attending Saturday classes • Tracing of ALWHIV by	• Shortage of NIMART nurses working alone, sometimes • ALWHIV waiting for service during tea time and lunch time (long queues resulting in long waiting time). • ALWHIV had challenges with disclosure • ALWHIV said tablets make noise • Culture, values and believes interfere with adherence • Some ALWHIV defaulted medications as they find out their true status • No training up-dates for NIMART nurses and circulars arriving late sometimes	• Political benefits like availability of TAC to provide advocacy • Establishment of support group for adherence purposes • Health Information sharing to empower ALWHIV • Reduce waiting time by utilization of community health workers (CHW) • Availability of HIV directorates at National, Provincial and District levels • SANC regulations provide guidance on ethics practice	• Political interference • High defaulter rate • Fear to be stigmatized • COVID-19 rules restrict people to gather around in large numbers • Weather conditions • Bad roads (dangerous road conditions)	•

phone • Lab results explained to ALWHIV and parents or guardians • Availability of ARV drugs • Availability of resources like vital monitors, lab equipment and stationery for collecting blood specimens			

5.2.1.1 Internal Factors

❖ **Step 1**

Internal factors are those that exist within the health-care system and aid the institution in reaching its goals. These variables can have a good or negative impact on how services are delivered (Bezuidenhout, 2014). They include the facility's strengths, such as personnel and material resources. According to the Empowerment Model (EM), if the facility has adequate employees to teach ALWHIV, the goal of optimizing transition would be met (Vorming et al., 2015). ALWHIV could be motivated to stick to their treatment or drugs if enough health care practitioners are trained in NIMART. They can also be altered to meet the study's aims. Human resources, competencies, financial costs, and services are examples of internal elements.

❖ **Step 2**

The flaws are those aspects that may obstruct ALWHIV's optimal transition in the institution. Insufficient staff in highly populated facilities could jeopardize the achievement of optimizing the transition. Shortage of drugs in facilities and sometimes depot could demotivate and demoralize ALWHIV to utilize facilities and keep their appointments regularly (Vorming *et al.,* 2015). Human resources, expertise, financial costs, and services were all discussed.

5.2.1.2 External Factors

- **Step 3**

The benefits of PESTLE enabled the participants to use them to their advantage allowing them to aid the facility in optimizing the ALWHIV transition (Bezuidenhout, 2013).

- **Step 4**

The threats of PESTLE could hinder the optimal transition in the facility (Bezuidenhout, 2013).The environmental factors like change in seasons could sacrifice the optimal transition of ALWHIV. For example, in summer it is always raining, gravel roads are swept away, bridges also and bushes become dense. Some of the ALWHIV stay far from the clinics and usually default their appointments during this period. If they don't have money to board a taxi or bus and are afraid to walk alone to the clinic, they default their medications hence adherence is compromised.

- **Step 5**

The researcher went over the data and made a list of the strengths before going over it again to make a list of the weaknesses, opportunities. The following questions were posed to the participants:

- How can we make the most of our abilities? (S)
- What should we do to address the problems that have been identified? (W)
- How can we make the most of our advantages? (O)
- How can we overcome the threats that have been identified? (T)

The results were transformed into actionable entities when the SWOT analysis was done and the last step and information from the SWOT matrix were employed. The method of combining the EM's basic concepts with the Build on Strengths, Overcome Weaknesses, Explore Opportunities, and Minimize Threats (BOEM) strategy. This was the method utilized to build the Optimizing transition of ALWHIV to adulthood care strategy in Limpopo Province's selected districts. As shown in Figure 5.1, internal elements included human resources, financial expenses, expertise, and services.

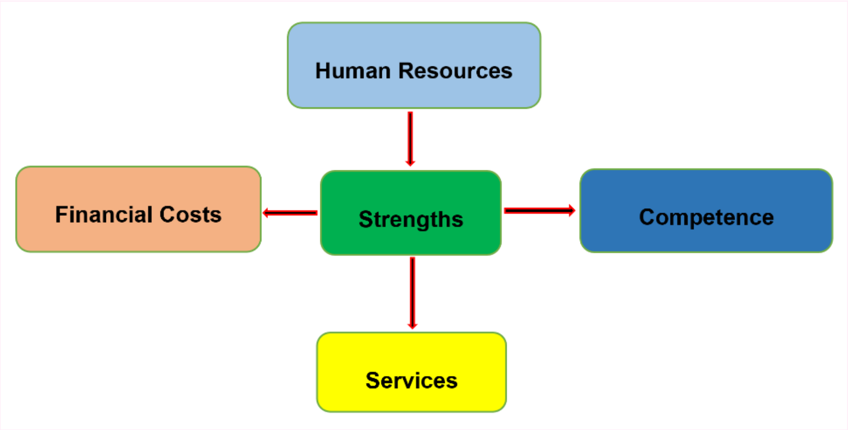


Figure 5.1:Internal factors: Strengths to enhance transition of ALWHIV

5.3 Description of Internal Factors

5.3.1 Strengths

Figure 5.1 illustrates the components that are described under the strengths. Strengths are the characteristic that gives the facility advantages against all odds. While weaknesses are characteristics which put the facility at a disadvantage or to a fail (Bezuidenhout, 2014). Both aspects, which arose from the study's findings, include human resources, competence, financial costs, and services, which have been conceptualized within the framework of the chosen EM, which has the principles of empowerment, motivation, and adherence.

5.3.1.1 Human Resources

Human resources are the employees of an organization who are viewed as assets in terms of the skills and talents required to perform specific tasks or jobs (Booyens and Bezuidenhout, 2013). Nurses, other health care workers, and operational managers (OMN) who have received NIMART training and provide information to adolescents with the goal of empowering, motivating behavioural change, and ensuring adherence to ART during the transition to adulthood.

The study's findings revealed that each PHC institution which the researcher visited has NIMART-trained nurses appointed permanently in that facility to render comprehensive and holistic HIV services to all clients. The health care facilities in public sectors have been rearranged to have three streams or consultation rooms based on ideal clinic realization system which are MCWH, and Preventative and Chronic stream. All facilities have an Operational Manager (OMN) to supervise health programmes, manage staff and conduct administrative roles. If all facilities were having sufficient staff and good infrastructure, service delivery would be of top quality in the health facilities.

The EM (Vorming *et al.,* 2015) was used and this should be patient-centred and in collaborative approach. Health care professionals providing care, both nurses of all categories and doctors in some of the facilities, including counsellors should all be user-friendly to the ALWHIV. They will be able to attract these adolescents into care and empower them with knowledge. This will enable ALWHIV to make decisions concerning their health. The staff should also provide the support needed by the ALWHIV without judging them.

Findings of the study further revealed that ALWHIV always get all the services that they need in one stream, like family planning, including their medications. OPM were there to support the staff and monitoring that order forms were written and submitted in time to avoid complaints on shortage of drugs. This showed the researcher that HIV is also considered among the most important of health care services.

Findings revealed that health care professionals were always sharing information on the reality of HIV to parents and guardians, including the ALWHIV themselves when they gave advice or health education. As alluded in the conceptual framework that the fundamental reality about HIV should always be maintained when motivating the ALWHIV so that they have positive thinking (Vorming *et al.,* 2015). Parents and some of the ALWHIV also appreciated the service they received from the facilities showing that besides the staff shortage and the long queues, the service they received was excellent. Some parents viewed the nursing staff as friendly and supportive; if their medications were finished at the clinic, they requested them politely to go and collect at the hospitals.

5.3.1.2 Competencies

Competence is described as an individual's capacities and potentials, which comprise the knowledge and skills needed to accomplish his or her obligations or job (Booyens et al., 2013). Competence refers to the effective quality or extent of performance of a typical function, according to the Oxford English Dictionary (2014). In the study, competencies were observed in the form of knowledge and skills identified by the ALWHIV and their parents or guardians from health care experts. Twenty years ago, receiving an HIV diagnosis was terrifying. The knowledge and abilities of health care personnel in Primary Health Care (PHC) facilities were insufficient to handle this illness. The Department of Health (DoH) began capacitating professional nurses with knowledge and skills concerning HIV matters as vital.

Vorming, et al, 2015, the Empowerment model revealed that people with chronic conditions should be competent in managing themselves and their conditions if they are stable. Thus HIV/AIDS is no longer considered chronic but self-manageable condition. ALWHIV are now independent and thus their competence should be measured by coming for follow-up visit regularly, viral load should be suppressed, they should gain weight and taking their medications daily by themselves. The EM showed that this is a process whereby people should have more control over decisions and actions affecting those needing care (Vorming *et al.,* 2015). Therefore, to enhance this transition, the NIMART course was needed as a key and a skill to work with these ALWHIV. When ALWHIV motivated themselves after receiving the information from health care professionals, they would be self-competent in making their own health decisions. For example, if they don't know their partners' status, they will be confident in using a condom to prevent reinfection. With the knowledge they have acquired, NIMART nurses empower the parents and guardians to be more supportive to their adolescents. They were given information concerning medications and the side effects to look for on their children. They were taught to use their cell phones or watch which could buzz or beep to remind them about time to take their medications. They were given information on the importance of disclosure and many more things for them to be able to support these adolescents as they transit to adulthood and becoming more independent, learning to take responsibility for their own health.

Findings of the study showed that some of the ALWHIV were competent and able to manage themselves well. Some verbalized that they are no longer accompanied by parents, they are taking full responsibility on their health matters. Findings of the study also revealed that there were some adolescents who ones defaulted their medications and become very sick and some even contracted TB. They said they will never default their meds again till the cure is found. Most of the professional nurses where the study have been conducted were NIMART-trained. Therefore, they have the necessary skills and capabilities to empower the ALWHIV and their parents with the necessary information. Again, the majority of them were also trained in a course on youth friendly services for the smooth running of all services concerning adolescents’ youth matters without judging them. This could enhance or improve compliance amongst the ALWHIV (Vorming *et al.,* 2015). If programme managers together with facility managers support NIMART nurses through workshops and updates, monitoring the implementation of HIV guidelines and policies, many ALWHIV could remain in care and be able to manage their health with a better understanding of the disease.

To enhance the competencies of NIMART nurses, OMN should assist in arranging on-site in-service training in the facility and as per local areas. The district should hold workshops on HIV updates at least once a year or if new issues arise. This will result in ALWHIV receiving and managing high-quality health-care services. The person responsible for training at the district level should always have a budget to continue training the new professional nurses who are employed in care and those furthering their studies from lower categories to professional positions. NIMART nurses should also assist ALWHIV and their parents in counselling and giving extensive education concerning disclosure. Counselling skills should always be revised and be at the tip of their fingers because findings of the study also revealed disclosure is a problem for both ALWHIV and their parents. This could assist both to come to terms and improve their relationships, hence, remaining in care and adherence also increases. The health care professionals also give support to ALWHIV and their parents to take instructions given to them concerning their medications. They further showed the knowledge they have through teachings in various topics concerning the health of ALWHIV and their parents so they can make informed decisions, as they grow, on issues like medications and adherence, reproductive health issues, hygiene and many others. The knowledge and skills which health care professionals had were much appreciated.

The health care professionals also showed competence in their work because they always reviewed their clients as they came for appointments. Findings of the study showed that if blood was collected from ALWHIV or their parents, the results and implications were explained to them upon their return. ALWHIV were motivated and appreciated the service showing that their needs and values were met. If ALWHIV became motivated even adherence became easy (Vorming *et al.,* 2015). Furthermore, to enhance the transition health care professionals taught adolescents that if they missed their appointment dates, there will be community based cadres who will be sent to visit them. Some parents and ALWHIV were happy about that while others showed that they don’t want to be followed-up. ALWHIV and their parents were also traced telephonically on a weekly basis if they missed their appointments before the Tier.net programme automatically put them on Lost to Follow-Up (LTFU) in 3 months’ time.

5.3.1.3 Financial Costs

Financial expenses are concerns about adding value to a product or service; they involve the availability of finances and equipment, as well as their upkeep for day-to-day operations (Booyens et al., 2013). Adding value towards the facilities is when the DoH makes it a point that basic equipment for daily use and drugs should always be available. All facilities had at least a NIMART-trained nurse who could do the work easily and of high quality. They could conduct HIV and treatment counselling. Their competence and skills could attract the enrolment of large numbers and the defaulter rate could be reduced.

The hiring of new staff, training of courses and updates conducted with the nurses could enhance the capacity of professional nurses. Thus, competent professional nurses could deliver and reduce waiting time in the facilities. Some ALWHIV were mostly of poorer families, coming for their appointments at the facility and not receiving quality care could impact them in a negative way. Though the HIV services are free, ALWHIV are still human beings to be treated with decency. Resources like drugs and equipment should always be available, serviced and functional at all times.

ALWHIV and their parents should be motivated and empowered to expect the same care provisions from their nearby facilities (Vorming *et al.,* 2015). Since some ALWHIV came from compromised families, being near the facilities could be easy and save time, medical adherence could also improve. ALWHIV and parents who depend solely on grants should also be given workshops on budgeting so that they can use the money cost-effectively.

NIMART-trained nurses follow the HIV guidelines every time when consulting and reviewing ALWHIV to minimize litigations. Even before referring these adolescents to another level, they first contact the doctors for further opinion combining that with reference to the guidelines. The health care professionals also check the vital signs of the adolescents using vital monitors and scales on a daily basis and asking them for any side effects because the body of a person do change. The findings continued to show that NIMART nurses do pill counting as the ALWHIV and their parents came for collection of treatments. The use of guidelines reduces unnecessary referrals to the hospitals and that is value for money to both clients and the DoH. Some participants showed that they got their medications every time they go for check-ups, some showed that sometimes one medication is not there, and they are referred to go and collect at the other hospitals.

Empowerment is about patient-centeredness and if empowerment is done in every step, ALWHIV would be self-determined and autonomous in their health care management (Vorming *et al.,* 2015). Parents and guardians should also show their competence by supporting their children, encouraging and motivating them to take medications daily and at the correct time. Encourage them not to miss their appointment visit and to tell nurses to allocate them on the appointment system if they still attend school.

5.3.1.4 Primary Health Care Services

The PHC services concern all the four A's in the health care facilities which are **A**vailability, **A**ffordability, **A**ccessibility and **A**cceptability. PHC is described as a form of essential health care that has been proven scientifically and socially acceptable by society through the use of technology and is available to all citizens of the country (DoH, 2016). These are the services rendered by NIMART-trained nurses for HIV counselling, individual counselling, couple counselling or PICT (Provider Initiator Counselling and Testing) to initiation and management of HIV to ALWHIV. All these HIV services should be available on daily basis and are rendered free to all the public facilities.

5.3.1.4.1 Availability

According to the EM, availability of services involves empowerment, motivation, and medical adherence (Vorming *et al.,* 2015). ALWHIV should have the ability to set goals that they want to achieve in future (Vorming *et al.,* 2015). Nurses and other health care specialists from NIMART are constantly on hand in the facilities to help. Health care professionals, especially NIMART-trained nurses, should learn to ask ALWHIV questions when they come for follow-up visits and listen attentively to their feedback and intervene immediately where necessary (Vorming *et al.,*2015). For example, ALWHIV could have been abused sexually or otherwise or having sexually-transmitted infections (STI) for the first time and not sure how s/he could approach the nurse. This could assist and motivate ALWHIV to always keep their appointment dates.

Health care professionals should avail themselves in time and knock-off in time following their standard operation procedures. Drug availability could impact positively on the adolescents when they come to the clinic to get their medications. Even laboratory tools should always be available so that ALWHIV could be monitored well using their cohort months. The findings of the study showed that ALWHIV always get the services they need at the clinics and hospitals, if ever they were referred. Health care professionals were always there to give the services comprehensively with love and passion for their work. NIMART-trained nurses were always available to render service to the ALWHIV in a friendly manner.

Furthermore, the study's findings revealed that some health care practitioners were able to persuade ALWHIV to attend school while complying to their drug regimens. They do so by also scheduling weekend appointment dates for those who attend Saturday classes. This could boost the adolescents comprehensively and meaningfully and enable them to manage their treatments. This is so because motivation is about the involvement of both the patient and the health care professional who entered a collaborative partnership centred on a patient’s goal setting and self-management (Vorming *et al.,* 2015). This was very appreciated by the adolescents to see that there are people who cared for them and wanted to see their success without judging them. Parents also showed much appreciation on these issues and that adolescents can come alone to the clinic if parents agreed with that. Health care professionals were always available to give health information's on various topics, assisting with school projects concerning health issues and doing health assessments before giving them their medications on their check-up visits. All these could help in optimizing the transition of ALWHIV to adulthood care.

5.3.1.4.2 Affordability

Affordability refers to the low cost or reasonable cost of HIV services in all PHC clinics, as well as their ability to be afforded (Vorming et al., 2015). For transition to be achieved in all facilities, ALWHIV should be able to afford the services regarding HIV, meaning that the facility should be within reach and offer services free. Even if the adolescents did not have money for transport, they should be able to walk themselves to the facility to get the service. Services like counselling if they come across some challenges of life, adherence classes or support groups where they can learn from others and many other services scheduled for youth, because they are still like others, irrespective of their condition.

In this study, findings showed that every ALWHIV can attend HIV programmes at free in the government facilities. Most of the facilities visited are found in the middle of the communities where they can be accessed by ALWHIV. Furthermore, the majority of the teenagers may walk to the clinic and receive the treatments they require without having to pay for transportation. Those from far can use buses or taxis because the distance to the facilities are within 5-8 km. Some facilities are next the main road where public transport pass by. But despite all these, the turn-up for ALWHIV is still very low in some facilities. The EM showed that people with long-term illnesses should be taught or empowered to know that their illnesses are being transformed into comprehensive self-management illnesses (Vorming *et al.,* 2015). With good motivation, ALWHIV, especially those living far from health care facilities, could be given transfers and enrol and receive care nearest to their home facilities.

Moreover, findings revealed that some ALWHIV during the interview showed that many of the adolescents were not taking medications. They suggested that if the adherence clubs could be moved from the clinic to the community, maybe more ALWHIV could come and enrol by just seeing their peers. The nurses could come once a month during weekends and give medications too. They further showed that some have defaulted due to anger when they found about their true status. Therefore, ALWHIV need to be encouraged and motivated so that their needs, values, and feelings are identified (Vorming *et al.,* 2015).

5.3.1.4.3 Accessibility

The term "accessibility" refers to the ability to use personal health services on a timely basis in order to get the greatest possible health outcome (National Health Care Disparities Report, 2011). Most of the PHC centres operate from Monday to Sunday. Health professionals start working from 07:00-18:00. Some facilities continue with night duty or call system. Though HIV services are not rendered during the night, ALWHIV could still access the service within the stipulated hours of work, and in case of emergency they can still be attended to, even at night. ALWHIV have the right to visit any facility they want to seek medical help of any sort starting from counselling until the enrolment to care. Some facilities are next to the tarred roads and are easily accessible.

Findings of the study revealed that some ALWHIV and their parents or guardians were having problems with money for transport before they were transferred to the clinics, especially those who started their treatment at the hospital level and were then transferred to the clinics. They did, however, express relief throughout the shift because the distance from home to the clinic is shorter and the expense of transportation is low. Thus, when they were transferred to their nearest health facilities the burden was relieved. Accessibility was also seen to be achieved easily and enhance the health outcomes.

5.3.1.4.4 Acceptability

Acceptability refers to the ability to consent to, accept, receive, or participate in a PHC clinic service.

It is the acceptance of services and the use of such services (Tran et al., 2019). To optimize the transition, ALWHIV should find the service acceptable to them. They should be satisfied with all the services rendered unto them without being stigmatized. The health care professionals should display transparency by explaining every procedure they do to the adolescents and their parents. Health care professionals should include ALWHIV and their parents/guardians in decision-making and allow them to set their own achievable health goals (Vorming *et al.,* 2015).

As part of the strategy the researcher worked with NIMART nurses to counsel ALWHIV to comply with treatments, show them the advantages of joining support groups, adherence clubs or classes. Talking with them using the language they understood most and considering their values in life. If they consented, it should be written down and the date and time, including the venue, given. This might also assist in recruiting many ALWHIV, hence, keeping them in care. In some facilities, support groups were dormant and the researcher through the OPM and the NIMART nurses advocated for full functionality of the support groups and adherence clubs.

5.3.2 Weaknesses

Weaknesses are also classified as internal factors which influence or have the impact on transition of ALWHIV (Concise Oxford Dictionary, 2014). The focus of the debate was on the flaws that surfaced from the findings. Figure 5.2 summarizes the internal factors as weaknesses which can hinder transition to adulthood.

5.3.2.1 Human Resources

One of the study's findings indicated a shortage of nurses as one of the flaws. Each (one) NIMART nurse was assigned to a stream or cubicle. Nurses do not relieve each other in streams, unless if patients in that stream were finished. This is one reason which makes ALWHIV not to want to wait in long queues in the PHC.

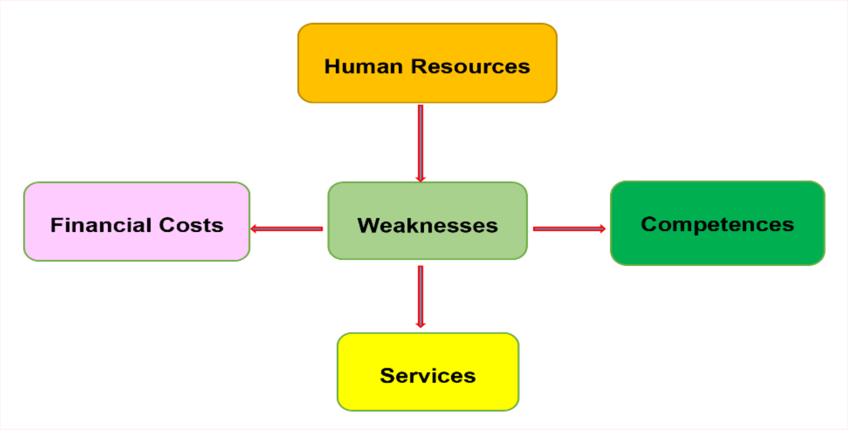


Figure 5.2: Internal factors: Weaknesses

In some facilities, even the infrastructure has been a problem because there might be one consultation or two, but with services combined. On some days though, the staff were available and the space to work in would be minimal considering also the privacy of the patient to be treated in a dignified manner. If an emergency patient arrived the queue becomes slower for the stream combined with emergency services. Those awaiting service for that stream would have to wait in the queue until the patient is stabilized or would be assisted in other streams. Though NIMART nurses were available as the input source, shortage of NIMART nurses remained a weakness to this point. They work as one professional nurse per stream or cubicle on some days. When they go for tea or lunch, even though they rotate, it makes no change because each nurse has patients waiting in the stream, resulting in impatience for ALWHIV queuing or waiting for a longer time. Of the ALWHIV who were interviewed, some responded that nurses were friendly and supportive showing that they were always available for patients. ALWHIV should always be motivated not to focus on what people say, but focus on their goals and what benefits thy would achieve (Vorming, *et al.,* 2015).

5.3.2.2 Competencies

Findings showed that some ALWHIV were very competent and able to manage their medications well. These was observed as the ALWHIV went for their medical check-ups, when health care professionals conduct pill counting during consultations. Parents were acknowledged for putting effort in supporting their children to take medications correctly and in time. That enhance the transition of ALWHIV because some parents and the ALWHIV were supporting one another. Competency was also shown by some parents and guardians when they took the initiative of disclosing the HIV status to their adolescents because it strengthen the relationship between themselves and communication becomes more transparent.

Furthermore, the study revealed that community health workers (CHW) were allocated to facilitate support groups and give health education to the ALWHIV and their parents in support of the program to enhance transition. The findings revealed that some biological parents failed to disclose the status to their children because of fear. Roberts (2018) and WHO (2016) showed that disclosure is a process that needed skill. Furthermore, it gives both parents and adolescents freedom and independence to live their lives and be able to make informed decisions. Since ALWHIV were also neglecting to reveal to their spouses or girlfriends, such non-disclosure became a concern, and others claimed that they lacked the abilities to do so. During the disclosure process, some parents indicated they required help from health care providers.

5.3.2.3 Financial Costs

The findings of this study revealed that some ALWHIV were poor and lacked financial support from their relatives. Due to unemployment and poverty experienced by ALWHIV and their parents, some were failing to join support groups because of money problems, especially those who came from afar. The study showed that some parents and ALWHIV pleaded that grant money received is too little and does not cover their basic needs, and that they should also be given food parcels. The findings showed that the weakness was that the budget for conducting workshops and update review courses seem not to be enough on the side of the nurses. The nurses were not taken for update courses or workshops regularly and sometimes they catch up with the changes late when they receive the guidelines or policies. Drug shortage was a challenge and a weakness, especially for those in regimen 2. If one drug was in short supply, they would go and collect at the hospital where sometimes they also don’t get and would get prescriptions to buy it at a chemist. Some parents and ALWHIV tended not to add value on the use of their money, because some combine the Western medications with the traditional ones because of the culture, values and beliefs they live in. This contributed to poor adherence for both ALWHIV and the parents doing or practicing such systems. With the tablets which make noise, though it is harmless practice, ALWHIV usually took the tablets out of their containers and put them in small plastic bags to avoid noisy containers.

5.3.2.4 Services

5.3.2.4.1 Availability

Shortage of drugs was unavoidable despite ordering in time and referring adolescents to go and collect at the hospitals have negative impact on them when they think of the long queues at the hospital and financial constraints from their families. Health care professionals talked to them politely to go and collect there if borrowing from the nearby facilities failed. ALWHIV often did not go to the hospital for treatment, they waited for their next appointment date without drinking medications. Findings continued to show that others tell the truth that they did not go to hospital and they were not drinking. Another weakness as part of the findings is that ARVs are not collected during the night because of the risks. The risk that they are being used in the production of illegal drugs like Nyaope.

5.3.2.4.2 Affordability

HIV services are affordable everywhere in the public institutions. They are rendered from morning till evening from Monday to Sunday, including holidays, but excluding only during the night. The challenge presented during the summer season when it always rains. The bumpy dangerous gravel roads with potholes delayed early arrival for those using transport; most of the roads were gravel. Taxi fare was not affordable.

5.3.2.4.3 Accessibility

Because of their HIV status, several ALWHIH and their parents did not use their clinics to get HIV services, according to the findings. They would leave their nearby facilities because of fear to be seen and known by those who knew them like friends, relatives and even neighbours. Fear of being stigmatized by HIV sacrificed their accessibility to get service near their homes. The study showed that to those from afar there is poor follow-up because sometimes they lacked money for travelling. Some could not travel and reach their clinics during heavy rains because the rivers became flooded and small bridges were swept away. In some areas potholes and roads which are not constantly maintained made it difficult for the buses and taxis to reach their areas on time. That contributed to ALWHIV to default their appointment day or miss it. Some defaulted for good and some resumed their treatment when roads were conducive for them to travel. Those who did not show up in care after the bad weather, were sent written messages to consult the clinic through the help of the CHW. The quality of care was always maintained by health care professionals and accessibility was possible. However, HIV services were not rendered after hours and during the night.

5.3.2.4.4 Acceptability

In this study, some of the facilities had poor infrastructure which led to poor privacy. Because of the stigma associated with HIV, some ALWHIV and their parents were scared to join the clubs, according to the findings. As stated in the conceptual framework, people must be empowered and motivated to take full responsibility for their health (Vorming et al., 2015). Counselling and HIV education should take place on a daily basis. There should also be public awareness initiatives to try to influence people's minds about stigmatization. Some participants stated that they had to come very early during check-up days so that they could get first positions and go home early.

Thus, because some days nurses were very few, people would be many. Those who stayed nearby said sometimes they went back home and have lunch and come back because the service would be slow combined with poor infrastructure in facilities with minimal space for work. Findings further showed that some people took long in the cubicles and some not even depended on the service to be given for that individual. For example, one coming for family planning without any complaints won’t take much time like the one coming for first ANC booking where services are combined due to poor infrastructure. The researcher, through the OPM of the facilities, advocated for park homes with the department so that ALWHIV could be motivated to use facilities.

The long waiting time in some facilities contributed to the defaulting of ALWHIV because they didn’t want to be seen in those long queues by friends or neighbours as they have feared stigmatization. This is a weakness for many ALWHIV in some facilities, hence, the defaulter rate remains high in many facilities. Though HIV services were not offered during the night because of the safety risk to the staff, like if adolescents could come for counselling services when they are drunk, and results became positive, they could perpetrate violence.

Findings of the study stated that both ALWHIV and their parents still found the HIV services very acceptable. Shortage of staff on some days resulted in long waiting times. If the DoH could hire more professional nurses and enrol them in NIMART courses, transition could be optimal. Figure 5.2 summarizes the internal factors as weaknesses in the transition of ALWHIV following the findings of the study.

5.4 Description of External Factors

External factors are elements or influences that can have an impact on HIV service delivery. They have an impact on how services are delivered in the facility, either as opportunities or threats (Bezuidenhout, 2014). External elements include opportunities, which are qualities that can be exploited to the facility's benefit and are useful in achieving the desired aim of maximizing ALWHIV to adulthood care transition.

Threats are qualities that can have a negative impact on the facility and are damaging in the delivery of services (Bezuidenhout, 2014).

The external elements depicted in Figure 5.3 include political will, economic, socio-cultural, technological, environmental, and legal considerations (PESTLE).

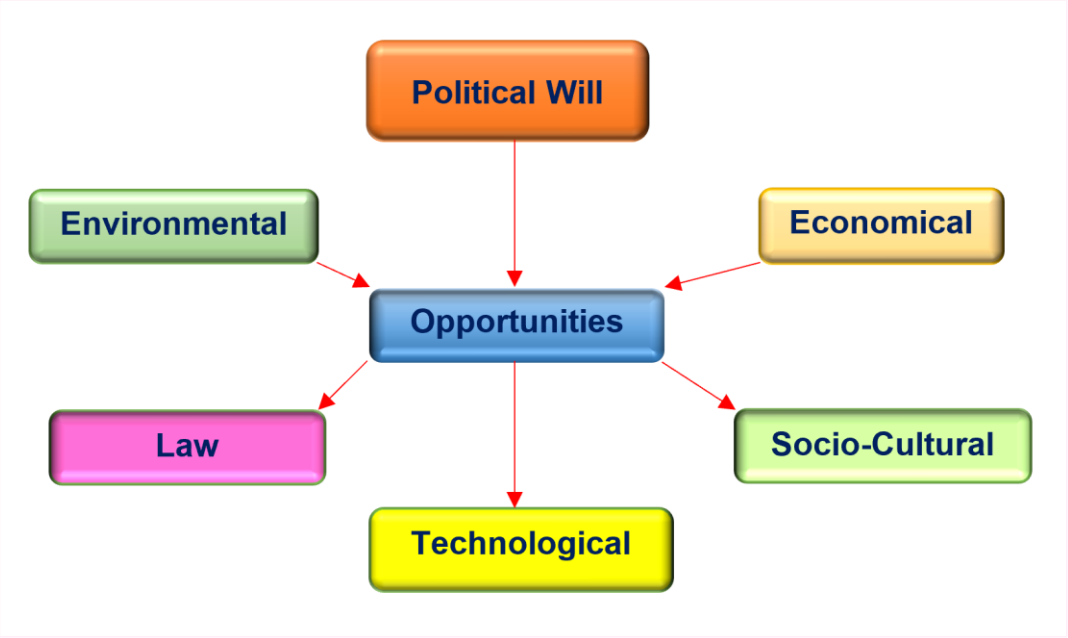


Figure 5.3: External factors: Opportunities

5.4.1 Opportunities

PESTLE will be used to describe opportunities for ALWHIV and their parents or guardians to receive HIV services. The PESTLE approach was utilized in this study to look at the external factors, which are the Opportunities. The following are some of the opportunities that have arisen as a result of the findings:

5.4.1.1 Political Factors

Political variables include the authorities and powers conferred by the country's constitution or government policy. Political influences can have a beneficial or bad impact on an organization (Booyens et al., 2013). The findings revealed that there is political will to establish and sustain a health care service system that brings all of the various health services closer to the community in order to accomplish the strategic planning objectives of universal access to health care facilities. The majority of the hospital's services are now provided at the clinic as well. Because those health practitioners were assigned to the clinic, patients were no longer transferred from the clinic to the hospital for chronic medicine collection, consultation with a doctor, psychologist, dietician, or social worker. The entire clinic follows a resource-sharing model, with services such as dentistry, dieticians, doctor consultations, TB management, and ARV introduction for children and adults, as well as their programs, all provided within the clinic. Even though some of the facilities do not have a visiting doctor, the resource sharing strategy allows health services to remain operational and usable.

South Africa has the Constitution which governs the country and everybody should follow what the Constitution stipulates. Within the Constitution are the Patient’s Rights Charter. Again, nurses have their organization, the South African Nursing Council (SANC) which governs their scope of practice. All these charters protect both the patients and the nurses when they work together in a patient-nurse relationship. In South Arica, HIV is accorded more weight in political camps. If things are not going smoothly in HIV patients, like if there is shortage of HIV medications across the provinces, if political organizations weigh in, the solution came by the blink of an eye (very fast). Non-profit organizations like the Treatment Action Campaign (TAC) is one of the many organizations in South Africa speaking on behalf of and monitoring HIV matters and ARV recipients across the provinces.

By 2030, the DoH aims to have reached its target of having HIV-free generation. But that could not be reached if ALWHIV do not comply with their treatment. The threat remains a matter of confidentiality because political camps don’t agree with that. So, unless a cure is found it will be difficult for the DoH to reach the target because people are infecting others continuously.

Findings of the study showed that disclosure for both ALWHIV and their parents still is the weakest link. ALWHIV has the right to report anywhere if they were mistreated in the health facilities by health professionals. And because HIV goes with the stigma attached, ALWHIV want to protect themselves and their families from all the nasty behaviours they could be subjected to if their status is shared with others. Findings of the study revealed that some ALWHIV and their parents indicated that HIV is a family issue and not to be known by other people, not even relatives. However, if they can find out that their status is known outside their concern, and report to organizations like TAC legal action could be taken.

5.4.1.2 Economic Factors

Most people affected by the HIV pandemic are poor (Booyens *et al.,* 2013). Currently, because of COVID-19 pandemic, unemployment is very high. Some ALWHIV are unemployed, some still at school and some dropped out of school. Some of those who had jobs in the past were retrenched due to the COVID pandemic. Some parents or guardians were also living in poverty and depending on grant money and food parcels from social relief. The government has added R350 to those who are jobless from 18 years and above here in South Africa as a relief measure from COVID-19, but it is very little because the inflation rate is also high and everything is expensive.

Both ALWHIV and their parents, if employed, could buy nutritious food for themselves which will boost their immune system. Again, money would assist them during travelling when going for their appointments or they could join HIV programmes like adherence clubs or support groups where adolescents with chronic diseases meet and share their experiences. According to the report, HIV programs are conducted in all facilities and are provided free of charge to all public health care institutions so that all inhabitants of the country can benefit from them. . These services were made available even in deep rural areas and the standard operating procedures are set for both the communities and the staff working there. All ALWHIV were initiated on treatment before they defaulted, either at the hospital or at the clinic. Therefore, ALWHIV cannot deny the fact of seeking medical assistance because the service is free, very affordable and acceptable. Findings of the study showed that some ALWHIV and the parents lived in poverty and depended on grant money for a living. The money did not cover all their basic needs and they appealed to get food parcels from social relief programmes from the Social Development Department.

5.4.1.3 Socio-Cultural Factors

Through a person's lifestyle, attitude, education, and cultural effects, socio-cultural elements influence his or her health (Vorming, et al., 2015; Booyens et al., 2013). ALWHIV need to be supported by all sectors without any discrimination for them to develop and adapt to good lifestyle behaviour and having a positive attitude towards understanding HIV as part of their health life. Knowledge empowerment on medical adherence should always be given when they come for their appointments (Vorming, *et al.,* 2015). The effects of culture could impact negatively or positively on an individuals' life. Findings of the study showed that some parents who understood HIV matters well took the opportunity to test early in the facilities after being given the information concerning HIV. Some took their children for testing since they were sick for a long time without being cured. The positive attitude and their lifestyle benefited their children as ALWHIV because they started medications early as their diagnoses were also early by the time they started to become sick. This was a great opportunity for both parents and their ALWHIV.

5.4.1.4 Technological Factors

The application of scientific knowledge for practical goals in HIV services is referred to as technological elements (Oxford Dictionary, 2014). They are concerned with or deal with medical advancements and the provision of newly designed equipment (Bezuidenhout, 2014). Technology is becoming more influential in the fourth industrial revolution and gaining more favour in the world. The use of technology is also applicable in health departments. Technology as an opportunity factor plays an important role in registering patients, diagnosing, recording, and tracing of patients. This could be in the form of computers, cell phones, testing kits for medical diagnosing, to mention a few.

The findings of the study indicated that after the clients tested positive, they were registered via a computers programme called TIER.net. These computers are also connected to National Provincial and district levels for monitoring purposes. Furthermore, the study indicated that facilities also have landline phone or cell phones with airtime and data bundles for facility use like when reporting daily and weekly statistics, in some facilities Wi-Fi is also available to make tracking and reporting easy. Some facilities no longer use manual tick registers, but do it electronically on computers. Every month the computer generates a report to indicate those who missed their appointment so that they can be called or traced early for their treatments. After three months if they are not coming for medication the system automatically reports them as defaulters. Findings of the study showed that technology makes it easier also for NIMART nurses and the OMN to even check those whose viral load suppressed at 6 months or at 12 months using a cohort system and intervene quickly. This is also a great benefit to ALWHIV because they prefer quick services, retrieving their files is also quicker and can take one or two minutes. The use of SVS (phones) these days for checking and reporting the tracer medications is also helpful because it allows nurses to see which drugs are in stock compared to the number of patients they have, to avoid under and over stock because ALWHIV become bored if they did not get their supplies. Health care professionals were also trained on the use of computers which also benefited the ALWHIV because consultation time will be reduced. Some will not even have the money to go and collect medicines at the hospital, hence, accessibility will be jeopardized.

5.4.1.5 Laws/Legal Factors

The law/legal factors are rules and regulations that a country acknowledges as governing the behaviour of its citizens and that can be enforced by levying penalties against those who break them (Oxford Dictionary, 2014). The legal factors are relevant to the service circumstances, such as patient care (Bezuidenhout, 2014). SANC rules and regulations oblige all nurses practicing in South Africa to follow the rules and regulations when performing their tasks. The findings revealed that rules, protocols, and laws govern HIV/AIDS concerns such as ALWHIV secrecy and HIV status. Discrimination against patients based on their HIV status is considered a crime.

In South Africa HIV matters are regarded as confidential because a nurse is not allowed to share the status of a client with another person either a close relative like mother, father or any child without the consent of the client. The matter remains confidential between the two people. So, nurses are covered by the law of shared confidentiality within the work environment where they can share the status of the client amongst themselves for the purpose of treating the patient. This serves as a benefit for ALWHIV because health care professionals do not have the right to harm them as clients, physically, emotionally, psychologically or otherwise. The rights of the ALWHIV are always taken into consideration just like others because they are also human beings. Findings of the study showed that health care professionals are provided with guidelines and protocols to execute their duties well. Managers should always monitor the implementation through audits, on site in-service training, attending seminars and workshops to keep themselves abreast with the latest information. These could prevent or minimize lawsuits as a result of mismanagement by patients. If ALWHIV could be stigmatized, s/he could report misconduct of the health care professionals. Laws could also pose a threat to ALWHIV because if they don’t behave themselves correctly towards the health professionals like swearing and threatening them, especially males, they can also be reported for misconduct and be charged by a court of law. To prevent lawsuits during the workshops, nurses should always be motivated and empowered to always use guidelines when consulting patients.

5.4.1.6 Environmental Factors

Environmental influences include the state of the economy, education level, and relationships with family and friends, all of which have a significant impact on health, although the most widely considered aspects include access to and usage of health care services, as well as climate change (Bush, 2016). People may profit or have issues as the seasons change. In this investigation, it was discovered that some of the settlements were dispersed, that some parts were mountainous, and that the majority of the roads were gravel and uneven. Some ALWHIV and their parents alluded that during winter they felt very comfortable because they don't just miss their appointments. They wear their warm clothes and go for their medications, unlike in summer where there are always rain and slippery roads. Even community-based cadres work well in winter doing the tracing of defaulters and other duties as there are no heavy rains, floods and slippery roads. The researcher even got the chance in some areas to talk with the counsellors to enforce maintenance of roads with the roads and transport managers at the municipality for the smooth running of health services.

5.4.2 Threats

The threats were also classified under Political, Economic, Social, Technology, Law and Environment (PESTLE). They helped the researcher to identify the activities which can hinder the facility to achieve its goals. Figure 5.4 summarizes threats as external factors as they occurred from the findings of the study.

Figure 5.4: External factors: Threats for transition of ALWHIV

5.4.2.1 Political Factors (Political Will)

People with long-term illnesses need self-determination, autonomy, and empowerment to be successful. According to the EM, both the patient and the health care professional should negotiate or come to an agreement on how the patient wants to manage their health (Vorming et al., 2015). Therefore, health care professionals like NIMART nurses should be provided with policies, protocols and guidelines for them to keep abreast with information as they are dealing with adolescents and not give outdated information. Findings revealed that sometimes policies and guidelines are received late in the facilities while the information was long out. Non-governmental organizations for people living with HIV could take action against health care providers if wrong information was shared or given to their members. Such could pose a threat in achieving the goal to optimize transition of ALWHIV. The study further showed that both parents and their ALWHIV had problems regarding disclosure which, in turn, prevented them from joining adherence clubs or support groups. This caused some parents and ALWHIV to go and register in faraway clinics so that people who knew them would never see them in the nearby clinics. Because motivation is a driving force to change behaviour (Vorming *et al.,* 2015), NIMART nurses should continue giving counselling until both find and accept themselves without looking at other people outside. Even their medical adherence could improve.

Findings revealed that some parents and ALWHIV travelled more than 5 km to their chosen facilities—usually, those who were avoiding being seen and known by friends, neighbours and relatives in the same village or community. Findings revealed that both Vhembe and Mopani districts are still having scattered villages which also posed a safety risk. During heavy rains which cause slippery roads and floods some defaulted their medications because they cannot reach their facilities. People in the political fraternity should avail themselves during campaigns and strengthen the motivation that using the nearby facility is the best and is cost-effective.

5.4.2.2 Economic Factors

While empowering people to take charge for their own health, motivating them to change their lifestyle or behaviours, they will learn more of their strengths and capabilities (Vorming *et al.,* 2015). These factors could hinder the strategy to optimize transition. Health care practitioners cannot share medical adherence to people who are starving. Economic factors affect ALWHIV and their families because many are from poor family backgrounds where poverty is very rife. Most of the working parents were of the low-income class as domestic workers while others depended on grants for a living. Findings of the study revealed that some parents and ALWHIV requested that they get food parcels from Social Development relief projects because the money they received was very little and could not cover all their basic needs.

The EM revealed that through motivation and empowerment ALWHIV are assisted to grow in all spheres of life, to be able to take decisions in what they do (Vorming *et al.,* 2015). NIMART nurses could also motivate ALWHIV who dropped out of school and are unemployed to start sustainable green projects in clinics and schools, where they would plant and sell the vegetables and earn some income. Facilities, in return, could benefit because the surroundings will be cleaner, hence, those ALWHIV would be monitored and the defaulter rate reduced. Economic factors as threats for ALWHIV and their parents include COVID-19 as another pandemic in our country which increased the unemployment rate. Many of our youth in the country, including ALWHIV, are jobless. As a result of the COVID-19 epidemic, some people who worked in a variety of fields lost their jobs during the lockdown. Some ALWHIV defaulted their treatment since then because they were afraid to contract the disease because PHC facilities were always full, hence, the long queues and slow service due to shortage of staff and poor infrastructure. Thus, the COVID-19 pandemic and its ramifications, is another reason which could hinder the optimal transition for ALWHIV.

5.4.2.3 Socio-Cultural Factors

Knowledge is the master key in the empowerment model (Vorming *et al.,* 2015). As mentioned before, some long-term chronic illnesses are transformed to be self-management of care, and HIV is one of those conditions where people can take charge of their own health. ALWHIV should be empowered with knowledge and motivated to have a vision for the future (Vorming *et al.,* 2015). ALWHIV should be assisted to know their needs, values and believes. To differentiate right from wrong and be able to choose well because they should own and manage their own health. Socio-cultural factors were found to have contributory roles in the transition of ALWHIV to adulthood care. Findings revealed that in adulthood care, ALWHIV can make and take decisions concerning their lives and health. Some don't understand the reason for continuing taking treatments daily as they no longer feel pain or symptoms, thus, another reason for defaulting by some. Therefore, motivation and empowerment should be considered a key role during the ALWHIV transition for adherence purposes (Vorming *et al.,* 2015).

Socio-cultural threats can hinder transition as findings of the study revealed that some ALWHIV were delayed in getting their ARVs because of the effects of family cultures, attitudes of their parents and those revolving around them and poor or lack of understanding of HIV issues, which were problematic. However, some parents did not believe that HIV is real and could affect people in great numbers, whether children or adults. Later when their children started to be ill, some consulted traditional and faith-based healers and some also performed family rituals. But the results were not effective. Moreover, findings continued to show that some parents said that they just agreed to sign for their children to be tested because they were critically ill and that they could die. When the results came out positive, the children were initiated on ARVs. Then few weeks and months later their health improved and they were discharged from the hospital.

Though some parents saw that their children were sick, they did not bother themselves to go for testing, they continued with their beliefs until they or their children died. Many ALWHIV are today orphans because of these belief systems.

This showed that ALWHIV and their parents who believed in using traditional medicines should be motivated and empowered with knowledge not to default taking the medications, even if they go there for something else. Seminars and workshops for traditional healers and faith-based organizations are also important in order to achieve the goal of optimizing transition. Those organizations should also be motivated to refer patients early before they are critically ill if they are not improving under their care.

5.4.2.4 Technological Factors

Amongst the facilities visited for the purpose of this study, some were no longer using manual tick registers, but were consulting patients electronically using computers (e-tick register). If the network is off-line, the service gets slow or is not available at all for a few hours or even the whole day. Therefore, during this time adolescents got bored waiting for files to be retrieved manually and to be consulted as they could not go home without a service. Such interruptions could also hinder optimal transition in some ways. Furthermore, findings revealed that facilities without a landline phone has been given cell phones which are loaded with airtime on a monthly basis. The challenge is that if the air time is used up early before month-end, thus cutting communication with those who missed their appointments and need to be called by nurses, especially those who are from far villages where community-based cadres could not reach because of demarcation boundaries. Besides, that study showed that sometimes ALWHIV and their parents give false address and false phone numbers which makes it difficult for even the community-based cadres to trace them. Findings also showed that besides shortage of drugs, if stock visibility for medications is not reported on a weekly basis, medications could get finished or those with lower needs could be overstocked and for those with greater needs like HIV drugs less are ordered compromising the strategy to optimize transition because ALWHIV could go home without medications. The laboratory specimen tubes sometimes get depleted from the hospital making it impossible for blood to be taken from ALWHIV on their cohort months.

5.4.2.5 Law/Legal

Studies showed that empowerment provides a tool intended to facilitate the inner motivation, to check the knowledge the individual had (Vorming *et al.,* 2015). According to the study's findings, there was no policy in place regarding the disclosure of HIV+ status. Both ALWHIV and their parents were afraid of being stigmatized and discriminated against by society and people they lived with. The findings also found that some parents did not inform their children or love partners about their HIV status, and that some parents are married. Living with the secret also posed challenges to ALWHIV in their relationships. Though everybody has the right to choose, it poses a threat to the DoH to reach or have an HIV-free generation by 2030 as one of their targets. Therefore, for the purpose of medical adherence, NIMART nurses should continue counselling, empowering, and motivating both ALWHIV and their parents so that one day they could feel relieved and understand that disclosure is important for one to be independent in their lives.

5.4.2.6 Environmental Factors

Environmental factors could hinder the optimal transition of ALWHIV because sometimes they cannot be prevented. With all the empowerment and motivation, this could fail the achievement of optimal transition of ALWHIV. The districts where the study was conducted, i.e., Vhembe and Mopani are rural. Some areas are rocky and mountainous and scattered from one another exacerbated by gravel roads. Findings of the study showed that some ALWHIV alluded that during winter it is better even though it is cold because they don’t miss their appointments. Unlike in summer when it is always raining, causing floods and roads to be slippery and treacherous for cars to travel because of the potholes as most of the roads are gravel and not constantly maintained.

Bushes which become dense in summer pose a threat or a weakness to ALWHIV and the parents because those far away from the clinic cannot walk alone because of rapists hiding in the bush or climbing trees to see those who would be vulnerable like adolescents. This resulted in some ALWHIV missing their appointment dates and came when the rain stopped. Again, the COVID-19 pandemic rules posed threats to ALWHIV because they do not allow people to gather in large groups at the same time. ALWHIV could no longer come together as groups for information sharing for the purpose of adherence.

5.5 SWOT Analysis Matrix

Findings and conversations were used to create the SWOT analysis matrix. The positive and negative, internal and external aspects discovered were reflected in the SWOT analysis matrix (Table 5.3). These factors assisted the researcher to achieve the objectives in optimizing the transition for ALWHIV. The external factors are those which can hinder the transition in the facilities, and the internal ones are those which enhance the transition. Strengths, Weaknesses, Opportunities, and Threats were used to create the SWOT matrix. The BOEM approach, which stands for Building from Strength, Overcoming Weaknesses, Exploring Opportunities, and Minimizing Threats, was formed as a result of the investigation. During the discussion above, for both the internal and the external factors, the conceptual framework was integrated within the discussion. The conceptual framework had three core principles following the EM by (Vorming *et al.,* 2015), thus, Empowerment, Motivation and Medical Adherence.

Table 5.3: SWOT Analysis Matrix

	Strengths	Weaknesses	
INTERNAL FACTORS	**Human resources** • In all facilities there were NIMART-trained nurses rendering HIV services to ALWHIV. • All facilities have CHWs to assist in tracing defaulters • In all facilities there is an OMN available to manage and supervise. • Heath care workers were supportive and user-friendly towards the ALWHIV and their parents. • Some health care professionals were trained in a course on youth-friendly services.	**Human resources** • Shortage of NIMART nurses on some days	**INTERNAL FACTORS**
	Competence • NIMART nurses showed	**Competence** • No HIV services rendered during the	

	knowledge and skills when executing their duties. • Most of the professional nurses were trained on NIMART course and some also train youth-friendly courses. • They refer to guidelines and policies before referral of patients. • NIMART nurses showed competence and skills by reviewing patient files during assessment on follow-up days.	night, except in an emergency. • The budget is insufficient for conducting workshops and updates for nurses.	
	Financial cost • HIV services are free in all public health facilities. • Some facilities are within 5-8 km and some can walk themselves while others could use transport. • Teach parents and ALWHIV value for money, motivate them. • Low-income households receive grants and sometimes food parcels from Department of Social Development. • Teach ALWHIV who are unemployed to start green projects so that they can generate some income.	**Financial cost** • High unemployment rate among ALWHIV (those out of school) and their parents-some unable to attend adherence or support classes.	

Continued/…

Table 5.3: SWOT Analysis Matrix (continued)

	Strengths	Weaknesses	
INTERNAL FACTORS	**Services** **Accessibility** • Some clinics visited were within 5 km and some ALWHIV could reach with ease. • Some ALWHIV just walk, some use taxis' or buses.	**Services** **Accessibility** • Gravel roads with potholes delay quick arrival to the clinic • Rainy season	INTERNAL FACTORS
	Affordability • Services for ALWHIV are free and affordable. • Others were able to use own transport.	**Affordability** • Bad roads delayed those from afar in arriving to the clinic early. • Long waiting times.	
	Acceptability • Staff availability, support groups accepted by ALWHIV. • Health workers shared the same language and values with ALWHIV. • Youth-friendly health care workers accepted by ALWHIV and parents.	**Acceptability** • Fear and stigma affect acceptance to adherence classes or groups. • Some ALWHIV fetch medications in faraway clinics because they don't want to be seen by friends and relatives.	
	Availability • HIV services always available at clinic. • Health care workers always available to render services • Youth-friendly services always available.	**Availability** • Collection of medication not rendered during the night.	
EXTERNAL FACTORS	**OPPORTUNITIES**	**THREATS**	EXTERNAL FACTORS
	Political • HIV guidelines and policies for management. • S.A. Constitution (Patient's rights) • Availability HIV directors and committees at all levels. • Some ALWHIV receive grants and food parcels from social workers. • NGO partnerships with DoH.	**Political** • Mismanagement may lead to lawsuits. • Shortage of human and material resources to provide the services. • Insufficient supervision by programme managers.	
	Socio-cultural • Availability of staff sharing the same language with patients. • Family members, guardians, peers, pastors provide support. • Socializing with others at school and in churches • Support groups or adherence	**Socio-cultural** • Modern versus tradition • Some believe in traditional practices causing delay in getting ARVs.	

	clubs.		
EXTERNAL FACTORS	**TECHNOLOGY** • All the clinics visited had a cell phone with airtime or landline phone and SVS phone connected to National line for reporting drug availability. • All facilities had a computer with Tier.net programme, HPRS connected to National. • Laboratory and Transport services scheduled for all clinics to collect specimens and bringing the results. • Technology for tracking lab results are available. • WiFi installed in some facilities and patients registered.	**TECHNOLOGY** • SVS cell phones can be lost or stolen. • WiFi not working in some clinics; still using manual registers for data. • Computer can be broken or crashed or stolen.	EXTERNAL FACTORS
	Law/Legal • ALWHIV has the right to privacy and confidentiality. • SANC regulations • HIV guidelines and policies are available in all facilities.	**Law/Legal** • Fear for litigation of both staff and ALWHIV. • Failure to make correct assessments. • Failure to record legibly.	
	Environmental • Winter season recommended as better by ALWHIV. • Some facilities near tarred roads and user-friendly.	**Environmental** • Summer seasons recommended not to be user-friendly due to rain, slippery roads, floods and bushy villages. • Gravel roads with potholes delay quick arrival. • COVID-19 and its laws pose a big threat to everybody.	

5.6 Development of the Strategy

The SWOT matrix guides the creation of the strategy. The researcher developed the strategy using the information from the SWOT matrix. As shown in Table 5.4, the strategy to maximize ALWHIV transition to adulthood care was established by grouping: Building on strengths, Overcoming weaknesses, Exploring opportunities, and Minimizing threats (BOEM).

Table 5.4: Developed Strategy through BOEM

Strengths	**Building on Strengths**
Availability of staff	• Work with NIMART-trained nurses to develop schedules to start support

trained NIMART nurses and OMN.	groups or adherence clubs where they are not functional and to strengthen the available ones in some facilities. • OMN should monitor the functionality of adherence or support groups once initiated.
Empowerment of NIMART nurses (knowledge and skills)	• Arrange with programme managers in the districts to offer workshops and seminars as part of support and supervision to NIMART nurses. • OMN should encourage on-site in-service training. • OMN should conduct audit on ALWHIV files to see if assessments and recordings are done properly.
Availability of HIV guidelines/protocols	• Work with OMN and programme managers to ensure that updated guidelines and protocols are always available. • Programme managers should have awards ceremony annually for best NIMART nurses in the implementation of guidelines.
Friendly health care workers who provide health education and health assessment	• OMN to ensure that all NIMART nurses are trained on youth friendly services for the sake of ALWHIV.
Support from health care workers, parents, guardians, peers.	• Motivate NIMART nurses to give support to ALWHIV, their parents and guardians. • Appreciate parents and guardians who are supportive to their ALWHIV at all levels of life and encourage those who are not supportive to do so. • During support group meetings encourage peers to support one another like when they are at school (avoid bullying each other).
Availability of Tier.net programme	• Work with OMN to ensure that data captures update this programme regularly. • Ensure that OMN and NIMART nurses understand the generated report on this programme.
Given weekend check-up dates if attending Saturday classes.	• Motivate NIMART nurses to continue the good work for these ALWHIV as they are also human beings with needs like others and the right to get educated.
Tracing of ALWHIV by phone.	• Advocate for enough airtime and data bundles from logistic manager at the district which can be used for the whole month at the clinic for tracing those who missed or default treatment because some don’t want CHW in their families.
Lab results explained to ALWHIV and parents or guardians.	• Motivate health care workers to continue treating people with dignity and respect, not as objects. • ALWHIV and their parents have the right for information.
Availability of drugs	• Plan with the OMN how best they can monitor SVS drug reporting • Again, work with the OMN to monitor ordering of drugs to avoid shortage • OMN should ensure that all drugs in the pharmacy room are controlled using a stock card on daily basis.
Availability of resources like vital monitors, lab equipment’s and stationary for collecting	• Motivate the asset manager to have revenue enough to service or maintain equipment’s if not buying new ones. • OMN should ensure that inventory is done on monthly bases to ensure that equipment’s are always available and functional.

blood specimens	

Continued/…

Weaknesses	**Overcoming Weaknesses**
Shortage of NIMART nurses working alone sometimes.	• Motivate the Provincial DoH to employ more registered nurses who will be trained on NIMART course.
ALWHIV waiting for service during teatime and lunch time (Long queues resulting in long waiting time).	• Work with the OMN to advocate for park homes where there is inadequate space as needed by the ideal clinic realization. • Where the space is enough with all the resources encourage nurses to use appointment strategy to book ALWHIV and others for appointment. • Educate ALWHIV and the community on the importance of adhering to time and date given. • Motivate staff to practice time management at all times and to rotate during meal times if possible.
Both ALWHIV and their parents had challenge with disclosure.	• Motivate NIMART nurses and counsellors to strengthen the issue of disclosure during consultation. • Disclosing earlier assist both individuals to be independent and take responsibility for their own health. • Early disclosure had more benefits for ALWHIV as mentioned before in the study.
ALWHIV said tablets make noise.	• Work with NIMART nurses to teach ALWHIV to accept who they are and to love themselves. • Teach ALWHIV to mind their business like if they worry about the noise another adolescent with diabetes mellitus is worried about the injection for their whole life every day.
Culture, values and believes interfere with adherence.	• Plan with NIMART nurses to understand different cultural believes and their values to people. • Very important talk with the language best heard by the patient to prevent misinterpretations. • Clarify myths. • Above all win the ALWHIV to adhere to the medications never to stop medications.
Some ALWHIV defaulted medications	• Plan with NIMART nurses to find the root cause around defaulting and deal with it. • Strengthen counselling. • Encourage ALWHIV to join support group or information sharing classes.
Opportunities	**Exploring Opportunities**
Political benefits like TAC.	• Working with partners from non-governmental organizations became a benefit when the DoH in Limpopo was under administration, and there was shortage of HIV drugs, when political camps came on board, within few days all hospitals and clinics were having the stock and patients got helped.
Establishment of support group for	• Plan with OMN and NIMART nurses to start support and adherence clubs as they could assist ALWHIV to find themselves and adhere to their

adherence purposes.	treatments. - This will assist in the reduction of defaulter's rate increasing the retention or the remaining in care high. - Where support groups are there but dormant, encourage NIMART nurses to start recruiting as they come for the appointment visits.
Information sharing to empower ALWHIV	- Work with youth friendly nurses and NIMART nurses to give information ALWHIV and others came for youth activities in the facility. - Though it's time for COVID-19 if youth are available and not many observe COVID rules and spend 5-10 minutes just to give information.
Reduce waiting time	- Work with the OMN to advocate for park homes where there is inadequate space as needed by the ideal clinic realization. - Where the space is enough with all the resources encourage nurses to use appointment strategy to book ALWHIV and others for appointment. - Educate ALWHIV and the community on the importance of adhering to time and date given. - Motivate staff to practice time management at all times and to rotate during mealtimes if possible.
SANC regulations	- Motivate NIMART nurses and other staff to abide by the rules, guidelines and policies and scope of practice to avoid disciplinary by mother body, removal from the roll and litigations
Availability of HIV directorates at National, Provincial and District level	- Engage the district HIV programme directors to visit facilities as support visit to NIMART nurses and to check if implementation of guidelines is followed. - Programme managers should not visit as fault finders but empower nurses and give praises where they are due or to those who are doing well.
Threats	**Mitigation of Threats**
Political interference	- Working with the OMN and the shop stewards of different organizations in the facility (clinic committees) could calm the situation when problems arise and could assist both ALWHIV and staff to work harmoniously. - Nurses fear to be in the court of law and to be removed from the roll or their licence to practice taken away.
High rate of defaulter.	- Planning with OMN and NIMART nurses to find the root cause from ALWHIV because this might be caused by many factors and once ALWHIV default in care it is difficult to win them back to HIV care.
Fear to be stigmatized	- Planning with OMN and NIMART nurses and engage other community structures to conduct awareness campaigns, workshops especially when COVID rules are at ease. - Celebrating world AIDS day in the disadvantaged communities - Advocating for ideal clinic infrastructure either building new ones, renovation of old ones or adding park homes and employing more staff to better the service.
COVID-19 rules restrict people to gather around in large numbers	- Both health care professionals and ALWHIV are affected by this pandemic badly. - Working with HIV programme directors and OMN to counsel and debrief nurses in this time of need cold be appreciated. - Some ALWHIV have defaulted their treatments since this pandemic because of fear to contract the virus as they don't feel any pain. - Advocate for fogging or fumigation once a month with the district risk

	manager since deep cleaning in the facilities is a challenge (shortage of cleaners).
Bad roads to PHC facilities	• Advocate with the municipal manager for roads and transport to maintain roads constantly especially those with potholes so that ambulances, cars taxis and buses could access the area for those who are far from the clinic.

5.7 Summary of Strategy Development

Figure 5.5 presents the summary of the process followed to develop the strategy to enhance optimization of transition of ALWHIV to adulthood.

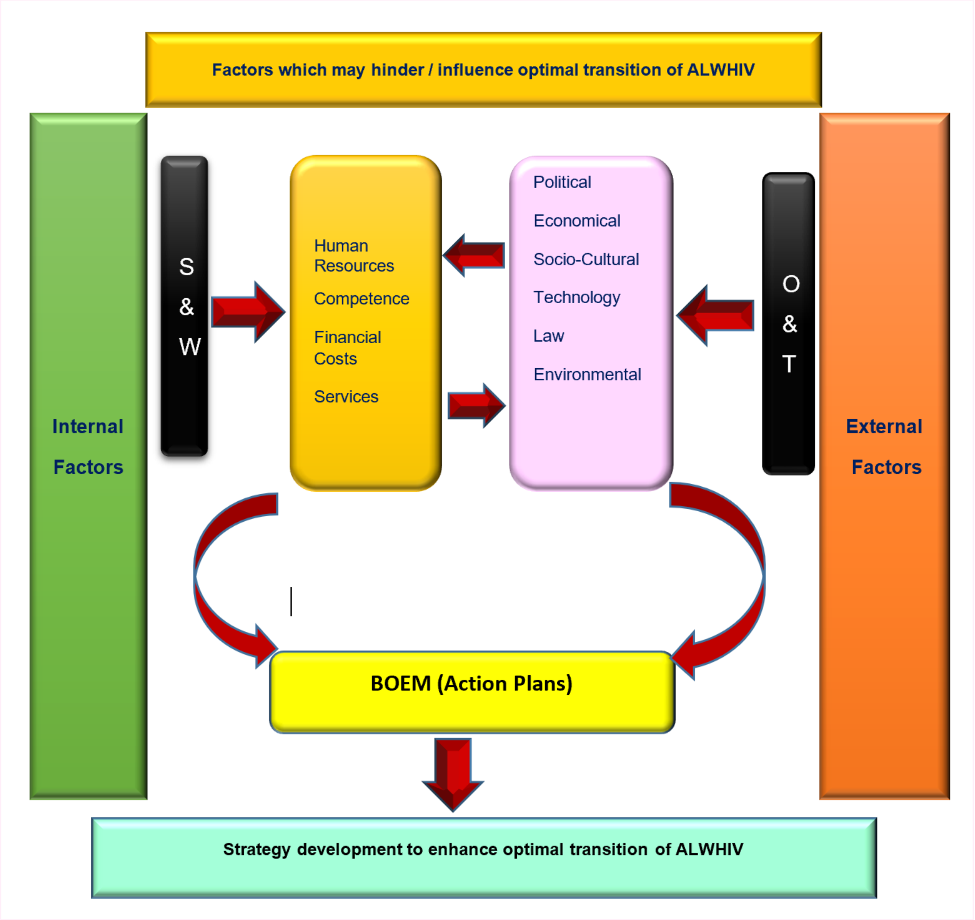


Figure 5.5: Developed strategy for Transition

5.8 Summary

This chapter focused on strategy development, and a SWOT analysis was used to identify internal elements such as strengths and weaknesses that could affect ALWHIV's transition to maturity. PESTLE analysis was utilized to uncover external elements that were influencing or obstructing ALWHIV's optimal transition to maturity through opportunities and threats. During the strategy's consideration of the data, the EM of change was incorporated. BOEM (Building on Strengths, Overcoming Weaknesses, Exploring Opportunities, and Minimizing Threats) was used to create the action plan. It was critical to establish a strategy that would optimize the transition of ALWHIV to adulthood in the Limpopo Province's selected districts. The researcher offers the validation of the developed strategy in the following chapter.

CHAPTER 6

VALIDATION OF THE DEVELOPED STRATEGY FOR ALWHIV

6.1 Introduction

The previous chapter discussed how to establish a strategy using SWOT analysis, a SWOT matrix, and practical strategies such as maximizing strengths, limiting weaknesses, exploring opportunities, and minimizing threats (BOEM). The goal of the plan was to improve ALWHIV's transition to adulthood. This chapter focuses on testing the developed strategy to see if it can be used to help the ALWHIV. The researcher deemed it relevant to use the NIMART nurses to validate the strategy as they would be the ones expected to implement the developed strategy.

6.2 Validation of the Developed Strategy

Validation, according to Chinn and Kramer (2015), is a scientific procedure in which the created study is checked for accuracy. Validation was carried out in this study to ensure the applicability of the created method and to address the gap highlighted by the study's findings. Validation was carried out by 18 NIMART trained nurses from the study's facilities in the Vhembe and Mopani district. Two nurses were sampled from the facilities were the study was conducted. The generated plan was assessed to see if it matched the requirement for authenticity and utility.

6.3 Methodology for Validation of the Developed Strategy

Validation, according to De Vos et al. (2012), is a process for determining the credibility of empirical information in relation to a discipline's scientific model. The generated study was validated through the use of a quantitative research method to optimize the transition of adolescents living with HIV. In the main study, the two districts of Vhembe and Mopani were sampled, and they were also utilized to validate the devised technique.

Four (4) PHC facilities in Makhado municipality, 3 in Thulamela municipality and 2 in Greater Giyani where the ALWHIV were accessing health care services were used. The validation strategy took a quantitative design. The respondents were chosen using probability sampling technique, in the facilities where the study was conducted, two NIMART trained nurses were sampled from the list of all NIMART nurses. All those with NIMART course were given the chance to participate if having an interest. The researcher prepared two pieces of papers written 'yes'. Those who hand pick 'Yes' paper and agreed to participate they become the despondence, if they don't want to be part of the study , they put back the papers mixed and given those who want to participate for hand picking. The sampling process was explained above. In this context, eighteen (18) NIMART-trained nurses who are providing HIV care to ALWHIV at PHC were sampled.

6.4 Data Collection

The researcher scheduled a date with the NIMART nurses who were involved in the project and set a date for the purpose of issuing the research questions. Meetings were held in their facilities because the research was not funded, the researcher failed to get a common venue as it was expensive. The researcher stated that the goal of the validation was to analyse the strategy's applicability and efficiency in order to optimize ALWHIV transition. The participants were given semi structured questions, having the space to write their comments. Participants were given two weeks to complete the questions, and a date for collection was given. The researcher provided each participant with a summarized copy of the developed BOEM strategy (Table 6.1). A worksheet for actionable checklists were provided to read and to have their input to improve the strategy. On the agreed date of the workshop, the researcher attended the workshop with the NIMART nurses. A brief overview of the research, the study's findings, and the established strategy were provided.

Building on strengths, overcoming weaknesses, exploring possibilities, and minimizing risks were discussed by participants in four groups (BOEM). The researcher acted as a facilitator, allowing the participants to discuss and ask clarifying questions, as well as provide feedback on how to improve the strategy's quality. The participants were also given self-administered questionnaires to complete, which the researcher used to validate the method. An area was provided at the end of each intervention for participants to write their opinions or remarks. As the study came to a close, the researcher made some closing remarks to express his gratitude to all of the participants. The participants signed the attendance register, (Refer to Annexure M on Page 247 to see the tool used to validate the developed strategy).

Table 6.1: Checklist of actionable plans

Building on Strengths	
Strategy Activities	
Human resources Staff availability	• NIMART nurses should always be available and enough for HIV services to optimize transition. • Service delivery should be user-friendly to all adolescents.
Developing functional AC	• Develop schedules to start functional support groups, adherence clubs and empowerment classes for youth. • Strengthen available adherence clubs if they are dormant or inactive to optimize transition of ALWHIV. • OMN to monitor the functionality of support groups for optimal transition of ALWHIV.
Support system	• NIMART nurses should be supportive to ALWHIV and their parents to strengthen counselling on disclosure for optimal transition. • Programme managers should conduct supervision support quarterly to assist optimal transition of ALWHIV.
Computer literate	• NIMART nurses should be empowered on Tier.net programme to check ALWHIV who missed their appointment and to do early tracing for optimal transition.
Trustworthiness	• Build rapport with ALWHIV to gain trust, to assist with optimal transition of ALWHIV. • Teach them to know what shared confidentiality means to avoid confusion.
Drug Availability	• Availability of drugs and functional material resources at all the times
Policies/Guidelines	• Always give ALWHIV updated new information as health care professionals to optimize transition.

Accessible services	• NIMART nurses should always avail themselves during weekends for those adolescents attending Saturday classes. • Empower ALWHIV and orientate them on the use of appointment system. • Teach them time management to optimize transition. • Services should always be available, affordable, accessible and acceptable.
Strategy	**Activities**
Human and material resources	• Motivate the DoH in Limpopo to employ more professional nurses who will be trained NIMART course to enhance optimal transition of ALWHIV in facilities. • Advocate for park homes where there is poor infrastructure to enhance optimal transition of ALWHIV.
Management of long waiting time	• Strengthen the use of appointment system where there is adequate infrastructure. • Educate ALWHIV on using youth zones and out of school hours or time. • Motivate staff on time management to avoid complaints through long waiting time. • Fast track waiting lines or queues • Facilities with more staff to consider moving support groups to the community where CHWs and a lower category nurse could be allocated for support and giving medications.
Counselling	• Strengthen counselling on disclosure to increase acceptability of status to ALWHIV it could optimize transition. • Strengthen adherence to medication to reduce defaulter's rate and utilization of condoms to prevent re-infections.
Drug utilization	• Have sufficient drugs available in stock, use SVS report to identify understock and overstock of drugs. • Order drugs in good time, follow schedules, to optimize transition. • Borrow from nearby facilities or hospitals if depot is having shortages to optimize transition.
Empowerment	• Teach ALWHIV assertive skills and to love themselves for who they are in motivating them to join support clubs. • Clarify myths to avoid misunderstanding and talk to the language best heard by the clients to optimize transition.
Strategy	**Activities**
Policies	• Ensure availability of updated policies and guidelines are available to consult ALWHIV on current information to optimize transition.
Awareness campaigns Budget	• Teaching traditional healers and faith-based leaders to understand HIV matters, and encourage them to let their followers not to stop clinics or hospital medications could optimize the transition. • Parents and ALWHIV who receive social grant should be taught the value of using money cost-effectively, especially those from afar to avoid defaulting due to financial constraints.
Training	• Every health care professional should be NIMART and computer literate.

	• Train cadres or CHWs to be peer leaders for support to optimize transition. • Trained peer leaders could be promoted to lead support groups for information sharing to optimize transition
Partnership	• Non-Governmental Organizations (NGOs) like the Foundation for Professional Development (FPD) and others could assist with workshops and seminars for updates, this could enhance optimal transition of ALWHIV.
Use of allied	• Utilization of CHW for tracing defaulters.
COVID-19 rules versus health education	• Though its' COVID-19 use 5-10 minutes in giving information if ALWHIV are available including others.
Empowerment	• Use appointment time and teach them to adhere to time scheduled. • Teach nurses to comply and work within their scope of practice to avoid litigations and to enhance optimal transition of ALWHIV. • Encourage nurses to enter competitions on award giving ceremonies as it boosts morale and could assist in optimizing transition.
Strategy	**Actions**
Clinic committees	• Engage clinic committee to work hand in glove with the clinic staff to avoid unnecessary complaints from ALWHIV.
Environmental factors	• Encourage the supervisor for roads and transport to see the importance of roads maintenance for accessibility of health services and to optimize transition.
Causes of defaulting	• Identify factors causing ALWHIV in defaulting, poor preparation during transition could hinder optimal transition.
Awareness campaigns	• Post-COVID-19 work with community stakeholders in creating awareness campaigns to address stigma to fast track optimal transition.
Infrastructure	• OPMs to work with clinic committees to advocate for park homes where the infrastructure is poor with no enough space to market the service to the new adolescents to optimize transition.
COVID-19	• Motivate the district risk manager for fogging and fumigating facilities following COVID-19 positive clients as this could hinder optimal transition.

6.5 Data Analysis

Descriptive statistics was used to analyse responses of the respondents and that was expressed in frequencies and percentages.

6.5.1 Presentation of the Validation Results

The results were presented utilizing the actionable plans indicated in Table 6.1 by the researcher. The participants agreed that the strategy was relevant to the field of work and that it may assist in optimizing the transition of ALWHIV to adulthood care.

6.5.1.1 Biographical Data of the Participants

The participants' biographical information is shown in Table 6.2. A total of 18 people were chosen to take part in the validation of the newly designed approach. All of the volunteers were South Africans who were familiar with the cultures and beliefs of the people they were serving. The age group ranged from 20 to 59 years old, indicating that they were familiar with the Department of Health's culture and were useful in confirming the strategy created. The participants were chosen because they were providing HIV health care on a daily basis. The knowledge and skills they possess were valued to be relevant to validating the developed strategy. Most of them had a diploma/degree in Nursing and a specialty in primary health care (PHC) and all were NIMART-trained nurses.

Table 6.2: Biographical data of participants (n=18)

Variable	Characteristics	Frequency (n)	Percentage
Gender	Male Female	7 11	39% 61%
Age	20–29 30–39 40–49 50–59	2 5 8 3	11% 28% 44% 17%
Ethnicity	Venda Tsonga Pedi	11 7 0	61% 39% 0%
Professional Rank	Clinical Nurse Practitioner Registered Nurse	12 06	67% 33%
Professional Qualification	Basic Diploma/Degree in Nursing Honours/master’s in nursing	15 03	83% 17%
Years of Experience	>5 years	3	17%

	6-10 years	7	39%
	<11 years	8	44%
Years of being trained on NIMART	>2 years	5	28%
	<2 years	13	72%

6.5.1.2 Presentation of Results

Table 6.3 summarizes the participants’ responses from the Strategy Validation process.

Table 6.3: Response from Strategy Validation

Strategy	Activities	Response
Human resources Staff availability Developing functional AC	• NIMART nurses should always be available and enough for HIV services to optimize transition.	100%
	• Service delivery and should be user-friendly to adolescents.	100%
	• Develop schedules to start functional support groups, adherence clubs and empowerment classes for youth.	100%
	• Strengthen available adherence clubs if they are dormant or inactive to optimize transition of ALWHIV.	100%
	• OMN to monitor the functionality of support groups for optimal transition of ALWHIV.	100%
Support system	• NIMART nurses should be supportive to ALWHIV and their parents to strengthen counselling on disclosure for optimal transition.	100%
	• Programme managers should conduct supervision support quarterly to assist optimal transition of ALWHIV.	100%
Computer literate	• NIMART nurses should be empowered on Tier.net programme to check ALWHIV who missed their appointment and to do early tracing for optimal transition.	100%
Trustworthiness	• Build rapport with ALWHIV to gain trust, to assist with optimal transition of ALWHIV.	100%
	• Teach them to know what shared confidentiality means to avoid confusion.	100%
Drug Availability	• Availability of drugs and functional material resources at all the times.	100%

Policies/Guidelines	- Always give ALWHIV updated new information as health care professionals to optimize transition.	100%
Accessible services	- NIMART nurses should always avail themselves during weekends for those adolescents attending Saturday classes.	100%
	- Empower ALWHIV and orientate them on the use of appointment system.	100%
	- Teach them time management to optimize transition.	100%
	- Services should always be available, affordable, accessible and acceptable at all times.	100%
Overcoming Weaknesses		
Strategy	**Activities**	**%**
Human and material resources	- Motivate the DoH in Limpopo to employ more professional nurses who will be trained NIMART course to enhance optimal transition of ALWHIV in facilities.	100%
	- Advocate for park homes where there is poor infrastructure to enhance optimal transition of ALWHIV.	100%
Management of long waiting times	- Strengthen the use of appointment system where there is adequate infrastructure.	100%
	- Educate ALWHIV on using youth zones and out of school hours or time.	100%

Continued/…

Table 6.3: Response from Strategy Validation (continued)

Overcoming Weaknesses		
Strategy	**Activities**	**%**
Management of long waiting times	- Motivate staff on time management to avoid complaints through long waiting time.	100%
	- Fast track waiting lines or queues.	100%
	- Facilities with more staff to consider moving support groups to the community where CHWs and a lower category nurse could be allocated for support and giving medications.	100%
Counselling	- Strengthen counselling on disclosure to increase acceptability of status to ALWHIV it could optimize transition.	100%
	- Strengthen adherence to medication to reduce defaulter's rate and utilization of condoms to prevent re-infections.	100%
Drug utilization	- Have sufficient drugs available in stock, use SVS report to identify understock and overstock of drugs.	100%
	- Order drugs in time, follow schedules, to optimize transition.	100%
	- Borrow from nearby facilities or hospital if depot is having shortage to optimize transition.	100%
Empowerment	- Teach ALWHIV assertive skills and to love themselves for who they are in motivating them to join support clubs.	100%
	- Clarify myths to avoid misunderstanding and talk to the language best heard by the clients to optimize transition.	100%
Exploring Opportunities		
Strategy	**Activities**	**%**
Policies	- Ensure availability of updated policies and guidelines are available to consult ALWHIV on current information to optimize transition.	73%
Awareness campaigns Budget	- Teaching traditional healers and faith-based leaders to understand HIV matters and encourage them to let their followers not to stop clinics or hospital medications could optimize the transition.	100%
	- Parents and ALWHIV who receive social grant should be taught the value of using money cost-effectively, especially those from afar to avoid defaulting due to financial constraints.	100%
Training	- Every health care professional should be NIMART and computer literate.	100%
	- Train cadres or CHWs to be peer leaders for support to optimize transition.	100%
	- Trained peer leaders could be promoted to lead support groups	100%

	for information sharing to optimize transition.	

Table 6.3: Response from Strategy Validation (continued)

Strategy	**Activities**	**%**
Partnership	• NGOs like FPD and others could assist with workshops and seminars for updates, this could enhance optimal transition of ALWHIV.	100%
Use of allied	• Utilization of CHW for tracing defaulters.	100%
COVID-19 rules versus health education	• Though its COVID-19 use 5-10 minutes in giving information if ALWHIV are available including others.	89%
Empowerment	• Use appointment time and teach them to adhere to time scheduled.	100%
	• Teach nurses to comply and work within their scope of practice to avoid litigations and to enhance optimal transition of ALWHIV.	100%
	• Encourage nurses to enter competitions on award giving ceremonies as it boosts morale and could assist in optimizing transition.	100%
Mitigation of Threats		
Strategy	**Actions**	**%**
Clinic committees	• Engage clinic committee to work hand in glove with the clinic staff to avoid unnecessary complaints from ALWHIV.	100%
Environmental factors	• Encourage the supervisor for roads and transport to see the importance of roads maintenance for accessibility of health services and to optimize transition	100%
Causes of defaulting	• Identify factors causing ALWHIV in defaulting, poor preparation during transition could hinder optimal transition.	100%
Awareness campaigns	• Post COVID-19 work with community stakeholders in creating awareness campaigns to address stigma to fast track optimal transition.	100%
Infrastructure	• OPMs to work with clinic committees to advocate for park homes where the infrastructure is poor with no enough space to market the service to the new adolescents to optimize transition.	100%
COVID-19	• Motivate the district risk manager for fogging and fumigating facilities following COVID-19 positive clients as this could hinder optimal transition.	100%

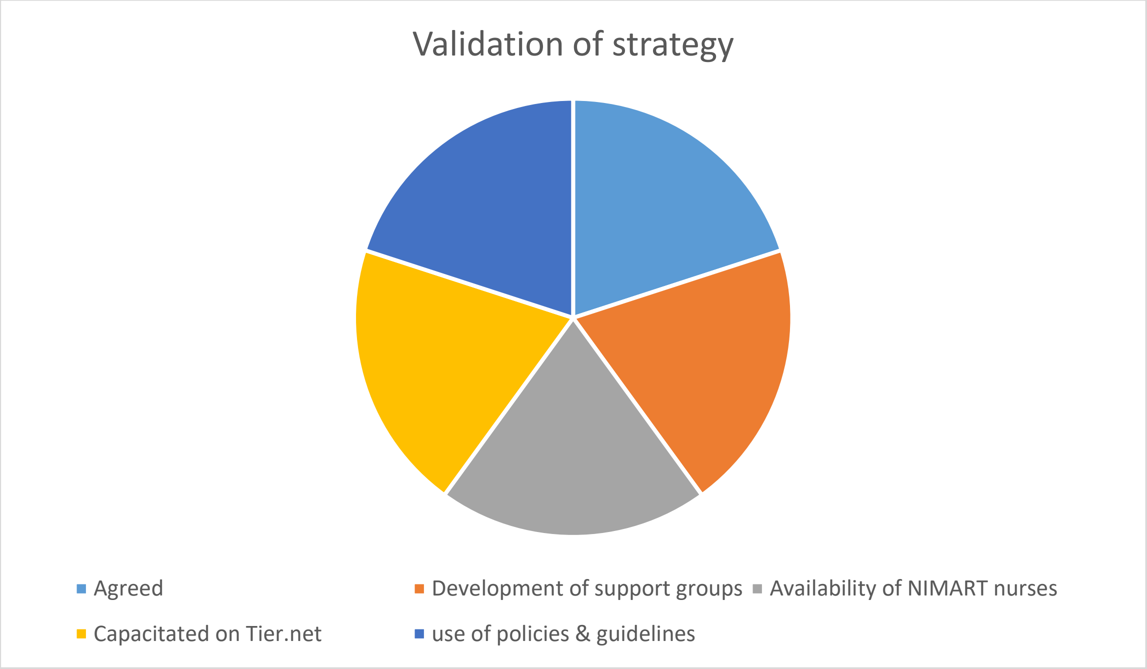
6.6 Discussion of the Validation Results

This section discusses the findings in terms of their strengths, shortcomings, opportunities, and threats for the developed strategy to optimize the transition of adolescence living with HIV.

6.6.1 Strengths and Weaknesses

The debate that follows is focused on strengths and flaws.

6.6.1.1 Strengths



Validation of strategy was done by 18 respondence who agreed to be part of the study. All the respondence agreed with the established method to maximize ALWHIV transition to adulthood based on the validation results. To build on strengths we should overcome the weaknesses. All participants **(100%)** strongly agreed that NIMART nurses should always be available for adolescents whether positive or negative with HIV to offer services and that they should be friendly towards them. Roberts, 2018 attest to the above, showing that health care professionals should be empowered with knowledge and skills for them to provide holistic services to the people. **100%** of participants strongly agreed that development of support groups, empowerment classes or adherence clubs are important for all adolescents with chronic conditions, and that community-based cadres should assist in maintaining them once they are established and managers should assist in monitoring the functionality to optimize the strategy. UNAIDS, 2017 in their study revealed that people suffering from the same chronic condition should be grouped together, to start support classes in the facilities, where they could come together and share their experiences thus it could help others to deal with their obstacles in life.

Furthermore the study revealed that health care professionals should be more supportive to children and their parents or families who are desperate and going through hardships so that they remain in care for a long time. All participants (**100%)** strongly agreed that NIMART nurses should be supportive to both ALWHIV and their parents to gain trust so that they can disclose the status to their children and be able to talk about it as it is difficult for many people. But because of staff shortage they are failing to give satisfactory individual support to the clients. Roberts (2018) revealed that disclosure is no one-day job, but it is a process which needs to be dealt with thoroughly, following the steps as discussed in the previous sections above.

Furthermore, all participants strongly agreed that all health care professionals should be computer literate and know how to use programmes like Tier.net. **100%** participants strongly agreed that drug availability should be found in pharmacy and depot to prevent these adolescents from defaulting because some families depend solely on their clinics due to financial constraints. All participants agreed that programme coordinators should ensure that new updated policies and guidelines reach the facilities in time. **100%** of the participants agreed that during weekends and holidays NIMART nurses should always be available at work to offer service for ALWHIV, they should also teach them on how the appointment system works. Studies revealed that people are living in the technology world , and therefore employees should be technology literate and move away from doing things manually (Mark, et al, 2019; Abadiga, et al, 2020).

The main goal in terms of enhancing strengths was to increase the number of NIMART nurses in order to improve the transition of ALWHIV to adulthood. The one responsible for training at the district level should always have a sufficient budget for training new staff and conducting update workshops for nurses.

6.6.1.2 Weaknesses

Findings showed that all participants agreed that if DoH in Limpopo could hire the staff or professional nurses who will be trained in the NIMART course that would assist in optimizing the transition, shortage of staff could hinder optimal transition. **100%** of participants showed that managers in the facilities where the space is inadequate should motivate the department to provide park homes if building new structures is not possible because it is a strong factor which could hinder optimal transition. Vorming, et al, 2015 attest that for the institution to yield good production, the employer should provide all the necessary materials to their employees hence the working environment should be conducive. This could assist to curb the long waiting queues and promote optimal transition of ALWHIV. All participants (**100%**) agreed that fast-tracking of long waiting queues and managing time by the staff could reduce unnecessary complaints. **100%** agreed that with more or enough staff moving support groups to the communities could motivate ALWHIV to comply with their medications and reduce defaulter rate hence new enrolment could increase. Furthermore, **100%** agreed that poor communication and lack of confidence could hinder disclosure between parents and ALWHIV and affect optimal transition. **100%** agreed that shortage of drugs could hinder optimal transition and some ALWHIV are from poor families, therefore, ordering should be done in time and SVS report should be analysed to detect stock shortages or stock surpluses. Borrowing stock from other facilities could be done to close the identified gap which could hinder optimal transition. **100%** agreed that myths or false statements should be clarified because it could hinder optimal transition of ALWHIV.

6.6.2 Opportunities and Threats

The following topics focused on Threats and Opportunities.

6.6.2.1 Exploring Other Opportunities

Findings of the study showed that **100%** of the contributors strongly agreed that guidelines are available, but **27%** did not agree that they arrive in the facility in time; **73%** attested that policies are available, but were not given enough attention. Studies showed that for people to be productive at work, they should be provided with policies and guidelines to keep them abreast with what is happening around them (WHO, 2016; Mark, et al, 2019 & Abadiga, et al, 2020). Participants strongly agreed (**100%)** that traditional leaders and faith-based leaders who honour the invitations during campaigns receive information on HIV matters and motivated to refer their patients before they are critically ill if they are not getting better in their care. Findings also showed that **100%** of participants agreed that during empowerment the information for budgeting should be taught so that ALWHIV and families who are financially constraints could learn to save time and money by using facilities next to them rather than travelling to far clinics for the services (Vorming, et al, 2015). Because we are living in the fourth industrial revolution, when technological literacy is required, **100%** of participants strongly agreed that health care workers should be computer literate.

The DoH is introducing electronic tick registers which are already in use in some facilities. Newly employed professionals should be trained in NIMART courses immediately to optimize transition. All the participants agreed that training cadres to be peer supporters could be an opportunity to the staff and help to optimize transition of ALWHIV. **100%** agreed that good partnership with NGOs could benefit ALWHIV and optimize transition as the nurses could be supported with workshops to benefit the youths.

According to the findings of the study, **89%** of participants agreed that if adolescents are available, they should be given mass education while waiting for consultations, as long as the COVID-19 regulations are followed. Vorming, et al, 2015 revealed that every time when ALWHIV are in the health institution, they should be empowered by knowledge concerning all the spheres of life, so that they can take informed decisions in all their actions. **11%** never agreed or denied that health information should not be given during the COVID-19 period, but allow ALWHIV to take medications and go home. Health information would be given post-COVID-19, unless the situation needs urgent attention**.**

6.6.2.2 Threats

Findings following this strategy regarding minimizing threats showed that **100%** of all participants found it accommodating without any activity that they disagreed upon. Participants (**100%)** strongly agreed that facilities should have functional clinic committees who liaise with nurses to encourage good relationship with the society because it reduces complaints. **100%** of participants showed that clinic committee members could also work with other community structures outside the facility to ensure that roads are also maintained by roads and transport officers for the sake of services for all youth in the community so that youth services are accessible and affordable. The participants (**100%)** further revealed that it is clear and acceptable to try and find the root causes of the high defaulter rate amongst the ALWHIV as it hinders transition, medical adherence could improve. **100%** of participants showed that clinic committee members could also work hand in glove with the OPM in requesting park homes in facilities where there is not enough space for the services to prevent ALWHIV from running away due to long queues. **100%** of participants showed that following COVID-19 positive cases, the department should send infection control teams for deep cleaning or fogging of the facility because adolescents could be threatened, and this can also hinder transition.

6.7 Applicability and Suitability of the Developed Strategy

The established technique was found to be suitable and relevant by all participants in maximizing the transition of ALWHIV to adulthood care. Participants indicated that the strategy developed was good, clear, acceptable, and understandable. If it can be implemented, it could improve the ALWHIV after they transit to adulthood because at primary care they were not encountering problems. Participants were also of the view that if facilities could have available human and material resources, complimented with good infrastructure, the strategy could be easily implemented and ALWHIV could be attracted and motivated to remain in our care while reducing the rate of defaulters. Furthermore, results showed that advocating for park homes can also curb shortage of space in the facilities where the space is not enough. The respondents clearly indicated that facilities working shift hours, for example, on Wednesdays, there are more nurses, but the space is not adequate to accommodate them making nurses to linger around. Generally, the strategy is good and understandable, and the implementation would be easy.

6.8 Summary

The method was tested on 18 NIMART respondents who were not involved in the main trial. The respondents were chosen because of their expertise in HIV matters as they consult ALWHIV on a daily basis rather than using ALWHIV and their parents because they sometimes could not be more informative. In all the facilities where the study was conducted, two NIMART nurses per facility. The researcher prepared or cut small papers, write two yeses only on the two of them. Put them in a plastic bag, where each respondents would pick one. Those who picked the yes paper and agreed to be part of the study became the respondents. Semi -structured questions were supplied to them for completion and were given the date when the questionnaires would be collected by the researcher. Validation was done by distributing questionnaires to respondents who chose the ‘yes’ piece of paper and volunteered to be part of the study. They were given two weeks to complete the questions. The researcher called (phoned) the respondents a day before to remind them about collection of the questionnaires. All 18 participants completed the questionnaires; thus, no redundant ones were found. The researcher allowed the participants to make their recommendations or suggestions which the researcher considered. The study's conclusions, limits, recommendations, and summary will be presented in the following chapter.

CHAPTER 7

LIMITATIONS, RECOMMENDATIONS, SUMMARY AND CONCLUSIONS

7.1 Introduction

This chapter would entail study's limitations, recommendations, and conclusion of the study suggestions.

7.2 Purpose of the Study

The goal of the study was to devise a strategy that would optimize the transition of ALWHIV patients from childhood to adulthood care in Limpopo Province, South Africa.

7.3 Objectives of the Study

The following were the three objectives, which were divided into three phases:

7.3.1 Phase 1: Qualitative Research Objectives

- Explored and describe the knowledge of ALWHIV during transition to adulthood care.
- Describe challenges faced by parents/guardians during the transition to adulthood care.
- Explore the support given to ALWHIV by parents/guardians during the transition to adulthood.

7.3.2 Conclusion Based on the Development of the Strategy: Phase 2

- The researcher develop the strategy that would enhance the optimal transition of ALWHIV to adulthood.

- The strategy was developed using Chinn and Kramer (2015) SWOT analysis.

- From the results of the study, the researcher identified the strength and weaknesses within the PHC facilities which could hinder or enhance the transition of ALWHIV to adulthood.

- Opportunities and Threats from outside the facility were also identified.

- After SWOT analysis, the BOEM strategy was developed, which means building on strengths, overcoming weaknesses, exploring opportunities and minimizing threats as identified from the results which could impact the transition strategy negatively or positively.

- This lead us to phase 3 which is validation of strategy.

7.3.3 Conclusion Based on Validation of the Developed Strategy: Phase 3

- To test the plan that has been established. This was done by 18 NIMART nurses sampled from the same facilities where the study was conducted.

- Those respondents were not part of the study, but the researcher saw them fit and suitable, chose them because of their knowledge on HIV matters to see if the strategy developed was relevant and applicable rather than using the participants in this regard. The researcher also commend them to give inputs if any to can modify the strategy.

- Though some of the things could not be changed overnight, like infrastructure and employment of staff, some of the CHW's with grade 12 could be trained to back-up the nurses and do peer or patient accompaniment after the ALWHIV had transitioned.
- These CHW's could do accompaniment, strengthen adherence and follow up visits and encourage joining of support groups till the adolescent understand and be able to manage himself or herself.
- By so doing the rate of defaulters could be reduced.

7.4 Summary

The aim of the study was to develop the strategy to optimize the transition of ALWHIV in the selected areas of Vhembe district, Limpopo Province. The objectives of the study were met by collecting data from the participants, thus, ALWHIV and the parents/guardians to achieve objectives 1- 3 of the study through qualitative approach. Objective 4 was validation of the strategy which was achieved by collecting data from the NIMART nurses, the respondents who were not part of the study, but chosen because of the relevance and their knowledge and expertise in HIV matters though quantitative approach. Findings of the study though SWOT analysis and BOEM approach assist the researcher in developing the strategy which is recommended to be used in the PHC facilities where the study was conducted because results could not be generalized.

7.5 Limitations of the Study

The study was undertaken in the selected districts which are Vhembe, Mopani Thulamela and other districts like Waterberg, Capricorn and Sekhukhune were not selected. The limitations of the study were that research findings are contextual and cannot be generalized to other districts and municipalities of Vhembe and Mopani and not the whole of Limpopo Province.

7.6 Recommendations

The researcher conducted this study to develop a strategy to optimize transition of ALWHIV to adulthood. The study's findings, as well as the established strategy, will be submitted to the Department of Health at the provincial and district levels. The goal was to encourage and motivate ALWHIV to take responsibility for their own health as they reached maturity care independence. Nursing practice, nursing education, and research were all used to make recommendations. Basically, a plan to optimize ALWHIV's transition to adulthood had been developed. It is suggested that the proposed strategy be applied in the primary health care facilities where the study was conducted, namely in the districts of Mopani and Vhembe. Recommendations made were to improve support and encourage disclosure to ALWHIV as they transit to adulthood, and that they remain in care until such time that a cure is found.

7.6.1 Nursing Practice

- Work with district to increase human and material resources (infrastructure) to ensure a successful transition.
- Ensure that all professional nurses are NIMART-trained nurses to curb the shortage in making the strategy a success.
- Health facilities should be user-friendly to accommodate all teenagers with their own teenage problems so that they can be free to share their

life experiences.

- Present the findings to the managers to enhance procurement of park homes in facilities where there is a dire need of space.
- Work with managers to assist ALWHIV who are stable and compliant to register with the service provider (CCMDD) to receive their treatments at the external pick-up points nearby.
- CHWs can assist in tracing of defaulters and in maintaining support groups to be functional.
- Assist NIMART nurses during the preparations for transition of ALWHIV to adulthood.
- Assist policymakers in the district or province during the updates of adolescents on HIV guidelines or policies.

7.6.2 Nursing Research

The researcher proposes further research amongst the ALWIHV:

- Challenges that ALWHIV and their parents faced concerning disclosure.
- Challenges that ALWHIV experienced regarding sexuality versus disclosure issues.
- Challenges of condom utilization amongst adolescents.
- Cultural beliefs that delayed proper diagnosis of HIV.

7.6.3 Basic Education

- Basic education on HIV matters should be included in school curricula so that the youth become aware and understand the meaning around stigma and to support its condemnation as it may lead adolescents to adhere to treatment.

7.7 Contributions

My contribution in conducting this research was the development of a strategy to optimize the transition of adolescents living with HIV to adulthood at the selected districts of Vhembe in in Limpopo Province of which I successfully did.

7.8 Conclusions

The main aim of the study was to develop the strategy to optimize transition of ALWHIV in the selected district of Limpopo Province. The study followed a mixed design and conducted in three phases as follows: In phase 1, it was empirical data where the objective was to explore and describe the knowledge of ALWHIV during transition to adulthood and to describe challenges faced by parents/guardians during the transition to adulthood. Phase 2 was the development of a strategy to optimize the transition of ALWHIV which was achieved by using PESTLE and SWOT. The findings and BOEM assisted the researcher also in the development of a strategy. Phase 3 was validation of strategy developed whereby the researcher used NIMART nurses because of their knowledge and expertise in HIV matters as the information could assist in the strategy developed, and this phase was done using quantitative approach.

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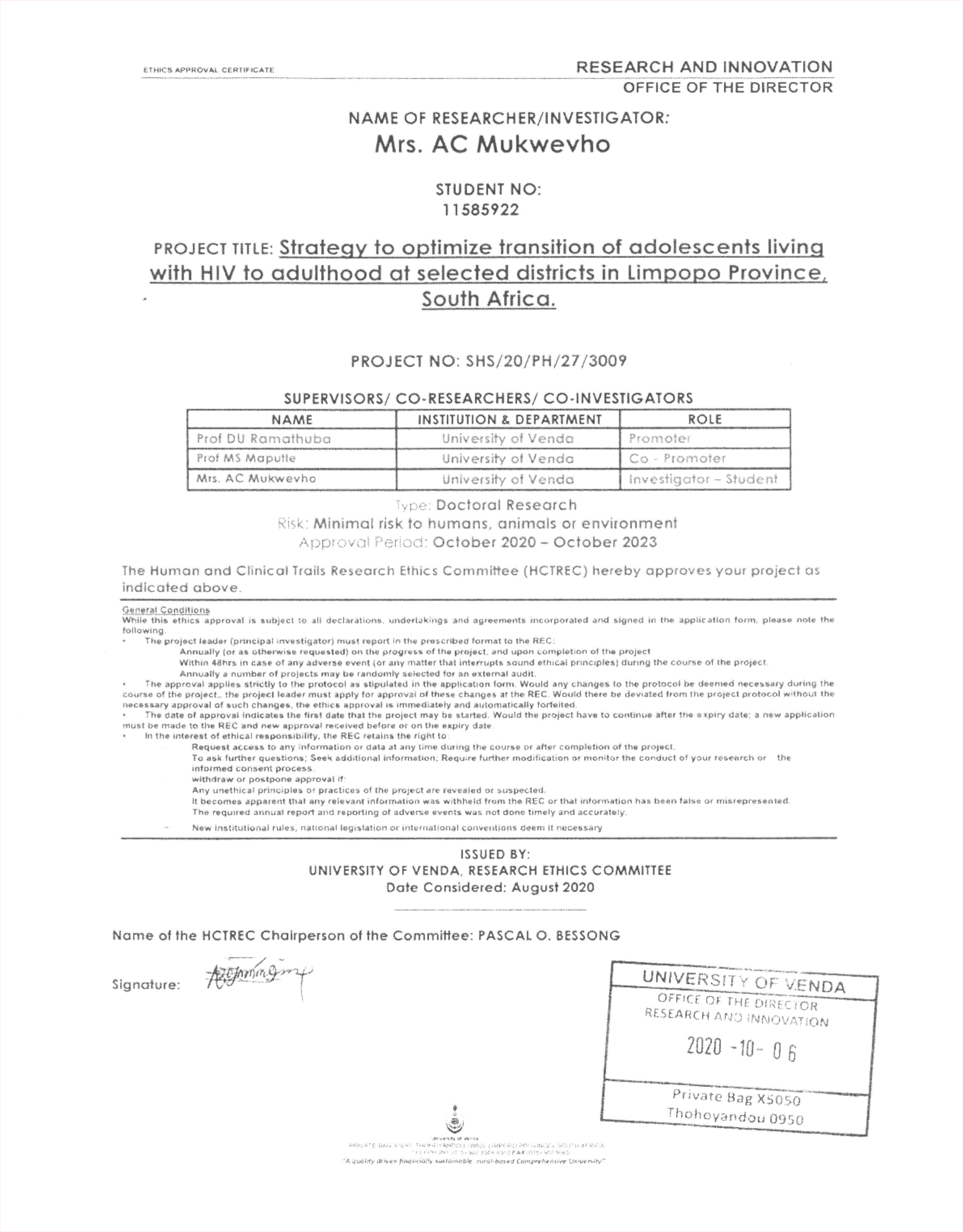
ANNEXURE A

ETHICS CLEARANCE CERTIFICATE FROM THE UNIVERSITY OF VENDA



ETHICS APPROVAL CERTIFICATE

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mrs. AC Mukwevho

STUDENT NO:
11585922

PROJECT TITLE: Strategy to optimize transition of adolescents living with HIV to adulthood at selected districts in Limpopo Province, South Africa.

PROJECT NO: SHS/20/PH/27/3009

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Prof DU Ramathuba	University of Venda	Promoter
Prof MS Maputle	University of Venda	Co - Promoter
Mrs. AC Mukwevho	University of Venda	Investigator – Student

Type: Doctoral Research
Risk: Minimal risk to humans, animals or environment
Approval Period: October 2020 – October 2023

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

General Conditions

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

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

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

Name of the HCTREC Chairperson of the Committee: PASCAL O. BESSONG

Signature:

UNIVERSITY OF VENDA
OFFICE OF THE DIRECTOR
RESEARCH AND INNOVATION
2020 -10- 06
Private Bag X5050
Thohoyandou 0950

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
"A quality driven financially sustainable, rural-based Comprehensive University"

ANNEXURE B

LETTER TO THE DEPARTMENT OF HEALTH

School of Health Sciences
University of Venda
P/Bag x5050
Thohoyandou
0950

01 March 2019

Limpopo Provincial PHC Manager
P/Bag x9302
Polokwane
0970

Dear Sir/Madam

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH

I, Mukwevho Azwinndini Cecilia, student number 11585922, am a PhD student in Nursing at the University of Venda. I am conducting a study titled: Strategy to optimize the transition of adolescents living with HIV to adulthood at selected areas of Limpopo Province, South Africa.

The study will be conducted in ARV health facilities such as clinics and gateway clinics in hospitals. The study is conducted under the supervision of Prof M.S. Maputle and Prof D.U. Ramathuba. The study seeks to develop an information strategy to support adolescents living with HIV/AIDS in preparation for transiting to adulthood care. It is hoped that this will fully empower them with knowledge to take responsible decisions. All adolescents, parents/guardians and NIMART nurses in South Africa will benefit from the study.

The interview will be conducted to people who will consent to the study and ethical considerations will be observed. The name and dignity of the participants will be preserved by observing the following ethical standards throughout the research, voluntary participation, freedom to withdraw without penalty and informed consent. Participants' names will remain anonymous throughout the research process. Audiotapes and digital data will remain under lock and key and will be destroyed two years after the publication of the report. The information related to the interview will also be accessible by my supervisors and an independent coder.

Thank you in advance for your support

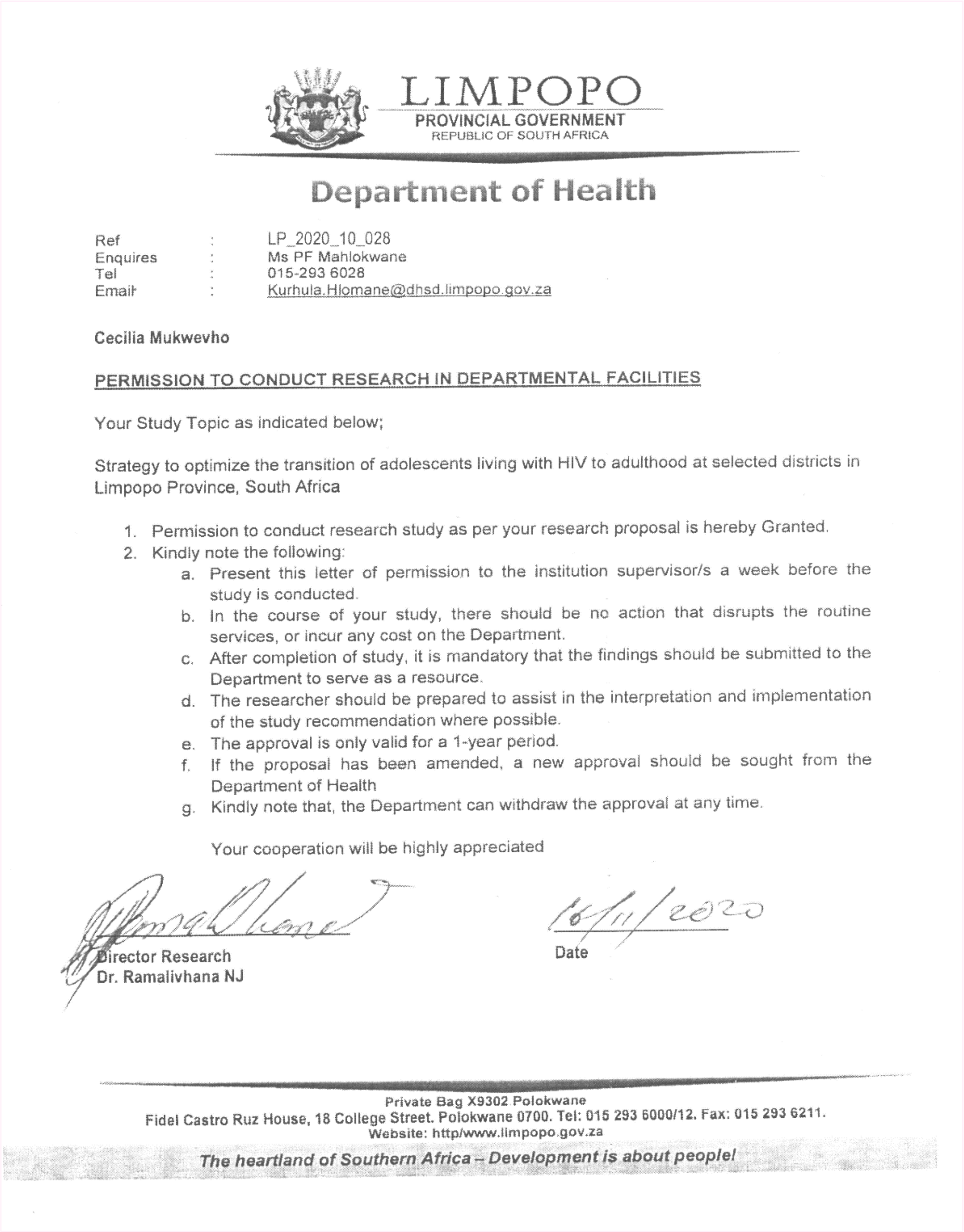
Yours Sincerely

Researcher

A.C. Mukwevho

ANNEXURE C

PERMISSION FROM THE DEPARTMENT OF HEALTH TO CONDUCT THE STUDY



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

Ref : LP_2020_10_028
Enquires : Ms PF Mahlokwane
Tel : 015-293 6028
Email : Kurhula.Hlomane@dhsd.limpopo.gov.za

Cecilia Mukwevho

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

Strategy to optimize the transition of adolescents living with HIV to adulthood at selected districts in Limpopo Province, South Africa

1. Permission to conduct research study as per your research proposal is hereby Granted.
2. Kindly note the following:
    a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
    b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
    c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    e. The approval is only valid for a 1-year period.
    f. If the proposal has been amended, a new approval should be sought from the Department of Health
    g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

Director Research
Dr. Ramalivhana NJ

16/11/2020
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

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ANNEXURE D

LETTER TO THE DISTRICT

P.O. Box 441,
Vuwani
0952
Enquiry: Mukwevho A.C
Cell No: 079 633 7626

The District Executive Manager (DEM)
Name of District
……………………………………

Dear Sir/Madam

Request for Permission to Conduct Research Study

I Mukwevho A.C, student number 11585922 hereby request to conduct a study in the facilities under your district. The study is conducted to fulfill the requirements of Doctor of Philosophy at the University of Venda in the School of Health Sciences.

The topic of my study is: Strategy to optimize the transition of adolescents living with HIV to adulthood in Limpopo Province, South Africa.

The research findings may assist in improving the care of ALWHIV to optimize their transition to adulthood. Furthermore, the study will be conducted with consenting participants. Participants will be allowed to withdraw from the study at any time without being victimized. Confidentiality will be maintained throughout the study.

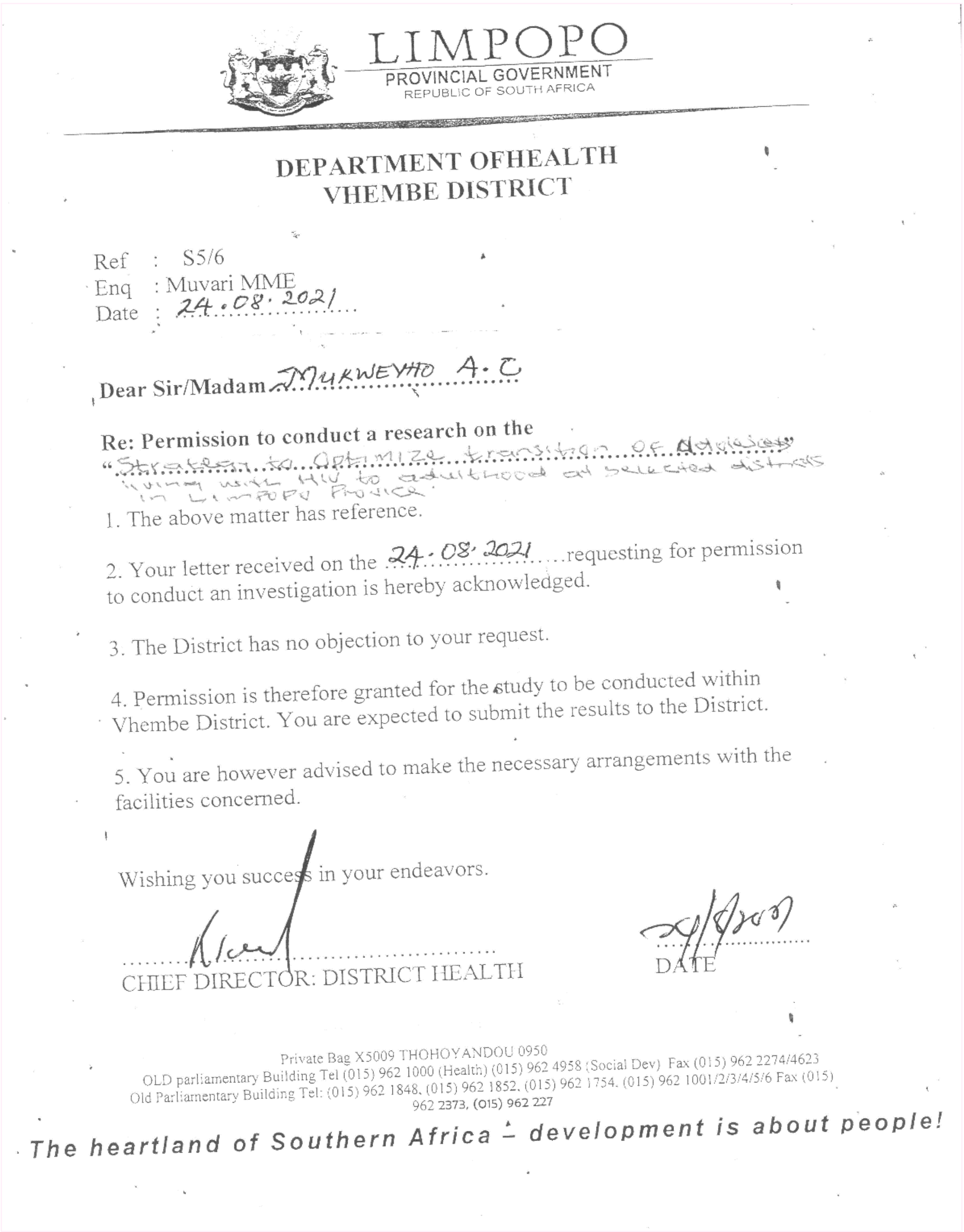
I will be happy if my application is approved.

Yours Faithfully

A.C. Mukwevho

ANNEXURE E

PERMISSION FROM VHEMBE DISTRICT DEPARTMENT OF HEALTH TO CONDUCT THE STUDY IN LIMPOPO PROVINCE



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OFHEALTH
VHEMBE DISTRICT

Ref : S5/6
Enq : Muvari MME
Date : 24.08.2021

Dear Sir/Madam MUKWEVHO A.C

Re: Permission to conduct a research on the "Strategy to Optimize transition of Adolescents living with HIV to adulthood at selected districts in Limpopo Province**"**

1. The above matter has reference.

2. Your letter received on the 24.08.2021 requesting for permission to conduct an investigation is hereby acknowledged.

3. The District has no objection to your request.

4. Permission is therefore granted for the study to be conducted within Vhembe District. You are expected to submit the results to the District.

5. You are however advised to make the necessary arrangements with the facilities concerned.

Wishing you success in your endeavors.

CHIEF DIRECTOR: DISTRICT HEALTH

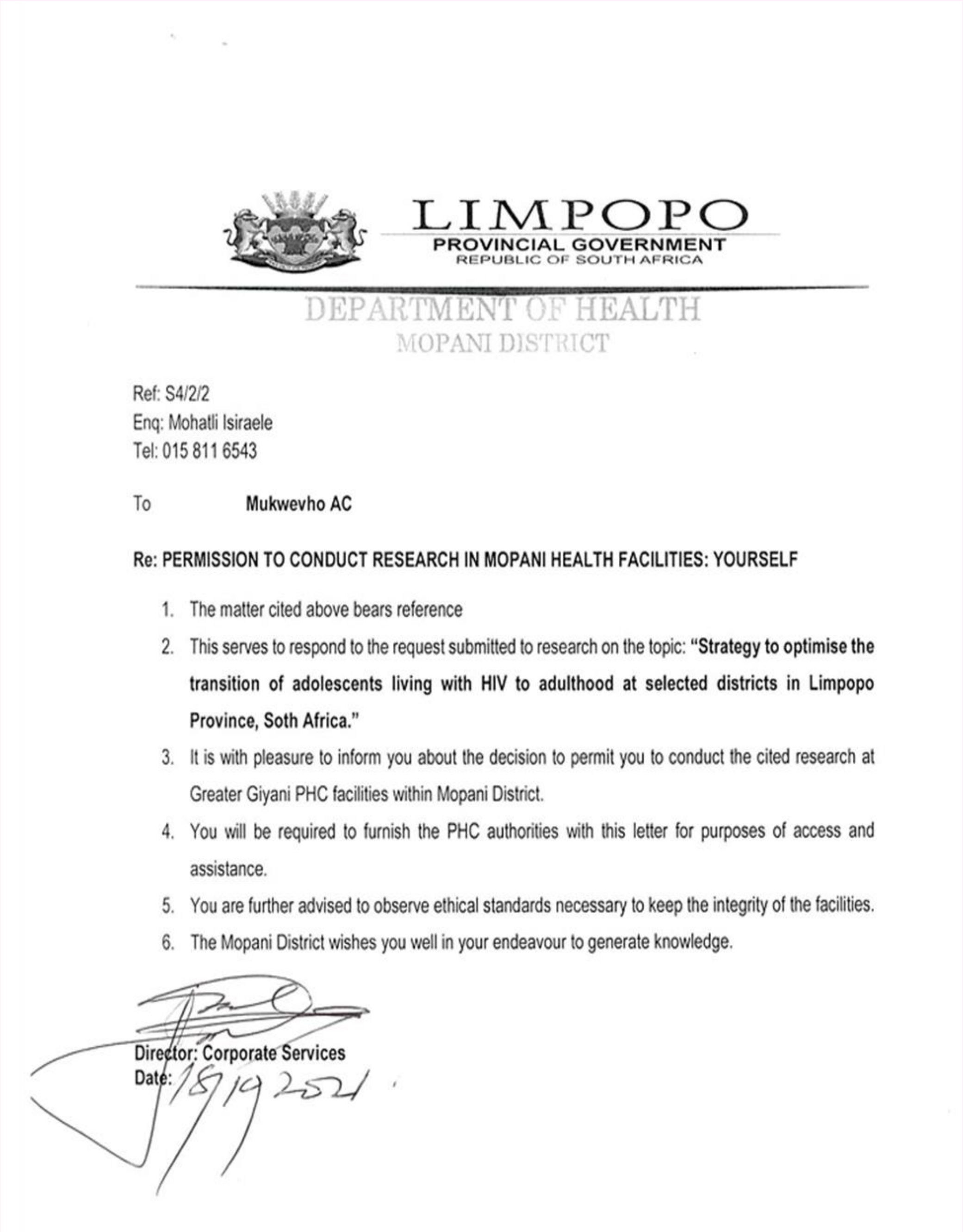
24/8/2021
DATE

Private Bag X5009 THOHOYANDOU 0950
OLD parliamentary Building Tel (015) 962 1000 (Health) (015) 962 4958 (Social Dev) Fax (015) 962 2274/4623
Old Parliamentary Building Tel: (015) 962 1848, (015) 962 1852, (015) 962 1754, (015) 962 1001/2/3/4/5/6 Fax (015) 962 2373, (015) 962 227

The heartland of Southern Africa – development is about people!

ANNEXURE F

PERMISSION FROM MOPANI DISTRICT DEPARTMENT OF HEALTH TO CONDUCT THE STUDY IN LIMPOPO PROVINCE



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA
DEPARTMENT OF HEALTH
MOPANI DISTRICT

Ref: S4/2/2
Enq: Mohatli Isiraele
Tel: 015 811 6543

To **Mukwevho AC**

Re: PERMISSION TO CONDUCT RESEARCH IN MOPANI HEALTH FACILITIES: YOURSELF

1. The matter cited above bears reference
2. This serves to respond to the request submitted to research on the topic: **"Strategy to optimise the transition of adolescents living with HIV to adulthood at selected districts in Limpopo Province, Soth Africa."**
3. It is with pleasure to inform you about the decision to permit you to conduct the cited research at Greater Giyani PHC facilities within Mopani District.
4. You will be required to furnish the PHC authorities with this letter for purposes of access and assistance.
5. You are further advised to observe ethical standards necessary to keep the integrity of the facilities.
6. The Mopani District wishes you well in your endeavour to generate knowledge.

Director: Corporate Services
Date: 18/10 2021

ANNEXURE G

UNIVEN INFORMED CONSENT

RESEARCH ETHICS COMMITTEE

UNIVEN Informed Consent

Title of the Research Study:

Principal Investigator/s/researcher: (*Name, qualifications*)

Co-Investigator/s/supervisor/s: (*Name, qualifications*)

Brief Introduction and Purpose of the Study:

Outline of the Procedures: (Responsibilities of the participant, consultation/interview/survey details, venue details, inclusion/exclusion criteria, explanation of tools and measurement outcomes, any follow-ups, any placebo or no treatment, how much time required of participant, what is expected of participants, randomization/group allocation)

Risks or Discomforts to the Participant: (Description of foreseeable risks or discomforts to for participants if applicable e.g. Transient muscle pain, VBAI, post-needle soreness, other adverse reactions, etc.)

Benefits: (To the participant and to the researcher/s e.g., Publications)

Reason/s why the Participant May Be Withdrawn from the Study: (Non-compliance, illness, adverse reactions, etc. Need to state that there will be no adverse consequences for the participant should they choose to withdraw)

Remuneration: (Will the participant receive any monetary or other types of remuneration?)

Costs of the Study: (Will the participant be expected to cover any costs towards the study?)

Confidentiality: (Description of the extent to which confidentiality will be maintained and how will this be maintained)

Research-related Injury: (What will happen should there be a research-related injury or adverse reaction? Will there be any compensation?)

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

(Supervisor and details) Please contact the researcher (Tel no.), my supervisor (Tel no.) or the University Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

General:

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

ANNEXURE H

CONSENT FORM

Statement of Agreement to Participate in the Research Study:

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

Full Name of Participant: ………………………….. Date: ………………….. Time: …..………

Signature: ………………………….

I, ……………………….………………… herewith confirm that the above participant has been fully (*Name of researcher*)

informed about the nature, conduct and risks of the above study.

Full Name of Researcher: ………………………….. Date: ………………….. Time: ….……….

Signature: ………………………….

Full Name of Witness (If applicable): ……………………………. Date: …………………..………

Signature: ………………………….

Full Name of Legal Guardian (If applicable): ……….………… Date: ……………….….………

Signature: ………………………….

Please note the following:

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

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

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

References:

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

Department of Health. 2006. *South African Good Clinical Practice Guidelines*. 2nd Ed. Available

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ANNEXURE I

CONSENT FORM: XITSONGA TRANSLATION

Mpfumelelo wa nwana ku suka ka mutswari/muhlayisi

Xitatimende xa mpfumelelo wa n'wana

Mulavisisi: Mukwevho A.C

Nomboro ya rinqingho: 079 633 7626

Nhloko mhaka: Strategy to Optimize Transition of Adolescents Living with HIV in Selected Districts of Limpopo Province, South Africa.

Mina Mukwevho A.C ndzi endla ndavisiso hi phurojeke leyi vuriweke laha henhla.

Xikongomelo I ku humelerisa ndlela yo antswa leyinga pfunaka vhantswa lava va hanyaka na xitsongwatsongwana xa HIV, lava hanyaka vakha vateka maphilisi leswaku va lunghiseriwa kuva rixaka ra minzuku. Ndhawu leyi hlawuriweke ku endla ndzavisiso lowu hika ti distriki tin'wana a Vhembe Limpopo.

Nsirelelo wa vana na timpfanelo tavana swi sirheleriwile kuya hi nawu. Mavito, malembe na swinwana a swinga tirisiwi ku ta tirha swoka swingari ntiyiso ku endlela vusirheleri.

Hinkwaswo leswi swingata vulavuriwa ku tava xihundla exikarhi ka muntshwa na mulavisisi.

N'wana kumbe muntshwa u ta pfumeleriwa ku tshika kuva xirho nkarhi u n'wana na u n'wana loko anga lavi kuva xirho kungavi na nziho kumbe ku panichiwa.

Loko n'wana a lava kuva xirho xa phurojeke, kambe vatswari vanga pfumeli, n'wana ya loye ange pfumeleriwi ku ngenelela kumbe kuva xirho xa phurojeke leyi.

Vito ra n'wanai: …………………………………… Siku: ………………………

Vito ra mutswari: ………………………………….. Siku: ………………………

Nomboro ya rinqingo: ……………………….

Mpfumelelo wa mutswari/muhlayisi

Ndzipfumela/Adzipfumeli le swaku n'wana ava xirho xa phurojeke

Vito: …………………… Nsayino: ………………………….. Siku……………….

ANNEXURE J

ASSENT FORM

Strategy to optimize the transition of adolescents living with HIV to adulthood at selected areas of Limpopo Province, South Africa

Investigator: Mukwevho A.C

Contact number: 0796337626

My name is Cecilia Mukwevho, am conducting a research to explore and describe your experiences during transition to adulthood and to determine your needs during this period as you are living with HIV. The purpose is to develop a strategy to optimize the transition of ALWHIV to adulthood in Vhembe and Mopani districts in the Limpopo Province.

You will be asked questions at your convenient place for a period of 30-45 minutes you will relax and freely share your ideas. I will be using the semi-structured interview and the voice recorder to capture all your information. There will be no risks or discomfort, but if you could feel that the topic evokes emotions and remind you of some bad experiences and you feel you want to stop, you are free to do that and terminate or free to continue.

Participation is voluntary. Confidentiality will be considered we will not use your name in the study but codes will be given. No rewards will be given. We will further request the consent for your participation from your guardian, or parent.

I have read this form or someone has read it to me. If I did not understand something, I will ask the researcher to explain it to me. I can always ask the researcher a question about the study if I don’t understand something. I will be given a copy of this form, if I need to keep it.

Please tick one box:

☐ YES, I want to be in this study and I know I can change my mind later.

☐ NO, I do not want to be in this study.

Child’s Name (Print): ………………….

Child’s Signature: ……………………….

Date: …………………Age: ……………………Gender: ………………

The following should be completed by the researcher who is conducting the assent process if the child agreed to be in the study. Check all that apply.

- the child is capable of reading and understanding the assent form and has signed above as documentation of assent to take part in this study.
- the child is not capable of reading the assent form, but the information was verbally explained to him/her. The child signed above as documentation of assent to take part in this study.
- the child had ample opportunity to have his or her questions answered.

Printed name of person obtaining agreement: …………………..…………………

Signature of person obtaining agreement: ………………………………………

Date of signature: …………………………………………………….………….

ANNEXURE K

INTERVIEW GUIDE

The following questions will guide the researcher during the interview with the participants to accomplish the goal of developing a strategy of supporting adolescents living with HIV during the transition period at the selected districts of Limpopo.

Data were collected during the day as participants come for their appointments. The main questions for ALWHIV will be:

1. ‘Share with me how it is for you to be an adolescent living with the virus as you are transiting to adulthood?
2. Describe your support needs during this period? This question will explore participants’ experiences and will be followed by probing.

The questions for parents/caregivers will be:

1. Describe the challenges you are facing as a parent/guardian of an ALWHIV during transition to adulthood? And support you need if any during her or his transition to adulthood?

These questions will be followed by probing questions.

ANNEXURE L

TRANSCRIPT OF DATA COLLECTION

Strategy to optimize transition of ALWHIV in selected districts of Vhembe Limpopo Province

Introduction

The researcher will sample three adolescents from each facility and two guardians or parents.

The total will be 27 adolescents and 18 parents=45 participants.

Key: R=Researcher P=Participant/Adolescent
Mak=Makonde Shayandima=Shayas Madombidzha=Madom Muila=Muil Tshakhuma=Tshakh Wayeni=Way Makhuvha=Makh Ntluri=Ntl Vhurivhuri=Vhuri

TRANSCRIPT NO 02

Male Adolescent Way 02

Researcher: Afternoon Wayeni 02 and how are you?

Participant: Afternoon I'm fine though is very hot.

Researcher: Mm today is very hot. As you have read the letter to participate in the study and sign the consent form. Today is the day that we said we shall meet so that we can have the interview. Are you still interested to participate?

Participant: Yes, I'm still interested nothing has changed. I'm ready.

Researcher: Ok, I'm happy for that. Remember that our conversation will take 45min to an hour and I will be using a book to write and also the tape recorder to make things easy for us to spare time especially on my side because I might forget some of the things so the recorder will help me during transcribing.

Participant: Yes, its fine I don't have a problem.

Researcher: Now share with me anything related to HIV and your life including the experience you have.

Participant: Ok, I am 17 years of age and my childhood was very painful and very demanding from my mom and grand mom because I was always sick. My family depend mostly on grant funds because my mom was not working. I never saw my father visiting our family. And as a child you cannot ask where your father is. If I can compare I can say our family is living in poverty. Mm, I still remember very well. My body was covered by sores, some oozing water and some oozing pus. My grand mom took me to the traditional doctor several times and I was smeared with black concussions. Those sores came and go but not healing completely. My hair was very thin and people always told me that I had marasmus because my weight was very low. There was a time when I hate myself because I had this smell which was very terrible sometimes.

What I know is that I grew up drinking certain medications that my mother used to go with me to collect at the hospital and sometimes I would go with my grandmother to the traditional healer for medications too. I was very tiny always having flue, severe chest pain and difficulty in breathing, Mom said I had chronic pneumonia therefore I will take my medication for a long time.

As a child I did not even have the interest of knowing what is happening to me. Every time when we visit the hospital, I remember that nurses would take my vital signs, then separate us from our parents and teach us things related to HIV like how HIV is transmitted from one person to the other, things which does not transmit the disease and many other things. There were months that I was taken blood and nurses always told my mother that my medications would be determined by my weight. At that time, they use to give us packets of soft porridge and juice saying that the weight would increase quickly.

As time goes by nurses and the doctor told us that I'm becoming better but my body is not responding well to medications. They taught my mom how to give me medications, like setting a clock so that I don't miss that time. But it was like really my body was not responding. I remember in one appointment the doctor said next month I will change your medications if the results are not good. At that time, I was not feeling any problem in my body and I was taking my medications every day. All the health care professionals I pass by were very friendly to us. They talk to us using our language so that we can understand. Then in my next appointment my results were bad

Again, and my medications were changed to regimen 02 as the doctor said. Then I continued with the medications for another 6 months before they took blood again. My health improved very rapidly as I was adhering to my medications. I felt like I'm no longer sick, my life became of good quality. My mom and I appreciated the service very much. I started to hate the appointment date due to be taken blood.' Oh my God what did I do to deserve this? That was when nurses were failing to get my blood and I was crying by then'.

I continue with my treatment at the hospital for few years until things were ok. From there, the doctor said he is happy about everything. 'I will transfer you to the nearby clinic, said the doctor'. Mom answered and said' I will be relieved from transport problem.' Then the doctor wrote a letter for me to take to the clinic. The nurse gave us two packets of soft porridge and juice including my medications and off we go.

The following day mom took the letter to the clinic. I didn't go with her. When my appointment arrived, we go together for my medications. Was doing grade 9. We follow the queue until we get to the nurse. Sometimes nurses are very few and we took almost a day to get the service. It is very tiresome. In the consulting room the nurse ask to see my pills and count them. She ask me how am I taking my treatment and I explained.' Now you are a grown up man you must be responsible with your life, the nurse said to me.' Then she turn and look at my mom 'did you tell him already'. My mom stumble and just laugh.

My mom supported me very much and loves me a lot. My father is always in Gauteng for work. He is also very supportive. My relationship with my friends and teachers at school is good. I also have good friends in church. In 2018 I ask my mother about my chronic pneumonia. At this time I knew I had HIV. I read it on my file. Then she said pneumonia is a very dangerous condition keep on taking your pills. I told her she is lying to me I knew I had HIV mom, why are you lying to me.' I trusted you all these years, but why, why me?

Researcher: Mm, I see, then what happened?

Participant: Two days later mom called me to accompany her to my grandmother's house in another village nearby. On arrival she called both my grannies and we sat down in the house. Mom said 'My parents and my son, please forgive me, my son and I are HIV+. I was afraid to talk all these years because I was scared that you won't support me, and that you might tell other relatives about our status. My boy please forgive me I was just protecting you. That was how I discover about my status apart from seeing it in the file. My granddad called me and hug me. Don't worry my boy you will drink medications and be strong. Look at me, my sugar diabetes and my pressure are controlled because I'm taking my pills. Then I told my grannies that even my mom should go to the clinic and register so we can drink together and she agreed.

Researcher: When saying pressure what was he referring to? You mean Blood Pressure?

Participant: Yes, that's it. I respect my grandparents very much, they love me a lot and I was forced to forgive my mom and make peace with her. This things cost me for three months without taking medications. One day the community nurses brought a letter for me saying that I'm wanted at the clinic because I missed my appointment (tracing). I ended up deciding to go there, making peace with my mom and return to care again.

Researcher: Eish, ja your grannies were very supportive. So since then have you disclosed your status to someone? And how is your love life?

Participant: No I haven't told anyone about my status. My mom told me I should never share my status with any one. I had a girlfriend we started dating in 2019 September. We had sex twice in our relationship. We did not use a condom. I love this girl and we school together. I told her that I'm not in a rush to get a baby. This is a disease of secrets and lies. Parents usually don't tell the truth and is painful when you find out. I'm the third child in the family, my two siblings are not drinking and this makes me very sad. I think both parents should be held responsible and tell their children everything at an early stage so that we adjust early knowing that your parents are also like yourself. If I know the status of my parents I think the frustration would be limited. I suggest that the department should have a policy where parents are held accountable to disclose the true status to the child. This can build adolescents to grow well understanding themselves, learning to be independent and able to make decisions about their lives.

As an adolescent I don't want to die early, I had big dreams in my life that I want to accomplish. I pray that medications can be found so we drink and be cured and live our lives to the full. The main reason why I drink medications is that I fear death. Don't want to go in those days of my childhood where I spend most of my days in hospitals.

Researcher: In your views, what do you think can be done to strengthen transition so that adolescents remain in care when they find out the truth about their conditions?

Participant: I strongly believe that there should be no secrecy amongst parents and their children who are exposed. Both should explain the matter at an early age and continue to do so as the child is growing up. This can limit the frustration and anger of finding out the right thing late when you were told the wrong diagnose at first and cling on that. Knowing early might help the adolescent to have WhatsApp groups that we can create and help us to discuss things that concern us. Even our love lives might reduce the fear that if I don't condomize I might be transferring the disease to an innocent person. Also, the support clubs help us to share our views with others and the things we experience in life. Ii also think it would be better if the department could create youth centres where we could meet as youth with multi-purpose activities. In the clinics they should hire more nurses and build clinics with more staff and space so that they can work faster. Giving us time to attend school on Saturdays and coming for appointment in the afternoon or on Sunday is a very good thing to adolescents.

Researcher: Thank you for all the information we have shared. This will be the end of our session. Have a good day and continue to take care of yourself, don't default your medications Again, because now you know the truth.

Participant: Thank you I will try. Have a safe journey home.

Transcript of the Parent/Guardian

Parent 02

Female Shayas 02

Participant: 2001 I became pregnant with my second child, a boy, who is now nineteen years old. HIV was still in fashion and very embarrassing if you test positive. I remember when we were given a group talk in the morning. After that we were told to go for testing one by one. It was still voluntary by that time when I arrive in the queue, I ask the counsellor if I can test but not given the results. I was very scared and not want to hear about HIV. I did not believe that the disease is real; nor can I be affected or get it. I trusted my husband very much, then I told the counsellor that I don't want to be tested. The nurse begged me but I refused.

Researcher: Ok, then what happened from there?

Participant: Well I continued with my ANC (Antenatal Care) until delivery. I then decided to go and give birth at another clinic and there were no complications, everything was okay and the child was also okay with a good weight, 2.9 kg. In my heart I said, "Here is my beautiful boy, healthy and everything is normal." The nurse who delivered me asked me about testing Again, but I still refused. Then I was discharged and go home with my child, six months later I wanted to do family planning. One of my friends told me that she knows a person (traditional healer) who gives "muti" for prevention (family planning) but you have to combine it with condom like it's a dual therapy.

Two years later my son started to have continuous gastroenteritis and vomiting. At home when it started they said “ndi ngoma” meaning that his fontanel is big and we took him to the traditional healer and we got some concussions and they make “nola” meaning some cut on the head and smeared black concussion. The diarrhoea was on and off and the child started to lose weight. I took the child to our church pastor and I did everything that was needed but all was in vain. Clinics I visited several times gave medications and drips, oral rehydration solutions but still the child was not better. One day, midnight, the child got this high fever and was jerking. I woke up my mother and we rushed to the clinic. On arrival the nurses took the child’s vital signs, give him medications, put the drip and gave the child oxygen. By that time I was already crying thinking the child will die. I’m not married and not working at the moment. I left school at secondary level.

The nurse asked my mother to let me go out of the room and sit at the reception so that they can stabilize the child. Within some few minute, 30 minutes or so, I saw the ambulance coming in and I knew my child is not getting better. Then we were transferred to the hospital and was admitted with the child while my mom was to sleep at the clinic until morning because it was midnight. The following day at hospital I was told the doctor ordered that I should go see the counsellor.

I was asked about HIV status and I said I have not yet been tested, then the counsellor gave me the information and asked me to do it for the sake of the child. I felt like I was going mad. What if it’s HIV+, what am I going to do, what will I say to my husband. I was very scared, and the child continued to be very sick. Two days later I went back to the counsellor for testing, I told myself that it is now or never. That day I was very scared but for my child’s sake I did it and I was HIV+. I followed all the procedures, and my child was also taken blood with my consent and the nurses showed me that he is HIV+. I prayed that he be healed and took medications. I called my husband and he never had questions, he said that the child will be given medication and that he will be ok, I was very shocked.

Three weeks later we were discharged and the child was given antiretroviral medications. I was taught how to measure all the medications using a syringe. Three weeks later there was a vast change the child became cool again. I started monthly check-ups and the child’s life improved dramatically, the diarrhea stopped together with the vomiting.

Researcher: Then tell me about the disclosure, how did you do it?

Participant: Since I told my husband that day I never told anyone else, not even my mother or my other two kids. I waited for my husband to come back so that we can discuss face-to-face because I had started with the pills when the child was still admitted. The doctor told me the child might have got infected when I was giving birth or while I was breastfeeding. I hate myself for this, I blame myself for refusing to test during ANC. I thought I was clever. As the child was growing, I’m sure he was ten years old, he asked me why he is drinking medications everyday whereas the siblings are fine. I told him that he is having asthma and is note cured so he should take medications daily and he said it’s fine.

At thirteen years his medications were changed and was given those of adults. That’s where the problem started, he told me that his pills are not for asthma because one child at school with a pipe medication to spray when he was having difficulty in breathing. “Why am I not using that pipe medication, and have never had difficulty in breathing? Tell me the truth mommy or else I will leave these things.” My conscious didn’t allow me to do so, I asked my husband to tell the child about our status but he refused saying that the child could swear at us and that we should leave him alone, he will find out as he grows up. So, I decided to keep quiet. My husband knew his status long before me that’s why he never asked questions when I told him the child and I tested positive for HIV. My child is now a defaulter, he is not taking medications and sometimes he sweared at me and I told him that he will die because he is not living my life, as long as I’m managing my own life and that of others I don’t care.

Researcher: Mm I think that might be burden to you?

Participant: Yes, you are right. How can a parent be happy Again, though they are drinking when their child is waiting to die outside there? These people are good when they are still children than when they start to grow and have rights ask questions, and as grownup adolescent you cannot force if he or she is refusing to drink. My child has defaulted long time since he started to question me why he has the disease. A nurse came many times to trace him but he refused. I’m also out of him. Teenagers can cause a person to be mentally ill.

Researcher: What support do you need as a parent?

Participant: From my side I need any support that could make my child to take medications. my husband and I are working so financially we are okay. Life is good in our family; the only thing is that our child is not drinking. Everything is there. We tried anything that a parent can do for the child to be better and see himself like others. I told him that what is done is done until such time that cure is found. We gave all the support to him but all in vain.

Researcher: Mm that is hard for a parent but keep on trying one day he will understand. Thank you.

Conclusion on Data Collection Transcript

The researcher in the previous chapter showed that she recruited three adolescents from the nine (9) sampled facilities. Then she also sampled two (2) parents or guardians from those facilities to be part of the study. Data collection in qualitative studies was determined by data saturation meaning that as the researcher was busy collecting there were no new information coming in. During the collection of data in the researcher tried to find themes and sub-themes which she put aside in the field notes and that guided her to be able to see that saturation has been reached because most of the participants gave the same information already shared by other participants. Therefore, the researcher minimized the transcription by not repeating the same scripts with the same information one –by one during transcribing.

ANNEXURE M

VALIDATION INSTRUMENT

Strategy to Optimize Transition of Adolescents Living With HIV

Instructions

1. Tick the correct space.
2. Do not write your name, only the code.

Section 1: Biographical Data

Participant code			
Gender	M F		
Age			
Nationality	South African	1	
	Other, specify	2	
Occupation	Prof nurse	CNP’s	
Years of Experience			
Qualification	Diploma	Degree	Post Degree
NIMART-trained	Yes	No	

Section 2: Strategy to Optimize Transition

Building on Strengths				
Strategy	**Activity**	**Agree**	**Strongly Agree**	**Not Agree**
Sufficient human resource to optimize transition of ALWHIV	Is the staff availability enough to provide HIV services and to optimize transition in your facilities? Are the staff user-friendly?			
	Are there functional support groups in your facility, if no are there schedules to develop them?			
	Is the manager supportive in the adherence or support groups or classes to optimize transition?			

Continued/…

Sufficient human resource to optimize transition of ALWHIV	As NIMART nurses is the support you give to ALWHIV and their parents enough to assist them with disclosure to optimize transition? Do programme managers visit for supervision?			
	Is it necessary for health care professionals to be computer literate?			
	Do you always explain the procedure to be done and give the reason to ALWHIV and their parents to obtain trust? Do ALWHIV know about confidentiality and shared confidentiality			
	Are drugs and material resources always available?			
	Are new updated policies and guidelines arrive at the facilities in time?			
	Are NIMART nurses always available in the facilities during weekends or holidays?			
	Can appointment system assist in optimizing transition of ALWHIV?			
	In-service training of staff on time management could assist in optimizing transition for ALWHIV?			
	Are services in line with the 4A's (available, affordable, accessible and acceptable for ALWHHIV?			
Overcoming Weaknesses				
Competence and support	Will hiring more professional nurses assist in optimize transition of ALWHIV?			
	Will poor or shortage of space delay optimal transition of ALWHIV?			
	Do long waiting time contribute in hindering optimal transition of ALWHIV?			
	Can time management reduce adolescents' complaints and optimize transition?			
	Educating ALWHIV on youth zones, and fast-tracking waiting lines, can they assist in optimizing transition?			
	Is it necessary for support groups to be moved to the communities?			
	Do ALWHIV receive enough counselling before the transition?			

	Managing stock availability in drugs could assist in optimizing transition?			

Continued/…

	Do you think myths could hinder optimal transition for ALWHIV?			
Exploring Opportunities				
Exploring opportunities	Do you receive up-dated policies and guidelines in time, and are nurses using them very often?			
	Do you conduct meetings or awareness to traditional and faith-based leaders concerning HIV matters? Teaching the value for money (budgeting) could assist in optimizing transition of ALWHIV.			
	Will computer training help in the nursing fraternity?			
	Can CHWs be trained to give support to ALWHIV during transition? Can training of peer leaders assist in optimizing transition of ALWHIV? Can NGO's in the department of Health assist in optimizing transition by providing workshops to the NIMART nurses?			
	COVID-19 increased ALWHIV in defaulting medications? Nurses no longer share information to ALWHIV since COVID-19 started.			
	Award giving ceremonies could reduce staff burn-out and assist in optimizing transition of ALWHIV.			
Mitigation of Threats				
Infrastructure	Are youth important in clinic committees to cascade information to the community?			
	Poor maintenance of roads could jeopardize optimal transition of ALWHIV?			
	Finding out factors leading to defaulting treatment could optimize transition in ALWHIV.			
	Post COVID-19 positive work with community structures to address stigma related issues.			
	Clinic committees could help OPMs where there are no enough space to get park homes, this could assist transition of ALWHIV. Can COVID-19 positive cases in the facility hinders optimal transition of ALWHIV?			

	Is the strategy developed implementable?			

ANNEXURE N

CONFIRMATION OF LANGUAGE EDITING

Prof Donavon C. Hiss

Cell: 072 200 1086 | E-mail: hissdc@gmail.com

20 January 2022

To Whom It May Concern

This serves to confirm that I have edited the language, spelling, grammar and style of the **Doctor of Philosophy (PhD)** dissertation by **Azwinndini Cecilia Mukwevho**, titled: “**Strategy to Optimize the Transition of Adolescents Living with HIV to Adulthood at Selected Districts in Limpopo Province, South Africa**” The manuscript was also professionally typeset by me.

Sincerely Yours

Cert. Freelance Journalism, Dip. Creative Writing, MSc (Medicine), PhD