

# **Exploration of adherence to treatment challenges experienced by HIV positive adolescents in Insiza District, Zimbabwe**

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## **Keywords**

Adherence

Adolescents

HIV

AIDS

Zimbabwe

Care

Treatment

Challenges

Retention

Outcomes



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## Acronyms

AIDS- Acquired Immune- Deficiency Syndrome

ALHIV- Adolescents Living with HIV

ART- Anti-Retroviral Therapy

CATS- Community Adolescent Treatment Supporter

CNO- Community Nursing Officer

DHE- District Health Executive

DMO- District Medical Officer

DNO- District Nursing Officer

HIV- Human Immune- Deficiency Virus

IGAC- Insiza Godlwayo AIDS Council

KI- Key Informant

NGO- Non-Governmental Organisation

PEPFAR- President's Emergency Preparedness Fund for AIDS Relief

PMTCT- Prevention of Mother-to-Child transmission of HIV

UNAIDS- Joint United Nations Programme on HIV/AIDS

WHO- World Health Organisation



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## **ABSTRACT**

### **Background**

Zimbabwe has a high burden of HIV with a prevalence of 13.8% among the 15 to 49-year old population in 2016. As at 2017, the national antiretroviral treatment (ART) programme initiated over 1.1 million people living with HIV in Zimbabwe on treatment. Success of ART depends on optimal adherence to treatment and long-term engagement in care. Adherence to ART is challenging in general; and even more complex for the adolescent population living with HIV. The combination of physiological, mental and psychosocial development changes which occur during adolescence creates a complex interface with adherence to treatment. Understanding the perspectives of HIV positive adolescents with regards to challenges that they experience with adherence to HIV treatment is important for improving treatment outcomes. The current study explored the challenges faced by adolescents living with HIV who are registered to receive ART in Insiza District of Matabeleland South Province, Zimbabwe.

### **Methodology**

An explorative qualitative study approach was adopted. In-depth interviews were conducted with 27 non-adherent adolescents who were registered to receive ART from Nkankezi, Zhulube and Singwango clinics in Insiza in 2017. Qualitative data were digitally recorded, transcribed verbatim and subjected to thematic analysis.

### **Results**

The study identified that the challenges faced by adolescents on ART are both personal and interpersonal. These challenges are experienced at individual, family and community levels. The study found that these challenges intersect with structural barriers related to health systems and medicine. Even where interventions such support groups were implemented to support adherence, the participants reported challenges in using these interventions for their benefit.

### **Conclusion**

This study confirmed that adolescents on ART face complex interrelated challenges at an individual as well as external level. Comprehensive strategies that address the entire spectrum from

individual to structural are imperative to improve adherence in this key population, and these need to be rigorously evaluated to maximize their impact upon roll-out.



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## Declaration

I, Rickie Malaba, hereby declare that this study is a true reflection of my own research, and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted for a degree examination at any other institution of higher education.

Signed: 

Date: 15 November 2019



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## CHAPTER 1. INTRODUCTION

### 1.1 State of the Global HIV/AIDS Pandemic

Globally, 77% of the people living with HIV are on treatment (UNAIDS, 2017). The provision of ART to HIV patients has changed the trajectory of the HIV/AIDS pandemic by preventing AIDS-related deaths, improving quality of life of persons living with HIV and AIDS, and reducing transmission rates of HIV (Haberer *et al.*, 2017). The global scale-up of ART has been the primary contributor to the 48% decline in deaths from AIDS-related causes in 2016 (UNAIDS, 2017), and brings hope for the universal goal of ending AIDS by 2030 (WHO, 2016).

Despite the notable improvements in HIV treatment programmes, adolescents remain disproportionately affected by the HIV/AIDS epidemic with 150 adolescents dying from AIDS-related causes everyday (UNICEF, 2016). In 2016, there were 2.1 million adolescents living with HIV globally (Mark *et al.*, 2017). Slogrove *et al.* (2017) indicate that HIV incidence as well as HIV-related mortality trends show increases amongst the adolescent population. Adejumo *et al.* (2015) further add that there are limited health systems interventions that target the adolescent age group. The population of adolescents living with HIV is increasing, due to enhanced survival of those who are vertically infected and the increase in incidence in the adolescent population (Slogrove *et al.*, 2017).

In order to achieve desirable clinical outcomes, particularly viral suppression, optimal adherence to treatment is required (Sahay *et al.*, 2011). Optimal adherence in ART is defined as a client taking 95% of the prescribed medications at the required times and dosages (Reda & Biagdilign, 2012). High mortality due to HIV amongst adolescents has been linked to poor adherence to treatment (Inzaule *et al.*, 2016). In cases of poor adherence to ART, treatment failure ensues and this leads to the development of opportunistic infections; which are responsible for high morbidity and mortality in adolescents living with HIV.

The adolescent population is largely neglected in the global AIDS response. Reductions of new infections, deaths, stigma and discrimination are important in fast-tracking efforts to end AIDS globally by 2030 (UNAIDS, 2016). Reducing the risk and vulnerability in adolescents through enhancing leadership, commitment and investment in programmes and data is required to improve

health outcomes. Specific targets to end the AIDS epidemic by 2030 are included in the Sustainable Development Goals (UNICEF, 2016). In order to strengthen the global health response to adolescent HIV, there is a need to analyse the epidemic, identify key bottlenecks affecting delivery, and sharpen plans for better impact.

Adolescence is a period of significant physical and psychosocial evolution where concrete thinking, invincibility, risk taking, autonomy and decreased parental supervision may be determinants of adherence to treatment (Agwu & Fairlie, 2013). As such, it is important to explore the experiences of this key population during this period to increase our understanding of how adherence to ART can be improved. The current study defines adolescence as the growth period of 10-19 years, as per WHO (2009) definition.

Globally, there were an estimated 250,000 new HIV infections amongst adolescents in 2015 (UNICEF, 2016). The decline in new HIV infections in adolescents has been extremely slow since 2010. A strong programme pivot, a dramatic change in leadership support and financing of several HIV prevention and control programmes are required to scale up the global AIDS response (UNICEF, 2016). Without effective interventions for the populations at greatest risk of infection, there will not be change in the current trajectory of the HIV epidemic in adolescents.

Globally, an estimated 41,000 adolescents aged 10-19 years died from AIDS-related illnesses in 2015 (UNICEF, 2016). AIDS-related deaths in adolescents occur primarily among vertically-infected adolescents and long-term survivors of mother-to-child transmission. Therefore, this urgent reduction in AIDS-related deaths in adolescents can only be achieved if programmes perform better at finding adolescents living with HIV, linking them to quality care and retaining them or reducing loss to follow-up. It is further argued that consent policies and laws must be changed to respect the autonomy of adolescents (Wong *et al.*, 2017). There is a need for the development of new programmatic and policy innovations that are informed by the adolescents and youth they are intended to serve. The current low rates of HIV diagnosis and treatment initiation among adolescents and young people continue to present a significant challenge to the epidemic control of HIV.

## 1.2 State of the HIV/AIDS pandemic in Sub-Saharan Africa

The sub-Saharan African (SSA) region is most affected by HIV/AIDS globally contributing 43% of new infections globally. It is home to the largest number of people living with HIV with over 26.5 million HIV positive people living in this region (Amushe *et al.*, 2017). It is home to 6.2% of the world's population but over half of the total number of people living with HIV in the world (UNAIDS, 2017). Sub-Saharan Africa represents 77% of women with HIV globally, 79% of AIDS deaths and 92% of the world's AIDS orphans (Mills *et al.*, 2008). At the end of 2016, ART coverage for children and adolescents was at 51% while the coverage for the adult population was at 61% (UNAIDS, 2017).

Despite the continuing severity of the epidemic, huge strides have been made towards meeting the UNAIDS 90-90-90 targets in SSA. By the end of 2016, 76% of people living with HIV were aware of their status, 79% of them were on treatment and 83% of those on treatment had achieved viral suppression (UNAIDS, 2017). New HIV infections have shown a general decline over the past decade with some variation between countries. Adolescents and other key populations such as sex workers and men who have sex with men have significantly higher HIV prevalence rates (UNAIDS, 2017). The disparity in HIV prevalence between genders in SSA is significant with females bearing the greater burden of disease (UNAIDS, 2017). This has been attributed to the existence of high levels of transactional sex and age-disparate sexual relationships in many countries, which increase young women's vulnerability to HIV. The UNAIDS assessment of demographic and health surveys carried out in 2014 in the Sub-Saharan African region suggests that adolescent girls and young women aged between 15 and 24 years faced higher levels of spousal physical or sexual violence than women from other age groups.

ART programmes have been scaled-up dramatically in SSA over the past decade (UNAIDS, 2017). Challenges in ensuring that patients adhere to treatment are exacerbated by humanitarian emergencies and food insecurity in the SSA region and as a result, only half of all people living with HIV in SSA in 2016 had achieved the viral suppression necessary to prevent onward HIV transmission.



### 1.3 HIV/AIDS in Zimbabwe

Zimbabwe is a low-income country in Sub-Saharan Africa and has a high burden of HIV. The HIV prevalence in 2015 was 13.8% (United States President Emergency Preparedness Fund for AIDS Relief-PEPFAR, 2016). The Zimbabwean health system has been adversely affected by unfavourable socioeconomic conditions (Chevo & Bhatasara, 2011). The poor economy and adverse social conditions are determinants of poor health outcomes including those on HIV treatment. The Zimbabwe Population-Based HIV Impact Assessment (ZIMPHIA) reported that prevalence of HIV varies geographically in Zimbabwe with 11.4% in Manicaland to 22.3% in Matabeleland South Province (PEPFAR, 2016).

Between 2015 and 2016, HIV related deaths in adolescents increased by 5% in Zimbabwe despite the rapid scale up of ART availability to this age group (Zimbabwe Ministry of Health and Child Care-MOHCC, 2016). Poor adherence to treatment is one of the causes of high morbidity and mortality due to HIV in adolescents (Haberer *et al.*, 2017).

Adherence to treatment by HIV-infected adolescents remains a challenge as it involves juggling the complex matters related to their transition into adulthood. According to the 2015 Zimbabwe HIV programme report, 59% of HIV positive adolescents in Zimbabwe were non-adherent to ART (MOHCC, 2016). The new “test and treat” guidelines adopted by the Zimbabwe MOHCC in November 2016 aligns with the WHO recommendations to initiate all individuals who test positive for HIV regardless of immunological status as well as clinical stage (WHO, 2015). This approach increases the number of patients who are starting treatment early in disease progression without ever having developed symptoms and therefore may present different adherence patterns and challenges (Fox & Rosen, 2017).

The Zimbabwe National Health Strategy (2016-2020), acknowledges the HIV/AIDS epidemic as a significant public health problem that is threatening the socioeconomic fibre and capacity of the health sector to attend to the needs of the population (UNICEF, 2016). The rate of decline of adolescent HIV infections is lower than the national average rate and as such enhanced interventions targeting this key sub-population are critical. In 2016, the Government of Zimbabwe adopted the differentiated care approach to provision of ART to different sub-populations, including adolescents living with HIV (ALHIV).

In Zimbabwe, primary healthcare providers often do not recognize HIV infection among adolescents. The evidence on successful efforts to get adolescents and young people into HIV testing and link them to treatment is also insufficient. A recent systematic review of the uptake and positivity rate of HIV testing services among children and adolescents (aged 5–19 years) reported that approaches evaluated to date have not been tailored to meet the needs of this age group. Instead, they replicate strategies for adults and do not consider the specific barriers that adolescents face (Wong *et al.*, 2017).

#### **1.4 Problem statement**

The population of adolescents living with HIV is increasing due to longer survival of perinatally infected children and high HIV incidence of behaviourally infected adolescents (Davies *et al.*, 2017). As such, it is important to understand the dynamics related to adolescents' experience of living with HIV, including treatment, as the success of treatment programmes hinges on good adherence (Rosen *et al.*, 2007). Globally, HIV-related mortality amongst adolescents increased by 50% between 2005 and 2012, while the mortality in other age categories decreased by 30% during the same period (Denison *et al.*, 2015). This observation is linked to the challenges faced by adolescents with regards to adherence to treatment. Adherence to ART among adolescents is particularly complex due to the psychosocial and development pressures associated with transition to adulthood, orphanhood, stigma and neurocognitive deficits (Sohn & Hazra, 2013). ART adherence levels are a powerful predictor of survival in adolescents living with HIV (Mills *et al.*, 2008). To date there are no studies which describe in depth, the challenges faced by HIV positive adolescents on ART in Zimbabwe, particularly following the roll out of the November 2016 HIV care and treatment guidelines, which saw an upsurge in the number of HIV positive adolescents being initiated on ART without need for further initiation criteria as with the previous guidelines. As such, the purpose and rationale for this study was to provide further insight on the challenges faced by adolescents on ART while setting the tone for the development of acceptable interventions that will improve the quality of care that is provided to this vulnerable sub-population.



## **1.5 Outline of thesis**

This thesis comprises of six chapters. The current chapter set the context of the study by outlining the status of adolescent HIV/AIDS pandemic. The second chapter presents a review of the literature related to challenges faced by HIV positive adolescents on ART. Chapter three describes the methodology that was employed to carry out the study and further discusses the ethics considerations related to such an inquiry. The fourth chapter presents the study findings while chapter five is a discussion of the results. Finally, chapter six presents the conclusions and recommendations drawn from this study.



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## CHAPTER 2: LITERATURE REVIEW

### 2.1 Introduction

Adherence to ART is considered as a key component of the global fight to halt and reverse the effects of the HIV epidemic (UNAIDS, 2016). To mitigate the impact of HIV at a large scale, it is important to address the global, regional and country level challenges faced within the HIV/AIDS response. HIV treatment adherence rates among adolescents living in Sub-Saharan Africa are estimated to be at 60% (UNAIDS, 2016). Adherence is not stagnant and needs to be assessed continuously as the factors leading to non-adherence may change over time, necessitating different approaches to address those (Agwu & Fairlie, 2013). Adherence is defined as the extent to which a client's behaviour coincides with the prescribed health care regimen as agreed through a shared decision-making process between the client and the health care provider (WHO, 2003).

Non-adherence to ART is an active or passive process whereby the patient deviates from the treatment regimen (WHO, 2003). Non-adherence is the single most significant challenge to successful management of HIV- infected individuals, especially adolescents (Agwu & Fairlie, 2013). The Zimbabwe health system expects all health facilities to provide a minimum package of services that include adherence support for adolescents on ART.

There are several factors that have been reported as barriers to treatment adherence for HIV positive adolescents and these are classified or grouped as individual, family and community as well as health systems factors (Kim *et al.*, 2014). These factors will be discussed in turn.

### 2.2 Individual factors

Individual factors that influence ART adherence are those personal characteristics and determinants that inform behaviours, attitudes and perceptions related to taking medication correctly and consistently (Kariuki *et al.*, 2016). These include forgetfulness, self-stigma, treatment literacy, perceptions about ART, age, mental health instability, and method of HIV transmission (Haberer *et al.*, 2017).

Patient characteristics such as lifestyle affect adherence to ART (Kariuki *et al.*, 2016). On the other hand, individual level barriers to adherence such as forgetting, worrying about disclosure of HIV

status, falling asleep before taking ART, being away from home, and varied schedules including school attendance are common (Agwu & Fairlie, 2013). Additionally, factors such as feeling well may be associated with non-adherence by resultant complacency about ART, leading to passivity and neglecting to take ART.

In a qualitative study among adolescents living with HIV and caregivers in Zambia, it was revealed that adolescents living with HIV have few self-help skills and tools at their disposal to help with adherence (Denison *et al.*, 2015). As such, an individual's inherent ability to cope with challenges associated with ART will negatively influence their adherence to medication if they are not supported by additional skills and tools.

### **2.2.1 Forgetfulness**

In a meta-analysis of 125 studies carried out in 38 countries on the barriers to ART, forgetfulness was identified as a common challenge to ART adherence experienced by adolescents living with HIV (Shubber *et al.*, 2016). Adolescents tend to forget to take their medication regularly in situations when their daily routines are disturbed such as when they are away from home when visiting relatives or attending boarding school. In a qualitative study involving adolescents on ART in South Africa, Hornschuh *et al.* (2017) found that adolescents may forget to carry their medication to school or forget to use their pill reminders. Additionally, the use of alcohol as well as feeling better tend to be associated with forgetting to take treatment in the adolescent age group. However, clients who report forgetting as the reason for their bad adherence, should be subjected to further inquiry as Shubber *et al.*'s systematic review showed that this reason is often given by clients who may have bad adherence due to other barriers that are deemed socially unacceptable such as substance abuse.

### **2.2.2 Self-stigma**

Stigma is defined as an act of ostracism that is deeply discrediting, dynamic and with diverse effects that may be felt or enacted (Block, 2009). Arrey *et al.* (2015), on the other hand, describe self-stigma as a feeling of worthlessness, blame, guilt, shame, low self-esteem, dejection and

inferiority complex that an individual experience in response to a particular phenomenon. Self-stigma is an important factor that affects adherence to ART in adolescents (Haberer *et al.*, 2017). Self-stigma often leads to a desire by adolescents on ART to be secretive about their HIV status in order to avoid inadvertent disclosure of their status (Hornsuh *et al.*, 2017). Some adolescents feel that taking medication in front of their family or peers may cause them to be embarrassed about having HIV and thus eventually stop taking the medicines routinely (Hornsuh *et al.*, 2017). Additionally, self-stigma has negative effects on mental and physical health, including low self-worth and high self-blame (Block, 2009).

A longitudinal qualitative study in Zimbabwe by Busza *et al.* (2018) indicated that self-stigma made it difficult for people living with HIV to engage with services. In a qualitative study in Zambia, Denison *et al.* (2015) noted that self-stigma is closely related to disclosure of HIV status such that ALHIV will not disclose their HIV status to their peers fearing that this will expose them to stigmatisation. As such, ALHIV will not take their medication outside their home leading to missed doses when they travel or living in a boarding school set up. In Zimbabwe, one out of every three adolescents living with HIV aged 15-19 years feared being gossiped about, and adolescents were more likely than any other age group among PLHIV to feel ashamed of their infection, blame others for it, feel suicidal and exclude themselves from social gatherings with other adolescents (UNICEF, 2016). Self-stigma therefore remains a significant barrier to inclusion, access to prevention, treatment, care and support among adolescents living with HIV (UNICEF, 2016).

### **2.2.3 Treatment literacy**

Treatment literacy is defined as one's knowledge about the medicine they are taking, what it can or cannot do, and its use as well as possible adverse effects (Dunn, 2006). Wawrzyniak *et al.* (2013) argue that treatment literacy for adolescents is complex and evolving as age-appropriateness of the available knowledge changes throughout the adolescent phase. Therefore, access to and skillful use of health-related information is required to influence adolescents' decision-making on a day-to-day basis and longer term behaviour change. Achieving adequate health literacy is therefore imperative for improving health outcomes for adolescents living with HIV.

Adolescents often display gaps in knowledge about the broader implications of being HIV positive and taking life-long ART (Bernays *et al.*, 2016). A limited capacity to understand the importance of ART adherence may lead to misinformation and resultant poor ART adherence (Dunn, 2006). Adequate treatment knowledge includes having an understanding of the benefits of taking ART as a non-curative intervention (Agwu & Fairlie, 2013). In a mixed-methods study conducted in Kenya, Kariuki *et al.* (2016) observed that those with low literacy have challenges understanding the implications of poor adherence to treatment. Additionally, poor health literacy contributed to low rate of adherence to ART in adolescents (Kalichman *et al.*, 2015).

#### **2.2.4 Perceptions about HIV treatment**

Adolescents' perceptions and beliefs about ART may influence their decision to adhere to the treatment. Negative perceptions about ART are fueled by the way one views side effects, the strict adherence required, considering the treatment as an inconvenience as well as distrust of the medication (Horne *et al.*, 2007). A patient's perceptions may be influenced by their environment as well as the relationship with the health service provider (Conwad, 2007). It is therefore important for the service provider to ensure that the patient perceives the treatment plan as a joint effort that respects their background and understanding of the treatment plan (Vermeire *et al.*, 2001).

Some adolescents assume that ART medication is only to be taken when one is feeling sick (Kagee *et al.*, 2011). As such, individuals with such perceptions will only adhere to treatment schedules when they are feeling sick. Intervals where the adolescent is feeling well will therefore be characterised by defaulting on treatment. In their systematic review, Shubber *et al.* (2016) concur that there may be a concern for those adolescents who perceive themselves as being generally well. This observation is underscored by the perception that ART would not be beneficial if one does not have any overt clinical signs and symptoms. The perception of ART side effects may also impact negatively on adherence behaviour (Shubber *et al.*, 2016). When one experiences severe adverse events upon commencing ART, they may discontinue if they allude the events to the treatment.

### **2.2.5 Age**

The adolescent age group is particularly at high risk of lower treatment adherence to ART (Kim *et al.*, 2018). However, within this vulnerable age group, the age at which one is diagnosed as HIV positive as well as the age of commencing ART may influence their long term adherence patterns. In a cohort study conducted in Tanzania, Chaudhury *et al.* (2018) identified the older adolescent age as a factor associated with poor engagement with care including treatment adherence. They postulated that the younger adolescents may have adherence support from their caregivers and therefore demonstrate better adherence to treatment than older adolescents. Additionally, a retrospective cohort study done in Zimbabwe indicated that late age of starting ART showed poor adherence compared to those who start ART in childhood (Kranzer *et al.*, 2017).

On the contrary, Ghidei *et al.* (2013) found that when clients are engaged with treatment for longer periods, they tend to show improvement in adherence patterns. As such, this would suggest that older adolescents should demonstrate better adherence than their younger counterparts. In their narrative review of the contemporary issues related to treatment adherence, Adejumo *et al.* (2015) suggest that younger age may be related to poor adherence. Furthermore, children who commenced ART early in life may have been subjected to sub-optimal treatment regimens. This is compounded by the need to navigate the complex health systems from caregiver dependency to a period of self-autonomy (Sohn & Hazra, 2013).



### **2.2.6 Mental Health**

The World Health Organisation (WHO, 2003) defines mental health as subjective well-being, perceived self-efficacy, autonomy, competence, intergenerational dependence and recognition of the ability to realize one's intellectual and emotional potential. It has also been defined as a state of well-being whereby individuals recognize their abilities, are able to cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their communities. Mental health is about enhancing competencies of individuals and communities and enabling them to achieve their self-determined goals. It is a critical and neglected global health challenge for adolescents infected with HIV (Vreeman *et al.*, 2017).



Mental disorders are characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning (Parcesepe *et al.*, 2018). Adolescents living with HIV are at high risk for mental health challenges particularly if they have bad general health status characterised by recurrent opportunistic infections (Mellins & Malee, 2013). Adolescents living with HIV experience emotional and behavioural problems, including psychiatric disorders, at higher than expected rates, often exceeding those of the general population and other high-risk groups (Mellins & Malee, 2013). These challenges impact negatively on adherence to ART (Shubber *et al.*, 2016; Vreeman *et al.*, 2017).

In a mixed-methods exploratory sequential study design that employed a tri-phasic descriptive approach with a longitudinal cohort in Zimbabwe, Duffy *et al.* (2017) identified that alcohol use and depression negatively impact ART adherence. Poor general mental health status results in impaired cognitive function and coupled with stressful life events associated with HIV infection lead to poor adherence to treatment (Mellins & Malee, 2013). Additionally, adolescents living with HIV have reported lower levels of self-esteem compared to their uninfected peers and they tend to shun any forms of support that would assist with treatment adherence (Le Prevost *et al.*, 2018).

In a qualitative study conducted by Ramaiya *et al.* (2016), it was noted that adolescents on ART face psychosocial challenges such as loss of one or more parents, chronic domestic abuse, financial stressors restricting access to medical care and education, and high levels of internalized and community stigma among peers and other social contacts. Furthermore, the vulnerabilities associated with being orphaned due to HIV start long before a child's parent dies; with children witnessing the devastating affects within their own home, some of which perceive to be adverse effects of the ART that their parents were taking thus making them default treatment (Sharer *et al.*, 2016).

A positive mental framework towards adherence may be associated with autonomy and control over the adolescent's health and wellbeing while conversely, a negative mental framework views adherence as a reminder of HIV infection, difference from peers, and stigmatization (Vreeman *et al.*, 2017). Stigmatizing aspects of HIV infection negatively impact mental health outcomes like depression and adherence to ART among adolescents, particularly during this developmental period when body image and the social desirability to fit in are strong motivators of behaviour.

### **2.2.7 Mode of HIV infection**

In a mixed-methods study conducted in Thailand, the findings indicated that the method of transmission of HIV may influence one's adherence (Xu *et al.*, 2017). Perinatally infected adolescents have more experience with regards to treatment and may also have benefitted from parental support in the early stages of treatment, while behaviourally infected adolescents often acquire the infection at a stage of autonomy with limited support from parents or caregivers (Fields *et al.*, 2017). On the other hand, HIV fatigue and difficult transition in care are more specific to perinatally infected adolescents while stigma and emotional readiness to start long-term treatment are common challenges faced by behaviourally-infected adolescents (Fields *et al.*, 2017).

In a cross-sectional qualitative study in Ghana, decreased self-motivation and misunderstanding the benefits of ART have also been observed more in behaviourally infected adolescents (Ankrah *et al.*, 2016). However, some factors such as forgetting, not feeling like taking medication and medication acting as a reminder of HIV infection are common to both behaviorally infected and perinatally infected adolescents (MacDonell *et al.*, 2013).

Long-term survival of children with perinatal HIV infection is accompanied by unanticipated needs in the management of complications of treatment, sexual and reproductive health, mental health needs and issues of higher education and career training (Mofenson & Cotton, 2013). Perinatally infected adolescents usually have a complex clinical history that could obfuscate their adherence patterns (Mofenson & Cotton, 2013). Perinatally HIV-infected adolescents are regarded as a highly unique patient sub-population, because they have been infected before development of their immune systems, been subject to suboptimal ART options and formulations, and now face transition from complete dependence on adult caregivers to becoming their own caregivers (Sohn & Hazra, 2013). As such, their adherence to ART will be affected by their childhood experience of being on ART.

## **2.3 Family factors**



The family support system plays an important role in treatment adherence (Richter *et al.*, 2004). The family factors related to treatment adherence in HIV positive adolescents include family knowledge of ART, family support, disclosure of HIV status and the socio-economic status of the family. These will be discussed in turn.

### **2.3.1 Family knowledge of HIV treatment**

Knowledge of ART is described as an understanding of the issues pertaining to medication mechanism of action, indications for use, benefits and possible adverse events (Batamwita *et al.*, 2011). A qualitative study done on Zambian adolescents living with HIV identified that an adolescent on ART will benefit from a family with correct and accurate information about adherence to treatment (Sanjobo *et al.*, 2008). A supportive family that enables developmentally appropriate knowledge about HIV and ART to be shared with infected adolescents is an asset for good treatment outcomes (Cluver *et al.*, 2015). The family should be able to understand the unique needs of adolescents on ART and this becomes a vital tool in promoting good adherence to ART (Callahan *et al.*, 2017).

A cross-sectional study in Uganda showed that the knowledge of the family members about the benefits of ART was associated with the adolescent taking drugs timeously, regularly assisting younger adolescents in understanding their own HIV status, and motivating them to take their medication (Arage *et al.*, 2014). A study conducted in Tanzania identified that adolescents who had a knowledgeable caregiver were likely to report good adherence to ART (Nyogea *et al.*, 2015).

A knowledgeable family will handle cases of misinformation about ART better (Sahay *et al.*, 2011). Myths related to ART, such as relationship between medication and deformation of the body, tend to discourage adolescents on treatment, leading to poor adherence. As such, the family should be able to dispel any such inaccuracies related to ART; thereby promoting good adherence (Mavhu *et al.*, 2013). On the other hand, older caregivers as in the case of grandparents with deteriorating memory and poor comprehension of complex treatment regimens are unable to optimally support adherence to ART (Skovdal *et al.*, 2011).

### **2.3.2 Family support**

In a mixed method study conducted by Nyogea *et al.* (2015) in Tanzania, it was found that living with a non-parent caregiver was a risk factor for poor adherence for children and adolescents on ART. The family support structure is important for promoting adherence to treatment by HIV positive adolescents.

Sahay *et al.* (2011) indicate that the absence of close monitoring and encouragement within the home may result in poor adherence. Moreover, in circumstances where the caregiver is in bad health, this becomes an important determinant of the quality of support that an adolescent receives towards adherence to treatment. Nyogea *et al.* (2015) also point out that involvement of the father may positively affect adherence behaviour of the adolescent. As such, male parent involvement has become central to some family based adherence interventions (Ugwu & Eneh, 2013).

The family may offer moral and psychological support to individuals infected with HIV. Lack of care and neglect from family may lead to poor adherence to ART in HIV positive adolescents (Kalichman *et al.*, 2015). Caregivers are responsible for facilitating their children's access to HIV care and their adherence to treatment. Support from caregivers may improve health outcomes in children, but often this support is not provided as the caregivers fear that it will promote HIV stigma and discrimination. Ultimately, the support is not provided optimally and adherence to treatment is negatively affected (Busza *et al.*, 2018).

In a qualitative study conducted in South Africa, Knight *et al.* (2016) also pointed out that the existing inter-relationships within the family have a bearing on the quality of support that adolescents infected with HIV will receive from their family. Poor adherence will therefore be noted in families that do not demonstrate resilience or strong relations amongst each other. Adolescents living with HIV may also experience stigma and discrimination from within their families where their HIV negative family members treat them differently from the rest of the family (Kalichman *et al.*, 2015).

### **2.3.3 Disclosure of HIV status**

The World Health Organisation recommends disclosure of status to HIV-positive children by school age in order to improve adherence (WHO, 2013). Disclosure should be done incrementally as adolescents may require multiple opportunities to comprehend the meaning of their status. Adolescents are not passive recipients of disclosure, but are actively engaging in searches to understand their illness and need to take medication. Disclosure approaches must be adapted for the child's developmental processes, especially when accompanied by HIV-related cognitive delays. (Cluver *et al.*, 2015). Disclosure of HIV status may be daunting, particularly for families negotiating stigma, illness and bereavement (Cluver *et al.*, 2015). Well-informed families will promote early disclosure of HIV status to adolescents living with HIV and this has been associated with good adherence to ART. A multi-country qualitative found that disclosure of HIV status to adolescents perinatally infected with HIV is a central motivation factor for adherence (Bernays *et al.*, 2016). Non-disclosure of HIV status to HIV-infected adolescents by their caregivers will impact negatively on treatment adherence, particularly when adolescents begin to question their ART regimen and express regimen fatigue (Agwu & Fairlie, 2013). Additionally, in a cross-sectional mixed-methods study in South Africa, adolescents who knew about their positive HIV status prior to 12 years had on average higher adherence (Cluver *et al.*, 2015).

The role of caregivers in the disclosure process is important. A systematic review of studies done in sub-Saharan Africa found that caregivers of HIV positive adolescents should be directly involved in disclosing the status of their dependents but they require adequate disclosure support themselves (Aderomilehin *et al.*, 2016). Daskalopolou *et al.* (2017) in a multi-centre cross-sectional study, found that disclosure of HIV status to family, friends, and a stable partner may be linked to improved health outcomes for people living with HIV.

HIV positive caregivers who understand the importance of adherence to ART tend to be motivated to disclose the HIV status to their infected adolescents (Das *et al.*, 2016). Disclosure of adolescent's HIV status was also shown in a cross sectional study in Zimbabwe to improve adherence and retention in HIV treatment programmes (McHugh *et al.*, 2018). When parents do not disclose the HIV status to their infected children, this undermines their adherence to ART (Midtbo *et al.*, 2012). On the other hand, in a cross-sectional study in Kenya, Vreeman *et al.* (2014) concluded that the relationship between adherence to ART and disclosure is complex. They viewed disclosure of HIV status to an infected adolescent as a traumatic event that can be accompanied by

feelings of anger, hopelessness and rebellion, which may lead to temporary or longer-term adherence problems (Vreeman *et al.*, 2014).

#### **2.3.4 Socioeconomic status**

Cluver *et al.* (2015) classified socioeconomic status of the family as an important structural determinant for ART adherence. A low socioeconomic status presents challenges for adolescents on ART and their families. A cross-sectional study done in Ghana showed that adolescents from low income households experienced greater challenges with treatment adherence in general and ART specifically (Masa *et al.*, 2018). A sound socioeconomic status within the household may assist in mitigating determinants for bad adherence (Moret *et al.*, 2018).

Socioeconomic hardships tend to force adolescents living with HIV to lose focus of the future (Masa *et al.*, 2017). Under conditions of poor socioeconomic status, people tend to prioritise the now and lose sight of the future. Adherence to treatment is considered as an activity that benefits the future and will not be prioritized in situations of socioeconomic hardships (Masa *et al.*, 2017). Phanuphak and Phanuphak (2017) showed that sustainable socioeconomic interventions for adolescents living with HIV led to good adherence to ART for adolescent girls in South Africa. Burch *et al.* (2016) also postulated that the associations between low socioeconomic status and virological non-suppression are mediated through ART non-adherence.

Food is important to patients on ART (Kariuki *et al.*, 2016). Some patients may not take the medicines frequently on a daily basis as advised because they may not have enough food. Lack of enough food can lead to non-adherence to ART. Food insecurity hinders adherence as patient's fear starting ART due to lack of enough food. Adherence is worsened by food insecurity (Kariuki *et al.*, 2016; Moret *et al.*, 2018).

There may also be the added burden of purchasing medicines to treat opportunistic infections associated with HIV infection (Sanjobo *et al.*, 2008). Furthermore, Mills *et al.* (2008) argue that the barriers to adherence amongst impoverished individuals may be due to the interactions of poverty with other factors such a depression and substance abuse rather than the poverty itself.

## 2.4 Community factors

The community factors that may affect adherence to ART by HIV positive adolescents include knowledge, traditions and norms within the community, geographical location of the community, economic development, school environment and stigma.

### 2.4.1 Community knowledge, traditions and norms

The knowledge and traditions within the community about ART influence adolescents' health seeking behaviour including adherence (Arage *et al.*, 2014). However, these may be mitigated by adolescents' understanding of the benefits of ART, as they develop favourable attitudes through understanding the benefits of ART and taking the drugs timely and regularly.

A qualitative study conducted in Zimbabwe found that the availability of community health promoters with accurate knowledge together with other community support networks such as religious groups and income saving schemes help to overcome obstacles related to treatment adherence (Scott *et al.*, 2013). However, if the information from these community support systems is inaccurate, adolescents on treatment may be faced with misinformation that will impact negatively on adherence practices (Arage *et al.*, 2014). It is therefore important to ensure that community health workers are up to date with regards to information related to ART and adherence to treatment (Mokwele & Strydom, 2017).

Knight *et al.* (2016) assert that the traditions related to community obligation determine the extent of support that an adolescent on ART may receive. Where obligation is not guaranteed or limited, the adolescent on ART faces social support challenges. Additionally, religious traditions have also been observed to have both good and bad influences on uptake of health services including adherence to treatment as favourable support from the religious contacts can be seen as social capital required to support adolescents on ART (Ransome *et al.*, 2018). Identification of traditions that may pose challenges to treatment adherence is necessary to roll out successful HIV treatment programmes (Hodgson *et al.*, 2014).



#### ***2.4.2 Geographical location and economic development***

Shubber *et al.* (2016) assert that the treatment adherence challenges faced by adolescents on ART may be related to geographical location as seen in settlements that are far from health services and have poor road networks to promote good supply chain management of ART commodities. Moreover, stock outs of ARV medicines were identified to be frequent in rural locations with poor communication and networks. The relationship between geography and good treatment outcomes is not a straight-forward however as Mills *et al.* (2018) did not find any differences in their meta-analysis between sub-Saharan Africa and North American communities with different socio-demographic characteristics for adolescents taking ART.

In Zimbabwe for instance, the land redistribution exercise has either led to the establishment of communities in locations without nearby health services, or increased the burden on certain health facilities through abrupt increase of the catchment population without setting up the appropriate infrastructure at the health facilities (Deininger *et al.*, 2002).

In a mixed-methods study conducted in Uganda, adherence to ART was shown to vary between rural and urban communities with rural communities showing significantly lower adherence than urban communities (Senkomago *et al.*, 2011). Additionally, the economic development of a society affects livelihoods and access to food that has been shown to influence treatment adherence behaviours.

Frequently changing the place of residence is also linked to disturbance in good adherence behaviour (UNICEF, 2016). Regional migration in particular, was shown to be associated with poor adherence to ART as clients have to be established within the new treatment system (Lima *et al.*, 2009).

Adolescents who experience structural problems such as lack of medical insurance, problems with work or school, concerns about dealing with family and looking after children, housing instability, lack of transportation to clinic visits or to obtain medications, may have lower adherence (Agwu & Fairlie, 2013). The higher prevalence of comorbidities in resource-limited settings such as tuberculosis, malaria, malnutrition, and the consequent polypharmacy and drug-drug interactions resulting from treatment may also impact adherence. On the contrary, areas with sound social

protection systems would reduce the impact of these determinants of adherence to treatment (Bates *et al.*, 2015).

### **2.4.3 School environment**

For adolescents attending school, an unfavourable school environment such as one where there is no provision for adherence support through peers is a barrier to adherence (Nyogea *et al.*, 2015). Furthermore, in boarding school settings, the child caretakers may not possess adequate skills to support good adherence behaviour for adolescents on ART (Haberer *et al.*, 2009). Mavhu *et al.*, (2013) however found that if the school promotes good adherence through provision of education and psychosocial support, adolescents enrolled in this school demonstrate good treatment adherence behaviours.

The learning environment in schools should be supportive to adolescents on ART so as to optimize their chances of having good clinical outcomes (Galea *et al.*, 2018). In their qualitative study conducted in Peru, Galea *et al.* proposed that there should be integration between support provided to adolescents on ART both at school and at home so that there are seamless transitions by the adolescent between the two environments. It is particularly important that there be no contradictions in the health promotion messages provided through both platforms.

### **2.4.4 Community stigma**

Community stigma is described as an attribute, behaviour and reputation that is socially discrediting towards a particular sub-population within a society (Visser *et al.*, 2009). Such behaviour would therefore cause members of the society to distance themselves from HIV positive adolescence thereby depriving them of any community support. Stigma reduction is therefore a critical component for controlling the HIV/AIDS epidemic.

The systematic review and meta-analysis conducted by Katz *et al.* (2013) alludes to the role of community stigma in compromising the essential role of social ties which in turn limits adolescents' ability to successfully adhere to treatment. Furthermore, community stigma was reported to be at the forefront in fueling self-stigma in ALHIV (Richter *et al.*, 2004).

Adolescents living with HIV who belong to communities where stigma is rife face additional challenges related to discrimination, isolation and resultant limited support for treatment adherence (Grossman & Stangl, 2013). Adolescents living in urban communities or those that have high population densities reported more cases of stigma compared to rural communities with sparse populations (Miller *et al.*, 2017). Furthermore, the community's environmental and cultural context interact with individual challenges to treatment adherence (Kim *et al.*, 2017). Supportive communities tend to demonstrate good treatment outcomes. In a qualitative study conducted in Uganda, Mburu *et al.* (2013) pointed out that despite the maturing HIV epidemic and widespread availability of ART, stigma within the community continues to be a concern for adolescents living with HIV. They further added that support groups contribute to destigmatizing HIV in the communities.

## **2.5 Health systems factors**

The relationship between the health service provider and the patient may affect adherence to ART (Kariuki *et al.*, 2016). Most research has focused on addressing individual barriers and not adequately addressed other barriers such as structural and health system issues (Wong *et al.*, 2017). Adolescents value caregiver support and positive interactions with healthcare workers. They desire making autonomous decisions regarding HIV diagnosis and disclosure. Health system factors that may pose treatment adherence challenges include human resource capacity, health service delivery, transition in care and medicine related barriers. The health system factors affecting ART adherence are discussed in the following sections.

### **2.5.1 Human resources for health capacity**

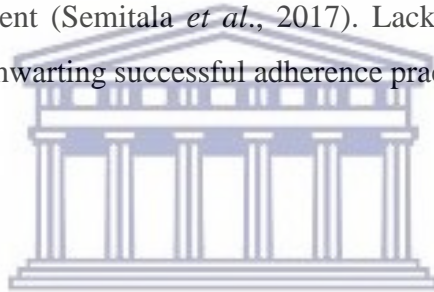
The human resource capacity in health systems is important as rapid expansion of ART in relatively weak and under-resourced health services may exacerbate poor adherence (Sengayi *et al.*, 2013). The scarcity of healthcare professionals who are experienced in adolescent healthcare management further impacts the adherence counselling and support needed to maintain optimum adherence to treatment levels in adolescents living with HIV (Agwu & Fairlie, 2013). As such, the



current human resources available for managing adolescent HIV are ill-equipped to fully understand the complex psychosocial situations and clinical histories of their clients.

Good quality adherence counselling for HIV treatment should be able to fully address the concerns and beliefs that clients have about taking medication so as to promote optimum adherence behaviour (Kalichman *et al.*, 2015). The ability to provide adequate counselling for HIV positive adolescents is critical to promote adherence (Takarinda *et al.*, 2016). Human resources for health should be distributed well, and possess the right knowledge, skills as well as motivation so as to improve care and treatment outcomes for adolescents living with HIV (WHO, 2009).

Knowledge of the clinical and psychosocial complexities of managing adolescent patients infected with HIV is essential for health service providers (Agwu & Fairlie, 2013). A qualitative study conducted in Uganda revealed that an efficient human resource supply in the health sector fosters good adherence to HIV treatment (Semitala *et al.*, 2017). Lack of friendliness by health care workers has been identified as thwarting successful adherence practices in adolescents living with HIV (Wong *et al.*, 2017).



### **2.5.2 Health Services**

In a systematic review and meta-analysis, Kim *et al.* (2014) found that adherence to HIV treatment challenges are related to the quality of health care received from the health facilities. Teasdale *et al.* (2016) describe adolescent-friendly services as those that provide a comprehensive package of adolescent sexual reproductive health which includes peer psychosocial support within an environment that promotes confidentiality. Once health services are considered to be unfriendly by the adolescents, they tend to reject them; resulting in missing their scheduled appointments and ultimately their medication refills which result in poor adherence (Kim *et al.*, 2014).

Several service delivery modalities to improve adherence to ART by HIV positive adolescents such as the use of multi-media technology to remind clients to take their medicines, are not available in resource-limited settings (Haberer *et al.*, 2017). Vogt *et al.* (2017) suggest that in such resource-limited communities, tailoring the health services package to suit the needs and context of the adolescents may improve treatment outcomes.

Adolescents may face challenges when they transition from paediatric ART health services to adolescent services where transition in care is poorly monitored (Slogrove *et al.*, 2017). These include infrastructural challenges, limited staff training, poor communication between paediatric and adult ART departments as well as unclear guidelines to aid the process (Dahourou *et al.*, 2017). There is a need for intersectoral and multilevel responses to allow smooth transition from paediatric to adolescent HIV care (Sohn *et al.*, 2017). Lack of familiarity with the patient's medical situation as well as increased work burden in the health facilities may affect transition from paediatric to adolescent HIV care (Litson *et al.*, 2012).

### ***2.5.3 Medicine related factors***

The adverse effects of medication have also been identified as a possible barrier to treatment adherence (Dessalegn *et al.*, 2015). Conwad (2007) identifies pill burden, dosing frequency, food requirements, medicine tolerability and other safety concerns as important determinants of treatment adherence that health service providers have to address in managing adolescent living with HIV. For younger adolescents, complicated treatment regimens have been shown to cause challenges in adherence to medication as well as leading to treatment fatigue (Mills *et al.*, 2008).

The introduction of single dose medications has been associated with improved tolerance of HIV treatment and therefore better adherence to medication (Jacob *et al.*, 2017). On the event of treatment failure or other indications for use of more complex regimens, adherence challenges are compounded by the restricted access to second and third line treatments in resource limited countries (Bernays *et al.*, 2016).

## **2.6 Conclusion**

The literature review identified that whereas ART is capable of improving one's quality of life, there are many challenges that adolescents who are HIV positive face while taking this life-saving medication. These challenges may be associated with individual, family, society and health system factors. The next chapter addresses the research methodology that was used in the study.

## CHAPTER 3. METHODOLOGY

### 3.1 Introduction

The study methodology is described in this chapter beginning with the aim and objectives. This is followed by a description of the study design, study setting and study population and sampling process. The data collection and analysis procedures are also outlined in this chapter. The steps taken to ensure rigour as well as the ethics considerations are also presented.

### 3.2 Study Aim

The aim of the study was to explore treatment adherence challenges experienced by HIV positive adolescents in Insiza district, in Zimbabwe.

### 3.3 Study Objectives

- To explore the experiences of HIV positive adolescents enrolled into HIV treatment programmes in Insiza district.
- To explore adherence behaviours of adolescents on ART in Insiza district.
- To explore barriers to adherence amongst adolescents living with HIV in Insiza district.

### 3.4 Study design

This study adopted an explorative qualitative approach. This approach was chosen because the study objectives sought holistic answers to the adherence challenges that HIV positive adolescents encounter and how they deal with them in everyday life. As such, the explorative qualitative study design adopts an interpretive paradigm thereby making it suitable to meet the objectives soundly (Baum, 1995). Additionally, Jack (2000) assert of the value of qualitative study designs in eliciting evidence informed decisions for public health issues such as adherence to treatment. Adolescent health and ART adherence are complex issues and the qualitative research approach provides better insight of the participants' perspectives. The explorative qualitative study design allowed for the researcher to obtain rich descriptions of the study topic. Furthermore, in order to better understand complex public health phenomena, it is beneficial to study them in their natural state (Lambert & Lambert, 2012). The explorative qualitative study design is also better suited to explore the relationship between the adolescents and their service providers (Meyer, 2000). The

explorative qualitative study design enabled the researcher to understand the meaning which participants assign to their experiences. Participants were able to share first-hand knowledge on the study topic through this approach (Neergaard *et al.*, 2009). The study design adopted was flexible and this enables new findings to be made with regards to experiences of adolescents on the study topic (Baum, 1995).

### **3.5 Study setting**

The study was carried out in the rural district of Insiza, which is located in the South-West region of Zimbabwe in Matabeleland South Province. The district is under the agro-ecological region 5 which is characterised by erratic rainfall and regular drought spells. The population is of low socioeconomic status with a poverty index of 77% (ZIMSTAT, 2015). Insiza is 469 km south-west of the capital city, Harare, and 77 km south-east of Bulawayo, the second largest city in Zimbabwe. The catchment population in the district is 100,333 (ZIMSTAT, 2017) of which 26% are aged between 10 and 19 years.

In Insiza district, the main socioeconomic activities are subsistence farming and small scale commercial mining. The most commonly spoken language is isiNdebele, although multiple languages are understood by most of the community. The population has 49.2 % males which is similar to national demographics (ZIMSTAT, 2012). According to the last national population census conducted in 2012, the average household size is 4.7 members.

Filabusi District Hospital, which is the main referral centre in Insiza District, is located centrally within the Filabusi Growth point. Filabusi is the capital of Insiza district. There are 15 primary health facilities in the district. All these health facilities provide comprehensive HIV care and treatment services for all age groups. The district hospital provides community outreach services through a network of community health workers who are affiliated to each primary health facility and are under the supervision of the district community health nurse. This system is facilitated by inter-referral between the community and the health facilities.

### 3.6 Study population

The study population composed of HIV positive adolescents who are living in Insiza District and registered for ART services from Nkankezi, Zhulube and Singwango Clinics. Additionally, I ensured that only the adolescents who have been reported [by health professionals] within the district ART programme to have had poor adherence to treatment, were recruited. I obtained the information about the adherence patterns of adolescent clients from the district HIV care team, the nurses in charge at the three selected health facilities as well as the community health workers through written and verbal requests as well as review of the program monitoring documents.

### 3.7 Sampling procedure

Moule and Hek (2011) define a sample as a portion of the study population composed of members from which information will be collected. In this study, I purposively sampled HIV positive adolescents with allowance for maximum variability in terms of age (range 11 to 19years), sex and period on treatment. Only adolescents who had their HIV status disclosed by their family were enrolled in the study so as to avoid accidental disclosure. Additionally, selection criteria included those adolescents who have been on ART for at least 6 months as these were considered to have meaningful experience to contribute to the research topic. All the caregivers of adolescents involved in the study were informed in detail about the research process.

I received the HIV patient monitoring information from Nkankezi, Zhulube and Singwango clinics and adolescents who met the inclusion criteria were listed and invited to participate in the study. When I could not get enough participants from the Nkankezi clinic beneficiaries' list, I proceeded to engage Zhulube and Singwango clinics till saturation was reached. A total of 27 adolescents on ART were recruited and interviewed. Saunders *et al.* (2018) argue that saturation must be operationalized in a way that is consistent with the research objectives. As such, I felt that no further data collection was required after the 27<sup>th</sup> interview as the themes were no longer any different from those that had already been identified.

Five key informants were purposively sampled to identify those with considerable experience and knowledge related to direct service provision to adolescents in the ART programme. Key informants are considered to be the gatekeepers of the knowledge (Creswell & Miller, 2000).

These consisted of a community health worker, community nurse, a clinic nurse, an HIV positive adolescent's parent and a community adolescent treatment supporter (CATS). The key informants were recruited with assistance from the Insiza district health executive team as well as the Insiza Godlwayo AIDS Council who arranged individual briefing meetings for me to inform the key informants on the requirements of the study prior to enrolment. The identified cadres reviewed the study information sheets and provided signed consent prior to further engagement.

### **3.8 Data collection**

Data were collected through the use of in-depth, individual interviews with all the recruited participants who consented to the process. This method was chosen because of its ability to extract the view of the study participants more deeply (Boyce & Neale, 2006). In-depth individual interviews are ideal when exploring complex issues related to adolescent adherence to ART (Ritchie *et al.*, 2003). I conducted the interviews in English and IsiNdebele depending on the preference of the participant. I digitally recorded all the interviews at the place of residence of the participants to ensure that they are comfortable and there is minimal disturbance.

The interviews lasted between 40 and 60 minutes. I used the interview guides (Appendix 6 & 7) during the conversations. When interviews with the adolescents were concluded, I proceeded to interview the five key informants individually at their homes for four of them and at the health facility for the clinic nurse. The key informants' interviews were all done in English. The entire data collection process lasted 2 months.

There were challenges getting to meet some of the study participants due to political activities that characterised the data collection period. As such, I deferred the data collection period until there was calm within the community. I transcribed the recordings from the interviews verbatim, proceeded to do the translations for those transcripts which were in isiNdebele then stored them in a password protected study file. I made notes of the non-verbal cues during interviews which were also consolidated and stored with the interview transcripts. Completed consent forms were safely locked away in IGAC participant information cabinets.



### **3.9 Data analysis**

Data analysis is important in qualitative research methods to elicit meaning from the transcribed text. Thematic analysis was adopted for this study. The data analysis process began alongside data collection and this was particularly helpful as it helped me to refine the prompt notes within the interview guides. Vast amounts of data were obtained from the in-depth individual interview transcripts and observational field notes and as such a systematic approach was imperative (Pope *et al.*, 2000). The data analysis steps taken were familiarisation, coding, development of themes then finally integration and interpretation. This steps are described in turn.

#### **3.9.1 Familiarisation**

This was conducted thorough listening to the recordings over and over as well as re-reading the transcribed information and notes. It is important for the researcher to gain an overview of the data before delving into the intricacies of analysis (Srivastava & Thomson, 2009). During the familiarisation stage I took note of the important words and phrases related to the study topic. Where clarity was sought or on the event of seemingly contradictory statements, I proceeded to read the transcripts and also check with the participants involved via telephone. Familiarisation was important in starting the process of searching for meanings from the data and make a summary of key impressions. Following familiarisation, the next step was to identify and note patterns form the transcripts through coding.

#### **3.9.2 Coding**

At this stage, the data were disaggregated into segments using manual coding to group conceptually similar data together. Segments with related information were colour coded similarly. The codes were subsequently grouped into categories from which themes were identified (Braun & Clarke, 2006). The notes made during familiarisation were used to guide the coding process so as to remain in sync with the research topic. The codes that had the most emphasis from the data were highlighted. Similarly, those codes with unclear information were corroborated or contradicted with the participants and key informants to ensure that the data were a true reflection

of the meanings which the participants meant for them. Robson (2011) asserts that meanings should be coded as they are described by the participants. The underpinning approach was to identify those codes that are related to the research aims and objectives and as such the challenging experiences related to ART adherence, adherence behaviours and the views of the key informants were coded.

### ***3.9.3 Identifying themes***

The next step was to create themes from the grouping of codes. Through sorting and clustering the codes, the meaning of the data was derived and organised into the themes. Reference was made to this research's introduction and literature review to ensure that the themes remain within the context of the research topic. I continually reverted to the codes and data transcripts to guarantee that the themes still remain an accurate reflection of the views of the study participants. The next step was to review the themes and develop arguments in response to the research problem.

### ***3.9.4 Integrating the themes and interpretation***

The last step of the data analysis was to refine the themes and integrate them to address the context for the research aim and objectives. This was done through mapping the themes so that it becomes possible to interpret the researching findings with regards to describing the experiences, adherence behaviours of adolescent living with HIV and on ART, as well as the views of the key informants. Throughout the data collection and analysis process, the approach remained rigorous through observation of the following.

## **3.10 Rigour**

Rigour is important in qualitative research of this nature so as to ensure that the results and interpretation of the study findings are credible and trustworthy. At the time of study design, I took great care to select participants with unique depth and breadth of lived experiences related to the research topic in a quest to ensure rigour (Morse *et al.*, 2002). Additionally, rapport was established with each participant and a considerable period of about two months was spent in the field.



Participants were also constantly contacted to explain certain aspects of the data. The steps I took to warrant general trustworthiness of the study and specifically its credibility are described in turn.

### **3.10.1 Trustworthiness**

Trustworthiness is the quintessential framework for the measure of rigour in a qualitative study (Billups, 2012). It is indeed a complex process to achieve relevance and transferability of the study findings. I made efforts to observe good quality approaches throughout all the stages of the research commencing with the planning stage right through to the interpretation of study findings. This will also be borne in mind during dissemination of the study findings. I purposely ensured that there is systematic coherence across the whole design process despite some challenges during data collection where there was some political instability in the district.

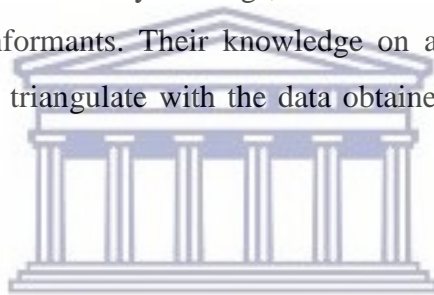
The primary lens throughout this inquiry has been always be that of the study participants (Creswell and Miller, 2000). Constant critique of the emerging issues was done. As I am a health practitioner, through reflexivity I made use of a study journal to document the entire process so as to constantly reflect on my self-awareness. All the details of the study were chronicled in this study fieldwork journal from the beginning to the end of the study. From time to time, I checked to see that the processes are still aligned to the study protocol. The approach to this was a combination of epilogue, interpretive commentary as well as bracketing out personal experiences so that only the perspective of the research participants emerges as the outcome of the inquiry and not my own perspective.

While the interview guides generally remained unchanged, I added a few prompts based on the experience of the initial interviews so that the questions were explicit to the study participants (Legard *et al.*, 2003). As such, the questions asked are clear and open ended (Mack *et al.*, 2005). Lincoln and Guba (1985) consider member checking to be the most critical technique for establishing credibility in qualitative research. I did this through seeking informant feedback on the validity of the information I had gathered. This was done face to face with the first 17 participants while the telephone was used for the rest of the participants and the key informants as these data were transcribed when I had left the field. Member checking confirmed credibility of both the information and the narrative account.

### **3.10.2 Credibility**

Provision of adequate details of the study setting was done to improve research credibility. All stages of the study are comprehensively described so as to give a clear picture of the study setting with particular reference to the determinants that may correlate with addressing the study aim and objectives (Gifford, 1998). These descriptions contribute towards the development of an audit trail such that the study methodology and rationale for all the decisions taken is understandable and available. The important questions to answer in the audit trail are related to the inference-whether it is logical as well as ensuring that the findings are grounded in the data. Such an audit trail will make the narrative account credible (Creswell & Miller, 2000).

To further ensure credibility of the study findings, the information from the interviews was discussed with the five key informants. Their knowledge on adolescent treatment adherence challenges was sought so as to triangulate with the data obtained through the interviewing the adolescents.



### **3.11 Ethics Considerations**

The study ensured there was minimal risk incurred by the participants by adhering to ethics standards. Enrolment into the research was voluntary with participants and the participants' identities protected throughout the study. Clear explanation of the processes involved in the study as well as purpose of the study was given with the aid of information sheets. Upon reading the study information sheets, I briefed the adolescents who consented to participate in the study and proceeded to recruit them. I also prepared beforehand a team of community health workers to refer any participants who would require further services as interviews may not always go according to plan (Boyce & Neale, 2006). However, during this study, no participant reported any distress arising from the process. I assured all the study participants of the availability of referral services should they suffer any distress during the course of the research and beyond. There was equal access for all the participants who met the inclusion criteria to participate in the study.

Cash *et al.* (2009) encourages researchers to seek ethical clearance for social science, biomedical or epidemiological activities that entail systematic collection of data with the intention to generate

new knowledge. As such, in this study I obtained ethics clearance from the Medical Research Council of Zimbabwe (MRCZ) as well as the Biomedical Research Ethics Committee of the UWC. Additionally, support for the study was obtained from the Ministry of Health and Child Care, Insiza Godlwayo AIDS Council, and community leaders in Singwango, Nkankezi and Zhulube areas.

Participation in the study was voluntary and I informed the participants that they were free to withdraw from the study at any point during the research when they deem necessary without consequence. The study is set to benefit the adolescents living with HIV as from it, I have made recommendations to address the multitude of challenges that they face with regards to treatment adherence.

Confidentiality was maintained at the highest standards and all the records from the field will be deleted permanently 3 months after completion of the study. These records are safely stored in password protected devices while the hard copies are in a locked cabinet. Only adolescents who have disclosed their HIV status to their families were allowed to participate in this study so as to avoid inadvertent disclosure or undue pressure on those who were not yet ready to disclose their HIV status. For those adolescents under the age of 16 years, consent from their parents or legal guardians was obtained while they provided assent to participation. No records from the participants' medical history were shared to anyone who was not involved in their care or the study.



### **3.12 Conclusion**

This chapter outlined the methodology used to conduct this research. Data collection and analysis procedures were described. The chapter further described the steps that were taken to ensure that the study was rigorous while ensuring that the processes meet high ethical standards. The next chapter presents the findings of the study.

## CHAPTER 4: FINDINGS

### 4.1 Introduction

This chapter outlines the findings from the research. A description of the characteristics of the study participants is given and this is followed by the findings related to the challenging experiences of the adolescents who are on ART. These challenges are discussed under the main themes that emerged from the data which are individual related challenges, family related challenges, community challenges and those related to health service delivery.

### 4.2 Description of the study participants

A total of 27 adolescents were enrolled onto this study. They came from the Nkankezi, Zhulube and Singwango areas of Insiza district. Their age ranged from 11 to 19 years. Eleven participants were male and 16 females. Their experience on taking ART ranged from one year to 12 years. Twenty-six of the participants had attained at least primary school education while one of them had never been enrolled into school. All the adolescents enrolled in this study had demonstrated a history of poor adherence to ART in the 6 months preceding the data collection for the study. Additionally, I interviewed 5 key informants: a community health worker, a peer counsellor, a community nurse, a clinic nurse and one caregiver of an adolescent living with HIV. The informants were recruited from the three communities selected for the study as follows: community health worker (42 years, Female, Nkankezi), a Community Adolescent Treatment Supporter (19 years, Male, Nkankezi), a community nurse (32 years, Female, Singwango), a clinic nurse (28 years, Female, Singwango) and a parent of an adolescent living with HIV (53 years, Female, Nkankezi).

### 4.3 Main themes

The reported experiences related to the challenges faced adolescents on ART were categorised into five themes, namely *individual*, *family*, *community*, *health system* and *medication* related challenges. These findings are summarised in table 1 and will be described in turn.

**Table 1: Themes and sub-themes**

<b>Theme</b>	<b>Sub-theme</b>
1. Individual challenges	1.1 Self-stigma 1.2 Poor mental wellbeing 1.3 Low ART literacy 1.4 Forgetfulness 1.5 Low perception of risk related to defaulting 1.6 Non-disclosure of HIV status 1.7 Relationship stressors
2. Family-related challenges	2.1 Unfavourable family environment 2.2 Poor socioeconomic status 2.3 Low family ART literacy 2.4 Inadequate family support 2.5 Family conflicts
3. Community-related challenges	3.1 Inadequate community support 3.2 Intransigent support groups 3.3 Fear of discrimination 3.4 Harmful cultural practices
4. Health service-related challenges	4.1 Rigid treatment review schedules 4.2 Unfriendly clinic staff 4.3 Long distances to health facilities 4.3.3 Lack of voice
5. Medication-related challenges	5.1 Misunderstanding treatment instructions 5.2 Medicine side-effects 5.3 Treatment fatigue 5.4 Unpalatable medication

#### ***4.3.1 Individual challenges***

Under the main theme, *individual challenges*, stigma, poor mental wellbeing, low ART literacy, forgetfulness, low risk perception, non-disclosure of HIV status and relationship stressors were reported as barriers to adherence to ART.

##### ***4.3.1.1 Self-stigma***

Participants revealed that they experienced self-stigma which emanated from the way they understood their condition and how their HIV status affected the way they thought they should

interact with others. As a consequence of this, participants stated that these feelings would cause them to be less receptive to any assistance particularly that related to adherence to treatment as they thought those that were there to offer assistance did not understand their situation. Some participants indicated that they would voluntarily discontinue their medication as they thought it was partly responsible for the negative way that they felt.

*I can't help but think that this condition that I have may be a curse of some sort. I tend to ask "Why me?" "What did I do wrong?" And of course I cannot answer these questions (Girl, 17 years, Zhulube).*

The participants also indicated that they did not get adequate answers within their community once they sought to understand why they were infected with HIV. They felt that the community would stigmatise them for their status.

#### **4.3.1.2 Poor mental wellbeing**

Many participants reported incidents of feeling depressed about their condition. They mentioned that this would destabilize them; thereby contributing towards poor treatment adherence. Others related the feelings of depression to unanswered questions related to how and why they got infected with HIV while some of their peers and siblings were HIV negative.

*Sometimes I really get depressed when I think of why I am infected with HIV. My parents are not around to give me answers, my grandmother does not like to talk about it. It is during these times that I do not feel like taking my ARVs ((Boy, 14 years, Nkankezi).*

The unavailability if someone to provide specific answers relating to one's HIV status also proved to be a contributor to poor mental wellbeing in adolescents on ART. In some cases, the adolescents indicated that they went for extended periods in denial of their HIV status.

*It took me a long time to accept my HIV positive status as I had never had sex before. No one had explained to me that I could have been infected by my mother during pregnancy. So during the days I was in denial I would miss my medication frequently and I was constantly in and out of hospital (Girl, 17 years, Zhulube).*



Some participants related the depression that they experienced to a general low standard of living within the household which was fueled by the strain that their care placed on extended family in general and their grandparents in particular. An environment like this was reported to perpetuate negative mood states where the adolescents became disengaged from most daily activities including eating and taking medications.

*Besides thinking about living with HIV- which is in itself stressful, I am often depressed by other issues like having my grandmother struggling to pay my school fees or buying food for us (Girl, 15 years, Nkankezi).*

A community adolescent HIV treatment supporter indicated that when their beneficiaries are depressed, it became difficult to reach out and assist them with adherence counselling.

*While some of our friends understand the need to ensure consistence and correct use of medicines, often times they neglect this important information when they are in a general bad mood or something bad has happened to them (Peer Counsellor).*



#### **4.3.1.3 Low ART literacy**

The key informants as well as some adolescents concurred that while there are several platforms for the distribution of knowledge related to HIV, there were some grey areas that were not properly understood and as such, would influence ART adherence behaviour. Sound literacy levels are required to understand the adherence counselling messaging in light of the multi-media approach to adherence counselling that is employed in lowest income countries such as Zimbabwe. It was reported that the mass testing exercises usually linked to programmes such as circumcision did not place much emphasis on the care and support for those who tested HIV positive. This approach would then leave the adolescents without adequate information to effectively follow the demands of the treatment regimen.



*I learnt of my HIV positive status just before I had a circumcision done. This news came as a shock to me and since then I have struggled to understand and accept the realities of being HIV positive and to meet the expectation of taking ARVs every day when I do not feel sick (Boy, 16 years, Zhulube).*

Some adolescents felt the information that they received from health workers was inadequate to explain the side effects to medication that may occur despite seemingly good adherence behaviour. As such, this would cause the adolescents not to take their medication regularly as they did not entirely trust its effectiveness.

*I have had several talks with health workers but I still do not fully understand why this condition cannot be cured, why I should take my medicine everyday even though I am not sick. My mother used to take her medicine everyday but she died last year (Boy, 16 years, Singwango).*

This finding was corroborated by the community nurses who indicated that upon home support visits, they still came across adolescents who did not understand some basic issues about their treatment.

*There are instances where our clients tell us that they do not understand the meaning of some of the terms we use related to treatment, either from the nurse or at the pharmacy department (Community Nurse).*

#### **4.3.1.4 Forgetfulness**

Simply forgetting to take ART at the prescribed times was a common reason given for poor ART adherence by the adolescents enrolled in the study. This forgetful behaviour was aggravated by life activities such as schooling, travel and household chores. The participants indicated that they

had some level of support to remind them to take their medication through peers but these peers or caregivers would also forget at times.

*On the two occasions where I missed my doses for ARVs, I had travelled and forgot to carry my medication with me. The following day, when I went to the nearby clinic, they could not supply me medication as I had left my records at home as well (Girl, 19 years, Zhulube).*

Most girls indicated that their household chores were key in their forgetfulness. This was further affected by the need to attend to their education through homework and related activities.

*On the times when I missed my doses, I simply would have forgot. Perhaps I was busy with homework or household chores, I don't know but I tend to remember when it's too late, like in the following morning or something (Girl, 15 years, Zhulube).*

#### **4.3.1.5 Low perception of risks related to defaulting**

Despite acknowledging that ART needs to be taken consistently to endure meaningful treatment outcomes, it emerged that some adolescents had a low perception of risk related to defaulting treatment. Others felt that by merely considering how healthy they felt and looked, it was enough justification to miss some doses.

*I look at myself and think that I am healthy enough and should not be taking medication every day (Boy, 15 years, Singwango).*

Previous experience of missing doses and not experiencing any illness was reported to promote poor adherence behaviour. One girl reported that they thought the risks related to defaulting were purposely exaggerated by health service providers so as to ensure good adherence.

*I often hear about the risks associated with defaulting but when I miss my ARV doses, none of that happens to me (Girl, 19 years, Nkankezi).*

#### **4.3.1.6 Non-disclosure of HIV status**

Non-disclosure of their HIV status was a common theme that emerged from engagement with the study participants. The challenges they reported indicated that adolescents were not too keen to disclose their HIV positive status to many people as they feared that this would expose them to stigmatisation and discrimination. All the participants in this study had disclosed their status to their immediate families and only a few had informed the extended family. This made them to act discretely with regards to taking treatment around their relatives and friends who they had not disclosed to and in some cases they would not take the medication altogether. This finding was also confirmed by the community nurse.

*Adolescents with adherence challenges usually have not disclosed their positive HIV status to anyone and as such cannot get people to support them when they have problems (Community Nurse)*

The study also identified disclosure as a process that limited the freedoms of the HIV positive adolescents as they felt they would thereafter be indebted to the persons that they disclose their HIV status to. As such, the frustrations related to disclosure of an HIV positive status were expressed by the study participants.

*Living with HIV makes you to be always under “control”, it is either the nurse or your parents who are always telling you what you can and cannot do. Neighbours and friends think they have a right to tell you what to do because of your HIV positive status. Sometimes I regret having disclosed my status because people see that first and disregard that I am also a normal person who can make decisions for themselves (Girl, 17 years, Zhulube).*

#### **4.3.1.7 Relationship stressors**

Most of the older adolescents involved in relationships attested to the effects that relationships may have on their adherence behaviour. The experiences reported included support in most cases where the partner was aware of their status but also poor adherence patterns where the partner had not been informed about the HIV status. It was reported that during times when relationships were facing challenges, this would cause additional stress to the HIV positive adolescent who in turn would be withdrawn from all forms of support including treatment.

*My boyfriend understands that I am living with HIV and is usually supportive when it comes to taking medication. When we have our fights, I notice that this is the period when I tend to miss some doses of my ARVs as he is not available to provide the usual support (Girl, 19 years, Nkankezi).*

#### **4.3.2 Family related challenges**

Under the main theme, family-related challenges, an unfavourable family environment, poor socioeconomic status, low ART literacy within the family, inadequate support, family conflicts and complex family dynamics were reported as challenges affecting adherence to treatment. These findings are described in turn.



##### **4.3.2.1 Unfavourable family environment**

Family disorientation was a common finding from participants who were orphaned or staying with extended family. Such environments were reported to be unfavourable for adolescents, who were in need of support to ensure good treatment adherence. Some adolescents felt that the different treatment they got at home was detrimental to good adherence practices.

*My elder brothers are both HIV negative. Sometimes I feel like my grandmother treats me differently from them. I would like her to see me as a normal child, maybe these tablets that I am taking are responsible for this unwelcome special treatment? I don't like it! (Boy, 14 years, Nkankezi).*

It emerged that staying under the care of extended family meant that support for adherence was minimal. The counselling process at the health facilities does not cater for potential extended family that may be available to provide care for the HIV positive adolescents.

*When I moved in to live with my sister, she had no time to take care of me, she did not know much about HIV and also had no money to give me when I have to go to the clinic for review. The situation was difficult for me. My sister does not work and depends on her husband to support her and myself. The husband is usually not around (Boy, 19 years, Zhulube).*

Some key informants attested to the complex family environments that the HIV infected adolescents had reported. The combination of poor socioeconomic conditions in the country which are exacerbated by the increased vulnerability of adolescents living with HIV, led to unstable family dynamics where they are moved from one caregiver to another. consequently, some adolescents would be forced to stay with caregivers who do not have much interest and skills to take care of them. Additionally, a change in the environment would cause the adolescents to be faced with the HIV status disclosure dilemma to caregivers whom they have not yet develop trust in.

*Family support is ever-changing. Some caregivers get fatigued and adolescents are moved regularly within the extended family (Community Health Worker).*

In some cases, the participants indicated that the lack of trust for a new caregiver led to non-disclosure and therefor lack of the envisaged support that the new caregiver would provide.

*I do not trust some of the family members and so I will not tell them about my positive HIV status (Boy, 15 years, Zhulube).*

#### **4.3.2.2 Poor socioeconomic status**

Most adolescents indicated that their families could not raise extra funds to purchase the nutritious food required for optimal health. Additionally, adolescents reported that at times they would not have money to travel to the clinic to adhere to clinic appointments or pick up medication.

*Shortage of money to travel to the clinic as well as buying food poses difficulties for me to stay on treatment without missing doses (Girl, 14 years, Singwango).*

Health care workers further attested to these challenges by indicating that the distances that clients have to travel to get to their clinic appointments on time were prohibitive, some requiring the younger adolescents to travel with their caregivers thereby further straining the family that was already struggling.



*Some of our patients have noted that the health facilities are not easily accessible, either they are too far and there is no transport to take them to the clinic or the patients do not have transport money (Nurse).*

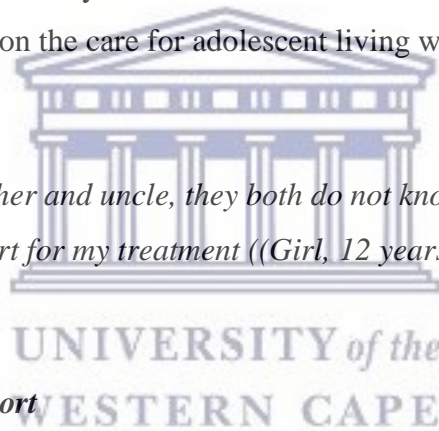
Other adolescents reported that they did not feel it was a worthy investment to spend the little funds that they had to travel for routine clinic appointments. This perception would then lead to defaulting of clinic appointments and resultant missing of medication doses were refill was delayed.

*Sometimes we do not have money for bus fare to go to the clinic for review. We feel that it is too expensive to look for money to go all the way, only to be given the pills. The authorities should send the pills by post because when we go there all they do is just give us the pills, no examination, no nothing (Boy, 17 years, Nkankezi).*

#### **4.3.2.3 Low family ART literacy**

Another challenge associated with the disrupted family set up was that adolescents living with HIV typically move around within the extended family and as such end up staying with caregivers who do not understand living with HIV or being on ART and how to support one such adolescent. Even when a guardian got counselled on how to care for an adolescent living with HIV, there was no mechanism within the community to ensure that with the change of residence, the new guardians would also be taught on the care for adolescent living with HIV.

*I live with my grandmother and uncle, they both do not know much about ARVs so they do not provide much support for my treatment ((Girl, 12 years, Zhulube).*



#### **4.3.2.4 Inadequate family support**

Some adolescents reported that they do not get sufficient adherence support at home. Participants reported that they only or mostly get support from health workers and community health workers. They mentioned that there was a need for this (support) to be complemented with support in the home to ensure optimal adherence to treatment. This was particularly so for those adolescents who attend boarding school and commonly default on treatment during school holidays where their caregivers were not as supportive as the school health masters who provide adherence support during the boarding period.

*I wish my mother would be more supportive of my treatment because when I am at home I need someone to encourage me (Girl, 14 years, Zhulube).*

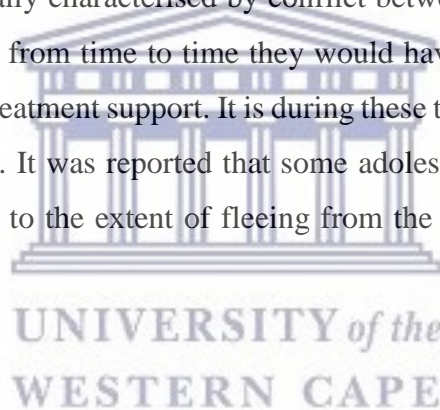


Some participants indicated that placing the burden on their elderly caregivers to remind them when to take medication was not always practical as they had their own other “issues” to deal with.

*I usually forget to take my medicines every day at the same time, I live with my grandmother and she too forgets to check on my medication (Boy, 12 years, Nkankezi).*

#### **4.3.2.5 Family conflicts**

The adolescent period is generally characterised by conflict between children and their families. Some adolescents reported that from time to time they would have conflicts with the caregivers who are also meant to provide treatment support. It is during these times when they would be prone to missing doses of medication. It was reported that some adolescents would isolate themselves during periods of conflict even to the extent of fleeing from the homestead to stay with distant relatives or friends.



*At one time I had a conflict with my father and he wanted to beat me up so I ran away from home to stay with my uncle for some time. I left my medication at home and so I missed my medication for those days. I also could not get my uncle to assist me as I had not disclosed to him and my mother had told me not to tell any relatives about my HIV positive status (Girl, 19 years, Singwango).*

#### **4.3.3 Community related challenges**

Under the main theme of community-related challenges, inadequate community support, intransigent support group activities, fear of discrimination and harmful cultural practices were reported by the study participants. These challenges are described in turn.

#### ***4.3.3.1 Inadequate community support***

A common psychosocial support instrument available for adolescents living with HIV within the community is through the support groups that are coordinated by the MOHCC and peer educators. It emerged from this study that this CATS model alone was not adequate as those that were not in the group would face challenges with treatment adherence. Those adolescents who could were not regular members of peer support groups or did not like the group dynamics would then miss out on the adherence support that these groups provide.

*My child started missing medication doses when they left the adolescent support group. We had to encourage him to go back to the group even though he had mentioned that he did not like some people in the group (Caregiver).*

The community support group activities were described as intransigent. It emerged from the study that the rigid nature of the intervention was frustrating for some. These groups have set meeting times and the agenda for the meetings is predetermined by the coordinator, leaving those with specific challenges related to adherence to treatment with nowhere to go.

*The available support mechanisms are not adequate. They are not flexible, there is only one size fit all such as the CATS model. What if I prefer support from my siblings and not a stranger? The clinic considers that to be wrong, but sometimes I think my brother would understand my situation better than the CATS (Boy, 18 years, Nkankezi).*

Other participants felt that the support groups did not provide them ample opportunity to present their unique challenges. Some study participants indicated that the support groups tended to be dominated by others and as such they did not benefit from attending them.

*My support group in the village has older guys who cannot relate to my situation. I do not think it is helpful but the community health worker says it is important that I attend the support group sessions every fortnight. Most of the times I just listen to the others talking (Boy, 16 years, Nkankezi).*

It also emerged from older adolescents that the Community Adolescent Treatment Supporter (CATS) model did not allow them adequate exposure to economic strengthening activities and so attending the regular support groups would disadvantage them economically.

*The model of support groups we are in now do not allow us to make meaningful progress with our lives socioeconomically. The group activities have no funding and always talk about HIV all the time. We also want to start projects, lead productive lives and be independent from our parents (Boy, 19 years, Zhulube).*

#### **4.3.3.2 Fear of discrimination**

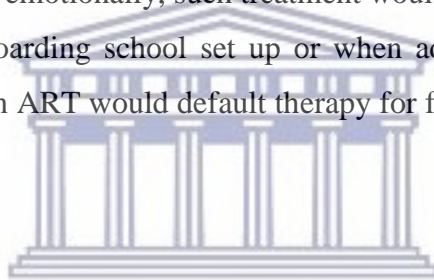
Some participants reported that they did not desire to be known in the community as an adolescent living with HIV as this would make them a target for unfair treatment and discrimination by their peers or the community at large. As such, they would not seek any assistance with regards to improving their adherence to treatment and in certain circumstances would abandon the ART all together so as to avoid inadvertent disclosure.

*People always say HIV infection is not a death sentence, I understand that but stigma and discrimination are as good as a death sentence. So when I disclose my HIV status to people, it is like I have a death sentence due to the pain I suffer from discrimination. Some people gossiping about how I got infected and so on (Girl, 17 years, Nkankezi).*

It emerged from this study that the stigma and discrimination suffered within the school set up had long lasting effects on the life of the adolescents living with HIV. Due to the fear of discrimination, some HIV positive adolescents would not form any friendships at school and this further isolated them.

*I have heard some of my friends at school gossiping about other children who they know are taking ARVs. So I decided not to tell anyone that I am also on treatment (Boy, 13 years, Zhulube).*

Some participants also reported unfair treatment from their colleagues at school. Besides hurting the adolescents living with HIV emotionally, such treatment would also lead to poor performance at school. Furthermore, in a boarding school set up or when adolescents were camping for a sporting event, those who are on ART would default therapy for fear of discrimination once their HIV status is known.



*Our peers at school who are HIV negative should be educated about HIV and ART so that they better understand our circumstances and stop stigmatising us (Girl, 14 years, Singwango).*

Other participants indicated that the discrimination was also demonstrated by their teachers. They reported that in an attempt to provide special treatment to adolescent living with HIV, this kind of treatment led to further isolation and stigma.

*At school, the other children as well as the class teacher treat me differently, like they think that I am weak, this special treatment is not nice sometimes (Boy, 15 years, Zhulube).*

Community health workers also indicated that while they are available to provide psychosocial and adherence support to adolescents living with HIV, their services were not always welcomed by the clients. To have a community health worker regularly visiting your household was described as equivalent to announcing one's HIV status to the entire community. This led to some beneficiaries being reluctant to accepting community health worker support.

*Some adolescents living with HIV may not like the idea of a “stranger” coming to visit them regularly in their homes and “talk about HIV” (Community health worker).*

#### **4.3.3.4 Harmful cultural practices**

Societal norms, cultures and beliefs that hinder good adherence to treatment also emerged as an important challenge faced by adolescents on ART. Insiza is a rural district with strong cultural norms and practices. Some adolescents reported to have been influenced by their family and peers to seek the services of traditional healers particularly if they were not satisfied by the services at the clinic and were given advice detrimental to their adherence.

*In our village, a lot of people believe in traditional healers. Once I visited one who told me to take some herbs and in order for those herbs to work, I had to throw away my ARVs (Boy, 19 years, Singwango).*

Some harmful advice was reported to be obtained from religious leaders who would blame the opportunistic infections that one got from time to time on the ARVs themselves. This would urge the adolescents on ART to default in a bid to ‘reduce the opportunistic infections’.

*Some of my clients visit traditional healers or prophets who tell them that the ARVs are making them sick and this makes them default (Community Health Worker).*

#### **4.3.3.5 Lack of voice**

As adolescents are getting more and more access to information, it emerged from this research that they felt their own voices and opinions were not considered in the development of interventions to improve service delivery. As such the adolescents would then shun such interventions meant for improving adherence to ART. Some study participants indicated that they thought the medications were part of some experiment which they have not been fully briefed on and would therefore not adhere to treatment.

*Adolescents note that they are not recognised fully. They are not invited to participate in decision making with regard to their care. All they hear is that there are new guidelines that they should follow or else treatment will not be successful (Community Health Worker).*

#### **4.3.4 Health service related challenges**

Under the main theme of health service-related challenges, the rigid treatment review schedules, unfriendly clinic staff and long distances to the health facilities were reported to pose challenges in adhering to ART. These experiences are described in turn.

##### **4.3.4.1 Rigid treatment review schedules**

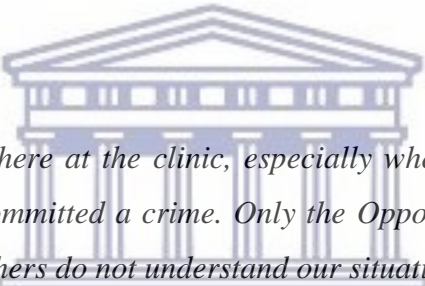
Adolescents, particularly those in school, pointed out that they faced challenges when clinic review days clashed with school activities. They reported that it was difficult to get their health service providers to re-schedule the review appointments as adolescents were deemed to require specialist care that was available at certain times determined by the trained nurses. It was equally difficult to reschedule school events such as examinations and sports. As such, adolescents would go for some days without ART medicines until they make it to the next review appointment. Furthermore, in the rural areas, ART services were not offered on weekends.

*I find it difficult when the review date falls on a day when I am supposed to be at school because when I miss school, my friends will want to find out where I was, I would prefer all my review dates to be on a weekend (Boy, 12 years, Nkankezi).*

Navigating the clinic appointment schedules had implications on unintended disclosure of HIV status as the adolescents on ART would have to explain to their friends why they missed school when they were apparently well.

#### **4.3.4.2 Unfriendly clinic staff**

The way participants were treated by clinic staff was mentioned as a critical barrier to care. Some adolescents reported that health services were usually poor if they were provided by nurses who do not usually review them.



*I do not like the atmosphere at the clinic, especially when I go alone, you feel like an outcast, like you have committed a crime. Only the Opportunistic Infections department nurses are good to us, others do not understand our situation (Girl, 17 years, Zhulube).*

Other adolescents revealed that the services at the local clinics were better than those at the district hospital. It was reported that the nurses who worked at the larger district hospitals seemed a lot busier and less caring than the local clinic nurse that they were used to. Therefore, adolescents would not attend health facilities where they felt the nurses were mean or they would return home without consultation if they found a nurse they were not fond of at the clinic.

*At the district hospital where I am often referred to see specialists, I find that the environment there is not friendly. Everyone seems to be busy and minding their own business, they do not have time to chat with you like they do at our local clinic (Boy, 16 years, Nkankezi).*



Other participants indicated that they were upset by some statements made by health care workers at the clinic. Patient confidentiality was often ignored within the crowded consultation rooms at the clinics.

*The nurses at the clinic usually say offending statements with regards to people living with HIV and for some of us who will be seated in the waiting room, it is hurtful (Girl, 19 years, Zhulube).*

For younger participants, there was mention of difference in the type of care they were now receiving at the adult clinics which was less personable than at the paediatric units. They indicated that such treatment discouraged them from attending health facilities.

*I do not look forward to my monthly clinic visits for review. The nurses are not friendly; they usually seem to be very busy to attend to all my concerns. This was not the case when I was younger and used to come with my granny for review (Boy, 14 years, Singwango).*



#### **4.3.4.3 Long distances to the health facilities**

The distance that patients have to travel to the health facility emerged as a common challenge faced by adolescents on ART. This was compounded in some cases by delayed provision of services notwithstanding that the clients would have to travel long distances again back to their homes. At times this led to the postponement of review appointments until such a time as when one has access to free transport.

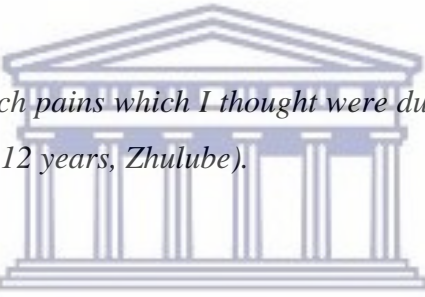
*We walk long distances to the clinic to get treatment. When we arrive there, we are served very late and then we have to travel long distances back home. This is frustrating sometimes (Girl, 19 years, Nkankezi).*

#### ***4.3.5 Medication related challenges***

Under the main theme of medication-related challenges, the side effects, misunderstanding treatment instructions, treatment fatigue and unpalatable medicine formulations were reported by the study participants. These will be described in turn.

##### ***4.3.5.1. Medicine side effects***

Where adolescents were not properly counselled on the nature of the adverse effects that may arise from taking ART as well as how to deal with these, this posed as a serious challenge to good adherence. Some adolescents reported that they had skipped medication doses on the face of adverse events.



*At one point I had stomach pains which I thought were due to the ARVs and so I decided to stop medication (Girl, 12 years, Zhulube).*

One of the key informants indicated that the reason why their beneficiaries did not tolerate medicine adverse events well was because of the way the nurses explained them. It emerged that the routine counselling messages offered to adolescents taking ART did not adequately address the array of side effects that may result from taking medication.

*As nurses we have to be able to understand the side effects profile of ARVs fully so that we explain to our patients in a way that will be clear to them (Clinic Nurse).*

It was also reported in this study that the management of medicine side effects was not prioritised by the health service providers. Beneficiaries did not know what to do upon experiencing any adverse events. This led them to have no option but to discontinue medication.

*When a patient does not understand the side effects of ART, they may be forced to discontinue treatment if no one gives them a remedy. At times it is just about having someone to assure them that this is temporary (Community Nurse).*

#### **4.3.5.2 Misunderstanding treatment instructions**

The current treatment counselling procedures were described as rigid and do not cater for those adolescents who may have problems with understanding the instructions. As such, some adolescents alluded poor adherence behaviours to be influenced by misunderstanding the treatment instructions. Some key informants attested to that they would discover during routine support activities that the adolescents are not adhering well to treatment because they would not have understood the treatment instructions from the health care workers in the first place.

*Sometimes when we review the way clients are taking medicines we see that they may not have understood the instructions. It is important therefore to reinforce treatment messages at each visit to our clients (Peer Counsellor).*

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Some participants further explained that they felt the nurses did not fully understand their situations. This made the nurses to provide generic advice that did not adequately address the concerns of their adolescent clients.

*Others have indicated that the support they receive in the clinic in terms of treatment advice is not enough since the nurses do not fully understand the difficulties that patients face (Community Health Worker).*

#### **4.3.5.4 Treatment fatigue**

Adolescents who had been taking ART for several years reported that at times they do not want to continue taking medication as the medicine was overburdening their bodies. Treatment fatigue was reported despite support from the family and the health system to persevere with medication. Some adolescents voiced that they were now bored with regular hospital visits for the “same thing”.

*Sometimes I feel I am tired of taking medication as my body will be feeling weak. During these times I delay taking my medication or miss doses until I am feeling much stronger (Girl, 19 years, Nkankezi).*

Despite the availability of psychosocial support in the form of family members, it emerged that the feeling of being fed-up with treatment was a real barrier to good adherence. This was particularly so in adolescents who were taking ART since childhood.

*I have been taking these ARVs since I was young, sometimes I wake up and just feel fed up and then I don't take my medicines even though my grandmother tries to encourage me (Boy, 13 years, Zhulube).*

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Other participants indicated that there was no ‘excitement’ with taking ART and therefore they would tend to skip medications regularly as the pills ‘reminded’ them of how boring life can be.

*Sometimes the thought of taking medication is just boring and so I decide to skip doses (Boy, 16 years, Zhulube).*

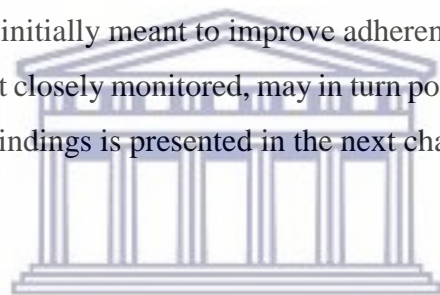
#### **4.3.4.7 Unpalatable medication**

It emerged from this study that in the early phases of treatment, some adolescents felt that the medication was unpalatable. Additionally, the pill burden would exacerbate this effect where the adolescents were supposed to take medication for other opportunistic infections.

*In some instances, the clients say that the pills are unpalatable within the first few weeks but they get used to the taste as time goes on (Clinic Nurse)*

#### **4.4 Summary of Findings**

The themes emerging from the study showed that adolescents living with HIV and enrolled on ART face several challenges - both personal and inter-personal. Additionally, some challenges are related to interventions that are initially meant to improve adherence to treatment such as support groups. This interventions, if not closely monitored, may in turn pose as barriers to good adherence to ART. A discussion of these findings is presented in the next chapter.



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## CHAPTER 5: DISCUSSION

### 5.1 Introduction

This chapter will discuss the key themes emerging from this qualitative inquiry - individual challenges, family related challenges, community related challenges, and health facility related challenges as well as medication related challenges – in relation to the literature. The chapter is concluded with a discussion of the study limitations.

### 5.2 Individual challenges

While the challenges experienced by HIV positive adolescents are complex and are experienced at multiple levels, it was important to note that in this study adolescents identified challenges such as stigma, poor mental health in the form of depression, forgetfulness, low risk perception, disclosure of HIV status and relationship stressors as barriers for good adherence to ART.

Self-stigma was a common challenge that adolescents reported to be a barrier to disclose their HIV status as well as seek services. Hordes *et al.* (2018) allude to HIV-related self-stigma as a driver for adolescents to shy away from services and exist in their own “private world”. This research showed the relationship between stigma and other downstream barriers to good ART adherence as reported by the adolescents and their service providers. Bernays *et al.* (2015) also described self-stigma as being at the centre of a complex interplay of social and developmental factors. The findings from this study further suggest that there may be an interface between stigma and other “external factors” as adolescents would then avoid all other available avenues of support for fear of stigmatisation. Stigma is indeed a harmful societal phenomenon that needs to be addressed to ensure sustainable control of HIV in vulnerable sub-populations such as adolescents (Stangl *et al.*, 2013).

Forgetfulness has been shown to be directly related to poor HIV treatment adherence (Haberer *et al.*, 2017). In this study, the finding of note was that adherence behaviours linked to forgetfulness were related to the complex stage of development associated with adolescence within the context of a poor socioeconomic context. The study findings suggest that while forgetfulness is a common

barrier to ART adherence, the study participants described other life events such as the need to engage in education and household chores may cause one to forget their medications more regularly. Additionally, forgetfulness was also described at the level of the caregivers; thereby compromising the assumed support that the adolescents have in their social support system.

Another important individual level challenge identified in this study was the effect of interpersonal relationships on adherence behaviours. Indeed, the absence of psychosocial support in the form of a life partner (boyfriend or girlfriend in the context of this study) may influence adherence. Additionally, when the relationships face challenges, these may translate to poor treatment outcomes such as bad adherence. Dahourou *et al.* (2017) describes a similar situation which they attribute to the enhanced vulnerability that adolescents living with HIV expose themselves to as they pursue social advancement in the form of companionship.

### **5.3 Family level challenges**

The family challenges of note described in this study involve the complex family dynamics that include conflict, inadequate support and underprivileged socioeconomic environments. In Zimbabwe the provision of comprehensive HIV care services has been decentralised countrywide such that primary health care facilities are able to offer HIV prevention, diagnosis, and treatment as well as support services to adolescents. However, Cluver *et al.* (2018) assert that it is important to ensure that adolescent who receive these services have an enabling family environment. In this study, the challenges faced by adolescents at home were related to inadequate knowledge by their family support system underpinned by general family disorientation that characterised most of the families from which the study participants were drawn from.

It is well documented that poor socioeconomic conditions at the household level can compromise the ability to ensure optimal treatment adherence support for HIV positive adolescents (Kariuki *et al.*, 2016). This study linked several effects of a poor socioeconomic status characterised by inadequate funds for transport fess to visit the hospital and little money to purchase food to poor ART adherence behaviours. A related finding was that living in poor socioeconomic conditions will hinder adolescents living with HIV to attend to activities that support treatment adherence directly such as support group meetings, but opt to look for more income in the form of menial



employment. Fatti *et al.* (2018) point out that alleviation of the socioeconomic burden through the provision of social grants could assist with treatment adherence in older adolescents.

#### **5.4 Community level challenges**

All communities in the Zimbabwe health delivery system have a network of community health workers and peer counsellors who have been trained in the provision of adherence support. It was however important to note in this study that despite this support, adolescents remain with crucial challenges to ART adherence with some challenges emerging within the context of the community health system. The CATS-led adolescent support groups proved to be a challenge for some adolescents as they lacked diversity in terms of curriculum to cater for different stages of adolescence as well as diversity to improve other facets of the lives of adolescents. Grosso *et al.* (2018) indicate that such youth-led interventions should be furnished with technical as well as expressive financial support to endure sustainability as well as meaningful engagement.

Despite widespread community education, advocacy and sensitisation exercises in Zimbabwean districts, harmful cultural practices were identified in this study as an important barrier to good adherence behaviours in adolescents. Tinasti (2018) assert that cultural harm reduction interventions should accompany any treatment programmes so that the cultural context becomes a “safe space” to support good adherence practices. This study showed that some adolescents seek alternative and harmful practices due to the gaps that exist within the conventional standard of care. The study showed that the current treatment modalities such as adolescent support groups were not well differentiated to address the diverse sociocultural challenges that adolescents from different societies may have.

#### **5.5 Health service delivery challenges**

Upstream factor challenges such as long distances to the health facilities also play an important role in adherence to treatment. This study found that the effects of long distances to health facilities were further exacerbated when adolescents would brave through the long distances only to arrive at the health facilities where the services are not friendly to their cause. Mesic *et al.* (2017) argue

that all efforts to expand health systems so as to improve coverage of care should be matched by similar interventions that ensure quality improvement in service delivery. In this study, the health services were noted to be another driver of community stigma through events such as accidental disclosure of one's HIV status and general rudeness on the part of health care workers.

For adolescents with many activities happening in their lives, the health systems need to be adapted to facilitate smooth transition from paediatric care to adult care. It was noted in this study that adolescents who had been on ART since childhood preferred the paediatric services that they had grown accustomed to as the health service providers there were familiar with their "story". Dahourou *et al.* (2017) suggest the need to provide pre-transition services such that those adolescents most at risk of poor transition should be provided with hybrid community and health system based support to ensure smooth transition and retention in care.

## **5.6 Medicine related challenges**

The challenges related to medication that were identified as barriers to ART in this study included adverse effects, treatment fatigue and inadequate understanding of the medication. It is generally agreed that over the years, the ART medicines available have fewer side effects and as such are more tolerable. However, this study pointed out the role of pre-treatment counselling as some adolescents erroneously attributed some feelings to the effects of ART and thus would discontinue medication. Kwarisiima *et al.* (2017) add that while adverse events are uncommon with ART, when they occur and one discontinues treatment, it is difficult to retain them in care as they fear a repeat of the previous experiences.

The role of food in promoting uptake of medication is described well by Hordes *et al.* (2018). This is consistent with the findings from this study where adolescents linked poor adherence behaviours to unavailability of food or the money to buy food. However, most adolescents indicated that once they understood the importance of taking medication regularly and the risks associated with poor adherence to ART, they tended to be less affected by the unavailability of enough food at home.

## **5.7 Study limitations**

The study was carried out in a rural population and thus it may be challenging to apply the findings to urban-based adolescents. Additionally, the sample was drawn from adolescents who had history of poor adherence but had been retained in care. As such, this does not represent those adolescents who are no longer in care and face the most challenges related to poor adherence.



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## CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

### 6.1 Conclusions

This study, through its exploratory qualitative methodology, was ideal to unearth a deep understanding of the interplay of factors that are attributed to poor adherence behaviour. Additionally, I am now in a position to better appreciate the complex and interrelated challenges faced by HIV positive adolescent on ART. As such, the study described each level at which the challenges interact with the individual patient, the family, community as well as the health system.

The information obtained from this study will contribute to improved understanding of the adolescent sub-population in relation to HIV care and treatment. This additional knowledge provides a basis for the development of interventions that will be acceptable to this population in a bid to control the HIV epidemic and achieve global sustainable development targets related to adolescence and HIV care. The study demonstrates the different dynamics related to navigation of barriers to care by adolescents and also highlighted how this affected adherence.

Adolescents remain a key population who are often underserved by the available interventions for the prevention and control of HIV. The researcher acknowledges that while ART has the potential to improve care and treatment outcomes of adolescents living with HIV, adherence to treatment remains a key feature for the success of ART, particularly in the adolescent population who evidently are dealing with several multicomponent life huddles that they have to navigate.

The barriers to adherence to ART which are described in this study point towards the need for careful considerations of the circumstances of each client prior to initiation of ART. In the study, the researcher found that certain structural barriers such as an unstable family environment may not exist across the board for the entire population and as such, the particular interventions to curb the effect of such barriers may not work for all the adolescents within the care and treatment program.

The findings of this study contribute an additional voice to the conversation regarding the need for sensitized care to be given to the delicate adolescent population in order to foster successful transition from the childhood care and treatment program to adult care. It is important for the health

service providers as well as the adolescents themselves to identify a common understanding of the various factors that may contribute to success or failure with regard to the prevention and treatment of HIV especially during the transition period. In addition, the findings herein may be considered in designing care and treatment programs for adolescents, which are not necessarily related to HIV.

Understanding the effects of certain community norms as well as cultures outlined in this study is important for aligning the community health system to the needs of its vulnerable patients such as adolescents living with HIV and further amplifies the effectiveness of community based interventions which are delivered within the context of normal everyday life such as the community-based adolescent support groups. Such initiatives are sustainable as they build on the daily chores of the family members.

## **6.2 Recommendations**

Based on the information obtained from this study, the researcher makes the following recommendations related to parents/guardians of adolescents living with HIV, Health care workers, HIV positive adolescents, Programme Managers, School Principals, Community leaders and Researchers.



### ***Parents/Guardians***

The study described several scenarios where children face family-oriented challenges to treatment adherence. The researcher therefore recommends that caregivers of ALHIV should continually update their knowledge about HIV and its treatment so that they are well versed with best practices and support their dependents appropriately. Within the home environment, caregivers should actively inquire about the adherence behaviours of their adolescents who are taking ART so that they promptly intervene where there are signs and symptoms of poor adherence. The researcher further recommends that parents and guardians of ALHIV should understand the effect that poor mental health such as depression or other common mental disorders has on the adherence to ART. As such, this will create a platform where ALHIV are free to consult their caregivers for support.

### ***Health Care Workers***

Health care workers play a pivotal role in ensuring that adolescents living with HIV adhere to their treatment regimens. The study found that some health care workers do not possess the necessary soft skills to optimally address the needs of ALHIV. As such, the researcher recommends that there should be periodical capacity building interventions for health care workers through mentorship so as to promote good counselling skills within the service providers. Additionally, health care workers should also be aware of other services offered by the social service department so that they promptly initiate referrals where indicated. It will also be important to review the health care worker monitoring systems such that their daily practices do not inadvertently fuel HIV stigma when attending to ALHIV. As health workers engage ALHIV, they should deliberately inquire about their household dynamics which may affect treatment adherence and as such, model their counselling message to help the ALHIV navigate those situations successfully.

### ***HIV Positive Adolescents***

The study identified some challenges to treatment adherence which are linked to the individual who is living with HIV. The researcher therefor recommends that ALHIV should make use of available mechanisms such as cellphone reminders or treatment buddies to address the challenge of forgetting to take their medication regularly. Health service providers as well as parents are encouraged to assist ALHIV to develop daily routines that do not distract them from taking their medication. ALHIV should also be linked to interventions that address HIV-related stigma such as social asset capacity building classes. should be adapted and scaled up for ALHIV. Furthermore, the researcher recommends that ALHIV should consider disclosing their HIV status to an individual who is capable of providing support.

### ***Programme Managers***

The researcher recommends that programme managers should scale up of differentiated models of care for adolescents on ART so that there are comfortable schedules for appointments as well as an enabling youth-friendly environment to provide counselling services towards promotion of



good adherence practices. Programme managers are encouraged to look beyond the support groups in rolling out interventions to promote good adherence practices for adolescents who prefer an alternative to the support groups. Additionally, programme managers are to promote collaboration with the education department to address disruptions for those in care and attending school. Managers should also continuously review and revise programme tools to ensure that they address relevant issues to the dynamic challenges faced by adolescents on ART. For instance, there is an urgent need to roll out registers that accurately track the transition periods from childhood to adolescence and from adolescence to adulthood. Furthermore, mental health surveillance should be integrated into routine adherence monitoring procedures for the adolescent age group. This study found that there was significant effect of poor mental health on adherence to treatment.

### ***Community Leaders***

Monitoring and coordination of support group activities within the community is recommended and these activities should be done under the auspices of the community leadership. The research found that certain community cultures and practices contribute to the rise in stigma and discrimination which ultimately promotes poor adherence to ART. The researcher therefore recommends that community education with support from the leaders should be prioritised so that the community has access to accurate information regarding HIV/AIDS in general and ART in particular so as to reduce stigma. Community leaders are also pivotal in raising the level of awareness of the community members on the challenges faced by adolescents on ART so that the community can provide support to them.

### ***School Principals***

The researcher recommends that there should be periodic and capacity building exercises such as training workshops for teachers at schools - particularly boarding schools - to enable teachers to better care for adolescents who are taking ART within the school set up. School managers should actively provide surveillance to ensure that teachers provide evidence-informed accurate teaching about HIV/AIDS and ART adherence. The classroom can be used to support discussions aimed at dispelling ART related myths while promoting peer-support within the learning environment.



## ***Researchers***

Following the exploration of the challenges faced by HIV positive adolescents who are taking ART, further research is recommended on the differences in the experiences of perinatally infected compared to those who are behaviourally infected. The study identified that the challenging experiences are related to the length of time that the adolescents are on treatment as well as available family and community support. In this regard, it is also advisable to explore the differences in challenges related to treatment adherence in early treatment in comparison to those who have been on treatment of longer times.

Further research to identify the mechanisms to address forgetfulness that are acceptable to modern day ALHIV. This is necessary as lifestyles have changed over time and as such the interventions should be relevant to the modern day adolescent and their families.

A further exploration on the role of mental health in supporting adherence to treatment is also recommended.

Finally, the research recommends rigorous evaluation of the available interventions to support adherence with an aim to identify mechanism of aligning them with the complex challenges described in this study.



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## Appendix 1: Participant information sheet



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### INFORMATION SHEET

**Project Title:** Exploration of adherence to treatment challenges experienced by HIV positive adolescents in Insiza district, Zimbabwe.

#### **What is this study about?**

This is a research project being conducted by Rickie Malaba at the University of the Western Cape for a mini-thesis for a Masters in Public Health. You are invited to participate in this research project because you value your experience, knowledge and perceptions related to the research topic. The purpose of this research project is to find out and improve our understanding on the different problems faced by HIV positive adolescents with regards to adherence to treatment. It is hoped that the findings from this study will provide information that will be used to improve the services given to adolescents living with HIV.

#### **What will I be asked to do if I agree to participate?**

You will be asked to provide signed consent prior to taking part in an interview that will last about an hour. There you will be asked questions related to your experience as an adolescent living with HIV. During the interview, what you say will be recorded and the discussion will include the challenges you have faced with regards to adherence to treatment. The interview will be done at your home or any place you are comfortable with. Privacy will be ensured throughout the interview and if you feel that at any time you need to discontinue, this will be allowed with any consequences to you. We will also get back to you once we consolidate the information from the interview to confirm with you if they represent your views accurately. Once the study has been concluded, the final results will also be shared with you. We will also contact you when the need arises for any

clarifications. You will not be obliged to answer any questions that you feel are inappropriate or insensitive. If you feel you have any further questions during the interview you may seek clarification at any time.

### **Would my participation in this study be kept confidential?**

The researcher will protect your identity and the nature of your contribution. Codes will be used to ensure that there is no information in the research notes that will personally identify you. Only the researcher will have access to the identification key of the code. To ensure your confidentiality, the information from the interviews will be locked away safely. Access to the recording device will also be password protected. Once transcription is completed the original recordings will be destroyed permanently. All the devices used in the interviews will be stored in a lockable cabinet. If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities, information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break discretion to fulfil our legal responsibility to report to the designated authorities.

### **What are the risks of this research?**

There may be some risks from participating in this research study. As the subject under discussion may make you feel uncomfortable. The researcher will nevertheless minimise such risks and act quickly to assist you if you experience any discomfort, emotional or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance. All human interfaces and talking about self or others carry some amount of risks.

### **What are the benefits of this research?**

The benefits of this research include the researcher learning more about the challenges faced by individuals like yourself with regards to adherence to HIV care and treatment. There may be no direct benefit to you personally but we hope that in the future other people might benefit from this study through improved understanding of your challenges related to the subject under inquiry. The findings are expected to contribute to improvement in care and support for adolescents living with

HIV, their families as well as the community at large.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participation at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**What if I have questions?**

This research is being conducted by Rickie Malaba from the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Rickie Malaba at:

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Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Senate Research Committee. (**REFERENCE NUMBER:** BM18/1/9)



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## Appendix 2: Key Informant information sheet



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### INFORMATION SHEET

**Project Title:** Exploration of adherence to treatment challenges experienced by HIV positive adolescents in Insiza district, Zimbabwe.

#### What is this study about?

This is a research project being conducted by Rickie Malaba at the University of the Western Cape for a mini-thesis for a Masters in Public Health. You are invited to participate in this research project because you we value your knowledge related to the research topic. The purpose of this research project is to find out and deepen our understanding on the different challenges faced by HIV positive adolescents with regards to adherence to treatment. It is hoped that the findings from this study will provide information that will be used to improve the services given to adolescents living with HIV.

#### What will I be asked to do if I agree to participate?

You will be asked to provide signed consent prior to taking part in an interview that will last about an hour. There you will be asked questions related to your experience and knowledge related to treatment adherence related to adolescents living with HIV. During the interview, what you say will be recorded and the interview will be done at any place you are comfortable with. Privacy will be ensured throughout the interview and if you feel that at any time you need to discontinue, his will be allowed with any consequences to you. We will also get back to you once we consolidate the information from the interview to confirm with you if they represent your views accurately. Once the study has been concluded, the final results will also be shared with you. We will also contact you when the need arises for any clarifications. You will not be obliged to answer any

questions that you feel are inappropriate or insensitive. If you feel you have any further questions during the interview you may seek clarification at any time.

### **Would my participation in this study be kept confidential?**

The researcher will protect your identity and the nature of your contribution. Codes will be used to ensure that there is no information in the research notes that will personally identify you. Only the researcher will have access to the identification key of the code. To ensure your confidentiality, the data from the interviews will be transcribed and stored in password protected devices. Access to the recording device will also be password protected. Once transcription is completed the original recordings will be destroyed permanently. Prior to that, all devices will be stored in a lockable cabinet. If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities, information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

### **What are the risks of this research?**

There may be some risks from participating in this research study. As the subject under discussion may make you feel uncomfortable. The researcher will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. All human interactions and talking about self or others carry some amount of risks.

### **What are the benefits of this research?**

The benefits of this research include the researcher learning more about the challenges faced by adolescents living with HIV with regards to adherence to HIV care and treatment. There is no direct benefit to you personally but we hope that in the future other people might benefit from this study through improved understanding of the challenges related to the subject under investigation. The findings are expected to contribute to improvement in care and support for adolescents living

with HIV, their families as well as the community at large.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**What if I have questions?**

This research is being conducted by Rickie Malaba from the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Rickie Malaba at:

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**[drrickiemalaba1@gmail.com](mailto:drrickiemalaba1@gmail.com)**



Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

**Prof. Uta Lehmann**  
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**School of Public Health**  
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This research has been approved by the University of the Western Cape's Senate Research Committee. (**REFERENCE NUMBER: BM18/1/9**)



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### Appendix 3: Consent Form- Adolescents



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**Title of Research Project:** Exploration of adherence to treatment challenges experienced by HIV positive adolescents in Insiza district, Zimbabwe.

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

\_\_\_\_\_ I agree to be audiotaped during my participation in this study.

\_\_\_\_\_ I do not agree to be audiotaped during my participation in this study.

**Participant's name:**

**Participant's signature:**

**Date:**

#### Appendix 4: Consent Form – Key Informants



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**Title of Research Project:** Exploration of adherence to treatment challenges experienced by HIV positive adolescents in Insiza district, Zimbabwe.

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

**Participant's name:**

**Participant's signature:**

**Date:**

**Appendix 5: Consent Form – Parent/ Caregivers**



**UNIVERSITY OF THE WESTERN CAPE**  
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**Title of Research Project:** Exploration of adherence to treatment challenges experienced by HIV positive adolescents in Insiza district, Zimbabwe.

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

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**Participant's name:**

**Participant's signature:**

**Date:**

**Appendix 6: Interview guide- Adolescents**

1. Can you tell me about yourself?

*Prompts*

- Age
- Gender
- Level of Education
- Are your biological parents alive?
- How far do you stay from the clinic?

2. Can you tell me about your experience since receiving an HIV diagnosis?

*Prompts*

- How did you find out about your HIV status?
- When were you enrolled to care?
- How do you feel about the services?

3. What has been your experience in taking ART?

*Prompts*

- How frequently do you miss doses?
- What sort of support do you have?
- What is your view on the role of treatment?

4. What are your views on the services provided at the health facility?

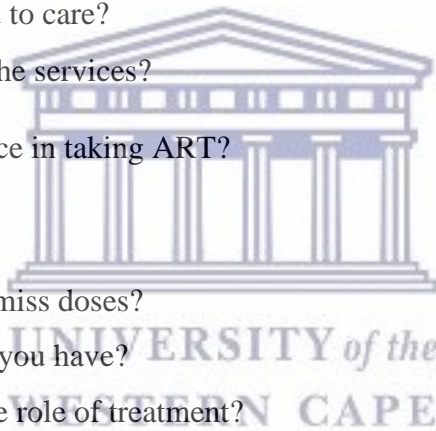
*Prompts*

- What do you think of the quality of services?
- How do you feel about attending the clinic for services?
- Do you seek services elsewhere?

5. What do you think are the main reasons that make it difficult to take medicines consistently?

*Prompts*

- What was going on in your life when you missed doses?
- What support did you get from home of the health facility?



- Do you receive any stigma or discrimination? From where?

6. What do you think can be done to support you to take ART consistently?

Prompts

- From family, friends, support group, health services?
- Others?



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## Appendix 7: Interview guide- Key informants

1. Describe your role in the adherence of adolescents to ART.

*Prompts*

- Designation
- Number of years in the current position

2. What do you think are the main reasons why adolescents do not adhere well to ART?

3. What interventions do you think will improve the adherence of adolescents on ART?

4. Is there adequate support for adolescents on ART?

*Prompts*

- From where?



5. What challenges do the adolescents discuss with you?

*Prompts*

- Are challenges similar for males and females?

6. How do you think disclosure impacts adherence to treatment?

7. What are your views on the counselling process for adherence to ART?

8. What is your view on non-adherence?

## Appendix 8: Information sheet- Parents



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Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)

### INFORMATION SHEET

**Project Title:** Exploration of adherence to treatment challenges experienced by HIV positive adolescents in Insiza district, Zimbabwe.

#### What is this study about?

This is a research project being conducted by Rickie Malaba at the University of the Western Cape for a mini-thesis for a Masters in Public Health. Your child has been invited to participate in this research project because we value their knowledge related to the research topic. The purpose of this research project is to find out and deepen our understanding on the different challenges faced by HIV positive adolescents with regards to adherence to treatment. It is hoped that the findings from this study will provide information that will be used to improve the services given to adolescents living with HIV.

#### What will your child be asked to do if they agree to participate?

The participant will be asked to provide signed consent prior to taking part in an interview that will last about an hour. The questions to be asked are related to their experience and knowledge related to treatment adherence related to adolescents living with HIV. During the interview, what is said will be recorded and the interview will be done at any place they are comfortable with. Privacy will be ensured throughout the interview and the opportunity to discontinue at any time will be availed with no consequences to them. Once the study has been concluded, the final results will also be shared with you. We will also contact your child when the need arises for any clarifications. They will not be obliged to answer any questions that they feel are inappropriate or insensitive. If you feel you have any further questions, you may seek clarification at any time.

### **Would your child's participation in this study be kept confidential?**

The researcher will protect your identity and the nature of your contribution. Codes will be used to ensure that there is no information in the research notes that will personally identify you. Only the researcher will have access to the identification key of the code. To ensure your confidentiality, the data from the interviews will be transcribed and stored in password protected devices. Access to the recording device will also be password protected. Once transcription is completed the original recordings will be destroyed permanently. Prior to that, all devices will be stored in a lockable cabinet. If we write a report or article about this research project, your child's identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities, information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you and your child that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

### **What are the risks of this research?**

There may be some risks from participating in this research study. As the subject under discussion may make your child feel uncomfortable. The researcher will nevertheless minimise such risks and act promptly to assist if your child experiences any discomfort, psychological or otherwise during the process of their participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. All human interactions and talking about self or others carry some amount of risks.

### **What are the benefits of this research?**

The benefits of this research include the researcher learning more about the challenges faced by adolescents living with HIV with regards to adherence to HIV care and treatment. There is no direct benefit to you personally but we hope that in the future other people might benefit from this study through improved understanding of the challenges related to the subject under investigation. The findings are expected to contribute to improvement in care and support for adolescents living with HIV, their families as well as the community at large.

**Does your child have to be in this research and may they stop participating at any time?**

Participation in this research is completely voluntary. One may choose not to take part at all. If your child decides to participate in this research, they may stop participating at any time. If they decide not to participate in this study or if they stop participating at any time, they will not be penalized or lose any benefits to which you otherwise qualify.

**What if the participant has questions?**

This research is being conducted by Rickie Malaba from the School of Public Health at the University of the Western Cape. If there are any questions about the research study itself, please contact Rickie Malaba at:

**School of Public Health**

**University of Western Cape**

**Private Bag X17**

**Bellville 7535**

**Cape Town**

**+263 772 387 546**

**[3678322@myuwc.ac.za](mailto:3678322@myuwc.ac.za)**

**[drrickiemalaba1@gmail.com](mailto:drrickiemalaba1@gmail.com)**



Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

**Prof. Uta Lehmann**

**Director**

**School of Public Health**

**University of the Western Cape**

**Private Bag X17**

**Bellville 7535**

**Email: [ulehmann@uwc.ac.za](mailto:ulehmann@uwc.ac.za)**

**Prof. Anthea Rhoda**

**Dean of the Faculty of Community and Health Sciences**

**University of the Western Cape**

**Private Bag X17**

**Bellville 7535**

**[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)**

This research has been approved by the University of the Western Cape's Senate Research Committee. (**REFERENCE NUMBER:** BM18/1/9)



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**Appendix 9: Assent Form – Participant less than 16years of age**



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**Title of Research Project:** Exploration of adherence to treatment challenges experienced by HIV positive adolescents on ART in Insiza district, Zimbabwe.

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

**Participant's name:**

**Participant's signature:**

**Date:**



## Appendix 10: uGwalo Lombiko



### UNIVERSITY OF THE WESTERN CAPE

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**E-mail:** [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)

**Isifundo:** Ukucubungula ubunzima obuphathelene labatsha abasehlelweni lokulwatshwa kwengculazi ngamaphilisi esigabeni sakoGodlwayo eZimbabwe.

#### **Simayelana lani isifundo lesi?**

Lolugwalo luyachasisa uhlelo lwezifundo ezenziwa nguRickie Malaba oseUniversity ye Western Cape ukuze enelise ukugqiba imfundo zakhe zaphezulu kunhlelo zempilakahle kazulu.

Ngakho siyakunxusa ukuze uphathise kuloluhlelo ngoba silethemba lokuthi ulolwazo olufanele loludaba. Limfundo sikhangelele ukuthi izaphathis labasebenza kwezempilakahle ukuthi benelise ukusiza laba abaphethwe yingculazi, ikakhulu abatsha ngendlela engcono.

#### **Kuyini okuzabuzwa abangena kulesisifundo?**

Wonkumuntu ozavuma ukuba lilunga laloluhlelo kuzamele atshengisele ukuthi uzikhethete njalo kancindizelwanga ukuze abe lilunga ngokusayina ephepheni. Imbuzo izabe iphathelene lendaba zokunatha amaphilisi yilaba abasehlelweni lokulatshwa wengculazi kanye lobunzima abahlangana labo. Ingxoxo esizaba lazo zizagcinwa ngumtshina kamabonakude njalo sizaxoxela lapho eliyabe lichelesile khona ukuthi sixoxe. Malingezwa loba nini ukuthi alisenelisi ukuqhubeka ngaloluhlelo, liyamulekekile ukuthi lingaqhubekeli phambili. Sizabuya njalo silazise ngempumela yalezingxoxo ukuze lenelise ukuthola ithuba lokuba lesiqiniselelo sokuthi ngempela lokhu okukhulunyweyo livumelana lakho. Konke okuzokhulunywa kuzaba yimfihlo njalo akulandlela okungaziwa ngayo ukutho ngubani oyabe ekhulumile. Ngokusemthethweni njalo, ma singahlanaga lolwazi olwezehlakalo ezingekho emthethweni kuzamele sibikele iziphathamandla zomthetho.

#### **Kungabe kulengozi ukuba lilunga lohlelo lolu?**

Indaba esizaxoxa ngazo zingabangela ukungaphatheki kwabatsha ngakho sizazama ngayo yonke indlela ukuthi uzizwe uhlalisekile ngaso sonke isikhathi. Lapho okudingakala khona, sizalazisa lapho elingathola khona usizo olusebangeni eliphezulu.

### **Isifundo lesi sizanceda ngani?**

Kukhangelelwe ukuthi uhlelo lolu luzaveza obala indubeko ezihlangana labatsha abanatha amaphilisi okulapha ingculazi. Lina ngokwenu lingabe lingatholi lutho kodwa kusiya phambili kuzavezeka indlela ezingcono zokuphatha abatsha abakuhlelo lokulatshwa kwengculazi.

### **Mele ngenzenjani ma ngilemibuzo?**

Ma kungabakhona okunye elifuna ukukuzwisisa ngalesisifundo lingadinga u Rickie Malaba kukheli leli elilotshwe ngaphansi:

**School of Public Health**

**University of Western Cape**

**Private Bag X17**

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**[drrickiemalaba1@gmail.com](mailto:drrickiemalaba1@gmail.com)**



Ma lingaba lesizatho sokuzwa okunengi ngaloluhlelo langamalungelo enu kumbe kulensolo elifuna lisazise ngazo lingadinga u:

**Prof Uta Lehmann**

**Director**

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Isifundo lesi sivunyelwe yi University of the Western Cape's Senate Research Committee.

**(REFERENCE NUMBER: BM18/1/9)**



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