UNIVERSITY OF THE WESTERN CAPE

Faculty of Community and Health Sciences

Exploring the experiences and perceptions of adolescents and young adults of adherence to Antiretroviral therapy treatment at a referral Opportunistic Infection Clinic in Harare, Zimbabwe

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A mini thesis submitted in partial fulfilment of the requirements for the degree of Master of Public Health at the School of Public Health, University of the Western Cape

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Zimbabwe
Facilitators

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DECLARATION

I declare that this thesis entitled "*Exploring the experiences and perceptions of adolescents and young adults to antiretroviral therapy treatment at a referral opportunistic infection clinic in Harare, Zimbabwe*" is my own work. It has not been submitted for any degree or examination in any other university and that all the references I have used or quoted have been acknowledged.

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LIST OF ABBREVIATIONS

AYAs	Adolescents and Young Adults
AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral drugs
ART	Antiretroviral therapy
CATS	Community Adolescent Treatment Supporters
DSD	Differentiated Service Delivery
HIV	Human immunodeficiency Virus
MOHCC	Ministry of Health and Child Care
NMTPAC	National Medicine and Therapeutics Policy Advisory Committee
PCOE	Parirenyatwa Centre of Excellence Opportunistic Infection Clinic
PHC	Primary Health Care
STI	Sexually Transmitted Infection
TB	Tuberculosis
VL	Viral Load
VLS	Viral Load Suppression
OIC	Opportunistic Infections Clinic
SEM	Socio-Ecological Model
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
UNFPA	United Nations Population Fund
US	The United States
WHO	World Health Organization
ZIMSTAT	Zimbabwe National Statistics Agency
ZIMPHIA	The Zimbabwe Population-based HIV Impact Assessment
ZDHS	Zimbabwe Demographic Health Survey

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ABSTRACT

Background: The HIV pandemic continues to have a significant impact on global public health with approximately 39 million people infected with HIV. According to estimates, there are 1.65 million adolescents living with HIV worldwide, of which 85% live in sub-Saharan Africa. While HIV/AIDS-related mortality is decreasing for most age groups, it is not declining for Adolescents and young adults (AYAs) (aged 15–24 years). Poor adherence among AYAs contributes to the poor outcomes of HIV interventions. The aim of the current study was to explore the experiences and perceptions of antiretroviral therapy (ART) adherence among AYAs at a referral Opportunistic Infection Clinic in Harare, Zimbabwe.

Methodology: The study employed qualitative methods, where data was collected through semi-structured in-depth interviews with 12 AYAs and 5 key informants at a referral Opportunistic Infection Clinic in Harare, Zimbabwe. All the interviews were audio-recorded, and Shona recordings were translated to English before transcription. An inductive thematic analysis was done.

Results: The study identified four levels of facilitators and barriers at the individual, family/ peer, community, and structural levels. The study found that AYAs had adequate knowledge about adherence to ART and the benefits. It also revealed that family and peer support were key facilitators that improved ART adherence. The key informants underscored the importance of counselling and youth friendly services. The clinic provided services through a multiskilled team. In addition, peer counsellors, known as Community Adolescent Treatment Supporters (CATS), provide additional support to AYAs. The main barriers to ART adherence were internal and external stigma. In addition, the challenges and conflicts brought about by the transitioning to adulthood, side effects and multi-dose regimen were noted as barriers to adherence to ART.

Conclusion: Differentiated service platforms and HIV competent families are key facilitators while internal and external stigma are the main barriers to ART adherence. It is recommended that ART for AYAs be provided using the differentiated service delivery framework with emphasis on increased mix of peer-led interventions with a static clinic offering AYAs friendly services.

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CHAPTER 1. INTRODUCTION

1.1 BACKGROUND

HIV remains a pandemic of global public health importance with 39 million people living with HIV (UNAIDS, 2023). Over half of people living with HIV live in sub-Saharan Africa (U\NAIDS, 2023). Adolescents and young adults (AYAs) aged 15–24 years constituted 1,2 billion of the global population in 2021. This translated to 16% of the world population (UNICEF, 2023). Of the world's population of people aged 10–24 years, approximately 89% live in less developed countries (UNICEF, 2019). According to estimates, there are 1.65 million adolescents living with HIV worldwide, of which 85% live in sub-Saharan Africa (UNICEF, 2023a). In the era of ART, when HIV-related mortality is decreasing significantly in most age groups, AIDS-related mortality for AYAs is not declining (Society for Adolescent Health and Medicine, 2023). Poor HIV treatment outcomes have been observed in AYAs compared to children and adults, despite the existence of effective ART regimens (Society for Adolescent Health and Medicine, 2023; van Wyk & Davids, 2019; UNAIDS, 2016b). Unfortunately, there is limited data on ART for AYAs because of poor data disaggregation (Slowgrove et al., 2017; UNAIDS, 2018a). Most routine data available for programming lumps children with adolescents (0–15-year age group) and then report adults as 15 years and over - an age range that includes AYAs (UNAIDS, 2019; UNAIDS, 2023).

According to UNICEF (2023), around 80% of all new HIV infections among 15–19-year-old adolescent girls in 2022 were in sub-Saharan Africa. Only about 26% of adolescent girls aged 15-19 years and 33% of adolescent boys of the same age were reported to have comprehensive and correct knowledge of HIV and AIDS (UNAIDS, 2016b). Results from Botswana, Cameroon, Jamaica, Swaziland, and Zimbabwe show that HIV prevalence increases with increasing age among young people (UNICEF, 2015).

1.2 HIV/AIDS IN ZIMBABWE

Zimbabwe has a comparatively young population, with 32% of the estimated total population of 15.2 million, being adolescents and young adults (aged 10-24 years) (UNICEF, 2023a). Further, Zimbabwe is one of the sub-Saharan African countries with the fifth-highest HIV burden globally (World Population Review, 2024), with a prevalence of 12%, which translates

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to approximately 1.2 million people living with HIV (ZIMPHIA, 2020). According to UNAIDS (2023), over 85,000 adolescents were living with HIV in Zimbabwe in 2022. New infections are seven times higher in females aged 15-29 years compared to males (Ministry of Health and Child Care (MoHCC), 2018b). There were 226 and 1,689 new infections recorded in this age group in 2022 for males and females, respectively (UNAIDS, 2023a). The MoHCC initially adopted the millennium development goals to track HIV elimination 90-90-90 targets by 2020 (MoHCC,2018b). It renewed this commitment by adopting the revised sustainable development goals 95-95-95 targets by 2030 as a strategy to achieve epidemic control of HIV as a public health threat by 2030 (ZIMPHIA, 2020).

1.3 ANTIRETROVIRAL THERAPY IN ZIMBABWE

The Ministry of Health in Zimbabwe premised its national health system on the primary health care (PHC) approach (MoHCC, 2021). The number of health facilities offering ART and other HIV and AIDS services increased from seven sites in 2004 to 1,545 (94% of all health facilities) at the end of 2015 (MoHCC, 2018b). The health system seeks to provide comprehensive HIV services by providing preventative, promotive and curative packages appropriate for each level of care. The architecture of the referral system is hierarchical, with higher levels offering more complex services at central hospitals. ART services were initially centralized. The ministry has since made efforts to decentralize and provide differentiated services packages at each level of care to ensure that children, adolescents, and adults have improved access to HIV services. The number of facilities offering paediatric ART services increased from 255 in 2010 to 1,434 in 2016 (MoHCC, 2018b).

1.4 ADHERENCE TO ANTIRETROVIRAL THERAPY

Adherence to ART is defined as '*the extent to which a person's behaviour-taking medications, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider'* (Neupane, Dhungana & Ghimire, 2019, p. 2). The optimal adherence level to achieve viral suppression is 95% or more in the Zimbabwean HIV Care and Treatment Guidelines (National Medicine and Therapeutic Advisory Committee (NMTPAC) and MoHCC, 2013). Viral suppression leads to a reduction in drug resistance and reduced cases of treatment failure with first-line drugs (Nachega et al., 2009). This allows for maintaining an affordable, sensitive regimen, which is critical in low-resource settings such as Zimbabwe.

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1.5 HIV AND ADOLESCENTS AND YOUNG ADULTS

The United Nations defines an *adolescent* as an individual between the ages of 10-19 years (UNICEF, 2023). It further defines a youth as an individual between the ages of 15-24 years. Adolescents and youth are often referred to as 'young people' (UNICEF, 2023). Young people or Adolescents and Young Adults (AYAs) are the focus of this thesis. The critical feature of AYAs is the transition from being a child to becoming an adult. Critical issues during this transition include physical maturity, psychosocial stress, hormonal changes-induced activities, peer pressure, sexuality and acts of rebellion (UNICEF, 2023). There is also an issue of assuming personal responsibility for HIV care and being moved from the familiar children's clinic to the youth section and, ultimately, the adult section of care. This process is fraught with challenges for the youth, their caregivers and health service providers from the paediatric and adult sections of the clinics (Society for Adolescent Health and Medicine, 2023). Studies in the African region and Zimbabwe have shown that AYAs remain a vulnerable group despite the introduction of ART, with poor ART adherence and poor HIV treatment outcomes, including inadequate viral suppression, morbidity, and increased HIV mortality compared to adults on ART (van Wyk & Davids, 2019). One causal factor for poor ART adherence is the assumption that as they graduate into adolescence, the need for parental adherence monitoring ceases to be necessary.

1.6 PROBLEM STATEMENT

According to studies conducted in Zimbabwe, adolescents have a higher risk of treatment failure than children and adults (Mavhu et al., 2020; MoHCC, 2018b; Ferrand et al., 2017; Shroufi et al., 2013). This is corroborated by other studies in Sub-Saharan Africa that AYAS have worsening morbidity and mortality trends in comparison to children and adults since the advent of ART (Nachega et al., 2009; Lowenthal et al., 2014). Unique challenges in AYAs preclude them from achieving expected adherence levels despite adequate knowledge (Hornschuh et al., 2017). The latest review of the HIV treatment strategy in Zimbabwe cites AYAs as a priority population that requires further research to combat the high incidence of HIV infection and poor treatment outcomes in this age group (MoHCC, 2018b) compared to adults living with HIV/AIDS on treatment. Suboptimal adherence and poor retention in care were the leading causes of poor HIV treatment outcomes (ibid). There remains a gap in

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qualitative research on barriers and facilitators to ART adherence in AYAs in Zimbabwe. A study looking at ART outcomes in a cohort of adolescents living with HIV aged 10-19 years in a rural setting found that there was a need for adherence support (Bygrave et al., 2012). A study on AYAs at Mpilo Hospital in Bulawayo, Zimbabwe, showed that excellent HIV treatment outcomes and retention in care for AYAs that are comparable to the adult population could be achieved by providing tailor-made services for AYAs (Shroufi et al., 2014).

It is therefore necessary to have an in-depth understanding of ART adherence and engagement in HIV treatment from the perspective of AYAs so that challenges peculiar to this age group are addressed. The study may provide information that could better understand the AYAs' experience and contribute to a possible population-specific ART adherence intervention.

1.7 AIM AND OBJECTIVES

This study aimed to explore the experiences and perceptions of ART adherence among AYAs in-depth at a referral Opportunistic Infection Clinic in Harare, Zimbabwe.

The objectives of this study were:

1. To explore the experiences of adherence to ART of AYAs living with HIV.
2. To describe knowledge about and perceptions of ART of AYAs.
3. To explore the understanding of health service providers about challenges to adherence to ART among AYAs.

1.8 THESIS OUTLINE

Chapter One: Introduction of the research and description of the problem analysis, statement, and rationale for conducting the study. The study aims and objectives are also outlined in this chapter.

Chapter Two: Literature review on ART amongst AYAs and the paediatric and adult populations in general.

Chapter Three: Description of the study design and methods used to conduct the study, including rigour and ethical considerations.

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Chapter Four: Presentation of study findings.

Chapter Five: Discussion of study findings concerning the reviewed literature.

Chapter Six: Conclusion of the study and recommendations to improve ART adherence for AYAs.

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CHAPTER 2. LITERATURE REVIEW

2.1. INTRODUCTION

The literature review takes into cognizance that AYAs are confronted by a myriad of factors at different levels of influence in health behaviour as conceptualized in the socio-ecological model (SEM) (Williams et al., 2017). The SEM has been used as a theoretical framework to unravel the complex behaviour in health research across the continuum of HIV care, reproductive health and barriers to adherence and retention in care (Mukumbang, Mwale & van Wyk, 2017, Babalola et al., 2017, Yakob and Ncama, 2016; Gombachika et al., 2012). The SEM is illustrated in figure 2.1 below.

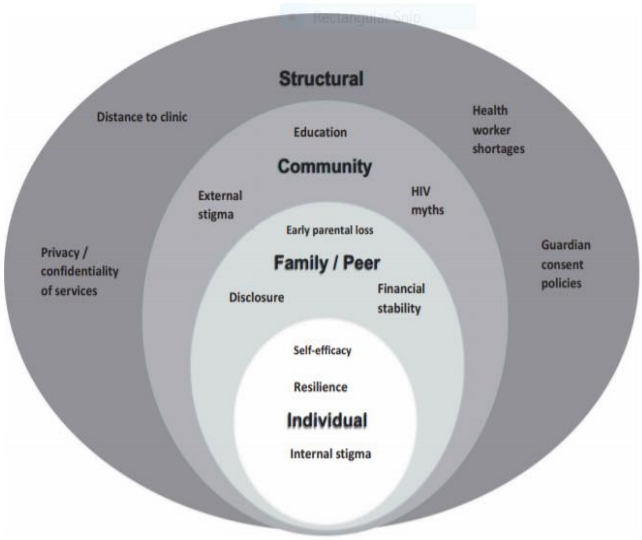

Fig. 2.1: The four socio-ecological model levels that can potentially affect health behaviours, with factors that operate at each level (Source: Williams et al., 2017).

The SEM conceptual framework, which considers the person, their relationships with others, and how they modify their behaviour to fit the social context, posits that a person's behaviour is coherent within a dynamic network of intrapersonal, interpersonal, community, and health policy characteristics (Gumede et al., 2019).

2.2 INDIVIDUAL LEVEL FACTORS

It is recognized that optimal ART adherence is the most critical factor that contributes to reduced morbidity and mortality among people living with HIV/AIDS. Barriers are the factors that pose a challenge to achieving optimal adherence to ART despite the health system working

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hard to improve ART adherence. Facilitators are factors and strategies the health system utilises to improve adherence to ART among individuals and caregivers towards optimal levels to achieve favourable clinical outcomes. (Buh et al., 2022). At the individual level, this section discusses facilitators and barriers to optimal ART adherence guided by the existing literature.

2.2.1 Facilitators of Adherence to ART

The individual facilitators that will be discussed are knowledge about adherence to ART, the past medical narrative, making ART an integral part of life, concealment strategies, reminders (self-efficacy/resilience), peer support and adherence clubs.

Knowledge about adherence to ART

The AYAs who understood the concepts of adherence, benefits of optimal adherence to ART, undetectable = untransmittable, and the negative consequences of not being adherent were more likely to be adherent. Having correct knowledge about adherence to ART enables adolescents to maintain scheduled doses as prescribed (Hornschuh et al., 2017, Maskew et al, 2016).

Adherence

Understanding what adherence is, defining it in practical terms, and explaining why it is important in HIV treatment (Denison et al., 2015) is critical in encouraging adherence.

Benefits

AYAs who are aware and experiencing the benefits of being adherent, such as living a healthier life, especially those that had prior challenges such as failure to thrive, recurrent chest infections, and absenteeism from school due to being sickly, are motivated to maintain the status quo (Williams et al., 2017).

*Consequence*s

Some AYAs were driven to remain adherent because they were aware of potential harm that could occur due to incomplete adherence, such as treatment failure, drug resistance, and health deterioration to AIDS (Hornschuh et al., 2017; Hlope et al., 2023).

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Undetectable = Untransmittable

For sexually active AYAs, it was encouraged that they were aware that ART, in addition to improving health and quality of life, ART can also be used for the prevention of HIV transmission (Ngure et al., 2020). Adherent AYAs on ART, with serial viral load monitoring, can achieve undetectable viral load (VL) levels where they have no chance of transmitting HIV during sex. Therefore, the knowledge that achieving undetectable levels of VL reduces transmission can motivate AYAs to adhere to ART (Eisenger, Dieffenbach & Fauci, 2019; Ngure et al., 2020).

Past Medical Narrative

It has been recognised that AYAs who were tested and commenced on ART after a history of recurrent medical conditions such as recurrent pneumonia or pulmonary TB tend to maintain optimal adherence (Denison et al., 2015; Mattes, 2014). Encouragement to maintain treatment can be optimised by a simple reminder of previous disease patterns.

Making ART an integral part of life

Those adolescents who have had full disclosure of their status and have, in turn, managed to disclose their status to significant partners in their HIV journey, including family members or guardians, school teachers and friends, find it easier to adhere to ART as they receive support in the form of reminders and scheduling life activities in a manner that accommodates ART dosage time (Hornschuh et al., 2017). The support from the inner circle facilitates optimal ART adherence as the school and daily lifestyle activities are designed to support health requirements (Madiba & Josiah, 2019).

Concealment strategies

It has been noted that AYAs are not prepared to take ART in front of peers, friends, and some family members to whom they have not disclosed their status for fear of unintentional disclosure and fear of being stigmatized, rejected from social networks, and isolated

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(Hornschuh et al., 2017; Denison et al., 2015). Several strategies have been employed to enable AYAs to take their drugs as scheduled without revealing their status and are outlined below.

Wrapping pills

To avoid detection, AYAs wrapped the ART in either tissues or paper and kept it in clothes or personal luggage (Hornschuh et al., 2017; Denison et al., 2015). This strategy has been used to improve ART adherence.

Recharging cell phone or buying airtime

Other youths have come up with ways to leave the company of intrusive people by pretending to either buy airtime or recharge phones, thereby creating personal space to discreetly take medication and remain adherent (Lowenthal et al., 2014; Hornschuh et al., 2017).

Homework

The AYAs who are always in a shared space with fellow students, such as boarding school or staying with relatives whom they do not trust or who are not aware that they are on ART can find privacy by hiding ART with their books and take them while doing homework (Hornschuh et al., 2017; Madiba & Josiah, 2019).

Restroom

In circumstances where AYAs find themselves in a constrained environment, and they have their ART on them, whether wrapped up or doing homework, using the restroom can be utilized to create that safe space to take medication and remain adherent (Novitsky et al., 2018; Madiba & Josiah, 2019).

Reminders- self-efficacy/resilience

According to the literature, AYAs sometimes forget or are overwhelmed by different competing interests due to educational, physical, social, work, and sexual activities (Kim et al., 2016; Hornschuh et al., 2017; van Wyk & Davids, 2019). These are complications met in living with chronic disease that impose limitations on an already turbulent development phase. (Novitsky et al., 2018; Williams et al., 2017). To keep on track with ART, AYAs have devised reminders as part of coping strategies to achieve optimal adherence in the face of adversities.

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These include using alarms on clocks or phones, family members, and partners and taking ART at convenient times (Hornschuh et al., 2017; Denison et al., 2017). These strategies are briefly outlined below.

Alarms on Clocks or Phone

AYAs set a reminder on their phone or alarm clocks for dosage times. These gadgets can be theirs or those of family members (Hornschuh et al., 2017; Denison et al., 2015).

Family members

The principal caregiver or other family members are useful reminders of the scheduled time for taking ART and clinic appointments. They can also encourage AYAs to eat healthily and reinforce positive living (Williams et al., 2015).

Partners

Where AYAs are in a stable sexual relationship and have disclosed their status, partners are effective in reminding each other to take medication.

Convenient time

Settling for a convenient time to take ART when other tasks are done and the AYAs are most likely relaxing at home facilitates optimal adherence. The routine will eventually act as a reminder to adhere (Maskew et al., 2016; Rowell-Cunsolo & Hu, 2020).

Peer Support

Engaging peers in the delivery of HIV services, including ART delivery, should be a priority in designing differentiated service delivery (DSD) models for key populations (Reif et al., 2019). Adolescents are a unique population and tend to value interaction with peers who are of the same age and HIV-infected, and on drugs (MOHCC, 2018b). These interactions can take different approaches: clinic youth clubs, support groups, adherence clubs, and Community Adolescent Treatment Supporters (CATS) (Willis et al., 2019).

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Clinic Youth Club

According to Mukumbang et al. (2018), ART adherence clubs are an effective DSD intervention that can be used to improve adherence and retention for clients above 18 years who meet a set criterion for clinical stability. The youth club is one such forum that meets at a specified time at a venue, usually within the facility, to discuss common issues being faced by AYAs on ART. The convener is usually a health worker, nurse, or counsellor who facilitates discussions and ensures quick access to required health services (Wilkinson, 2013).

Support groups

Support groups are usually comprised of AYAs who either poorly controlled HIV, have/are not adherent, or have other identified challenges. These are specific intervention vehicles to improve adherence, retention and access to care using peer-to-peer support. Follow-up with frequent laboratory monitoring, such as VL testing and clinical parameters, to determine whether there is any laboratory and clinical progression of the patient's condition (Willis et al., 2019). These interventions have been recognised to improve adherence to ART among AYAs (Willis et al., 2019; Mukumbang et al., 2018).

Community Adolescent Treatment Supporters

CATS are trained, mentored, and supported adolescents and young people living with HIV who are on ART, who provide information, counselling, and support for other adolescents and young people living with HIV (UNICEF, 2015; Mavhu et al., 2013; MoHCC, 2018b). They achieve this through home visits, clinic visits, and support groups. The design of this peer-to-peer intervention was based on the unified theory of behaviour change (Mavhu et al., 2013). This intervention approach was pioneered by Zvandiri-AFRICAID in Zimbabwe. The use of peer treatment supporters, CATS in Zimbabwe is effective in improving ART adherence, improve retention, and improved outcomes such as improved viral suppression rates in a clinical trial in Gokwe, Zimbabwe (Willis et al., 2019). It is a best practice that has been scaled up and implemented nationally in Zimbabwe and 11 other countries. The CATS model has been fully integrated within national systems and service delivery across the HIV care cascade (MoHCC, 2018b).

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Adherence Clubs

Wilkinson (2013) described an ART adherence club, where 30 clinically stable patients met for approximately two hours outside a clinic, led by a lay facilitator, to discuss pertinent issues about HIV, ART refill, and check for well-being. This club was supported by a nurse who accepted referrals from the facilitator and attended to their medical needs. This model was found to be a cost-effective way to scale up HIV care based on a pilot in Western Cape in 2011 and similar studies (Wilkinson, 2013; Mukumbang et al., 2018). The study highlighted the importance of peer involvement in the HIV Care continuum. The critical elements for success were a collaborative implementation process, flexibility to meet patient needs, patient participation, political support, and overall acceptance of the model by patients and service providers. The model provides differentiated services, frees much-needed space in health facilities, reduces the cost of HIV care, and allows clinical staff to concentrate on other areas of need (WHO, 2016; IAS, 2016).

2.2.2 Barriers

The individual barriers that were reviewed include the side effects of ART, substance abuse and internal stigma.

Side Effects of ART

Side effects of ART have been blamed for suboptimal adherence (Hornschuh et al., 2017; Denison et al., 2015). The common side effects of ART include nausea and vomiting, loss of appetite, abnormal sleep patterns, especially oversleeping, and rashes. The non-adherence attributed to side effects may be worsened if the adverse effects complicate the adolescents' school life, such as feeling drowsy during exams and where AYAs must sacrifice the dosage schedule to enable performance at school (Maskew et al., 2016; Williamson et al., 2017). Efforts have been made to reduce the pill burden by having a fixed dose regimen taken once daily (Hornschuh et al., 2017). The pill burden, primarily related to large numbers of pills and taking medication at different times of the day, which is commonly associated with the second and third-line ART regimens, has been found to contribute to suboptimal adherence. Bloating and generalized discomfort have been reported from these regimens (Okatch et al., 2014; Maskew, 2016).

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Substance Abuse

Several studies have shown that youth engaging in substance abuse, such as drugs and alcohol, for either peer acceptance or because of mental health issues are not adherent to ART. Some explanations proffered include fear of unplanned disclosure and being forgetful (Williams et al., 2017; Madiba & Josiah, 2019; Hornschuh et al., 2017). Affective disorders are one of the common mental health encountered in AYAs indulging in substance abuse, leading to impaired adherence (Ramos et al., 2018).

Internal Stigma

Stigma is as an attribute or quality that "significantly discredits" an individual in the eyes of others and may result in failure to choose safer sex methods such as condoms due to poor self-esteem and lack of confidence (Pantelic et al., 2019). This affects self-efficacy, self-confidence, and may result in poor ART adherence. With internal stigma, the process occurs within a particular culture or setting in which the HIV-infected subscribes to negative attitudes about their status and considers themselves discreditable or unworthy (Sweeney & Vanables, 2016). This is detrimental to the quality of life for an individual and, at a population-level, poses an increased risk of spreading STIs and HIV due to fear of disclosing own status.

2.3 FAMILY/PEER LEVEL FACTORS

The barriers at the family/peer levels are non-disclosure of HIV status to the adolescent, unintended disclosure, lack of private space and social barriers.

2.3.1 Non-disclosure of HIV status to the adolescent

In a qualitative study, Fields et al. (2017), looking at barriers to ART adherence amongst perinatally and behaviourally infected youth in New England, found that barriers were based on the lived experience and interaction with multi-layered psychosocial context and the clinical environment. The common barriers were poor appreciation of risk, ART as a reminder of the infection, and nondisclosure, but the context was different for each group (Bukenya et al., 2019).

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2.3. 2 Unintended Disclosure

Fear of unintended disclosure and subsequent stigma (discrimination) is a major limiting factor to AYAs, stopping them from taking medications in the presence of their peers (Hornschuh et al., 2017; Kim et al., 2014). The perception is that inadvertent exposure will lead to the loss of affection among friends and relatives (Madiba & Josiah, 2019). In some instances, they are constrained to the extent of failing to keep their drugs on themselves. AYAs will rather miss clinic appointments if they feel that going to the facility will expose their HIV status to the community or among fellow students. AYAs fear being isolated and rejected (Lowenthal et al., 2014; Denison et al., 2015).

2.3.3 Lack of private space

Many adolescents struggle to take ART in the presence of peers or strangers. For AYAs, this challenge was observed in the boarding school environment and those kept in institutions such as orphanages (Yang, 2018). A similar environment could be simulated by the presence of relatives or visitors, with some failing to take ART as instructed (Madiba & Josiah, 2019; Maskew et al., 2016; Hornschuh et al., 2017).

2.3.4 Social Barriers

The social barriers that contribute to suboptimal adherence in AYAs include transport problems, family circumstances and social issues.

Transport Problems

The AYAs may be located far from the Opportunistic Infection (OI) Clinic - making it necessary to use a mode of transport for clinical appointments. This can be disruptive regarding time clashes with other activities such as school and work. This can lead to the failure to meet scheduled appointments, resulting in AYAs running out of drugs (Hornschuh et al., 2017). For low socioeconomic status AYAs, the cost of transport can lead to missed appointments due to a shortage of money for transport (Bukenya et al., 2019; Hornschuh et al., 2017; Kim et al., 2014).

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Family circumstances

Most AYAs were either orphaned with the loss of one or both parents, creating difficult social circumstances. As a result, most AYAs living with HIV were in vulnerable circumstances (Denison et al., 2015; Madiba & Josiah, 2019). This exposed AYAs to insecure living circumstances where they were neglected, suffered abuse, did not get full disclosure about their HIV status, and a general environment that did not promote optimal care. This made being adherent to ART difficult. Those in institutional accommodation lamented lack of privacy and loss of freedoms, especially being placed in a boarding school environment or a home (Madiba & Josiah, 2019; Denison et al., 2015). Social networks did not exist, contributing to suboptimal adherence to ART (Ajuna et al., 2021). AYAs could be under the custody of social workers or in institutions of care, where institutionalization presented difficulties. The challenges included the loss of personal privacy (Williams et al., 2017). For orphaned AYAs, the lack of parental support was found to create an environment where they made health decisions alone without sufficient knowledge of their consequences and safety (Ajuna et al., 2021).

Social factors

A conducive living environment was a recognized facilitator for ART adherence. Providing a positive living environment and encouraging the AYAs to adhere to ART and clinic appointments is important for young adolescents. A supportive family unit, especially the principal adult caregiver, is essential. The term family in this context includes biological parents, extended family members, friends, or any other caregivers who are providing support (Williams et al., 2017; Ajuna et al., 2021). The influence or roles played by the caregiver are diverse and change with time as the AYAs grow in autonomy. The roles include choosing the correct age to disclose the condition, determining the rationale for taking medications daily, and supervising the uptake. As they grow, it focuses on encouragement and being a constant reminder that medication is taken (Ajuna et al., 2021). There is need to take periodic physical counts of pills, emotional support, and age-appropriate explanations for taking medications until their status is fully disclosed (Williams et al., 2017, Hornschuh et al., 2017; Denison et al., 2015).

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2.4 COMMUNITY LEVEL FACTORS

The community-level factors that influence adherence are external stigma and spiritual health (Fields et al., 2017).

2.4.1 External Stigma

Commonly referred to as felt or enacted stigma, external stigma describes any prejudice that arbitrarily distinguishes persons because of their perceived inferior status conferred by a confirmed or suspected HIV-positive status or state of health (USAID, 2006). HIV stigma is patterned along known social exclusion criteria that include gender, race, socioeconomic standing, and identified risk groups (e.g., women, men who have sex with men, and sex workers) (Sweeny & Vanable, 2016). In an ethnographic study with South African children, Bhana (2008) described how HIV stigma and issues such as race, gender, class, age, and sexuality are interrelated. These socialisations were central to creating discrimination based on popular discourses that perpetuate inequities (Sweeny & Vanable, 2016). A study in South Africa that explored knowledge on adherence barriers and facilitators and experience of ART adherence amongst AYAs like other studies found that the common barriers to adherence were HIV status disclosures and stigma (Lowenthal et al., 2014; Kim et al., 2016; Yang et al., 2016, Hornschuh et al., 2017). According to Sweeny and Vanable (2016), the linkage between external stigma and poor adherence to ART could be explained by the postulated mechanisms, including (a) enhanced vulnerability to mental health difficulties, (b) reduction in self-efficacy and (c) concerns about inadvertent disclosure of HIV status. Studies found that while participants had adequate knowledge about adherence, common barriers to optimal adherence still existed, which included stigma and disclosure of the HIV status. These challenges were corroborated even in high-resource settings in the US (Fields et al., 2017).

2.4.2 Spiritual Health

Religious beliefs have been observed to be a barrier to sexual health risk communication amongst those living with HIV (Finocchario-Kessler et al., 2011; Medved, 2017). Finocchario-Kesler et al. (2011) observed that those who believed God had a role in HIV/AIDS treatment outcomes were less likely to achieve 90% adherence to ART compared to non-believers. There are scenarios where an adolescent on ART is derailed from keeping on the current regimen because of a prophetic declaration of being healed and not requiring ART. In some cases, they

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are encouraged (misled) to believe that they can raise their faith level to an extent where healing will take place. In both cases, the spiritual realm leads to treatment interruption that can lead to selective growth of resistant viral strains, leading to treatment failure and clinical deterioration of AYAs (Denison et al., 2015; Medved, 2017). Where the adolescents are still under the care of an adult, the caregiver's beliefs can impede adherence (Denison et al., 2015; Hornschuh et al., 2017).

2.5 STRUCTURAL FACTORS

At the structural level, health facility factors, quality and quantity of counselling services, and transition and autonomy affect adherence to ART. These are policy and service provision arrangements that are made at higher levels of government.

2.5.1 Health Facility Factors

This section will examine relevant literature on differentiated service delivery platforms, distance, and transport costs, waiting time, and space for youth at the clinic. These health facility factors have a bearing on the effectiveness of ART services provided to AYAs.

Differentiated Service Delivery Platforms

The differentiated service delivery (DSD) framework is an innovation to rethink improved service delivery for people living with HIV (PLHIV) across the continuum of care to meet their preferences and expectations while reducing the burden on the health system (UNAIDS, 2014; WHO, 2015; International AIDS Society (IAS), 2016). While community ART refill groups (CARGs) focusing on clinically stable patients were the most popular form of DSD, WHO (2016) posited that this could be extended to clinically unstable patients and specific populations.

All DSD platforms have four building blocks that define the intervention:

1. Where (place of service provision - HIV clinic, community, or home)?
2. When (frequency of activity – monthly, quarterly or six months)?
3. Who (service provider- doctor, nurse, pharmacist, community health worker or patient)?

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4. What (service offered- ART Initiation/ Refills, Adherence support, OI Treatment)? (WHO,2016; IAS, 2016; WHO, 2015).

The MoHCC (2018a) embraced DSD in HIV services delivery, including but not limited to CARGs, CATS, Youth clubs and multi-monthly ART supply during the COVID-19 pandemic. Review of the literature reveals DSD concepts are being utilized in low-resource settings in Southern Africa (Hornschuh et al., 2017; Maskew et al., 2016; Yang et al., 2018; Lowenthal et al., 2014).

Distance and transport costs

The distance between the clinic and the client can act as a barrier to adherence, as it may take too much time to travel to the clinic. The time taken may limit the AYAs' attempt to live a "normal" life, such as attending school regularly to avoid unintended disclosure of their status. The implied cost in terms of monetary value required for transportation to and from the clinic can act as a barrier to ART adherence (Maskew et al., 2016; Denison et al., 2015).

Waiting time

The health system factors that determine the time spent at the facility can act as a barrier to adherence to ART and clinic appointments, especially depending on the age and life schedule of the AYAs. Generally, the longer the time taken at the facility, the more likely it becomes a barrier (Maskew et al., 2016; Hornschuh et al., 2017).

Space for youth at the clinic

Lack of youth-friendly services at the facility due to lack of physical space or deliberately allotting time for a dedicated youth-friendly clinic time, preferably manned by healthcare workers who have been specifically trained in providing adolescent health services, including sexual reproductive health, in a conducive manner, will lead to suboptimal adherence to ART(Benson & Hosek, 2015; Denison et al., 2015).

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Quality and quantity of counselling services

According to Argawala et al. (2019), counselling services were at the core of most adherence support interventions as counselling allowed the development of personal relationships and dynamic communication processes between AYAs living with HIV and trained counsellors that resolve personal, social, or psychological problems and difficulties. Counselling services were observed to play a key role in ART adherence amongst people living with HIV, particularly AYAs and children (Musayón-Oblitas et al., 2019). Access to adequate counselling services was a key determinant of favourable HIV treatment outcomes especially viral load suppression (VLS), clinical improvement and prolonged sensitivity to ART regimens (Musayón-Oblitas et al., 2019). Other schools of thought stated that the interplay between the health system and the AYAs on treatment, their caregivers and the health providers was critical for improved HIV treatment outcomes. Counselling services are known to be required throughout the HIV continuum of care, from HIV testing, initiation of ART, ART adherence, and disclosure, during counselling sessions, efforts to understand AYAs' ART uptake, whether VLS or not, are crucial (Maskew et al., 2016; Hornschuh et al, 2017; Ajuna et al., 2021). Counselling services have been recognised as an essential package to support ART adherence in the Indian response to the HIV pandemic (Argawal, 2019). In Kenya, studies have been conducted to understand and improve adherence using the Intensive Adherence Counselling (IAC) protocol utilising the 5As: assess, advise, assist, agree and arrange approach. IAC was found to be an effective intervention and adopted in the public health service in Kenya (Lukyamuz et al., 2021). Variants of IAC have subsequently been adopted to improve adherence to ART in AYAs with poor adherence to ART as a remedial intervention (Beja et al., 2022). Expert patients have been used to improve access to ART adherence and lifestyle challenges through the introduction of CATS in Zimbabwe, which is guided by evidence (Willis et al., 2019).

2.5.2 Transition and Autonomy

Two studies looked at transitioning from paediatric to adult care as a potential barrier to ART adherence in a low-resource setting in the Dominican Republic (DR) and a high-resource setting in the US. According to Pinzon-Iregui et al. (2017), the process of transitioning from a paediatric patient to an adult in the DR is fraught with traumatic experiences; there are different

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perspectives on dealing with adherence during transition and barriers related to stigma and social support. Weiner et al. (2009) explored the experiences of youth who transitioned from paediatric to adult care in the US and found that the youth had unmet needs for improved continuity of care, assistance with logistics, increased communication with providers and caregivers, and individualized management of the transition process. It was also established that adequate preparation was required if the transition process were to succeed and avoid potentially serious health consequences. Adult providers should be able to provide developmentally appropriate transition interventions that address loss, disclosure, and sexual behaviour along with medical requirements to manage the needs of youth with HIV.

2.6 CHAPTER SUMMARY

This chapter looked at the interplay of individual, family, community, and structural factors that are at play to either improve or reduce optimal adherence to ART in AYAs. On the positive side, personal motivation, family support and youth-friendly facilities support ART adherence, while side effects of drugs, stigma, alcohol and substance abuse, and long waiting times tend to hurt ART adherence.

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CHAPTER 3. METHODOLOGY

3.1 INTRODUCTION

This chapter presents the methodology used in the study. A description of the study design, sampling procedures, data collection and analysis, and rigour are provided. Ethical considerations are also discussed.

3.2 STUDY CONTEXT

The study was conducted at the Referral Opportunistic Infection Clinic in Harare, which serves as a clinical centre of excellence for ART. By being a referral clinic, it serves a diverse clientele not limited to its environs, ensuring diversity of participants in terms of socioeconomic status, ART treatment stages, and adherence patterns. The clinic is one of the pioneering Opportunistic Infection Clinics in Harare.

The Clinic also offers a differentiated AYAs service through a dedicated Youth Corner that offers ART, psychosocial support and Sexual and Reproductive Health Services, providing optimal participant support. It was, therefore, easier to recruit participants with known adherence patterns, the basis for purposive sampling. The clinic is readily accessible by public transport, making it convenient for the participants. Additionally, it is an environment that AYAS were already familiar with and would be comfortable with for interviews.

3.3 STUDY DESIGN

The study used an exploratory qualitative research approach to explore the experiences and perceptions of AYAs. This research was suitably addressed by the interpretive approach, where reality was best defined from the AYAs' perspective, considering their circumstances (Robson and McCartan, 2011; Hornschuh et al., 2017). Qualitative research was determined to be suitable for addressing the experiential nature of the research question, enabling the researcher to understand in depth the experiences of adherence in AYAs. The qualitative approach is flexible. This allowed the study to pursue emergent themes. As a result, the study enabled the researcher to understand the adherence issues from the lived experience of the AYAs, facilitated the synthesis of appropriate strategies to improve ART adherence (Jack, 2006).

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The objectives of this study were:

1. To explore the experiences of adherence to ART of AYAs living with HIV.
2. To describe knowledge about and perceptions of ART of AYAs.
3. To explore the understanding of health service providers about challenges to adherence to ART among AYAs.

3.4 STUDY POPULATION AND SAMPLING

This section describes the study population and sample that was recruited for this study.

3.4.1 Study Population

The study population refers to all cases, which are the objects or people of interest to the researcher as they meet a specified criterion (Robson and McCartan, 2011: 276). The population included all AYAs aged 18-24 years living with HIV on ART being attended at the referral OI opportunistic infection clinic.

3.4.2 Key Informants

Key informants in this study were the health service providers and CATSs. Eligible health service providers selected had worked at the opportunistic infection clinic dealing with adolescents and young adults for at least two years. They included doctors, nurses, pharmacists, and counsellors. CATS were young adults living with HIV who had been recruited for an adherence support club run by Zvandiri-Africaid supporting AYAs being treated at the clinic. The CATS must have received the prescribed basic training required to support AYAs. A total of five key informants, three health service providers, and two CATS were purposively selected for their insight into adherence for the youth. The key informants were invited over the phone, and the interviews were conducted in person at the clinic.

3.4.3 Participants

Using clinic registers, purposive sampling was to be used to identify adherent and non-adherent adolescents and young adults for inclusion in the study. The inclusion of both adherent and

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non-adherent AYAs would provide the research with the best information, to address the aims and objectives of the study (Ritchie, 2003; Robson & McCartan, 2011). A brief description of the study was provided to eligible AYAs on the clinic day by the counsellor at the Adolescent' Clinic. The potential participants were invited for a meeting with the researcher where detailed information was provided at the Adolescent' Clinic conference room, where potential participants who consented to participate were enrolled. Enrolment criteria for the adolescents and young adults were those aged 18-24 years, an age where they can individually consent to participation in research due to the sensitive nature of HIV. The AYAs had to have been on ART for ≥6 months, had to have ≥1 viral load result in their records, and may have belonged to an adherence club. The exclusion criteria were current illness or acute mental distress requiring hospitalization, period of <6 months on ART and a client with no viral load results in their medical records, as viral suppression was used as a biological marker of adherence. The qualitative design was employed to explain, describe, and provide in-depth interpretation of findings, therefore according to literature, 12 AYAs were a sufficient sample (Marshall, 1996b; Maxwell, 2013). Initially, participants were to be purposively recruited (excluding key informants) through various support groups, youth clubs, and the AYAs, who had yet to be assigned to a club or support groups. The Parirenyatwa Centre of Excellence Opportunistic Infection Clinic(PCOE) was not seeing patients as usual due to COVID-19 restrictions on movement and the need to maintain social distancing. As a result, the youth club and support groups were cancelled for the year. The adolescent clinic was also disrupted by the use of multi-month dispensing (MMD) which was employed to limit the number of clients at the facility by dispensing four to six months of ART supply instead of usually up to three months. Therefore, based on feedback from facility managers, participant recruitment occurred on-site at the PCOE using the convenience sampling method. Recruitment occurred on days when AYAs were allocated for refill and review, mainly on Mondays and Fridays. As a result, the AYAs interviewed were the ones who had shown up on dedicated adolescent clinic days and were going through counselling. The researcher engaged AYAs who had agreed to receive further information about the study irrespective of self-reported adherent status. The researcher also made it clear to potential participants that the researcher was independent and not affiliated with the health facility. A total of 12 participants were recruited. Of the 12 AYAs recruited six were members of an adherence club, and the others were not. Both males and females were recruited in the sample. Seven males and five females were recruited.

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3.5 DATA COLLECTION

As it is recommended to use pilot studies as a way "to develop relevant lines of questions" before conducting the actual study and to assist with the process of refining data collection plans and procedures (Yin 2009, p92), a pilot study at a local authority OI clinic preceded the main data collection. The data collection tools were refined to make it easier for AYAS to discuss the sensitive issues of ART by adding more open questions and discussing sexual activity at the end of the interview. Data collection occurred over five weeks between August and September 2020. Data was collected at the Parirenyatwa Centre of Excellence (PCOE) Opportunistic Infection Clinic. The researcher first went to the health facility to introduce himself and the research and seek permission from facility managers to conduct research. The researcher also used this introductory visit to obtain feedback from facility managers regarding the best method to recruit participants. Data was collected using a semi-structured, in-depth interview guide (Appendix 1). Appropriate probes were used to ensure that the issues were adequately interrogated. The AYA interview guide was pretested at an OI Clinic offering similar services in Harare to determine if it suited this research. After evaluating the guide, emergent issues were to be incorporated, and issues needing clarification, such as ambiguous statements, were corrected. Questions regarding sexual activity and health were added. The interview guide for AYAs, health workers, and CATS was developed separately. The research team comprised the principal researcher (myself), a member of staff, and an assigned counsellor to assist with the coordination of participants at the venue. The participants were interviewed in a language of their choice, English or Shona, which are the commonly spoken language s in Harare. All the interviews were audio-recorded; any Shona interviews were translated into English. Demographic data for all participants, such as age, sex, educational level, and marital status, were captured using a dedicated form (Appendix A1). For AYAs and CATS, the self-reported mode of HIV acquisition was captured on this form as well. The research team comprised the principal researcher (myself), a member of staff, and an assigned counsellor to assist with the coordination of participants at the venue.

3.6 DATA ANALYSIS

An inductive thematic process, where codes were derived from the research question and data, was used for the analysis (Robson & McCartan, 2011). The essence of this exploratory research was to capture the lived experiences and perceptions of AYAs about adherence to ART and be

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able to pursue emergent themes, as there was no prior theorem used to guide the thematic analysis (Braun & Clarke, 2006; Cresswell & Miller, 2000).

3.6.1 Familiarisation

The researcher carried out the interviews for participants and key informants in a language of their choice which was either Shona or English, allowing him to familiarize himself with the developing dataset. The researcher transcribed the audio tapes and read through the transcripts several times to familiarize himself with the data and generated initial codes.

3.6.2 Codes

The codes generated were compared between the researcher and the supervisor to develop a coding frame, which was then used to code the rest of the dataset (Braun and Clarke, 2006). Emergent codes were incorporated, and the transcripts were reviewed in an iterative process. The analysis was done manually, and codes were marked using highlighters in the script.

3.6.3 Identifying themes

Codes were collated into related groups and compared against each other to develop themes (Braun and Clarke, 2006). Thematic analysis was used to search for and identify common threads that extended across the entire interview or data set (theme) that were pertinent to the experiences and perceptions of the youth (Braun and Clarke, 2006). The analysis was based on describing what was said about adherence and the interpretation of the meaning attached to statements and experiences (Sandewolski, 2000; Robson and McCartan, 2011).

3.6.4 Integration

Themes were examined against each other and back to the original data set. Themes were internally coherent, consistent, and distinctive. Data within themes cohered together meaningfully, while clear and identifiable distinctions between themes was made. The themes were then defined and refined to capture the essence of what they capture and according to their meaning (Braun & Clarke, 2006; Robson & McCartan, 2011).

3.7.5 Report writing

The final step was to do a write-up, which told the complicated story of the data analysed in a way that convinces the reader of the merit and validity of the analysis (Braun and Clarke, 2006;

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Robson and McCartan, 2011; Mack et al., 2005). Simple descriptive statistics were used to interpret demographic attributes.

3.7 RIGOUR

Qualitative research has important standards that can be used to determine its value and veracity distinct from those employed in quantitative research (Denvers, 1999). They are credibility (ensuring researchers' representation of themes fit with participants' views), dependability (ensuring findings are consistent, logical, traceable and clear), conformability (ensuring interpretations were clearly derived from the data) and transferability (findings can be applied outside the study settings i.e.) (Denvers, 1999; Robson & McCartan, 2011). According to Lincoln and Guba (1985), the most important aspect of rigour is trustworthiness: whether the findings are worth using and if they reflect truth grounded in context.

The steps taken include keeping a research journal in which the researcher would record the whole research process to facilitate an audit trail (Creswell & Miller, 2000; Robson and McCartan, 2011). The researcher used reflexivity, being aware of his personal bias or attitudes towards HIV and adherence to ART in the youth and documenting measures that would be employed to counter these from affecting the research process (Creswell & Miller, 2000; Malterud, 2001, Robson and McCartan, 2011). Data would be provided to enable external parties to follow through the research process and understand how themes were generated so that where desirable, the study could be translated into different settings.

3.8 ETHICS CONSIDERATIONS

Ethics clearance for the study was obtained from the University of the Western Cape Bio-medical Research Ethics Committee (Appendix 7). In Zimbabwe, permission was obtained from the Medical Research Council of Zimbabwe and the Ethics Review Committee at the OI Clinic (Appendix 8 & 9).

The autonomy and dignity of potential participants were respected by offering them a voluntary opportunity to participate in the study. An explanation that research was part of the Master of

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Public Health training, and they were free to participate or opt out was provided. In addition, all these details were provided in a participant information sheet in either English or Shona. Informed consent was requested from participants who were aged ≥18 years. The consent forms are attached in Appendixes 5 and 6, catering to the AYAs and key informants, respectively. The participant information sheet for AYAs and key informants are attached as Appendix 3 and 4, respectively. In addition, the interviews were conducted in a manner that complied with institutional COVID-19 regulations, with the interviewer providing surgical face masks for interviewees and maintaining recommended physical distance.

All participants were assured of anonymity regarding the audiotapes. Unique identifiers and transcripts were kept in a secure cabinet and accessed only by authorized personnel. It was emphasized that they were free to withdraw at any time during the interviews. All participants were alerted of the risk of emotional distress. Counselling services were made available during or after the study at the clinic's dedicated counselling unit or through a referral; information was provided in the patient information sheet (Appendix 3 and 4). Research findings would be used to improve ART adherence in HIV programming; this is one of the potential benefits to the youths.

3.9 CHAPTER SUMMARY

The chapter described how the twelve participants and five key informants were recruited into the study, the study design, how data were collected during the COVID-19 pandemic, and the ethical considerations.

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CHAPTER 4: RESULTS

4.1 INTRODUCTION

This chapter presents the findings of the study. A codebook was generated, and the main themes and related subthemes were identified. A brief overview of the themes and subthemes with codes is summarized in Table 4.1. A brief description of the participants will be provided.

4.2 DESCRIPTION OF PARTICIPANTS

There were 12 AYAs participants, ranging from 18 to 23 years. Seven (58%) were male and five (42%) were female. Of the 12 participants, 10 (83%) self-reported perinatal infection and 2 (17%), both females self-reported sexually acquired infection. Of the two who reported horizontal infection, one had a mother with a disability, and the other had two siblings with disabilities. A total of 5 key informants took part in the research - which comprised 2 CATS, 2 Counsellors, and a medical doctor. The CATS were both aged 21 years old, with one male and the other female.

Table 4.1 Results of thematic analysis

Themes	**Subthemes**	**Codes**
ART Adherence	Knowledge of how to be adherent	Taking ART as prescribed by a doctor or health worker Daily ART intake
	Understanding the benefits of being adherent	Adoption of a healthy lifestyle (exercise and diet) Adherence improves the quality of life
	Consequences of being non-adherent	Non-adherence leads to clinical deterioration Virus resistance due to suboptimal adherence
Facilitators	Motivational messages	Living to pursue a career To look after children Live a normal life
Coping Strategies	Concealment	Hiding tablets in the house or a wallet Pretending to use the bathroom Refer to pills as airtime bundles Hiding tablets in tights or clothes
	Reminders	Alarms using clock/phone. Family/friends Taking tablets as a family.
Health Service Factors	Staff attitude	Accommodating Polite and cheerful
	Peer-to-peer support	Youth club Support groups CATS

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Themes	Subthemes	Codes
		Personalized services/needs assessment guided services
	The transition from childhood	Age at transition The experience
	Counselling	General counselling Adherence counselling Living
	Nutritional and Welfare Support	Provision of food Vulnerability assessment Adolescents in difficult circumstances
Social Factors	Home environment	Supportive guardian/parent Assistance from siblings Explain HIV status
	The role of significant others/ caregivers	Support from friends, partners, and caregivers Accompany to clinic Reminders on appointments Reminder taking ART
Barriers	Medication-related	Daily medication intake Side effects Develop rashes or reactions. Not getting sick Pill burden
	Social	Stigma Fear of isolation Influence from society Poor family support Fear of inadvertent status disclosure. Lack of privacy
	Personal	Busy schedule Denial of HIV status Anger at parents for infecting or non-disclosure Failure to understand the reasons for taking treatment, Alcohol and drugs abuse Mental health problems. Forgetting to take treatment
	Socioeconomic	Poverty Food insecurity Expensive transport Livelihoods
	Health Facility	Long waiting time at the clinic Poor service from the private sector Associating with a designated Opportunistic Infection Clinic Unintended disclosure of HIV status
	COVID-19 pandemic	Lockdown and international public health regulation Social Distancing Clinic schedule disruption

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Themes	Subthemes	Codes
Sexual and Reproductive Health Rights	Sexual Health and behaviour	Sexually Transmitted Infections Discordant partner and future fertility Safer sex Promiscuity
	Reproductive Health Rights	Human rights and disclosure of status to a partner

4.3 ART ADHERENCE

Findings suggested that having the correct knowledge about their condition, being HIV positive, and the rationale for treatment and the way to take ART correctly were found to promote optimal ART adherence among AYAs. Some of the issues that were found to contribute to the understanding of ART adherence included knowledge on how to be adherent, adherence health benefits, and consequences of non-adherence. Other participants even understood that adherence extends to dietary and physical fitness advice. Some participants knew that lack of adherence could lead to viral resistance to ART**.**

4.3.1 Knowledge about how to be adherent

The participants who demonstrated adequate knowledge of what adherence entails reported optimal adherence. This knowledge included taking ART as prescribed by the doctor or health worker. They also understood that taking ART daily was required to maintain their health and strong immunity.

Taking ART as prescribed by a doctor or health worker

Participants understood the need to take their ART because their health providers explained it well.

> *"I was told that I should accept my HIV status. Then I should adhere to my medications so that I remain healthy. And the viral load continues to be suppressed."* - Female, 23 years

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Daily ART intake

It was clear to the AYAs that they were required to take ART without missing doses if the treatment was to achieve the desired goal: keeping healthy. Adherence was appreciated in a very simplified manner as a life-long commitment.

> *It is to take your medications on time every day for the rest of your life… Like what I know, like the way you take your drugs like if you have been told that you take at a particular time, like 6 mornings, 6 evenings, you should like you are supposed to stick to those eh times. And you start using those times of 6 in the morning, 6 in the evening. You are not supposed to miss. Is that so?(*Male, 23 years).

4.3.2 Understanding the Benefits of Being Adherent

Adherence was linked to health, improved quality of life and the necessity to avoid the deterioration of HIV as expressed by different AYAs. A balanced diet was desirable. In this regard, optimal adherence included maintaining adequate nutrition. Participants understood that adherence to ART improves their quality of life.

> *I was told that this virus inside me will increase if I do not continue taking my tablets. And after it continues to increase, it will turn to the AIDS stage, when it can no longer be controlled. There is nothing that can be done. That is more of what they call stage 3, but I know that if you do not take tablets, you end up being very serious (*Male, 18 years).

Another participant echoed this:

> *If I do not take drugs, I am risking myself. Yeah, from, you know getting sick. Because if I take my medicine properly, I have protected myself. So that I will not, eeh, get ill. And it benefits me that I will stay fit and keep my health. And if I am healthy, I am able, I can be able to do anything. So, medicine is part of my life. I must take it seriously (*Male, 21 years).

Some participants showed a simplistic understanding of the importance of the immune system in keeping one healthy. This helped them accept the need for a consistent daily schedule for taking ART medication.

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*And then you do not say like maybe today you have taken, tomorrow you skip, no. You are supposed to take drugs every day. (pause) You are supposed to take it every day. So that, like, your antibodies stay strong in your body. Like, maybe let us say you take today, today you take at 6, tomorrow you take at 8, your antibodies need to remain strong so that, like if it is 6, let it remain 6, if it is 7, let it remain so (*Male, 23 years).

Yet other participants had a more comprehensive understanding of ART adherence and immunity in a more scientific way, that nonadherence leads to increased viral load and a failing immune system.

*Adherence is good for your health, number 1. Number 2, aah if you do not take your drugs well (throat clearing) your viral load will increase, and the soldiers in the body will decrease. CD4 count that is the body's soldiers will be reduced very much. They were teaching us, they said viral load must be low and CD4 high (*Female, 23 years).

AYAs understood the importance of a nutritious diet to maintain hydration, a supply of significant nutrients to maintain a healthy body and regular exercise to keep fit.

*Eating healthy such as eating "sadza" [maize meal, staple food], beans and fish. The meal contains food with proteins, carbohydrates, fats, vitamins, mineral salts, and veggies. Having a balanced diet is important for us on ART (*Female, 23 years).

*Yes, they said there must be a balanced diet. You must eat a balanced diet to keep your body fit and exercise more often. (pause) Yeah (*Male, 20 years).

4.3.3 Consequences of Being Non-Adherent

The AYAs were aware that non-adherence could lead to possible clinical deterioration that could result in frailty and recurrent sickness that would lead to being unwell and hospital admissions.

*I take my medication as per prescription and never should default because if I default, I will fall sick, and everyone will know my status also that I might die if I fail to take my medication prescribed (*Female, 19 years).

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The participants were aware that suboptimal adherence could create an environment in which treatment-resistant HIV strains survive in their bodies, leading to treatment failure. A participant who was on a second-line ART regimen was apprehensive about what would happen should that regimen fail.

> *I am adherent because I do not want to develop resistance to 2nd line ART as I am not sure 3rd line is effective and convenient to take (*Male, 21 years).

> *Oh, they said if you miss your treatment, you will end up in a state where the virus will be drug resistant if you miss your pills, or if you default. The virus will be drug resistant. And it will grow more, more viruses in your body and if you keep on missing your dosages, you will go on the second line, and after the second line, 3rd line, and after 3rd line, there will be no other medication that you will be able to take that can suppress the virus (*Male, 20 years).

4.4 FACILITATORS

Participants described an awareness of circumstances that militate against treatment adherence and outlined strategies they used to achieve optimal adherence in their peculiar circumstances, including self-motivation messages.

4.4.1 Motivation Messages

Some participants adapted to their status in a way that enabled them to draw inspiration and strength from their HIV status and circumstances rather than despair. AYAs maintained the desire and focus on living, growing up, achieve set goals, and keep adhering to ART and pursuing meaningful activities.

> *I like to sing; I like listening to music. I spend my time watching TV and exercising. I am quite a shy kid. I do not go out that much. I am an indoor person I am talented in dancing and have a dream of growing up to be a musician (*Male, 21 years).

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A pregnant participant, on realizing that they had a chance to prevent transmitting HIV infection to their unborn child, became motivated to maintain optimal ART adherence.

> *I take the medication at 7 pm every day. But there is a time, when I was pregnant, and there are challenges I encountered so at times I used to skip, until my viral load increased. So, I considered and found that it is not useful to skip medications. I will be endangering my child. So, taking medication consistently, at the assigned time, be it 7 or 8, not changing the times, will reduce the viral load (*Female, 21 years).

4.5 COPING STRATEGIES

The participants raised the issue of employing coping strategies that included some concealment as well as several reminder mechanisms to achieve optimal adherence.

4.5.1 Concealment Strategies

Some participants described situations in which they had to maintain optimal adherence in circumstances where visitors or peers were present, and they did not want to disclose their status. Key informants corroborated this.

A participant described how they had to hide their medication in different sections of the house to avoid visitors from discovering their secret.

> *So, I will be hiding my things (ART), in a hidden place. And there that is when, that is when I sometimes find it, sometimes difficult. That I end up waiting for them (visitors) to sleep. Or I would know that I have 2 rooms that I use, sometimes I put my tablets in the bedroom and the others in the kitchen. But I hide, hide them. I might lock the door, then I take. Or, then sometimes, we might sleep late…. But it might be my time to take drugs, and that is when it becomes difficult. So, I will end up waiting for them to sleep, then I can take the drugs (*Male, 22 years).

AYAs reported having to take tablets in privacy that they would have wrapped up when in a crowded place.

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*Taking time to use the bathroom in a boarding or party setting and take tablets already packed in a secluded area in the bathroom (*Male, 20 years).

*.... I have said not disclosing could be fine, but you cannot miss your meds because there are some people around. So, you should take note of your times, and when it's time, you go to the bathroom and take the drugs. If someone walks in and asks you just say, they are just my tablets (*Female, 21 years).

One of the participants described a situation where they had to stay away from home because of work but had to share accommodation. In a bid to maintain adherence and avoid their status being discovered, they chose to keep their tablets in their wallet. They would refill when they were alone.

*Carrying a week's supply in the wallet and keeping the wallet on my person, all the time. I take the pills when no one is seeing me (*Male, 22 years).

It sometimes became necessary to discuss ART while amongst those who did not know the HIV status of the participants particularly during follow-ups by the CATS in the community. The participants and key informants used a prearranged code.

*...referring to ART as airtime, data bundles, or network for codified communication (*Key Informant).

Participating ladies revealed that they would conceal their ART treatment in tights with pockets and take them as indicated in a secure environment to avoid accidental disclosure to peers or family members who were not aware of their HIV status.

*For girls, we advise that they should wear tights with pockets where they keep their medication in advance so that when it's time, just go to the bathrooms or toilets and take their medication privately (*Female, 19 years).

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4.5.2 Reminder Strategies

Some AYAs reported forgetting to take ART because they were naturally forgetful or because of external circumstances. To curb non-adherence from these challenges and improve adherence to desired levels, AYAs had devised several ways to remind themselves that it was time to take ART. AYAs indicated that using alarm clocks or the phone would serve as a reminder of the time to take tablets.

> *... And then secondly, I use my time. And then I now know that by 7 o'clock I will be taking my medicine (*Male, 23 years).

In another household, the alarm clock and the regular 2000hrs news bulletin were used to improve ART adherence.

> *We have a wall watch also when it is time for the news at 8, we will be alert (*Male, 22 years).

Family members and principal caregivers were reported to play a role in reminding AYAs that it is time for medication.

> *One, like I am reminded by my grannies. And then secondly, I use my time. And then I now know that by 7 o'clock I will be holding my babe (laughter) (*Male, 23 years).

Some AYAs reported that they were reminded to take ART by siblings or guardians who were aware of their HIV status.

> *My sisters who are my legal guardians remind me to take tablets when it's time (*Female, 21 years).

The support from caregivers was recognized as encouraging optimal adherence.

> *Granny's support makes it easier to take ARVs because she reminds me, like an alarm (*Female, 18 years).

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Disclosure of HIV status to family members was described as liberating because the AYAs were then free to discuss medication-related issues with their family members and get moral support. Some AYAs indicated that their HIV-positive family members teamed up with them in taking their medication. Taking ART as a family resulted in optimal adherence for these participants.

> *We take ART at the same time as a family. Both my parents are on ART so, it makes it easy for us. When they take their medication, I take mine also (*Male, 20 years).
>
> *...and taking my medication at the same time as daddy (*Female, 19 years.
>
> *Aah, we help and remind each other together with my parents (*Male, 20 years).

4.6 HEALTH SERVICE FACTORS

The health facility provided a conducive environment for the care of AYAs. Staff attitude and peer-to-peer support were reported to provide a safe environment in which to access services that encouraged adherence.

4.6.1 Staff Attitudes

The OI Clinic environment had a bearing on the experiences AYAs were exposed to, depending on how the staff treated them: staff includes counsellors, CATS, nurses, medical doctors, pharmacists, and laboratory scientists. The motivated staff treated clients with due respect and were accommodating and cheerful., resulting in an atmosphere where clients were relaxed and positive about their clinic environment. Overall, participants were happy with the attitude of the OI staff.

> *I have not faced any challenges. Normally when I come here, I just do whatever needs to be done, following all the stages and I get my medication and go back home. I have never seen something like being ill-treated* (Male, 18 years).
>
> *The health staff is polite and very cheerful (*Male, 20 years).

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This was corroborated by key informants, who demonstrated passion and understanding of adolescents in the OI Clinic and the need for services that were delivered in a manner that empowered them.

> *We try to strengthen their knowledge base in terms of understanding what adherence is about. And aah, we also try to talk to them about the issues regarding adolescence, as you would understand that adolescence, it included, aah a lot of changes in their bodies… (*Key Informant).

The staff highlighted the importance of providing personalized services that are age appropriate:

> *To do more programs or engagements with them (AYAs), probing them in ways that are very friendly and age specific (*Male, 29 years).

4.6.2 Peer-to-Peer Support

The adolescent clinic was being run as a safe and secure space for AYAs. One critical consideration was ensuring that on dedicated Adolescent Clinic days, there was no mixing of adults and adolescents in their space. AYAs required a special approach to peer-to-peer support as they identified better with those of the same age. Through youth clubs for those with laboratory evidence of undetectable viral load (adherence) and support groups for those with suboptimal adherence and high viral load count, AYAs could interact and learn from their peers.

Youth clubs or support groups

AYAS valued advice from their peers, and sometimes just interacting with contemporaries who were also living with HIV and on ART made them realize that it was not a lone battle. They were then able to empower each other and solve their problems.

> *We just used to speak about positive living at CHIEDZA [support group] and discussed how to take ARVs tablets* (*throat clearing)* (Female, 23 years).

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Support groups are specifically for those not doing well on ART to try and improve adherence and, ultimately, the viral load.

> *… an intervention that is specific to their current challenges. So CHIEDZA is catering to adolescents that are between 11 and 19 with detectable viral loads. So, what they do now, this I'll go through a 12-month session where they meet once every month on a Saturday. There they will meet other peer educators and peer counsellors here, umm, then they will be taught about various issues regarding dealing with aah barriers to adherence, various issues regarding their adolescence, as a stage in human development, regarding other issues. At the end of the year, depending on VL a participant can graduate to the youth club if they achieve undetectable levels (*Key Informant).

The importance of belonging to small groups was beneficial to some.

> *Small group, like they wanted to build our friendship, that as ado... we remain united. And then we will be telling each other like I could be having my problem, and each one will be having their problem. And then, we could share the problems. There are also times when my buddy is not taking drugs well, I could counsel them, that you should do this and that so that you live well (*Male, 23 years).

Interacting with peers in similar circumstances helped some AYAs to answer pertinent questions, such as whether they were the only ones infected and learning that others managed to live with HIV infection.

> *The first days were hard for me because I used to ask myself why I am the only one in our family on treatment, but with the support group that I attend and where I stay, I was taught by others that I am not alone (*Female, 21 years).

Community Adolescent Treatment Supporters (CATS)

The key informants also cited the use of CATS as a customized way to reach out to AYAs, who they described as reluctant to be lectured and more willing to engage with someone of their age and in similar circumstances. The CATS described some of their roles and activities in supporting AYAs to be adherent.

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*… we offer home visits for young people and monitor adherence, seeing that they are taking their drugs well. And talking to them (*Key Informant).

*I offer individual counselling sessions. Then focus group discussions with young people about HIV and AIDS. And, sometimes sharing my lived experience with them to motivate them to keep taking drugs well (*Key Informant).

*… not all of them require monitoring adherence. Some will just want someone to tell their stories, their life experience, and stuff (*Key Informant).

One of the CATS described the work schedule of supporting AYAs.

*Each week, I make sure that I send SMS to all assigned AYAs. Then if we realize that we are sending an SMS and sometimes there is no response. Then we do phone calls. And, we have our WhatsApp group as young people, all the young adults from Parirenyatwa. The one with WhatsApp is free to get into the group. And we discuss a lot of topics in that group. And those without phones, some use their parents'. It will depend on whether the parent is comfortable to join that group (*Key Informant).

The CATS receive basic training to enable them to provide the support required.

*How to talk to adolescents who are HIV positive and how to provide counselling services to support adherence to ART, keeping clinic appointments …. Some adolescents will be going through a stressful period, for example, will be abused, some are orphans and usually, stress is the major reason why adolescents default. We were also taught about the demerits of defaulting from antiretroviral treatment. Like if they default, their viral load will increase and the CD4 count will decrease. Which means the patients will be vulnerable to a lot of diseases (*Key Informant).

The clinic staff reported that the COVID-19 pandemic had disrupted the clinic, especially the function of small groups and CATS.

*It is difficult nowadays because of the lockdown. Youth Club activities have been stopped. Communication over the phone with adolescents is a major challenge (*Key Informant).

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*The use of virtual platforms or WhatsApp groups has been difficult for some clients because smartphones and data are unaffordable (*Key Informant).

According to key informants, the Adolescent Clinic annually conducts a needs assessment to identify issues of concern for the AYAs, and identified issues are incorporated into programming for the following year.

*The identified needs such as computer literacy, and web designing … Partners have been invited to fill gaps as needed. The Harare International School provided computers…(*Key Informant).

The participants reported benefiting from some of these programs.

Yaa. (pause) And I also love, aah designing and music. Right now, I am not working but I can make a living from those skills (Male, 21 years).

4.6.3 The Transition from Paediatric Care to Adolescent Clinic

The participants reported how helpful they found taking ART from the Adolescent Clinic compared to their experience at the Infant Clinic (at the same facility or some coming in as referrals.) They shared the circumstances surrounding the transition.

*It was because of transport costs so I began to come alone (*at 11 years*) to reduce the transport cost (*Male, 24 years).

*... collecting ART on my own at the Ado at 13. When I started, it was not hard because, I do like some friends, and I knew that I was not the only one who was HIV positive, we are many. And then we are one family. So, then that is how we would encourage each other. If my buddy, gives me support that we should walk this path and we should do it this way then I follow him. Haa. (*Male, 23 years).

The transition was reported as an empowering experience by a participant referred to the Adolescent Clinic for treatment failure from a previous facility, the Infant Clinic.

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*So, last year I started seeing things differently. I started collecting my drugs. Coming to the hospital, seeing other kids, and understanding the life I am living, even about why I am taking my tablets, my medicine, and why I must take them (pause). Because growing up as a kid, there was just being brought to me. Because sometimes I was not being able to take my drugs seriously. Or even actually get scared, that I must drink medicine. Because I never quite understood why. But, by that time, they told me the reason why I am taking tablets. Because I have never really been disclosure (*Male, 21 years).

A participant who transitioned within the same facility reported the transition as smooth and engaging.

*Haa, it was normal to me. Nothing had changed. Plus, I had been used to coming with my mother, so, coming alone was a little bit hard, but I got used to it. Umm, in the infant's clinic, ha-ha that was all about parents. My mother was the one who did the most things, I was seated. She would say let us go. I did not even do anything. But here at the Adolescents, you do things on your own and there will be counselling, and everything will be done to you, directly to you, so (*Male, 20 years).

4.6.4 Counselling

The participants reported receiving regular counselling from the Adolescent Clinic during their visits. The participants were satisfied with provided counselling services as they found them relevant.

*Counselling… Adherence, why are you taking your pills and relationships, relationships, they also talk about it. And not to miss your dosage, that's adherence, ya (*Male, 20 years).

*Like things they used to say, as you must take, you should take your drugs well. Being HIV positive is not the end of the world. You can do something else in life (*Female, 18 years).

*...counselling, when we go for counselling, we feel free and not shy as we will be of the same age groups as adolescents (*Female, 19 years).

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*The ado clinic has motivated me to take ART more consistently because they disclosed to me my HIV status and told me the reasons why I am taking medication daily (*Male, 21 years).

According to clinic staff, they offer different counselling services to meet their clients' needs. Counsellors clarified their role in the clinic.

*…my role is to give, umm, psychosocial support to, uhm both adolescent and adult clients. Umm, by offering counselling services. Aaah, basic counselling services, and adherence counselling…. As well as, umm enhanced adherence counselling, aah, to those who have a high viral load. ---forming youth clubs umm for those who, umm, who have a suppressed viral load and, aah responsible for, aah. forming support groups, aah, in partnership with other, aah, organizations who support us, Uhm, o establish support groups for those adolescents who have a high viral load. Umm, to assist adolescents, umm, in terms of, aah, disclosure to, to their partners because, you see, some of these adolescents are now sexually active…(*Key Informant).

The central role of routine adherence counselling was important during clinic visits. The counsellors used it as a springboard to probe and determine whether AYAs were mentally prepared for full disclosure and any other support required.

*issue of adherence, we try to strengthen their knowledge……We understand that during adolescence some would start to understand that they are living with HIV and some would want to, understand what it involves, and even when they are getting into relationships they might want to disclose to their partners, so we always go through the processes of disclosure so that at the end we promote the overall wellbeing of our adolescents (*Key Informant).

The key informants acknowledged that adolescence as a development stage posed additional challenges to AYAs living with HIV.

So, if, (HIV*) negative adolescents have problems already, you know about identity crisis issues and so forth. So, it also affects HIV-positive patients. HIV itself, as a*

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*chronic condition, complicates matters. Ant, it is made worse because they are not going to take their medications as well (*Key Informant).

4.6.5 Sexual and Reproductive Health

The Adolescent Clinic provide sexual and reproductive health (SRH) services to AYAs who were attending primarily for ART. The clinic offered free female and male condoms. Hormonal methods such as the combined oral contraceptive pill and the mini pill for lactating mothers were provided. Cervical cancer screening was being offered at the clinic. The clinic had appointed a focal nurse for SRH and created a support group for AYAs who had babies requiring special support to maintain optimal adherence. These services were critical to allowing AYAs who were getting sexually active to focus on ART adherence.

Ok, they said you must use condoms, yeah, and protection (Male, 20 years).

*They had explained that when you want to have a child you go and see your doctor, and you will be taught, both you and your partner. That is what I heard (*Female, 23 years).

4.6.6 Nutritional and Welfare Support

The Adolescent clinic staff recognized adolescents in vulnerable, and challenging circumstances that required support.

*I stay by myself in Chitungwiza [satellite town]. My father and mother died. I was still young, around 4 years (*Male, 21 years).

*I am living positively with HIV. I was born like that. I knew I had HIV, when I was, in 2008. My mother and father passed on (*Female, 23 years).

*I am an orphan. Both parents are late. I am also an only child. I have no siblings (*Male, 21 years.

A participant who lives alone with a poor support system remarked.

Yeh, I am a boy aged 22 years I stay in Kuwadzana [suburb]. I stay alone. I stay alone because my mum is not around. She went to work. She started going to Namibia in

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*2005. So, from there, I stayed with my aunties, then I changed to aunt, aunt, then I stayed with my uncle. So, in 2012 when I was in Form 1, I went to stay with my grannies, my father's mother. From there, I went to the rural areas, then I came back. Then I started staying alone. From 2012 up till now, I have been, I can say, I have been staying by myself. From there I was alone. I would be paying rent etc. But I am sometimes faced with situations of taking drugs and feeding myself (*Male, 22 years).

The clinic staff conducted a vulnerability assessment to identify clients that could benefit from additional support to improve adherence.

*So, we have, aah, one of the criteria or the point that we look for is whether someone is an orphan, for example, if they're young children if they're malnourished and we put them, give them priority if they're food insecure (*Key Informant).

The adolescent clinic had been able to provide limited nutritional and welfare support to identified vulnerable clients in a bid to improve ART adherence amongst the clientele.

The facility had sourced limited food stuff that was given to selected participants.

So currently at the clinic, we have a food program, and we are giving food to some of our patients that we would have seen to be vulnerable (Key Informant).

*So, we give them mealie meal, … peanut butter, beans, and cooking oil as well. So yes, at the clinic we have a facility, and we have a program that we are doing in terms of meeting some of the challenges that the adolescents will be having in terms of the nutritional component (*Key informant).

4.7 SOCIAL FACTORS

There are social circumstances primarily determined by the social construct of the environment surrounding the adolescents that positively influenced their optimal adherence to ART. These include supportive parents/ guardians, siblings, caregivers, and friends.

4.7.1 Home Environment

AYAs with a strong social support structure in the form of the immediate family or any other guardian playing the adult caregiver role reported that it was easier for them to achieve optimal

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adherence to ART. According to the participants and key informants, they received support such as reminders to take ART and attend clinic appointments.

> *My sisters who are my legal guardians remind me to take tablets when it's time (*Female, 21 years).

Participants reported receiving assistance on living with HIV from their siblings

> *I am an orphan, raised by elder siblings who have been my principal caregivers. They disclosed my HIV status to me when I was 13 years old (*Female, 21 years).

Family members helped the participants to understand their HIV status.

> *I received information because I asked them what was happening. They were not clear with me the first time but when I started asking questions that is when it went clear to me that I was HIV positive and I was then given additional counselling by Sister (Nurse), … remember the name. But that is when I started to know (*Male, 20 years).
>
> *… my grandmother told me it happens in life. It is not the end of the road. And she said I should accept (*Female, 18 years).

4.7.2 The Role Played by Significant Others/Caregivers

The AYAS that had supportive caregivers reported receiving encouragement and being accompanied to the clinic, making it easier for them to access services and keep scheduled appointments. The support was provided until they had achieved the capacity to attend clinics on their own.

> *Then I turned 17/8 and started to collect my medication by myself, I used to come to the clinic with my sisters and my sister-in-law to the infant section (*Female, 23 years).
>
> *They help me this way. when I come from the hospital, they take my book, read it, and see what is required. Then they take note of my date. So, they are like an alarm, so that even when I am at work and concentrating when the review date is close, they call me to remind me that next week I should be there. They keep on telling me that I should continue to take my medication. That is how they help me (*Male, 18 years).

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A participant reported finding support from a close friend regarding his HIV-positive status and taking ART.

> *I disclosed this to one of my friends when I was out of town and due for a refill managed to collect my resupply and maintained a supportive friendship (*Male, 22 years).

Attending scheduled appointments is very important for AYAs, as attending scheduled reviews is a proxy for adherence. A health staff was quoted stating:

> *we assume everyone who has missed, an appointment is not taking medication. So, we, aah, we do, aah follow-ups on these who have missed their, who have missed their clinic appointments. And we also do reminders to those adolescents who, aah, are having high viral loads (*Key Informant).

4.8 BARRIERS

AYAS reported that some circumstances made it difficult for them to take ART as expected, even when they had adequate knowledge about how to take ART correctly and were aware of the undesirable consequences of failing to achieve optimal adherence. Reported barriers varied from those related to side effects of the drugs, forgetting, being afraid to be isolated and discriminated by peers and family members, denial, and poor social circumstances.

4.8.1 Medication-related Barriers

AYAS reported failing to take ART as prescribed because they faced challenges from the medication they were taking. The participants indicated that side effects that affected and sometimes dissuaded them from taking the ART drugs included feeling sleepy or dizzy after taking drugs. As a result, they usually take ART before sleeping, however, this made it challenging for them to be adherent when they were in company or in social activities such as parties and sports activities. These challenges are exacerbated for the AYAs attending high school or studying for a career. The participants were also concerned about taking medication

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when they did not have access to decent meals, yet others developed reactions or rashes due to some drugs.

Daily medication intake

Some AYAs developed fatigue after being required to take daily medication for life. This issue was reported amongst participants who had perinatal infection and who, in some instances, were not fully aware of why they were required to take the medication.

> *By the time I was no longer being given medicine daily, I would skip doses. So sometimes I would take tablets, and sometimes I would not. Then there was a time that I stopped. I realized that I was not getting sick* (Male, 21 years).

Side effects

Some participants reported that they had to stop taking the ART drugs because they experienced side effects such as nausea and vomiting, feeling dizzy, bad dreams and, seeing things or hearing voices that no one else could hear, and changes in appetite. These symptoms were said to be worse when starting ART or changing drugs. In some cases, AYAs stopped for long periods before seeking attention, while some were discovered during VL monitoring.

> *Tenolam-D has low and fewer side effects than Tenolam-E. I had weird dreams. Umm, and visions that were (subtle laugh), you saw things that were not there (*Male, 20 years).
>
> *I am on HIV medication. I started taking the drugs in 2007. So, I take Tenolam-E and Atanazivir. I take the medication at 7 pm every day. But there is a time, when I was pregnant, and there are challenges I encountered so at times I used to skip, until my viral load increased. So, I considered and found that it is not useful to skip medications. You will be endangering your child. So, taking medication consistently, at the assigned time, be it 7 or 8, not changing the times, will increase the viral load (*Female, 21 years).
>
> *…like during my first day of taking the drugs, I used to have bad dreams. But then it faded with time. Then sometimes I feel dizzy. Then I once had a bit of loss of memory, but I think I am recovering (*Female, 23 years).

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Other participants reported non-specific side effects that they attributed to being on ART. According to one participant feeling off led them to not adhere to ART as prescribed.

> *After taking Tenolam-E I might make wake up feeling off, might feel sleepy, or I may just sweat (*Male, 22 years).

Some AYAs had to stop taking ART for varying periods, from a missed dose to stopping for up to three weeks, because of side effects. This was despite their awareness of the negative consequences of suboptimal adherence. While some acknowledged restarting on their own, they remained anxious about their health until when they had VL results, confirming that they had undetectable levels.

> *Aah, I stopped (*because of side effects*), I think for 2-3 weeks. Then I came here because what had happened is, I had stopped and then continued by myself. So, I came here for a viral load (*Female, 23 years).

Developing rashes or reactions

The development of rashes and unusual reactions to medications were cited as barriers.

> *I will be having rashes. And my eating habits change. It means I will require more food with the drug, Abacavir (*Male, 22 years).

A key informant cited that side effects act as barriers to optimal adherence.

> *I would have very interesting dreams. And other reactions. Then as time went on, I developed breasts (gynaecomastia) and only continued treatment after reassurance from the clinic (*Key Informant).

Not getting sick

Participants tended to discontinue taking ART because they did not suffer any ill effects when they skipped doses.

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I would skip doses. So sometimes I would take tablets, and sometimes I would not. Then there was a moment when I stopped. I realized that I was not getting sick (Male, 21 years).

Pill burden

AYAs on simpler regimens using the fixed-dose combination, usually in the first line, tend to adhere optimally compared to those taking many tablets at a time.

*So those that are on simpler regimens, they are doing better than those that are on complex regimens (*Key Informant).

4.8.2 Social barriers

AYAS reported that the major barrier to adhering to ART was stigma. They were concerned about being discriminated against once their status was known. The guardians, especially parents, were also concerned about stigma, with some delaying disclosure. To avoid disclosure of status to peers and family members, AYAs often end up missing appointments or not taking ART as prescribed.

*Eeh, so I talked about non-disclosure either from their parents, or even clients when they get into a relationship. Or especially they get married to someone who is, who's got a different status to them (*Key Informant).

*Here, it can be a challenge because when you say I am going to the hospital. There is a section where there are sick people who are admitted. Then here you will be known that the department we are in is this (OI). So, I will be trying not to be noticed, by people, all right. As I mentioned, if I just go outside and go that side, I can meet a friend, or... Everyone will know that aah, that is what he came for. Umm (*Male, 22 years).

Fear of inadvertent status disclosure of HIV status

AYAs reported severe fear of accidental disclosure, case in point, was when AYAs were concerned about their schoolmates finding out about their HIV status. They ended up defaulting

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to protect themselves from being seen taking medication and arousing suspicion. They reported failing to take ART due to being forgetful when it was because they were afraid of accidental disclosure. One participant shared the experience of such AYAs that she learned from a support group.

> *They say that they forget at times. Some will be thinking that they will be laughed at by their colleagues, like the ones at school, they say that for example in boarding schools they say how do I get the medication out, and if people ask what will, I say. So those are the reason they do not take drugs (*Female, 21 years).

Fear of isolation

Acceptance by peers was noted to be important. Some participants shared that fear of being denied love and companionship could act as a barrier to optimal adherence to ART.

> *Aah, they say peer pressure, to go to parties and stuff. And they eventually must miss their doses. And others say, aah critics, from people saying you are, you use, and they would have to leave them and at the same time they default. Yaa-peer pressure (*Male, 20 years).

Lack of privacy

AYAS reported that the lack of privacy in taking ART, which they regarded as an intimate matter, was a hindrance to effective ART adherence. AYAs reported being embarrassed to take ART in public in institutional care and school environments.

> *someone will be at boarding school, and they do not know how they can take their drugs (*Male, 23 years).
>
> *... some experience problems such as when they are boarders at school it is difficult for them to take their medication in the presence of their friends (*Female, 19 years).

Influence from Society

The AYAs identified the negative influence they receive from society, especially peers, to reduce optimal adherence. Participants received negative sentiments about being on ART when young and not clinically unwell, while others were looked down upon because of their HIV

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status. Participants reported ending up stopping ART therapy based on misinformation. Reports by support group participants and key informants corroborated this.

> *They can be influenced by their friends not to take their medication by merely looking at their physical appearance and friends who convinces them that they are okay (*Female, 19 years).

Some participants reported mixed feelings from society that create confusion amongst participants. According to the participants, they receive mixed signals, with some sections of society being inclusive and respectful of those living with HIV. On the other hand, some members of the public were disparaging and conveyed negative sentiments. As a result, some AYAs reported a loss of self-esteem and reduced self-efficacy, leading to suboptimal adherence to ART.

> *There are different views- others feel pity for you, others say it's normal, and it is not shocking. Then others get shocked by it (*Male, 21 years).
>
> *Sometimes I may fail to take drugs because I will be embarrassed to take ART in the company of my friends* (Male, 22 years*).*

Poor family support

Dysfunctional family units that were not providing a safe environment in which AYAs could find love, identity, feel valued and moral support for their normal development and for being HIV infected were said to be a cause for poor adherence. AYAs on ART reported that they were exposed to stress and therefore required caregivers who could provide reassurance and who were emotionally aware to respond to their needs. Some AYAs could not disclose their status to parents or guardians because they felt the adults could not handle matters or were incapacitated.

> *I would have genuinely forgotten and there is no one to remind me. ...people at my house do not know I am on ART. Just my mum who is deaf and dumb, and my little sister who is too young to understand what is happening to me (*Female, 23 years).

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AYAs who were orphaned ended up staying with extended family members who were not supporting them or grew up in child-headed families where there was no adult caregiver.

> *I stay by myself as I lost both parents at 4 years of age* (Male Young Adult, 21 years).
>
> *… let us say, staying with extended family who are not supportive, they will not be comfortable, where they are staying, for them to be continuously taking drugs* (Male, 23 years).

Dysfunctional family units were described as failing to provide support for treatment.

> *If I still remember I came in 2018 and they have called only once. Ever since. We do not even talk to each other on the phone, and I also do not care to talk to them. They have not provided support in taking ART or attending the clinic. (*Female, 18 years).

Visiting was reported to be a barrier to correct uptake by participants as it constrained them.

> *Having visited or being visited at your house is inconvenient for taking ART (*Male, 21 years).

4.8.3 Personal barriers

Adolescence is a transitional period from childhood to adulthood. During this period of personal growth, activities such as sleepovers, busy schedules, and use of alcohol and drugs were reported as barriers to optimal adherence.

Forgetting to take treatment due to social activities

Participants reported that they forgot to take ART because of social engagements:

> *Maybe I would have visited and forgotten to carry the drugs (*Male, 21 years).
>
> *…you left in the morning saying I am going and will be back. And then you decide, haa, let me sleep over, transport has flung or what, that is when you might forget* (Male, 23 years).

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Busy schedule

Some participants cited busy schedules, making it difficult for them to keep to appointments or support groups and affecting optimal adherence.

> *These days, I am busy nowadays, so I no longer do support groups* (Male, 23 years).

Denial of HIV status

Some participants reported not being able to accept their HIV-positive status, especially given that it is, in their opinion, attributed to sexual activity and promiscuity.

> *…. Even though I attended a lot of counselling and a lot of groups, there was no difference. I could not accept it (*Female,18 years).

> *… when my father died. He was also HIV positive and when he found out his status, he was in denial. He did not believe that HIV existed, and he refused to take the treatment. He died a few months after he found out, he was positive (*Key Informant).

Angry with parents for infecting them or non-disclosure

Participants had challenges accepting their HIV status. The process was worse in some participants who were angry with their parents for infecting them and delayed disclosure of their HIV status.

> *I started questioning the reason why I had to take the medication every day. My mother had convinced me that I was supposed to take them every day or I was going to die because of the chest pains. My mother eventually told me about my status and explained my father's death. She explained that he was also HIV positive when he died. I understood that it was not their fault, but at the same time, I was hurt because they were not honest with me from the onset* (Female, 21 years).

> *... they are so bitter, and some are having grief-related issues because some of them will be blaming their parents for infecting them. Some of them will be having aah, aah*

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*actual grief because we have seen some who are orphans or they are experiencing several challenges which, aah, could act as barriers, to their fence (*Key Informant).

In an instance, a young adult resorted to running away from home and required counselling to forgive her mother and improve her ART use.

*A few weeks after my mother told me about my status I ran away from home. ... I stayed in South Africa for 3 years ... That is where I got counselling at a clinic ... I opened to them about my situation and that helped me to forgive my mother. ... I accepted my medical condition and I have moved on with my life. I now religiously take my medication (*Female, 21 years).

Some participants expressed that they had challenges overcoming their negative attitude toward those living with HIV.

*Because I used to ask myself how people who are HIV positive, like how, do they live, and what kind of people are those. I thought if I were HIV positive, I would kill myself (*Female, 18 years).

Failure to understand the reasons for taking ART

Participants reported facing challenges with understanding the rationale for taking daily medication. Some participants were not proffered their HIV-positive status but were given different and unconvincing reasons.

*Ya. Because I was never told why I needed to take medication. I was just being told I was sick of mumps and chest pains until I read in my records that I was HIV positive (*Male, 21 years).

Not feeling sick

The participants who had been told that they would get sick if they did not take ART realized that missing doses did not result in the said sickness, and therefore stopped taking medication. Even participants aware of their status reported that they continued missing doses as they did not suffer any immediate consequences.

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*I think that when a person sees that they are "healthy", and they are not sick, they think that they should stop taking medication (*Female, 23 years).

Alcohol and drugs abuse

AYAS admitted that the use of alcohol and drugs made it difficult to take ART consistently, leading to suboptimal adherence. The suboptimal adherence happened **t**hrough getting addicted, unplanned sleepovers, and getting intoxicated leading to missed doses and inconsistent clinic attendance.

*Coz, I used to take drugs too much cocaine, cannabis, and cigarettes (*Female, 18 years).

Key informants also reported alcohol and drug abuse as a barrier.

*… but we always caution them about the demerits of drinking alcohol. Some of them can forget to take their medication when they are drunk (*Key Informant).

Mental health problems

Mental health disorders were reported as a barrier to optimal adherence. Clinic staff cited depression and anxiety as the conditions that they routinely screen in AYAs for early treatment to increase ART adherence.

*we can talk about depression. Umm, I routinely screen for depression Uhm, using a tool we call SSQ14. Umm, so if a client aah scores, umm half Uhm, which is 7/14 Uhm, that client need, uhm counselling because it shows that aah that client has depression. And some of the characteristics of depression, aah, its hopelessness, aah despair, and aah which then impact one's, aah adherence (*Key Informant).

psychological well-being as well. For those that are having stressful experiences, we could see that adherence could be affected. So, you could see someone having a

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*suppressed viral load this year, then the following year they will start to have viral load starting to go high (*Key Informant).

Forgetting to take treatment

Participants reported missing doses because they would forget. Forgetfulness was reported to be more frequent at the time of initiating ART.

*Yes, sometimes I forget. But not for more than 2 days. Like for a day or two… (*Female, 23 years).

*I sometimes forgot (*Doses of ART*), Sometimes because of the place where I will be (*Male, 21 years).

4.8.4 Socioeconomic barriers

AYAs living with HIV reported either losing one or both parents, coming from a broken home, and, in some instances, child-headed households. Some reported that because of these circumstances, they were living in poverty. They were food insecure and sometimes failed to attend clinics because they could not afford bus fares. AYAs reported that coming from food-insecure homes interfered with their ability to take ART as prescribed. A participant lamented that they were not getting rations at the OI Clinic, which was standard at another treatment centre.

*Everyone was treated for free and given food rations at the previous facility where I was treated, which I found beneficial (*Male, 22 years).

The lack of food was corroborated as a challenge by staff.

*… food program, that we are giving food to some of our patients that we would have seen to be vulnerable. So, we have, aah, one of the criteria or the point that we look for someone is an orphan, for example, if they're young children if they're malnourished, we put them, give them priority if they're food insecure. So, we give them mealie meals, we give them peanut butter, beans, and cooking oil as well (*Key Informant).

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There was concern about food insecurity from CATS.

> *… food shortage is a major challenge, and for some, it is because they are homeless, and face discrimination. is there any way that you can help the adolescents in terms of food provision? (*Key Informant).
>
> *For most of my clients, (the main challenge) is food shortages. The pills are affecting them if taken on an empty stomach (*Key Informant).

It was reported that due to poverty, some participants had to transition at an early age from the infant clinic to the ado clinic, as fares for one person were more affordable than for two.

> *It was because of transport costs so I began to come alone (*at 11 years*) to reduce the transport cost (*Male, 22 years).
>
> *When staying in the rural areas, I would face high transport costs to come and collect in Harare because I could not risk going to a nearby hospital…(*Male, 18 years).

Participants expressed concern about not having decent livelihoods due to a lack of skills and the COVID-19 pandemic that was ongoing.

> *Before the COVID-19 lockdown started, aah, when it then started, I was in Karoi. That is what I was doing about earthmoving. Now I just sell small items to survive (*, 22 years).
>
> *Life was easier when my father was alive, but after his death, my mother was the sole breadwinner. We are three in our family, ... My mother had to provide for me, and my siblings, and she would often engage in vending as a major source of livelihood (*, 23 years).

4.8.5 Health Facility Factors

AYAs raised concerns about barriers associated with the health facility offering ART treatment. Amongst the issues raised were long waiting times, being seen at a known HIV treatment centre, which enabled the community to infer about their HIV status, and poor service by private healthcare providers.

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Long waiting time

Participants raised concerns about the time spent within the adolescent clubs at the clinic for services being too long and inconvenient.

> *The OI Clinic will be full of clients, and it takes a long time before you are served. You do not want to meet people that may recognize you (*Male, 22 years).

> *If they shorten their program a little bit. So that (chuckle), we can be quickly attended to. Some days when you come, we are here for about 2hoursin. And they will be like no one coming to attend. And that will be stressful. We will be just seated. And yeah (,* 20 years).

Unintended disclosure of HIV status

Some AYAs reported that being a client at a stand-alone OI Clinic at a big hospital would reveal the AYAs' HIV status to anyone who saw them at that clinic, which is undesirable.

> *Haa. Here, it can be a challenge because when you say I am going to X Hospital. There is a section where there are sick people who are admitted. Then here you will be known that the department we are in is this (OI). So, I will be trying not to be noticed, by people, ... But you will be, you will be in that area. Everyone will know that aah, that is what he came for. Umm. That is why I like the previous facility (just a house) (*Male, 22 Years).

> *I am uncomfortable coming to a designated OI Clinic as anyone who sees you there will assume that you are on ART. There is a high possibility of meeting familiar people (*Male, 22 years).

Poor service from the private sector

It was observed that private practitioners were not comfortable providing ART to children and AYAs living with HIV. Health staff at the clinic reported that.

> *That was the doctor I was seeing whenever I got sick. Dr. Y would prescribe ART and a pharmacist would get drugs from a nearby central hospital without explaining to me what was happening (*Male, 21 years).

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*I think in general private practitioners are sceptical or they are scared to manage children and adolescents with HIV. So mostly they are in the government sector (*Key Informant).

4.9 SEXUAL AND REPRODUCTIVE HEALTH RIGHTS

One of the notable characteristics of AYAs was their involvement in intimate relationships, which involve sexual encounters. These relationships were fraught with challenges on their own and living with HIV posed additional challenges.

4.9.1 Reproductive Health Rights

Participants admitted to being anxious about whether to disclose their HIV status to partners. They feared either being rejected or not being believed, that they acquired it perinatally. They faced challenges in identifying the right time in the relationship to disclose. The participants reported reduced ART adherence as they avoided taking ART in the presence of partners with whom they reported spending time.

*Aah, currently we have 1-year dating, and yeah that is it 1 year. And I have not told her that I am on ART. Uhm, no I am afraid to ask her, coz if she asks me if (laugh, mumbling). Uhm, I think it will end when I tell her that I am positive, (mumble, laugh), and on ART. That is my fear. That is my only fear (*Male, 20 years).

*In short, when we come here, we discuss those sexual issues: if you love a woman, you should be honest with them that I am HIV positive. Not to hide, that after letting us say 10 years of staying together, they won't be knowing, they discover. It leads to the breaking up of relationships and causes you to get into jail or what. We also learn that if we fall in love with someone living with HIV and I am on ART, no problem. And then the child may be protected from HIV. It will depend on the viral loads and how we take our drugs and practice safer sex (*Male, 23 years).

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The participants and CATS who disclosed their statuses described receiving support.

> *He knows that I am positive, and he is negative, and he is ok with it (*Female, 23 years)

> *She understood and she was Now supporting me, putting SMS reminders, have you taken your drugs.? Then something happens (*Key Informant).

The key informants and participants were both concerned about how best to manage disclosure that the participant was living with HIV to respect the partner's human rights without compromising the participant's rights.

> *And then, to someone who is not positive, I can tell them that I am like this like that. So, if they can take it, that is when we can be in love. If they cannot take it like we won't be able to sleep together. Because they have their rights and I have my rights., disclosure & human rights, sexual abuse (*Male, 23 years).

The participants acknowledged their concern about their partner's reaction to being HIV positive.

> *Like you will be considering and checking which one, if I disclose to them, they can take it. So, you will be checking that, you will be reading them to see that if I tell this person about my status, how will they take it*? (Male, 23 years).

According to a key informant, stigma hampers disclosure.

> *… main fear… find it difficult to disclose their status, Uhm, to their sexual partners it is because of stigma. Umm…. So, some adolescents are not taking their medication, uhm because they are afraid to be seen by their partners that they are taking their medication. …it is now difficult for me to take my medication when I am with my boyfriend (Key Informant).*

4.9.2 Sexual Health and Behaviour

Participants reported difficulty coping in relationships with discordant partners, especially a lack of clarity of future fertility.

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*(sigh) He is HIV-negative, and I am positive, and I think it will be very unfair. And I do not think that I would want to have a child (*Female, 23 years).

Some participants were worried about having infected children despite counselling.

*I am afraid of infecting them(children) (*Female, 23 years).

Yet other participants believed it was safe.

*I was told at CHIEDZA that a couple who are HIV positive can have an HIV negative child if they are adherent and follow medical advice (*Male, 21 years).

Despite this knowledge, there was concern about fertility and it was an issue that some participants had shelved.

*Aah, this has, kind of changed for me. This had kind of changed for me. In a whole lot of areas. The fact that I am 21. Time is running out, may, to do something. So, I just need, my, push forward. So, starting a family is not on my (muffle) to-do list (*Male, 21 years).

Participants reported being sexually active, with some having been treated for sexually transmitted infections (STIs) and, in another instance, unwanted pregnancy, although they admitted that they had been counselled on safer sex practices. Participants reported having unprotected sex even when they knew about safer sex practices. According to the key informants, there is an interaction between status disclosure and safer sex.

Umm, so you see some of these adolescents aah when you talk to them, they tell you that I spent a night two nights at my boyfriend's place. So, they tell you that it is now difficult for me to take my medication when I am with my boyfriend. Even during the day, whenever they have their boyfriend, even if it is their time, uhm to take medication, they cannot take that medication because they have not disclosed the status, aah to the boyfriend. uhm, that is when, aah as counsellors come in to support them on how they can best disclose their status because aah disclosure comes with benefits and has some challenges. So as counsellors, we try to equip them with skills on how best they can,

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*aah disclose aah, their status also empower them, uhm so that they can be able to, to stand for themselves in practicing safer sex and maintain optimal adherence (*Key Informant).

This was corroborated by participants who would not ask their partner about their HIV status despite having unprotected sex because they did not want to state theirs. As a result, practising safer sex became a challenge.

Uhm, no I am afraid to ask her, coz she asks me if (*laugh, mumbling) But if it takes us far, I will just have to decide to tell her (*Male, 20 years).

A 21-year-old patient on ART who had unprotected sex with a 21-year-old male of unknown status and ended up with an unwanted pregnancy had this to say:

No (I don't know his HIV status). No one knows the other's status… …

*They had explained that when you want to have a child you go and see your doctor, and you will be taught, both you and your partner. That is what I heard (*Female, 21 years).

While a self-reported sexually transmitted HIV participant had this to say:

*Yaa, I used to sleep around to sustain myself, sometimes with protection sometimes without (*Female, 18 years).

In their HIV journey, a participant who admits to getting infected by a partner now reports practicing safer sex.

I started being sexually active at 19. So, I was dating this other guy. I started dating him at 18. I went for an HIV test, it was negative. Then 19,20 and 21, I was still dating that person, that is how I got to find out that I was positive at 20 (Female, 23 years).

In the current relationship, she describes different circumstances.

*He knows that I am positive, and he is negative, and he is ok with it; we use protection (*Female, 23 years).

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Sexually Transmitted Infections (STI) were reported as occurring and difficult to handle by both participants and key informants.

> *.. maybe an STI somewhere. ...they do not come straight saying I have an STI to the nurses…. young people that they come through me…. Refer privately to the nurse focusing on SRH (*Key Informant).
>
> *Yes (I am sexually active), with the one who was HIV positive, and I contracted STIs after the encounter (*Key Informant).

The findings of the study indicate three extended themes, namely the conflict between the school and clinic, the need for HIV-competent households, and adolescent-friendly HIV services.

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CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

This chapter discusses the results of the study in comparison to known literature. The study sought to describe the experiences and perceptions of adolescents and young adults regarding adherence to antiretroviral therapy treatment at a referral Opportunistic Infection Clinic in Harare, Zimbabwe. The socio-ecological model is relevant to unpack adherence, a complex health behaviour determined by the interaction between the individual and environmental factors at the family, social and structural levels to influence adherence to ART. The socio-ecological model has been effectively used to examine the HIV continuum of care and adherence to ART (Babalola et al., 2017; Mukumbang, Mwale & van Wyk, 2017; Yakub & Ncama, 2016). The findings of this study are delved into using the socioecological model which was used to guide literature review.

5.2 INDIVIDUAL FACTORS

5.2.1 ART Adherence Knowledge

This study noted that adequate knowledge about ART adherence plays an important role in influencing optimal adherence amongst the AYAs. The knowledge is acquired through interaction with carers, peers and with the health system leading to increased self-efficacy, which improves ART adherence at the individual level. These findings are comparable to adolescents in a similar setting in Soweto, where it was observed that healthcare givers had successfully transferred knowledge about ART adherence from parents and caregivers to the patients as they grew (Hornschuh et al., 2017). In this study, it was observed that while some participants had a basic understanding of ART adherence, explaining why it was important for them to follow instructions, other participants demonstrated an understanding of the underlying principles behind adherence, such as immunity, viral biology, and the need for healthy eating. The study also showed that AYAs understood the benefits of being adherent to ART, which is expected to lead to improved quality of life and avoid deterioration of AIDS. In some cases, participants who had been sickly before commencing ART had first-hand experience of the consequences of being non-adherent, which led to clinical deterioration that resulted in frailty and recurrent sickness which is different from the literature reviewed (Maskew et al., 2016; Hornschuh et al., 2017). That AYAs had basic understanding of ART adherence and the

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benefits thereof is consistent with studies on adherence to ART amongst the youth (Yang et al., 2018; Rowell-Cunsolo & Hu, 2020; van Wyk & Davids, 2019).

5.2.2 Facilitators / Coping Strategies

The study found that AYAs improved ART adherence with motivational messages and coping strategies. The participants described drawing inner strength and focus to live, grow up, achieve set goals and to keep healthy by adhering to ART and pursuing meaningful activities. Coping strategies, e.g. concealment and reminders were found to improve adherence to ART in previous studies (Hornschuh et al., 2017).

5.2.3 Side Effects/ Medicine Effects

Despite possessing the knowledge of ART adherence and employing some coping strategies to improve ART adherence, AYAs still face barriers at the individual level. Side effects were perceived as a barrier to adherence by the respondents in this study. The main adversity about medication was the requirement for daily ART intake at the same time despite their school and social activities. A wide range of side effects, including rashes, sleep disturbances and non-specific unwellness made it difficult to take ART as prescribed. Side effects, generally expected or experienced early on in treatment initiation, emerged as an important barrier. This finding is consistent with the literature on barriers to ART adherence in the same age group, which found out that fear of or experiencing side effects caused non-adherence among AYAs on ART.(Hornschuh et al., 2017) This study did not profile side effects based on the self-reported mode of HIV transmission as in the two studies in South Africa (Hornschuh et al, 2017 & Maskew et al., 2016).

5.2.3 Substance Abuse and Mental Health

The study found that, like other adolescents and young adults, ART adherence was reduced amongst youth who took an excessive amount of alcohol and those who engaged in substance (drug) abuse. It is accepted that AYAs are exposed to the use of alcohol and substances as part of normal development (UNAIDS, 2016b). Indeed, according to literature, substance abuse and alcohol are recognized barriers for AYAs and adults on ART (Kim et al., 2014). While HIV disease progression may cause mental symptoms, according to literature, mental health problems, especially depression, have deleterious effects on ART adherence (Mavhu et al.,

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2013). This may explain why the clinic made routine assessments for depression and insisted on a counselling session at each visit to check participants' wellbeing.

5.2.4 Adolescent Life Activities

The study showed that normal age-appropriate activities such as attending school, parties and sports led to adolescents' busy schedules. These activities were shown to present a barrier to optimal ART uptake by AYAs as they were not ready to reveal their HIV status to their peers (Yang et al., 2018; Maskew et al., 2016). The youth who engage in unplanned events such as sports or sleepovers are likely to miss taking their medication as prescribed. It was also found that AYAs forgot to take medication. Forgetfulness occurred earlier during the commencement of ART. AYAs would conveniently forget to take medications in the presence of others. This is consistent with findings in Zambia and South Africa (Denison et al., 2015; Hornschuh et al., 2017).

5.2.5 Internal Stigma and Disclosure of HIV Status

Internal stigma which was expressed as reluctance to disclose HIV status to family members and sexual partners was a major barrier among the participants. Internal stigma was inferred from parents and guardians who were uncomfortable disclosing the HIV status to the growing adolescents. Fear of inadvertent HIV status disclosure has resulted in some youth being uncomfortable with spending time at designated OI clinics. Others are travelling long distances to collect ARVs at centres where they are unlikely to meet people who would recognize them and deduce their status. Previous studies found that internal stigma, which can be expressed as reluctance to disclose HIV status, was one of the common barriers to ART adherence among the youth (Kim et al., 2014; Lowenthal et al., 2014; Yang et al., 2016). According to a recent study on the impact of HIV in the Zimbabwean population, internal stigma remained an important barrier, with participants on ART not sharing their status but being detected by finding therapeutic levels of ART drugs in their blood (Zimbabwe Population-based HIV Impact Assessment (ZIMPHIA 2020, 2021). While counselling services have been implemented in the Adolescent Clinic, discrimination against HIV-infected persons is because of their perceived inferior health status conferred by a confirmed or suspected HIV-positive status or state of health and the implied sexual promiscuity (USAID, 2006). This affected perinatally infected participants, resulting in anger at parents for nondisclosure and their role

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in infecting them. Some AYAs had long periods of denial of HIV status and anger at parents over non-disclosure or infection, which accentuated failure to understand the reason for taking treatment as the adolescent transitioned from childhood to ado autonomy. These findings are consistent with findings in similar age groups in South Africa and Botswana (Hornschuh et al, 2017; Lowenthal et al, 2014).

5.3 FAMILY/ PEER RELATED FACTORS

5.3.1 Family Support

In this study, family members played a pivotal role in improving adherence to ART by providing support in reminding adolescents to keep clinic schedules, take medication and deal with the HIV positive status. This was in the form of providing information about HIV, especially deciding when to disclose the HIV-positive status to the growing adolescent and accepting them as worthwhile household members. According to this study, AYAs who came from a supportive home environment that included supportive guardian(s), receiving assistance from siblings, dietary and nutritional support, a stable household, psychosocial support and appropriate HIV status disclosure had improved ART adherence. The role of significant others/ carers in either taking patients to the clinic or reminders of clinic days and taking ART was found to improve ART adherence in cases where participants managed to disclose their HIV status to family or friends without suffering discrimination. Some family members could support each other beyond just reminders from family members, and they took ART as a family at the same time (Denison et al., 2015).

The family environment in some instances was shown to be detrimental to optimal ART adherence amongst AYAs where there was delayed HIV status disclosure and lack of support. Negative family dynamics that posed a barrier to optimal adherence were shown to include poor family relations, unsupportive guardians, lack of adequate personal privacy or inadequate accommodation, and lack of support on clinic attendance or taking medications. The household arrangements that posed a barrier to optimal adherence were a child-headed household, being orphaned, and staying alone. AYAs who did not have HIV status disclosure at the appropriate age due to carer limitations or denial had trouble with maintaining optimal adherence and understanding the rationale for daily ART intake. Accordingly, it appeared that an HIV-Competent Family Environment was important for improved ART adherence in the study

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(Williams et al., 2017). The HIV-competent family was an important facilitator to optimal ART adherence for the AYAs on ART(Williams et al., 2027; Hornschuh et al., 2017).

5.3.2 Peers

The role played by peers or contemporaries in positively influencing adherence behaviour of AYAs is important. Peer involvement in the form of CATS, support groups, edutainment programs and adolescent clubs was found to be particularly effective because AYAs found comfort in learning about HIV from AYAs in the same circumstances. CATS were found to be effective communicators and role models for youth living with HIV. Participants indicated that the presence of CATS helped them understand that they were not the only youths who were infected with HIV perinatally or sexually. They also found encouragement that they could live with the virus if they adhered to the recommendations of health staff and that disclosure was easier among peers. Participants attested to the positive interaction among peers, which made it easier to face challenges from ART and the support groups, like CHIEDZA, with nonadherent AYAs graduating to the youth club within a year. These findings are consistent with a pilot study conducted in rural Zimbabwe that led to adopting CATS in the HIV treatment strategy (Willis et al., 2019; MoHCC, 2018b).

5.3.3 Sexual and Reproductive Health Rights

On the contrary, AYAs found it challenging to deal with sexual health issues with their partners, resulting in unsafe sexual encounters and acquiring STIs despite admitting to being counselled on safer sex practices and the need to disclose HIV status to partners. The issues of handling discordant partners and future fertility were particularly contentious amongst the participants. According to available literature in similar age groups in Malawi, this is a common challenge and may be explained by unsafe sex, and promiscuity (Gombachika et al., 2012),.

The study found that AYAs had adequate knowledge that reproductive health rights are human rights. AYAs in Harare, like their counterparts elsewhere, have difficulty in handling sexual relations amongst themselves (Kim et al., 2014; Yang et al., 2018).

Despite the Adolescent Clinic providing comprehensive sexual and reproductive health services, including condoms, hormonal family planning methods and cervical cancer screening the prevalence of STIs require further study. STIs were treated either by the SRH Nurse or the

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usual medical staff. It is going to be difficult to reduce the incidence of HIV if the practise of unsafe sex continues unabated.

5.4 COMMUNITY FACTORS

5.4.1 External Stigma

Enacted or external stigma was found to be a barrier to improved ART adherence amongst the participants. The findings are consistent with literature that identified external stigma as a barrier to accessing HIV services in general and ART adherence in particular among the youth. Studies in South Africa, Zambia, and Botswana on AYAs on ART found that external stigma was a major barrier to ART adherence. (Kim et al., 2014; Lowenthal et al., 2014; Yang et al., 2016; Hornschuh et al., 2017). In a meta-analysis/ review of published articles on ART adherence covering the world, stigma was a major barrier (Kim et al., 2014). According to this study, stigma interacted with other factors at the individual, family, and structural levels to reduce participants' optimal adherence. HIV stigma was patterned along known social exclusion criterion that includes gender, race, socio-economic standing, and identified risk groups (e.g., women, men who have sex with, men, and commercial sex workers). At the individual level, participants avoid being seen taking ART tablets or disclosing HIV status to friends and family members, creating an environment that promotes missed doses. Within families, some participants only disclosed to a particular family member because they were afraid to be judged. Participants who disclosed their status felt they were treated as inferior household members. In some instances, there was delayed disclosure of HIV status to AYAs because parents or guardians were not ready to discuss their role, particularly amongst perinatally infected participants. These concerns have been expressed in previous studies in Southern Africa (Maskew et al., 2016, Hornschuh et al., 2017; Davids & van Wyk, 2019). It is important to find a novel way to tackle external stigma if the optimal adherence to ART among AYAs is to improve.

5.4.2 Socioeconomic Background

The AYAs who participated in this study came from vulnerable backgrounds. The majority reported perinatally acquired HIV infection which implied loss of either a parent or both that explain why they were either orphaned, stayed with guardians, or came from a child-headed household. Due to the social norms, female AYAs are more vulnerable than their male counterparts. The clinic found a way to empower the vulnerable AYAs so that they could attain

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food security as nutrition is important for AYAs living with HIV for optimal ART adherence. While the clinic is providing support after appropriate assessments it may be necessary to mainstream food security into the HIV care continuum. A novel intervention is cash transfer as Cluver et al. (2015) have shown that cash transfers and improved social protection can improve HIV treatment outcomes in the vulnerable adolescent girls and young women It is important to build resilience of the AYAs as the literature points to poor education opportunities, diminished academic accomplishments, lingering economic disadvantages and a hesitancy to marry as their lives progressed into adulthood (Feigelman et al., 2017).

5.5 STRUCTURAL FACTORS

5.5.1 Adolescent Friendly Services

The opportunistic Infection Clinic schedule was arranged to create a safe space for interacting with paediatric and adolescent patients without mixing with adult patients. The AYAs were further segregated into an adherence youth club, support groups, and special interest groups such as IT edutainment. The study showed that the AYAs found the health workers' attitudes and services to be adolescent-friendly (WHO, 2015; IAS, 2016; MoHCC,18b).

5.5.2 Health Staff Attitudes

The health staff displayed a professional outlook and accommodated the clientele they served politely and cheerfully. According to literature, negative staff attitude is a recognized barrier to providing ART Services (Benson & Hosek, 2015; Denison et al., 2015; Argawala et al., 2019; Beja et al; 2022). The OIC staff related to their clients and caregivers in a personal manner, which was important for a service that is driven mainly through counselling and mutual trust. According to literature, this is a key ingredient to successful service provision for HIV services (Hornschuh et al., 2017;Argawala et al., 2019; Ajuna et al., 2021). The Clinic provided services through a multiskilled team including psychologists (counsellors), nurses, medical doctors, laboratory scientists, pharmacists, and midwives. In addition, peer counsellors, known as CATS, were employed to provide an additional layer to reach AYAs.

The study found that there was poor HIV service provision for adolescents and young adults in the private sector. From this study, it can only be inferred that there is poor training or that the working model does not provide adequate time for critical services such as counselling at

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every visit. Further research is needed to understand the challenges and guide appropriate action.

5.5.3 Peer-Led Health Service Provision

The study showed that peer-to-peer support and service provision were important in the form of an adherence youth club for those with VLS, various support groups for AYAs with detectable VL, and CATS to provide peer counselling and support. Interaction with fellow adolescents helped the youth to understand that they were not fighting a lone battle (Lukyamuz et al., 2021). AYAs expressed that they listened to advice from their peers better as they find it easier to relate to (Willis et al, 2019. IAS, 2016). It was also noted that personalized services guided by a needs assessment consistent with differentiated services platforms were user-friendly (WHO, 2016). It appears critical that ART service provision incorporates a strong peer-led component,

5.5.4 The COVID-19 Pandemic

With the use of International Health Regulations, the COVID-19 pandemic precautions were a shock, which altered the way the study was conducted by introducing quarantine, partial lockdowns and the public health measures of social distancing, wearing face masks, and frequent handwashing using either soap or sanitisers which disrupted health systems especially OI clinic attendance and conduct of health clinics. Clinics were affected by patient scheduling, which led to the disruption of adolescent youth clubs and support groups and the maximum number of AYAs permitted per clinic session. AYAs faced transportation challenges, interrupted home follow-ups, and limited interpersonal communication. According to Mirzaei et al. (2022), people living with HIV are marginalized people whose access to ART and psychosocial support was interrupted by the COVID-19 pandemic despite mitigations such as telemedicine and multi-month dispensing.

5.5.5 Counselling Services

Consistent with literature reviewed, adequate counselling was central to the services offered at the Adolescent Clinic (Ajuna et al, 2021). This was supported by findings from both the participants and the key informants that highlighted that adherence counselling was offered at

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every visit to the OI clinic. This finding is consistent with the reviewed literature (Denison et al., 2015; Maskew et al., 2016; Hornschuh et al., 2017). Enhanced ART adherence counselling was provided to AYAs with detectable VL which is consistent with the literature (Lukyamuz et al., 2021; Beja et al., 2022). It was established that participants with VLS were enrolled in a youth adherence club at the facility, whereas those with detectable VL were enrolled in support groups where specific activities were employed to improve ART adherence. This was either done at the facility or through the involvement of partners such as CHIEDZA. These included edutainment activities and peer support. Expert peer support was provided through CATS, whose adherence support activities included counselling services on social circumstances, adherence counselling extending to daily monitoring of taking ART by phone, or the active involvement of parents or guardians. This adherence support has been shown to be effective and has been adopted in the public sector in Zimbabwe (MoHCC 18b; Willis et al., 2019). Counselling services were a package that covered initiation, caregivers on taking ART for AYAs and, gradual disclosure to AYAs on living with HIV and understanding why they need to take medication daily, and disclosure of the HIV status to sexual partners. Discussing sexuality and fertility before indulgence was a part of the package. The counsellors also helped AYAs to take progressive responsibility for taking ART and subsequent transition from the Paediatrics Clinic to the Adolescent Clinic. The counselling services rendered were consistent with a defined package in the public sector (Kim et al., 2014; Hornschuh et al., 2017; Argawal et al., 2019; Beja et al., 2022). Counselling services remain the glue that holds service provision for AYAs living with HIV across the cascade of HIV care especially adhering to ART.

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CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

The introduction of effective ART has transformed HIV care, especially among adult patients, leading to improved treatment outcomes (Van Wyk & Davids, 2019). HIV treatment outcomes remain poor amongst AYAs despite the availability of effective ART (Bukenya et al., 2019; van Wyk & Davids, 2019; ZIMPHIA 2020, 2020; Society for Adolescent Health and Medicine, 2023). The WHO seeks to fast-track the end of HIV/AIDS as a public health problem through the 95-95-95 initiative (UNAIDS, 2021a). Optimal adherence to ART is key to viral load suppression which is key to improved HIV outcomes (Hornschuh et al., 2017; Argawala et al., 2019; Neupane, Dhungana & Ghimire, 2019). In the current study, it was shown that AYAs had adequate knowledge about adherence to ART and the benefits thereof. It has been shown that while individual knowledge of ART adherence is important, the psychosocial support provided by the family environment is important to improve adherence. These attributes summarized by HIV-competent families included support in attending clinics, reminders on taking medication, acceptance of the HIV-positive member, early and age-appropriate disclosure, and lack of discrimination (stigma) (Denison et al., 2015; Hornschuh et al., 2017; Williamson et al., 2017; Madiba et al., 2019; Ajuna et al., 2021).

On the other side, as one of the barriers, participants cited conflict between their daily activities such as school, social activities involving peers such as sports and drinking alcohol that precludes privacy from taking ART without disclosure of status to peers (Maskew et al., 2016; Hornschuh et al., 2017; Argawala et al., 2019). According to participants, internal and external stigma were barriers that affected them, especially when it came to sexual and reproductive health, with a dilemma on whether to disclose or not disclose to a sexual partner, and how to negotiate safer sex practices without disclosure. Fertility needs were important for improved ART adherence in the study.

The interventions and services received at the adolescent clinic, which involved a multi-skilled team with a mix of peer-led interventions, were found to be suitable and friendly by the participants and providers. The opportunistic infection clinic went beyond providing ART, it also focused on providing psychosocial support, especially counselling services, an adolescent youth club, support groups, CATS, edutainment, and Sexual and Reproductive Health services.

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6.2 LIMITATIONS AND REFLEXIVITY

This was small-scale qualitative research for the Master of Public Health research training, it was therefore not feasible to carry out data collection until data saturation was achieved because of time and resource constraints. This limited the sample size. The COVID-19 pandemic affected the clinic setting by limiting youth participation in Adolescent' Clinic activities such as clubs and support groups. Purposive sampling was not feasible, but convenience sampling was used instead. Non-verbal communication and cues were limited due to the use of face masks. The social distancing requirements due to COVID-19 regulations precluded customary conversation norms that promote interviewer-interviewee rapport.

As an older researcher who does not have experience living with HIV, my interpretation of some of the issues young people raised is from a different viewpoint from which a researcher of the same age and HIV status would have interpreted them. Despite these potential shortcomings, I still managed to elicit information that may be useful for enhancing interventions for AYAs, a group disproportionately affected by HIV.

6.3 RECOMMENDATIONS

Based on the findings of this study, the following recommendations are made:

- It is recommended that ART for AYAs be provided using the differentiated service delivery framework with emphasis on an increased mix of peer-led interventions with a static clinic offering AYAs-friendly services.
- Further research is recommended on private sector participation in the care of AYAs on ART.
- It is recommended to do further research on strengthening HIV family competencies to improve ART adherence among AYAs.
- It is recommended to carry out research on ways to reduce HIV stigma among AYAs and their caregivers.

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APPENDIX A1 DEMOGRAPHIC DATA FORM FOR AYAS

Unique identifier :

Age : …….years

Sex : Male Female

Marital Status : Married Single
Divorced Widowed

Educational level : Grade 7 Ordinary Level Advanced Level

Tertiary Qualifications:

Employed : Yes No

Sector/ Profession :

Mode of HIV Acquisition: Vertical
Horizontal
Unknown

(Mode of infection was collected during the interview and populated in retrospect)

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APPENDIX 1: INDEPTH INTERVIEW GUIDE

Subject Number: **Date:**

Interviewer's Name……

Interview conducted at

1. Can you tell me how you ended up being treated at this clinic?
2. How did you find out about your HIV status?
    - At what age?
    - Where did you find out?
3. Please tell me about the medicines that you are taking.
4. Can you tell me about your experience of starting treatment?
5. May you please explain what you were told about treatment.
    - Medication? Dietary?
6. How do you feel about the treatment that you are on?
    - Side effects, change of medication/brand?
7. We understand that taking tablets every day can sometimes be challenging can you tell me about some times when you may have missed or stopped taking your medicines?
    - Why do you think some young people fail to take their medication?
    - What do you think makes it easier for young people to take medication as directed.
    - What works for you?
8. What are some of the reasons that might have made it difficult for you to take your medicines in your experience?
    - What were your circumstances when you started missing or stopped taking your treatment?
    - Health facility/ staff
    - Social support from family, friends, support group or significant others

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9. In your experience how has it been living with HIV in your circumstances
    - Do you feel that your HIV status is accepted in your social circles?
    - Internal and external stigma
    - Have you managed to discuss your status? Family, peers, and sexual partners.

10. What do you think would make it easier for the youth to take their medications properly?
    - Personal, family/significant others, health system factors
11. Can you tell me if there have been any changes in how you have been receiving treatment in the past few years?
    - Has your experience of taking medication changed with age and the time you take your ART?
    - Transition, autonomy, and preparations for transition.
12. Regarding sexual health, I would like to enquire about your experiences. Are you sexually active?
    - Safer sex practices
    - Access to sexual and reproductive health services, family planning, PMTCT and treatment sexually transmitted infections
    - Planned fertility.

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APPENDIX A2 DEMOGRAPHIC DATA FORM FOR KEY INFORMANTS

Key Informant

Unique identifier :

Age : …….years

Sex : Male Female

Educational level :

Tertiary Qualifications:

Profession :

Experience :

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APPENDIX 2: KEY INFORMANT INTERVIEW GUIDE

1. Describe your role in this facility.
2. How do you assist the adolescents and young adults on the management of HIV treatment?
    - Disclosure of HIV status
3. What information regarding adherence to ART is provided to adolescents and young adults?
4. Who provides this information?
5. What processes are followed to prepare AYAS for ART?
6. How do AYAS react when they are told about this treatment? In your experience how do AYAS react to being started on treatment?
    - Change of ART regimen
7. What services are provided by the health facility?
8. What are the counselling and psychosocial support available to AYAS and their guardians?
9. What are some of your experiences in providing ART to the AYAS?
    - Health provider personal experiences/perceptions. Health facility related issues.
10. What are some of the reasons AYAS may not adhere to their medication?
11. What can the facility do to help AYAS address these challenges?
    - Role of partners or other players
12. What does your facility do to track AYAS' non-adherence?
13. How does your facility handle transition from paediatric to youth care?

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APPENDIX 3: PARTICIPANT INFORMATION SHEET FOR AYAS

INFORMATION SHEET AYAS

Project Title: Exploring the experiences and perceptions of adolescents and young adults on adherence to Antiretroviral therapy treatment at a referral Opportunistic Infection Clinic in Harare, Zimbabwe.

What is this study about?

This is a research project being conducted by Hardwicke Matikiti. The research is being conducted for a mini thesis for the Master of Public Health at the University of the Western Cape. You are invited to take part in this research project because I value your knowledge and experiences. Your participation will help me understand some of the reasons that may have made it difficult for adolescents and young adults, like you, to take your HIV medication. Please read this information carefully before you decide whether to take part in the project. Feel free to ask any questions about the research project or information in the document.

The purpose of this project is to find out some of the reasons that make it easier or difficult for adolescents and young adults from always taking their HIV medication. It is hoped that this research will provide recommendations on how to make it easier for adolescents and young adults to take their HIV medication.

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

You will be given a participant information sheet which explains what the project is about. If you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read or what has been read and explained to you and you agree to take part in the research project. You will be given a copy of the participant information and consent form to keep for your records.

You will be asked to participate in a face-to-face interview with the researcher. The interview will be one hour long. The interview will be conducted at the clinic or at any other location that is convenient for you. You will be asked questions about how you have been taking your medication and any challenges you have experienced in taking your medication. The interview will be recorded using a voice recorder. The interview will be recorded to ensure that I capture all the information you provide.

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Would my participation in this study be kept confidential?

I will protect your identity and the nature of your contribution. To ensure your anonymity, a code will be placed on the typed interview notes. Using an identification key, I will be able to link your data to your identity. I will be the only person with access to the identification key.

To ensure your confidentiality, I will be the only one with access to the voice recording and you will not be personally identified. All voice recorded interviews and hand-written notes will be kept in a locked cabinet and will be destroyed at the end of the research. I will keep a copy of your signed consent form in a locked cabinet and will destroy it at the end of the research. All typed notes will be kept on a password protected computer.

If a report or article is written about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authority, such information that comes to my attention concerning child abuse or neglect or potential harm to you or others. In this event, I will inform you that I must break confidentiality to fulfil my 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. You may feel upset or sad talking about your HIV status or relive some bad experiences related to previous incidents. It is possible that you may feel embarrassed by some of the questions. I 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.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help me learn more about some of the challenges or facilitators that contribute to adolescents and young adults like you to take their medicine in the way they do. It is hoped that this research will help identify ways to help adolescents and young adults take their HIV medication in the correct manner and at the right time. This will help to keep them healthy.

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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 penalised or lose any benefits to which you otherwise qualify. It is important to note, that this research is not part of your treatment.

What if I have questions?

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

School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
+263 (772) 866322
hardiemat@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:

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University of the Western Cape
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Bellville 7535
ulehmann@uwc.ac.za

Prof Anthea Rhoda
Dean: Faculty of Community and Health Sciences
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This research has been approved by the University of the Western Cape's Biomedical Research **Ethics Committee REFERENCE NUMBER: BM19/10/20**

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APPENDIX 4: PARTICIPANT INFORMATION SHEET FOR KIS

INFORMATION SHEET FOR KEY INFORMANTS

Project Title: Exploring the experiences and perceptions of adolescents and young adults on adherence to Antiretroviral therapy treatment at a referral Opportunistic Infection Clinic in Harare, Zimbabwe.

What is this study about?

This is a research project being conducted by Hardwicke Matikiti. The research is being conducted for a mini thesis for the Master of Public Health at the University of the Western Cape. You are invited to take part in this research project because I value your knowledge and experiences. Your participation will help me understand some of the reasons that may have made it difficult for adolescents and young adults to take HIV medication. Please read this information carefully before you decide whether to take part in the project. Feel free to ask any questions about the research project or information in the document.

The purpose of this project is to find out some of the reasons that make it easier or difficult for adolescents and young adults from always taking their HIV medication. It is hoped that this research will provide recommendations on how to make it easier for adolescents and young adults to take their HIV medication.

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

You will be given a participant information sheet which explains what the project is about. If you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read or what has been read and explained to you and you agree to take part in the research project. You will be given a copy of the participant information and consent form to keep for your records.

You will be asked to participate in a face-to-face interview with the researcher. The interview will be one hour long. The interview will be conducted at the clinic or at any other location that is convenient for you. You will be asked questions about how you have been taking your medication and any challenges you have experienced in taking your medication. The interview will be recorded using a voice recorder. The interview will be recorded to ensure that I capture all the information you provide.

Would my participation in this study be kept confidential?

I will protect your identity and the nature of your contribution. To ensure your anonymity, a code will be placed on the typed interview notes. Using an identification key, I will be able to link your data to your identity. I will be the only person with access to the identification key.

To ensure your confidentiality, I will be the only one with access to the voice recording and you will not be personally identified. All voice recorded interviews and hand-written notes will be kept in a locked cabinet and will be destroyed at the end of the research. I will keep a copy of your signed consent form in a locked cabinet and will destroy it at the end of the research. All typed notes will be kept on a password protected computer.

If a report or article is written about this research project, your identity will be protected.

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In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authority, such information that comes to my attention concerning child abuse or neglect or potential harm to you or others. In this event, I will inform you that I must break confidentiality to fulfil my 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. You may feel upset or sad talking about yourself or others regarding HIV and its treatment. I 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.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help me learn more about some of the challenges or facilitators that contribute to adolescents and young adults like you to take their medicine in the way they do. It is hoped that this research will help identify ways to help adolescents and young adults take their HIV medication in the correct manner and at the right time. This will help to keep them healthy.

***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 penalised or lose any benefits to which you otherwise qualify. It is important to note, that this research is not part of your treatment.

What if I have questions?

This research is being conducted by Hardwicke Matikiti, School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Hardwicke Matikiti 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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APPENDIX 5: CONSENT FORM FOR AYAS

PARTICIPANT CONSENT FORM- ADOLESCENTS AND YOUNG ADULTS

Title of Research Project: Exploring the experiences and perceptions of adolescents and young adults on adherence to Antiretroviral treatment at a referral Opportunistic Infection Clinic in Harare, Zimbabwe

The study objectives have been described to me in a language that I understand. All my questions about the study have been answered. I fully understand what my participation will involve, and I agree to participate out 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…….

Biomedical Research Ethics Committee
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APPENDIX 6: CONSENT FORM FOR KIS

PARTICIPANT CONSENT FORM- KEY INFORMANTS

Title of Research Project*:* Exploring the experiences and perceptions of adolescents and young adults on adherence to Antiretroviral therapy treatment at a referral Opportunistic Infection Clinic in Harare, Zimbabwe

The study objectives have been described to me in a language that I understand. All my questions about the study have been answered. I fully understand what my participation will involve, and I agree to participate out 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.

Key Informant's name…….

Key Informant's signature……

Date…….

Biomedical Research Ethics Committee

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APPENDIX 7: UWC ETHICAL CLEARANCE

UNIVERSITY of the WESTERN CAPE

OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 4111/2948
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07 February 2020

Mr H Matikiti
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM19/10/20

Project Title: Exploring the experience and perceptions of adolescents and young adults to antiretroviral therapy treatment at a referral opportunistic infection clinic in Harare, Zimbabwe.

Approval Period: 3 February 2020 – 3 February 2021

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

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APPENDIX 8: MRCZ ETHICAL CLEARANCE

Telephone: 08644073772/791193
E-mail: mrcz@mrcz.org.zw
Website: http://www.mrcz.org.zw

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazowe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL

MRCZ/B/1955 **01 August, 2020**

Dr. Hardwicke Matikiti
Box A955
Avondale
Harare

RE: -Exploiting the experiences and perspectives of adolescents and young adults of adherence to ART Treatment at a referal OI Clinic in Harare

Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review: -

- Completed MRCZ 101 new application form
- Study protocol
- Informed Consent Forms (English and Shona)
- Interview Guides (English and Shona)
- Data collection tool
- **APPROVAL NUMBER : MRCZ/B/1955**

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF MEETING : EXPEDITED**
- **APPROVAL DATE : 01 August, 2020**
- **EXPIRATION DATE : 31 July, 2021**

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ offices should be submitted three months before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (0242) 791193, 0864407377203 or by e-mail on mrcz@mrcz.org.zw

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.
- In addition to this approval, all clinical trials involving drugs, devices and biologics (including other studies focusing on registered drugs) require approval of Medicines Control Authority of Zimbabwe (MCAZ) before commencement

Yours Faithfully

.....

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
2020 -08- 01
APPROVED
P.O. BOX CY 573, CAUSEWAY, HARARE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

https://uwcscholar.uwc.ac.za/

APPENDIX 9: PERMISSION TO CONDUCT RESEARCH AT PARIRENYATWA

All communications should be addressed to
"THE GROUP CHIEF EXECUTIVE"
Telephone: 701520-701554/7
Fax: 706627
Website:www.parihosp.org

PARIRENYATWA GROUP OF HOSPITALS
P.O Box CY 198
Causeway
Zimbabwe

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
2020 -07- 20
RECEIVED

22nd October 2019

Dr. H. Matikiti

REQUEST FOR PERMISSION TO CARRYOUT RESEARCH AT PARIRENYATWA HOSPITAL

The Parirenyatwa Group of Hospitals hereby grants you permission to carryout research as requested subject to the following conditions:-

1. The student has ethical clearance from the Medical Research Council of Zimbabwe (MRCZ) or Joint Research Ethics Committee (JREC).
2. The researcher sponsors all payments for any tests involved.
3. The hospital incurs no cost in the course of the research.
4. The relevant department is notified in advance and the Head of section/ward signs acknowledgement of such notification.
5. The conduct of the research does not interfer or interrupt the daily service provision by the hospital.
6. Formal written feedback on research outcomes must be given to the Director of Clinical Services.
7. Permission for publication of research must be obtained from the Director of Clinical Services.

PARIRENYATWA GROUP OF HOSPITALS
CLINICAL DIRECTOR
22 OCT 2019
P.O.BOX CY198,CAUSEWAY
HARARE

Thank you.

Yours sincerely

.....
MR. A.J.V. Maunganidze
CLINICAL DIRECTOR

Board members: *Dr G. Sikipa (Chairman), Mr J.B.M Fleming(member), Dr C.L. Dhliwayo(member), Mr M.H Khalpey(member), Mr R. Mvududu(member), Mr T.A Zigora(GCE), Prof C.E Ndlovu*

https://uwcscholar.uwc.ac.za/