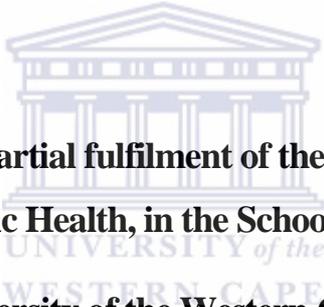


**Exploration of adherence to antiretroviral treatment amongst adolescents  
in a low socio-economic urban setting in Cape Town, South Africa.**

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**3409645**



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

**Supervisor: Prof. Brian van Wyk**

**Date: 12 March 2017**

## **KEYWORDS**

Access

Adherence

Adolescent

Antiretroviral treatment

Caregivers

Health care system

Peri-natally acquired infection

Psycho-social support

Sexual health

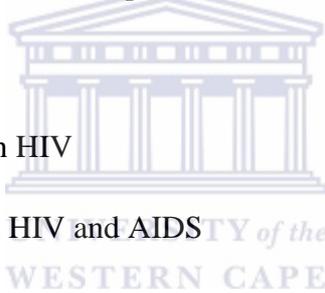
Young people

School



## ABBREVIATIONS AND ACRONYMS

ART	Antiretroviral Therapy
ARV	Antiretroviral
HAART	Highly Active Antiretroviral Treatment
HCT	HIV counseling and testing
IAS	International AIDS Society
LDL	Lower than Detectable Limit
NNRTI	Non - Nucleoside Reverse Transcriptase Inhibitors
NRTI	Nucleoside Reverse Transcriptase Inhibitors
PI	Protease Inhibitor
PLHIV	People Living With HIV
PLWHA	People Living with HIV and AIDS
REACH	Reaching for Excellence in Adolescent Care and Health study
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

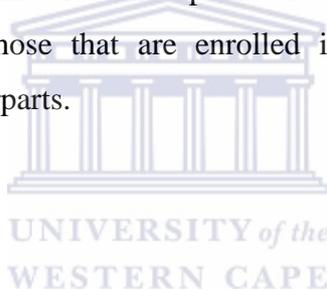


## ABSTRACT

### **Background**

HIV has reached epidemic proportions globally with Sub-Saharan Africa carrying the greatest burden (71%). It is estimated that there are 37 million people world-wide infected with HIV, and an estimated 6.8 million live in South Africa. Globally there were 2.1 million adolescents living with HIV in 2014.

Improved access to Antiretroviral Therapy (ART) has led to a steep decline in HIV incidence and HIV-related mortality. Yet despite these successes in terms of HIV treatment outcomes, HIV-related mortality amongst adolescents has increased. Adolescents are defined by the WHO as individuals between 10 and 19 years old. WHO states that adolescents have poorer access to ART, are at a higher risk of disengaging from care and have special needs to keep them motivated to remain in care. The uptake of adolescents into the South African ART programme is low and those that are enrolled into the programme have poorer adherence than their adult counterparts.



### **Aim**

The aim of the study was to explore the factors that influence adherence to ART amongst adolescents in a primary health care clinic in a low socio-economic, urban setting in Cape Town.

### **Methodology**

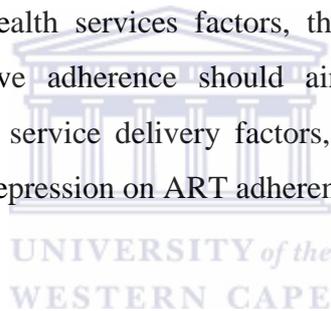
An exploratory qualitative design was employed where data was collected through two key informant interviews with staff from an urban primary health care clinic. Four focus group discussions and eight individual in-depth interviews were held with adolescents and young people who accessed ART at this health facility. Audio data was digitally recorded and transcribed verbatim. Data was analyzed using content analysis.

## **Results**

The study identified school commitments, strained teacher-pupil relationships, negative household dynamics and ill-treatment by non-biological caregivers as major reported barriers to adherence. In addition, poor service delivery, missing and misplaced files and long waiting times came under major criticism. Fear of intended or unintended disclosure of HIV status, perceived stigma and discrimination, treatment fatigue and having unstructured lives, profoundly influenced ART adherence. Finally, having a strong support system, disclosing to a trustworthy person and having goals and ambitions served as motivators to remain adherent to ART.

## **Conclusions**

This study highlighted the complexity of ART adherence amongst this age group due to school factors, social factors, health services factors, therapy related factors and patient factors. Interventions to improve adherence should aim to address treatment fatigue, disclosure, household dynamics, service delivery factors, as well as the impact of school commitments and symptoms of depression on ART adherence amongst adolescents.



## DECLARATION

I declare that, “Exploration of adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa,” is my own work, that it has not been submitted for any degree examination in the university and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full Name: Dr. Lee-Ann Crystal Davids

Signed: .....



Date: 12 March 2017

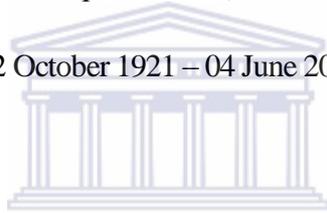


*Dedication*

I dedicate this work to my late maternal grandparents.

Mr. Stephen Robile, “Dadda”

22 October 1921 – 04 June 2004



And

UNIVERSITY of the  
WESTERN CAPE

Mrs. Chrissie Elsie Robile (Nee Malgas), “Mamma”

01 March 1924 – 21 March 1994

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*Soli Deo gloria... Glory to God alone*

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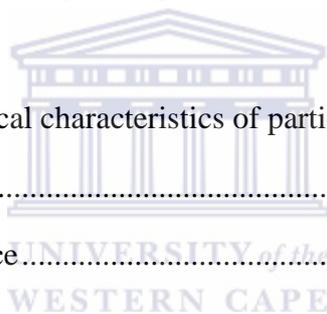
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## CHAPTER ONE

### INTRODUCTION

#### 1.1 BACKGROUND

HIV has reached epidemic proportions globally with Sub-Saharan Africa carrying the greatest burden (71%) (World Health Organization [WHO], 2015). WHO (2015) estimates that there are 37 million people world-wide infected with HIV and an estimated 6.8 million live in South Africa. Globally there are 2.1 million adolescents living with HIV (WHO, 2015) with the majority (58%) of these being female (Idele *et al.*, 2014). Nearly one sixth of all new infections occur between 15 and 19 years old (Davies & Pinto, 2015). Idele *et al.* (2014:145) suggest that globally “...about 830 adolescents were infected with HIV everyday of 2012”. The burden of adolescent HIV incidence has attracted the attention of the International AIDS Society (IAS) and one of the objectives of the recently held 21<sup>st</sup> International World AIDS Conference in Durban was the promotion “...of HIV responses that are supported by and tailored to the needs of at risk populations or people living with HIV [PLHIV], including...young people” (IAS, 2016:4).

The progression of HIV disease can be reversed with strict adherence to a complex regimen of highly active antiretroviral treatment (HAART). HAART became publicly available in South Africa in 2004 following the approval of the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa by the Cabinet in November 2003 (Simelela & Venter, 2014). The aim of this plan was that HIV positive patients with a CD4 count of less than 200 should be able to access ART at no charge from an accredited public sector health facility from each one of the country’s districts. As a result the “*first generation of peri-natally infected children is now entering adolescence*” (Cotton *et al.*, 2010:751).

Improved access to HAART has led to a steep decline in HIV incidence and HIV-related mortality (WHO, 2015). Yet despite these successes in terms of HIV treatment outcomes, HIV-related mortality amongst adolescents has increased. Adolescents are defined by the WHO as individuals between the ages of 10 and 19 years (WHO, 2013). It is only amongst the adolescent age-group in which AIDS-related deaths are increasing (Davies & Pinto, 2015). WHO (2013) has identified that mortality amongst adolescents has increased globally by about 50% between 2005 and 2012. Reports by WHO (2015) and The Joint United

Nations Programme on HIV/AIDS [UNAIDS] (2015) have identified HIV as being the second leading cause of mortality amongst adolescents globally. Furthermore, HIV-related deaths amongst adolescents have tripled since 2000 (UNAIDS, 2015). WHO (2013) argues that the reason for this statistic is primarily due to insufficient prioritization of adolescent health in national health programmes, poor provision of appropriate HIV testing and counselling (HCT) services and substandard follow-up care for adolescents who test HIV positive and who require HAART. Furthermore the report states that adolescents have poorer access to HAART, are at a higher risk of disengaging from care and have special needs to keep them motivated to remain in care (WHO, 2015). In addition, the Global Burden of Diseases Study 1990 - 2013, found that HIV/AIDS, road injuries and drowning were the leading causes of death for adolescents between 10 and 14 years old (Mokdad *et al.*, 2016).

The uptake of adolescents into the South African ART programme is low and those that are enrolled into the programme have poorer adherence than their adult counterparts (Hislop, Maartens & Nachega, 2009; WHO, 2015). A South African survey found that relative to other age groups, less than 50% of adolescents who require HAART are on treatment (Davies & Pinto, 2015). It is argued that a unique approach is necessary in the management of adolescents on HAART because adolescence is a transitional period. These transitions occur on physiological, psychological and intellectual levels (Cotton, Jaspan, Li, Natrass, O'Brien & Rabie, 2010). The changes that accompany these transitions can be very stressful to both the adolescent and his /her family and caregivers. In addition, the usual stressors experienced by adolescents may be compounded by the psycho-social dynamics associated with HIV as a disease such as stigma, discrimination and structural deprivations. Adolescents are thus likely to experience very unique challenges with regards to ART adherence. The management of adolescents on HAART has to take cognizance of the complexity of biological and psychosocial changes and developments which take place in the life of adolescents (Bekker, Johnson, Wallace & Hosek, 2016).

Local and international data do not accurately estimate uptake of ART among the adolescent group because routine data are not captured/reported separately for adolescents. This is because patients younger than 15 years are considered paediatric patients and those older than 15 years are considered adult patients. We do however know that HIV incidence is the highest in the 15-24 year old age group (UNAIDS, 2013). UNAIDS (2014:14) recommends “... enhanced age-disaggregated data collection and reporting, as well as development of

*robust surveillance strategies to monitor trends and outcomes for children and adolescents*". Idele *et al.* (2014) also assert that in order to improve health outcomes of adolescents, enhancement of routine data collection, analysis and reporting on adolescents are essential.

Optimal adherence to a specified antiretroviral regimen is crucial to ensure that the patient achieves virological suppression (avoids viral replication) and remains virologically suppressed. There is a close association between reported non-adherence and viral load. Maskew, Bor, Maclead, Carmona, Sherman and Fox (2016) reported that the National Health Laboratory Services (NHLS) database revealed declining virological suppression amongst adolescents in the public sector since 2004. Significant and consistent motivation is thus necessary for HIV positive adolescents on ART to persist on a life-long ART regimen. Bekker, Cotton, Maarten, Meyers, Venter and Wilson (2008) acknowledge that optimal adherence for HIV treatment (ART) is set significantly higher than for other chronic diseases, which makes it even more difficult to achieve.

Non- or poor adherence to ART is the most significant challenge in ensuring patients remain virologically suppressed (Malee & Mellins, 2013). Non-adherence can be due to a number of factors. Malee and Mellins propose that the barriers to adherence may be patient-related, structural, provider-related, disease-related, medication-related or psychological barriers. WHO (2015) and UNAIDS (2014) further assert that other factors such as the legal age of consent, policies and parental consent laws are barriers to accessing ART by adolescents and remaining adherent. The factors leading to non-adherence may change over time and as such adherence needs to be monitored longitudinally and dynamic approaches sought to address patterns of non-adherence (Larkan, van Wyk, Stevens & Saris, 2015).

## **1.2 PROBLEM STATEMENT**

Adolescents face very unique challenges on both physiological and psychosocial levels. In addition, adherence to ART in itself is a complex problem. The factors associated with sub-optimal adherence to ART among adolescents in Sub-Saharan Africa have not been adequately explored (Gross *et al.*, 2013). In the Western Cape province no previous research into adherence to ART amongst adolescents has been done. The current research explores cultural and context-specific issues pertaining to adherence to ART amongst adolescents.

### **1.3 OUTLINE OF MINI-THESIS**

This qualitative research enquiry will be presented in the following order:

Chapter 1: Introduction

Chapter 2: Literature Review

Chapter 3: Research Methodology

Chapter 4: Presentation of Results

Chapter 5: Discussion of Results

Chapter 6: Conclusions, recommendations, suggestions for further research and the strengths and limitations of the study.



## CHAPTER TWO

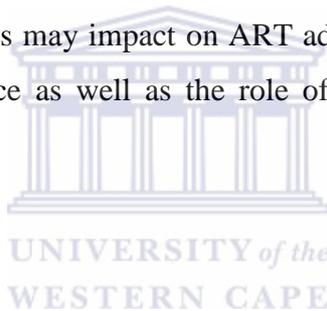
### LITERATURE REVIEW

#### 2.1 INTRODUCTION

WHO (2013) classifies the barriers to ART adherence as: socio-economic, health care team- and system-related, therapy-related and patient-related factors. I will explain each one of these factors in turn.

#### 2.2 SOCIO-ECONOMIC FACTORS

Many factors in the social and economic environment of adolescents have the potential to impact on their health and health-seeking behavior, and in this particular case, their adherence to ART. WHO found that adolescents remain socially and economically vulnerable to HIV (2013). This first section will discuss how various elements in the social and economic surroundings of patients may impact on ART adherence. I will discuss the impact of the school sector on adherence as well as the role of financial support and household factors.



##### 2.2.1 School sector

The education and employment sectors play an important role in access to HIV care and remaining in care (UNAIDS, 2013). These two sectors have the potential to form strong and important links to the health care system. At school, learners can be taught in an evidence-informed yet culturally sensitive manner about HIV and the importance of remaining in HIV care (Davies & Pinto, 2015). However, not all studies have found an association between adherence and being less educated or not being part of the formal education system (Chesney, 2000).

Chesney (2000) proposes that health care providers may be over-emphasizing the influence of education on adherence as it made no difference in adherence in their cohort. Williams *et al.* (2006) found that repeating a grade in school may in fact be associated with marginally decreased adherence. This may be particularly important since some HIV positive adolescents may suffer cognitive delay (Reisner, Mimiaga, Skeer, Perkovich, Johnson & Safren, 2009). HIV positive youth can have specific neurocognitive problems such as poorer executive function when compared to their HIV negative counterparts, and experience

problems with inhibition and cognitive flexibility (Hoare, 2016). Hoare argues that good executive functioning is necessary to cope with daily activities, which, in the case of an adolescent may include dealing with the intellectual demands of school. Neurocognitive impairment could thus lead to failing a grade in a mainstream school which could lead to poor adherence (Williams *et al.*, 2006). This casts some doubt on the positive impact of mainstream schooling on adherence since optimal cognition for academic progress in school is essential in South Africa.

### **2.2.2 Financial support**

Cluver *et al.* (2016) suggest that financial support may be important for adults on ART. This type of support may include, amongst others, government grants or food security. Cotton *et al.* (2010), report from their qualitative enquiry with 26 HIV positive adolescents from communities with low socio-economic status in the Western Cape province, that participants felt their lives would be significantly improved if they received support in the form of food or money. All participants in this study knew their HIV status with the majority having been peri-natally infected. WHO (2013) also argues that social and financial support is critical to assist HIV positive adolescents. For example, financial support will enable adolescents who live far from the health facility to access health facilities. It will also enable them to purchase nutritional food that will contribute towards keeping them healthy.

UNAIDS (2013) recommends that social-protection programs should be “HIV sensitive” and should include access to quality HIV care and treatment, access to good education and economic support. The impact of financial support was also explored by Boyes, Cluver, Orkin and Sherr (2014). The authors argue that “*structural deprivation increases HIV risk by increasing psychosocial problems*” (Boyes *et al.*, 2014:13). Cluver *et al.* (2015:20260) further argue that “*...social and structural deprivation is negatively impacting adolescents’ capacity to protect themselves and others*”. Bekker *et al.* (2015) suggest that cash incentives may encourage safer sex practices and reduce economic vulnerability to HIV and its repercussions. Bermudez, Jennings, Ssewamala, Nabunya, Mellins and McKay (2016) found that Ugandan adolescents with a greater economic advantage had a higher chance of remaining adherent to ART. Hudelson and Cluver (2015) and McPherson *et al.* (2015) assert that further exploration is required of precisely how financial incentives relate to ART adherence.

Cluver *et al.* (2016:79) report from their cross-sectional study of adolescents receiving HAART in the Eastern Cape that “cash plus care” was associated with increased adherence to ART over the recent short term (past 7 days). Examples of cash support may be government welfare grants or food security whereas types of care initiatives may be being part of a HIV support group or receiving good parenting. An example of a cash and care initiative may thus be receiving a government grant and good parenting concurrently. They recommend that a combination of different support interventions may be more successful in reducing non-adherence than an isolated intervention. Thus, financial support on its own may provide welcome relief to HIV positive adolescents but when combined with other forms of support it will be more successful in reducing non-adherence.

### **2.2.3 Household factors**

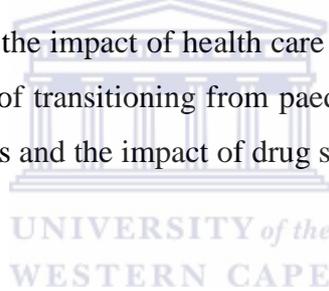
Household factors may include factors in the home and family environment which could have an influence on ART adherence such child-parent/caregiver relationships, sibling relationships and family routines. Family support is also associated with adherence to HIV care and treatment amongst adolescents. Brown, Lourie and Pao (2000) argue that parenting and family dynamics play a greater role in enabling adolescents to adjust to their HIV status and that the disease process itself is of lesser significance in the adjustment process. The UNAIDS (2014) also contends that parents play a crucial role in the context of HIV as they influence their child’s value system, attitudes and behaviors related to health. Mellins, Brackis-Cott, Dolezal and Abrams (2004) found that when controlling for age, caregiver/family factors such as poor parent-child communication, poor caregiver quality of life, high parent/caregiver stress levels and lower levels of disclosure were the most strongly associated with non-adherence. Cotton *et al.* (2010) confirmed this positive association between good parenting/family relationships and adherence to HIV care by adolescents. Goode, McMaugh, Crisp, Wales and Ziegler (2003) found that there is an interaction between the adolescent’s ART regimen and the family routine. They suggest that the interplay between *these* factors may compound the challenge to optimal adherence. Furthermore, Bhana *et al.* (2016) found that there is an association between good parent-child and other family relationships and positive health outcomes of the affected children. Interestingly, Williams *et al.* (2006) and Reisner *et al.* (2009) found that if the primary caregiver was an adult other than the biological parent, then adherence was improved. This could be attributed

to the biological parent having medical comorbidities or possible guilt and depression about mother to child transmission of HIV (Haberer & Mellins, 2009).

Sharer, Cluver, Shields and Ahearn (2016) found that sibling support was consistently associated with good mental health. They conducted this survey in households that had children between the ages of 10 and 17 years old in both rural and urban districts in the Western Cape and Mpumalanga. Good mental health, in turn, may have a positive impact on adherence. Williams *et al.* (2006) further suggest that family dynamics and characteristics should be assessed prior to initiating HAART to adolescents who acquired HIV infection peri-natally so that targeted intervention strategies can be directed towards the household to minimize the risk of non- or poor adherence.

## **2.3 HEALTH CARE TEAM AND SYSTEM-RELATED FACTORS**

Under this heading I will discuss the impact of health care system factors on adherence. This section will focus on the impact of transitioning from paediatric to adult health care, having adolescent-friendly health services and the impact of drug stock-outs.



### ***2.3.1 Transition from paediatric to adult health care***

As previously mentioned HIV positive clients are broadly classified into paediatric (0-15 years) - and adult patients (older than 15 years). Adolescents have very unique needs and therefore recommendations used for adult and paediatric groups can often not be strictly applied to adolescents (WHO, 2013). There is no specific provision made for the needs of adolescents and Maskew *et al.* (2016) suggest that the South African ART programme has no official age cut-off for transitioning from paediatric to adult health care. HIV positive adolescents might have received good paediatric care but not be familiar with how the adult health care system works. The complexities associated with transition from paediatric to adult health care might serve as a barrier to remaining in HIV care (UNAIDS, 2014). These complexities may be related to paediatric patients being accustomed to a well-structured paediatric clinic and being familiar with certain health care practitioners. In addition they may be used to being accompanied to the clinic by a caregiver but during adolescence may be expected to go to the health facility on their own. They further argue that the experience of adolescents progressing to adult health care in resource-limited settings is minimal and poorly

understood. Therefore it needs to be better understood in order to implement strategies to facilitate the transitioning process. Wiener, Kohort, Battles and Pao (2009) argue that there may be poor communication between paediatric and adult health care services thus leaving the momentous task of explaining their HIV and ART history to the adolescents themselves. The adolescent may find it stressful to explain details of their medical history and potentially give an inaccurate account of their medical history. This could lead to prescribing an incorrect drug regimen which could result in virological failure. Loss of medical documents/clinic files may have a similar consequence as important details about the patients' medical history and prior ART exposure may be lost. This too may lead to prescribing an incorrect ART regimen which may lead to virological failure or adverse drug reactions if medication is prescribed to which the patient is allergic. Whitehouse (2013) suggests that good management of medical records is pivotal for continuity of care and that problems with medical records are the cause of a high proportion of adverse incidents.

### **2.3.2 Adolescent-friendly health services**

An understanding relationship has to exist between adolescents and staff members in order to facilitate good adherence to ART (Ferrand, 2016). This entails health care workers having good attitudes and being responsive to the needs of adolescents. Pontali (2005) also suggests that skilled staff is necessary to develop adherence programs which could include integrated sexual and reproductive health care as well as being vigilant to the barriers to adherence. This begs the question of whether specifically trained adolescent health care staff is necessary to look after these clients.

Underwood, Hendrickson, Lynn, Van Lith, Kunda and Mallalieu (2014) found that rigid clinic operating times may impede timely ART collection. This could lead to adolescents running out of medication when they miss appointments and subsequent bouts/periods of poor adherence. Chesney (2000) and Hudelson and Cluver (2015) found that the health care system and patient-provider relationships played a significant role in adolescents remaining adherent to ART. Cotton *et al.* (2010) also assert that specialized adolescent clinics which carefully consider the needs of adolescents may optimize care delivered to this group of people.

Ferrand (2016) reports that structural factors such as distance to the clinic, waiting times, drug shortages and negative health care worker (HCW) attitudes, are all associated with poor adherence. Long distances to the clinic may impede adherence if adolescents do not have the financial means to cover transport expenses to the health facility. Furthermore, long waiting times at the health facility may discourage them from going for routine follow-up to the clinic as they may have other demands on their time such as school commitments. Ferrand also reports that good adherence is facilitated by an understanding relationship between the health care provider and the patient; health care providers need to be sensitive and responsive to the specific needs that HIV positive adolescents have.

### ***2.3.3 Drug stock-outs***

The health facility has to ensure a regular and timeous supply of medication to ensure treatment adherence. Reda and Biadgilign (2012) found that an inconsistent supply of ARV drugs may severely impact adherence in a negative way. According to a survey done in 2008, 34% percent of low- and middle income countries experienced ARV drug stock outs (WHO, 2010, as cited in Reda & Biadgilign, (2012). Medication stock-outs may thus lead to poor adherence which could lead to virological failure and other adverse patient outcomes. The recent *South African National Stop Stock Outs Survey* (2015) found that of the 60% of South Africa's public health facilities surveyed, one in four experienced a shortage of ART or TB medication at least once during the preceding year.

## **2.4 THERAPY-RELATED FACTORS**

This section will highlight the impact of the medication itself on adherence. I will discuss how the complexity of ART regimens and side-effects of ARV drugs impact on adherence.

### ***2.4.1 Complexity of Antiretroviral treatment regimens***

ART regimens should be as simple as possible after accounting for efficacy and tolerability (Nuttal, 2006). Reisner *et al.* (2009) found an association between a simple ART regimen and good adherence. Pontali (2005) also suggests that ART regimens should be tailored to the patient's routine. If possible adolescents should be given a fixed dose combination as the simplification of ART regimens impact positively on ART adherence (Nuttall, 2006). A fixed dose combination tablet consists of two or more active components in fixed dosages. High

rates of non-adherence to ART amongst adolescents highlight the need to make treatment regimens simpler and more tolerable (Penazzato *et al.*, 2015).

The current South African Department of Health ART guidelines (2015) make provision that all treatment naïve adults and adolescents can be started on a fixed dose regimen of Tenofovir, Emtricitabine and Efavirenz. This is assuming that there are no contra-indications to any one of these drugs. Peri-natally infected adolescents may be heavily treatment experienced and not qualify for the fixed dose combination but their treatment regimens should still be simplified where feasible. The South African HIV Clinicians Society (2013) advises that reducing the pill burden to one pill once a day has been reported to improve adherence but that adherence counselling is still essential. The REACH (Reaching for Excellence in Adolescent Care and Health) study also found an association between adherence and pill burden (Murphy, Belzer, Durako, Sarr, Wilson & Muenz, 2010). The use of other medications such as treatment for co-morbidities and prophylactic treatment can also increase the pill burden and this may adversely impact on adherence.

Antiretroviral medications need to be taken every day for the duration of the patient's life. This process may be experienced as tedious by some adolescents. Merzel, Van Devanter and Irvine (2008) identified regimen fatigue as a major factor impacting on older adolescents' ability to remain adherent to a treatment regimen. Haberer and Mellins (2009) also found treatment fatigue to be common amongst children with chronic diseases. The severe impact of treatment fatigue on ART adherence inspired the *BREATHER* Trial. The *BREATHER* trial examined the potential for drug-free weekends in children, adolescents and young people who are on an Efavirenz-based first line ART regimen (Butler *et al.*, 2016). Participants were randomised into a continuous seven day regimen group or a five day regimen group with a break on weekends. The end result was that a five-day regimen was not inferior to a seven-day regimen in maintaining viral load suppression. In addition, "...overall reduction in drug exposure could reduce long-term toxicity for individuals..." (Butler *et al.*, 2016:9). Furthermore, the shorter cycle was found to be beneficial for participants' social lives. Adherence was similar between the two groups but slightly better in the shorter cycle group. This was a multi-continent study and the findings of this study should thus be considered by all health planners as it may significantly improve adherence and overall patient well-being.

The development of more innovative drug formulations such as other long-acting intramuscular ARV injections may also aid in improving ART adherence in this group (Margolis *et al.*, 2016). This means that patients will not have to take medication on a daily basis thus decreasing the likelihood of treatment fatigue. Long-acting injectable agents may be comparable in efficacy to daily oral agents. The *LATTE 2* trial found that giving a combination of long-acting Cabotegravir (an Integrase Inhibitor) and long-acting Rilpivirine (a Non-nucleoside Reverse Transcriptase Inhibitor [NNRTI]) intramuscularly every 4 weeks or every eight weeks showed that up to 95% of participants remained virologically suppressed at week 32 of follow-up.

#### ***2.4.2 Side-effects of Antiretroviral treatment***

When prescribing an ART regimen it is important to consider the side effects as they may impact the client's adherence. Some classes of antiretroviral treatment are associated with changes in body shape particularly the Nucleoside Reverse Transcriptase Inhibitor (NRTI), Stavudine (Bekker *et al.*, 2008). Until recently Stavudine was still commonly used as a first-line agent in the treatment of HIV. Some of the typical changes are lipoatrophy - which is the loss of subcutaneous fat tissue and commonly involves the face and limbs (Bekker *et al.*, 2008). It is important to note that these changes cannot be reversed. Since adolescence is a period of becoming increasingly more aware of one's physical appearance, it is sensible to avoid the use of Stavudine during this period (Bekker *et al.*, 2008).

### **2.5 PATIENT-RELATED FACTORS**

Chesney (2000) described patient factors such as drug and alcohol use, gender and age as being important in relation to ART adherence. I will discuss how issues such as disclosure of HIV status, mental health, substance abuse, gender differences and adolescent high-risk behavior impact on ART adherence.

#### ***2.5.1 Disclosure of HIV status***

Non-disclosure negatively impacts on retention in care (WHO, 2013). Brown *et al.* (2000) stated that non-disclosure may lead to adolescents hiding their medication and avoiding getting refills at the health facility. After conducting focus group discussions with 25 youths from an urban primary health care clinic in Chicago, Roa (2007) found that half of the group

would skip treatment dosages in an attempt to hide their HIV status. Disclosure can be considered two-pronged. In the case of a peri-natally infected adolescent, a responsible parent or caregiver should disclose their status to the child in a developmentally appropriate manner. Secondly, the infected adolescents may or may not decide to disclose their HIV status to others (Nuttall, 2006). Hudelson and Cluver (2015) found that if caregivers had not disclosed the infected adolescents' HIV status to him or her, it may have a negative influence on their adherence. The process of disclosure is often delayed due to fear on the part of the caregiver or health care worker (Nuttall, 2006). Caregivers may fear indirect disclosure of their own HIV status should they disclose to the child. Nuttall (2006:3) further suggests that “disclosure of HIV status to children should begin prior to adolescence during a period of relative stability in the child’s medical and social environment”. This period could be at a time when a caregiver is still primarily responsible for collection and administration of the child’s medication. In addition, it could happen when a child is attending a dedicated paediatric clinic with support group facilities for both the child and the caregiver (s).

If adolescents disclose their HIV status to a trustworthy person(s), they are more likely to receive support in the form of knowledge and resources to help them cope with their HIV diagnosis and to access and remain in HIV care (WHO, 2013). However, in a workshop held in South Africa to determine the values and practices of young people with HIV, it was found that adolescents preferred to keep their status to themselves (WHO, 2013). Merzel *et al.* (2008) however found that disclosure may improve adherence but that this strategy may only be effective under certain circumstances. Disclosure may be hindered due to a fear of stigma (Nabukeera-Barungi, 2015). A study done amongst adolescents in Cape Town found that young people did not disclose their HIV status to friends as they feared stigma and being mistreated by their peers (Cotton *et al.*, 2010).

All patients with diseases and disabilities may potentially face stigma but stigma associated with HIV is multigenerational in nature and involves many social stereotypes pertaining to transmission (Haberer & Mellins, 2009). If an adolescent discloses their HIV status, they may thus indirectly be disclosing their parent’s HIV status too and vice versa. Both generations may then experience stigma as a result of this disclosure. HIV stigma may involve PLWHA and their associates being treated with impartiality and being discriminated against (Parker & Aggleton, 2003, as cited in Wei, Xiaoming, Harrison, Zhao & Zhao, 2016). There are many

different forms of HIV stigma such as enacted stigma (i.e. overt behaviours) and perceived stigma (i.e. awareness of stereotypes) (Herek, Gillis & Cogan, 2009, as cited in Wei *et al.*, 2016). Pantelic, Shenderovich, Cluver and Boyes (2015) found an association between experiencing HIV stigma and negative health outcomes. HIV-stigma is also associated with negative emotions amongst children such as sadness and depression (Wei *et al.*, 2016). This in turn has a negative impact on ART adherence.

HIV-related stigma and discrimination in the work place and education system is a problem faced by many HIV positive adolescents and youth (UNAIDS, 2013). Young people are thus at risk of non- adherence to HIV care when faced with discrimination.

### **2.5.2 Mental health**

Mental health problems are more common among long-term survivors of peri-natally acquired HIV infection (Mallee & Mellins, 2013). A cohort study of 34 HIV positive adolescents in a primarily urban setting in Washington, United States of America, showed that 85% of participants had at least one clinical psychiatric disorder or acute symptom that required treatment as defined by the diagnostic and statistical manual of mental disorders, and at least half had a current or prior diagnosis of depression or another psychiatric illness (Pao, Lyon, D'Angelo, Schuman, Tipsin & Mrazek, 2000, as cited in Brown *et al.*, 2000). Adolescents with HIV face the same challenges as other adolescents but in addition they have to cope with very unique stressors. These may include dealing with stigma, living with an incurable illness, exposure to pain and the loss of a parent(s) (Mallee & Mellins, 2013). Williams *et al.* (2006) found that recent stressful events are strongly associated with non-adherence. Reisner *et al.* (2009) found an association between non-adherence and mental illness especially anxiety and depression. Uthman (2014) found in a meta-analysis that patients with depressive symptoms were 42% less likely to achieve optimal adherence to a HAART regimen.

An adolescent may be predisposed to mental illness as a result of being HIV positive. Efavirenz, from the NNRTI class should thus be avoided in adolescents with a psychiatric history (Bekker *et al.*, 2008). Mental illness in HIV positive adolescents can lead to poor ART adherence and risk-taking behavior (Laughton, Cornell, Bovin & Van Rie, 2013). This

risky behavior can include risky sexual behavior, early sexual debut and substance abuse. Mental health practitioners can thus play a very useful role in assessing and maintaining adherence (Brown *et al.*, 2000). Brown *et al.* (2000) and Aylward (2002) also note that instead of an adolescent presenting with a clear-cut mental diagnosis some may present with very subtle neuropsychological deficits. These features can be determined biologically as a direct result of the virus or genetic predisposition or it can be determined by the social context.

Malee, Williams, Montepiedra, Nichols, Siroius and Storm (2008) found that HIV positive children and young adults have IQ scores in the low average range and 16% of HIV positive adolescents compared to 5% in the general population have cognitive impairment. They further assert that this cognitive impairment may influence adherence to medication.

Hoare (2016) found that HIV positive youth had poor cognitive inhibition and had poor executive function which may impact on daily activities. In addition, they found that HIV may affect decision making. All these characteristics are necessary to navigate through adolescence, to be less impulsive and to make good decisions about their health such as remaining adherent to an ART regimen. The adolescent phase involves physical, cognitive and emotional changes (WHO, 2013). WHO argues that because of these changes adolescents may have a decreased ability to make important decisions such as decisions about their personal lives and health care. This, together with their decreased perception of risk and poor cognitive inhibition may impede on their adherence.

The literature on mental health of HIV positive adolescents overwhelmingly points to poor mental health amongst this vulnerable group. However, despite HIV positive youth having increased vulnerabilities, "...some studies show that many are presenting with behavioural health problems that are the same or less than uninfected peers" (Bhana *et al.*, 2016:50). Furthermore the authors suggest that a number of studies have found a similar prevalence of psychiatric disorders between HIV positive and HIV uninfected youth. They did an enquiry into resilience amongst peri-natal HIV positive adolescents in South Africa. The authors found that there were numerous factors on an individual, family and community level which influence resilience amongst HIV positive youth and help them to cope with a chronic, highly stigmatised illness which requires strict adherence to a rigid treatment regimen. Some of these factors on an individual level included having self-esteem and self-regulation.

### **2.5.3 Gender differences**

Hudelson and Cluver (2015) in a systematic review of the literature found that there is an association between gender and non-adherence to ART amongst adolescents. Gross *et al.* (2013) found that the only independent risk factor for poor adherence was being male with an odds ratio of 3.2. It is uncertain from the study exactly how male sex contributes to poor adherence and further work in this regard needs to be done. Chesney (2000) also found that male gender was negatively associated with adherence to ART. Bakanda *et al.* (2011) did an observational study among various age groups in Uganda and found males on ART had higher mortality; this was the largest study of its kind in Africa. Other literature has contradictory findings. Williams *et al.* (2006) found that female gender was associated with marginally significant increases in non-adherence. Reisner (2009) in their review of the literature also found an inconsistent association between non-adherence and gender. There are thus gaps in understanding if gender contributes to non-adherence and if so, how exactly it does contribute.

### **2.5.4 Adolescent risk-taking behavior**

The adolescent phase is often accompanied by the need to experiment and defy authority (Adams & Berzonsky, 2006). Adolescents are also particularly likely to succumb to peer pressure and as a result experimenting with alcohol and substances in this phase is very common. Substance abuse is both an independent risk factor for non-adherence as well as a compounding factor for the development of mental illness which in turn leads to non-adherence (Mellins, 2009). Substance misuse can lead to disinterest in self which may lead to non-adherence and substances such as cannabis and amphetamines can lead to frank psychiatric problems which may lead to non-adherence. Self-reported Methamphetamine use in the Western Cape ranges between 9 and 12% (Plüddemann & Parry, 2012), 66% life time alcohol use and 23.6% lifetime cannabis use (MRC, 2011). A study by Chesney (2000) found that patient-related factors especially substance and alcohol abuse appeared to be the principle factors associated with non-adherence.

In addition to possible mental illness and substance use, adolescents' sense of immortality and invincibility places them at a higher risk of defaulting ART and HIV care. Their sense of immortality may make them believe that they do not need ART. Hoare (2016) also asserts that adolescent decision-making favours more immediate and tangible reward as opposed to

more distant, positive health benefits. Nglazi *et al.* (2012:25) suggest that adolescence “...is often associated with deviations from expected or prescribed behavior”. This, they argue, may influence adolescents’ ability to take care of their illness and follow clinic appointments.

## **2.6 SUMMARY**

Numerous factors have been postulated to be responsible for the decreased adherence to ART amongst adolescents. Most of the data however comes from a first world setting and is done on either adult or paediatric populations. This data is then extrapolated to adolescent populations but this is seldom appropriate. It is however clear that the dynamics of adherence amongst the adolescent population is complex. Data on the factors which influence adherence to ART amongst adolescents in South Africa is limited and in the Western Cape Province, there is no documented research on this subject matter. It is this information that provides the impetus for the current study.



## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 AIMS AND OBJECTIVES**

The aim of the study was to explore the factors that influence adherence to ART amongst adolescents in a primary health care clinic in a low socio-economic, urban setting in Cape Town. The following specific objectives were pursued:

- i. To explore socio-economic factors that may influence adherence to ART among these adolescents
- ii. To explore the health-systems factors that influence adherence to ARTs
- iii. To explore the therapy-related barriers to adherence to ARTs
- iv. To explore patient-related factors that influence adherence to ART

#### **3.2 STUDY DESIGN**

An exploratory qualitative design was employed as it enabled the researcher to gain better insight into the unique individual, cultural and contextual challenges related to ART adherence in this research setting (Baum, 1995). This design was chosen because ART adherence is considered a very complex phenomenon and requires an in-depth understanding of the socio-cultural as well as the biological environment in which it occurs - it cannot exclusively be explained by straight forward patterns of causality. Qualitative research is interested in understanding a phenomenon from the perspective of the participants. In this case the researcher was concerned with understanding the meaning which HIV positive participants on HAART attach to the factors which they believe may influence adherence. In addition, the researcher sought to gain an understanding of what key-informants such as health care workers believe may influence adherence.

By collecting qualitative data, the researcher was able to provide thick and rich descriptions of the study topic (Jack, 2006). This form of data collection allowed participants to tell their own stories which in turn assisted the researcher to understand the meaning which participants assign to their experiences with ART.

### **3.3 STUDY SETTING**

This qualitative enquiry took place at a primary health care clinic, which was located in an urban residential area in the greater Cape Town area. The township is home to a predominantly black community. During discussions with the research assistant I also learnt a lot about the community. She lives in the area where most of the participants live and gave me useful insights regarding the general household set-up in the area as well as common family dynamics. She also orientated me to the community dynamics. During the previous political regime (Apartheid) this community was largely marginalized and exploited. The area covers 13.46 square kilometers and has a total population of 64 269 with more or less equal numbers of males and females. Of this number 96.3% are African, 2.7 % are Coloured and 0.2% are White (Statistics South Africa, 2012). It is part of the Cape Town metro which carries the heaviest burden of HIV disease in the Western Cape (5.2%).

The health facility where the research took place is one of two health facilities in the area in which it is located. Locally it is referred to as the TB clinic or the Baby clinic to distinguish it from the other health facility in the area. The clinic provides immunization services, care for sick babies, TB treatment for drug susceptible and drug resistant TB and HIV care for adults and children (wellness care and ART). It also provides ante-natal care and family planning services. HCT is also performed at this clinic. The clinic is open Monday to Friday from 07:30-16:30. It is closed on the weekends and public holidays. The clinic has a pharmacist, two resident doctors, nurses, admin staff and a psychologist who comes to the clinic once a week. In addition, the facility also receives assistance from many non-governmental organisations.

It is situated adjacent to a high school and opposite a primary school. A number of the youth who access this facility come from these two surrounding schools and would utilize the clinic facility before or after school. The number of adolescents who access the clinic for ART and HIV care is not known as adolescent data is categorized as either paediatric or adult data.

### **3.4 STUDY POPULATION AND SAMPLING**

The study population comprised of HIV positive individuals between 10 and 19 years of age (adolescents as defined by WHO) who are enrolled for ART at the selected primary health care clinic in 2015/2016.

Twenty six participants were recruited into the study. Twenty signed informed consent forms were returned prior to commencing data collection. The final sample consisted of 17 participants. Two participants were very late for the Focus Group Discussion (FGD) and were thus excluded. Potential participants' clinic files were screened beforehand and then approached for their participation. Details such as demographics, ART initiation date, ART regime, adherence and latest viral load were recorded. This was essential to ensure a sample with maximum variation.

This particular sample size was selected as it was thought that it would not lead to under or over representation of certain groups and opinions. The researcher also thought it may be unlikely to recruit a larger number of adolescents as they may be reluctant to engage in honest conversation with someone they perceive to be in a position of authority. This is due to the researcher previously having been a medical doctor at this particular facility and the power dynamics that exist between the patient and practitioner may impede honest discussion especially when participants are much younger. All participants were attendees of the facility where the research took place.

In the proposal submission I had said the study population would be between 10 and 19 years old. However, two of the participants matriculated last year (20 and 22 years old respectively) and the other 20 year old was still in Gr.12. There was also a young lady who is pursuing tertiary studies at a local college. I thought it appropriate to include them in the sample as they were likely to experience similar issues to that experienced by other adolescents. I employed purposive sampling with the help of a research assistant. Participants were recruited into the study based on the following characteristics:

- HIV positive on life-long ART for at least six months
- Between 10 and 22 years old
- Participants were resident in the area where the research took place as well as neighbouring areas. These areas are in close proximity to one another with similar socio-economic status

A final sample was generated to ensure maximum variation:

- 50% were younger than 15 years old and 50% older than 15 years old.
- There was a mixture between adherent and non-adherent participants. This was determined by perusing participants' clinic notes prior to the FGDs. In the clinic notes participants' adherence and viral loads were documented.
- Similar representation of males and females.

### **3.5 SUMMARY DESCRIPTION OF SAMPLE**

Study participants were adolescents and young people who accessed ARVs at the particular health facility at the time data collection was taking place. Participants were all on ART for at least one year when data collection commenced. There were male and female participants and there was a mixture between adherent and non-adherent participant. Participants' clinic notes were screened prior to data collection.

### **3.6 PROCESS OF NEGOTIATING ACCESS TO THE FACILITY**

Previously the researcher was employed at the facility in her capacity as ART physician. She occupied this position from 2011-2014. During the latter part of 2014 the researcher developed a keen interest in the study topic and informally engaged with staff to determine what they thought the feasibility of such a project would be.

During 2015 an informal meeting was held with the facility manager to inform her of the proposed study. At the time I was still waiting to receive ethical approval from the University of the Western Cape. The research assistant was also approached at the time. A subsequent meeting followed with the facility manager on 21 January 2016 where I was advised on the process of applying for ethical approval from the City of Cape Town. In principal the facility manager accepted my request to conduct the project at this primary health care facility pending approval from the City of Cape Town and the sub-district manager.

An online application for access to the facility was made to the City of Cape Town on the 23<sup>rd</sup> of January 2016. On the 26<sup>th</sup> of February 2016 approval was received from the subdistrict manager dated 08 February 2016 (Appendix J).

The resident ART doctors and nursing staff were approached and a meeting was set up with them. During this meeting I discussed my proposed plans for the project and aimed to obtain

their buy-in. They were willing to assist wherever necessary. A separate informal meeting was also held with the visiting psychologist. During this meeting I informed her of my plans and requested her assistance with referrals if I discovered during the interviews that a participant may need to be seen by a psychologist. She agreed to this. Two participants were referred to her.

### **3.7 RESEARCH ASSISTANT**

The research assistant is an employee at the facility where the project took place. She was approached last year (2015) to enquire if she would be interested in participating in the position as research assistant. She is currently employed as a HIV and TB clerk at the facility. She is fluent in English and Xhosa. I approached her as she knows the clinic system very well, she enjoys working with youth and she has previously worked on a research project. Our first official meeting took place on the 18<sup>th</sup> of February 2016. She was briefed on the purpose of the study as well as the format.

Numerous meetings and training sessions took place between the researcher and the research assistant. The assistant was also provided with tools such as stationery and airtime to contact potential participants as well as copies of the participant information sheet and informed consent forms so that she may be familiar with the content. The research assistant was briefed on the general purpose of the project, its aims and objectives. She was trained on the ethics of qualitative research and the utmost importance of maintaining participants' anonymity and confidentiality. We also discussed what her expectations were and misinterpretations and misunderstandings about the purpose of the project were corrected. Furthermore the process of sampling was discussed and how she would assist me with this. In addition I conducted training with her regarding focus group discussions and one-on-one interviews as she would also be assisting me with translation during these interviews should the need arise.

The research assistant was incredibly optimistic and helpful. I personally debriefed the assistant after each data collection event which she was a part of. She was also aware that she could call me at any time if she required further discussion regarding certain elements which she may have found difficult to deal with such as hearing accounts of trauma experienced by participants. When all data collection was complete, both the assistant and researcher were jointly debriefed by the researcher's supervisor. This final debriefing was done one day after the last data collection event.

### 3.8 DATA COLLECTION METHODS AND PROCEDURE

The researcher conducted all the data collection events herself and employed the assistance of a Xhosa-speaking interpreter only where absolutely necessary. The main source of data was semi-structured in-depth interviews and FGDs which were audiotaped with a digital recorder and transcribed verbatim. It was also translated to English where necessary. The data collection started with two individual key-informant interviews which were conducted with two nursing sisters who provide HIV and ART services at the facility. These interviews were conducted in English and were very informative. The key informant interviews generally orientated me to the subject.

Four focus group discussions were held in a language the participants preferred i.e. English or isiXhosa and at a time that suited them. The groups were divided according to age and gender as follows:

- i. Girls 10-14 years old – 3 participants
- ii. Girls 15 years and older – 7 participants
- iii. Boys 10-14 years old – 4 participants
- iv. Boys 15 years and older – 3 participants



The focus group discussions were followed by eight individual in-depth interviews. Two participants were selected from each FGD. Those who appeared to have further valuable insights to render were approached after the FGD to be interviewed individually. These individual in-depth interviews were also conducted in the language of the participant's choice i.e. English or isiXhosa. They were audio taped and transcribed verbatim. All data collection took place at the health facility. Data collection was completed in five weeks and the original estimate was four weeks. The assistance of a transcriber and translator were employed. The research assistant was also the translator. The researcher also took notes during all interviews and paid careful attention to verbal and non-verbal cues.

The interviews and FGDs were semi-structured making use of open-ended questions and prompts. An interview guide was compiled for this purpose in order to ensure standardization (Appendix H, I & J).

### **3.9 DATA ANALYSIS**

Data analysis is used to generate meaning and understanding from the large volumes of data generated in qualitative research whilst trying to maintain the integrity and trustworthiness of the data. To analyze the data I have made use of content analysis. Content analysis is generally a more detailed form of data analysis and is widely used to analyze qualitative data. Hseish and Shannon (2005) propose three approaches to qualitative content analysis namely conventional, directed and summative content analysis. I found conventional analysis better suited to this qualitative enquiry. In this type of analysis codes are derived from text data directly. Conventional content analysis is generally used where the study design is descriptive and to allow new categories and ideas to emerge from the data as opposed to imposing preconceived notions on the data. It involves grouping the data initially into codes; and then placing them into categories and finally forming themes.

Analyzing the data started with reading and re-reading the transcripts several times. This was done concurrently with reading the field notes, personal reflections and reading entries from my research diary. The field notes proved invaluable as the researcher was able to reflect on non-verbal cues and subtle nuances of the participants which she made a note of during the interviews. Transcripts of the key informant interviews were also used to orientate the researcher to the data. Transcripts were analyzed one at a time starting with the focus group discussions.

Transcripts were initially read twice. On reading it a third time the researcher made pencil notes in the margin of all the main issues that relate to disengagement with care which came out from the text. The researcher was as inclusive as possible and also considered the things which were not being said such suggestive statements and links between statements in different parts of the interview. Then, the list of all codes was transferred onto a separate page. In the next step the researcher re-wrote the list of codes but this time highlighting codes which were duplicated or emphasized by the participants. Similar codes were then grouped together and in the last step themes were developed.

### **3.10 RIGOUR**

Rigour is applied to ensure credibility and trustworthiness of the data. Rigour was applied at every point of the research enquiry. I employed the following strategies to ensure the data is rigorous.

*Reflexivity* means the researcher must be consciously aware of herself - her possible biases, preconceived ideas about the topic, etc. I constantly engaged with myself by keeping a journal documenting how I was thinking and feeling at every stage of the process. After every data collection event I wrote a reflection on the process and how I was feeling at the time and submitted this to my supervisor within 24 hours of the data collection event. As I am trained in a more reductionist philosophy, I had to constantly remind myself to be receptive to the idea that new knowledge will be gained from the participants and not approach the subject matter with a hypotheses already in mind. This was further enhanced by the manner in which the questions were asked i.e. open-ended questions as part of semi-structured interviews. Researcher reflexivity took place at every point during the research.

*Triangulation* is a process whereby the “...researcher searches for convergence among multiple and different sources of information to form themes and categories in a study” (Cresswell & Miller, 2000:126). During the research project I searched for common themes in the different elements of the process namely the literature review, individual in-depth interviews and focus group discussions and during analysis of the data.

In addition I provided *thick, rich descriptions* of the study participants, study setting and the themes of the study. This entailed giving dense and detailed accounts of the participants, the study setting and the themes of the qualitative study (Cresswell & Miller, 2000). It also involved providing very fine and detailed information. According to Cresswell and Miller (2000) a thick description makes the study tangible to the reader. Thus, because thick descriptions create the feeling that the reader is able to experience the events, it adds credibility to the study.

### **3.11 ETHICS CONSIDERATIONS**

Permission to conduct the research was obtained from the Biomedical Research Ethics Committee of the University of the Western Cape (Appendix I). Permission was also sought

from the Department of Health. Participation in the research was completely voluntary and the identities of the participants were protected. I explained to participants that I would like them to be part of the research until the entire process has been completed but they may withdraw consent at any point if they are unwilling to continue. I am of the opinion that the study was of benefit to the participants and other adolescents who may need ART as it will give us insight into what we can do to enhance adherence to ART and ultimately to have better health outcomes. The participants may have benefited as they may have found that the FGD was a support mechanism when they realized that others face similar problems to what they are facing. The intention of the researcher was not to bring any harm to participants in any form but the researcher realized that inadvertent emotional/psychological harm may come to participants when for example sensitive or traumatic topics come up. The researcher was acutely aware of this and when it appeared that a participant was distressed then arrangements were made for appropriate referral if the researcher was not able to herself remedy the situation. I also made the resident psychologist at the facility aware of my intended research. Everyone who met the criteria had equal access to participate in the research. No-one was given preference. In this way the principle of justice was adhered to.

The participants were between 10 and 22 years old. As anticipated, a large number of participants were under 18 years old and thus parental consent had to be obtained. For participants between the ages of 10 and 18, the participant had to provide assent and the parent/caregiver had to grant consent. For those older than 18, only participant consent was required. I designed a consent form in Afrikaans, English and Xhosa as well as an assent form in these languages. The participant information sheet was also available in Afrikaans, English and Xhosa. There was a participant information sheet for participants and one designed for parents/guardians. In addition, participants who were part of the focus group discussion had to sign a *focus group confidentiality binding form* (Appendix E) in which they agreed to uphold the confidentiality of the group discussions by not disclosing the identity of other participants as well as their contributions. The researcher protected participants' confidentiality at all cost but it is up to all those in FGD to uphold confidentiality of other participants in the group. The risk of a participant of a FGD breaking confidentiality could not be completely excluded.

## CHAPTER FOUR

### RESULTS

#### 4.1. INTRODUCTION

This chapter outlines the results of the study. The first section presents a description of the study participants, the second the barriers to ART adherence, and the last section those factors that facilitated ART adherence among HIV positive adolescents on ART who participated in this research study.

#### 4.2. DESCRIPTION OF STUDY PARTICIPANTS

Study participants were adolescents between 10 and 22 years old who accessed ART at a primary health care clinic in a low socio-economic urban area on the outskirts of Cape Town at the time of the study. Participants older than 19 years were included as they were either current or recent school-going adolescents and considered to be experiencing similar issues to adolescents who met WHO definition of 10-19 years.

Seventeen adolescents were recruited into the study of which ten were female and seven male (Table 4.1). Eight participants were between the ages of 10 and 15 years (early adolescence) and nine were older than 15 years (late adolescence).

Most respondents (n=13) were on first line ART which included two Nucleoside Reverse Transcriptase Inhibitors (NRTIs) and one NNRTI; four were on second line ART which consisted of two NRTIs and one Protease Inhibitor (PI).

More than half of the sample of participants (n=10) had optimal adherence which is defined as greater than 95% adherence to a daily drug regimen (Table 4.1) (Bekker *et al.*, 2008), while 41.1% (n=7) had poor adherence as recorded in their clinical records.

Five (29.4%) participants' clinical records lacked regular viral load result documentation. Of those who had a viral load result documented in their clinical records only six were recorded as being virologically suppressed in the preceding year.

Furthermore, the exact commencement date on HAART was not documented for eight participants as only the year the patient started ARVs was recorded. However, it was definitely more than a year as per study inclusion criteria.

**Table 4.1. Demographic and clinical characteristics of participants**

Participant	Age	Gender	Schooling	Adherence	Last VL	ART initiated	ARV regimen
1	22	Female	Matriculated 2015	Good	Lower than detectable Limit (LDL) (2014)	24/11/2006	2 <sup>nd</sup> line
2	17	Female	Gr.7	Poor	105 (2015)	2013	2 <sup>nd</sup> line
3	20	Female	Matriculated 2015	Good	LDL (2015)	2015	1 <sup>st</sup> line
4	20	Female	Gr.12	Good		2015	1 <sup>st</sup> line
5	15	Female	Gr.9	Poor	22 (2015)	2015	1 <sup>st</sup> line
6	22	Female	Tertiary College	Poor	777 (2015)	January 2014	1 <sup>st</sup> line
7	17	Female	Unknown	Good		25/04/2015	1 <sup>st</sup> line
8	14	Male	Gr.7	Poor	1454 (2014)	17/07/2011	1 <sup>st</sup> line
9	14	Male	Gr.8	Good			1 <sup>st</sup> line
10	10	Male	Gr.5	Good	LDL (2015)	17/04/2014	1 <sup>st</sup> line
11	13	Male	Gr.7	Improved	LDL (2016)	26/03/2004	2 <sup>nd</sup> line
12	18	Male	Gr.12	Good	LDL (2014)	30/05/2006	1 <sup>st</sup> line
13	16	Male	Gr.10	Good	54 (2015)	16/01/2015	1 <sup>st</sup> line
14	18	Male	Gr.10	Poor			2 <sup>nd</sup> line
15	10	Female	Gr.3	Good	LDL (2015)	2006	1 <sup>st</sup> line
16	13	Female	Gr.6	Good		+/- 2012	
17	13	Female	Gr.7	Poor	108(2014)	2007	1 <sup>st</sup> line

### **4.3. BARRIERS TO ADHERENCE**

The reported barriers to ART adherence (Table 4.2) were organised according to the following main themes:

- School factors;
- Socio-economic factors;
- Health services factors;
- Therapy related factors; and
- Patient factors



**Table 4.2. Barriers to adherence**

THEME	SUB-THEME	DESCRIPTION OF CODE		
SCHOOL FACTORS	Conflict between school and clinic	Afternoon classes		
		Communication about absence from classes		
	Strained relationships with teachers	Negative teacher attitudes		
		Fear of unintended disclosure by teachers		
SOCIO-ECONOMIC FACTORS	Lack of financial support	Pay someone to collect medication		
		Access private health care		
		Transport expenses		
		Buy ARVs		
	Household dynamics	Ill treatment by caregivers		
		Only HIV positive sibling		
HEALTH SERVICES FACTORS	Service delivery	Long waiting times		
		Nursing staff shortages		
		Missing files		
		Long travelling distance to clinic		
		Unintended disclosure		
	Quality of care	Negative health care worker attitudes		
		Unsupportive health care system		
		Discrimination against treatment defaulters		
		Verbal abuse		
		Inappropriate management of health complaints		
		Disrespect shown to parents		
		THERAPY-RELATED FACTORS	Medication Factors	Side effects
				Pill burden
				Medication unpalatable
Treatment Routine	Treatment fatigue			
	Interferes with leisure activities			
	Rigid treatment schedule			
	Forgetfulness			
	PATIENT FACTORS		Disclosure	Dynamics of disclosure
Fear of stigma and discrimination				
Denial				
Forbidden to disclose				
Lack of knowledge about diagnosis				
Perceived stigma		Fear of being stereotyped		
		Routine creates suspicion		
Adolescent behaviour		Feeling invincible		
		Unstructured lives		
		Alcohol use		
		Rebellion		
Mental health		Shame at mode of HIV transmission		
		Anger at mother for peri-natal transmission of HIV		
		Depression		
		Loneliness		
Disease factors		Feeling well		
		No physical benefit of treatment		

### **4.3.1 School factors**

The factors in the participants' school environment that impacted negatively on their ART adherence were *Conflict between school and clinic times* and *Strained relationships between learners and teachers*.

#### ***Conflict between school and clinic***

Participants identified two areas of conflict between the school and the clinic which impacted on their ART routine and clinic visits, namely *The need to attend afternoon classes*; and *The need to communicate with teachers when they will be absent from class*.

#### ***Afternoon classes***

Participants were required to attend afternoon classes on most days after school. These classes were held at the same time that they would usually go to the clinic to collect their medication. Thus they had to make a choice of, either attending additional classes at school or going for scheduled clinic visits and/or collect medication. Clinic visits usually take place on a monthly basis. Patients are informed of the date for collection of the next months' supply of medication. This means that patients are required to return to the clinic on that scheduled follow-up date which is normally on the day the medication finishes or the day before.

*In school we have different periods..., and here [at the clinic] you are told to come after school because they [the clinic staff] can't help you. So I personally prefer to come after school, but that means I have to miss the afternoon classes. - 17 year old girl*

*It would be nice for us to come at our own time, so that we do not have to miss our school work. That way we can be able to balance our life. Your school work doesn't suffer because of the clinic appointments, and vice versa. - 18 year old boy*

### ***Communication about absence from classes***

The participants reported that they had to obtain permission from their class and/or subject teachers to go to the clinic. Participants found this particularly difficult as they preferred not to reveal the exact reason for clinic visits to all their teachers and found this type of communication quite challenging. They feared that disclosing to the teacher that they have HIV and must go collect their ART is risky because it may lead to unintended disclosure. They feared that teachers may unintentionally reveal their status to others in the class. They also felt that it may be difficult for teachers to understand their health dilemma which involves having a chronic illness requiring regular clinic visits and which is highly stigmatised.

*During the day it is difficult to miss the classes because we have different periods with different teachers, for example if you tell your class teacher s/he might not tell others that you have this problem because other teachers are not understanding. - 20 year old girl*



### ***Strained relationships with teachers***

Some participants described the relationship with their teachers as strained. This posed a barrier to adhering to clinic appointments. The strained relationships with teachers were the result of *Negative teacher attitudes* and *Fear of unintended disclosure of their HIV status by teachers*.

### ***Negative teacher attitudes***

Some respondents described their teachers as having negative attitudes. They perceived their teachers to have dismissive attitudes towards them. Many respondents opted for selective disclosure and did not necessarily want to tell their teachers of the exact reason for their clinic visit because they feared teachers' response should they tell them.

*Another problem when you ask a permission to go to the clinic, the teachers are so curious they want you to tell them the reason for your visit...And when you refuse to tell them they will assume that you are going for family planning and they will be*

*angry. Their attitude makes it difficult for you to sit him/her down and explain your problem. - 20 year old girl*

### ***Fear of unintended disclosure by teachers***

Participants were concerned that teachers may inadvertently reveal their status to others, such as fellow learners when they are angry. Previous experience with some of their teachers made them weary of sharing sensitive information such as their HIV status with them.

*Okay my life orientation teacher is not a friendly person. She likes to shout, beat and [is] always angry. When she is angry, she says a lot of things out of anger; imagine now if you tell her about your status, and when she is angry she burst out in front of everyone. The best way is to keep this to myself. - 16 year old boy*

### **4.3.2. Socio-economic factors**

This section describes how social factors impact on adherence. Social factors can be defined as influences such as economic and living conditions which shape the conditions of daily life. Participants reported that a *Lack of financial support* and *Household dynamics* impact negatively on ARV adherence.

#### ***Lack of financial support***

Participants identified four ways in which having financial support (or means) could facilitate adherence to treatment, namely *Paying someone to collect their ARVs*, *Accessing private health care*, covering *Transport expenses* to the health facility and *Buying antiretroviral medication* should they run out.

#### ***Pay someone to collect medication***

Participants suggested that having financial support or means could enable them to pay someone to collect their medication on their behalf. In this way they would not be seen waiting to receive HIV care and thus unintended disclosure would be avoided. They

expressed that this would assist them with adherence to clinic appointments and consequent ART adherence as they would then collect their medication on a regular basis and thus not run out of treatment.

*Actually I was going to hire someone so that someone can help me to go and fetch my treatment for me and bring it back to me and I can pay back yah that is what I was going to do. Some of us are afraid of people, you can take your medicine and drink but when you come back they gonna stare. You get scared of the people. You are scared of what people will say about your pills, they can be so judgemental. Hiring someone would make things much easier. - 18 year old boy*

### ***Access private health care***

Some participants mentioned that they would like to have the option of accessing private health care facilities in areas other than where they currently reside. In order to do this they would need financial assistance as private health care in South Africa is not free. They felt that this would aid in avoiding unintended disclosure and as such help with adherence.

*P2: I will tell that person at home that I should go to private clinic or hospital*

*F: Okay so you would use the money for private hospital, why would you do that?*

*P2: Because I do not want to be seen*

*F: And you think when you come here to this clinic somebody can see you? (P2 interjects: Yes) So would you go to a private hospital in this area or other area?*

*P2: I would go [to] other area. - 14 year old boy*

### ***Transport expenses***

A barrier highlighted to accessing clinic care was lack of money for transport to the health facility. Participants expressed that financial support would aid with transport expenses to the clinic which in turn would help them to adhere to clinic appointments.

*...I can take a transport to come to the clinic. - 14 year old boy*

*Oh... maybe I can use it [financial support] for a taxi fare to collect my medication. - 18 year old boy*

### ***Buy antiretroviral medication***

Participants noted that financial support would assist them with adherence by purchasing ART privately should they run out of medication. This would be particularly useful at the times when the clinic is not accessible for example in the evenings, over the weekends and on public holidays.

*If my pills were not enough I would buy more so that they can sustain me till my next date. At times the clinic can be very busy full of people, so if I had money, I would not wait in the queues. - 13 year old girl*

### ***Household dynamics***

Negative household dynamics were reported to have adverse impacts on adherence for participants in the current study. Some of the respondents were orphaned and had strained relationships with their caregivers. The household dynamics identified which presented barriers to adherence were *Ill-treatment by caregivers, Being the only HIV positive sibling* and *Feeling like an outcast amongst family members.*

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### ***Ill treatment by caregivers***

Some participants highlighted that they were being ill-treated at home by their caregivers. Those who were fostered reported that caregivers would insult them with harsh words and blame them for their own infection. This impacted negatively on their relationship with caregivers which resulted in participants feeling lonely and discontinuing their medication as they too wanted to be deceased like their parents. This phenomenon appeared to be particularly common amongst the participants who were orphaned and were cared for by relatives or foster parents.

*Yoh, when I am feeling bad, I stop taking my pills. For example, when I have quarrelled with my mother, - sometimes she says things that are not so nice. Like saying she never infected me. My mother is not my biological mother mos. My biological parents are dead. So when she talks like that I feel lonely and I feel bad, I stop taking the pills because I also want to die. - 18 year old boy*

### ***Being the only HIV positive sibling***

Some participants found it hard to come to terms with their HIV status when they are the only sibling who is HIV positive and all other siblings were HIV negative. This led to denial which in turn influenced adherence.

*My mother told me that she is also positive. But my question is: we are three but I am the only one who got infected. How did that happen? I am still asking myself. - 16 year old boy*

### ***Feels like an outcast amongst family***

One participant expressed that his HIV status made him feel like he did not belong to his family. He felt that if he were HIV negative he would feel a greater sense of belonging amongst them. He expressed that he wished to stop taking his ART in order to be more like his family.

*I would not feel different from them [if I was HIV negative], now I feel like an outcast, I am the only person with this thing [HIV] and I do not belong here, I feel like staying away from them... I wish I could stop taking medication [ART] and be like them. - 18 year old boy*

### ***4.3.3 Health services factors***

The factors related to the health care services which impacted negatively on participants' ART adherence were: *Service delivery* and the *Quality of care* received.

#### ***Service delivery***

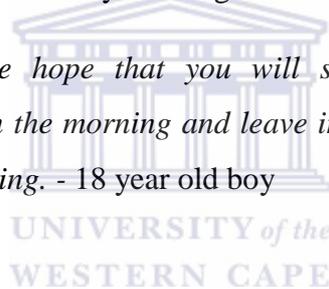
Participants identified service delivery issues such as *Long waiting times*, *Nursing staff shortages*, *Missing/misplaced files*, *Long travelling distances to the clinic* and *Unintended disclosure* as barriers to ART adherence.

### ***Long waiting times***

Long waiting times were identified as a significant deterrent to adhering to clinic appointments in all focus group discussions and all one-on-one interviews. Participants mentioned that regardless of what time of the day they presented at the clinic they would inevitably wait a long time before they are assisted. Waiting times were experienced as very stressful as some participants would come to the clinic very early hoping to be assisted and still go to school. However, this was often not the case and they would leave the clinic very late. As a result, participants would miss clinic appointments in order to avoid being absent from class and indirectly this would negatively impact on treatment adherence.

*...sometimes if you come here at half past 8 and the doctor doesn't attend you... doctors can make you wait for a very long time before they can attend you. You can come here at 8am and they only start to attend you at 9. Mind you, you will go home at 4 that is why I get bored... - 13 year old girl*

*You come here with the hope that you will spend few hours and go home; unfortunately you come in the morning and leave in the afternoon when the cleaning staff already started cleaning. - 18 year old boy*



### ***Nursing staff shortages***

During the interviews participants mentioned that when accessing the clinic at certain times of the day, such as after school, they would experience a shortage of nursing staff to assist them. This would make clinic appointment adherence as well as treatment adherence difficult since nursing staff are required to review patients clinically and prescribe medication. This would mean that patients had to access the clinic on a different day which in turn leads to school absenteeism and running out of medication.

*If I go to school in the morning and come here in the afternoon, I find nurses gone. - 15 year old girl*

### ***Missing/Misplaced files***

Participants mentioned that at times reception staff would not be able to find their clinic file. Without adequate clinical records it is very difficult to assist patients especially those on chronic medication such as ART. Patients would thus be requested to come to the clinic on a different day to allow reception staff to find their clinic folder. This discouraged participants from following up for clinic visits and thus led to them missing clinic appointments and running out of treatment.

*I do go home without help, they keep losing my folder and sending me home and ask me to come back tomorrow. When I come again, they will say it is you again, and they are not keen to help me. Mind you I ran out of medication. - 15 year old girl*

### ***Long travelling distance to clinic***

Participants mentioned that they had to commute a very long distance to access the health facility. This was so regardless of whether they were coming from home or from school. However, they also acknowledged the necessity of going for regular clinic follow ups regardless of the exorbitant distances they had to travel to the health facility. The long travelling distances may however prove a barrier to some.

*Because I am walking a long walk from school and come back and it is ... It is a must for me to come here irrespective of the long distance I travel from school. - 14 year old boy*

### ***Unintended Disclosure***

This particular health facility is divided into four sections- a pharmacy, a sick baby/ immunisation section, a Tuberculosis department and a section for patients who are coming for HIV care and follow-up. Therefore, depending on what service patients are coming to the clinic for they would be guided to go wait in that particular section. Where you wait in the clinic was thus an indication of what type of care you are seeking. Participants were thus concerned that the section they were waiting in may lead to unintended disclosure of their HIV status.

*One time I came to fetch my medication and I saw my neighbour, now she knows [I am HIV positive] because it's obvious that people who wait this side are HIV positive... - 16 year old boy*

### ***Quality of care***

Poor quality of care negatively impacted on treatment and appointment adherence. Some quality of care matters highlighted were *Negative health care worker attitudes, Discrimination against treatment defaulters, Verbal abuse experienced from HCWs, Inappropriate management of health complaints and Caregivers being treated with disregard.*

### ***Negative health care worker attitudes***

Participants reported that in some cases patient-staff relations impacted negatively on adherence. Some participants experienced unpleasant interactions with health care workers which had an adverse impact on their adherence. They felt that health care workers were rude towards them and thought this could be due to health care workers experiencing a lot of stress.

*Some of the nurse[s] they have...what do I say... they are cheeky yah like when they have stress, they take out their stresses to innocent people. - 13 year old boy*

### ***Unsupportive health care system***

Key informants felt that the health care services rendered at this facility did not focus on the specific needs of adolescents and that systems were needed in order to cater for their unique needs.

*I don't think we have systems in place yet because there is nothing that focuses on them (adolescents). They are just in another group of adults taking ARVs so there is nothing focusing specifically on assisting them so I would say we do not have a system that really supports them maybe if we could establish something that really*

*focus on them because [they] are just dumped among the adults because they are just part of the whole group who is taking the ARVs. - K.I.*

### ***Discrimination against treatment defaulters***

Participants witnessed how patients who had defaulted their treatment and clinic follow-up visits were discriminated against when they returned to the clinic to re-start their medication. They described that those who had good adherence would receive preferential treatment. One participant, who was defaulting at the time of data collection, cited that the reason he was not going back to the clinic was because he too will be discriminated against by being made to wait until those with good compliance have been assisted and will experience verbal abuse should he return to re-start his medication.

*F: What is the reason you feel that you can't come to the clinic to get a card and re-start your treatment?*

*P: Is that I am scared because it's been a while since I came to the clinic.*

*F: And what are you scared of?*

*P: Like the doctor is going to shout at me*

*F: Anything else?*

*P: The doctor will shout at me, and I will have to wait at the clinic since they will start with the non-defaulters. That makes me angry. - 18 year old boy*

### ***Verbal abuse***

Some respondents reported that they were shouted at by HCWs. They felt that this kind of verbal abuse discouraged them from following-up for clinic visits especially when they had a valid reason which barred them from coming to the clinic. This is how a 14 year old participant responded when asked what would encourage him to be more compliant with his ARTs and clinic appointments.

*By other people when they support me and the nurse doesn't shout at me when I skip a day. When they told me to come and then I have a something or a problem then I*

*don't come. When I come back then they shout at me. It makes me feel not to come back.* - 14 year old boy

### ***Inappropriate management of health complaints***

Some participants were unhappy with HCW attitudes/responses to their complaints. They felt that when they had a genuine health complaint that this was not taken seriously by HCWs and that they did not receive the appropriate treatment for their health concerns.

*There are some of the staff members that shout at you or put you down when you tell them you have something [a medical complaint]. They put you down and say no, that will go away in no time but that time you are the one feeling the pain. It is sore.* - 13 year old girl

### ***Caregivers being treated with disregard***

Some participants experienced HCWs as being disrespectful towards their parents. This occurred when the accompanying parent was unable to give a good account of their HIV positive child's wellbeing. Participants experienced witnessing their parents being disrespected as very stressful, especially when the parent accompanying them to the clinic is not the primary caregiver. These negative attitudes by HCWs contributed to poor adherence.

*My mom doesn't know my problem, when the doctors ask what's wrong with the child; she will point them to me. They do not like that, they say to my mom, why do you want us to ask the child when you are here. She tells them that I do not stay with her, I stay with my sister. The doctors sometimes become mean to my mom, sometimes they just let us be.* - 13 year old girl

### ***4.3.4 Therapy-related factors***

The therapy-related factors that impacted negatively on ART adherence were *Medication factors* and the *Treatment routine*.

### ***Medication factors***

This section will focus on the impact *Side effects*, *Pill burden* and *Palatability of medication* has on treatment adherence.

#### ***Side-effects***

Many participants reported that side-effects of the ART were a barrier to treatment adherence. Nausea, vomiting and dizziness were commonly reported side-effects. Anticipating these side-effects discouraged participants from taking their ART.

*I don't feel good because the pills that I am drinking they make me feel like I am going to vomit and every day when I think that I feel like I will not drink the pills. - 14 year old boy*

#### ***Pill burden***

Participants reported poor compliance due to the high pill burden. This phenomenon manifested itself particularly amongst those on a second line ART regimen who said they would be more compliant should they be placed on the once daily Fixed-Dose Combination (FDC). However, it appears they did not realise that if you are on second line ART (which includes a PI that has to be dozed twice daily) that you could not be placed on the once daily FDC. The following was mentioned by a participant who was defaulting 2<sup>nd</sup> line ART at the time the FGD took place.

*Also I would love them to change my stream and put me on the one tablet regime, if I can have only one tablet I can comply with my medication. - 18 year old boy*

#### ***Medication unpalatable***

Some participants who were on a second line ART regimen which included Alluvia, a PI, mentioned that the tablets were big and unpalatable and that this discouraged them from taking their medication.

*...its tiring and boring to take this medication for all the time it is not nice... and its [the tablets] big... - 22 year old girl*

### ***Treatment routine***

Very high levels of adherence to a strict treatment routine are necessary for virologic suppression in patients on HAART. This strict treatment routine was identified as a barrier to optimal treatment adherence. *Treatment fatigue*, a *Rigid treatment schedule*, the fact that it *Interferes with leisure activities* and *Forgetfulness* contributed negatively to ART adherence.

### ***Treatment fatigue***

Treatment fatigue was mentioned as a barrier to treatment adherence in each one of the FGDs and all of the one-on-one interviews. Participants expressed boredom at having to take the treatment every day for the rest of their lives and that there was no prospect of ever stopping the treatment. The idea of life-long treatment made some participants ambivalent towards their medication.

*I sometimes feel that this thing that I have to take the pills every day does not sit well with me, I just get bored and feel like I could just throw them in the bin... - 13 year old girl*

*Because it has been a while since I started taking the pills, I started when I was staying in Mandela at Worcester, but I was not used to them by then. I always ask mom and my sister, when I will ever stop taking these pills and my sister says, you will take them till you die. So that is why I do not like them. - 13 year old girl*

### ***Rigid treatment schedule***

Participants were frustrated by the rigid treatment schedule and felt that there was no flexibility allowed in terms of dosing times. This led to non-adherence. Participants were concerned that if they took their ARVs after the scheduled times that they may experience negative physical effects. Though every effort should be made to take ARVs at the same time

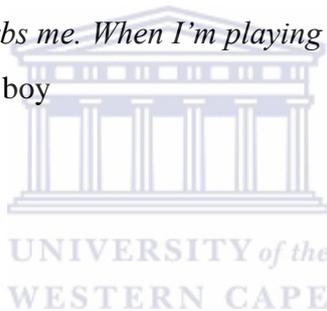
every day, the notion that negative effects will result if taken at a different time is not necessarily scientifically accurate, yet this was the only message that was communicated to them by the health workers.

*Yah, I also miss them sometimes. I am a playful person. So at times I miss my time and I do not want to take them after that time because I do not know if they will have negative effects after.* - 16 year old boy

### ***Interferes with leisure activities***

The younger participants expressed frustration at the fact that they would be playing and then be called home to come take their medication. They felt that it imposed on their leisure activities.

*When I'm playing it disturbs me. When I'm playing they will call me [to come take my medication].* - 14 year old boy



### ***Forgetfulness***

Forgetting to take prescribed medication is common amongst patients on chronic treatment. This was also found to be the case amongst these adolescents on HAART who also experienced forgetting to take their medication on occasion. This served as a barrier to adherence.

*Yes I forget [to take medication] sometimes.* - 13 year old girl

*It would help me by reminding me when it is time [to take the medication]. I usually forget to take my medication.* - 14 year old boy

### ***4.3.5 Patient factors***

The patient-related themes that emerged as impacting negatively on ARV adherence were *Disclosure, Self-stigma, Adolescent behaviour, Mental health factors* and *Disease factors*.

## ***Disclosure***

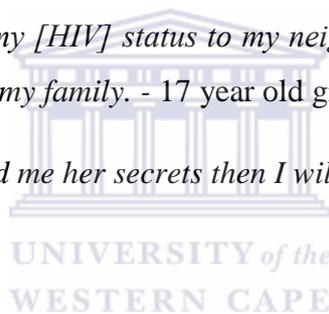
The literature which has been reviewed highlights the importance of disclosure in treatment adherence. In this study, issues around disclosure were identified as barriers to good treatment adherence. These were: *Dynamics of disclosure*, *Fear of stigma and discrimination*, *Denial*, *Being forbidden to disclose* and *Lack of knowledge about their diagnosis*.

### ***Dynamics of disclosure***

The discussion around whether or not disclosure to others impacts on adherence was very vibrant. Participants felt that if they would disclose, they would wait until they are in a trustworthy relationship and would first try and establish if the other party trusted them too. There was also a preference to disclose to close family members only.

*I don't want to disclose my [HIV] status to my neighbour or to my friends. I want to disclose my status only to my family. - 17 year old girl*

*If I trust her and if she told me her secrets then I will tell her mine. - 14 year old boy*



Some participants however felt that disclosing to others would make the process of going to the clinic and taking treatment much easier.

*I think it would be better, because when everybody knows about your status, you do not need to hide yourself when taking your treatment and even when you are going to the clinic everybody knows. - 20 year old girl*

Amongst the younger participants it was common to not disclose in response to parental concerns about possible indirect disclosure of parents' HIV status. Some participants said their parents forbid them from disclosing their HIV status.

*Because my mother told me that I must not tell anyone [about my HIV status]. - 10 year old girl*

*They prohibit us from talking about it [our HIV status]. - 14 year old boy*

Furthermore, some participants were anxious that their HIV status may be disclosed either intentionally or unintentionally. This posed a major barrier to disclosing to significant individuals in their lives such as intimate partners. This is particularly pertinent when they start engaging in sexual activity as it holds implications for their intimate partner (s).

*...imagine now if you can tell her [girlfriend] about your [HIV] status, and when she is angry she burst out in front of everyone. The best way is to keep this to myself. - 16 year old boy*

### ***Fear of stigma and discrimination***

The vast majority of participants cited fear of stigma and discrimination as a reason for not disclosing. They felt that others lacked knowledge about HIV and that this may lead to them making inappropriate and hurtful remarks. This was a common trend amongst those going through early adolescence (10-15 years) as well as those going through late adolescence.

*It could be difficult in the sense that if you have a gathering and you are eyeing a guy, that guy will not come to you, knowing that you are positive, that will never happen. - 20 year old girl*

*It's the fear, you are scared that she will dump you, and she will tell others too. When she spreads the news, other girls will not want to be involved with you. They will think that you will infect them. - 16 year old boy*

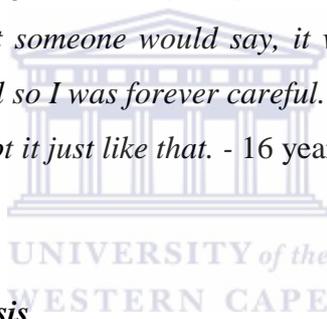
### ***Denial***

Denial about being HIV infected was a common phenomenon amongst participants and this hindered adherence. This was common regardless of the route of transmission. One participant was in denial about her HIV status and struggled to come to terms with the manner in which she was infected. She subsequently defaulted ART for a number of months and became very ill to the point where she could not care for herself.

*I was still in denial that I am HIV positive, I was raped by someone very close to me. I was raped by a guy staying next door... They did the test and it came positive, I was in disbelief, I could not accept the news. I cheated my medication [ART] and lied to grandmother. In the mornings on my way to school I throw them away, as I was not taking my treatment I was losing weight, and I developed sores on my body. I could not do anything for myself, I was unable to even take a bath, and my grandmother was bathing me. - 15 year old girl*

Denial was also very common amongst peri-natally infected adolescents. They felt that they had taken the necessary precautions to avoid contracting HIV horizontally but learnt that their efforts were in vain as they were anyway infected as a result of peri-natal transmission.

*Yoh the first year of starting treatment [ART], I took a whole week off from treatment. I was in denial, I thought someone would say, it was a lie. I was always careful. I learnt about HIV at school so I was forever careful. When I went for testing it was like a dream, I could not accept it just like that. - 16 year old boy*



### ***Lack of knowledge about diagnosis***

Some participants reported initially being ambivalent towards their medication because they were not sure why they were using it.

*And erh I did not love my medication. Why not? Because I don't know the reason why I'm eating this medication. - 22 year old girl*

### ***Perceived stigma***

Participants were aware of certain cultural beliefs held by the community about HIV. They were not necessarily personally exposed to these stereotypes but they internalised some of these beliefs. They experienced *Fear of being stereotyped*, *Fear of intended or unintended disclosure* and they felt their *Treatment routine creates suspicion*.

### ***Fear of being stereotyped***

Numerous stereotypes were mentioned. Some did not want to disclose as they were aware of cultural and social beliefs held by the community about HIV and how it is transmitted. Other participants felt that assumptions would be made about how they were infected with HIV.

*Xhosa people associates HIV with being a whore. - 15 year old girl*

*What I am scared of is that, people can label you with all sorts of names. They will say do you see that one, she is so and so. They do not even know how you got infected in the first place and already they think that they know. - 17 year old girl*

### ***Routine creates suspicion***

Some participants expressed that the routine of going to the clinic and taking medication may create suspicion amongst their peers and thus lead to unintended disclosure.

*It does not sit well with me, because people will be suspicious, they will have questions about my frequent visits to the clinic. That does not make me feel right. - 18 year old boy*

*If I could drink in the morning only that could help because it would never disturb me because some of my friends get suspicious. Why all the time at 7[in the evening] my parents always call me inside. What am I doing at home when they call me inside? - 14 year old boy*

### ***Adolescent behaviour***

There were some characteristics unique to adolescents which impacts on their ART adherence. These characteristics include *Feeling invincible*, having *Unstructured lives*, *Alcohol usage* and *Rebellion*. These factors were often accompanied by non-disclosure which compounded its negative impact on ART adherence.

### ***Feeling invincible***

During the interviews it was revealed that some participants felt invincible and were non-adherent because they thought no harm would come to them if they opted to not take their ARVs.

*Sometimes I feel like I am [healthy] like everyone else. Sometimes I feel like I don't want to take them because I always have to drink it. - 14 year old boy*

### ***Unstructured lives***

The adolescents in this study reported that they often go to late-night parties and sleep-overs. They felt that if they were out late that they could not just leave the social event in order to take their medication. Or if they only returned home the next day they would skip their treatment. Their unstructured lives presented a major barrier for the participants to adhere to a strict treatment regimen.

*There are times when there is a party somewhere and my friends will be attending and I also have to go with them. In those instances we come home the following day, and I will miss my pills. Those gatherings are fun, I can't leave fun mos. - 18 year old boy*

*Sometimes, like holiday like December like its few party. And so like if I was at a party with friends, like maybe I am whatever place with my friends but my friends did not know I was HIV positive. So when it was 9 o'clock it was difficult to just leave. So I would just think argh, so what if I don't take them, nothing will change I will just take them on another day. - 15 year old girl*

### ***Alcohol use***

Participants reported alcohol use as a barrier to adherence to ART. They were informed that one cannot use ART and alcohol together. Thus, instead of not using alcohol at a party, they would rather opt to not use their ART for that particular evening.

*F: What happens if you drink a little bit too much alcohol? Do you still drink your treatment?*

*PI: No, because the doctors said there is going to be trouble when you mix drugs and alcohol*

*F: So what happens if you were maybe drinking beer the Friday night, Saturday and Sunday night?*

*PI: Then you don't drink the pills. - 18 year old boy*

### ***Rebellion***

Key informants reported that adolescents on ART, just like other adolescents, are rebellious during this stage of their lives and this is further complicated by being on ART. This, she suggested, posed a challenge to ART adherence.

*Okay uhm it's a challenge because uhm some of them are in that stage because they are teenagers of being rebellious so now there is this thing of ARVs. If maybe we got some who started when they were 5 years but once they reach that age they are very negligent because it is like to me they are kids at times, they are adults and they are kids at the same time. - K.I.*

### ***Mental Health***

The mental health factors which impacted negatively on ART adherence were *Shame at mode of HIV transmission, Anger at mother for peri-natal transmission of HIV, Depression, Suicidal ideation, Loneliness and Hopelessness.*

#### ***Shame at mode of HIV transmission***

One participant felt intensely ashamed at the fact that she was infected through being sexually assaulted. This led to her not being adherent to her treatment and as a result she fell very ill.

*Eh when I first found out I was HIV positive it was difficult, it was not easy. I feel like I'm dirty. I embarrass my family because I am young because I am HIV positive and there was no one explaining to me as a positive person that this and this. - 15 year old girl*

*No... yes... I think I was 14 years old I was raped with my neighbour I call him uncle but I don't tell my aunt I tell my grandmother because I was scared and shy and embarrassed. - 15 year old girl*

### ***Anger at mother for peri-natal transmission of HIV***

Many of the peri-natally infected participants expressed anger at their mothers who in some cases were deceased. They felt that if their mothers took ART then they possibly would not have been burdened by needing chronic medication. Only one participant implicated his father in his disease profile.

*Because somebody told me, because my aunty had told me once. She said what made me to become HIV, it's because my mother and my father had the disease so my mother did not drink the pills [ART] so that I could not have HIV. My mother did not drink it so that is why I become HIV positive. - 14 year old boy*

*Yes because I ask myself why did my mom not drink those pills [ART], now I could be better like everyone. - 14 year old boy*

### ***Depression***

Depressive symptoms were very common amongst participants especially older participants. Many participants said they had experienced thoughts of wanting to die.

*Iyoh, I wasn't feel happy because sometimes I was try to kill myself. - 22 year old girl*

### ***Suicidal ideation/intent***

One participant mentioned how she had an incomplete suicide attempt following numerous struggles related to her HIV status.

*One day it was a Sunday, I was still staying with my aunt, when everybody was preparing to go to church. I said to them I was not feeling well. They left, and I took all my pills [ART] and mixed them, I was trying to kill myself, I had enough of life and challenges... I took all of the pills and drank them with milk. I lied on the bed. My brother came and he called an ambulance. I was admitted and the nurses drained the pills and I recovered. - 22 year old girl*

### ***Loneliness***

Adolescence is characterised by a desire to fit in. This was no different amongst the participants in this study. Many of the younger participants felt lonely and as though they do not fit in because they are on chronic medication. They considered this to be an abnormal state of being.

*F: When you say you want to be like everyone else, what does that mean?*

*P: To be like a normal person, when I am taking these ARVs I don't feel like a normal person because everybody does not drink these pills. I feel like I am the only one here that drinks these pills. - 14 year old boy*

*Is that it is me alone at my home that is drinking the medication and that it makes me ... it makes me feel very lonely. - 14 year old boy*

### ***Hopelessness***

It was common for participants to have dreams and aspirations and this served as a facilitator to treatment adherence. However some of them cited feeling extremely hopeless and this impacted negatively on their ART adherence.

*Not now like last year a lot because I feel bored and I feel no future. I am dirty I feel like I take the pills to the toilet and flush [the pills]. - 15 year old girl*

### ***Disease Factors***

Some of the barriers to adherence were directly linked to the disease. These were: *Diagnosis of HIV taken lightly* and *Not experiencing any physical benefit of treatment*.

#### ***Diagnosis of HIV taken lightly***

One of the participants reported that she did not think a diagnosis of being HIV positive was to be taken seriously until she fell ill and realised the importance of being on ARVs.

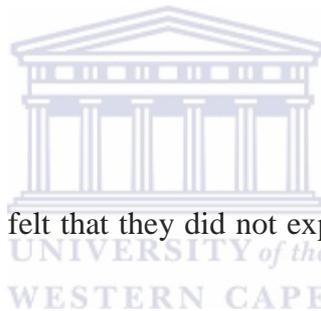
*I was 14 years old but when I first found out [that I am HIV positive]. It was in June 2012. But I had no problem and I did not take it seriously. Like, they came to school to test us and they said I was HIV positive and they gave me a letter to take to the clinic. I never bothered doing that. I did not care. - 18 year old girl*

#### ***No physical benefit of treatment***

Some of the younger participants felt that they did not experience any physical benefit from being on ART.

*I feel but I am not believing it that they are helping me but I believe that I am just drinking them to know that I will be fine. That's all. I don't believe that it will heal me. - 14 year old boy*

*Because I drink them everyday nothing is happen to me. I always drink it and I stay the same. Nothing changes. - 14 year old boy*



#### 4.4 FACILITATORS OF ADHERENCE

The findings from the interviews highlighted many barriers to adherence but it also highlighted factors which motivated participants to remain adherent to their ART regimen. This section will focus on the facilitators of adherence. The reported facilitators to ART adherence (Table 4.3) were organised according to the following main categories:

- Support system;
- Patient factors;
- Disclosure;
- Disease factors; and
- Daily routine

**Table 4.3. Facilitators of adherence**

Category	Codes
Support system	Being part of a HIV support group
	Family support
	Support from clinic staff
Patient factors	Goals/ambitions
	Spiritual strength
	Strong leadership qualities
Disclosure	Being disclosed to
	Support from friends
Disease factors	Fear of AIDS and death
	Seeing others live well with HIV
Daily routine	Reminders from TV programmes

#### **4.4.1 Support System**

A strong support system/network proved vital for these young people on ART. They spoke fondly of those who support them on a daily basis when they are discouraged to take their treatment or to attend clinic visits. This support network was made up of *HIV support groups*, *Family support* and *Support from clinic staff*.

##### ***Being part of a HIV support group***

In general, those participants who were part of a support group were a lot more outspoken about their HIV status and a lot more knowledgeable. Very few participants however were part of a support group. Even though participants said it helped them to be part of a support group, when viewing their clinic notes, they did not necessarily always have better adherence than those participants who were not part of the support group. Those who did attend the local support group (Ayabonga) also said they received help from some of the adult supervisors to collect their medication.

*I ask mummy here at Ayabonga, she comes and collects my pills... - 18 year old boy*

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##### ***Family support***

Those participants who still had a biological mother identified very strongly with her and found it to be a very supportive relationship especially if the mother was also HIV positive and on ART. Some also identified siblings to be important in their support structure and they often reminded them to take their medication.

*Okay we are four, it's me, my mom, and my 2 sisters. But I am close to my mom. Me and my big sister we quarrel a lot, even out of nothing. She knows about my treatment but when we have fights she doesn't say anything about it, even when I am tired of taking it they encourage me to continue. They always check if I take my treatment and they will notice that I am not taking it. We are such a close family but I am closer with my mother. - 16 year old boy*

### ***Support from clinic staff***

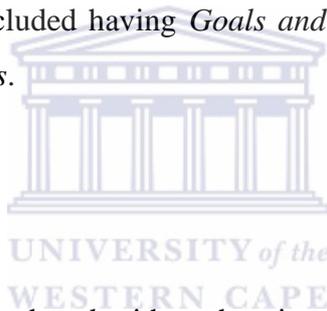
Participants found some staff members to be very understanding and supportive. Even when they were noticed by staff members in the community they would encourage them to continue their treatment. Participants really appreciated this gesture.

*I like the fact that most of the staff are people that I know and they like to ask me about my treatment, they take concern about my appointments. They also ask my mother “Is your child still taking his medication?” And she will tell them if I stopped.*

- 16 year old boy

### **4.4.2 Patient Factors**

There were a number of factors on an individual level that assisted participants in being adherent to their ART. These included having *Goals and ambitions*, *Spiritual strength* and having *Strong leadership qualities*.



#### ***Goals and ambitions***

Even though participants were burdened with a chronic and highly stigmatised illness they still had the will to live and all of them mentioned future goals and ambitions. These goals were academic, financial and family-related.

*Eh when I finish school I want to become a teacher and have a wife with two children and pay mother for everything she has done for me and be independent. To have a car, a house to show that I am a grown man now and I am working.* - 16 year old boy

#### ***Spiritual strength***

Participants found their journey with HIV and ART very difficult albeit to different degrees. Many found strength in their belief in a higher power and attributed their perseverance with ART to their relationship with a higher spiritual authority.

*This did not sit well with me, since I grew up saved, I was praying to God for strength and I knew that whatever was happening in my life at that moment it was going to pass. - 22 year old girl*

### ***Strong leadership qualities***

Some of the older participants felt a lot peer pressure to go along to parties and other social events which often meant that they would not be able to take their treatment on that particular day. Others however were strong enough to not go along with the crowd and to act responsibly about their academics and treatment.

*I do not go with the flow. Crowds have influence, so when my friends invite me to join them, I tell them to go and enjoy themselves, I will follow them later. - 18 year old boy*

### **4.4.3 Disclosure**

Disclosure can be considered two-pronged; firstly one needs to be disclosed to and secondly you may choose to disclose to someone else. Some respondents found both of these to be useful for treatment adherence.

### ***Being disclosed to***

Many participants reported that their adherence had improved once their HIV status had been disclosed to them and they understood why they had to take this chronic medication. Some of the older adolescents had been taking ART for a very long time before they knew what the medication was for which made them averse to taking the medication. However once they were disclosed to, they were more accepting of the fact that they needed ART.

*...because I am HIV positive and they didn't tell me I'm HIV positive and I get HIV positive with my mom. She tried but she didn't plan about this and also she tried to make me understand but end of the time I was understand and then I was just welcome this medication. - 22 year old girl*

### ***Support from friends***

Some participants identified best friends whom they felt very comfortable speaking to. These friends would remind them to take their medication and even accompany them to the clinic.

*Yah because I feel like I am free, even when he visits my place or I visit his place I feel free to take my medication. When I am sleeping over at his place, when I say I am going to take my pills he understands and even remind me some days. - 18 year old boy*

### **4.4.4 Disease Factors**

Participants identified factors which had a direct bearing on the disease which helped them to be more compliant with their medication. These were: *Fear of AIDS and death* and *Seeing others live well with HIV*.

#### ***Fear of AIDS and death***

Respondents feared the development of opportunistic infections, extreme pain and death. Some of them had already previously been admitted to hospital or had a severe opportunistic infection.

*What encourages me [to take my ART], is the fear of illness. I am scared of pains, when you are not complying with your treatment you fall sick and I do not want to lose weight. I want to remain healthy, and I do not want to look different from other people. - 18 year old boy*

*No, I will take it [ART]. I do not have a choice. I do not want to be sick, and I do not want to die. I want to die of accident not of AIDS, I do not want to be hospitalized because of AIDS, and I do not want that. - 16 year old boy*



### ***Seeing others live well with HIV***

Some participants witnessed how parents and others known to them were on ART and were able to continue with their lives despite having a chronic illness. Some of these people were their role-models and they tried to imitate their example.

*Okay what encourages me [to take my ART] is the fact that there are too many people who are HIV positive, even around here. My coach has it. I didn't believe it, I told myself that I still have a life ahead; I can grow and be old as coach. - 16 year old boy*

### ***Daily Routine***

Participants described events in their daily routine which served as a reminder to take their medication. One such a reminder was the popular daily television programme, "Generations". Participants used the time of this show as a reminder that they needed to take their medication. This however was only effective when evening doses of ART had to be taken.

*Maybe it is the two of us, watching Generations. In my mind there is something that tells me to take my pills. - 13 year old girl*

## **4.5 SUMMARY**

The barriers to treatment adherence were identified as: conflict between school and clinic times, strained relationships with teachers, difficult family dynamics. In addition there were barriers related to the health care services rendered such as the quality of care received, strained patient-staff relations, unhappiness about service delivery and the patient flow at the health facility. Medication side effects, pill burden, treatment fatigue and the rigid treatment routine were also identified as having a negative impact on treatment adherence. Dynamics which occur at an individual level also contributed significantly to non-adherence such as lack of disclosure, symptoms of depression, perceived stigma, behaviours unique to adolescents and feeling ashamed about the mode of transmission. Of note was how respondents feared unintended disclosure from those who may be aware of their status, this impacted on their willingness to disclose.

The facilitators to adherence included receiving support from family and friends they have disclosed to as well as motivation received from health care workers. Participants also had goals and ambitions and derived strength from their religious beliefs. In addition, respondents were encouraged by seeing how healthy other HIV positive people are.



## CHAPTER FIVE

### DISCUSSION

#### 5.1 INTRODUCTION

In this chapter I will present a discussion on the findings of the study (barriers and facilitators of adherence) in the light of existing literature.

#### 5.2 BARRIERS TO ADHERENCE

##### *School factors*

School commitments, communication with school teachers and negative teacher attitudes were found to play a significant role in both accessing the clinic, disclosure and adherence to ART. Participants often expressed feeling conflicted between school commitments and the need to attend clinic appointments. In addition, the need to communicate attending regular clinic visits to teachers posed a significant barrier to attending regular clinic follow ups as they feared unintended disclosure which may potentially lead to stigma and discrimination. The findings of the current study are in keeping with the literature which suggests that mainstream schooling may not necessarily always have a positive impact on adherence. In this study the routine of schooling also made clinic visits difficult and some participants felt that their frequent absences may lead to unintended disclosure of their HIV status. It is well documented that if adolescents disclose their status to a trustworthy person/people they are more likely to receive help in the form of knowledge and resources to help them cope with a HIV diagnosis and to access and remain in HIV care (WHO, 2013). This fear of unintended disclosure in the school environment may thus lead to poor adherence.

##### *Social factors*

A lack of financial support and negative household dynamics were found to have a negative impact on ART adherence. Of interest in this study was that none of the participants mentioned financial support as being important for basic necessities such as food as was highlighted in studies by Cotton *et al.* (2010) and Cluver (2015). Financial support was however identified as being able to assist in paying for private health care. A large number of participants expressed the desire to access private health care as a means of avoiding

disclosure and also avoid spending long periods of time at the health facility. The findings of the study are thus in keeping with the literature. Cotton *et al.* (2010) report from their qualitative enquiry with 26 adolescents in the Western Cape province that participants felt that their lives would be significantly improved if they received support in the form of money. Cluver *et al.* (2016) also suggest that financial support may be important in adults adhering to ART. Although the reasons supplied by participants in this study for needing financial assistance were unconventional, it was clear that financial support would make adherence to ART easier.

In the current enquiry, negative household dynamics had a profoundly detrimental effect on ART adherence. Participants cited negative relationships with non-biological caregivers as a barrier to adhering to ART with some orphans even saying they defaulted ART in an attempt to end their lives and be with their deceased biological parents. Furthermore, adolescence is characterised by a desire to fit in. Some respondents reported feeling like outcasts amongst their immediate family as a result of being HIV positive. Respondents expressed that they would feel a greater sense of belonging amongst their relatives if they were HIV negative. The findings are in keeping with the literature that identifies household dynamics as playing a pivotal role in adherence to ART. Brown and Lourie (2000) assert that parenting and family dynamics play a key role in enabling adolescents to adjust to their HIV status. Furthermore, Cotton *et al.* (2010) confirmed a positive association between good parenting/family relationships and adherence to HIV care by adolescents.

Given that there are so many factors in the household which may negatively impact on ART adherence, it therefore stands to reason that perhaps family dynamics need to be probed by health care workers and assessed prior to ART initiation and on an ongoing basis but especially in adolescents who have poor adherence. This is in keeping with a suggestion by Williams *et al.* (2006) that family dynamics and family characteristics should be evaluated prior to initiating ART in adolescents who acquired HIV infection peri-natally.

From this research enquiry it was also clear that an isolated social intervention would not be sufficient in aiding with adherence but that improving on a combination of factors would.

This is in line with findings from Cluver *et al.* (2016:79) that a “...combination of cash and care social protection was associated with reduction in past-week non-adherence...”

### ***Health Services Factors***

Numerous factors related to the health services rendered were found to have an adverse impact on appointment and ART adherence. Long waiting times and missing or misplaced files had a profoundly negative impact on treatment adherence. In particular, long waiting times were mentioned by all participants as a deterrent to adhering to treatment and clinic appointments. All participants mentioned long waiting times as a barrier to remaining adherent to treatment especially when they still had to honour school commitments. These findings are in keeping with those by Ferrand (2016) which recommends that adolescent ART services need to be youth-friendly and consisting of amongst others a youth-friendly waiting area, evening clinics and a dedicated clinic day. In addition, participants feared that the flow of patients at this health facility may lead to unintended disclosure of their HIV status. This is because the area in which you waited in the clinic was indicative of the treatment you were collecting which could thus lead to stigmatisation.

Missing and misplaced files also served as a major barrier to adhering to ART as adolescents would be told by clinic staff to return to the clinic on a different day to collect their medication. Adolescents experienced this as extremely stressful. It may potentially be dangerous too since adolescents, particularly peri-natally infected adolescents, may be heavily treatment experienced and thus not be able to accurately recount their disease and treatment history making accurate prescription difficult. Existing literature on adolescent ART adherence does not mention missing files as a barrier. This may be because a lot of the data on ART adherence amongst adolescents come from a first world setting where electronic medical records are often used.

Furthermore, patient-staff relations had the potential to impact on adherence either positively or negatively. Some health care workers had negative attitudes towards patients yet some respondents were sympathetic toward this and ascribed it to staff experiencing a lot of stress and taking it out on their patients. In addition, poor quality of care had a profoundly negative impact on ART adherence. We found that patients with good adherence would receive preferential care at the health facility and those who had defaulted would have to wait longer before they are assisted in addition to being verbally abused by health care workers. Patients

found this sort of treatment to be incredibly frustrating and this served as a deterrent to going back to the clinic for help if they had defaulted ART. The findings are in keeping with the literature by Chesney (2000) and Hudelson and Cluver (2015) who found that the health care system and patient-provider relationships played a significant role in adolescents remaining adherent to ART.

The key informant interviews revealed that often the unique attributes of adolescents were not completely understood by health care workers and that this impacted on service delivery to this group and resultant adherence. They were of the opinion that the health care system should be set up in such a way so as to focus on the unique needs of adolescents. Ferrand (2016) also recommends that ART care at youth-friendly health facilities should ideally be provided by trained health care workers.

### ***Therapy-related factors***

Some of the major barriers to treatment adherence were related to the medication and the treatment routine. As discussed in the literature review, very high levels of adherence to a rigid treatment routine are required for virological suppression in patients on HAART (Bekker *et al.*, 2008). Treatment fatigue was mentioned as a profoundly significant barrier to adherence by *all* participants. Participants in this study found the treatment routine associated with ART extremely rigid and were frustrated by the fact that apparently no leniency was allowed. This is in keeping with the literature by Merzel *et al.* (2008) that identified regimen fatigue as a major factor impacting on older adolescents' ability to remain adherent to a treatment regimen. There was even a suggestion from the older adolescents in this study that having ART-free weekends would greatly improve adherence. This may indeed be possible as recent findings from the *BREATHER* trial (Butler *et al.*, 2016) found that a five-day Efavirenz-based regimen was not inferior to a seven-day regimen in maintaining viral load suppression and it reduced toxicity associated with long-term exposure.

High pill burden was also identified as a barrier to treatment adherence especially amongst those on a second line ART regimen which usually includes the Protease Inhibitor, Alluvia, which has to be taken twice daily. The Alluvia tablet is a very unpalatable tablet and has unpleasant side-effects. This also contributes to poor adherence. This too is in keeping with

the literature that says high rates of non-adherence to ART amongst adolescents highlight the need to make treatment regimens simpler and more tolerable (Penazzato *et al.*, 2015). Higher rates of defaulting were reported from those on second line ART. This is in keeping with outcomes from the REACH study which found an association between treatment adherence and pill burden (Murphy *et al.*, 2010).

### ***Patient factors***

The dynamics of disclosure played a pivotal role in ART adherence amongst these participants. The majority of participants preferred selective disclosure in other words they chose to disclose their HIV status to some people but not to others. However, some participants felt that if everyone knew their HIV status it would make the process of accessing the clinic and taking ART a whole lot easier. Many participants chose not to disclose as they feared rejection, stigma and discrimination and this had a dramatic influence on adherence. Furthermore, some of the younger participants did not disclose in response to parents who forbid them to talk about their HIV status. This may be because if an adolescent discloses their HIV status they may also indirectly be disclosing their parent(s) HIV status. The findings are in keeping with the outcomes of a workshop held in South Africa that found that adolescents preferred to keep their status to themselves (WHO, 2013).

Furthermore, adolescence is a transitional phase which may be characterised by defying authority and a sense of invincibility. Many participants felt that no harm would come to them should they not take their medication. Their decision making thus seemed to favour more immediate benefits than long term reward. In addition, the lack of structure such as attending late-night parties and sleep-overs made it difficult to adhere to a rigid, daily treatment regimen. These attributes together with alcohol usage were all associated with poor adherence. These issues were compounded by non-disclosure and a combination of any one of these factors proved particularly detrimental to ART adherence. These findings correlate with the literature. Hoare (2016) found that HIV positive youth had poor cognitive inhibition and had poor executive function which may impact on daily activities such as decision making. All these characteristics are necessary to navigate through adolescence, to be less

impulsive and to make good decisions about their health such as remaining adherent to an ART regimen.

Depression, anger and loneliness also stood out prominently as having a negative influence on adherence. A review of mental health of HIV positive youth suggested that they experience emotional and behavioural problems, including psychiatric disorders, at higher than expected rates, often exceeding those of other high-risk groups (Mellins, 2013; Hoare, 2016). This is in keeping with the literature by Uthman (2014) that found that patients with depressive symptoms were 42% less likely to achieve optimal adherence to a HAART regimen.

### **5.3 FACILITATORS OF ADHERENCE**

#### ***Support system***

Receiving support from HIV support groups, health care workers and family members was perceived to have a positive influence on adherence. Participants with an HIV positive parent identified very strongly with that parent and also reported receiving support from siblings to remain adherent to their ART. These findings are in keeping with the literature by Sharer *et al.* (2016) that examined the relationship between parent and sibling support amongst children affected by HIV and AIDS. Sharer *et al.* (2016) found that support from siblings was a significant source of support and that it was positively associated with mental health. This (good mental health) in turn may have a positive impact on adherence.

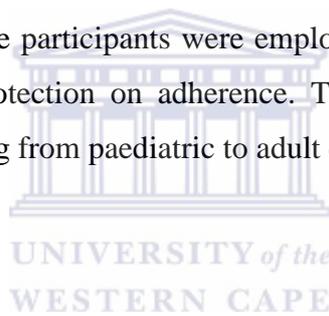
The current study also found that participants had improved adherence once their HIV status had been disclosed to them and also received support from friends to whom they have disclosed their HIV status. These findings are in keeping with the literature from WHO (2013) that says if adolescents disclose their status to a trustworthy person/people they are more likely to receive help in the form of knowledge and resources to help them cope with a HIV diagnosis and to access and remain in HIV care. Sharer *et al.* (2016) also suggest that further research is required to determine how social support adds to resilience amongst children living in settings with a high burden of HIV such as South Africa.

### ***Patient factors***

Having goals and ambitions served as a motivating factor for remaining adherent to ART. Having spiritual strength and strong leadership qualities was also associated with good adherence. Bhana *et al.* (2016) did an enquiry into resilience amongst peri-natally infected HIV positive adolescents in South Africa. Some of these factors on an individual level which influenced resilience included having self-esteem and self-regulation. The findings of our research are thus in keeping with this literature. Though participants had numerous household stressors as well as challenges on an individual level, many reported having goals and ambitions and being strong-willed such that they are not influenced by peer pressure.

### **5.4 LIMITATIONS OF THE STUDY**

The study had the following limitations: the researcher could not explore the impact of the employment sector as none of the participants were employed. The data did not sufficiently explore the impact of social protection on adherence. The researcher did not adequately explore the impact of transitioning from paediatric to adult care.



## CHAPTER SIX

### CONCLUSIONS AND RECOMMENDATIONS

#### 6.1. CONCLUSIONS

Very little is known about the factors which influence adherence to ART amongst adolescents. In addition, very limited research is available which describes these factors from the perspective of adolescents and young people. A qualitative study thus enabled the researcher to explore these factors from the perspective of the participants. The study sought to explore the factors that influence adherence to ART amongst adolescents in a primary health care clinic in a low socio-economic, urban setting in Cape Town. An exploratory qualitative design was employed which revealed many complexities associated with attempting to remain adherent to an often complex ART regimen, more so for adolescents who have very unique physiological and psychological attributes. The data revealed that school commitments made adherence to ART and clinic appointments very difficult as many a times there is conflict between school programmes and clinic times. This is because participants often had to attend afternoon classes and by the time they got to the clinic it would be closed. In addition, strained relationships with teachers made the process of accessing the clinic very difficult. We also found that household dynamics played a crucial role and ill-treatment by non-biological care givers had a profoundly negative impact on treatment adherence.

It was apparent that some participants were disappointed with the service delivery received at this health facility; missing or misplaced files and long waiting times stood out prominently as having a negative impact on ART adherence. All participants in this research study were tremendously frustrated about the long waiting times at the clinic. Furthermore, participants were very concerned that the flow of patients at the health facility may lead to unintended disclosure of their HIV status and this was offered as a reason for not following up for clinic appointments. In addition the quality of care at the facility came under criticism with some reporting verbal abuse, inappropriate management of health complaints and reports that those with good adherence received preferential care. All these discouraged participants from following up for clinic visits.

Therapy-related factors and in particular pill burden, a rigid treatment schedule and treatment fatigue was probably amongst the most common barriers associated with poor adherence. Treatment fatigue affected all participants and was the most prominent barrier to adhering to treatment. The development of more innovative drug formulations such as injectable ART and other long-acting ART may aid in improving ART adherence in this group.

Issues around disclosure in most cases had a negative impact on adherence however some participants reported receiving support from friends they had disclosed their HIV status to. Disclosure was found to be a very dynamic process. Four decades into the epidemic, HIV is still a highly stigmatised illness and many respondents in this study highlighted a fear of discrimination and stigma - both overt and perceived stigma - as barriers to remaining adherent to ART. Interestingly many of the younger participants reported being forbidden by their parents/caregivers to disclose their HIV status to others. This may be related to parental fears of indirect disclosure of parental HIV status.

Finally, unique adolescent attributes such as having unstructured lives and a sense of invincibility also made treatment adherence very difficult. This may be compounded by alcohol usage and non-disclosure. And lastly, sadness, depression and loneliness had a profoundly negative effect on treatment adherence in this cohort.

## **6.2. RECOMMENDATIONS**

Following data collection and an in-depth analysis of the wealth of data collected, the following recommendations are made for health care workers, ART users, parents/caregivers of HIV positive adolescents, policy planners/implementers, school teachers and the community. The researcher is of the opinion that these recommendations will go a long way in improving adherence to ART amongst HIV positive adolescents.

## **Health Care Workers**

Health care workers need to be aware of the barriers that influence adherence amongst adolescents and receive training specific on how to deal with HIV positive adolescents and be sensitive to their needs. They should enquire about symptoms of anxiety and depression at each visit and promptly refer all patients who present with these symptoms to a mental health care practitioner. All patients and caregivers should be treated equally and with dignity regardless of their level of adherence and patients and caregivers should not be verbally abused by health care workers. Every attempt should be made not to lose or misplace files/patient documents. Health care workers should enquire about disclosure, sexual partners and household dynamics at each visit.

## **ART users**

ART users should always consider disclosing their HIV status to at least one trustworthy and reliable person. They should seek out sources of support such as HIV support groups and spiritual groups to facilitate their adherence to ART.

## **Parents/caregivers**

Parents and caregivers need to be supportive of their HIV positive adolescents and/or foster children. They need to enquire from adolescents regarding their treatment adherence and be alert to symptoms of depression and anxiety.

## **Policy planners/implementers**

Policy planners and implementers need to design and implement adolescent-specific medical stationery/tools that address the barriers associated with adherence. They should prioritise, plan and facilitate the implementation of adolescent-friendly health facilities and systems such as more flexible clinic operating times, evening and/or weekend clinics and have dedicated clinic days for adolescents. Policy makers should facilitate the implementation of peer support groups as well as text messaging services to remind clients about their clinic dates. The roll-out and funding of long-acting ART should be prioritised. Policy makers should motivate for mandatory annual mental health screening for example an annual visit to the psychologist as well as mandatory evaluation of family dynamics prior to ART initiation and annually thereafter.

### **School teachers**

School teachers need to be aware that there are learners infected and affected with HIV at schools and therefore address the topic with sensitivity. They should provide ongoing education about HIV prevention strategies and be supportive of learners who require regular clinic visits. School teachers should provide evidence-informed teaching about HIV and avoid spreading messages which may have discriminatory undertones.

### **Community**

The community should facilitate programmes to decrease HIV-related stigma and discrimination. The community should also be supportive of those on ART and encourage the formation of support groups



## REFERENCES

- Adams, G. & Berzonsky, M. (2006). *Handbook of Adolescence*. Malden: Blackwell.
- Aylward, G. (2002). Cognitive and Neuropsychological Outcomes: More than IQ Scores. *Mental Retardation and Developmental Disabilities Research Reviews*, (8): 234-240
- Wiener, L., Kohort, B., Battles, H. & Pao, M. (2011). The HIV Experience: Youth Identified Barriers for Transitioning from Paediatric to Adult Care. *Journal of Paediatric Psychology*, 36 (2): 141-154.
- Bakanda, C., Birungi, J., Mwesigwa, R., Nachega, J., Chan, K., Palmer, A., Ford, N. & Mills, E. (2011). Survival of HIV-Infected Adolescents on Antiretroviral Therapy in Uganda: Findings from a Nationally Representative Cohort in Uganda. *PLoS ONE*, 6 (4): 1-6.
- Baum, F. (1995). Researching Public Health: Behind the Qualitative-Quantitative Methodological Debate. *Social Science and Medicine*, 40 (4): 459-468.
- Bekker, L., Cotton, M., Maarten, G., Meyers, T., Venter, F. & Wilson, D. (2008). *Handbook of HIV Medicine*. Southern Africa: Oxford University Press.
- Bekker, L., Johnson, L., Wallace, M. & Hosek, S. (2015). Building our Youth for the Future. *Journal of the International Aids Society*, 18 (1): 1-7.
- Bermudez, L., Jennings, L., Ssewamala, F., Nabunya, P., Mellins, C. & McKay, M. Equity in Adherence to Antiretroviral Therapy Among Economically Vulnerable Adolescents Living with HIV in Uganda. *Aids Care*, 28 (2): 83-91.
- Bhana, A., Mellins, C., Small, L., Nestadt, D., Leu, C-S., Petersen, I., Machanyangwa. S. & McKay, M. (2016). Resilience in Peri-natal HIV Positive Adolescents in South Africa. *Aids Care*, 28 (2): 49-59.
- Boyes, M., Cluver, L., Orkin, M. & Sherr, L. (2014). Cash, Care and HIV Risk for Adolescents in Southern Africa. *Journal of AIDS*, 28 (3): 389-397.

Brown, L., Lourie, K. & Poa, M. (2000) Children and Adolescents with HIV and AIDS: A Review. *Journal of Child Psychology and Psychiatry*, 41 (1):81-96.

Butler, K., Turkova, A., Inshaw, J., Compagnucci, A., Kenny, J., Saidi, Y., Musiime, V., Nanduudu, A., Cressey, T., Chalermpanmetagul, S., Scott, K., Harper, L., Montero, S., Riault, Y., Bunupuradah, T., Volokha, A., Flynn, P., Bologna, R., Kizito, H., Ramos, J., Nastouli, E., Klein, N., Giaquinto, C., Ford, D. & Babiker, A. (2016). Weekends-off Efavirenz-based Antiretroviral Therapy in HIV-infected Children, Adolescents, and Young Adults (BREATHER): A Randomized, Open-label, Non-inferiority, Phase 2/3 trial. *Lancet*, 16: 1-10.

Chesney, M. (2000). Factors Affecting Adherence to Antiretroviral Therapy. *Clinical Infectious Disease*, 30 (2): 171-176.

Cluver, L., Hodes, R., Sherr, L., Orkin, F., Meinck, F., Ken, P., Winder-Rossi, N., Wolfe, J., & Vicari, M. (2015). Social Protection: Potential for Improving HIV Outcomes Among Adolescents. *Journal of the International AIDS Society*, 18 (6): 20260-20267.

Cluver, L., Toska, E., Orkin, F., Meinck, F., Hodes, R., Yakubovich, A., Sherr, L. (2016). Achieving Equity in HIV-treatment Outcomes: Can Social Protection Improve Adolescent ART Adherence in South Africa? *AIDS CARE*, 28 (2): 73-82.

Cotton, M., Jaspán, H., Li, R., Nattrass, N., O'Brien, V. & Rabie, H. (2010). Positive Futures: A Qualitative Study on the Needs of Adolescents on Antiretroviral Therapy in South Africa. *AIDS Care*, 60 (22): 751-758.

Creswell, J. & Miller, D. (2000). Determining Validity in Qualitative Inquiry. *Theory Into Practice*, 39 (3): 124-130.

Davies, M-A. & Pinto, J. (2015). Targeting 90-90-90- Don't Leave Children and Adolescents Behind. *Journal of the International AIDS Society*, 18 (6): 20745-20751.

Department of Health. (2015). *National Consolidated Guidelines for the Prevention of Mother- to- Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults*. South Africa: Department of Health. [Online], Available: <http://www.doh.gov.za> [Downloaded: 10/10/2015 04:00PM]

Department of Labour. (2012). *Basic Conditions of Employment Act*. Government Gazette No 37955. South Africa: Department of Labour. [Online], Available: <http://www.labour.gov.za/DOL/downloads/legislation/acts/basic-conditions> [Downloaded: 01/04/2016 05:30 PM].

Ferrand, R. (2016). *Adolescent Adherence and Retention: The Weakest Link*. 21<sup>st</sup> International AIDS Conference, Durban.

Gonzales-Soldevilla, A., Pantin, H., Perrino, T. & Szapocznik, J. (2000). The Role of Families in Adolescent HIV Prevention: A Review. *Clinical Child and Family Psychology Review*, 3 (2): 81-92.

Goode, M., McMaugh, A., Crisp, J., Wales, S. & Ziegler, J. (2003). Adherence Issues in Children and Adolescents Receiving Highly Active Antiretroviral Therapy. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*. 15 (3): 403-408.

Gray, G. (2010). Adolescent HIV - Cause for Concern in Southern Africa. *PLoS Medicine*. 7 (2): 100-108.

Gross, R., Lowenthal, E., Mills, E., Nachega, J., Ndiaye, M., Nguyen, H. & Nyasulu, P. (2013). Risk Factors for Suboptimal Antiretroviral Therapy Adherence in HIV-infected Adolescents in Gaborone, Botswana: A Pilot Cross-sectional Study. *Patient Preference and Adherence*, 2013 (7): 891-895.

Haberer, J. & Mellins, C. (2009). Paediatric Adherence to HIV Antiretroviral Therapy. *Current HIV/AIDS Reports*, 6 (4):194-200.

Herek, G., Gillis, J., & Cogan, J. (2009). Internalised Stigma Among Sexual Minority Adults: Insights from a Social Psychological Perspective. *Journal of Counselling Psychology*, 56 (1),

32-43. In Wei, W., Xiaoming, L., Harrison, S., Zhao, J. & Zhao, G. (2016). The Relationship Between HIV Stigma, Emotional Status and Emotional Regulation Among HIV-affected Children in Rural China. *AIDS CARE*, 28 (2): 161-167.

Hislop, M., Maartens, G. & Nachega, J. (2009). Antiretroviral Therapy Adherence, Virological and Immunological Outcomes in Adolescents Compared with Adults in Southern Africa. *Journal of AIDS*, 51 (1): 65-71.

Hoare, J. (2016). *The Adolescent Brain: Understanding How Youth Perceive Risks and Healthcare Needs*. 21<sup>st</sup> International AIDS Conference, Durban.

Hsieh, H. & Shannon, S. (2005). Three Approaches to Content Analysis. *Qualitative Health Research* 15:1277 [Online], Available: <http://qhr.sagepub.com/content/15/9/1277> [Downloaded: 30.01.2014].

Hudelson, C. & Cluver, L. (2015). Factors Associated with Adherence to Anti-retroviral Therapy Among Adolescents Living with HIV/AIDS in Low and Middle Income Countries: A Systematic Review. *AIDS CARE*, 27 (7): 805-816.

Idele, P., Gillespie, A., Porth, T., Suzuki, C., Mahy, M., Kasedde, S. and Luo, C. (2014). Epidemiology of HIV and AIDS Among Adolescents: Current Status, Inequities, and Data Gaps. *Journal of Acquired Immune Deficiency Syndrome*, 66 (2): 144-153.

Jack, S. (2006). Utility of Qualitative Research Findings in Evidence-based Public Health Practice. *Public Health Nursing*, 23 (3): 277-283.

Kim, S., Gerver, S., Fidler, S. & Ward, H. (2014). Adherence to Anti-retroviral Therapy in Adolescents Living with HIV. A Systematic Review and Meta Analysis. *AIDS*, 28 (13): 1945-1956.

Larkan F., van Wyk B., Stevens, P. & Saris, A. (2015). Between the Clinic and the Community: Temporality and Patterns of ART Adherence in the Western Cape Province,

South Africa. *African Sociological Review*, 19 (2): 26-52.

Laughton, B., Cornell, M., Bovin, M. & Van Rie, A. (2013). Neurodevelopment in Perinatally HIV-infected Children: A Concern for Adolescence. *Journal of the International AIDS Society*, 18 (16): 18604-18615.

Malee, K. & Mellins C. (2013). Understanding the Mental Health of Youth Living with Perinatal HIV Infection: Lessons Learned and Current Challenges. *Journal of the International AIDS Society*, 18 (16): 18593-18603.

Malee, K., Williams, P., Montepiedra, G., Nichols, S., Siroius, P. & Storm, D. (2008). The Role of Cognitive Functioning in Medication Adherence of Children and Adolescents with HIV. *Journal of Paediatric Psychology*, 34 (2): 164-175. In Wiener, L., Kohort, B., Battles, H. & Pao, M. (2011). The HIV experience: Youth Identified Barriers for Transitioning from Paediatric to Adult Care. *Journal of Paediatric Psychology*, 36 (2): 141-154.

Margolis, D., González-García, J., Stellbrink, H., Eron, J., Yazdanpanah, Y., Griffith, S., Dorey, D., Smith, K., Williams, P. & Spreen, W. (2016). *Cabotegravir and Rilpivirine as Long-acting Maintenance Therapy: LATTE-2 Week 32 results*. Conference on Retroviruses and Opportunistic Infections, Boston.

Maskew, M., Bor, J., Maclead, W., Carmona, S., Sherman, G. & Fox, M. (2016). *The Youth Treatment Bulge in South Africa: Increasing Numbers, Inferior Outcomes Among Adolescents on ART*. 21<sup>st</sup> International AIDS Conference, Durban.

McPherson, P., Chigonezgo, M., Furguson, J., Armstrong, A., Kranzer, K., Ferrand, R. & Ross, D. (2015). Service Delivery Interventions to Improve Adolescents Linkage, Retention and Adherence to Antiretroviral Therapy and HIV Care. *A European Journal for Tropical Medicine and International Health*, 20 (8): 1015-1032.

Medicines SANS Frontiers / Doctors Without Borders, Southern African HIV Clinicians Society, Section 27, Rural Doctors Association of Southern Africa, Treatment Action Campaign & Rural Health Advocacy Project (2015). *Stop Stock Outs 3<sup>rd</sup> Annual National Survey: Interim Results*.

Mellins, C., Havens, J., McDonald, C., Lichtenstein, C., Chesney, M. (2009). Adherence to Antiretroviral Medication and Medical Care in HIV-infected Adults Diagnosed with Mental and Substance Abuse Disorders. *AIDS Care*, 21 (2): 168-177.

Mellins, C., Brackis-Cott, E., Dolezal, C. & Abrams, E. (2004). The Role of Psychosocial and Family Factors in Adherence to Antiretroviral Treatment in Human Immunodeficiency Virus-infected Children. *Paediatric Infectious Diseases Journal*. 23 (11): 1035-1041.

Merzel, C., Van Devanter, N., Irvine, M. (2008). Adherence to Antiretroviral Therapy among Older Children and Adolescents with HIV: A Qualitative Study of Psychosocial Contexts. *AIDS Patient Care and STDs*. 22 (12): 977-987.

Mokdad, A., Forouzanfar, M., Daoud, F., Mokdad, A., Bcheraoui, C., Moradi-Lakeh, M., Kyu, H., Barber, R., Wagner, J., Cercy, K., Kravitz, H., Coggeshall, M., Chew, A., O'Rourke, K., Steiner, C., Tuffaha, M., Charara, R., Al-Ghamdi, E., Adi, Y., Afifi, R., Alahmadi, H., AlBuhairan, F., Allen, N., AlMazroa, M., Al-Nehmi, A., AlRayess, Z., Arora, M., Azzopardi, P., Barroso, C., Basulaiman, M., Bhutta, Z., Bonell, C., Breinbauer, C., Degenhardt, L., Denno, D., Fang, J., Fatusi, A., Feigl, A., Kakuma, R., Karam, N., Kennedy, E., Khoja, T., Maalouf, F., Obermeyer, C., Mattoo, A., McGovern, T., Memish, Z., Mensah, G., Patel, V., Petroni, Z., Reavley, N., Zertuche, D., Saeedi, M., Santelli, J., Sawyer, S., Ssewamala, F., Taiwo, K., Tantawy, M., Viner, R., Waldfogel, J., Zuñiga, M., Naghavi, M., Wang, H., Vos, T., Lopez, A., Rabeeah, A., Patton, G. & Murray, C. (2016). Global Burden of Diseases, Injuries, and Risk Factors for Young People's Health During 1990-2013: A Systematic Analysis for the Global Burden of Diseases Study 2013. *Lancet*, 387: 2383-2401.

Murphy, D., Belzer, M., Durako, S., Sarr, M., Wilson, C. & Muenz, L. (2005). Longitudinal Antiretroviral Adherence among Adolescents Infected with Human Immunodeficiency Virus. *JAMA Paediatrics*, 159 (8): 764-770.

Murphy, D., Wilson, C., Durako, L., Muenz, L. & Belzer, M. (2010). Antiretroviral Medication Adherence Among the REACH HIV-infected Adolescent Cohort in the USA. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 13 (1): 27-40.

Nabukeera-Barungi, N., Elyanu, P., Asire, B., Katureebe, C., Lukabwe, I., Namusoke, E., Musinguzi, J., Atuyambe, L & Tumwesigye, N. (2015). Adherence to Antiretroviral Therapy and Retention in Care for Adolescents Living with HIV from 10 Districts in Uganda. *BMC Infectious Diseases*, 15: 520-530.

Nachega, J., Hislop, M., Nguyen, H., Dowdy, D., Chaisson, R., Regensberg, L., Cotton, M. & Maartens, G. (2009). Antiretroviral Therapy Adherence, Virologic and Immunologic Outcomes in Adolescents Compared with Adults in Southern Africa. *Journal of AIDS*, 51 (1): 65–71.

Nachega, J., Uthman, O., Peltzer, K., Richardson, L., Mills, K. & Ouedraogo, A. (2014). Association Between Antiretroviral Treatment Therapy Adherence and Employment Status: Systematic Review and Meta-analysis. *Bulletin of the World Health Organisation*, 93 (1): 29-41.

Nglazi, M., Kranzer, K., Holele, P., Kaplan, R., Mark, D., Jaspán, H., Lawn, S., Wood, R. & Bekker, L. (2012). Treatment Outcomes in HIV-infected Adolescents Attending a Community-based Antiretroviral Therapy Clinic in South Africa. *BMC Infectious Diseases*, 21 (12): 21-30.

Nuttall, J. (2006). The Adolescent with HIV Infection. *The South African Paediatric Review*. 1-11.

Pantelic, M., Shenderovich, Y., Cluver, L., & Boys, M. (2015). Predictors of Internalized HIV-related Stigma: A Systematic Review of Studies in Sub-Saharan Africa. *Health Psychology Review*, 9 (4): 469-490.

Pao, M., Lyon, M., D'Angelo, L., Schuman, W., Tipsin, T. & Mrazek, D. (2000). Psychiatric Diagnoses in Adolescents Seropositive for the Human Immunodeficiency Virus. *Archives of Pediatric Adolescent Medicine*, 154 (3): 240-244 in Brown, L., Lourie, K. & Poa, M. (2000) Children and Adolescents with HIV and AIDS: A Review. *Journal of Child Psychology and Psychiatry*, 41(1):81-96.

Parker, R., Aggleton, P. (2003). HIV and AIDS-related Stigma and Discrimination; A Conceptual Framework and Implications for Action. *Social science and Medicine*, 57 (1): 13-24. In Wei, W., Xiaoming, L., Harrison, S., Zhao, J. & Zhao, G. (2016). The Relationship Between HIV Stigma, Emotional Status and Emotional Regulation among HIV-affected Children in Rural China. *AIDS CARE*, 28 (2): 161-167.

Penazzato, M., Lee, J., Capparelli, E., Essajee, S., Ford, N., Ojoo, A., Pascual, N & Lallament, M. (2015). Optimizing Drugs to Reach Targets for Children and Adolescents Living with HIV. *Journal of the International AIDS society*, 18 (6): 20270-20280.

Plüddemann, A. & Parry, C. (2012). *Methamphetamine Use and Associated Problems among Adolescents in the Western Cape Province of South Africa: A Need for Focused Interventions*. Medical Research Council Policy Brief, South Africa, [Online], Available: <http://www.mrc.ac.za/policybriefs/Methamphetamine.pdf> [Downloaded: 05/05/2016 05:30 PM]

Pontali, E. (2005). Facilitating Adherence to Highly Active Antiretroviral Therapy in Children with HIV Infection. *Paediatric Drugs*, 7 (3): 137-149.

Reda, A & Biadgilign, S. (2012). Determinants of Adherence to Antiretroviral Therapy among HIV-infected Patients in Africa. *AIDS Research and Treatment*, 2012: 1-8.

Reisner, S., Mimiaga, M., Skeer, M., Perkovich, B., Johnson, C. & Safren, S. (2009). A Review of HIV Antiretroviral Adherence and Intervention Studies among HIV-infected Youth. *Top HIV med*, 17 (1):14-25.

Roa, D., Kekwaletswe, T., Hosek, S., Martinez, J. & Rodriguez, F. (2007). Stigma and Social Barriers to Medication Adherence with Urban Youth Living with HIV. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 19: 28-33.

Sharer, M., Cluver, L., Shields, J. & Ahearn, F. (2016). The Power of Siblings and Caregivers: Under-explored Types of Social Support among Children Affected by HIV and AIDS. *AIDS CARE: Psychological and Socio-medical Aspects of AIDS/HIV*, 28 (2): 110-117.

Simelela, N. & Venter, W. (2014). A Brief History of South Africa's Response to AIDS. *South African Medical Journal*, 104 (3): 249-251.

Southern African HIV Clinicians Society. (2013). *Fixed-dose Combinations for Adults Accessing Antiretroviral Therapy*. [Online], Available: <http://www.sahivsoc.org/societyguidelines>. [Downloaded: 10/08/2015 01:30 PM]

Statistics South Africa (2012). *City of Cape Town-2011 Census Suburb Mfuleni*. [Online] Available: <http://www.statssa.gov.za/publications/P03014/P030142011>. [Downloaded: 10/03/2015 06:00 PM]

Medical Research Council (2011). *Survey on Substance Use, Risk Behaviour and Mental Health among Gr. 8-10 Learners in Schools in the Western Cape Province, 2011*. [Online] Available: <http://www.mrc.ac.za>. [Downloaded: 05/05/2016 08:00 PM].

UNAIDS (2013). Thematic Segment: HIV, Adolescents and Youth. Geneva: UNAIDS, 1-27.

UNAIDS (2014). 90-90-90 An Ambitious Treatment Target to Help End the AIDS Epidemic. Geneva: UNAIDS, 1-37.

Underwood, C., Hendrickson, B., Lynn, M., Van Lith, M., Kunda, J. & Mallalieu, C. (2014). Role of Community-level Factors Across the Treatment Cascade: A Critical Review. *Journal of Acquired Immune Deficiency Syndrome*. 66(2): 311-318.

Uthman, O., Magidson, J., Safren, S., & Nachega, J. (2014). Depression and Adherence to Antiretroviral Therapy in Low-, Middle-and High-income Countries: A Systematic Review and Meta-analysis. *Current HIV/AIDS Reports*, 11 (3): 291-307.

Wassenaar, D. (2007). Chapter 4 - Ethical Issues in Social Science Research. In Terre Blanche, M. & Durrheim, K. (eds). *Research in Practice: Applied Methods for the Social Science*: 67-69. Cape Town: UCT Press.

Wei, W., Xiaoming, L., Harrison, S., Zhao, J. & Zhao, G. (2016). The Relationship between HIV Stigma, Emotional Status and Emotional Regulation among HIV-affected Children in

Rural China. *AIDS CARE*, 28 (2): 161-167.

Whitehouse, S. (2013). Retention of medical records. *Medical Chronicle*, 11 June.

WHO (2010). *Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector: Progress Report 2010*. Geneva, Switzerland. WHO, 2010.

WHO (2013). *Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV: Recommendations for a Public Health Approach and Considerations for Policy-makers and Managers*. Geneva. WHO: 1-81.

WHO (2015). *Fact Sheet on HIV*. [Online]. Available: <http://www.who.int> [Downloaded: 10/04/2016 07:00 PM]

WHO (2015). *Guidelines on When to Start Antiretroviral Therapy and on Pre-exposure Prophylaxis for HIV*. Geneva, Switzerland.

Wiener, L., Kohort, B., Battles, H. & Pao, M. (2011). The HIV Experience: Youth Identified Barriers for Transitioning from Paediatric to Adult Care. *Journal of Paediatric Psychology*, 36 (2): 141-154.

Williams, P., Storm, D., Montepieda, G., Nichols, S., Kammerer, B., Sirois, P., Farley, J. & Malee, K. (2006). Predictors of Adherence to Antiretroviral Medications in Children and Adolescents with HIV Infection. *Paediatrics*, 118 (6): 1745-1757.

## APPENDICES

### Appendix A: Information sheet for parents



University of the Western Cape

School of Public Health



### PARTICIPANT INFORMATION SHEET FOR PARENTS/GAURDIANS

**Project Title:** Adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

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

This is a research project being conducted by Lee-Ann Davids at the University of the Western Cape. We are inviting your child/dependant to participate in this research project because he/she is currently between the age of 10 and 19 years and accessing Antiretroviral treatment (ART) at this facility. The purpose of this research project is to try and identify what are the reasons or circumstances for adolescents to not remain compliant on their ARTs. We are hoping that if we have this information that assistance can be provided to patients and staff members to enable better compliance to medication.

#### **What will your child/dependant be asked to do if he/she agrees to participate?**

He/she will be asked to participate in a group discussion and possibly a one-on-one interview with the researcher and a translator if required. If he/she wishes to participate in the study he/she will be asked to sign a consent form. The interviews will last approximately 45minutes. The participants will be asked questions about things like their family support, schooling or work situation; their experience with ART and the clinic staff. The interviews will be conducted in a quiet room at the clinic at a time that suits them best.

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

The researcher undertakes to protect their identity and the nature of their contribution at all times. This study will use focus groups therefore the extent to which their identity will remain confidential is dependent on participants' in the focus group maintaining confidentiality. In addition, there may be some conditions under which confidentiality will be broken such as when the researcher is made aware of criminal activity which participants have been or are currently still victim of. Under these conditions, the researcher is compelled to break confidentiality and to report the criminal behaviour to the relevant authorities. If this situation does arise, the researcher will make the participant aware of her intention to break confidentiality.

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

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risk. We will nevertheless minimise such risks and act promptly to assist your child if they 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?**

The benefits to your child includes that they may find it supportive to meet and talk to other participants their own age that may be facing similar situations to theirs. If we are able to identify and explore the issues which contribute to poor compliance then your child may benefit if we act on this information and put measures in place to try and optimise the care of adolescents on ARTs

The results may help the investigator learn more about ART non-compliance and what leads to this problem. We hope that, in the future, other people might also benefit from this study through improved understanding of these issues.

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

Their participation in this research is completely voluntary. They may choose not to take part at all. If your child decides to participate in this research, he/she may stop participating at any

time. If they decide not to participate in this study or if they stop participating at any time, they will not be penalized or lose any benefits to which they otherwise qualify.

**What if my child has questions?**

This research is being conducted by Lee-Ann Davids *a Masters student at the School of Public Health* at the University of the Western Cape. If you have any questions about the research study itself, please contact Lee-Ann Davids at +27722333877 or at 9 Melina Street, Rosendal, Durbanville, 7550. Alternatively you may send an email to 3409645@myuwc.ac.za

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

Prof Helen Schneider  
School of Public Health  
Head of Department  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)



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## Appendix B: Participant information sheet



University of the Western Cape

School of Public Health



### **PARTICIPANT INFORMATION SHEET**

**Project Title:** Adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

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

This is a research project being conducted by Lee-Ann Davids at the University of the Western Cape. We are inviting you to participate in this research project because you are currently between the age of 10 and 19 years and accessing Antiretroviral treatment at this facility. The purpose of this research project is to try and identify what are the reasons or circumstances for adolescents to not remain compliant on their ARTs. We are hoping that if we have this information that assistance can be provided to patients and staff members to enable better compliance to medication.

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

You will be asked to participate in a group discussion and possibly a one-on-one interview with the researcher and a translator if required. If you wish to participate in the study you will be asked to sign a consent form. If you are younger than 18 years old, both you and your parent/guardian will have to sign the form. The interviews will last approximately 45 minutes. You will be asked questions about things like your family support, schooling or work situation, your experience with ART and the clinic staff. The interviews will be conducted in a quiet room at the clinic at a time that suits you best.

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

The researcher undertakes to protect your identity and the nature of your contribution at all times. This study will use focus groups therefore the extent to which your identity will remain

confidential is dependent on participants' in the Focus Group maintaining confidentiality. In addition, there may be some conditions under which confidentiality will be broken such as when the researcher is made aware of criminal activity which participants have been or are currently still victim of. Under these conditions, the researcher is compelled to break confidentiality and to report the criminal behaviour to the relevant authorities. If this does happen, the researcher will make you aware of her intentions.

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

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We 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?**

The benefits to you include that you may find it supportive to meet and talk to other participants your own age that may be facing similar situations than you are. If we are able to identify and explore the issues which contribute to poor compliance then you may benefit if we act on this information and put measures in place to try and optimise the care of adolescents on ARTs

The results may help the investigator learn more about ART non-compliance and what leads to this problem. We hope that, in the future, other people might also benefit from this study through improved understanding of these issues.

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

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

### **What if I have questions?**

This research is being conducted by Lee-Ann Davids, *a Masters student at the School of Public Health* at the University of the Western Cape. If you have any questions about the research study itself, please contact Lee-Ann Davids at +27722333877 or 9 Melina Street, Rosendal, Durbanville, 7550. Alternatively send an email to [3409645@myuwc.ac.za](mailto:3409645@myuwc.ac.za)

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

Prof Helen Schneider

School of Public Health

Head of Department

University of the Western Cape

Private Bag X17

Bellville 7535

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



Prof José Frantz

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

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

## Appendix C: Information sheet for key informants



University of the Western Cape

School of Public Health



### INFORMATION SHEET FOR KEY INFORMANTS

**Project Title:** Adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

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

This is a research project being conducted by Lee-Ann Davids at the University of the Western Cape. We are inviting you to participate in this research project because you are working with adolescents who are HIV positive and on antiretroviral treatment and you are considered to be very knowledgeable on the subject matter and will be able to provide the researcher with useful insights. The purpose of this research project is to try and identify what are the reasons or circumstances for adolescents to not remain compliant on their ARTs. We are hoping that if we have this information that assistance can be provided to patients and staff members to enable better compliance to medication.

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

You will be asked to participate in a one-on-one interview with the researcher and a translator if required. If you wish to participate in the study you will be asked to sign a consent form. The interview will last approximately 20 minutes. You will be asked about your experiences in working with HIV positive adolescents on antiretroviral treatment. The interviews will be conducted in a quiet room at the clinic at a time that suits you best.

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

The researcher undertakes to protect your identity and the nature of your contribution at all times.

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

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We 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?**

The results may help the investigator learn more about ART non-compliance and what leads to this problem. We hope that, in the future, other people might also benefit from this study through improved understanding of these issues.

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

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

### **What if I have questions?**

This research is being conducted by Lee-Ann Davids, *a Masters student at the School of Public Health* at the University of the Western Cape. If you have any questions about the research study itself, please contact Lee-Ann Davids at +27722333877 or 9 Melina Street, Rosendal, Durbanville, 7550. Alternatively send an email to 3409645@myuwc.ac.za

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 D: Assent form**



**University of the Western Cape**

**School of Public Health**



**ASSENT FORM**

**Title of Research Project:** Adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

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

This research project involves making audiotapes of the focus group discussions and one-on-one interviews. An audio tape will enable the researcher to record the information and transcribe it later which entails listening to the recording and typing out every word. This is being done because it will be very difficult to write down everything as the discussions are taking place. The audio tapes will be stored in a locked cupboard and only the researcher will have a key.

\_\_\_ 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 signature.....**

**Date.....**

**Appendix E: Consent form**

**University of the Western Cape**

**School of Public Health**



**CONSENT FORM**

**Title of Research Project:** Adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

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

This research project involves making audiotapes of the focus group discussions and one-on-one interviews. An audio tape will enable the researcher to record the information and transcribe it later which entails listening to the recording and typing out every word. This is being done because it will be very difficult to write down everything as the discussions are taking place. The audio tapes will be stored in a locked cupboard and only the researcher will have a key.

\_\_\_ 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 signature.....**

**Parents signature (if participant is <18years old).....**

**Date.....**

**Appendix F: Consent form for key informants**



**University of the Western Cape**

**School of Public Health**



**CONSENT FORM FOR KEY INFORMANTS**

**Title of Research Project:** Adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

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

This research project involves making audiotapes of the interview. An audio tape will enable the researcher to record the information and transcribe it later which entails listening to the recording and typing out every word. This is being done because it will be very difficult to write down everything as the discussion is taking place. The audio tapes will be stored in a locked cupboard and only the researcher will have a key.

\_\_\_ 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 signature.....**

**Date.....**

**Appendix G: Focus group confidentiality binding form**

**University of the Western Cape**



**School of Public Health**



**FOCUS GROUP CONFIDENTIALITY BINDING FORM**

**Title of Research Project:** Adherence to antiretroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. 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 understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

**Participant's name.....**

**Participant's signature.....**

**Date.....**

## Appendix H: Focus group discussion question guide

University of the Western Cape



School of Public Health



### FOCUS GROUP DISCUSSION QUESTION GUIDE

#### Question 1

Could you tell me how your financial situation and schooling impacts on you taking your medication?

*Prompts:*

Do you have enough time after school to access the clinic?

Is the clinic accessible after school?

Do you feel comfortable telling your teachers that you need to go to the clinic to get medication?

How does your employment routine and relationship with your employer influence if you go to collect medication?

How does your financial situation and family relationships impact on whether you collect and take your treatment?

#### Question 2

Tell me a bit about your relationship with the clinic and clinic staff?

*Prompts*

What do you like and dislike about the clinic and staff members?

What sort of support (if any) do you receive from the clinic and staff members?

Do you feel the clinic encourages you to take your medication?

What about the clinic and the staff do you think will motivate you to take your treatment?

Question 3

Can you tell me about your experience with taking your pills?

*Prompts*

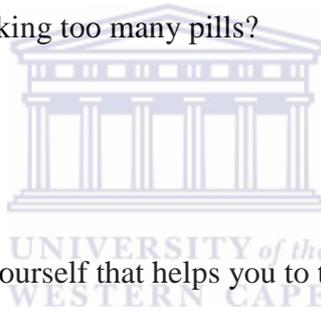
How do your tablets make you feel?

What helps you to remember to take your pills?

Why do you sometimes forget to take your pills?

Have your pills ever made you feel sick and what do you do if that happens?

Do you sometimes feel you are taking too many pills?



Question 4

What are the good factors about yourself that helps you to take your meds?

What do you think are bad things about yourself and your life that causes you to forget to take your meds?

*Prompts*

Tell me about what you and your friends do over the weekends?

Drugs. Alcohol. Excessive partying.

Question 5

How do you think speaking about your HIV status helps you to take your medication?

*Prompts*

Does your family encourage you to speak about your status?

Do you have a best friend?

Are you shy/ embarrassed about your status?

Question 6

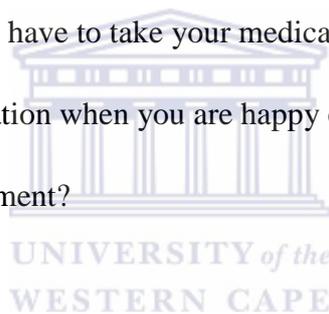
How do you think your mood influences whether you take your medication?

*Prompts*

Are you sometimes sad when you have to take your medication?

Do you prefer taking your medication when you are happy or sad?

How do you feel about your treatment?



Question 7

Do you think the treatment can improve your health?

Question 8

What do you think about having a “boyfriend” or “girlfriend”?

## Appendix I: Individual in-depth interview guide



University of the Western Cape

School of Public Health



### INDIVIDUAL IN-DEPTH INTERVIEW GUIDE

Explain to me how attending school and school commitments influences your clinic attendance and taking ART.

What are the issues at home and in your family that makes it difficult for you to take your treatment and come to the clinic?

Please explain how finances influences the way you take your treatment.

Please elaborate on your relationship with the clinic and the clinic staff.

How do you feel about the fact that you have to take treatment on a daily basis?

How do you feel about having a boyfriend or girlfriend?

What are the things which make it difficult for you take your ART?

What are the things which encourage you to take your ART?

How do you feel about telling your friends or family about your HIV status?

What effect do you think the treatment has on your body?

What are your plans for the future?

What do you do on the weekends?

Have you noticed if there are certain times in the day/week/year when it is difficult to take your treatment?

## Appendix J: Key-informant interview guide

University of the Western Cape



School of Public Health



### KEY-INFORMANT INTERVIEW GUIDE

Tell me about your experience with managing adolescents

Do you enjoy it: why or why not?

How do you think the adolescents' socio-economic situation influences their adherence to ARTs?

What do you think of the health-system set-up in order to cater for adolescents?

How do you think therapy side-effects influences adherence if at all?

How do you think patient-related factors influences adherence: age; substances; psychological issues;

Are a lot of the adolescents supported by their parents/family/guardians in this clinic? Do you think that influences adherence?

In your experience, is there a difference in the reasons offered by adolescents for non adherence vs. adults

Do you think adolescents on ARTs should be managed differently than adults?

How do you think disclosure impacts on adherence?

## Appendix K: Ethics clearance from UWC



UNIVERSITY of the  
WESTERN CAPE

UNIVERSITY OF THE WESTERN CAPE  
DEPARTMENT OF RESEARCH DEVELOPMENT

18 January 2016

### To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:  
Ms L-A Davids (School of Public Health)

Research Project: Adherence to anti-retroviral treatment amongst adolescents in a low socio-economic urban setting in Cape Town, South Africa.

Registration no: 15/7/254

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

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*

Private Bag X17, Bellville 7535, South Africa  
T: +27 21 959 2988/2948. F: +27 21 959 3170  
E: [pjosias@uwc.ac.za](mailto:pjosias@uwc.ac.za)  
[www.uwc.ac.za](http://www.uwc.ac.za)

A place of quality,  
a place to grow, from hope  
to action through knowledge

## Appendix L: Ethics clearance from City of Cape Town Municipality



CITY OF CAPE TOWN  
ISIXEKO SASEKAPA  
STAD KAAPSTAD

CITY HEALTH

Dr H el ene Visser  
Manager: Specialised Health

T: 021 400 3981 F: 021 421 4894 M: 083 298 8718  
E: [Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za)

2016-02-08

**Re: Research Request: Exploration of Adherence to Anti-retroviral Treatment amongst Adolescents in a low socio-economic urban setting in Cape Town, South Africa. (6610) (ID No: 10537)**

Dear Dr Davids,

Your research has been approved as per your request to explore the factors that influence adherence to ART amongst adolescents in a primary health care clinic in a low socio-economic, peri-urban setting in Cape Town.

**Eastern Sub District:**  
Contact People

Dr P Nkurunziza (Sub District Manager)  
Tel: (021) 850-4315 / 084 800 0644  
Mrs T de Villiers (Head: PHC & Programmes)  
Tel: (021) 850-4312

**Please note the following:**

1. All individual patient information obtained must be kept confidential.
2. Access to the clinics and its patients must be arranged with the relevant Managers such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 6 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number (10537) Please use this in any future correspondence with us.
5. No monetary incentives to be paid to clients on the City Health premises.

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR G H VISSER  
MANAGER: SPECIALISED HEALTH

cc. Dr Nukurunziza & Mrs de Villiers  
Dr Jennings

CIVIC CENTRE IZIKO LOLUNTU BURGERSENTRUM  
HERTZOG BOULEVARD CAPE TOWN 8001 P O BOX 2815 CAPE TOWN 8000  
[www.capetown.gov.za](http://www.capetown.gov.za)

Making progress possible. Together.