

**BARRIERS TO ADHERENCE TO ANTIRETROVIRAL TREATMENT AMONG  
ADOLESCENTS IN ONANDJOKWE DISTRICT, NAMIBIA**

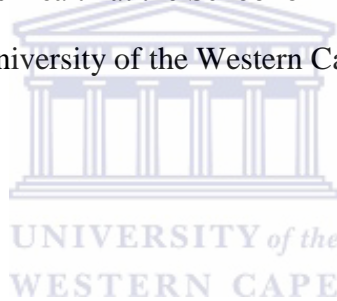
---

**Eliphas Hatutale John**

**3002983**

The submission of this mini-thesis is a component of fulfilling the requirements for a degree of  
Master's in Public Health at the School of Public Health in the

University of the Western Cape



**Supervisor: Prof Brian Van Wyk**

15 February 2017

## ABSTRACT

Poor adherence to antiretroviral therapy (ART) among paediatric and adolescent patients remains a big concern to health workers at Onandjokwe CDC clinic in Oshikoto Region of Namibia. Despite successes in the scale up of ART in Oshikoto Region the clinic experienced high prevalence of poor adherence to ART among adolescent patients. Out of 631 adolescents alive and on ART in this clinic, 154 (24%) had records of poor drug adherence between Jan 2015 and August 2015; which compared poorly to only 4 % of 7289 adults currently on ART who have records of poor adherence during the same period.

The aim of the current study was to explore barriers to adherence to antiretroviral therapy among these adolescents.

Among the study population of 631 adolescents on ART in Onandjokwe, a sample population of 154 had records of poor adherence (scored below 85%) to ART between June 2015 and August of the same year were considered for the study but among them 16 adolescents were recruited as the study sample. Additionally, 5 caregivers of adolescents on ART, 6 Healthcare Providers were selected as key informants.

A voice recorder and field notes were being used during *data collection*. Two 2 sessions of Focus Group Discussions (FGD) were held with adolescents while 2 FGD sessions held with 5 caregivers and 6 healthcare providers to elicit expert opinions. Lastly, 5 In-depth interviews were conducted with individual adolescents who missed ART medicine follow up for 1 month or more between January and August of 2015.

*Data Analysis* was performed using hand manipulation by grouping responses into main study objectives/themes. Data cleaning, translation of voice transcription from Oshiwambo to English language and incorporating of non-verbal expressions was also done

The *results* indicate that factors contributing to poor ART adherence among adolescents are patient and family related, socio-economic, and related to substance abuse, stigma and discrimination, health care and health systems, as well as the environment and weather.

## DECLARATION

I, Eliphas Hatutale John declare that *Barriers to adherence to antiretroviral treatment among adolescents in Onandjokwe district, Namibia* is my own work, that it has never been submitted before for any degree or examination at any other university, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

**Eliphas Hatutale John**

Signature:



DATE: 15 February, 2017



## **ACKNOWLEDGEMENTS**

This Study has been conducted with the on-going support from the Mini-thesis Supervisor Professor Brian van Wyk of the University of the Western Cape. Without his guidance, I may not reach where I have reached today with this study.

My great appreciation goes also to the Great Team of Onandjokwe ART Clinic for their active participation in the study and their enthusiastic provision of information.

Last but not least, I wish to express my gratitude to my family members and academic friends for their unwavering motivation and encouragement which help me to squeeze the study activities into my daily demanding duties.



<b>TABLE OF CONTENTS</b>	<b>Page</b>
<b>CHAPTER 1. INTRODUCTION</b>	<b>1</b>
<b>1.1 Global HIV Pandemic</b>	<b>1</b>
<b>1.2 HIV Epidemic in Namibia</b>	<b>1</b>
<b>1.3 Problem Statement</b>	<b>2</b>
<b>CHAPTER 2. LITERATURE REVIEW</b>	<b>4</b>
<b>2.1 Definition of Adolescence</b>	<b>4</b>
<b>2.2 Definition of Adherence</b>	<b>4</b>
<b>2.3 Causes of Poor Adherence to ART</b>	<b>5</b>
<b>CHAPTER 3. METHODOLOGY</b>	<b>15</b>
<b>3.1 Study Aim and Objectives</b>	<b>15</b>
<b>3.2 Study Design</b>	<b>15</b>
<b>3.3 Setting Description</b>	<b>16</b>
<b>3.4 Sampling</b>	<b>17</b>
<b>3.5 Preparation for Data Collection</b>	<b>17</b>
<b>3.6 Data Collection</b>	<b>18</b>
<b>3.7 Data Analysis</b>	<b>20</b>
<b>3.8 Study Rigour</b>	<b>21</b>
<b>3.9 Ethics Consideration</b>	<b>22</b>
<b>CHAPTER 4. RESULTS</b>	<b>24</b>
<b>4.1 Description of Study Participants</b>	<b>24</b>
<b>4.2 Themes</b>	<b>25</b>
<b>4.3 Patient and Family Related Challenges</b>	<b>28</b>
<b>4.3.1 Patient Related Factors</b>	<b>28</b>
<b>4.3.2 Caregiver Related Factors</b>	<b>31</b>



<b>4.4 Stigma and Discrimination</b>	<b>34</b>
<i>4.4.1 Stigma with Settings</i>	34
<i>4.4.2 Perceived and Actual Discrimination</i>	35
<b>4.5 Substances Abuse</b>	<b>36</b>
<b>4.6 Socio-economic Related Challenges</b>	<b>37</b>
<i>4.6.1 Lack of Family Income</i>	37
<i>4.6.2 Social Support Related Barriers</i>	38
<i>4.6.3 Cultural Beliefs and Practices Related Barriers</i>	39
<b>4.7 Health and Health Care Systems Related Challenges</b>	<b>40</b>
<i>4.7.1 Health Status of Adolescent on ART or of the Caregiver</i>	41
<i>4.7.2 Health Care Systems Related Challenges</i>	41
<b>4.8 Geographic and Weather Conditions Related Challenges</b>	<b>45</b>
<i>4.8.1 Geographic Conditions Related Factors</i>	45
<i>4.8.2 Weather Conditions Related Factors</i>	46
<b>CHAPTER 5. DISCUSSIONS</b>	<b>47</b>
<b>5.1 Patient and Family Related Challenges</b>	<b>47</b>
<i>5.1.1 Patient Related Barriers</i>	47
<i>5.1.2 Caregiver Related Barriers</i>	48
<b>5.2 Stigma and Discrimination</b>	<b>49</b>
<b>5.3 Substances Abuse</b>	<b>50</b>
<b>5.4 Socio-economic Related Challenges</b>	<b>51</b>
<i>5.4.1 Lack of Family Income</i>	51
<i>5.4.2 Social Support Related Barriers</i>	51
<i>5.4.3 Cultural Beliefs and Practices Related Barriers</i>	52
<b>5.5 Health and Health Care Systems Related Challenges</b>	<b>53</b>
<i>5.5.1 Health Status Barriers</i>	53
<i>5.5.2 Health Care Systems Barriers</i>	53
<b>5.6 Geographic and Weather Conditions Related Challenges</b>	<b>59</b>
<i>5.6.1 Geographic Related Barriers</i>	59
<i>5.6.2 Weather Conditions Related Barriers</i>	60

<b>5.7 STUDY LIMITATIONS</b>	<b>60</b>
<b>CHAPTER 6. CONCLUSIONS AND RECOMMENDATIONS</b>	<b>62</b>
<b>LIST OF REFERENCES</b>	<b>65</b>
<b>APPENDIXES</b>	<b>72</b>
<b>Annexure 1 Sample of Participant’s Consent Form</b>	<b>72</b>
<b>Annexure 2 FGD and In-depth Interviews Schedule</b>	<b>75</b>
<b>Annexure 3 Discussions and Interviews Guide</b>	<b>77</b>



## **CHAPTER 1. INTRODUCTION**

### **1.1 Global HIV Pandemic**

Globally, HIV/AIDS remains one of the greatest epidemics among human beings with an estimation of 36.7 million people living with HIV worldwide in 2015 of which two thirds live in sub-Saharan Africa (UNAIDS, 2016). Furthermore, over 90% of all children globally living with HIV, live in sub-Saharan Africa countries (UNAIDS, 2012). However, by 2010 the trend of HIV incidences has declined by 50% among children globally, and by 66% in Eastern and Southern African countries (UNAIDS, 2016).

As of December 2015, 2.1 million people became newly infected with HIV worldwide (UNAIDS, 2016). Antiretroviral therapy (ART) decreases the progression of HIV to Acquired Immune Deficiency Syndrome (AIDS) and prolongs and improves the quality of life (Bezabh et al., 2014). Over the last 8 years, deaths caused by AIDS related conditions have dropped significantly by 32% due to the introduction and expanded provision of ART in Namibia, Burundi, South Africa, Kenya, Zambia and Togo (UNAIDS, 2012).

From 2010 to December 2015, the percentage of adults and children accessing ART had increased significantly from 23% to 46% for adults and 21% to 49% for children (UNAIDS, 2016). According to the UNAIDS Report (2016), the increased access to ART was higher to 53% for adults and 63% for children in 2015 in Eastern and Southern African Countries. There is also a significant decline of people dying from AIDS related illness to 1.1 million in 2015 as compared to 2 million in 2005 (UNAIDS, 2016).

### **1.2 HIV Epidemic in Namibia**

As of 2015, more than 260 000 adult Namibians (from 15 years and above) and about 17 000 children are estimated to be living with HIV (MoHSS, 2016). However, the number of people dying from AIDS related diseases had dropped slightly from 3610 deaths in 2014 to 3100 in 2015 (UNAIDS, 2016). Onandjokwe District had the second highest HIV prevalence rate among pregnant women in Namibia of 25.7%, following Katima Mulilo district which reached 37.7% in 2012 (MoHSS, 2014). According to the HIV Sentinel Survey (2014), the HIV prevalence rate



among pregnant women in Onandjokwe has dropped to 22.4%, a drop which is attributed to the increased ART coverage. As per the current Namibian ART guidelines all HIV positive children below 15 years old, TB and HIV co-infected persons, HIV positive pregnant and lactating mothers, HIV discordant couples and all people living with HIV whose CD4 counts are at 500 copies and below should be put on ART treatment soon after the HIV positive test (MoHSS, 2014). By 2015, 83% of people known to be living with HIV were on ART in Namibia. Another strategy which contributes to high ART coverage is the Combination Prevention Strategy (CPS) that is being implemented aiming to prevent new HIV infections by putting all eligible patients on ART and ensuring sustained viral loads suppression (MoHSS, 2015).

### **1.3 Problem Statement**

About 154 (24%) of the total 631 adolescents currently on ART in Onandjokwe had records of poor ART adherence between January 2015 and August of the same year. During the same period, 23% of adolescents (10-19 years old) live on ART treatment in Onandjokwe were already switched to 2<sup>nd</sup> line regimens of ART treatment, primarily due to treatment failure with 1<sup>st</sup> line regimens (Onandjokwe, 2015). By June 2015, 133 out of 616 children (0-15yrs) on ART in Onandjokwe CDC were on second line ART regimens; which is far higher than 4.9% of adults (aged >15 years) switched to similar line of regimens within the same period (Onandjokwe, 2015). Apart from poor adherence, some patients may also be put on 2<sup>nd</sup> line regimens of ART treatment due to drug toxicity resulted from 1<sup>st</sup> line treatment regimens (MoHSS, 2014).

The second line medicines are relatively expensive and pose huge financial burden to health system as such procuring more 2<sup>nd</sup> line medicines may negatively affect the social and economic development of a country because more money will be channelled from developmental programs to medicine procurements.

Poor adherence to ART may not only lead to 2<sup>nd</sup> line regimens, in worse scenarios, it may lead to unnecessary deaths of people living with HIV and AIDS.

This study will form better understanding of barriers to ART adherence among adolescents in Onandjokwe ART Clinic and the results hopefully will be used by staff and authority to find the best strategies of addressing the problem.



## CHAPTER 2. LITERATURE REVIEW

### 2.1 Definition of Adolescence

The definition of adolescents from World Health Organization (WHO) defines “adolescents are young people between the ages of 10-19 years” (WHO, 2013: 1). Nachega et al. (2010) define adolescence as the growth period of children between 11-19 years of age. In Namibia’s ART clinics, adolescents are categorized into two (2) clubs, namely, teen club which includes 10 - 14 years children and the adolescents’ club which embraces adolescents aged 15 - 19 years.

This study considers adolescence as the growth stage of 10 -19 years of age as per WHO’s definition (WHO, 2013).

The common behavioural characteristics of adolescents are the increased demonstration of autonomy, rebellion, spending more time with peers than parents, self-identity and greater interest in privacy (Williams, 2016). These characteristics decrease with age increase (Williams, 2016). Adolescents are easily influenced by their peers (Williams, 2016).



### 2.2 Definition of Adherence

Good adherence to ART is one of the cornerstones for treatment success (Reda & Biadgilign, 2012). According to the Namibian National ART Guidelines (2014), ART adherence is considered *good or optimal* if the patient does not miss a dose or he/she misses less than 3 doses per month, earning a score at or above 95%. That definition corresponds with the assertions of Nachega et al. (2010) and Reda and Biadgilign (2012) that adherence is optimal if a patient scores 95% or more on taking his/her ART medications. Normally, the scoring of patient’s adherence to ART is established during pill count which is being performed by a health care provider at every patient visit to ART Clinic.

*Poor* adherence to ART leads to poor viral suppression by drugs and gives the virus high chances to multiply and weaken the body’s immunity against infections and diseases (Amberbir, Woldemichael, Getachew, Girma & Deribe, 2008). If a patient misses 4 – 8 doses per month,

adherence is regarded to be *fair or average* and will be scored from 85 to 94% (MoHSS, 2010). Adherence to ART is *sub-optimal* (below 85%) if more than 9 doses of ART medicine per month are being missed (MoHSS, 2014).

As a slight point of departure, Nachega et al. (2010) still categorize optimal adherence as from 70 – 90% and argue that such adherence level is effective for significant viral suppression. However, both sources acknowledge that optimal adherence is achieved if a patient takes ART medications properly by taking a correct dosage, at consistent scheduled times and throughout life.

Onandjokwe ART pharmacy dispenses medicines to adolescents on a monthly basis. If adolescent missed a follow up date with 3 or more days then she/he scores below 85% of ART Adherence which constitutes poor adherence to ART, because she/he misses 9 or more doses per month.

### **2.3 Causes of Poor Adherence to ART**

In sub-Saharan African countries, several studies are now being conducted to learn more on factors that influence adolescents' adherence to ART which have been poorly understood (Haberer et al., 2011). Other studies, although for general populations, have been conducted in China as well (Sabin et al., 2008) after the government expands the accessibility of HIV medicine but some patients still develop AIDS.

With their qualitative study design on the determinants of poor adherence among adolescents on ART in Africa, Reda and Biadgilign (2012) found that, the causes of poor ART adherence are related to patient and family factors, stigma and discrimination, substance abuse, socio-economic challenges, health care and systems, including medication preparations challenges. However, Santelli, Song, Garbers, Sharma, and Viner, (2016) contend that income inequalities are associated with most of the social determinants of health. Additionally, Haberer et al. (2011) contend that some adolescents perform poorly on ART adherence due to lack of family support, changes in environments and sickness of self or of the support person. Furthermore, Fetzer et al. (2011) stress that disclosure to children about their HIV statuses is one of the cornerstone factors that facilitate good adherence to medicine.

### 2.3.1 *Patient and Family Barriers*

#### i) *Patient Related Factors*

Nabukeera-Barungi et al. (2015) report that boys are likely to become stubborn by refusing to take ART medicine than girls.

An interesting discussion comes from Naar-King and colleagues (2006) that lack of self-efficacy (inability to produce the desired results) of adolescents is usually a result of rebellion behaviours and may actually lead to poor adherence to medicine taking (Naar-King et al., 2006). Some adolescents exhibit the act-out behaviours and walk out of their homes to stay with non-relatives and as result, they stop taking ART medicine (Wenger, Gifford, Liu, Chesney & Golin, 1999). Other authors who express a similar understanding said adolescents have unique behavioural characteristics which make them vulnerable to adhere poorly to the prescriptions of medicine, including of ART (Nachega et al., 2010) and that is usually the manifestation of rebellion and arrogance (Reda & Biadgilign 2012).

Some studies have explained that adolescence is characterized by risk taking, exercising of autonomy and identifying self with a certain group of youth (Institute of Medicine and National Research Council Committee US, 2011), which usually creates rebellion against the will of parents. That antagonism may cause the caregiver to use force onto adolescent to take medicine, which may lead to further rebellion and child abuse (Nabukeera-Barungi et al., 2015).

Other possible causes of poor adherence to medicines among adolescents are the noticeable frequent mental distress, peer pressure and physical changes (Arrive et al., 2012). Additionally, the requirement of taking medicines every day is boring and exhausting (Amberbir et al., 2008). Naar-King et al. (2006) and Nabukeera-Barungi et al. (2015) underscore the frequent psychological distress of some adolescents as a significant factor that leads to adolescents missing ART doses periodically.

One of the common challenges of adherence to ART among all patients is forgetfulness (Dahab et al., 2008; Perry et al., 2012; Peralta, Belzer & Palmer, 2009). Peralta, Belzer and Palmer (2009) acknowledge that some other psychosocial problems such as death of a loved one, instability in the family, financial hardships, depression and others may be the causes of forgetfulness in patients.

Some adolescents are playful by nature and they tend to forget the times of taking medicine because they are occupied with sport games even during the times of supposedly taking medicine (Nabukeera-Barungi et al., 2015).

Some adolescents especially those who started taking medicines when they were still babies, tend to stop taking ART medicines due to fatigue (Nabukeera-Barungi et al., 2015).

While some sick adolescents become more committed to ART medicines to recover, others tend to stop taking ART medicines during sickness because they regard ART as useless by not preventing them from getting sick (Nabukeera-Barungi et al., 2015).

#### *ii) Family Related Factors*

Some parents have difficulties to inform children about their HIV statuses, resulting in children not knowing the reasons of taking medicine and because of that lack of knowledge some children refuse to continue taking ART medicine, and that leads to poor adherence to drugs (Vaz et al., 2010). The authors continue to highlight the patient and family related barriers to ART adherence by outlining the limited parent-child communication, forgetfulness of the caregiver, misinformation among family members regarding the child's treatment, caregiver sickness and alcoholism (Vaz et al., 2010; Reda & Biadgilign, 2012).

Another contribution to patient-family related barriers is from the study by Haberer et al. (2011), which finds that lack of psychological support from caregivers, not knowing of own HIV status and disrupted routines of taking medicines due to increased family movements for example family visits and migrations are also some of the predictors of poor adherence to ART.

Older caregivers such as grandparents often forget to give or remind adolescents to take their medicines in time (Nabukeera-Barungi et al., 2015). Caregivers with poor understanding of HIV disease and its treatment offer poor support and children under their care demonstrate poor adherence to ART medicine taking (Ankrah et al., 2016).

### 2.3.2 *Stigma and Discrimination*

#### i) *Lack of Environmental Privacy*

Environmental stigma is caused by lack of privacy in places of confinement such as school hostels, functional gatherings and foster homes (Ankrah et al., 2016). Peralta, Belzer and Palmer (2009), say that some adolescents in boarding schools do not take their medicine until they get a chance to a toilet or bath room where there is good privacy. Discussing the environmental factors, Green and Britten (1998) acknowledge that stigma and discrimination cause some patients to be reluctant in taking their HIV medication at work and other public places such as school hostels in the case of adolescents.

#### ii) *Perceived Discrimination*

Some adolescents do not disclose their HIV status to their teachers because they can't control how far this information will reach (Thoth, Tucker, Leahy & Stewart, 2014). They fear rejection, should their HIV status information reach their peers (Thoth, Tucker, Leahy & Stewart, 2014). As a result, these adolescents do not get teachers' psychological support, hostel privacy support to take medicine and easy permission to go out to collect medicines from clinics during school classes (Thoth, Tucker, Leahy & Stewart, 2014).

Fear of rejection by a love partner is a big hindrance to HIV disclosure (Nabukeera-Barungi et al., 2015). Some young mothers in new love relationships are reportedly disassociate themselves from their children (including adolescents) who live with HIV or on ART, fearing that their new boyfriends will reject them after learning their HIV statuses through that of their children, leaving adolescents with no support (Nabukeera-Barungi et al., 2015).

### 2.3.3 *Substance Abuse*

The active use of alcohol by adolescents and alcohol abuse by treatment supporters remains one of the few relatively consistent predictors of poor adherence on ART in US (State Department of Health, 2006). Patients who abuse alcohol easily forget to take their medicine regularly because

of being intoxicated (State Department of Health, 2006). Some patients who abuse substances develop mental illness characterized by poor judgements and poor self-care including taking of medicine (Reda & Biadgilign 2012).

#### *2.3.4 Socio-economic related Challenges*

##### *i) Lack of Income*

Reda and Biadgilign (2012) highlight that user-fees are some of the health care factors which make clients reluctant to seek care in fear of costs resulting in patients missing their ART doses. Sabin et al. (2008) provide similar sentiment that high cost to medicine deters patients to access medicine.

Although antiretroviral medicines are free of charge in most sub-Saharan African countries, many patients struggle to access ART Clinics due to lack of transport fares (Ankrah et al., 2016). Transport is a scarce service in some rural areas and the only few vehicles available charge high transport fees which often, some of the orphans and treatment supporters cannot afford to pay to reach ART centres (Michaud et al., 2010).

There are some adolescents who run out of ART medicine and never show up again because they cannot afford to pay for frequent travels to ART centres due to financial constraints of parents (Ankrah et al., 2016).

Interestingly, with their observational quantitative study, Haberer et al. (2011) have associated high income per family with poor adherence to ART medication among children. The authors substantiate this to poor social support that is usually found within rich families as opposed to greater social support among the poverty stricken ones.

##### *ii) Weak or lack of Social Support*

According to the Institute of Medicine and National Research Council Committee (2011) in the United States, adolescents are very sensitive to their own identity and environment where they grow and live and they are easily being influenced by their peers to follow or divert from instructions (including of medical instructions) given to them by parents. Psychological barriers



such as lack of support, homelessness, family instability and domestic violence make adolescents more vulnerable to stop taking ART medicines (State Department of Health, 2006).

Feeling motivated is one of the facilitators to ART medicine adherence as opposed to loneliness, isolated and discriminated (Nabukeera-Barungi et al., 2015). Adolescents staying in school hostels lack parental motivation and support to continue taking ART medicine (Nabukeera-Barungi et al., 2015).

One of the social determinants affecting ART adherence among adolescents is poverty that leads to lack of food and transport money to health facilities (Nabukeera-Barungi et al., 2015). It is a common understanding that a poor community is unlikely to support adolescents with transport money to collect their ART medicine in time. Adolescents who lack food, report having abdominal pains if they take ART medicine on empty stomach (Nabukeera-Barungi et al., 2015). Other common socio-economic constraints which affect adherence to ART medicine negatively among adolescents are the social migration of their biological young parents to towns, food insecurity (avoidance of taking medicine on empty stomach) and believing in holy-water or faith healing (Bezabh et al., 2014).

Young parents migrate to towns to seek jobs, leaving children in the care of older grandparents who naturally easily forget (Bezabh et al., 2014).

### *iii) Cultural Beliefs and Practices*

Peralta, Belzer and Palmer (2009) say that because patients fear the interactions of ART medicines and herbal preparations, they tend to stop ART until the course of herbs is completed, thereby constituting poor adherence by missing the doses of ART.

Reda and Biadgilign (2012) share their findings of myths, misconception and denial of the existence of HIV status as important markers of poor adherence to ART. Some caregivers urge adolescents to stop ART medicine when they are being initiated on other medicines or herbs,

believing that ART medicine will not work together with other medical or herbal preparations (Reda & Biadgilign, 2012).

Peralta, Belzer and Palmer (2009) acknowledge the influence from peers to other adolescents to stop medication that it is based on their poor understanding of the ART medicines. Some patients including adolescents believe that taking medicine for many years will kill the virus and the patient will live a normal life without medicine (Nabukeera-Barungi et al., 2015). Other patients and caregivers believe in faith healing, saying that HIV infection is curable by a prayer alone (Nabukeera-Barungi et al., 2015). In Ethiopia, one of the major constraints of adherence to ART among people living with HIV is the belief in and practice of Holy water rituals (Bezabh et al., 2014). Many defaulters are reported coming back to ART clinics to resume medicines when they are in stages of dying from HIV related diseases (Bezabh et al., 2014).

### *2.3.5 Health and Health Care Systems*

#### *i) Health Status of Adolescent on ART or of Treatment Supporter*

Some diseases will require the patient to take extra tablets and it becomes confusing to the patient and caregivers whether she/he should continue taking ART medicine or pause taking it (State Department of Health, 2006). On the other hand, when the treatment supporter becomes sick, the guidance to adolescent to take ART medicine often weakens (State Department of Health, 2006).

Adolescents know little about their future and the progression of the disease (Bikaako-Kajura et al., 2006).

#### *ii) Health Care Systems*

The heavy pill burden per patient is another predictor of nonadherence to ART among adolescents (Biadgilign, Deribew, Amberbir and Deribe, 2012).

Some ART medicines, more specifically syrups have an unpleasant taste or a terrible smell which make adolescents uncomfortable and reluctant to take the medicine (Nabukeera-Barungi et al., 2015).

Nabukeera-Barungi et al. (2015) emphasize that stock-outs of familiar medicine usually leads to the issuance of alternative medicine which is often not liked by most patients.

Some adolescents who experienced or evidenced adverse events of medicine have records of poor adherence to medicine because they fear the possible side-effects (Ankrah et al., 2016; Dahab et al., 2008). Peralta, Belzer and Palmer (2009) urge health professionals to educate patients and treatment supporters the reasons of achieving good viral suppression and how to recognize and report medicine side-effects.

Poor adherence counselling based on poor understanding of guidelines misleads patients and treatment supporters (Perry et al., 2012). Perry et al. (2012) find out that the lack of updated information materials of new medicine regimens is one of the challenges to ART adherence among adolescents. Apart from the use of text messaging, adolescents may get more understanding of HIV disease and its treatment on social media during their own free time if an internet page is created and information on it is frequently updated (Perry et al., 2012).

Roberts (2004) indicates that some patients become submissive and do not dare asking clarity about their ART medication due to behaviours of unsupportive staff in health care facilities. Some staff members are unsympathetic or inconsiderate of the patient's circumstances which leads to poor adherence, instead of assisting, the patient is subjected to verbal abuse (Kammann, Williams, Chesney & Currier, 1999).

Apart from low levels of education achieved by grandparents, the language barrier between the caregiver and health care provider contributes to poor understanding of prescriptions which leads to poor adherence to medication (Dahab et al., 2008).

Hospitalization and regime complexity are challenges experienced by both the patient and caregivers regarding the routine taking of ART medicine (Roberts, 2004). When the patient is admitted in hospital, the caretaking shifts from caregiver to healthcare providers who in most cases are not trained in HIV care or do not know whether the patient is on ART medication (Roberts, 2004). As a result, patient may go for days without taking his ART medicines (Roberts, 2004).

Due to their vulnerable behaviour of being easily getting irritated, some adolescents leave ART clinic due to long waiting queues before receiving ART medicines from pharmacy (Ankrah et al., 2016).

One of the cornerstones of accepting the status of living with HIV and its lifelong therapy is disclosure program (Mburu et al., 2014). Mburu et al., (2014) share 4 categories of disclosure, namely: parents disclose their own HIV positive status to adolescents; healthcare provider or guardian informs the HIV positive adolescent that he or she is HIV positive; adolescent him/herself informs the third party that he/she is being diagnosed as HIV positive and the fourth category is when the guardian discloses the HIV positive status of the adolescent to a third party.

There is a greater chance of dropping medicine by adolescents who start to understand life circumstances but are not being offered HIV disclosure services (Evangeli and Foster, 2014).

To achieve good adherence, it is important that adolescents are being properly informed of their HIV statuses and they disclose it to their caregivers as well (Bikaako-Kajura et al., 2006). Complete disclosure helps to motivate the HIV infected adolescents to adhere to their daily medicine taking (Bikaako-Kajura et al., 2006).

Biadgilign, Deribew, Amberbir and Deribe (2012) have spelled out how the lack of disclosure leads to poor understanding of HIV infection and the benefits of ART medicine. If the caregiver does not understand the disease she/he will have difficulties in understanding the need for disclosure (Biadgilign, Deribew, Amberbir and Deribe, 2012). In that case, health providers should provide caregivers with detailed HIV infection and treatment information in the language the caregivers understand (Biadgilign, Deribew, Amberbir and Deribe, 2012).

In the event of lack of disclosure to adolescents, they may not know the correct reasons of taking medicines and they may act-out by refusing to continue taking medicines (Bikaako-Kajura et al., 2006).

In their qualitative study of exploring the barriers, facilitators and outcomes of HIV disclosure among adolescents in Zambia, Mburu et al. (2014) establish three main barriers to disclosure, namely, community norm that it is unheard off for parents to discuss sexual issues with their children; fearing HIV stigma and the assumption that adolescents are too young to understand the status of being infected with HIV, living with it, its treatment and how it spreads sexually.

### 2.3.6 *Geographic related Challenges*

Staying in distant rural areas from ART centres leads to lost to follow up or poor adherence to medicine due to limited transport to access ART centres (Nabukeera-Barungi et al., 2015).



## CHAPTER 3. METHODOLOGY

### 3.1 Aim and Objectives

The aim of this study was to explore barriers to adherence to antiretroviral therapy among adolescents in Onandjokwe, Namibia

The objectives of this study were:

- to explore patient and family related challenges to ART adherence among adolescents in Onandjokwe
- to explore stigma and discrimination in certain settings as challenges to ART adherence among adolescents in Onandjokwe
- to explore substances abuse as challenges to ART adherence among adolescents in Onandjokwe
- to explore the socio-economic challenges to adherence to ART among adolescents in Onandjokwe
- to explore the health and health care systems related challenges to ART adherence among adolescents in Onandjokwe
- to explore geographic and weather related challenges to ART adherence among adolescents in Onandjokwe

### 3.2 Study Design

The exploratory qualitative study design was used to investigate barriers to adherence to ART among adolescents in Onandjokwe District. Green and Britten (1998) contend that exploratory qualitative study broadens the scope of understanding by being flexible to study people from different backgrounds, varying settings and can dig deep to get un-volunteered information.

Through qualitative research, the attitudes, beliefs, and preferences of the adolescents, caregivers and health care providers can be studied (Green & Britten, 1998). The exploratory study might capture this sort of information and thus it is being chosen for this study, regardless of its disadvantages such as being labour intensive and time consuming during data analysis (Pope, Ziebland & Mays, 2000).

The qualitative exploratory design may elicit what is unknown by the researcher but known by caregiver and adolescent on ART (Green & Britten, 1998). It can be used to explore meanings given to certain phenomenon, understand cultures and explain them and their influence on ART adherence (Secker, Wimbush, Watson & Milburn, 1995).

With their study of Adherence to ART and retention in care of Adolescents in Uganda, Nabukeera-Barungi et al. (2015), were able to form a better understanding of barriers to and facilitators of ART adherence among adolescents, using both Focus Group Discussion and In-depth Interview techniques.

### **3.3 Setting Description**

To facilitate a good analysis in qualitative studies a thick description of the ART setting and well documented changes and evolutions should be included (Gifford, undated; in Kerr, Taylor & Heard, undated). The ART clinic is in Onandjokwe district which is situated in Oshikoto Region, one of the 14 regions of Namibia. The district serves almost 85% of 181 600 catchment population of Oshikoto Region (National Census, 2011).

Onandjokwe ART CDC is a spacious clinic with 24 rooms, providing ART to about 7289 patients by August 2015, after it transferred many patients to newly established Integrated Management of Adult Illnesses (IMAI) Sites with the aim of ART decentralization (Onandjokwe, 2015). The clinic is manned by 1 medical officer, 6 nurses, 4 pharmacist assistants and 8 health assistants, (formerly known as community counsellors), offering HIV counselling and testing, and voluntary medical male circumcision, prevention of mother to child transmission, pre-ART, TB/HIV and ART care. Care services are subdivided into paediatric, adolescents' friendly and adult care.

Since the design of this study in 2012, so many changes have happened. The providers formerly known as community counsellors are now renamed as Health Assistants after being absorbed into Government employment when donor funding declined.

### **3.4 Sampling**

Rice and Ezzy (1999) support the use of purposeful selection in recruiting participants for qualitative studies because it targets the information rich subjects. This study used the strategy of purposeful selection of participants who were drawn from a population of information rich, who are believed to know more on the subject of poor adherence to ART i.e. adolescents with records of poor adherence to ART medicine in Onandjokwe within the period between January 2015 and August of the same year.

Among the *study population* of 631 adolescents on ART from January 2015 until August 2015 in Onandjokwe, a *sample size* of sixteen (16) adolescents was considered for interviews from the *sample population* of 154 adolescents who had records of poor (below 85%) ART adherence within the same period.

The Senior Data Clerk of Onandjokwe ART (1) using the Electronic Patient Management System (ePMS) had selected the names of 16 adolescents with records of poor ART adherence from January 2015 to August 2015. Their patient care booklets (PCB) were retracted and verified by the nurses and health assistants by manually checking the pharmacy sheets and encounter pages of the PCB to confirm that adolescents had missed 9 or more doses per month. A laptop was used to record all patients' personal particulars including pseudo identifiers. To avoid information loss, a field notebook to capture non-verbal expressions and a voice recorder to record all interviews and discussions were also used.

To ensure that the study captures a full range of possible rich cases and to satisfy all its objectives, attempts were made to include 2 orphans, 2 adolescents aged 10 to 14 years, 2 adolescents who live far from the clinic (>10km) and 2 defaulters from school hostel.

### **3.5 Preparation for Data Collection**

After obtaining study permission from the Medical Superintendent of Onandjokwe Hospital on 29th July 2015, a briefing meeting was held by the Principal Investigator with the ART Nurse-in charge on the 3rd of August 2015.

On August 4, 2015, a meeting was held with 2 ART nurses, 5 Health Assistants (previously known as community counsellors), a Peace Corp Volunteer, Pharmacy Clerk, Defaulters Tracer, Senior



and Data Clerks to share the purpose of and their roles in the study. In the same meeting, the Key Informants and Interview Assistant for the study were selected. The training of health assistants and Data Clerks on interview tools, computer reports generation and sorting out the files of required participants took place on the 5th of August 2015.

### **3.6 Data Collection**

#### **i) Focus Group Discussions**

Liamputtong and Ezzy (2005) define a focus group discussion (FGD) as an organized meeting of participants who are believed to know the subject of discussion with the aim of understanding and describing perceptions, interpretations and beliefs regarding a particular issue, through interactions by 6 -10 individuals in a group meeting that lasts for 1-2 hours.

In this study, four FGDs (Figure 2) were held. On the 6<sup>th</sup> August 2015, the first group of 5 adolescents of 10-14 years of age attending Teen's Club Day was interviewed using Focus Group Discussions (FGDs) accompanied by caregivers and this was followed by the second FGD of 5 caregivers as key informants. To encourage truthfulness and honest interactions, the third FGD was consisted of 6 adolescents from 15-19 years of age with no caregivers accompanying. The last FGD session was held with Healthcare Providers as key informants on the 13<sup>th</sup> of August 2015.

#### **ii) In-depth Interviews**

According to Pope and Mays (1995), in-depth interviews, focus group discussions and observations are the three useful interview methods of Qualitative studies. In-depth interview is defined as a semi structured or unstructured interview which takes a form of conversation normally with 1 or 2 interviewee/s and tries to understand in more details personal feelings or experiences and often comprised of more sensitive information (Liamputtong & Ezzy, 2005). In this study, five (5) in-depth interviews were conducted with 5 adolescents listed having records of poor ART adherence within the period of January to August of 2015 to share their personal feelings and experiences regarding adherence challenges, see Table 1 below.

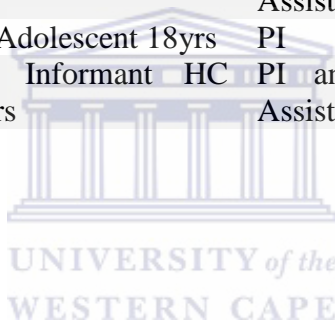
The Principal Investigator (PI) and Interview Assistant (IA) conducted all Focus Group Discussions. All in-depth interviews were conducted by the Principal Investigator to create a

conducive environment of open discussion and avoid the participant to feel being intimidated by interviewers.



Table 1. The Number of FGD and In-depth Interviews Sessions Held with Different Participants

Date	Interview Technique	Participant	Interview Facilitator	Venue
6/8/2016	FGD	5 Adolescents aged 10-14 yrs	PI and Health Assistant	Conference
	FGD	5 Key Informant Caregivers	PI and Health Assistant	Conference
	In-depth	F Adolescent 19yrs missed FU	PI	Eheke office Sc
	In-depth	M adolescent 16yrs missed FU	PI	Eheke office Sc
	In-depth	M Adolescent 17yrs Stays <10km LTFU	PI	Home
13/8/2016	In-depth	Distant F Adolescent LTFU	PI	Home
	FGD	6 adolescents, 15-19 yrs	PI and Health Assistant	Conference
	In-depth	Distant Adolescent 18yrs	PI	Home
	FGD	6 Key Informant HC Providers	PI and Health Assistant	Conference



### 3.7 Data Analysis

#### i) Description of Data Analysis

Due to its small size, this study used hand manipulation rather than computer software technique to sort out data for coding. In small studies, the time to learn how the software qualitative data management works will take too much time as opposed to sorting data by hand for individual interview transcripts (Willms & Johnson, 1993).

As Willms and Johnson (1993) affirm on the analysis of qualitative data, the data preparation for analysis of this study had begun already during data collection by noting responses in the field notes under the corresponding pre-formed study themes.

#### ii) Data Transcription

The recorded versions were translated from Oshiwambo (local) language to English by the principal investigator. The meanings of non-verbal expressions were also translated using English words and merged into respective transcribed interviews and discussions. The transcription

followed all discussions and interviews held in the order of occurrences and a word process file is produced of which two copies were made. Willms & Johnson (1993) recommend that two hard copies should be made, one stored as a backup and another one to be used as master-copy.

### iii) Data Interpretation

Sentences from different interviews and discussions were sorted, coded and categorized according to their similarities. After the connections of patterns, information was being synthesized and interpreted to give meaningful contributions to the themes derived from study objectives. Gibbert & Ruigrok (2010) emphasize the need to synthesize meanings and concepts before connecting them to their relevant study objectives/topics or themes.

### 3.8 Study Rigour

Rigour is defined as the soundness of the qualitative research findings, based on credibility, dependability, transferability and confirmability or triangulation but not on the counts, beliefs, biases or prejudices of the researcher (Gibbert & Ruigrok, 2010).

This study provides full findings from participants' responses and a thick description of the clinic, school and home settings of adolescents under study, to ensure *credibility*. Moreover, all changes which occur in the research methods, settings and during data collection are accounted and documented to ensure *dependability* of this study. Furthermore, the findings of this study reflect all facts and opinions from participants, in support of the literature review findings to build its truthfulness and trustworthiness such that findings are safely *transferable* to other homogenous health facilities and communities.

The completed transcription including all non-verbal expressions was checked by one two of the key informants together with the principal investigator to verify whether the meanings are conforming to what informers intended to communicate, a process known as *triangulation*, to evaluate credibility of the findings (Gibbert & Ruigrok, 2010). Gibbert and Ruigrok (2010) present four basic types: data, investigator, theory and methodological triangulations. In this study, the use of data from different sources such as adolescents with poor ART adherence, caregivers and health care workers as key informants, represents *data triangulation*. At least, this study also employs *investigator triangulation* by ensuring that the reports are being validated against what the

(Principal Investigator) PI noted during interviews and discussions. In the absence of other researchers, the two (2) ART Clinic nurses and the local research committee did member checking when they scrutinized and commented on the study report before it is finally printed. However, *theory triangulation* slightly feature when the 2 nurses will look at the interpreted information to scrutinize meanings given to narrated accounts, ideas, concepts and non-verbal expressions and give their inputs/perspectives and produce a common meaning. The non- connecting case (disconfirming case) is being presented as an isolated case in the findings to show the readers that information is not filtered but presented in totality, this builds greater credibility (Gibbert & Ruigrok, 2010).

### **3.9 Ethics Considerations**

This study was *approved* by the UWC Senate Research Committee, and permission was obtained from the Ministry of Health and Social Services Research Committee and Onandjokwe Hospital Superintendent.

The purpose of the study was shared with all participants before any interview or discussion commences. All participants were also informed about the added advantages of the study findings that health care providers can use to device appropriate strategies of addressing ART adherence challenges and maximize the number of adolescents benefiting from ART.

Before giving their consents, all participants were informed that the study is not of an experimental nature, it is merely discussions on what participants know. Prior to interviews, consent forms have been read and interpreted to all participants in their language, Oshiwambo. To avoid exploitation of the research subjects, all interviews and discussions did not commence until the agreement of participation was reached between the researcher and each individual participant or caregiver in case of minors (children under 15 years of age). This was followed by the signing of consent forms by all the agreed participants. All participants were being reminded of their rights of voluntary participation and of withdrawal at any time during interviews and discussions and no punishment follows such withdrawal. All participants and care-givers were assured of information confidentiality, which all materials containing shared information such as the voice recorder and field notes will be safely locked up and the computerized data will be protected by using a

password, to avoid access by unauthorized persons. Transcripts and all other field-notes are being stored under lock and key until all references to it become unnecessary and eventually will be destroyed with the shredding machine at work.

Participants remained anonymous throughout interviews and discussions as their names were not printed out and that they were not required to provide their real names during interactions, only pseudo identifiers assigned during consent forms signing were being used. Ethical issues have been considered throughout the whole study processes.

Participants were informed of possible threats posed by the research such as leakage of participants' confidential information or participant side-lining, but all control measures have been put in place to prevent these potential negative eventualities. Although all forms of harm have been avoided, the plan of emergency was prepared to offer counselling support should emotional harm occurred. People living with HIV are vulnerable to emotional harms due to emotional recalls and stigma (MoHSS, 2014). Considering the rights of minors (children under 15 years) whose capability of autonomy and self-privacy protection is limited, caregivers were made available throughout the earmarked FGD session to minimize the risk of emotional trauma.

A session of debriefing and verification were conducted with participant health care providers before the final write-up.

## CHAPTER 4. RESULTS

### 4.1 Description of Study Participants

The study recruited 16 adolescents of whom 9 were females and 7 were males. Five (5) males were among the group of 11 adolescents aged 15 - 19 years while the remaining 2 were among the group of 5 adolescents aged 10-14 years old. Females form the majority, around 56% whilst males form the rest of 44% of adolescent participants. In the categories of caregivers and health care providers, no male participated in the interviews.

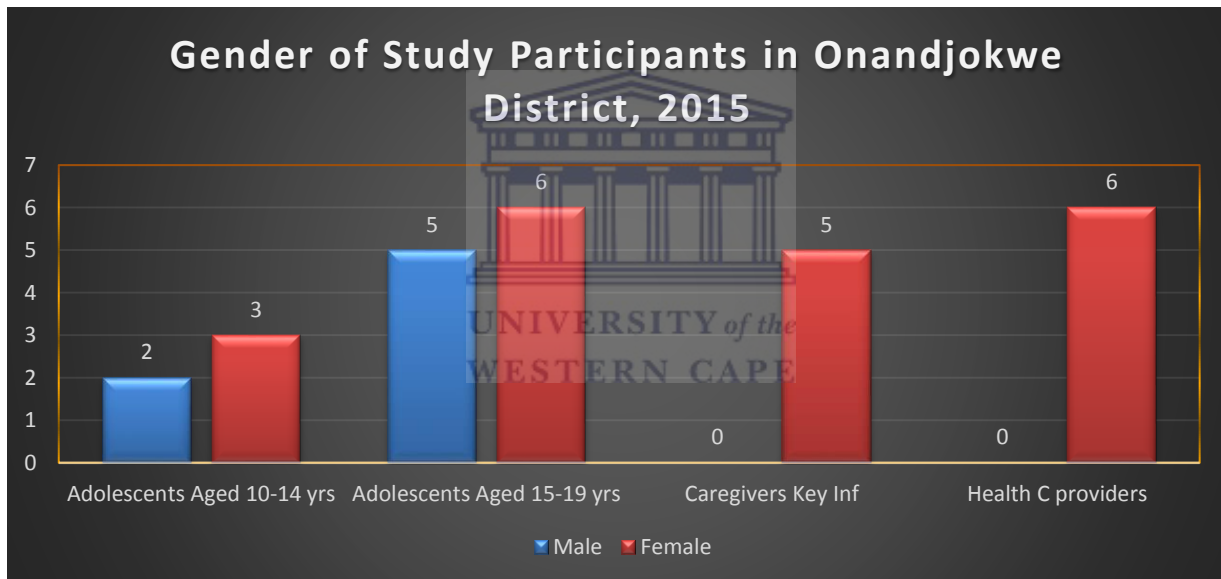


Figure 2. Demographic characteristics of study participants

As per table 2, the majority (68.8%) of adolescent participants were between the age of 15 -19 years, as compared to only 5 adolescents between the ages of 10-14 years. About 88% of adolescents participated in the study live in areas 10km or more far from the clinic. Adolescents orphaned constituted the majority of about 69% of all adolescents took part in the study.

**Table 2. Sociodemographic Characteristics of Adolescents Participants**

Demographic Characteristics	Variables	Frequency
Age in Years	10 -14	5
	15 – 19	11
Gender	Male	7
	Female	9
Home Distance from ART Clinic	<10 Km	2
	≥10Km	14
Biological Parents Alive	Both	5
	One	5
	None	6

## 4.2 Themes

Table 3. Themes and codes emerged from data analysis of group discussions and in-depth interviews on poor ART Adherence among Adolescents in Onandjokwe District

**Table 3. Reasons of Poor Adherence**

Main Themes	Sub-Themes/emergent themes	Coding Concepts
<b>Patient &amp; Family related factors</b>	Gender based vulnerability	01 Boys easily being influenced than girls to stop ART
	Juvenility and peer pressure	02 Rebellion, antagonism, disobedience and ignorance, refusing to take medicine 03 Forgetfulness 04 Sport addiction
<b>Caregiver related factors</b>	Psychological exhaustion & Loss of parents	05 Medicine fatigue/exhaustion 06 Lack of parental guidance, children orphaned adolescents become homeless 07 Spending days out, visiting relatives, holiday making
	Other activity burden	08 Household chores and high school demands
	Lack of proper guidance	09 Forgetful elderly grandparents as caregivers 10 Death of biological parents, leads to poor or no guardian care 11 Lack of supervision by caregiver 12 Carelessness 13 Young parents abandon children living with HIV 14 Poor following of medical instructions due to illiteracy status of elderly caregivers



		015 Ageing of the caregiver/grandparent
		016 Migration of parents to towns to pursue jobs
		017 Too many caregivers,
		018 Poor communication within the family, Holiday hosting
	Lack of HIV disclosure	relatives unaware if the child is on ART
		019 Lack of HIV disclosure to the child about own status
		020 Abandon ART and take children to traditional healers for herbs
		021 Abandon ART and take children for prayers only
		022 Lack of motivation to caregiver such as financial support
	Income insufficiency	023 Lack of transport for both Rx supporter and the child
	Stigma Setting	with 024 Fear entering the stand-alone Adolescents' Friendly ART clinic
<b>Stigma and Discrimination in Certain Settings</b>		025 Avoiding seen by others taking ART medicine in school hostels
		026 Parents refusing children to undergo disclose program, fearing blame for HIV infection
	Perceived Discrimination	027 Fear of being laughed at
		028 Fear of social rejection
<b>Substance Abuse</b>	Alcohol use and abuse	029 Alcohol use and abuse, intoxication
	Smoking	030 Smoking cigarettes
<b>Socio-economic related Challenges</b>	Lack of income	023 Lack of transport money
		031 Lack of social grants to orphans
	Lack of social support	032 Lack of parental guidance to orphans
		033 Lack of adequate food, pills on empty stomach
		034 Young mothers of adolescents on ART hide own HIV status from new lovers
	Community stigma to HIV infection	035 Visits during school holidays and community migration
	Cultural beliefs and practices	036 Resort to traditional medicine and practices
	Myths and misconceptions regarding ART	037 Beliefs that medicines are made from human brains,
		038 Beliefs that ART medicine causes greediness
		020 Religious driven ART drop-out, throw away medicine, alleging they have demons
<b>Health &amp; Health Care Systems</b>	Health status of adolescent on ART	039 Sick adolescent, disease burden, confused and unconscious patient
		040 Experienced or anticipating side-effects – psychological fear
		041 Sick caregiver not available to escort adolescent to clinic for medicine refill
	Health status of caregiver	042 Diminished autonomy due to hospitalization-patient relay on health care providers
	Health Care Challenges	043 Pill fatigue, pill burden
		044 Hostile/embarrassing counselling, shouting to patients deter others come for FU

045 Lack of knowledge of health care providers regarding ART in wards of admission  
 046 High staff turnover, patients loose familiar nurses and community counsellors  
 047 Long waiting queues at pharmacy and other service delivery points

Health Systems Challenges  
 - Poor implementation of frequent reviewed ART guidelines  
 - Limited access to ART and ART information

048 Poor or inappropriate adherence counselling,  
 049 Outdated messages and health educations, irrelevant, obsolete messages  
 050 Lack of self - read materials, take home readers and posters  
 051 Medicine issues - bitter taste and causing nausea  
 052 Stock out of familiar medicines, inadequate monthly supply  
 053 Replacing medicine with unfamiliar preparations, medicine with different labels  
 054 Weight based dose adjustment  
 055 Dose and regimen change based on guidelines review  
 056 Slow decentralization of ART service to clinics and other community points  
 057 Slow progress of Disclosure program to clinics providing ART

**Geographic & Weather related Conditions**

Hard-to-reach areas  
 Flood  
 Extreme cold temperatures

058 Lack of transport due to dense forests with no roads  
 059 Sandy tracks , long walking distances, overnight in-between before and after ART clinic  
 060 Roads are frequently washed away, cut-off some communities to access public ART clinics  
 061 Some adolescents miss ART refill follow ups (FU) due coldness

## 4.3 Patient and Family Related Challenges

### 4.3.1 Patient Related Factors

Under patient related factors leading to poor adherence to ART, participants have discussed gender based vulnerability, juvenility and peer pressure, psychological exhaustion, loss of biological parents, burden with other activities and unavailability of the client.

#### *i) Gender based vulnerability*

Some participants had revealed that gender factor plays a role in poor adherence to ART saying male adolescents are more easily being influenced by their peers to stop taking medicine than girls.

*As I observed, boys are easily influenced by their peers to drop medicine as compared to girls. Perhaps female parents have closer relationships with girls as opposed to male parents to boys, widening the chances of girls to discuss issues with parents, a platform boys do not have. (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

#### *ii) Juvenility and Peer Pressure*

Juvenility and peer pressure are some of the obstacles which were discussed during Focus Group Discussion. Both Caregivers and Healthcare Providers have expressed that some adolescents revolt against ART medicine taking. They ignore parental guidance and stop taking medicines.

*Rebellion especially among boys and peer influence is a common problem..., the child will refuse take medicine and ask you to give him money or buy him clothes first if you want him to drink the medicine. Failure to provide what is being asked for often leads to adolescents dropping their ART medicines. (Focus Group Discussion, Key Informant Caregivers, Onandjokwe).*

*The intolerant youths especially males will leave ART clinic before they collect their medicines, claiming the waiting queues are too long (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

*Some [adolescents] do not take their medicine because they disobey parents, they do not respect parents. (Focus Group Discussion, Adolescents aged 10 -14 years, Onandjokwe).*

*They disobey elders' instructions and often shout at them 'my mother is dead, you are not her'... (Focus Group Discussion, Key Informant Caregivers, Onandjokwe).*

iii) *Psychological Exhaustion and Loss of Biological Parents*

Another personal challenge being expressed during these interactions is forgetfulness.

*Sometimes I forget to take my medicine (In-depth Interview, 17 years old male Adolescent, Onandjokwe).*

It was also shared that exhaustion by taking medicine for a long period is one of the personal challenges.

*I heard some kids saying, they are discouraged because they take these medicines for a long time but their health is not improving... and because of poor supervision from parents, these kids bury doses of medicine underground and pretend to guardians that they took their medicine (Focus Group Discussion: Adolescents aged 15-19 years, Onandjokwe, 2015)*

It was reported from the study that some orphans who have no parental guidance are mostly likely to adhere poorly to ART medicine than those who have parents supporting them.

*My grandmother was the only source of my assistance to start and continue with ART treatment. After she died, I and my sister were moved in, to stay with uncle, the only relative I know. He never offered me transport or transport money to collect my ARV medicines (In-depth Interview, Adolescents aged 15-19 years, Onandjokwe).*

*Both our mother and farther are dead, leaving us three kids in the house... the new house owner is working at Luderitz, very far and he does not come home very often, leaving us struggling for food and transport money (In depth Interview, Adolescents aged 15-19 years, Onandjokwe).*

iv) *Burden with other activities and client unavailability*

Some adolescents on ART are very mobile and it becomes difficult for the clinic to supply them with their ART medicines regularly, resulting in many doses to be missed. Family members rarely share treatment needs of adolescents to a holiday hosting family as this is a different family which has no or limited medical background knowledge of the visiting adolescent.

*During school holidays, most adolescents go and visit relatives who have inadequate or no information regarding ART treatment from the adolescent's parents. They can spend a month long holiday with that family and not taking their ART medicines, in the due course, resulting in poor adherence (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

The study also found out that most adolescents are students and have high school demands on top of household chores, which makes it difficult for them to visit ART clinic during its operation times of the week.

*Me, there was a time I had too many school demands collided with my clinic follow up... as students we are required to adhere to school rules and regulations which say all students must be available for all classes, if you absent yourself, to go and collect your medicine from the clinic, you will be punished to dig a pit to bury wastes, deep enough such that the tallest pupil in your class should submerge...sometimes school work is so demanding such that you cannot sacrifice a day to the clinic (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe)*

It is not only the high school demand but house chores were also outlined as some of the factors lead to failure to collect medicine from clinics.

*Some parents do not care whether you take you medicine or not. They just want their house work to be completed... for example, you have to fetch water from a distant water point and by the time you reach home again your time of taking medicine has passed or you go look for cattle for a day or two and some parents will not bother reminding you to take*

*your medicine along* (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).

Some adolescents are reportedly missed their scheduled clinic follow ups due to playing of TV games or other sports such soccer or volleyballs.

*Some boys play soccer or other sports until their time of taking medicines passed.* (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).

#### **4.3.2 Caregiver Related Factors**

Participants have discussed lack of guidance to adolescents and lack of disclosure demonstrated by caregivers as some of the barriers to ART among adolescents.

##### *i) Lack of proper guidance*

The study has found out that there are adherence challenges among many orphans due to lack of parental guidance.

*It is also a pity that some adolescents are orphans and they are heading houses, no adult in the house to supervise their taking of medicine* (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).

One adolescent had also shared during the interview that orphans are struggling to keep up with their ART medicine in the absence of caring parents.

*I did not have money for transport. My grandmother who use to give me transport money has died two months ago and my father and mother are both dead while I was young...I don't get the pension money [social grant] to help paying for transport fares* (In-depth Interview, Adolescents aged 15-19 years, Onandjokwe)

Other study findings related to caregivers are that some guardians do not supervise the taking of ART by adolescents because they are too busy or they are just being careless.

*There are times that our parents are too busy to escort us to the clinic, resulting in so many doses being missed (Focus Group Discussion, Adolescents 10 -14 years, Onandjokwe).*

*Sometimes you don't have transport money and parents refuse to give you transport money because you fail to do this and that at home...some parents do not care collecting medicines for both of us (Focus Group Discussion, Adolescents aged 15-19 years Onandjokwe).*

*There are caregivers that are careless and ignorant...they have no difficulties of getting transport money neither do they have confusing regimens but still fail to comply with their kids ART prescriptions (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

One adolescent revealed that her mother is not keen to bring her to the clinic when the grandmother, her usual companion, becomes sick or absent.

*My grandmother was sick and my mother did not want to bring me to the clinic... she said there are naughty people in the surrounding of ART Clinic, if they see her in this clinic they will accuse her of being HIV infected and laugh at her (Focus Group Discussion, Adolescents 10 -14 years, Onandjokwe).*

The study has found out that young parents are reluctant to enter ART clinics, letting adolescents to go in alone for consultations and medicine collection.

*The problem is with young mothers, they do not want to be seen with their children in ART clinic...in many occasions such new dosage information does not reach them because they rarely accompany adolescents to information sessions (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*



Poor communication is usually associated with caregivers' low level of education has also emerged as a barrier between health care providers such as social workers or ART Adherence Counsellors and caregivers.

*There are parents who can't read or understand English which is commonly used on medicine labels. These medicine labels which contains dosage frequencies are often misinterpreted by caregivers... Caregivers who need social counselling also find it difficult to understand the message from the social worker who does not speak the local language. The hospital needs a social worker who is able to communicate and understand local language fully such that, the message get across very well to the caregiver (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

The nurses who were being interviewed have shared that many children under the care of aged grandparents have challenges of adhering to ART Treatment.

*Most adolescents are in the care of grandparents either because their first parents are dead or they abandoned and hide these kids from their new love relations...grandparents forget easily and have difficulties in following instructions including ART prescriptions...children under their care do often miss their ART doses due to confusion whether the dose was already taken or not (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

Study participants did also share that children are not only placed under the care of the elderly caregivers by young parents who do not want to be seen in ART Clinics but also by those who left rural areas for job searching in urban areas.

The study has also established that too many care givers for one adolescent give confusing messages regarding ART adherence instructions which leads to dosages missing.

*As healthcare providers, there are times that we are faced with problems of not knowing who is the constant caregiver of a certain adolescent...today the adolescent is brought by this one, tomorrow is being accompanied by another one, the next follow up is another*



*different treatment supporter and so forth. The continuity of adherence counselling is broken into pieces to different caregivers which is very confusing to the adolescent self and the health care providers as well (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

ii) *Lack of HIV disclosure of the caregiver*

It was also reported that some parents are refusing children to enrol in HIV disclosure program, anticipating children's anger towards them.

*Some parents are reluctant to allow children to enrol in disclosure program, preventing them to know their HIV positive status because parents fear of being blamed of infecting children, a situation which may lead to child-maternal rejection if not handled well (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

#### **4.4 Stigma and Discrimination in Certain Settings**

During interactions, study participants have attributed stigma from environment where adolescent lives as well as discrimination of the adolescent on ART to low commitment to HIV Treatment.

##### **4.4.1 Stigma with Settings**

It was revealed from interviews that young parents are reluctant to enter ART clinic fearing of being labelled as HIV positive by those seeing them entering the clinic.

*Some young parents avoid entering ART clinic due to stigma and in case the grandparent is sick or not at home, the adolescent will miss ART follow up for refills until granny is available to bring her again...these missed doses contribute to poor adherence (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

One health care provider said that the Adolescent Friendly Service Clinic becomes risky for stigma because it is being moved from the Main Centre where ART is being integrated with Antenatal, Postnatal care and Family Planning services to a stand-alone clinic.

The blue Patient Care booklet is another distinguishable ART material within the health care system that leads to stigma.

*Some of the patients avoid carrying the blue files to the pharmacy and if they do not see anyone to collect medicines for them, they just drop the files on benches and disappear without medicine (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

Students interviewed have also reported that they use to miss follow ups in fear of being laughed at by their peers, either in the school hostels or among unfamiliar people such as temporary host families during school public holidays. It also came out of the discussions that some parents prevent their children from getting ART medicines from their local clinics to anticipate stigma of reference.

*I take my medicine when there is no one in the room or I put my tablets in a plastic to the toilet room and drink them... if other students see that I take ART medicine, they will create mockery out of it, laughing and shouting at me because I am HIV positive (In-depth Interview, Adolescent aged 19 years, Onandjokwe)*

#### **4.4.2 Perceived and Actual Discrimination**

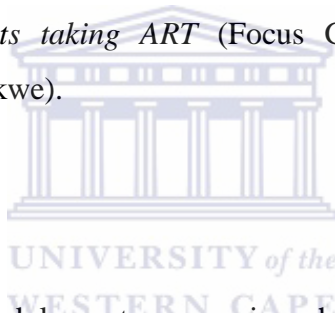
It was also discussed that there are some parents who fear their children seen collecting medicine by neighbours, hiding their own and of their children's HIV positive statuses. So to avoid such stigma of reference, they take their children to distant ART clinics and as a result of high transport fares, they return to Onandjokwe ART clinic after missed several follow ups.

*Despite rollout of ART, some parents, in fear of stigma, do not want their children to get ART medicine from their local clinics because they do not want to meet anyone they know at the clinic...they are among those who do not accompany children to clinics because they cannot*

*afford transport costs for them and their children* (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).

Some young mothers are reportedly hiding away from their HIV positive children in attempt to secure love relationship with new proposers who usual being kept unaware of their lovers' HIV positive status until the intimacy bond becomes stronger. These mothers were supposedly to guide their children on taking medicine, but they abandon their responsibilities and adolescents under their care become potential to poor adherence to ART.

*We have also noticed that women who found new sexual partners, tend to hide their HIV infection history by disassociating from or avoiding their HIV infected children until the new relationship is properly secured and settled. This results in lack of parental supervision of children, including adolescents taking ART* (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).



#### **4.5 Substance abuse**

Alcohol use and smoking by either adolescents or caregivers have come out of the study discussion as some of the predictors of poor ART adherence among adolescents

##### ***4.5.1 Alcohol use and abuse***

It was shared that some caregivers are abusing alcohol which is likely impairing their abilities to supervise and guide adolescents to take their treatments as prescribed. As a result, adolescents under the care of such parents are likely to miss some doses of their ART drugs.

*Many [caregivers] do not come to the clinic with their children or if they come they will abandon the clinic to shebeens for drinking because they are alcoholic addicted* (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).

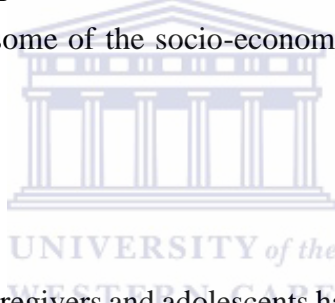
#### **4.5.2 Smoking**

During the Focus Group Discussion of adolescents of 15-19 years old, one participant had revealed that some boys on ART medicines do smoke which makes parents angry and becomes reluctant to continue giving them money for transport to collect their medicines.

*I heard that some boys do not want to follow what their parents tell them. When they are given money for transport to hospital they buy cigarettes and smoke which annoys their parents and they withdraw from helping them* (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).

#### **4.6 Socio-economic Related Challenges**

During this study, participants have indicated that lack of income per family with adolescents on ART, lack of social support, unsupportive cultural beliefs and practices to HIV treatment as well as myths and misconceptions are some of the socio-economic factors affecting ART adherence negatively among adolescents.



##### **4.6.1 Lack of Family Income**

Lack of transport money for both caregivers and adolescents has come out from each FGD sessions held as a challenge to access health facilities for the collection of ART medicines on time.

*When I was a small child I was not required to pay for transport like my grandmother. But now that I am 13 years old both of us are required to pay for transport and in many occasions money is not enough for the two of us* (Focus Group Discussion, Adolescents aged 10 -14 years, Onandjokwe).

*I missed to collect my medicine [from the clinic] because I did not have money for transport. My grandmother who used to give me transport money died two months ago* (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).

Another adolescent stressed that he missed his medicine because his parent did not have transport money to fetch medicine from home to hospital during his admission.

*First, I became sick and my grandmother brought me to hospital but we forgot my ART medicine at home and she had no enough transport money for going and coming back (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).*

During Key Informants' FGD, it came out that lack of national identification documents hinders the processing of social grants for orphans which can be utilized for transport fares to reach ART clinics and as a result some orphans have to drop their medicine.

*Some orphans and adolescents whose fathers are untraceable often miss ART follow ups due to lack of transport money because they do not receive government financial grants as many of them do not acquire national documentations required to qualify for the grant registration. Some fathers refuse to hand in copies of their national identity documents as required for the registration of adolescents for social grants (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

Some adolescents have revealed that lack of food made them stop taking ART medicines occasionally or longer period, depending on time of the next meal, thereby contributing to poor ART adherence.

*We are all children in the house with no food. We depend on Samaritan neighbours for food, there are times that they do not have enough food to share with us and we go to bed hungry. If I take medicine on empty stomach, I become hungrier and my stomach becomes painful. I can only take my medicine if I ate something at the time of taking the tablets (In-depth Interview, Adolescent aged 18 years, Onandjokwe)*

#### **4.6.2 Social Support Related Barriers**

The interaction during Health Care Providers' FDG has also revealed that the limited availability of social support networks which motivate adolescents to take lifelong therapies is another weakness in the society. Social support networks play a role of recruiting the suffering adolescents

and support them financially until they get the required national documents for national social grants.

*We managed to take some orphans with poor ART adherence to Save our Souls (SoS), a civil society which hosts the abandoned children and facilitates for acquiring national identification documents. However, they could not absorb all children that we identified having similar needs due to their limited housing facilities (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

The group of Health Care Providers has shared that adherence to ART is also being negatively affected by social migration of adolescents and caregivers alike.

*Our patients are too mobile and in most cases they leave to stay in other parts of the country without getting the treatment transfer letters which facilitate timely collection of medicines from the receiving health facilities. Without these letters, most patients get lost from treatment for months before reaching to the next clinic (Focus Group discussion, Key Informant Healthcare Providers, Onandjokwe).*



Some of the challenges are cross cutting between socio-economic and stigma and discrimination categories, for instance the issue of young mothers who disassociate with their children on ART to secure a new romantic relationship, thereby deserting adolescents with no parental guidance to take medicine or transport money for collecting ART drugs from the clinic.

*The most common reason of why some parents do not accompany their children to clinics for disclosure enrolment is because of hiding their own HIV statuses from the community or from their new lovers, fearing rejection (Focus Group Discussion, Key informant Healthcare Providers, Onandjokwe).*

#### **4.6.3 Cultural Beliefs and Practices Related Barriers**

The study has established that some parents have resorted to traditional herbs and stopped bringing their children to ART clinic for their medicine.

*Through neighbours we have learned that some adolescents have dropped ART because they are getting HIV treatment from traditional healers (Focus Group discussion, Key Informant Healthcare Providers, Onandjokwe).*

Several false beliefs which reportedly deter adolescents from taking ART medicines have come out from the discussions.

*At the beginning, I had a problem of swallowing tablets, because I heard that they are made from human brains especially from people who die from accidents (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).*

*Some of my peers are being influenced by others to drop their medicines based on rumours that ART medicine makes people greedy for food (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).*

The health care providers had also shared that some parents have stopped the ART treatment of their children, claiming that ART medicines have demons and the only solution to HIV is the healing prayer.

*During our lost to follow up patient tracking, we have witnessed ART tablets thrown away in the bush and some relatives have testified that they were thrown away because they carry demons (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

#### **4.7 Health and Health Care Systems Related Challenges**

Sickness of either the caregiver or of the adolescent on ART and other health systems related challenges did also come out during interviews and interactions as some of the stumbling blocks of ART adherence among adolescents.

#### **4.7.1 Health Status of Adolescent on ART or of the Caregiver**

##### *i) Health of the Adolescent*

Some interviewees revealed that suffering from another disease extra to HIV discourages them to continue taking their ART medicines either because they feel overwhelmed by diseases or they have too many tablets to take at one time.

Other study participants said sickness make someone too weak to access ART clinic for refills. One of the participants had also shared that he once was hospitalized after sustaining some injuries from a motor-vehicle accident and he too did not take his daily ART doses because he was unconscious and his family members were unaware of his whereabouts.

*I missed my doses at 2 occasions because I was admitted in the hospital twice this year and my medicines were left at home* (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).

##### *ii) Health of the Caregiver*

Another adolescent said that his grandmother as a care-giver fell sick and no other person was available or ready to take him to health facility for ART medicine collection and because he was too young travel alone, he missed his monthly follow up for medicine refill and eventually missed monthly doses which constitutes poor adherence to ART.

*In case a grandparent is sick or not at home, the adolescent will miss ART follow up for refills until granny is available to bring her again* (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).

#### **4.7.2 Health Care Systems Related Challenges**

##### *i) Health Care related Challenges*

As stated under personal related challenges, pill fatigue and pill burden are some of the issues also related to health care which discourage adolescents to take their medicine as prescribed.

The study presented that negative attitudes of some health care workers which deter patients from coming back after missing follow ups for fear of being embarrassed by health care workers.



*I observed the bad attitudes of health care workers to caregivers when your child misses follow up...you will be grilled with so many questions, harassed and embarrassed by consultants upon your return. ...if you are afraid to be embarrassed in front of fellow patients, you won't dare coming back ever (Focus Group Discussion, Key Informant Caregivers, Onandjokwe).*

It also came out from the study that changing doses or regimens of ART treatment for adolescents confuses some health care workers, adolescents and caregivers especially elderly caregivers.

*Changing the routine of taking medicine from the familiar band to a new one is confusing especially to elderly caregivers (Focus Group Discussion, Key Informant Caregivers, Onandjokwe).*

*Information regarding replacement medicine or dosage change that is appropriated to adolescent weight increase, is sometimes confusing to adolescents, health care workers and caregivers. And, these changes are inevitable if it is based on new study recommendations or supplier change. In many occasions, such new information does not reach caregivers because they rarely accompany adolescents to information sessions (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

ART stock-out is also one of the challenges as it increases the frequency of follow up to pharmacy thereby increasing transport costs to each family being affected by ART stock-out.

*There are times that hospitals experience stock out of ART medicines resulting in patients issued with medicines enough for one week only before coming back for the next supply...this requires the patient to travel a lot more than he/she normally does, increasing transport costs...families who cannot afford these frequent transport costs will default treatment (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

Both FGDs held by adolescents and caregivers have elicited that long queues in hospitals specifically at pharmacies, discourage both caregivers and adolescents to listen attentively to adherence counselling and other health education messages.

*The long queues to wait for medicine, usual at pharmacy are very discouraging...the intolerant youths especially males will leave before they collect their medicines* (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).

Medicines' bad smell or taste such as sourness discourages adolescents from taking ART medicine especially the syrup drugs.

*At the beginning, I had a problem of swallowing the syrup because of the bad taste, bad smell, bitterness and because it causes nausea* (Focus Group Discussion, Adolescents aged 10 -14 years, Onandjokwe).

The discussions also give details on adolescents missing ART doses due to bad experience or they fear medicine side-effects. Some participants were adamant that Efavirenz (EFV) one of the ART drugs, induces forgetfulness.

*EFV taking makes patients to forget whether the previous required dosage was already taken or not, which in many occasions is not being taken, causing the patient to miss such a dose* (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).

The discussion indicated also that some adolescents become reluctant to come for follow up and collect their ART medicine after losing their familiar nurses as normally happens during staff re-allocation or in situations of high staff turnover as the one that hit Onandjokwe ART Clinic in 2012.

*The disappearance of the nurses we knew well from Shanamutango [ART Clinic] left some of us demoralized. You get used to a certain friendly nurse and she/he disappeared without even informing you that is so discouraging* (Focus Group Discussion, Key Informant Caregivers, Onandjokwe).

*ii) Health Systems Challenges*

*a) Poor Implementation of the Frequently Reviewed ART Guidelines*

Outdated and inappropriate adherence counselling messages are some of the aspects leading to poor ART adherence being discussed.

*Nurses are not giving us adequate information on new methods of taking medicines and we end up giving medicines at wrong times (Focus Group Discussion, Key Informant Caregivers, Onandjokwe).*

*Some of the staff members are still giving the old messages regarding ART medicine dosing to patients during health education and counselling sessions. Majority of patients are taking a single dose at night but some health care workers are still telling patients to take medicine twice a day (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

*b) Limited Access to ART and ART Information*

Lack of take-home readers from which the adolescents or caregivers can get clear ART information during their own free time is also one of challenges being discussed.

*Adolescents and Caregivers are not keen to attend adherence and health education sessions and as such, readers and pamphlets might be very helpful source of information (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

It was being reported to this study that some adolescents are unwillingness to take unfamiliar medicine which they normally get based on their weight change or when the pharmacy experiences a stock-out of a common ART drug.

Adolescents staying near health facilities where decentralization of ART did not yet reach are still to travel long distances to collect their medicine.

*Some of the communities aren't lucky to have medicines brought to their nearest clinics as in other villages...we still have to walk the whole day to and from ART clinics...that is another*

*reason preventing us from collecting medicine (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).*

Although many health facilities in Oshikoto Region offer ART medicines, only few of them offer disclosure services. As a result, many Adolescents do not undergo disclosure program which is designed to help them professionally to know their HIV status.

*We need to make adolescents understand their HIV situations through disclosure processes but this is always being delayed because they come alone without a caregiver to consent for disclosure at Onandjokwe and the program does not exist in all ART outlets (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

#### **4.8 Geographic and Weather Conditions Related Challenges**

Participants have discussed factors related to land terrains and dense forests as well as adverse weather conditions which play a role in leading to poor adherence among adolescents



##### **4.8.1 Geographic Conditions Related Factors**

Some participants have alluded to hard to reach areas. Some areas are characterized by dense forests where there are no roads, resulting in a lack of transport for adolescents and other patients to reach health facilities and collect medicines in time.

*People who stay in areas surrounded by dense forests and are far from ART clinics are being faced with challenges of getting transport even if they have money. The only track roads existing in these forests are sandy and only 4 wheels drive vehicles can pass through (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

Another environmental challenge derived from the discussion above is the loose sand of some areas which make roads rough and risky for vehicles to get stuck as found in the most eastern parts of Onandjokwe district.

#### **4.8.2 Weather Conditions Related Factors**

The flood that destroyed various roads south western part of Onandjokwe district during 2010 was also discussed as one of the weather related challenges that prevents clients to access health facilities and collect medicines. The heavy rainfall of 2010 has resulted in a flood that washed away so many roads and cut-off communities to access health facilities including ART clinics.

*The floods of the year 2010 had washed away many gravel and track roads, resulting in the cut-off of some people to access health facilities (Focus Group Discussion, Key Informant Healthcare Providers, Onandjokwe).*

Another factor related to weather that was shared is cold temperature which is often being experienced during winter seasons. Some adolescents and caregivers avoid travelling during morning times and will only appear again late when the temperature improves.

*During winter, when it is too cold we wait until it becomes warm before starting to travel to the clinic and hope to come back home before it gets cold again, but those who come from far may find the clinic closed and they have to leave without medicine because they cannot overnight in the open and stand the cold to get their medicines in the next morning (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).*

Lastly, too hot temperature was also mentioned as one of the contributing factors of collecting medicine late or missing follow ups because they wait until it becomes a bit cooler before travelling to the clinic but usually will arrive after working hours and find the clinic already closed.

*Even if you get a permission form school to visit the clinic, you can only do that after school classes and that will be during midday when it is too hot to walk in the sun...the more you wait for the temperature to cool off the lesser time you have to find the clinic open (Focus Group Discussion, Adolescents aged 15-19 years, Onandjokwe).*

## CHAPTER 5. DISCUSSION AND INTERPRETATION OF RESULTS

### 5.1 Patient and Family related Challenges

Two sub-categories of patient and family related challenges have emerged from the findings of this study, namely patient and caregiver related barriers.

#### 5.1.1 Patient Related Barriers

This study re-affirms the presentations of Reda and Biadgilign (2012) that peer pressure, rebellion and antagonism are some of the behavioural characteristics causing adolescents to abandon their HIV treatment. Adolescents may act-out (Williams, 2016) against the taking of medicine, to vent and express anger to caregivers.

Too much movement of the adolescent as stressed by Amberbir et al. (2012) is being confirmed by this study in terms of multiple holiday visits to un-informed families and relatives that it leads to poor adherence to treatment because the holiday hosting family is usually not aware whether the visiting child is on ART medicine.

From this study, both caregivers and adolescents reported that forgetting the taking of ART doses remains significant among adolescents.

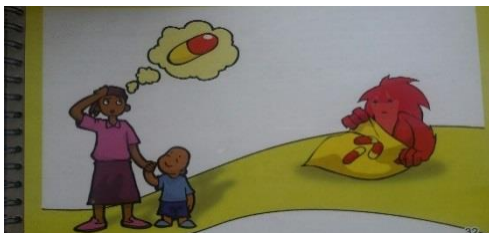


Figure 3. Caregiver forgets ART Dose for Adolescent. MoHSS, Pepfar & I-Tech, 2012

Although forgetfulness is usually associated with aging, Adolescents' forgetfulness is likely based on pre-occupation or being overloaded with other engagements such as school high demands, addiction to plays e.g. soccer, computer and TV games as well as household chores.

### **5.1.2 Caregiver Related Barriers**

Family movements as stressed by Amberbir et al. (2012) is being confirmed by this study in terms of holiday visits to un-informed family that it leads to adolescents poor adherence to ART. Apart from adolescent movements within the relative circles, migration of parents especially mothers leaving to central and western Namibian towns in search of jobs, affects ART adherence of their children who eventually being left in the care of grandparents. Elderly grandparents are normally forgetful and rarely able to read any instruction and may not follow the medical instructions properly (Dahab et al., 2008).

Although the literacy rate among 15 – 49 aged people is high in Namibia (93% of women and 91% of men), it decreases among the older populations especially with those residing in rural areas (NDHS, 2013). From the study, most adolescents under the care of elderly caregivers who are mostly illiterate are reportedly the ones with more adherence problems to ART than those cared by young adults. Dahab et al. (2008), agree that older and illiterate care recipients have difficulties of understanding counselling and instructions regarding the methods of taking medicines, thus have more adherence problems.

Young parents reportedly have fear of being labelled HIV positive if they are seen entering ART clinics, therefore, they became reluctant to escort adolescents to ART clinic missing the adherence counselling sessions. In case a grandparent gets sick, or encounters any hindrance to visit ART clinic, the adolescent is being abandoned to undergo ART counselling alone. As result the child may not capture the details of ART adherence instructions due to their age related low level of understanding.

Fetzer et al. (2011) find out that poor family communication and lack of disclosure are good markers of poor adherence and this study is in agreement to find out that the younger parents who refuse their children to undergo the program of HIV disclosure are fuelling poor ART adherence.

Some parents are reportedly refusing their children to go through HIV disclosure program, fearing that if adolescents learn about their HIV positive status, they will blame and accuse parents of being sexually careless and irresponsible by contracting and infecting their babies with HIV. Although this fear and the potential child-mother rejection form part of the aspects covered during HIV disclosure program sessions, some parents are adamant and against disclosure, letting their

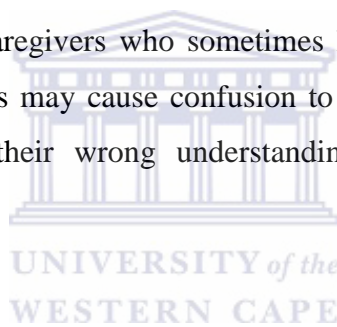


children continue taking ART medicines without knowing the important reasons of taking them, thereby increasing chances of children to skip some doses and that constitutes poor adherence to ART.

Lack of supervision has also emerged as one of the challenges to adherence to ART among adolescents. Lack of supervision to guide or motivate adolescents to take ART medicines as prescribed may be attributed to caregiver's ignorance, carelessness and alcohol abuse as well as lack of HIV disclosure within the family.

The study had established that some female caregivers abandon children on ART to avoid their love partners discovering their HIV positive statuses through index referencing. As a result, the abandoned adolescents may lose guidance and motivation of taking ART and that increases the risk of dropping the taking ART medicines.

Some adolescents have various caregivers who sometimes have different understanding about ART dosing. Too many caregivers may cause confusion to adolescents taking ART by giving different instructions based on their wrong understanding and interpretations of medical prescriptions.



## **5.2 Stigma and Discrimination**

Lack of privacy in boarding schools, foster houses and other public gatherings are good predictors of poor adherence to ART among adolescents (Mutwa et al., 2013; Roberts, 2004). Nabukeera-Barungi et al. (2015) assert that lack of privacy in boarding schools and other public places persuades adolescents to stop taking their ART medicines and eventually drop out of HIV care. Student adolescents who do not disclose to teachers find it difficult to get permission to attend the ART clinic appointments which leads to missing clinic follow ups.

The findings of this study are in agreement with Green and Britten's (1998) presentation that adolescents avoid taking their medicine in unconducive environments such as school hostels foster homes and at other public gatherings, fearing stigma and discrimination. By nature adolescents have a greater interest in their privacy (Williams, 2016), thus easily may avoid taking ART medicine in the presence of others. However, the study reveals that stigma is mostly perceived as



opposed to actually being practiced. Both students interviewed who stay in school hostels, have shared that they were never laughed at for taking ART medicines although they avoid doing it in the presence of other students. They also confirmed that they missed doses of ART due to fear of being laughed at because sometimes there is lack of confidential space to take the medicine. Likewise, none of the interviewed adolescents had reported being discriminated or rejected socially based on her/his HIV positive status. However, both students have revealed the fear of losing friends, should their HIV positive statuses become known. Vaz et al. (2010) have outlined that fear is one of the barriers preventing adolescents to take ART drugs openly.

One of the findings of this study is that young mothers hide their HIV status, to secure new love relationships and only allows disclosure when the relationship is securely established. Such lack of disclosure does negatively affect the ART adherence of children under her care.

A similar observation of young adults who are caregivers but reluctant to enter ART clinics in fear of stigma and discrimination is indicated by Mutwa et al. (2013).

### **5.3 Substance Abuse**

Alcohol abuse among caregivers is reportedly as one of the aspects leading to poor or lack of parental supervision over adolescents taking ART medicine. Young adolescents (10 -14 years old) who mostly require parental guidance are left unguided on taking ART medicine by caregivers who abuse alcohol intoxicated, a situation increasing chances of poor adherence to medicine.

Similar findings with this study are shared by Vaz et al. (2010) that alcoholism among care givers had made caregivers less caring to guide adolescents to take their medicines correctly.

Not only caregivers miss their responsibility regarding ART due to alcohol abuse. Some adolescents, who use alcohol, are reportedly adhere poorly to ART. Alcohol intake minimizes one's awareness of responsibilities and decreases the alertness of taking ART medicine in time (Vaz et al., 2010).

Some of the adolescents who adhere poorly to ART medicine reportedly smoke tobacco. Tobacco smoking does not only disturb metabolic processes of medicine taken, but it also leads to ignorance of ones responsibilities (Vaz et al., 2010).

## **5.4 Socio-economic Related Challenges**

### ***5.4.1 Lack of Family Income***

In its plan of Community Based ART (C-BART), the Namibian Ministry of Health aims to decrease the loss to follow-up of ART patients caused by long distances because C-BART program is expected to bring ART medicine to community points, closer to where recipients live and increase the linkage and retaining of HIV positive people on ART (MoHSS, 2014).

Adolescents are not yet financially independent, they depend on adults for transport fares. If the caregiver does not have money for transport, there is a high chance of the adolescent under her care not to collect ART medicine in time, resulting in missing to take some doses, a situation that constitutes poor adherence.

### ***5.4.2 Social Support Related Barriers***

Social movement within relative circles or outside the family, contributes also to poor ART adherence among adolescents. During school holidays, many adolescents visit relatives and family acquaintances who are often unaware of the adolescents' ART needs to support them. Stigma is likely the demotivating factor, discouraging families to disclose adolescent's ART needs to the holiday hosting family, thereby increasing chances of adolescents missing treatment during school holidays.

In the absence of parental guidance, orphans who head households find it difficult to manage household demands including taking medicine or guiding others as per medical prescriptions because these demands exceed adolescent's capability to handle them (Arrive et al., 2012).

Many orphans and other vulnerable adolescents do not receive social grants due to lack of national documents required to qualify them for social grants. The abandoned adolescent orphans are hardly accessing social grants to enable them to afford transport fares to ART clinics and to buy adequate food.

The nurses participated in the discussions said most of the orphan adolescents in Onandjokwe district depend only on healthcare providers and family members for their motivation to continue taking the lifelong treatment. If there were adequate social support clubs in the area, such a role

can be shared among all three bodies. However, there are limited social support clubs in Oshikoto Region and those in other regions are far, not accessible to most of adolescents living in Onandjokwe district who need motivation and encouragement to continue taking ART medicines. The only social support network, Save our Souls (SOS) available in Onandjokwe District is ever overloaded with clients.

### ***5.4.3 Cultural Beliefs and Practices Related Barriers***

Believing in and using of traditional medicine was also reported as a potential challenge to ART among adolescents. Most of the patients using traditional medicine stop taking ART either because they believe that they will be cured by traditional treatments or they fear possible side effects from the mixture of ART and traditional medicine (Dahab et al., 2008). The study discussions have also revealed that some HIV sufferers have resorted to traditional medicines and ignore ART. Practically, there is no evidence presented during the discussions, of patients being healed or cured from HIV by taking traditional medicine. Reportedly, most of HIV positive patients who dropped ART and had resorted to traditional medicines have died or returned to modern ART clinics while in irreversible dying conditions.

Reda and Biadgilign (2012) warn that myths and misconceptions prevent adolescents from taking ART medicines. During this study, some adolescents interviewed did report that some of their peers have stopped taking ART medicine because they falsely believe that ART tablets are made from human brains.

There is also a strong belief harboured by some preachers and patients from a certain new religions in Namibia that prayers alone can cure HIV and as a result, some patients stopped taking ART medicines. Some caregivers are among these believers and they influence adolescents living with HIV to drop ART medicine and confide in prayers only.

In most cases, caregivers are the ones taking adolescents to the ‘men of god’ for spiritual healing (Peralta, Belzer & Palmer, 2009). What is bad with spiritual healing practice is that the patient has to stop taking ART medicines (Bezabh et al. 2014).

These are some of the misconceptions hindering adolescents and adults from taking ART medications as prescribed, which constitutes poor adherence. The literatures reviewed have confirmed the unavailability of cure medicine for HIV infection, this disqualifies the claims of prayers curing patients from HIV and making such claims unreliable and mythic.

A belief that ART causes loss of libido was also shared during the study discussions and can be one of the reasons for adult adolescents (15-19 years old) to occasionally drop taking ART medicine.

As indicated by Haberer et al. (2011), interviewees in this study have also indicated that poor adherence among adolescents is primarily caused by lack of transport fares to ART clinics. Although it is disheartening to find out how orphans struggle to find transport money to ART clinics to collect their medicine, it is equally encouraging that the scale-up of ART rollout to many health facilities in the district is likely to reduce the transport burden.

## **5.5 Health and Health Systems Related Challenges**

### ***5.5.1 Health Status Related Barriers***

Health Care Providers who care hospitalized patients, do rarely support HIV patients to follow the course of ART due to their limited knowledge about ART. This is bad especially if the patient is unconscious or did not bring his ART medicine along when he/she is being admitted for a different reason for instance treatment for malaria, motor vehicle accident or others.

Hospitalization is confirmed by this study that it limits the interventions of family members who have knowledge about their relative's ART medicine. Adherence tends to become poor in the events of caregiver's illness when the adolescent is too young, who depends to the caregiver for taking ART medicine (Grierson, Bartos, Visser & McDonald, 2000).

### ***5.5.2 Health Care Systems Related Barriers***

#### ***5.5.2.1 Health Care Related Barriers***

From the discussions with health care workers and caregivers, it emerged that adolescents who experienced or were aware of bad side effects of medicines often adhere poorly to ART, possibly

fear side-effects attack from new unfamiliar medicine. Kammann, Williams, Chesney and Currier (1999; Roberts, 2004) agree that patients with a history of side-effects from other medicines tend to have poor adherence to ART due to fear of re-occurrence of adverse events.

The discussion spelt out that pill fatigue is also one of the factors affecting ART adherence negatively among adolescents. Some patients said that they avoided their medicines because of physical and psychological exhaustion as Amberbir et al. (2012) outlined. ART is a life-long course and with a combination of adolescence peer pressure and other life demanding responsibilities, this course is likely to become tiresome, leading to poor adherence to it.

To decrease the pill burden, most patients including adolescents on ART treatment in Namibia are now changed to a single dose of drugs combination in a form of one tablet taken at night.

Long waiting queues which are common in Onandjokwe ART clinic especially at pharmacy lead to caregivers or adolescents to develop impatience, irritability and loss concentration during both routine and special adherence counselling sessions, resulting in poor understanding of details of medicine taking and eventually, adhere poorly to ART medicines. Similar findings are cited by Dahab et al. (2008) who indicate that long waiting times in health facilities discourage patients to visit ART clinics to collect their ART medicines.



*Figure 4. Patients Waiting Benches at Pharmacy for Long queues. Photo by Eliphaz H, 2015*

In many occasions, impatient adolescents specifically males, leave the pharmacy before receiving their medicine due to long queues of waiting. In Onandjokwe the long queues are often common at pharmacy because both adult and adolescent patients use only one medicine dispensing outlet.

On the other hand, healthcare providers are forced by time pressures to speed up and finish the long queues within working time hours, making them time rushers/chasers during consultations

thereby leading to poor understanding of important information aimed to guide the treatment course of adolescents and as result, some adolescents will not take their medicines as prescribed.

The fast changing of medicine regimens, doses, labels or texture confuses both the health care workers and clients. The change of ART medicine in health care setting is normally necessitated by the change of child's weight, introduction of new drug, replacement of a famous drug from the market, stock out of usual medicine and in case of the recipient develops side effects from one of the current drugs.



*Figure 5. ART Medicine in Pharmacy. Photo by Eliphias H, 2015*

In most cases, these fast changes are enforced with the revised guidelines or a circular of which some health care workers misinterpret.

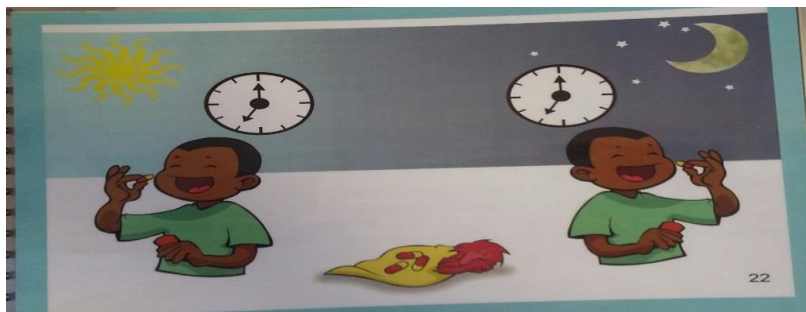
As new regimens being developed or improved to address most of the identified gaps, some health care workers do not capture or understand these changes and they continue giving health education and counselling based on the older versions of dosage instructions which become obsolete information, confusing and causing adolescents not to stick to the correct dosages and sometimes they discontinue taking medicines altogether.



*Figure 6. Three of the 4 editions of ART Guidelines within 6 years. Photo by Eliphias H, 2015*



Likewise, if the patient or caregiver is not familiar with the new dose or medicine, they may administer it at wrong times, missing the peak hours of maintaining the blood drug level. The findings from this study are in agreement with Reda and Biadgilign (2012) that poor adherence among adolescents can be caused by medication patterning challenges, lack of directions and public education.



*Figure 7. Outdated Dosage IEC Material in use for Adherence Counselling. MoHSS, Pepfar & I-Tech, 2012*

Lack of patient information, education and communication (IEC) materials which can be taken home and read at the clients own convenient time, is also one of the challenges of ART adherence discussed during the interviews. Adherence lessons can be understood better at rest than during the times when patients and their caregivers are anxious, irritated by long waiting queues or rushed and fearing whether they will find transport to go back home before dark.

Unpleasant medicine taste and smell are some of the challenges to ART adherence among adolescents, especially, among teenagers (10 – 14 years of age).

Some parents and caregivers have to award teenagers with sweets after she/he swallowed the sour medicine. In the absence of sweets, some teenagers refuse to take sour tasting, unpleasant smelling medicine or drugs which result in nausea especially liquid formulas, as required.

Bad attitudes of nurses and other health care workers deter some children who missed follow ups to come back because those who turned up are reportedly grilled with so many questions, harassed and embarrassed by consultants. In fear of this, some of the adolescents and caregivers decide not to turn up for medicine collection after they realized that a follow up is being missed.

### ***5.5.2.2 Health Systems Related Barriers***

Disease burden on health care system leads to poor quality of services being rendered because the limited numbers of healthcare providers is unable to address all the health care needs. The available healthcare providers tend to rush consultations to finish the queue, instead of listen thoroughly to the patient needs and address them properly.

Onandjokwe Management did well to integrate antenatal care (ANC), postnatal care (PNC) family planning, immunization and HIV care services under one roof albeit different rooms to avoid the clinic to be stigmatized. However, the adolescent Friendly Clinic is a stand-alone setting and offers solely HIV care services, making it uncondusive structure for stigma control and that deters mostly, the young caregivers from escorting adolescents taking ART.

The blue ART patient file increases the chances of stigma because of its uniqueness in colour and big size.

Competing priorities between health programs may lead to other constraints of adherence among adolescents. Malaria endemic has raised up again in areas of northern Namibia, demanding for the same resources required to run ART programs such as human resource, infrastructures, transport and money. More staff members have left the ART services to other programs, thereby leaving ART Services run with insufficient resources especially transport for early patient tracking.

Although adolescents are more interested in their privacy, they tend to confide in each other than they do to parents (Williams). By recognizing that, Onandjokwe has established a vibrant Teens



Club and the Adolescents Friendly Club Days to facilitate interactions and discussions of HIV infection, ART and sexuality information among adolescents.

The high staff turn-over that was experienced in Onandjokwe has negatively affected the Teens' Club service delivery, Adolescents Friendly Club Days and Adolescent Disclosure Programs.



*Figure 9. Famous Picture used for Adolescents Disclosure Program. MoHSS, Pefar & I-Tech, 2012*

These study findings are consistent with the findings of Fetzer et al. (2011) that lack of HIV disclosure is the recipe of poor understanding which leads to adolescents dropping off from ART medicines. Lack of disclosure enrolment which is normally recruiting adolescents under Teens' Club and Adolescent Friendly Club Days programs, contributes to poor adherence to ART because some adolescents in the age category of logic reasoning and understanding circumstances that affect them are not yet made to know the reasons of taking ART medicines. Once they start questioning the need of taking medicine but no one gives them a proper answer, they are likely to adhere poorly to ART.

The disclosure program helps adolescent to gradually know and understand the reasons of taking ART medication and the importance of taking them regularly as prescribed by the doctor or nurse, thereby enhancing commitment to medicine adherence.

Although disclosure program is proved beneficial to adolescents by improving acceptance of and adherence to ART, Mburu et al. (2014) acknowledge the refusal of some parents preventing their children to go through disclosure program. In most cases children come alone, unaccompanied by caregivers to ART centers to consent for disclosure enrolment (Lowenthal et al., 2014). The Ministry of Health and Social Services of Namibia has adopted the disclosure program for all teenagers and adolescents living with HIV, to assist them to understand their own HIV statuses and the need to continuously and consistently take ART medicines (MoHSS, 2014). The Ministry

of Health, with the support from Centre for Diseases Control and Prevention (CDC) is busy scaling up HIV disclosure program to all public ART offering facilities (MoHSS, 2014).

Some caregivers who in most cases are not the biological parents to adolescents under their care are reportedly disclose the HIV statuses of these adolescents publically and as a result adolescents move out, caning residences and drop ART medicines (Nabukeera-Barungi et al., 2015).

There are times that hospitals experience stock-out of ART medicines resulting in patients issued with medicines enough only for one or two weeks before coming back for the next supply. This requires the patient to travel a lot more than he/she normally does, increasing transport costs. Those who cannot afford these frequent transport costs for follow up visits will default treatment.

## **5.6 Geographic and Weather Conditions Related Challenges**

### ***5.6.1 Geographic Related Barriers***

The major part of Onandjokwe District is a hard to reach area, characterized by dense forests, long walking distances, loose sand and sandy road tracks (shown in the picture below), making it difficult to find vehicle transport.



*Figure 10. Loose Sandy Road Tracks in Dense Forests of Onandjokwe District. Photo by Eliphaz H, 2015*

Adolescents who stay and live in these villages are faced with challenges of timely transport to enable them collecting medicines including ART drugs from health facilities and keep adequate home stock of ARV drugs for daily dosages.

### ***5.6.2 Weather Conditions Related Barriers***

The unprecedented finding of this study is flood which occurs occasionally during rainy season and it destroys the roads' network in the southwestern areas of Onandjokwe and as a result cutting off those areas and limiting the accessibility of inhabitants to health facilities for their health needs including ART medicines.

In the absence or delay of a helicopter to deliver required humanitarian and health needs, patients experience a short supply of ART medicine and are compelled to abscond ART daily doses which constitutes poor adherence to ART.

Another weather barrier occurs during winter season when it becomes extremely cold that some adolescents and caregivers avoid travelling in cold, thereby missing medicine follow ups at ART clinics. If weather temperature becomes too hot, often during Autumn, some adolescents wait until afternoon hours when it cools off to travel to ART clinics but in many occasions, they would arrive after 17H00 and find the clinic closed, a situation forcing them to go back home with no medication to take for that week until they get another school permit for the clinic.

Adolescents are likely to be the most vulnerable to these environmental and weather related challenges because of their lack of income in the society.

## **5.7 STUDY LIMITATIONS**

Onandjokwe ART clinic has undergone a major transition period caused by the cessation of donor funding between year 2012 and 2014. Most of the computers for patient management databases are malfunctioning and could not be repaired or replaced due to lack of funds. Two other data clerks who use to capture and clean data have left the ART Clinic for other employment opportunities, causing a backlog of patient data waiting to be entered into ePMS and EDT systems

and the current data in the system is incomplete and unreliable to reflect for credible reports when queried for this study.

The nurses who were initially earmarked to participate in this study as key-informants because of their long time service in adolescent friendly ART programs have left the ART Clinic and were replaced in the discussions by others who worked with adolescents ART only for less than 3 months by then.

To improve adherence, new medicine preparations are developed as daily single dose known as fixed dose combination (FDC), replacing two doses per day which was commonly known during the development time of the protocol.

The process of protocol approval had been too long such that HIV data and programs evolution happened were significantly big thereby affected the baselines where this study was established on. As a result, data has to be readjusted.

During the FGD with adolescents of 10 -14 years old, interaction was very low with only three adolescents doing most of the talking. Some adolescents were almost mute, likely avoiding to offend caregivers if they reveal why they missed follow ups. Apart from motivating them to speak out, caregivers could not be moved out of the room because these adolescents were minors, whose right of participation is still being consented by caregivers.

One caregiver, a key informant had requested to be released before discussions ended, to escort her child to school to write examinations, resulting in the discussion to proceed with only 4 participants.

Although the exploratory study design sounds great for human behaviour studies, qualitative study methods in general are often being criticized of being more subjective, characterized by perceptions and beliefs as opposed to quantitative methods of having scientific proved facts (Green & Britten, 1998).

## CHAPTER 6. CONCLUSION AND RECOMMENDATIONS

In conclusion, this study had attempted to form a better understanding of barriers to adherence among adolescents in Onandjokwe.

Barriers established are related to the following main categories such as family and patient factors, stigma and discrimination, substance abuse, socio-economic issues, health and health care systems factors, geographic and weather related conditions as summarized in Figure 11 below. Under family and patient category the challenges are confirmed in two subcategories of caregiver and patient related challenges. Caregiver issues include, lack of parental supervision due to alcohol abuse, fear of stigma of reference, orphan discrimination, forgetfulness associated with ageing and dementia of caregiver, ignorance or child neglect, carelessness, avoidance of disclosure caused by fear of blame and rejection, lack of transport fares, too many caregivers, lack of HIV disclosure within family and relative circles and the fear of losing new intimacy relations. On the other hand, patient factors include attitude influence among peer groups, rebellion, disobedience, pill fatigue, sickness and disease burden, high school demands, sport addiction, being orphan and assuming adult household responsibilities as well as forgetfulness.

Stigma and discrimination in school and health facility settings also form part of barriers among adolescents to ART. Barriers related to staying in school hostels are the absence of conducive times and space to take ART medicine, presence of other students, fear of psychological abuse from others, fear of losing friends and fear of punishment following school absence to collect ART medicine.

Alcohol abuse among caregivers and adolescents was also established by this study as another determinant of poor ART adherence. Adolescents also face lack of social support networks, social grants, family support and transport money as socio-economic factors against taking ART medicines properly

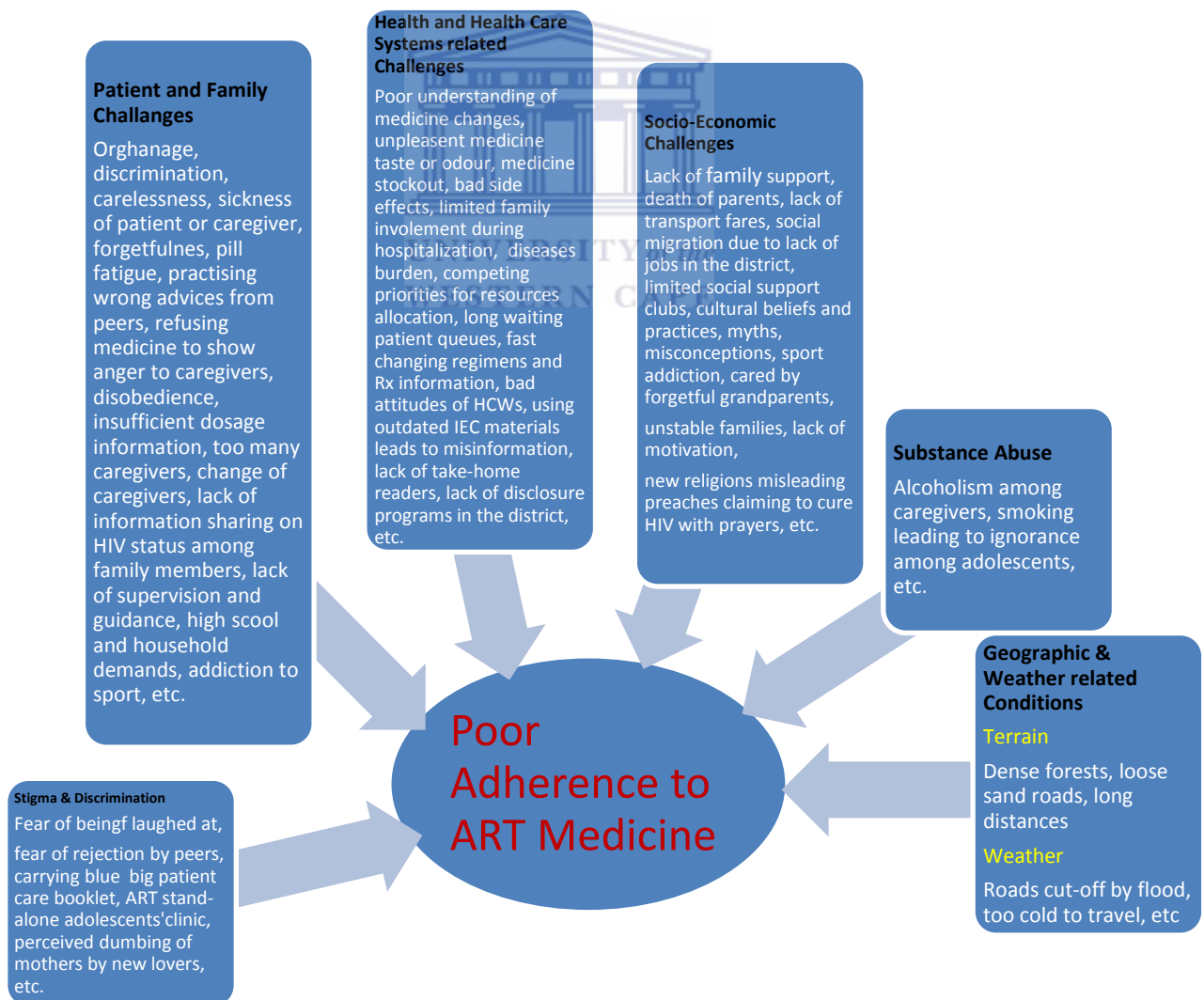
The study has also uncovered challenges of ART adherence which are related to health care and health systems such as poor understanding of treatment among health care workers, caregivers and adolescents caused by lack of disclosure and treatment doses or regimen change; lack of ART information due to poor supply of the take-home readable materials, outdated counselling materials

or avoidance of long waiting queues. Other healthcare related challenges are medicine stock-out, unpleasant medicine taste or odour, disease burden to health resources, conditions of hospitalization and the bad attitudes of health care workers.

Environmental factors such as staying in hard-to-reach areas of dense forests or loose sandy tracks prevent easy access of adolescents to clinics to collect ART medicines in time.

Bad weather conditions such as floods in summer which destroy roads, limits the accessibility of patients to health facilities. When it is too cold during winter seasons, patients wait until late to travel to the clinics and usually find the clinic closed.

*Figure 11. Summarized Determinants of Poor Adherence to ART among Adolescents in Onandjokwe District, 20152*



This study recommends the use a quantitative study to establish and compare the number of affected adolescents per each category of barriers to ART adherence if Onandjokwe District Hospital team decides to design appropriate interventions to address the challenges proportionally based on the availability of funds.

The study further recommends for another qualitative study to understand the fear of blame and rejection of parents who deny their children to undergo HIV disclosure programs.





## LIST OF REFERENCES

- Amberbir, A., Woldemichael, K., Getachew, S., Girma, B. & Deribe, K. (2008). Predictors of Adherence to Antiretroviral Therapy among HIV-Infected Persons: (2008). A Prospective Study in Southwest Ethiopia. *BMC Public Health Journal*, 30 (8):1471-2458
- Ankrah, N.A.D., Koster, E.S., Mantel-Teeuwisse, A.K., Arhinful, D.K., Agyepong I.A. & Lartey, M. (2016). Facilitators and Barriers to Antiretroviral Therapy Adherence among adolescents in Ghana. *Dove Medical Press*, 2016; 10:329-337. [Online], Available: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4801129> [Downloaded: 25/11/16 14:20 PM]
- Arrive, E., Dicko, F., Amghar, H., Aka, A.E., Dior, H., Bouah, B., Traore, M., Ogbo, P., Dago-Akribi, H. A., Eboua, T.K.F., Sy, S.H., Alioum, A., Dabis, F., Koumavi, D.E. & Leroy, V. (2012). HIV Status Disclosure and Retention in HIV-Infected Adolescents on Antiretroviral Therapy (ART) in West Africa. *PloS One Journal*, 21 (3): e33690 [Online], Available: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3310064/> [Downloaded: 06/03/13 12:32 PM]
- Beaglehole, R., Bonita, R. & Kjellstrom, T. (1997). *Basic Epidemiology*. Geneva: WHO Publications
- Bezabhe, W., Chalmers, L., Bereznicki, L., Peterson, G.M., Bimirew, M.A. & Kassie, D.M. (2014). Barriers and Facilitators of Adherence to Antiretroviral Drug Therapy and Retention in Care among Adult HIV-Positive Patients: A Qualitative Study from Ethiopia. *PloS ONE*, 9(5): e97353. doi:10.1371/journal.pone.0097353 [Online], Available: <http://journals.plos.org/plosone/article?id=10.1371journal.pono.0097353> [Downloaded: 21/09/16 14:48 PM]
- Biadgilin, S., Deribew, A., Amberbir, A. & Deribe, K. (2009). Barriers and Facilitators to Antiretroviral Medication adherence among HIV Infected Pediatric Patients in Ethiopia: A Qualitative Study. Ethiopia: John Hopkins University. [Online], Available: <http://www.sahara.org.za>
- Bikaako-Kajura, W., Luyirika, E., Prcell, D., Downing, J., Kaharuza, F., Mermin, J. Malamba, S. & Bunnell, R. (2006). Disclosure of HIV Status and Adherence to Daily Drug Regimens among HIV infected Children in Uganda. *AIDS and Behavior Journal*, (2006).10:85. [Online],



Available: <http://link.springer.com/article/10.1007/s10461-006-9141-3> [Downloaded: 11/25/16 10:54 AM]

Dahab, M., Charalambous, S., Hamilton, R., Fielding, K., Kielmann, K., Churchyard, G. & Grant, A.D. (2008). "That is why I stopped the ART": Patients' & Providers' Perspectives on Barriers to and Enablers of HIV Treatment Adherence in a South African Workplace Programme. *BMC Public Health Journal*, 2008(8):63, DOI: 10.1186/14671-2458-8-63. [Online], Available: <http://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-8-63> [Downloaded: 25/11/16 15:56 PM]

Evangelini, M. & Foster, C. (2014). Who, then What? The Need for Interventions to Help Young People with Perinatally acquired HIV Disclose their HIV status to Others. *AIDS 2014*, 28(3):S343-S346. DOI: 10.1097/QAD.0000000000000334. Royal Holloway University of London: Department of Psychology

Fetzer, B.C., Mupenda, B., Lusiana, J., Kitetele, F., Golin, C. & Behets, F. (2011). Barriers to and Facilitators of Adherence to Pediatric Antiretroviral Therapy in a sub-Saharan Setting: Insights from a Qualitative Study. *AIDS Patient Care STDS*, 25(10): 611-621

Gibbert, M. & Ruigrok, W. (2010). The "What and How" of Case Study Rigor: Three Strategies Based on Published Work. *Organizational Research Methods*, 13(4):710-737. [Online], Available:

<http://www.alexandria.unisg.ch/208773/1/Gibbert%20%26%20Ruigrok%20ORM%202010%20manuscript.pdf> [Downloaded: 12/08/2016 10:13 AM]

Green, S. & Britten, N. (1998). Qualitative Research and Evidence Based Medicine. *British Medical Journal*, 9(316): 1230-1232. [Online], Available: <http://www.bmj.com/cgi/content/full/316/7139/1230> [Downloaded: 19/09/00 11:42 AM]

Green, J. & Thorogood, N. (2004). *In Qualitative Methods for Health Research*. London: Sage Publications

Grbich, C. (1999). Action Based Methods in Qualitative Research for Health. *Qualitative Research in Health. An Introduction*. Sydney: Unwin & Allen: 203 – 206.

Grierson, J., Bartos, M., de Visser, R. & McDonald, K. (2000). HIV Futures II: The health and Wellbeing of People with HIV/AIDS in Australia. *Monograph Series Number 17*, La Trobe University

Haberer, J.E. Cook, A., Walker, A.S., Ngambi, M., Ferrier, A., Mulenga, V., Kityo, C., Thomason, M., Kabamba, D., Chintu, C., Gibb, D.M. & Bangsberg, D.R. (2011). Excellent Adherence to Antiretrovirals in HIV + Zambia Children is Compromised by Disrupted Routine, HIV Nondisclosure, and Paradoxical Income Effects. *PloS One Journal*, 21(6) e18505. [Online], Available: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3080873/> [Downloaded: 06/03/13 11:03 AM]

Haberer, J.E., Kiwanuka, J., Nansera, D., Ragland, K., Mellins, C. & Bangsberg, D.R. (2012). Multiple Measures Reveal Antiretroviral Adherence Successes and Challenges in HIV-Infected Ugandan Children. *PloS One Journal*, 7(5): e36737. [Online], Available: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3348916/> [Downloaded: 06/03/13 13:45 AM]

Institute of Medicine (US) and National Research Council (US) Committee on Science of Adolescence). (2011). The psychology of Adolescence-The Science of Adolescent Risk Taking: *Workshop Report*. Washington DC: National Academies Press

Kammann, E., Williams, P., Chesney, M.A. & Currier, J. (1999). Predictors of Adherence to Azithromycin prophylaxis for Prevention of Mycobacterium avium complex (MAC) Disease. 6<sup>th</sup> *Conference on Retroviruses and Opportunistic Infections*, Chicago, Abstract 444.

Liamputtong, P.R. & Ezzy, D. (2005). *Qualitative Research Methods*. Sydney: Oxford University Press

Lowenthal, E.D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K. & Ferrand, R.A. (2014). Perinatally Acquired HIV Infection in adolescents from sub-Saharan Africa: A Review of Emerging Challenges. *Lancet, Infect Dis*.14 (7): 627-39

MBESC (Ministry of Basic Education, Sport and Culture). (2002). *The Impact of HIV on Education in Namibia*. Windhoek: National Institute for Educational Development (NIED). [Online], Available:

<http://www.nied.edu.na/publications/aids/The%20impact%20of%20HIV%20and%20AIDS%20on%20education%20in%20Namibia.pdf>. [Downloaded: 6/03/13 14:02 PM]

Mburu, G., Hodgson, I., Kalibala, S., Haamujompa, C., Cataldo, E.D. & Lowenthal D.R. (2014). Adolescent HIV Disclosure in Zambia: Barriers, Facilitators and Outcomes. *International AIDS Society Journal*, 17(18866). [Online], Available: <http://www.popcouncil.org/research/adolescent-hiv-disclosure-in-zambia-barriers-facilitators-and-outcomes/pdf>. [Downloaded: 28/8/16 9:17 AM]

Michaud, P.A., Suris, J.C., Thomas, J., Gnehm, H.E. & Cheseaux, J.J. (2010). Coping with HIV Infection. A Multicenter Qualitative Survey on HIV Positive Adolescents' Perceptions of their Disease, Therapeutic Adherence and Treatment. *Swiss Med Wkly*, 2010 (140):247-53.

MoHSS (Ministry of Health & Social Services). (2015). *The Namibian AIDS Response Progress Report 2015*. [Online], Available: [https://www.unaids.org/sites/default/files/countries/documents/NAM\\_Narative\\_report\\_2015.pdf](https://www.unaids.org/sites/default/files/countries/documents/NAM_Narative_report_2015.pdf) [Downloaded: 9/17/16 10.23 AM]

MoHSS (Ministry of Health & Social Services). (2014). *National Guidelines for Antiretroviral Therapy*. 4<sup>th</sup> Ed. Windhoek: Directorate of Special Programs (DSP)

MoHSS (Ministry of Health of Health and Social Services) & Namibia Statistics Agency. (2014). *Namibian Demographic and Health Survey 2013 (NDHS)*. Windhoek: Directorate of Special Programs. [Online], Available: <https://www.dhsprograms.com/pubs/pdf/FR298/FR298/pdf> [Downloaded: 05/23/16 11:22 AM]

MoHSS (Ministry of Health & Social Services). (2012). *Report on the 2012 National HIV Sentinel Survey*. Windhoek: Directorate of Special Programs (DSP)

Mutwa, R., Van Nuil, J.I., Asimwe-Kateera, B., Kestelyn, E., Vyankandondera, J., Pool, R., Ruhirimbura, J., Kanakuze, C., Geelen, S., van der Wijgert, J. & Boer, K.(2013). Living Situation Affects Adherence to Combination Antiretroviral Therapy in HIV-Infected Adolescents in Rwanda: A Qualitative Study. *PLoS ONE* 8(4):e60073.doi:10.1371/journal.pone.0060073. [Online], Available: <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0060073> [Downloaded: 11/25/16 11:45 AM]

Nabukeera-Barungi, N., Elyanu, P., Asire, B., Katureebe, C., Lukabwe, I., Namusoke, E. Musinguzi, J., Atuyambe, L. & Tumwesigye, N. (Adherence to Antiretroviral Therapy and Retention in Care for Adolescents Living with HIV from 10 Districts in Uganda. *BMC Infectious Diseases. BioMed Central Journal*, DOI: 10.1186/s12879-015-1265-5. [Online], Available: <http://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-015-1265-5> [Downloaded: 11/25/16 14:31 PM]

Nachega, J.B., Hislop, M., Nguyen, H., Dowdy, D.W., Chaiso, R.E., Regensberg, L., Cotton, M. & Maartens, G. (2010). Antiretroviral Therapy Adherence, Virologic and Immunologic Outcomes in Adolescents Compared with Adults in Southern Africa. *J Acquir Immune Defic Syndr.* 51(1): 65-71. [Online], Available: <http://www.ncbi.nlm.nih.gov/pubmed/19282780> [Downloaded: 05/25/15 09:20 AM]

National Planning Commission (NPC). (2011). Namibia National Population Census Survey, 2011. Windhoek: Directorate of Statistics

Onandjokwe LMS (Onandjokwe Lutheran Medical Services). (2015). *ART Monthly Report, July 2015*. Ondangwa: Onandjokwe ART Clinic.

Onandjokwe LMS (Onandjokwe Lutheran Medical Services). (2013). *HIV Quarterly Report, January – March 2013*. Ondangwa: Onandjokwe ART Clinic.

Peralta, L., Belzer, M. & Palmer, A.P. (2009). Treating Adolescents with HIV: Tools for Building Skills in Cultural Competence, Clinical Care, and Support. *Antiretroviral Treatment and Adherence.* [Online], Available: <http://hivcareforyouth.org/adol?page=md-modulecomplete&mod=02> [Downloaded: 11/25/16 15:08 PM]

Perry, R., Kayekjian, K., Braun, M.C., Sheoran, B. & Chung, P. (2012). Adolescents' Perspectives on the Use of a Text messaging Service for Preventive Sexual Health Promotion. *Adolescent Health Journal*, 2011. (11):012 [Online] Available: [http://www.jahonline.org/article/S1054-139X\(11\)00645-8/fulltext](http://www.jahonline.org/article/S1054-139X(11)00645-8/fulltext) [Downloaded: 23/06/16 11:50AM]

Pope, C., Ziebland, S. & Mays, N. (2000). Analyzing Qualitative Data. *British Medical Journal*, 2000(320):114 – 116. [Online], Available: <http://www.bmj.com/cgi/content/full/320/7228/114> [Downloaded: 19/09/00 11:47 AM]

Reda, A.A. & Biadgilign, S (2012). Determinants of Adherence to Antiretroviral Therapy among HIV-Infected Patients in Africa. *AIDS Research and Treatment Journal*, 2012(2012): 574656. 1-8. doi10.1155/2012/574656. [Online], Available, <https://www.hindawi.com/journals/art/2012/57656/>

Rice, P.R. & Ezzy, D. (1999). Qualitative Research Methods. *A Health Focus*. Sydney: Oxford University Press. 40 – 50

Roberts, K.J. (2004). Barriers to and Facilitators of HIV-Positive Patients' Adherence to Antiretroviral Treatment Regimens. *AIDS Patient Care & STDs*, 14(3):155-168. Los Angeles: University of California. [Online], Available: <http://online.liebertpub.com/doi/abs/10.1089/108729100317948> [Downloaded: 25/11/16 12:43PM]

Sabin, L.L., DeSilva, M.B., Hamer, D., Kevi, X., Yue, Y., Wen, F., Tao, L., Heggenhougen, H.K., Seton, L., Wilson, I.B. & Gill, C.G. (2008). Barriers to Adherence to Antiretroviral Medications among Patients Living with HIV in Southern China: A Qualitative Study. *AIDS Care Journal*, 2008. 20(10):1242-1250. [Online], Available: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3888993> [Downloaded: 25/11/16 11:28 AM].

Santelli, J.S., Song, X., Garbers, S., Sharma, V. & Viner, R. (2016). Global Trends in Adolescent Fertility, 1990-2012, in Relation to National Wealth, Income Inequality, and Educational Expenditures. *Adolescent Health Journal*, 10:1054-1016. [Online], Available: [http://www.jaholine.org/article/S1054-139X\(16\)30320-2/fulltext](http://www.jaholine.org/article/S1054-139X(16)30320-2/fulltext) [Downloaded: 23/6/2016 11:26 AM]

Sarantakos, S. (1998). *Social Research*. Melbourne: Macmillan, 207 – 209

Secker, J., Wimbush, E., Watson, J.E. & Milburn, K. (1995). Qualitative Methods in Health Promotion Research: Some Criteria for Quality. *Health Education Journal*, 54: 74-87

State Department of Health. (2006). Adherence to Antiretroviral Therapy among HIV-Infected Patients with Mental Health Disorders. *HIV Clinical Resource*. New York: AIDS Institute. John Hopkins University. [Online], Available: <http://www.hivguidelines.org/clinical-guidelines/hiv-and-mental-health/adherence-to-antiretroviral-therapy/> [Downloaded: 11/25/16 12:22 PM]

Thoth, C., Tucker, C., Leahy, M. & Stewart, S.M. (2013). Self-Disclosure of Serostatus by Youth Who are HIV Positive: A Review. *Behavioral Medicine Journal*, (2014). 37:276-288. [Online], Available: [https://www.researchgate.net/publication/234019625\\_self-disclosure\\_of\\_serostatus\\_by\\_youth\\_who\\_are\\_hiv-positive/review\\_pdf](https://www.researchgate.net/publication/234019625_self-disclosure_of_serostatus_by_youth_who_are_hiv-positive/review_pdf). [Downloaded: 11/25/16 08:36 AM]

Vaz, L.M., Eng, E., Maman, S., Tshikandu, T. & Behets, F. (2010). Telling Children They Have HIV: Lessons Learned from Findings of a Qualitative Study in sub-Saharan Africa. *AIDS Patient Care Journal*, 24(4): 245-256

Wenger, N., Gifford, A., Liu, H., Chesney, M. & Golin, C. (1999). Patient Characteristics and Attitudes associated with HAART Adherence. *6<sup>th</sup> Conference on Retrovirus and Opportunistic Infections*. Chicago, Abstract 981

WHO (World Health Organization). (2013). WHO Definition. *Adolescent Health*. Washington D.C.: Department of Health and Human Services. [Online], Available: [http://www.who.int/topic/adolescent\\_health/en/index.html](http://www.who.int/topic/adolescent_health/en/index.html) [Downloaded: 07/03/13 09:12 AM]

Williams, Y. (2016). What is Adolescence? Definition, Stages & Characteristics. *Video and Lesson Transcript* 4:57. [Online], Available: <http://study.com/academy/lesson/what-is-adolescence-definition-stages-characteristics/> [Downloaded: 11/25/16]

Willms, D. & Johnson, N. (1993). *Essentials in Qualitative Research: A Notebook for the Field*. Newbury Park, CA: Sage, 372

UNAIDS (Joint United Nations Programme on HIV/AIDS). (2012). UNAIDS Global Report. [Online], Available: [http://www.gr2012/20121120\\_UNAIDS\\_Global\\_Report\\_2012\\_en.pdf](http://www.gr2012/20121120_UNAIDS_Global_Report_2012_en.pdf) [Downloaded: 07/03/13 12:07 AM]

## APPENDIXES

### Annexure 1

#### Sample of Participant's Consent Form

RECORD OF INFORMED CONSENT TO CONDUCT THE INTERVIEW	
Date: 6-13/8/2015	
Interviewer's Name: Eliphaz Hatutale John	
UWC student no: 3002983	
Tel: +264 65 221403	Fax: +264 65 221405
Email: <a href="mailto:hjeliphaz@yahoo.co.uk">hjeliphaz@yahoo.co.uk</a>	
Institution: Onandjokwe Lutheran Medical Services	
Interviewee's pseudonym: <i>to be filled accordingly</i>	
Places where interviews will be conducted: Onandjokwe ART Clinic, Eheke School Hostel & 3 homesteads in Onandjokwe District	

Thank you for agreeing to allow me to interview you. What follows is an explanation of the purpose and process of this interview/discussion. You are being asked to give your consent or on behalf of your child for me to conduct interview/discussions with you.

#### 1. Information about the interviewer

I am Eliphaz Hatutale John, a student at the SOPH, University of the Western Cape. As part of the requirements to obtain Master in Public Health, I am required to conduct several interviews/discussions for a certain relating to my work. I will be focusing on the *Barriers to Adherence to Antiretroviral Treatment among Adolescents in Onandjokwe District, Namibia*.

I am accountable to Prof. Brian Van WYK, my study supervisor who is contactable at +27 21 959 2173 or c/o SOPH Fax: +27 21 959 2872 or by email at: [bvanwyk@uwc.ac.za](mailto:bvanwyk@uwc.ac.za)

#### 2. Purpose and Contents of interview

The purpose of this interview is to fulfill one of the requirements of my study to obtain Master's Degree in Public Health from University of the Western Cape. The study findings may also help health care workers in Onandjokwe CDC Clinic for better understanding the challenges of



adherence to ART among adolescents and strategize appropriate interventions to address challenges and eventually maximize the benefits of antiretroviral drugs to adolescent patients.

Participants will not be given any medicine or substance as a testing intervention or device for this study.

The contents of this interview are not fixed but you are expected to give information you know about *Barriers to Adherence to Antiretroviral Treatment among Adolescents in Onandjokwe District*. Some contents may be related to the following: personal and family issues, stigma and discrimination in certain environments, substance abuse, socio-economic and health care and systems.

### **3. The interview process**

After this introduction, participants will give written consents. In case of children under the age of 15 years (determined on the basis of non-therapeutic nature of this study), caregivers will sign consent forms on behalf of their children. Each participant will then choose her/his pseudonym that will be used for the study. I will record those names in the filed-notes and voice recorder.

I will ask you some research questions which you will answer through verbal discussions. You are free to ask and answer or not to answer any question during the interview. Our discussions will be recorded throughout the interview with voice recorder. I will also take notes of your responses. Arrangements will be made to prevent interruptions of our discussions such as walk-ins or telephone calls, by hanging a 'DON' T DISTURB' notice on the door and unplug the telephone cable.

The interview/discussion will last between 45 to 60 minutes. I may do a follow visit at your place of stay for further clarifications if necessary.

Your participation and time spent in the interview will be acknowledged with the word 'Thank you'.

### **4. Anonymity of Respondents**

At all times, I will keep the source of the information confidential. All personal identifiers will be removed from records and I refer to you or your words by a pseudonym or invented name which you chose. I shall keep any other record of your participation locked away at all times, and destroy them properly after the data has been collected.

### **5. Things that may affect your willingness to participate**



The interview may touch on issues which can be very sensitive, emotional and personal. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

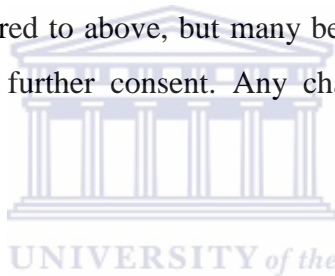
## **6. Agreement**

### **6.1 Interviewee's agreement**

Each participant will be asked to give her/his consent in writing. If he/she is a minor (<15 years of age), the caregiver will sign on her behalf.

### **6.2 Interviewer's agreement**

I shall keep the contents of the above research interview anonymous in the sense that the pseudonyms noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred to above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you



Signed (by the interviewer):

Date: .../.../2015

Place: Onandjokwe LMS Hospital

Signed (by the interviewee):

Date: .../.../2015

Place: Onandjokwe LMS Hospital

## Annexure 2

### FGD and In-depth Interviews Schedule

*Note: All adolescents interviewed had record/s of poor adherence in 2015 calendar year, FGD lasts not > 45 minutes, allow enough home travelling time before/after interviews.*

#### **Date: 6/8/2015 (Teens' Club Day), Method: FGDs**

- i. **Time:** 08H30 – 09H15  
**Venue:** ART Conference Room  
**Participants:** 5 Adolescents (Age 10- 14), Accompanied by 5 Caregivers  
**Interviewers:** Principal Investigator  
Health Assistant
- ii. **Time:** 09H16 – 10H03  
**Venue:** ART Conference Room  
**Participants:** 5 Caregivers (Key Informants' Interview)  
**Interviewers:** Principal Investigator  
Health Assistant

#### **Date: 6/8/2015, Method: In-Depth Interviews**

1. **Time:** 11H30 - 12H15  
**Venue:** Eheke School Office  
**Interviewee:** Female Adolescent (Age 19) missed FU  
**Interviewers:** Principal Investigator
2. **Time:** 12H20 - 13H00  
**Venue:** Eheke School Office  
**Interviewee:** Male Adolescent (Age 16) missed FU  
**Interviewers:** Principal Investigator
3. **Time:** 14H06 - 14H45  
**Venue:** Resident Oniihandi <10km, near CDC Clinic  
**Interviewee:** Adolescent (Age 17), history of LTFU during calendar year  
**Interviewers:** Principal Investigator

#### **Date: 13/8/2015, Method: In-Depth Interviews**

4. **Time: 08H00 - 08H45**  
**Venue:** Distant Residence, Indangungu >10km from CDC Clinic  
**Interviewee:** Adolescent (Age 18), LTFU  
**Interviewers:** Principal Investigator

**Date: 13/8/2015 (Adolescents Club Day), Method: FGD**

**iii. Time: 10H15 – 11H15**

**Venue:** Adolescents' Friendly Care Room

**Participants:** 6 Adolescents (Age 15-19yrs)

**Interviewers:** Principal Investigator  
Health Assistant

**Date: 13/8/2015 (Adolescents Club Day), Method: In-Depth Interviews**

**5. Time: 12H00 - 12H45**

**Venue:** Distant Olundje Residence from CDC Clinic (>10km)

**Interviewee:** Adolescent (Age 18) with a history of LTUF (returned)

**Interviewers:** Principal Investigator

**Date: 13/8/2015 (Ordinary W Day), FGD Key Informants: Expert Opinion & Validation**

**iv. Time: 15H00 – 15H45**

**Venue:** Adolescent Friendly Care Room 2

**Participants:** 6 ART Healthcare Providers (3 Nurses & 3 Health Assistants)

**Interviewer:** Principal Investigator



## **Annexure 3**

### **Discussions and Interviews Guide**

The questions of interview are based on themes and topics of the study and mostly are not pre-set  
The first Question - to Key informants: What do you notice are the challenges preventing adolescents to take all their doses of ART medicines as prescribed?

- to adolescents: what prevent/s you from drinking your ART medicines at your scheduled times? A probing question may follow “You said sometimes you do not have enough time to drink your medicine, may you elaborate on that?”

The Devil’s advocate questions were avoided i.e., “Some other adolescents will say they do not fear other people seeing them taking medicine, what is your opinion on that?”

Although clients were allowed to share more information as they prefer, few questions were being asked, probing on responses relevant to the study themes. Clarification was sought with questions such as, “May you elaborate more on that”?

The last question was: In your opinion, how barriers to adherence to ART among adolescents should be avoided?

The study Topics are:

Patient and Family barriers

Stigma and Discrimination in certain Settings

Substance abuse

Socio-economic barriers

Health Care and Health Systems Related Challenges and

Others