

**FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY IN  
ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE  
OF EXCELLENCE- A QUALITATIVE STUDY**

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OF EXCELLENCE- A QUALITATIVE STUDY**

**By**

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**DECLARATION**

I declare that **FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY IN ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE- A QUALITATIVE STUDY** is my own work and that all the sources that i have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before any other degree at any institution.



Tafireyi Marukutira  
**Full names**

29 February 2012  
**Date**

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### **ABSTRACT**

The aim of the study was to determine the factors that influence adherence to ART among adolescents who contracted HIV through vertical transmission. Qualitative research using descriptive phenomenology was conducted at Botswana-Baylor Children's Clinical Centre of Excellence.

Data was collected using in-depth individual semi-structured interviews. Eight (8) adolescents between 14 and 19 years who had been on ART for minimum of 4 years were interviewed. Thematic analysis of data was done and five (5) themes emerged from the participants' description of the experience of taking ART taking ART over a long period of time. The themes that emerged indicated the factors that influence adherence to ART, and they included knowledge and positive beliefs about ART, need for support, ART difficult treatment regimen, having a regular doctor and psychosocial emotional needs.

The findings suggested that the adolescents who contracted HIV through vertical transmission require support while continuing on a simplified long-term ART regimen after an assessment of their psychological well beings and periodic checks.

### **KEY CONCEPTS**

Adherence to ART, acceptable adherence, unacceptable adherence, factors influencing adherence, adolescents; vertical HIV transmission

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## CHAPTER 1

### ORIENTATION TO THE STUDY

#### 1.1 INTRODUCTION

The treatment of the human immunodeficiency virus (HIV) by antiretroviral therapy (ART) has prolonged the lives of many people living with HIV including the lives of a special group of people, the adolescents who contracted HIV through vertical transmission. These are the adolescents who were born HIV positive because the virus was transmitted to them from their HIV positive mothers during pregnancy, birth or breastfeeding. The adolescents who contracted HIV through vertical transmission start ART at a very young age and have to be on treatment for a long time. When they are still very young, they are supervised to take their medicines but as they grow older and reach adolescence and adulthood, they may have to take their medicines on their own (Naar-King, Parsons, Murphy, Chen, Harris & Belzer 2009:1092).

Antiretroviral therapy is administered in the form of highly active antiretroviral therapy (HAART), which is a combination of at least three different class drugs to suppress the HIV and stop the progression of HIV disease. In order to achieve the benefits of HAART, high levels of adherence to the ART are required (Ding, Wilson, Modjarrad, McGwin, Tang & Vermund 2009:1101). Non-adherence to ART may result not only in reduced treatment efficacy but also in the development of viral resistance and increased progression to AIDS (Protopopescu, Raffi, Roux, Reynes, Dellamonica, Spire, Leport & Carrieri 2009:599).

Adherence to long-term ART is a challenge to adolescents because, according to Protopopescu et al (2009:600), they experience pill burden and fatigue. Other challenges associated with adherence to ART in adolescents include decreased parental support, increased autonomy, stigma, difficulty in identifying with HIV-negative peers, anxiety about sexual relationships and future planning, low self-esteem as well as feelings of hopelessness (Williams, Storm, Montepiedra,

Nichols, Kammerer, Siros, Farley & Marley 2006:1746).

## **1.2 BACKGROUND TO THE RESEARCH PROBLEM**

In 2009 there were 33.3 million people worldwide living with HIV and AIDS (UNAIDS 2010:23), 2.5 million of whom were children. The majority (22.5 million) of those people living with HIV lived in sub-Saharan Africa.

Botswana is one of the countries with the highest HIV prevalence in sub-Saharan Africa (UNAIDS 2010) with an estimated HIV prevalence of 24.8% of adults 15 – 49 years of age. According to UNAIDS, the percentage of pregnant women who were HIV positive was 33% in 2005 and about a third of babies born to HIV positive mothers would contract HIV through vertical transmission in the absence of any interventions (UNAIDS 2010).

Botswana implemented a successful prevention of mother to child transmission (PMTCT) programme which was the first to distribute free ART to HIV positive people. As a result of the PMTCT programme, the percentage of pregnant women who were HIV positive fell from 38.6 % in 2003 to 24.3 % in 2009. Again, according to the USAID (2010) the proportion of babies born to HIV-positive mothers who were infected decreased from 20.7% in 2003 to less than 4% in 2009.

Prior to the rollout of the PMTCT programme, many children born to HIV-positive mothers contracted HIV through the vertical transmission. Because of the free ART, the HIV positive children were afforded the opportunity to live longer and healthy lives. As the provision of ART in national programs scale up, more HIV positive adolescents lived longer and reached adolescence and adulthood.

## **1.3 THE RESEARCH PROBLEM**

The Botswana-Baylor Children's Clinical Centre of Excellence (BCCCCOE) also known as the Botswana-Baylor Children's Clinic is an out-patient clinic that cares

for HIV positive children and adolescents. There are 618 adolescents (10-19 years) on ART attending clinic and the average age of clients at the clinic is 9 years according to the 2009 annual report. There are more than 2000 children on treatment at the centre. Adherence to ART among some of the adolescents is a major challenge. According to the clinic's monitoring and evaluation report, 6% of the total clients at the clinic failed treatment (detectable viral load of above 400 copies/ml) between July 1, 2008 and June 30, 2009 (BBCCCOE 2009:9). These clients fail treatment mainly because of poor adherence to the ART regimen. At any given time 45 % of them will have adherence to ART which is not acceptable.

Even though the effective adherence levels to ART have not been fully defined, the levels of adherence below 90-95% have been associated with poor response to treatment (Reisner, Mimiaga, Skeer, Perkovich, Johnson & Safren 2009:14). Poor adherence to ART among adolescents attending the BBCCCOE is of great concern because, where adherence levels are sub-optimal, the HIV may rapidly become resistant to therapy and progression to AIDS may be increased (Protopopescu et al 2009:599), hence the focus on adherence to ART among adolescents attending the BBCCCOE in this study.

#### **1.4 THE AIM OF THE STUDY**

The aim of the study was to determine the factors that influence adherence to ART among adolescents who contracted HIV through vertical transmission, attending the BBCCCOE.

##### **1.4.1 Research purpose**

The purpose of the study was to describe the factors influencing adherence to ART among adolescents at the BBCCCOE in order to target adherence interventions in Botswana.

##### **1.4.2 Research objectives**

The study set to describe factors influencing adherence by specifically answering

the following questions:

- What are the factors influencing adherence to ART among adolescents at the BBCCCOE?
- What supportive interventions can be implemented to promote adherence to ART among adolescents at the BBCCCOE?

### **1.5 SIGNIFICANCE OF THE STUDY**

The study sought to describe the factors influencing adherence to ART among adolescents at the BBCCCOE. The knowledge of such factors would assist in ensuring that programmes for adolescents include specific measures to improve adherence to ART treatment in Botswana. The health care workers would be in a better position to deal with adolescents once they understand the factors that promote or hinder adherence to ART.

Research on adherence to ART in HIV positive adolescents (who contracted HIV through vertical transmission) in Botswana is limited. Many studies on adherence to ART were done in adults and very few studies have examined adherence among HIV positive adolescents (Murphy, Wilson, Durako, Muenz & Belzer 2005; Murphy, Sarr, Durako, Moscicki, Wilson & Muenz 2003). In one of the few studies done on ART adherence in young people, it was found that only 50% of the American HIV positive adolescents reported taking their prescribed ART all the time (Murphy, Wilson, Durako, Muenz & Belzer 2001:34). The findings of the study would increase the body of knowledge on factors associated with adherence to antiretroviral therapy by adolescents in Botswana.

### **1.6 DEFINITION OF TERMS**

The following outlines the definitions of key concepts used in this study;

#### **Adherence**

According to the Pocket Oxford English Dictionary (2005), adherence means “to stick fast to substance, person, party, and opinion”. Adherence to treatment is defined as “the extent to which the patient continues the agreed-upon mode of

treatment under limited supervision when faced with conflicting demands, as distinguished from compliance and maintenance (Medical-dictionary online). ART should be taken 100% of the time for it to be effective. Adherence can also be measured subjectively using patient reports or objectively using pill counts.

For the purposes of the study, adherence refers to the extent to which adolescents' behaviour of taking ART corresponds with agreed recommendations from a health care provider (the doctors' prescription and health advice from nurses and health educators) meaning that ART is taken 100% of the time (every day as prescribed, not missing any dose of ART). Adherence can also be measured subjectively using patient reports or objectively using pill counts. In this study adherence would also be measured by means of calculations from pill counts (Paterson, Swindells, Mohr, Brester, Vergis, Squier, Wagner & Singh 2000:22) which are done every time a client comes to the clinic for follow up or for refill of their medicines.

**Acceptable (good) adherence** in this study was that between 95 and 100% while poor (**unacceptable**) adherence was anything below or above this range. Adherence above 100% may mean that a client took an overdose, repeated a dose such as after vomiting and this is also unacceptable adherence. Acceptable adherence was synonymous with good adherence while unacceptable adherence was synonymous with poor adherence to ART.

**ART** means the antiretroviral drugs used a combination of at least two different class drugs to suppress the HIV and stop the progression of HIV disease (Bendavid, Grant, Talbot, Owens & Zolopa 2011:211). ART was used in this study to refer to the drugs that the adolescents are taking, prescribed in drug combinations referred to as highly active antiretroviral therapy (HAART).

An **adolescent** is defined by WHO (World Health Organization) as an individual in the 10-19 age group (WHO 2010). In this study an adolescent is defined as per



WHO as a child between 10 and 19 years of age who contracted HIV through vertical transmission.

**A factor** is defined by the Pocket Oxford Dictionary (2005) as “one of the elements contributing to a particular result or situation”. In this study these elements (factors) contributing to acceptable or unacceptable adherence to ART are described.

**HIV positive:** A person is said to be HIV-positive when antibodies against HIV have been detected on a blood test or gingival exudates test (commonly known as a saliva test). Synonym: seropositive (UNAIDS 2011).

**Influencing** is defined as “the capacity or power of persons to be a compelling force on or produce effects on the actions, behaviour or opinions” (Webster’s Unabridged Dictionary of the English Language 2001). In this study, the same definition applies.

**Vertical transmission** of HIV is the transmission of HIV from an infected pregnant woman to her newborn child. Transmission can occur at any time during pregnancy, delivery or breastfeeding (De Cock, Fowler, Mercier, de Vincenzi, Saba, Hoff, Alnwick, Rogers and Shaffer 2000:1175) The same definition applied in this study.

### **1.7 META-THEORETICAL ASSUMPTIONS**

Assumptions refer to basic principles that are accepted as being true based on logic or reason without proof (Polit & Beck 2006:495). It was assumed in this study that:

- The experience of adolescents who are HIV positive and taking ART would put them in a position to give insight into what makes one to adhere or not to adhere to treatment.

- The critical truth can be found through in-depth individual semi-structured interviews about the factors that influence adherence to ART.
- The participants would be honest in their responses to the interview questions.

## **1.8. RESEARCH DESIGN AND METHODS**

This study is non-experimental and qualitative in nature with a descriptive phenomenology approach. Qualitative approach was used to develop a rich understanding of the phenomenon adherence to ART among adolescents as it exists in the real world and as it is constructed by individuals within the context of that world (Polit & Beck 2006:212). Phenomenology attempts to understand people's perceptions, perspectives and understanding of a particular situation (de Vos 2005:264).

The study population for the study comprised of HIV positive adolescents on ART attending the BBCCCOE. The adolescents had to meet the following inclusion criteria:

- Male and female adolescents aged between 10 and 19 years
- They must have been taking ART for at least 1 year.
- They must have contracted HIV through vertical transmission
- Signed informed consent by parent or caregiver. Adolescents in this study also had to sign an assent form. The age of consent in Botswana is 21(Botswana 2010:8).

A non-probability sampling purposive method was used to select study participants. The clinic has a record of adolescents who contracted HIV through vertical transmission on ART. Convenience sampling was also used to select the adolescents who were available and met the eligibility criteria. Adolescents with poor adherence and those with good adherence were included in the study and they were identified from the electronic medical record system (EMR) which

documents adherence at every visit. Those with poor adherence were also found in the treatment failure group. The sample size was not specified, the principle of saturation of data was adhered to.

Data was collected by means of in-depth individual semi-structured interviews and the interviews were audio recorded. Data on adherence to ART was collected from the electronic medical records system and was based on pill counts (proportion of what the client took against what client was expected to take). This was used to select the two groups of participants (compliant and non-compliant ones) in line with the inclusion criteria.

Data analysis for this study was thematic analysis according to Van Manen (1990) cited in Polit and Beck (2008: 519) using the holistic and the selective approaches. According to Van Manen, thematic aspects of experience can be uncovered or isolated from the participant's description of the experience.

The tape recorded interviews were first transcribed verbatim into text as Microsoft word document. The researcher read through each transcript to familiarise self with the data, get a sense of the whole and to search for meaningful segments or units. The researcher also listened to audio recordings of each transcript in order to verify the transcriptions. While reading the transcripts, the researcher made notes of any thoughts, observations and reflections that occurred. The notes comprised of recurring phrases, words or group of words with similar meaning or connotations.

The researcher then identified themes from within each section of the transcript. The final step involved weaving the thematic pieces together into an integrated whole to provide an overall structure to the data. The themes were clustered into identifying factors associated with adherence to ART.

### **1.9 SCOPE AND LIMITATIONS OF THE STUDY**

A qualitative study was done to allow in-depth understanding of the factors affecting adherence at the BBCCCOE. The adolescents who participated in this study attend the referral centre may allow for rich data regarding factors affecting adherence but this may not represent the same status quo in other facilities in Botswana.

Adherence in this study was extracted from the electronic medical record system and was calculated based on pill counts only and not based on virologic suppression. The implication is that some informants with good adherence may not have viral suppression even though categorised as being good with adherence to ART. Some patients with calculated acceptable adherence had detectable viral load indicating poor adherence or drug resistance. A perfect pill count with no viral suppression may also indicate pill manipulation.

### **1.10 STRUCTURE OF THE DISSERTATION**

Chapter 1: This chapter will give an overview and will serve as an introduction to the study. It will also give the background as the chapter gives an orientation of the study.

Chapter 2: The literature review

Chapter 3: This chapter will cover the research design, the research methodology as well as giving aspects of internal and external validity of the study.

Chapter 4: Data analysis, the research results and literature control.

Chapter 5: Conclusions, limitations and recommendations of the study.

## **1.11 CONCLUSION**

The background of the study, research questions and the research design has been introduced as well as the reflections on the significance of the study. The research design is meant to ensure both rigour and trustworthiness. The sampling methods, data collection techniques and the data analysis procedures were described. The next chapter focuses on the literature review.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

This chapter presents relevant literature pertaining to adherence to antiretroviral therapy (ART) in adolescents who contracted HIV through vertical transmission. A literature review is defined by Polit and Beck (2006:503) as a critical summary of research on a topic of interest, in this instance the factors influencing adherence to ART among adolescents at Botswana–Baylor Children’s Clinical Centre of Excellence (BBCCCOE). The aim of the review was to enable the researcher to gain insight into the problem under scrutiny, verify the significance of the problem, put the research problem in context and to determine the most appropriate methodology, including the research instrument (Burns & Grove 2007:93).

#### 2.2 PURPOSE OF THE LITERATURE REVIEW

The purpose of a literature review is to convey to the reader current knowledge on the subject at hand (Burns & Grove 2007:93). A literature review is critical in order to:

- identify a research problem and refines research questions.
- know what is already known about the research topic.
- identify the gaps in the literature.
- identify new clinical interventions to be tested during research.
- help identify appropriate research designs and data collection methods for the study.
- get insights for interpretation of study findings and implications of the study (Polit & Beck 2006:133).

Literature review was done in this study to determine the factors that influence adherence to ART in adolescents who contracted HIV through the vertical transmission.

## **2.3 SCOPE OF THE LITERATURE REVIEW**

A literature review in this study focused on HIV and ART as well as the relationship between response to treatment and adherence. The existing literature on adherence to ART among HIV positive adolescents was reviewed. The researcher reviewed various research reports, statistics and studies conducted globally including the country of the study, Botswana. The key concepts used for the literature review study were antiretroviral therapy, adherence to ART, factors influencing adherence to ART and challenges facing adolescents living with HIV regarding ART and adherence among adolescents. The key concepts were used as topics to discuss the literature reviewed.

## **2.4 LITERATURE REVIEW**

### **2.4.1 Antiretroviral therapy (ART)**

Anti-retroviral therapy (ART) refers to the use of pharmacological agents that have inhibitory effects on HIV replication. ART consists of a combination of at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease. If ART is taken reliably and correctly, the drugs can reduce the virus to a level in the blood when it can no longer be measured (undetectable), restore the immune system, prevent HIV transmission, reduce HIV-related morbidity and mortality and improve the quality of life (<http://www.who.int/hiv/topics/arv/en>).

ART is lifelong treatment which requires that the right doses of the right drugs must be taken at the right time. It is not a cure but it turns HIV and AIDS from being a fatal condition to a chronic one, manageable with medication. ART improves the quality of life of people living with HIV and AIDS (PLWHA), as they prevent the onset of opportunistic infections.

A dramatic reduction in HIV-related morbidity and mortality has been recognized in countries where ART has been widely available. Again expanded access to ART can reduce the HIV transmission at population level, impact orphan hood and

preserve families (WHO 2010). This is supported by evidence in a meta-analysis of the association between adherence to drug therapy and mortality (Simpson, Eurich, Majumdar, Padwal, Tsuyuki, Varney & Johnson 2006:15; Judd, Doerholt, Tookey, Sharland, Riordan, Menson, Novelli, Lyall, Masters, Trudor-Williams, Duong & Gibb 2007:918).

According to WHO (2010) progress report on global HIV/AIDS response, Botswana is one of the countries of the region with generalised epidemics that has achieved universal access to ART, providing it to at least 80% of patients in need. As a result of access to ART in Botswana, HIV related mortality shows a remarkable decrease and prolongation of the duration and quality of survival in HIV positive people.

Children who acquire HIV from birth should start their ART treatment as soon as the HIV diagnosis is established which is often at just a few months old (<http://www.aidsinfo.nih.gov/ContentFiles/AdultandadolescentGL.pdf>). If they are supported to adhere to medication, more HIV positive children survive into adolescence on chronic therapy.

Botswana has a national programme which offers ART for free for both prophylaxis and treatment. As of December 2010 the Botswana's public health system had 161 219 patients on ART and of this, 6.6% were children (Department of HIV/AIDS prevention and care, 2010). The total number of children and adolescents represents 80% of those in need of therapy according to the department of HIV/AIDS prevention and care, Botswana. The mortality rates have reduced as a result of ART access in Botswana.

Mortality trends in the US perinatal AIDS collaborative transmission study showed that there was a remarkable decrease in mortality and prolongation of survival in perinatally infected children (Kapogiannis, Soe, Nesheim, Abrams, Carter, Farley, Palumbo, Koenig & Bulterys 2011:1024). This was due to the availability and



access to ART. The implication is that these perinatally HIV infected children will have to be on ART for a long time and adherence to chronic medications becomes very important.

#### **2.4.2 Importance of adherence to ART in HIV management**

Adherence is critical in any treatment and it refers to the extent to which a person's behaviour, in terms of taking medications coincides with the prescribed treatment regimen and the advice given by health care providers (Osterberg & Blaschke 2005:487). Full benefit of medication can only be realized if patients follow prescribed treatment regimens and this is more important with HIV treatment where there is a risk of development of resistance with poor adherence.

Behaviours associated with adherence to ART such as taking doses at the same time every day, following food restrictions and not skipping doses as a result of irregularities in routines remain a challenge especially for young people living with HIV infection (Reisner et al 2009:14). High levels of adherence to ART (at least 95%) are needed to ensure optimal benefits of ART.

Though effective adherence levels have not been fully defined for ART, levels of adherence below 95% have been associated with poor response to treatment (Paterson et al 2000). Maintaining high levels of adherence remains a critical element of modern HIV care. Non-adherence to ART may result not only in reduced treatment efficacy but also in the development of viral resistance and increased progression to AIDS (Protopopescu et al 2009:599).

Adherence to ART can be measured in a variety of ways. Miler and Hays (2000) identified the following as approaches to measure adherence in patients on ART; patient self-reported adherence, clinician-estimated adherence, pill counts, patient diaries, clinic attendance, pharmacy records, plasma levels, surrogate or indirect laboratory markers and electronic monitors. Self-reported adherence is a simple method of assessing adherence and it involves asking patients how they took their

medication in an interview or in some cases by means of a survey. Patient self-reported adherence overestimates adherence by as much as 20 % but a self-report of non-adherence is a strong indicator and should therefore be taken seriously (Arnsten, Demas, Farzadegan, Grant, Gourevitch, Chang, Buono, Eckholdt, Howard & Schoenbaum 2001:1417).

An undetectable viral load and greater CD4 counts of greater than or equal to 500cells/ $\mu$ L are associated with acceptable adherence while a detectable viral load and later disease are associated with non-adherence (Murphy et al 2003:253; Murphy et al 2005:778; Murphy et al 2001:38; Williams et al 2006:e1749; Schwarz, Henry-Reid, Houser, & Ma 2001:120). The goal of treatment of reducing the viral load and increasing the CD4 count is actually protective for adherence. The relationship between these markers (CD4 and viral load) demonstrates a cycle which exists.

In a study on adherence to ART among HIV positive American adolescents, the results showed that only 41% reported taking all the prescribed treatment (Murphy et al 2001:27). Such low levels of adherence can easily lead to the development of viral resistance. Other studies done on adherence and intervention among HIV-infected in the United States on HIV and AIDS, found that youth overall rates of adherence in the 30 days prior to study enrolment ranged between 28.3% to 69.8% (Reisner et al 2009:15).

Implications of poor adherence include virologic failure and eventual resistance and deterioration of the clinical condition. Immunologic failure is also associated with poor adherence and these implications were demonstrated in a study in South Africa which showed that a cumulative adherence of <95% to drug-refill visits was significantly associated with both virologic and immunologic failure (El-Khatib, Katzenstein, Marrone, Laher, Mohapi, Petzold, Morris & Ekstrom 2011:3). El-Khatib et al (2011) investigated adherence to drug-refill as a useful early warning indicator of virologic and immunological failure among HIV patients on first-line

ART in South Africa and recommended drug-refill monitoring as one of the many adherence tools.

Pilot ARV treatment programmes in Cambodia, South Africa, and Uganda have achieved short-term adherence rates of about 90%, largely among adult patients (Oguda 2004). In a review of studies done in the United States on HIV ART adherence and intervention among HIV-infected youth overall rates of adherence in the 30 days prior to study enrolment ranged from 28.3% to 69.8% (Reisner et al 2009:15). These studies show the variation of adherence which is also geographical with adherence being higher in Cambodia, South Africa and Uganda. The implications would be that factors affecting adherence would be different in these geographical locations.

In an article on youth with HIV and AIDS certain developmental characteristics of adolescents such as their sense of invulnerability and difficulty in deferring gratification may present obstacles to acceptance of an HIV diagnosis, adherence to treatment, and use of HIV prevention measures (Botwinick, Bell, Johnson, Sell, Friedman, Dodds, Shaw, Martinez, Siciliano, Walker & Sotheran 2003:50). This is among the many factors that have been implicated as affecting adherence in the youth and the implications thereof. Other factors include disclosure, stigma, physical development and sexuality (Ding et al 2009:1100).

In Botswana adherence studies in adolescents living with HIV are limited. Phalade, Nthomang, Ngwenya and Seboni (2009) investigated challenges faced by adolescents living with HIV in Botswana and found that stigma, discrimination, HIV disclosure are associated with adherence.

#### **2.4.3 Factors influencing adherence to ART**

There are many factors that are associated with adherence in HIV-positive adolescents. In a paper presented at the AIDS Impact conference in 2009, researchers explored factors that impede as well as those that enhance effective

adherence to ART among adolescents living with HIV and AIDS (Phalade et al 2009). These researchers used a qualitative approach with focus groups and in-depth interviews and found that adherence to ART is a major problem for adolescents mainly because of stigma, discrimination, HIV disclosure as well as interference with school activities. This study was conducted in Botswana. The following categorizes some of the generic factors that influence adherence with highlights of those affecting adolescents;

#### ***2.4.3.1 Demographic factors***

Demographic factors such as age and gender described in literature have been inconsistent in predicting adherence in adolescents. Murphy et al (2005:768) found that the younger age group was associated with poorer adherence while in other studies there was found no association either adherence or non-adherence (Murphy et al 2001:35; Comulada, Swendeman, Rotheram-Borus, Mattes & Weiss 2003:392). Williams et al (2006:e1748) in their study on predictors of adherence to ART in children and adolescents with HIV infection found the worst adherence to be in the older adolescents aged 15 to 18 years.

Gender has not been shown to be a major demographic factor that influences adherence. Williams et al (2006:e1749) found that female subjects and those without English as their primary language had marginally significant increases in the odds of non-adherence.

School attendance was associated with better adherence in a longitudinal ART adherence study in adolescents living with HIV while unstable household as associated with poorer adherence (Murphy et al, 2005:35; Martinez, Bell, Camacho, Henry-Reid, Watson & Rodriguez, 2000:57). It is important to recognise such subtle factors because some of them may be targeted in intervention strategies.

### **2.4.3.2 Psychosocial factors**

Several studies identified a number of psychosocial factors associated with poor adherence and non-adherence to ART including HIV stigma, discrimination by friends and family members, depression, nondisclosure of HIV status, low levels of literacy, impact of long-term treatment on lifestyle as well as interference with school activities (Ayres, Paiva, Franca, Gravato, Lacerda, Negra, Marques, Galano, Lecussan, Segurado and Silva 2006:1004 ; Biadgilign, Deribew, Amberbir & Deribe 2008:55; Do, Phiri, Bussmann, Gaolathe, Marlink & Wester 2010:685; Phalade et al 2009; Reisner et al 2009:14).

In-depth interviews with HIV positive adolescents and their caregivers at various AIDS treatment centres in Sao Paulo, Brazil identified stigma and discrimination as the most important challenges for people living with HIV. The stigma was characterized by subjective feelings of embarrassment associated with social discrimination which affected the young people's identity. In Botswana, Phalade et al (2009) investigated challenges faced by adolescents living with HIV in Botswana and found that stigma, discrimination, HIV disclosure are associated with adherence.

HIV disclosure is expected to eventually improve adherence, this was found to be true in a study conducted in Botswana on adolescents' adherence to ART. Non-disclosure of HIV status was associated with poor adherence to ART (Phalade et al 2009). Similar findings were shown in other studies by Ayres et al (2006:1004), Dodds, Blakley, Lizzotte, Friedman, Shaw, Martinez, Siciliano, Walker, Sotheran, Sell, Botwinick, Johnson and Bell (2003:39) and Biadgilign, Deribew, Amberbir, Escudero and Deribe (2011:1757).

In Ethiopia factors associated with HIV/AIDS diagnostic disclosure to children living with HIV receiving HAART were investigated and the finding was that the proportion of HIV disclosure was very low (17.4%). The recommendations

included strengthening the referral linkage and health education tailored to educated caregivers to increase the rate of disclosure (Biadgilign et al 2011:17572).

In a literature review of HIV antiretroviral adherence and intervention studies among HIV-infected youth aged between 13 and 24 years, psychosocial factors especially depression and anxiety were consistently associated with poor adherence across studies (Reisner et al 2009:14).

In a study on psychosocial factors affecting medication adherence among HIV-1 infected adults receiving combination antiretroviral therapy in Botswana, the researchers found that alcohol use, depression and nondisclosure of status to partner were associated with poor adherence rates (Do et al 2010:685). Even though this study was not in adolescents, these factors may also be found in adolescents.

It would be assumed that social support system for an adolescent would promote adherence to ART. Surprisingly, in a review of literature on HIV antiretroviral adherence and intervention studies among HIV-positive youth conducted by Reisner et al (2009:15), there was no association was found between social support and adherence to ART. Stigma and discrimination by friends and family members were strongly associated with non-adherence to ART. However lack of family and social support was listed as one of the adherence concerns in adolescents (<http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>)

One interesting finding from a past study is the association of adherence with presence of a biological parent as opposed to any type of a caregiver (Williams et al, 2006:e1752). The researchers found that having an adult other than the biological parent as the primary caregiver (e.g. relative or other adult) and higher caregiver education level. There are many orphaned children as a result of the mortality associated with HIV but it looks like that in the event of a biological parent

being present, it is not protective. The presence of a just another adult caregiver who is not the biological parent seems to be protective for non-adherence (Williams et al 2006:e1752).

Social support, stigma and discrimination are important factors to be assessed during adherence counselling because of the implications they have on ART adherence. This is particularly important in adolescents especially where HIV disclosure has not occurred or disclosure has occurred but only within family members yet the adolescent still has to interact with friends in school or in the general community.

#### ***2.4.3.3 Medication related factors***

Medication related factors such as inconvenient dosing frequency, complex regimens, difficulty taking medications, dietary restrictions, pill burden, lack of belief in the effectiveness of medication and side effects of ART affect adherence (Chesney 2000:S171). A low pill burden was associated with improved adherence while both physical and psychological medication-related adverse effects were associated with poor adherence (Murphy et al 2003:253; Murphy et al 2001:36). These studies also showed that the longer the duration of taking ART the poorer the adherence. Long duration of therapy was associated with pill fatigue especially in the perinatally infected adolescents who may have started treatment early on in life (Ayres et al 2004:1001; Chesney 2000:S172, Ding et al 2009:1104). Other factors related to medication that may affect adherence include the type of drug, and a poor doctor-health-care provider relationship.

#### ***2.4.3.4 Adherence tools***

The use of reminder tools such as alarm clocks and pill boxes have been identified as some of the important factors that promote adherence to ART. In a study on pill boxes as adherence tools, Peterson et al (2007) estimated that pill boxes improved adherence by 4.1% to 4.5% and they were associated with a decrease of viral load of 0.34-0.37 log<sub>10</sub> copies/ml and a probability of viral suppression.

The use of pill boxes is fairly inexpensive and Peterson et al (2007) recommended the pill boxes to be a standard intervention to improving adherence to antiretroviral therapy.

The use of alarm clocks has always been known to be important as adherence tools that aid adherence to ART. A study done during the early stages of the HIV epidemic reported the use of alarm clocks to be effective. Mannheimer, Hirsh and El-Sadr (1998) conducted a study on the impact of an alarm device on ART adherence among patients in Harlem, USA. In the same study, Mannheimer et al found that patients were enthusiastic about the alarm device and after 3 months of using the device, 98% of the patients had 100% adherence levels.

Wise and Operario (2008) noted that there was patient satisfaction across studies that examined the use of electronic reminder devices to improve adherence to ART but there was conflicting evidence of improved virological and immunological outcomes in some studies. The conclusion from this review was that there was lack of definitive data resulting in insufficient evidence about the effectiveness of electronic reminder devices as strategies for improving adherence to ART.

In another qualitative study on understanding the facilitators and barriers of antiretroviral adherence, researchers found facilitators of adherence to include positive beliefs about medication as well as use of reminder tools which was reported in 58% of the participants (Curioso et al 2010:4). In this study one participant reported to be having a brain alarm which would buzz at the right time while others used alarm clocks.

In a marginal structural model analysis study on pillboxes as adherence tools, Peterson, Wang, van der Laan, Guzman, Riley and Bangsberg (2007) estimated that pill boxes improved adherence by 4.1% to 4.5% and was associated with a decrease of viral load of 0.34-0.37  $\log_{10}$  copies/ml and a probability of viral suppression. The use of pill boxes is fairly inexpensive and Peterson et al were



recommending the pill boxes to be a standard intervention to improving adherence to antiretroviral therapy.

#### **2.4.3.5 Health care providers and the clinical setting**

There was one interesting study done by Radcliffe, Tanney and Rudy (2006:111) on post-traumatic stress and adherence to medical treatment among youth with HIV which showed that maintaining regular follow-up care and treatment with a specific provider was associated with increased adherence. Having a consistent medical provider emerged as an adherence promoting strategy. In a qualitative study on understanding the facilitators and barriers of antiretroviral adherence in Peru, a relationship with a specific medical provider seemed to promote adherence (Curioso, Kepka, Cabello, Seguras & Kurth 2010:6).

Although existing data is limited, some aspects of the clinical setting may be associated with improved adherence. A friendly, supportive and non-judgmental attitude of health care providers, convenient appointment scheduling and confidentiality contribute to better adherence (<http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>).

#### **2.4.3.6 Other factors**

Factors such as lifestyle factors (homelessness, substance abuse) lack of education and mental illness affect adherence to ART (Chesney 2000:S173). School attendance was associated with better adherence in a study on ART adherence in adolescents living with HIV while unstable housing was associated with poor adherence (Murphy et al 2005:35; Martinez, Bell, Camacho, Henry-Reid, Watson & Rodriguez 2000:57).

#### **2.4.4 HIV and adolescents**

Older children and adolescents make up the largest percentage of HIV positive children cared for at HIV clinics globally. In Botswana, the HIV prevalence in young people aged 15-24 years is 16.9 % and 6.6% among adolescent aged 15-

19 years. Most adolescents acquire HIV through high-risk behaviours such as unprotected sex or through infected injection needles. A limited but increasing number of HIV-infected adolescents are long-term survivors of HIV infection acquired through vertical transmission. Such adolescents have been on long term ART experience and may have a unique clinical course that differs from that of adolescents infected later in life.

It is important to recognize the developmental stages of adolescents when it comes to adherence to ART. Piaget's cognitive theory describes the development of rational thought process in children. According to the Piaget's theory, the concrete stage lasts between 7 and 12 years old and the formal operation stage after the age of 12 years of age. The phenomenon of concrete thinking may have implications for trying to maintain the adolescents' adherence to ART especially if they are asymptomatic (Ding et al 2009:1103; MacDonell, Baar-King, Murphy, Parsons & Huszti 2011:47).

Certain developmental characteristics of adolescents such as their sense of invulnerability and difficulty in deferring gratification may present obstacles to acceptance of an HIV diagnosis, adherence to treatment, and use of HIV prevention measures (Botwinick, Bell, Johnson, Sell, Friedman, Dodds, Shaw, Martinez, Siciliano, Walker & Sotheran 2003:50). Adolescent stage is characterized by involvement in behaviour experimentation, risk taking, confronting a variety of options regarding romantic relationships; sexual behaviour, alcohol and drug abuse (Ding et al 2009:1103).

The behaviour becomes complex when the adolescent is HIV positive and has to manage the chronic HIV infection along with stigma that may be associated with the disease (Battles & Weiner 2002:161; DeLaMora, Aledort & Stavola 2006:75). The adolescents want to behave and act like their peers and adherence may become a challenge. They want to participate in all activities appropriate for their age hence taking timing off to take their ART may be a challenge. Adolescents

may also discover the realities of living with HIV and sometimes full disclosure of HIV status happens at this stage in their lives (Biadgilign et al 2011:e17572; Bikaako-Kajura et al 2006:S87). Adherence challenges may also be complicated by development of adverse events of ART (Ding et al 2009:1100).

In a meta-analysis by Reisner et al (2009:18) it was demonstrated that concrete rather than abstract reasoning skills was positively associated with adherence measures. Williams et al (2006:e1748) found an inverse relationship between adherence and age. They found that adolescents aged between 15 to 18 years had the worst adherence (76% overall, as compared to 83-89% in the younger children). The relationship between adherence and age reported in that study may be important when designing interventions to improve adherence in adolescents on ART.

#### **2.4.5 Interventions**

There are various ways of helping adolescents cope with issues around adherence to ART. A summary of strategies that can be used for enhancing adherence to ART include

- Directly observed therapy (DOT)
- Clarify instructions using a personal treatment plan
- Tailor drug regimen to suit patients' lifestyles
- Show patients how to keep medication diary
- Encourage pill sorting and convenient placement of pills
- Encourage planning ahead for changes in daily routine (weekends and holidays)
- Make clinic appointments convenient and pleasant and provide educational materials
- Refer patients for social support, treatment of substance abuse and for depression and stress (Gilkman, Walsh, Valkenburg, Mangat & Marcinak 2007:e1144; Purdy, Freeman, Martin, Ryder, Elliot-DeSorbo, Zeichner & Hazra, 2008:159; Hart, Jeon, Ivers, Behforouz, Caldas, Drobac & Shin 2010:e33; Berg,

Litwin, Li, Heo & Arnsten 2011:192).

Various research articles recommend directly observed therapy (DOT) to manage poor adherence (Gilkman et al 2007:e1144; Purdy et al 2008:159; Hart et al 2010:e33; Berg et al 2011:192). Gilkman et al (2007) used short duration of admission for specific cases of poor adherence for up to 7 days for DOT. Purdy et al (2008) followed up adolescents who were perinatally HIV infected and with viral load rebound or non-response on a stable ART regimen followed by a period of DOT in a clinic or hospital setting with serial viral load measurements. The research demonstrated that despite antiretroviral resistance, using DOT can lead to treatment response and therefore recommended that a period of clinic-monitored DOT may allow diagnosis of non-adherence.

An alternative to DOT without admission to a facility is patient-nominated treatment supporters who provide partial DOT at home. In a randomized controlled trial of trained patient-nominated treatment supporters providing partial directly observed ART in South Africa, it was found that there was significantly better CD4 response in the partial DOT arm compared to self-administered ART (Nachega, Chaisson, Goliath, Efron, Chaudhary, Ram, Morroni, Schoeman, Knowlton & Martens 2010:1273). Although this may be a cheaper alternative to being confined in a facility, further research is needed especially in the paediatric and adolescent population.

Another promising approach to serving HIV-positive youth is family-centred care where members of families affected by HIV receive care at the same clinic on the same day as reported by Botswana-Baylor Clinic (Musa-Aisien, Anabwani & Kostova 2004). It would also be interesting to find out if such a model would affect adherence in the adolescents.

In a study in the United States of America (USA), a secondary prevention programme called the Adolescent Impact was evaluated. The programme included

12-sessions of behavioural intervention incorporating group and individual work aimed at increasing HIV knowledge, disease management and risk reduction skills (Chandwani, Abramowitz, Koenig, Barnes & D'Angelo 2011). Based on the high attendance of HIV positive youth (94%) in the intervention group, the conclusion was that the relatively high attendance rates suggested that youth were receptive to the programme and its content.

The early stages of the epidemic have seen complicated drug regimens coupled with a high pill burden. Simplification of ART regimens may just improve adherence. Maggiolo, Ripamonti, Arici, Gregis, Quinzan, Camacho, Ravasio and Suter (2002:375) showed that simpler regimens with a lower number of pills and doses may help patients' compliance to therapy. A low pill burden, with at most twice daily dosing, fewer adverse events have been shown to have the greatest impact on patients' ability to adhere to ART (Stone, Jordan, Miller & Pilon 2004:808).

The use of the latest technologies such as short message service (SMS) reminders on adherence to ART among patients have been explored in the study done in resource-limited setting such as a rural clinic in Kenya through a randomized controlled trial. The findings revealed that 53% of the participants receiving weekly SMS reminders achieved adherence of at least 90% during the 48 weeks of the study compared to 40% in the control group (Pop-Eleches, Thirumurthy, Habyarimana, Zivin, Goldstein, de Walque, Mackeen, Haberer, Kimaiyo, Sidle, Ngare & Bangsberg, 2011). This technology may eventually benefit adolescents struggling with adherence even in resource limited settings where there is access to cellular phone networks.

The BBCCOE has adopted an adherence curriculum which is meant to assist health care providers in tailoring the needs of adolescents with adherence challenges (Botswana-Baylor Clinic Website). There is need however to tailor interventions based on Botswana specific research as opposed to international

findings.

## **2.5 CONCLUSION**

HIV-infected adolescents face a challenge of adherence to ART regimens as illustrated in the literature search above. The various factors associated with adolescents' adherence to ART in previous studies included demographics, psychosocial factors, HIV disease process, medication as well as provider factors. The literature review showed paucity of research from Botswana, specifically on the adherence to ART in adolescents who contracted HIV through vertical transmission as well as the lived experiences of adolescents regarding long-term ART. The significance of the study was verified by the literature review. In the following chapter, the research design and method will be presented.

## CHAPTER 3

### RESEARCH DESIGN AND METHOD

#### 3.1 INTRODUCTION

This chapter describes the research design and methodology used to describe factors that influence adherence to anti-retroviral therapy in adolescents attending the BBCCCOE. The chapter begins with a discussion of the research paradigms followed by a description of the design utilised in this study. Included are details of the study setting, population and sampling techniques, the data collection process data analysis procedures as well as related ethical issues. This study was set to answer the following questions:

- What are the factors influencing adherence to ART in adolescents at BBCCCOE?
- What supportive interventions can be implemented to promote adherence to ART in adolescents at BBCCCOE?

#### 3.2 RESEARCH DESIGN

A research design lays down the blueprint of how the study was conducted in order to maximize control over factors that could interfere with validity of the findings (Burns & Grove 2005:211). It guides planning and implementation in order to achieve the objectives of the study. The study was non-experimental and qualitative in nature with a descriptive phenomenology approach. The use of non-experimental research ensured that social processes occurring in natural settings were observed which might not be the case with experimental research. Data was collected without introducing any treatment or changes to the participants. A qualitative approach is used when researchers want to develop a rich understanding of a phenomenon as it exists in the real world and as it is constructed by individuals within the context of that world (Polit & Beck 2006:212). A qualitative design is set in the real world and natural settings (de Vos 2005:264).

Qualitative research draws on data collection methods such as interviews and

observation using a small number of participants because it does not presume to represent the wider population. Qualitative reports are presented in a descriptive and narrative style (Polit & Beck 2008:60). In qualitative research, people can describe their situations, feelings, perceptions and experiences in their own words. The advantage of qualitative research is the richness, individuality and the subjective nature of the respondents' perspective which are not amenable to scientific criteria. The critiques usually levelled against it is that it is not empirical and that the methods used in qualitative research have not been shown to be valid and reliable (Polit & Beck 2006:16).

In this study, a qualitative paradigm was used to allow for a deep understanding of adolescents living with HIV who were taking ART, to capture what they said about their experiences taking ART over a long period of time. The qualitative paradigm acknowledges the importance of the subjective experiential life-world of human beings, individuals' subjectively constructed knowledge, differences in understanding from different individuals and multiple realities. The study is therefore located within the naturalistic interpretivism paradigm. A qualitative approach in this study allowed for a deeper understanding of factors affecting adherence to ART by adolescents who are experts in their own right in taking ART.

A phenomenological approach was used to identify the phenomena of adherence as perceived by the adolescents in this situation. Phenomenology involves gathering people's perceptions, perspectives as well as understanding a particular situation representing it from the perspective of the research participant (de Vos 2005:264; Polit & Beck 2006:219; Christensen, Johnson & Turner 2011:368). A phenomenologist researcher examines the qualities of a participant's experience through conducting interviews, getting a story or observing the participant with the experience of interest (Connelly 2010). Phenomenology is concerned with the study of experience from the perspective of the individual. Connelly further explains that phenomenology focuses on humans as embodied beings who



experience life through their physical bodies.

According to Creswell (2007:58) the philosophical assumptions of a phenomenological study are:

- The focus of the study is on lived experiences of the participants
- The experiences of the participants are conscious experiences, and
- The essence of these experiences is the focus of the research, and the experiences are described and interpreted rather than explained or analyzed.

A descriptive phenomenological approach was chosen in this study. Descriptive phenomenology is a type of phenomenology developed by Husserl that emphasises the careful description of ordinary conscious experience of everyday life (Polit & Beck 2006:498). It was assumed in this study that the experiences of adolescents who were living with HIV and taking ART would give insight into what makes them to adhere or not to adhere to treatment. It was also assumed that critical truth can be found through in-depth interviews about how an adolescent who has been living with HIV and on ART for a long time whether with poor or good adherence to ART. Adolescents were expected to share their life experiences in this study which tell a story of why they are not adherent to ART. This could be through individual experience of being HIV positive and on lifelong therapy or in relations with the family that assist them. Adolescents with good adherence were also expected to share their experiences of how they are managing to maintain such good adherence levels.

A descriptive phenomenological research approach allowed for a description of the experiences shared by adolescents living with HIV. The focus in this study was the life experiences of this special patient population in order to describe what makes them have good adherence or poor adherence to ART.

### **3.3 RESEARCH METHOD**

Research methods give the logical process to be followed during the application of scientific methods and techniques when a particular phenomenon is investigated (Polit & Beck 2006:15).

#### **3.3.1 Sampling**

Sampling refers to the process of drawing elements from a population in order to obtain a sample (Christensen et al 2011:150). Sampling is also utilized in qualitative research even though it is less structured compared to quantitative research (de Vos 2005:327). The following defined the population from which the sample was drawn as well as the sampling process.

##### **3.3.1.1 Population**

A population encompasses the entire aggregate of cases that the researcher is interested in (Burns & Grove 2007:549). In this study, the population consisted of adolescents living with HIV and on ART being cared for at the BBCCOE. Target population refers to the aggregate of cases about which the researcher would like to generalize (Polit & Beck 2006:511, Burns & Grove 2007:549). The target population for the study comprised of adolescents aged 10 to 19 years living with HIV and on ART attending the BBCCOE. On the other hand, the accessible population is the aggregate of cases that meet the inclusion criteria and are available for a particular study (Polit & Beck 2006:495). The accessible population for the study comprised of adolescents attending the BBCCOE clinic during the data collection period. The inclusion criteria for the sample of adolescents included:

- Male and female adolescents aged between 10 and 19 years
- They must have been taking ART for at least 1 year.
- They must have contracted HIV through vertical transmission.
- They must have signed an assent form and caregiver/parent consent form.

The following was the exclusion criteria:

- Adolescents younger than 10 years or older than 19 years.

- On ART for less than 1 year
- HIV transmitted through other means, other than vertical transmission
- Failure to give assent or parental/caregiver consent
- Mentally handicapped and not capable of verbally communicating.

### ***3.3.1.2 Sample and sampling procedures***

A sample is a subset of the population or a set of cases selected from the population for a study (Christensen et al 2011:507). A sample is drawn for research purposes because it is not possible to study the entire population. The sample was selected based on the inclusion and exclusion criteria stated in the paragraph 3.3.3.1 above. A sample of the study participants for this study was drawn from is adolescents being cared for at the BBCCOE.

A non-probability sampling approach was used to select a sample of participants for this study. Polit and Beck (2006:505) define non-probability sampling as selection of sampling units from a population using non-random procedures such as in convenience, judgmental and quota sampling. Judgmental sampling, also called purposive sampling method was found suitable for the study. A judgemental sample comprises of participants who are likely to be able to provide information about the phenomenon under investigation (Burns & Grove 2005:352).

In the phenomenology approach, a sample is selected on the principle that all the participants must have experienced the phenomenon under study and should be in a position to articulate what it is like to have lived the experience (Polit & Beck 2006:274). The judgment in this study was based on the fact that HIV positive adolescents who contracted HIV through vertical transmission and have been on ART for at least a year would provide rich lived experiences regarding adherence to ART.

Adolescents with poor/unacceptable adherence and those with good/acceptable adherence were included in the sample and they were identified from the

electronic medical record system which documents adherence at every visit. The list of adolescents who contracted HIV through vertical transmission and were on ART for more than a year attending clinic was used to select the adolescents. Adolescents were sampled at a ratio of 1:1 for good/acceptable and poor/unacceptable adherence. Participation was only upon signing of an informed consent and assent.

#### **3.3.1.3 Sample size estimation**

The sample size could not be determined in advance, however, the minimum requirements for qualitative research were adhered to namely, data saturation. Data saturation is reached when no new data is generated during the data collection phase (Polit and Beck 2008:759). In qualitative research, sample size is usually determined based on informational needs (Polit & Beck 2006:273).

#### **3.3.1.4 Research setting**

A study setting is the physical location and conditions in which data collection takes place (Polit & Beck 2006:510). The study was conducted at the BBCCCOE, a public-private partnership clinic situated at the largest referral hospital in Botswana which takes care of HIV positive children from birth up to 21 years. The BBCCCOE is a referral centre for all complicated paediatric HIV cases including psychosocial complexities. The centre accepts referrals from all over peripheral facilities in Botswana. The centre has been operational since 2001 and it has many patients in their 9<sup>th</sup> year of ART and beyond, many of whom are now in their adolescent ages.

Services offered at the clinic include paediatric patient consultations for the HIV positive (including the caregivers and parents), counselling, initiation of ART and follow up care. Beyond the clinic, the staff also does home visits to patients with complex family situations especially when related to adherence issues. There are currently more than 2 000 patients on ART (Inclusive of the 618 adolescents) being cared for at the clinic. Care is provided by specialist paediatricians, adult

physicians as well as infectious diseases specialists. The nursing staff, social workers and psychologists form part of the health care team at this clinic.

### ***3.3.1.5 Ethical Issues related to sampling***

#### *Justice*

Justice refers to fair and equal treatment accorded to all participants. In this study inclusion and exclusion criteria were used to select study participants irrespective of gender or social status of the adolescent.

### **3.3.2 Data collection**

Burns and Grove (2007:536) define data collection as precise and systematic gathering of information relevant to specific research objectives or questions. Christensen et al (2011:274) stipulates that a researcher should adhere as closely as possible the data collection procedure as planned.

#### ***3.3.2.1 Data collection approach and methods***

Interviews were used as the main data collection method. An interview is a scenario where an interviewer asks the interviewee a series of questions and can be conducted face-to-face or over the telephone (Christensen et al 2011:56). In-depth interviews, defined by Boyce and Neale (2006:3) as a technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular situation were used. In-depth interviews provide for detailed information about a person's thoughts and behaviours. The interviews were semi-structured. A semi-structured interview involves a list of topics or broad questions that must be addressed in an interview called the interview guide to ensure that all questions are covered during the interview (Polit & Beck 2006:291).

In-depth individual semi-structured interviews were chosen for this study in order to gain a deep understanding of how adolescents living with HIV managed their adherence to ART. The understanding was not only limited to those with

poor/unacceptable adherence but also those doing well with adherence (with good adherence). Information was collected from both sides allowed for a comparison and to build an intervention approaches. The disadvantages of in-depth interviews are that they are prone to bias, can be time intensive, results not generalizable and require a certain level of expertise of the interviewer (Boyce & Neale 2006:3).

### ***3.3.2.2 Data collection instruments***

The interview guide was used as data collection instrument. It consisted of questions written to guide the interviewer in order to cover all areas required (Polit & Beck 2006:291). Open ended questions were used to enable the participants to talk freely about all topics on the guide and the probing questions were used as needed for additional information or clarification. The interview guide consisted of an introduction (including informed consent), a set of questions and closing comments (See annexure 9).

### ***3.3.2.3 Data collection process***

The interviews were conducted in a private consultation room which was not in use for general consultations giving study participants privacy to share their experiences. They were conducted in English by the researcher. However, a study nurse was available to translate if there was a need to do so. The researcher created a favourable, non-threatening environment by introducing himself to the participants, explaining the purpose of the interview and thanking them for their willingness to take part in the interviews. The participants were assured that the data gathered during the interview would be treated as highly confidential and it would not be reported in a manner that identifies or links them with the information. The consent to participate in the study was confirmed before the commencement of the interviews.

With the permission of the participants, all the interviews were audio-recorded and notes were taken during the interview in order to capture all the information and/or non-verbal observations. Each interview session took about 30 minutes.

One of the advantages of data collection through the use of interviews is that the interview focuses directly on the study topic and it is insightful. However if the questions are not well constructed, there could be bias, inaccuracies due to poor recall or the participants may give what they think the researcher wants to hear (Polit & Beck 2008:424).

One specific issue in this study was the researcher's dual role. The researcher was a regular consulting doctor for most of the adolescents who participated in the study. This may also have introduced bias as the adolescents try to please the interviewer who is the regular consulting doctor. This is called a reactive effect as interviewees might try to show only what is socially desirable (Christensen et al 2011:58). The researcher developed an interview guide which comprised of open-ended questions.

Interviews require a certain level of expertise of the interviewer (Boyce and Neale 2006:3). The researcher used various communication skills such as paraphrasing, reflection, listening and probing to enhance understanding, to guide the participants to elaborate on their responses and to give additional information where it was required (de Villiers & van der Wal 2004: 243). These skills enabled the participants to respond freely to open-ended questions using their own words, sharing their own stories with the researcher and to give in-depth information regarding their experience pertaining to long-term ARV.

Data collection was continued until data saturation was reached. If the respondents are good informants and are able to reflect on their experiences and communicate effectively, data saturation may be obtained with relatively few respondents. This was done as suggested by Tuckett (2004:53) through:

- Constant comparison of data
- Redundancy of themes.
- No new themes being picked up.

Data saturation was reached after 8 interviews were conducted.

#### **3.3.2.4 Ethical issues related to data collection**

Ethical issues to pay attention to consider regarding data collection include consent, protection of the rights of institutions, privacy, confidentiality and potential to harm (Allmark, Boote, Chambers, Clarke, McDonnel, Thompson and Todd 2009:48).

##### *Protecting the rights of the institution*

The research was approved by the department of Health Studies, University of South Africa (UNISA), the Health Research Development Committee (HRDC) with the Ministry of Health, Botswana and the Baylor College of Medicine (BCM) ethics committee. Permission to conduct the study was given by Botswana-Baylor Children's Clinical Centre of Excellence.

##### *Informed consent*

The researcher provided detailed information regarding the purpose and nature of the research to the participants and those who agreed to take part in the study signed a consent form. The informed consent covered four essential elements namely disclosure of essential information, comprehension, competency and voluntarism (Burns & Grove 2005:193). The participants were also informed of their right to decline to participate in the study or withdraw from the study at any point without explanation or consequences even though they had already signed a consent form. Letters of permission appear as Annexure 1, 3 and 4.

The researcher also explained the benefits from the study that once factors influencing adherence have been identified, the health care providers will be able to better manage adolescents' ART adherence issues and participants could benefit from interventions proposed to address adherence issues in the adolescents on ART (See Annexure 2, MOH Botswana Ethics application form). The caregivers signed an informed consent for their adolescent child to participate



in the study (see annexure 5, 6, 7 and 8). The child also signed an assent. The informed consent and assent were obtained by the researcher in the presence of a study nurse.

#### *Confidentiality, Anonymity and Privacy*

Confidentiality refers to researcher's responsibility to prevent the data gathered during the study from being divulged or made available to any other person. Confidentiality was upheld at all times and information shared with participants shall not be shared without permission. The participants were assured that the information would be used for the purpose of the research only and the results of the research would be made available to them on request. Interviews were conducted in a separate consultation room. No identifiers were included in the field notes or the voice recorder and data was treated anonymously.

#### *Non-maleficence*

This principle of non-maleficence refers to the researcher's duty to avoid, prevent or minimize harm to study participants (Polit & Beck 2006:87). This study involved minimal risk and potential emotional discomfort. A clinical psychologist was available at the centre for counselling if the need arose (see annexure 11 and 12). There were no incidences of emotional upsets during the study.

#### *Beneficence*

Beneficence is a fundamental ethical principle that seeks to prevent harm and exploitation and at the same time maximizing benefits for study participants (Polit and Beck 2006:496). There were no direct benefits to study participants. Potential benefits were for adolescents living with HIV if interventions suggested were implemented to help with adherence to ART.

#### **Reflexivity activity**

It is important to address the issue of power relations during interviews. Reflexivity is the ability to formulate an integrated understanding of one's own cognitive world

especially in understanding one's influence or role in a set of human relations (de Vos 2005:363). Alex and Hammarstrom (2008) warn that power relations can be created within an interview situation hence it is important to be aware of dominant perspectives. Reflexivity was employed by the researcher (being aware of his position as a consulting doctor) to assure the study participants and encouraging them to share their experiences. However the researcher did not document his own cognitive world going into these interviews.

### **Bracketing**

This refers a cognitive process of putting aside one's own beliefs. Being non-judgemental and remaining open to data as they are revealed and is carried out before and during data collection and analysis (Streubert & Carpenter 2003:25). The researcher, being a consulting doctor for some of the study participants ensured that there were no preconceived notions especially based on adherence status and remained neutral during data collection and analysis. By bracketing own experiences, the researcher was able to leave the position of a consulting doctor and get down to the study participants to understand their experiences as they take ART over a long period of time. However the researcher did not document his thought process of preconceived notions or ideas going into the interviews.

### **3.4 DATA ANALYSIS**

The data analysis for qualitative research is an active and interactive process (Polit and Beck, 2006:398). Morse and Field (1995) cited in Polit and Beck (2006:398) note that qualitative data analysis is a process of fitting data together, making the invisible obvious and linking and attributing consequences to antecedents. The purpose of data analysis is to organize, provide structure to, and elicit meaning from the data (Polit and Beck 2006:397). Data collection was done in English by the researcher and the collected data was preserved electronically. Thematic analysis according to Van Manen (1990) cited in Polit & Beck (2008: 519) using the holistic and the selective approaches was done. According to Van

Manen, thematic aspects of experience can be uncovered or isolated from the participant's description of the experience.

### **Holistic approach**

In holistic approach, the researcher reviews the text as a whole and tries to capture the meaning (Polit & Beck (2008: 519). The tape recorded interviews were first transcribed verbatim into text as Microsoft word document. The researcher read through each transcript to familiarise self with the data, get a sense of the whole and to search for meaningful segments or units. The researcher also listened to audio recordings of each transcript in order to verify the transcriptions.

### **Selective approach**

In this approach, the researcher highlights or pulls out statements or phrases that seem essential to the experience under study (Polit & Beck (2008: 519). While reading the transcripts, the researcher made notes of any thoughts, observations and reflections that occurred. The notes comprised of recurring phrases, words or group of words with similar meaning or connotations.

The researcher then identified themes from within each section of the transcript. A theme is an abstract entity that brings meaning and identity to a current experience and its variant manifestations (Polit & Beck 2006:404). Once the themes have been identified they become the object of reflection and interpretation through follow-up interviews with participants (Polit & Beck 2006:521). The final step involved weaving the thematic pieces together into an integrated whole to provide an overall structure to the data. The themes were clustered into identifying factors associated with adherence to ART.

The researcher suspended his presuppositions and judgments in order to focus on what was actually presented in the transcript data by means of bracketing. The main features and concerns regarding adherence to ART uncovered from the experience and confirmed by the research participants were produced as a table

with evidence from the interview, using a quotation which the researcher felt best captured the essence of the person's thoughts, and their emotions about the experience of the phenomenon being explored.

### **3.5 MEASURES TO ENHANCE TRUSTWORTHINESS**

The primary concern in qualitative research is not validity/reliability but trustworthiness. The criteria used for establishing trustworthiness include credibility, transferability, dependability and confirmability.

**Credibility** is the confidence in the truth of data and interpretations of them (Polit & Beck 2006:332). Prolonged engagement with the study participants was done in order to understand in-depth factors associated with adherence. Prolonged engagement is also important in order to build trust and rapport with participants. First contact was made to obtain assent and then to request consent from caregiver/parent and this was followed by the in-depth individual semi-structured interviews. This repeated contact enhanced credibility as the adolescent built trust in the process.

**Dependability** refers to data stability over time and over conditions and there can be no credibility in the absence of dependability. Dependability is similar to reliability in quantitative studies (Polit & Beck 2006:335). Audio tape was transcribed by the researcher and this was cross-checked with the field notes taken by the researcher.

**Confirmability** refers to the neutrality of the data, that is, the potential for congruence between two or more independent people about data's accuracy, relevance or meaning (Polit & Beck 2006:336). Confirmability in this study was enhanced by the availability of raw data on tape and transcriptions to verify the themes. The use of bracketing prior to data collection ensured the pure description of data. All pre-conceived ideas regarding the adolescents' adherence to ART were avoided. Observations recorded on the researcher's hand written notes were

part of the audit trail that was kept by the researcher.

**Transferability** refers to the extent to which findings from the data can be applied to other settings or groups and is thus similar to the concept of generalizability (Polit & Beck 2006:336). A detailed report (thick description) of the findings of this study provided sufficient information to permit judgements about contextual similarity. Based on the integrity of this study, other settings may decide on the applicability of the findings to their settings. The use of purposive sample of adolescents increased transferability.

### **3.6 CONCLUSION**

The research paradigms, the design and the research method utilised in this study were described as well as related ethical issues. The next chapter focuses on discussion of the data analysis, presentation and description of the research findings.

## **CHAPTER 4**

### **ANALYSIS, PRESENTATION AND DESCRIPTION OF RESEARCH FINDINGS**

#### **4.1 INTRODUCTION**

In this chapter, the research findings (including the literature control) of the study are presented. The findings were deduced from the analysis of the participants' interview transcripts as well as the researcher's observational and personal notes regarding the factors that influence adherence to antiretroviral therapy among adolescents attending the Botswana-Baylor Children's Clinical Centre of Excellence.

#### **4.2 DATA MANAGEMENT AND ANALYSIS**

The method of data collection used was in-depth individual semi-structured interviews. The researcher used an interview guide to collect data from the adolescents who contracted HIV through vertical transmission and had been taking ART for at least one year. The aim was to explore and describe the factors that influence their adherence to ART. Observational notes describe the events experienced through watching and listening whereas the personal notes are reflections of the reactions and experiences of the researcher (de Vos 2002:33). The participants consented to the use of an audio recorder during the interview. The collected data was preserved electronically.

Thematic analysis of data was done according to Van Manen (1990) cited in Polit and Beck (2008: 519) using the holistic and the selective approaches. According to Van Manen, thematic aspects of experience can be uncovered or isolated from the participant's description of the experience. Themes and categories were identified from the data. The themes that emerged provided in-depth understanding of the factors that influence adherence to antiretroviral therapy among adolescents attending the Botswana-Baylor Children's Clinical Centre of Excellence.

## **4.3 RESEARCH RESULTS**

### **4.3.1 Sample description**

The adolescents who participated in this study contracted HIV through vertical transmission and had been taking ART for at least one year. The minimum number of years that the study participants had been on ART was 4 years and the maximum was 9 years. These study participants therefore had a rich experience of long-term ART use from which factors that influence adherence to ART could be identified.

There were 5 female participants and 3 male participants aged between 14 and 19 years. There were equal numbers of adolescents with poor/unacceptable and good/acceptable adherence. The first interview was conducted on the 9<sup>th</sup> of August 2011 and data collection continued until saturation was reached with 8 participants.

### **4.3.2 Themes**

Five (5) themes emerged from the data analysis. The themes were identified as reflecting the factors influencing adherence to antiretroviral therapy among adolescents.

#### ***4.3.2.1 Theme 1: Knowledge and positive beliefs about ART***

The first theme that emerged related to knowledge and positive beliefs about the effectiveness of ART. Within the theme, two categories 'belief in the benefits of ART' and 'adherence to ART' emerged and the subcategories are as shown in the table 4.1 below. Each subcategory will be discussed.

**TABLE 4.1. THEME 1: Knowledge and positive beliefs about ART**

NO	THEME	CATEGORIES	SUBCATEGORIES
1	Knowledge and positive beliefs about ART	Belief in the benefits of ART  Adherence to ART.	Effect of ART on the HIV and HIV related diseases (4.3.2.1a)  Effect of adherence to ART on the levels of the HIV in the blood (4.3.2.1b).  Personal experience and attitude towards ART (4.3.2.1c).

#### **4.3.2.1a. Effect of ART on the HIV and HIV related diseases**

The participants expressed their belief in the benefits of ART and demonstrated substantial knowledge that ART suppresses the HIV virus and stops the progression of HIV disease as follows:

*“Well, I told myself that if i don’t take my tablets i will be sick” (18 year old female)*

*“I think there is no cure for HIV and this is all there is.....Unless if there is something now (smiling)” (18 year old female)*

*“Aah, I mean it’s ok that there are ARVs to help when I am sick but then it also means (16 year old male)*

*“That I have to continue with them for the eh....the rest of my life (16 year old male)*

#### **4.3.2.1b. Effect of adherence to ART on the levels of the HIV in the blood**

The participants demonstrated correct knowledge that if ART is taken reliably and correctly, the drugs can reduce the virus level in the blood, restore the immune system, prevent HIV transmission, reduce HIV-related morbidity and mortality and



improve the quality of life. This correct knowledge was apparent in the comment of one participant who stressed:

*“I know if i don’t take them properly my soldiers (referring to CD4) will go down and the bad guy (referring to HIV) will wake up and i will be sick (15 years male).”*

#### **4.3.2.1c. Adherence to ART**

There were self-reports of adherence and non -adherence to ART from the participants, the ratio of which was 50:50.

*“...(pause)..I take my meds every morning and evening (14 year old male)”*

*“...I just take them....every day...” (15 year old male)*

*“I take 6....That’s a lot but what can i do” (18 year old female)*

*“I know why i take them!” (18 year old female)*

#### **4.3.2.1d. Personal experience and attitude towards ART**

The following were some of the experiences shared by participants on their personal experience and attitude towards ART:

*“For me I remember I was sick when I started the meds and I became well after starting the tablets. So they are helping me” (17 year old male)*

*“Why do i have to take them anyway...” (14 year old female)*

*“I said why me!” (stressing the ‘me’) (18 year old female)*

**Belief in the benefits of ART: Literature control**

The participants demonstrated substantial knowledge about the benefits of ART but the knowledge was not consistent with adherence levels. This finding is supported by a quantitative study on factors influencing non-adherence to ART by Nyambura (2009:52). The majority of participants in that study knew that ART reduces the viral load and therefore prevent progression to AIDS. However, the findings of that study revealed no association between knowledge and adherence to ART. Nyambura (2009:53) points out that despite patients knowing the benefits of ART and the importance of adherence, there were other factors like stigma, missed clinic appointments that made them to default.

Knowledge about ART, belief in ART and personal experience on ART were identified as factors affecting adherence (Chirag 2007:56). Curioso et al (2010) conducted a qualitative study on the facilitators and barriers to antiretroviral adherence and the findings showed that positive beliefs about medication promote adherence. Factors such as doubting the efficacy of HAART, uncertainty of long-term effects and unwanted changes in body image were barriers to adherence to treatment (Mills et al 2006).

**Adherence to ART**

Adherence to ART can be measured in a variety of ways. Miler and Hays (2000) identified patient self-reported adherence as one of the approaches to measure adherence in patients on ART. There were self-reports of adherence and non-adherence to ART from the participants at the ratio of 50:50.

The participants who maintained good adherence acknowledged that it had been very difficult for them to be on ART for such a long time, but they persevered. These expressions did not however show loss of hope in these participants but it was just an expression of how difficult it had been for them all the years that they have been taking ART. The following are some examples of expressions by the adolescents:

*“Aah, it’s not easy.....ah” (18 year old female)*

*“Ah, I think for me it’s been difficult even though somehow I managed.....” (18 year old female)*

*“Ummm, I don’t know how I have managed, but I have.....God has been helping me (pause)...you know (14 year old female)*

The researcher asked the participants who maintained good adherence a question in the interview guide: **What advice would you give to a friend who is struggling with adherence to ART?** The following are some of the responses:

*“..If they don’t take their ART they will be sick. Don’t wait until you are sick. Like what happened to me” (18 year old female)*

*“I think it’s up to them really. If the tablets are working for you keep taking, but I think they always work” (17 year old male)*

The participants who do not adhere to ART expressed various reasons for non-adherence which included lack of motivation and pill fatigue. Pill fatigue was apparent in the following expressions of the participants:

*“I am tired..... I mean, how long will I take them?” (19 years old female)*

*“...ah, I just stopped, nothing had happened, I was tired and I just woke up and decided....better stop them” (19 year old female)*

*“It’s not an easy thing to do. It means every day you take your tablets, many of them” (18 year old female)*

*“Eish, sometimes it’s ok and sometimes...ah, it’s a problem” (16 year old male)*

### **Adherence to ART: Literature control**

In a qualitative study on adherence to ART among HIV positive American adolescents, the results showed that only 41% reported taking all the prescribed treatment (Murphy et al 2001:27). Such low levels of adherence can easily lead to the development of viral resistance. Other studies done on adherence and intervention among HIV-infected in the United States on HIV and AIDS, found that youth overall rates of adherence in the 30 days prior to study enrolment ranged between 28.3% to 69.8% (Reisner et al 2009:15).

The findings of this study are consistent with those of a study on medication - related factors affecting adherence by Chesney (2000:S171) which revealed that pill burden and lack of belief in the effectiveness of medication affected adherence to ART and that a low pill burden was associated with improved adherence.

#### **4.3.2.2 Theme 2: Need for support**

The second theme that emerged related to the need for support, three categories 'family support', 'friends' and 'society' emerged and the subcategories as shown in the table 4.2 below. Each subcategory will be discussed below.

**TABLE 4.2. THEME 2: Need for support**

<b>NO</b>	<b>THEMES</b>	<b>CATEGORIES</b>	<b>SUBCATEGORIES</b>
2	Need for support	Family support  Friends  Community	Assistance with taking medication (4.3.2.2a)  Disclosure of HIV status(4.3.2.2b)  Stigma and social discrimination (4.3.2.2c)

While sharing their experiences on ART, the adolescents in this study with good adherence acknowledged the importance of support from family, friends and the society. The family comprised of parents, siblings, grandmothers, aunties and caregivers.

#### **4.3.2.2a. Assistance with taking medication**

The adolescents expressed appreciation of the assistance regarding medication that they receive from family while others had no support of family.

*“Ever since my parents died, my grandmother has had to take care of me. I have a sister who also helps, but my grandmother really helped” (18 year old female)*

*“Yes she does help me, she reminds me” (18 year old female referring to sister)*

*“My mum helps me and....” (17 year old male)*

*“My mother keeps them and she tells me when it is time and I take them” (15 year old male)*

*“My parents remind me sometimes” (14 year old female)*

*“My mum doesn’t have to take them; no one has to take them” (18 year old female)*

*“...sometimes I forget. You know i am always home by myself most of the times. My mother works at night sometimes...ah..(looking down)” (18 year old female)*

*“They died” (16 year old male, referring to parents)*

*“She is at work most of the times; she leaves in the morning so sometimes I have to remember my meds without her” (16 year old male referring to an aunt)*

*“They died... (No eye contact)....(pause). I stay with my grandmother and grandfather and my sister. My auntie is at the cattle post” (19 year old female)*

### **Family support: literature control**

Family plays an important part in any kind of treatment. Family support may improve adherence or assist people living with HIV to maintain high levels of adherence. This finding agrees with studies in USA and Belgium that positive interpersonal relationship made adherence to ARV treatment successful (Mills et al 2006). The use of family members and peers to enhance ART adherence has emphasized the importance of social support in the treatment of HIV patients.

Bikaako-Kajura et al (2006:S88) reported in their study that older adolescents who had strong and supportive child-caregiver relationships were able to achieve good adherence even where disclosure of HIV status had not taken place. According to Castro (2005) and Mills et al (2006), not living alone, having a partner, social or family support, peer interaction and better physical interactions and relationships are characteristics of patients who achieve optimal adherence.

In Uganda, children enjoyed a supporting and trusting relationship with their primary caregivers and this promoted disclosure as well as adherence (Bikaako-Kajura et al 2006) In this study the researcher found that adolescents who expressed support from family and caregivers adhered to ART.

Curioso et al (2010:4) reported that interpersonal relationships were very important to be considered when looking for facilitators of adherence. In their study, Curioso et al found that family and friends reminded the participants to take their ART while others identified nurses and doctors as forming a support structure as well. In this

the adolescents reported that family members reminded them to take ART.

#### **4.3.2.2b. Disclosure of HIV status**

The adolescents who were interviewed had disclosed their HIV status to family, a few to friends and one to the teacher. Disclosure was mentioned by the adolescents with good adherence to ART (taking her ART at school) while those with poor adherence were secretive about their HIV status:

*“I just take them....ah! No one cares” (18 year old female)*

*“My friend and my guidance teacher know” (18 year old female)*

*“Ah, of course no..... Eish, that’s my secret akere..... Ah ah, what if he tell others.... (laughing).” (16 year old male referring to why they did not disclose)*

#### **Disclosure of HIV status: Literature control**

The finding is supported by Biakaako-Kajura et al (2006:S89) who reported that children were self-motivated to adhere to their ART following full disclosure of HIV status. The adherence motivation reported by Biakaako-Kajura (et al 2006) and other researchers came from the child knowing his/her HIV serostatus and understanding why ART was needed. Again stigma and discrimination by friends and family members were strongly associated with non-adherence to ART (Phalade et al, 2009; Miles et al 2006).

Biadgilign et al (2011:e17572) in their study were dealing with only 17.4% disclosure level and they found that non-disclosure was associated with poor adherence. In their study, Biadgilign and others showed that only 46.2% of the caregivers wanted disclosure when a child is above 14 years of age. This

demonstrates the variation which exists on disclosure yet there are clear benefits to disclosure of HIV status. It is through disclosure that a child or adolescent can understand what it means to be HIV positive and disclosure and the knowledge of HIV would be facilitators of adherence.

There are pros and cons of HIV disclosure and in a study by Ayres et al (2006:1002), caregivers' narratives indicated that delaying disclosure of HIV infection was a common measure taken to protect adolescents. The caregivers in this study believed that mischaracterisation of the "abnormality" represented by HIV infection might result in disclosure bringing more benefits than harm. However in this study early disclosure and acceptance of HIV status was more common in those adolescents with acceptable adherence.

Sometimes these adolescents may not disclose for fear of stigma and discrimination. Stigma and discrimination is clearly associated with poor adherence as demonstrated in a systematic review by Reisner et al (2009:15). Adolescents may also discover the realities of living with HIV and sometimes full disclosure of HIV status happens at this stage in their lives (Biadgilign et al 2011:e17572; Bikaako-Kajura et al 2006:S87). In-depth interviews with adolescents living with HIV aged between 10 and 20 and their caregivers at six different AIDS treatment centres in Sao Paulo, Brazil also identified stigma and discrimination as the most important challenges in living with HIV (Ayres et al 2006:1004).

In this study being secretive about HIV status (meaning no disclosure) was found in those adolescents with poor adherence to ART which may imply that being secretive about status may be a barrier to adherence.



#### **4.3.2.2 c. Stigma and social discrimination**

Stigma and discrimination was mentioned only as one of the reasons one participant (in the group that did not adhere to treatment) did not disclose their HIV status.

*“Ah, of course no..... Eish, that’s my secret akere..... Ah ah, what if he tell others....(laughing).” (16 year old male referring to why they did not disclose)*

#### **Stigma and social discrimination: Literature control**

The finding is consistent with a study by Phalade et al (2009) who investigated challenges faced Botswana adolescents living with HIV in and found that stigma, discrimination, HIV disclosure were strongly associated with non- adherence. Miles et al (2006) found that people who are open and had told their friend and family members about their HIV status were supported during ART treatment. Another finding of the same study by Miles et al (2006) was a significant relationship that exists between stigma and adherence to ART.

In a review by Reisner et al (2009:15), HIV stigma and discrimination by friends and family members were strongly associated with non-adherence to ART showing the importance of a stable home environment and at least support from the family. This showed that family support or a stable home environment with no stigmatization as at least supportive for an adolescent child on ART. According to Nyambura (2009:70) stigma, discrimination, lack of family and community support is huge obstacles to ART adherence.

#### **4.3.2.3 Theme 3: Difficult and complicated treatment**

The third theme that emerged related to difficult and complicated treatment and the categories that emerged include life-long treatment and type of medication. The subcategories are shown in the table 4.3 below. Each subcategory will be discussed.

**TABLE 4.3. THEME 3: DIFFICULT AND COMPLICATED TREATMENT**

<b>NO</b>	<b>THEMES</b>	<b>CATEGORIES</b>	<b>SUBCATEGORIES</b>
3	ART difficult and complicated treatment (medication regimen)	Lifelong treatment  Type of medication	Side -effects (4.3.2.3a)  Interference with daily activities/routine (4.3.2.3b)  Forgetfulness (4.3.2.3c)  Size of pills (4.3.2.3d)  Number of pills (4.3.2.3e)  Missing doses (4.3.2.3f)  failure to commit to lifelong Treatment (4.3.2.3g) regular doctor (4.3.2.3h)

The participants who did not adhere to treatment said that they forgot to take ARV drugs; they missed their treatment doses due to fear of stigma or disclosure. They mentioned pill burden as the cause of them to miss their treatment doses.

#### **4.3.2.3a. Side -effects**

Reports of patients vomiting or having stomach cramps were reported as what makes it difficult to maintain a good adherence to ART in adolescents interviewed in this study. These are the sample responses:

*“I used to take a few tablets, now I take too many and my stomach hurts all*

*the time” (19 year old female)*

*“Sometimes I vomit and waking up in the morning to take them before going to school is difficult” (14 year old female)*

*“And then sometimes I vomit eish..... (pause). It’s difficult” (16 year old male)*

*“Aah...sometimes I vomit in the morning....so maybe better tablets. Gape, eish....if also get that tablet for taking at night only, maybe it will help” (14 year old male)*

#### **Side-effects: Literature control**

Side effects to ART have been implicated in some studies as negatively affecting adherence (Maggiolo et al 2002:371; MacDonnel et al 2011:50). MacDonnell et al reported in their study exploring situational temptation that the three most tempting situations to miss medications as:

- If medicine caused physical symptoms
- If the medicine caused stomach upset or nausea or had an unpleasant taste and
- If the youth simply forgot to take the medication.

All these three situations are described in this study and some of the side effects may be long term. MacDonnell et al recommended that youths’ expectations of negative physical symptoms should be addressed in the first instance when considering beginning an HIV treatment regimen.

#### **4.3.2.3b. Interference with daily activities/routine**

Taking ART was a challenge for the participants especially as it is related to morning school start times or disturbed when they travelled. The following were some of the comments made by the adolescents in this study:

*“Ah... (smiling), akere it means we can't play together all the time, I have to run home to take my meds all the time” (16 years old male)*

*“...it's not easy...I wake up early in the morning, and if it is during school terms I have to quickly prepare for school, eat and then take my medicines at 7” (18 year old female)*

*“The last time I forgot them when I went to masimo (lands)....eish...” (16 year old male)*

*“... (pause).. and I have to take them same time every day, that's hard” (19 year old female)*

*“Gape, eish....if also get that tablet for taking at night only, maybe it will help” (14 year old male)*

### **Interference with daily activities/routine: Literature control**

Curioso et al (2010:4) reported that they identified many factors related to daily schedules which could improve levels of adherence and this included having a fixed routine and the use of adherence tools. Curioso et al found that having a fixed routine was the top adherence facilitator in their study. Similarly MacDonnell et al (2011:50) reported that if the ART regimen got in the way of a participant's daily schedule or if family and/or friends did not help support and remind participants to take their medications adherence would be affected.

Murphy et al (2003:254) also demonstrated that adherence was tied closely with daily routine which supports the assumption that working closely with adolescents to improve their organisational skills may be necessary to improve adherence. Fitting the ART doses into the daily routine was the challenge expressed by the adolescents in this study.

A change in daily routine was reported in 40% of patients as a reason for nonadherence in many studies (Chesney 2000:S173). A change in daily routine was also cited by Murphy et al (2003:252) in their study in adolescents on ART. This means that if anything changes during the morning or evening, the ART doses may easily be forgotten.

#### **4.3.2.3c. Forgetfulness**

Forgetting to take ART was a common experience expressed by adolescents who had poor adherence. Adolescents with good adherence who admit to forgetting to take their ART usually have corrective measures such as taking immediately one remembers. The following statements were expressed:

*“Sometimes I forget I have to take every day” (14 year old female)*

*“Eish.... (pause, looking down)...I told you it’s difficult. I try to take them but then....eish, sometimes I forget” (18 year old female)*

*“I don’t like the tablets. You are not supposed to forget them, you are supposed to eat before taking them, eih. Mathatha” (19 year old female)*

*“Yes....That means that before I go to school I take, that is when I wake up. And then in the evening after school I take. So if I forget in the morning and remember when at school.... I forget. Then in the evening I come home, but if there is sports and I come late, I take them late...eish. Then sometimes I forget” (16 year old male)*

#### **Forgetfulness: Literature control**

This finding was supported by studies on AIDS patients in USA, Canada, Belgium,

Brazil and Botswana that showed forgetfulness, fear of side effects and pill burden as reasons for ART non-adherence (William and Fourney 2000; Mills et al 2006).

In a review, Chesney (2000:S173) demonstrated that just forgetting or being busy was the commonest reason for non adherence with a prevalence of between 34% and 52%, this was followed by being away from home with 27-42%. Some of the reasons for forgetting in this study included travelling as well as the fact that it is supposed to be a daily habit and some end up forgetting.

Murphy et al (2003:252) found three most commonly endorsed reasons for non-adherence to ART in adolescents to be simply forgot (45.6%), did not have medication with them (42.1%) and change in daily routine (33.3%). In another study, Maggiolo et al (2002:374) found, forgetfulness was reported in 59.3% of the participants while being away from home was reported in 50.2%. Being away from home was similar to what was reported in this study.

- *Use of electronic devices*

The adolescents who adhered to ART mentioned the family members remind them to take medication, but they also use electronic reminders. The use of reminders ranged from alarm clocks, cell phones. There were some adolescents in this study who acknowledged the use of reminders such as alarms as what has been helping them over the years to maintain a good adherence to their ART. Their experiences showed these reminders as facilitators of adherence as shown by the following statements:

*“I always use my alarm to remind me as well” (17 year old male)*

*“...my grandmother helps and i also have an alarm clock (18 year old female)*

*“....and then even my alarm clock rings.....” (18 year old female)*

*“I set a reminder on my cell phone and it reminds me” (14 year old female)*

*“My auntie reminds me and I also check the time on the radio or TV....(pause). But if I had an alarm then it can remind me like when I am at school (16 year old male)*

There were adolescents mentioning the use of reminders as what motivates them to maintain good adherence as shown by the following statements:

*“Sometimes my mother sets an alarm for me. But she won’t buy me a cell phone” (15 year old male)*

*“My friend uses a cell phone” (15 year old male)*

The use of electronic devices such as alarm clocks, alarm watches as well as cell phones has long been recognized as a facilitator of adherence in all age groups. According to Mannheimer, Hirsh and El-Sadr (1998) adherence improved to 100% in 98% of patients using a specific alarm device indicating the importance of adherence supporting tools such as alarms even during the early stages of the HIV epidemic. The use of adherence supporting tools was also confirmed in a review paper by Chesney et al (2000:S174). In a study in Ethiopia on adherence in the paediatric population, researchers found that caregivers used reminders from cellular phone alarm systems (25.4%) followed by watches/clocks (46.4 %.) (Biadgilign et al 2008:58). The tools mentioned in Ethiopia by Biadgilign et al were similar to the findings in this study. The use of reminders through alarm clocks and cell phone was found to be a facilitator of adherence in this study.

Another question that was asked to study participants whether with poor or good adherence was the kind of help that they would ask for from the clinic or the government. Another adherence tool which helps to manage and remind to take ART is the pill box.

*“A pill box.....It organizes your tablets and you can always see when you have not taken them”. (18 year old female)*

*“It organizes your tablets and you can always see when you have not taken them” (18 year old female)*

In a marginal structural model analysis study on pillboxes as adherence tools, Peterson, Wang, van der Laan, Guzman, Riley and Bangsberg (2007) estimated that pill boxes improved adherence by 4.1% to 4.5% and was associated with a decrease of viral load of 0.34-0.37 log<sub>10</sub> copies/ml and a probability of viral suppression. The use of pill boxes is fairly inexpensive and Peterson et al were recommending the pill boxes to be a standard intervention to improving adherence to antiretroviral therapy.

Cell phones can be used as alarm clocks to set reminders but also the short messaging system (sms) can be used to send reminders. The use of mobile technology to improve adherence to ART has been documented and this followed the study on sms reminders in Kenya (Pop-Eleches et al 2011). There are other studies which have demonstrated benefit from the use of electronic reminder devices (Wise and Operario 2008).

At the time of this study at BBCCCOE there was a pilot project on the use of sms reminders and some of the clinic patients were participating on the project. The following were some of the statements mentioned by the adolescents regarding the use of this new technology:

*“...I also want the sim card and phone that others are getting” (17 year old male)*

*“And maybe the cell phone messaging.....the one with the phone. But I don't have a cell phone so maybe that won't be ok.... I don't know, anything....eish” (14 year old male)*



The study a rural clinic in Kenya was to investigate if mobile phone technologies improve adherence to ART in a resource-limited setting through a randomized controlled trial (Pop-Eleches et al 2011). The researchers found improved adherence with the use of the sms reminders. This technology may eventually benefit adolescents struggling with adherence even in resource limited settings where there is access to cellular phone networks as an adherence intervention. The question is on how effective if mobile phone technologies are implement on a large scale. The adolescents in this study want them and specifically to address their adherence challenges.

#### **4.3.2.3d. Size of pills**

The size of the pills also emerged as a significant subcategory with some adolescents specifically mentioning that their tablets are big as well as advocating for the small tablets. These were some of the thoughts expressed by the adolescents:

*“Maybe if i take like that tablets that you only take at night, the atripla tablet. Maybe i won’t forget that one” (18 year old female)*

*“You know my alluvia tablets are big. I don’t like those tablets...and then every (stressing the word) day i have to take them” (18 year old female)*

*“They are big..” (14 year old female)*

*“Small little tablets that are sweet” (14 year old female)*

(Maggiolo et al (2002:371) investigated factors associated with adherence and also found the size of pills to be a factor as it is the case in this study. There were adolescents in this study with poor adherence who did not like the fact that their pills were big. The size, number, taste of pills as well as doing times and side effects are all medication related factors that are associated with adherence

(Stone et al 2004:808; Murphy et al 2003:253; Murphy et al 2001:36).

#### **4.3.2.3e. Number of pills to take**

This subcategory emerged from adolescents sharing their experience that they take many tablets especially those with poor adherence. Less number of tablets was also a recommendation to the clinic as what the facility could do for the adolescents in order to improve adherence. This was investigated as early as in 2002 when Maggiolo et al (2002:375) showed that simpler regimens with a lower number of pills and doses may help patients' compliance to therapy.

*"..... (pause). I don't know. Maybe give me a few tablets (14 year old female)*

*"I used to take a few tablets, now I take too many and my stomach hurts all the time" (19 year old female)*

*"..(looking down) ya, I know. Maybe a few tablets then. Or just 1.....I don't know. Something!" (19 year old female)*

*"Well,....(sad), maybe if there was a time that I could take a break. Just stop them and rest. Maybe it would help" (19 year old female)*

#### **Number of pills to take: Literature control**

The number of tablets or pill burden may be a perception which just needs to be dealt with for some adolescents. Pill burden is known to be an adherence hindrance. This is in contrast to an adolescent in this study with good adherence who was taking a total of 6 tablets per dose and yet maintained good adherence. While acknowledging that the pill burden was high, there was however determination to continue knowing that there were not too many options available:

*"I take 6....That's a lot but what can i do" (18 year old female)*

There are various medication issues which have been implicated in literature to affect adherence including side effects, pill burden, size, taste, food restrictions as well as dosing times (Maggiolo et al 2002:371). Maggiolo et al showed that younger age, high number of pills, high frequency of doses and longer time on ART were predictors of non-adherent behaviour. A low pill burden is associated with improved adherence while both physical and psychological medication-related adverse effects are associated with poorer adherence (Murphy et al 2003:253; Murphy et al 2001:36). This is the picture shown in this study and the adolescents in this study were advocating for a low pill burden as what would enhance their adherence. A low pill burden, with at most twice daily dosing, fewer adverse events have been shown to have the greatest impact on patients' ability to adhere to ART (Stone, Jordan, Miller & Pilon 2004:808).

On the contrary, the early studies have actually revealed that a low pill burden and improved dose frequency may not necessarily promote adherence (Paterson et al 1998; Eldred, Wu, Chaisson & Moore 1998). These studies implicated other factors as opposed to pill burden or dosing frequency and this could explain the scenario of the adolescent taking 6 tablets per dose yet maintain adherence.

#### **4.3.2.3f. Failing to commit to lifelong treatment**

This subcategory reveals adolescents who were failing to commit to the fact that ART was a lifelong treatment and hence they had moments in their life where they have not seen the need to continue taking their ART. It almost seemed that with some of the adolescents they failed to understand or appreciate the fact that sometimes they are the only ones in a family or amongst a group of friends who have to take ART.

*“...I mean exactly that. My mum doesn't have to take them, no one has to take them” (18 year old female)*

*“I know why i take them! I said why me! (stressing the ‘me’) (18 year old female)*

*“Why do i have to take them anyway...” (14 year old female)*

*“...find a cure...(laughing)” (18 year old female on what the government should do for her to improve adherence)*

*“Aah, I mean it’s ok that there are ARVs to help when I am sick but then it also means that I have to continue with them for the eh....the rest of my life” (16 year old male)*

*“My friend is ok, he doesn’t take them and I have to take them, eish” (16 years old male).*

*“Well,....(sad), maybe if there was a time that I could take a break. Just stop them and rest. Maybe it would help” (19 year old female)*

*“I don’t know....(smiling). Maybe just don’t give me the tablets” (19 year old female)*

### **Failing to commit to lifelong treatment: Literature control**

Murphy et al (2001:36) showed that the longer the duration the adolescent has been taking ART the poorer the adherence. The minimum duration that adolescent was on ART in this study was 4 years and the maximum 9 years. This shows that adolescent interviewed in this study had a long experience with ART and those failing to realise or commit to a lifelong treatment were not doing well with adherence. One of the early assessments that needs to be done before initiating ART as per many HIV guidelines is a discussion of patient readiness for what is currently a lifelong commitment to therapy (Zolopa 2010:242).

#### **4.3.2.4 Theme 4: Having a regular doctor (my own doctor)**

Having a regular doctor emerged from the question of what the clinic can do for the adolescents to improve or maintain good adherence. Having a regular doctor or medical provider means that even in a clinic setting with many doctors, a specific doctor should be assigned to specific patients to follow up. This is currently not the status quo at BCCCOE. The point of discussion in this study was on what the clinic or government could do for the adolescent in order to improve adherence and the following was mentioned:

*“There are many doctors here at the clinic and they are always changing.....I want my own doctor....(laughing)” (18 year old female).*

While this adolescent may not have thought much about the need of a regular health care provider, there were some studies which have demonstrated this as a facilitator of adherence. Having a consistent health care provider can actually emerge as an adherence promoting strategy. Radcliffe, Tanney and Rudy (2006:111) studied post-traumatic stress and adherence to medical treatment among youth living with HIV and they showed that maintaining regular follow-up care and treatment with a specific provider was associated with increased adherence. In another study, with a qualitative design on understanding the facilitators and barriers of antiretroviral adherence in Peru, a relationship with a specific medical provider seem to promote adherence (Curioso, Kepka, Cabello, Seguras & Kurth 2010:6). These studies and the findings of this study show that maintain a regular health care provider may promote adherence in adolescents.

#### **4.3.2.5 Theme 5: Psychosocial-emotional needs**

This theme explains the implications of loss of a loved one especially a parent on adherence. Participants who lost a parent were not doing well on adherence to ART implying the lack of psychosocial-emotional support amongst adolescents living with HIV on ART.

**TABLE 4.4 THEME 5: PSYCHOSOCIAL-EMOTIONAL NEEDS**

<b>NO</b>	<b>THEME</b>	<b>CATEGORIES</b>	<b>SUBCATEGORIES</b>
5	Psychosocial- emotional needs	Stressful life situations	Depression  Anxiety  Bereavement

Williams et al (2006:e1745) found some factors associated with at least marginally significant increases in non-adherence to be occurrence of recent stressful life events, repeating in school and diagnosis of depression or anxiety. Clearly in this study a difficult experience as well as no family support or death of parents was expressed by those with poor adherence. There may be an element of bereavement or even depression in these settings reported in this study. The following were some of the expressions by the participants in this study:

*“Ever since my parents died, my grandmother has had to take care of me. I have a sister who also helps, but my grandmother really helped” (18 year old female).*

*“Yes she does help me, she reminds me” (18 year old female referring to sister)*

*“They died” (16 year old male, referring to parents)*

*“They died... (no eye contact)....(pause). I stay with my grandmother and grandfather and my sister. My auntie is at the cattle post” (19 year old female)*

In their study Murphy et al (2009:1102) found depression to be a factor associated with adherence and 49.4% of the participants were depressed as assessed by the Center for Epidemiologic Depression Scale. A meta-analysis also showed similar findings, depression and HIV treatment non-adherence was consistent and

interventions aimed at reducing depressive symptom severity were recommended (Gonzalez, Batchelder, Psaros & Safren 2011).

Other factors that may affect adherence include lifestyle factors such as homelessness, substance abuse, lack of education and mental illness (Chesney 2000:S173). Such factors did not come up in this study but should also be explored when faced with an adolescent with poor adherence.

- ***Innovative ideas to maintain adherence: Keeping an extra supply of ART***

These emerged from an adolescent's response to a question on suggestions to help friends who are struggling with adherence. They acknowledged that it was very easy to forget taking ART and their suggestions included

*“I now have a trick, I take my medicines to school. So I always keep some tablets in my school bag (18 year old female).*

*“I know sometimes I forget but I always take them when I remember”  
(17year old male)*

*“Make sure to always take your medicines. If you forget them then take immediately you remember” (15 year old male)*

#### **4.4 THE EXPERIENCE OF FIELDWORK BY THE RESEARCHER**

The opportunity to conduct qualitative research has been rewarding and a learning curve for the researcher. Adolescents form a significant proportion of the BBCCCOE and the majority of the adherence challenges at the clinic are found in adolescents. Having worked with the clinic for more than 3 years, the researcher wanted to contribute to solutions of how to best deal with adolescents on ART with adherence challenges. This prompted the researcher into a study to understand factors affecting adherence in adolescents at the BBCCCOE.

Observational notes were taken during the interviews as the researcher watched and listened to the participants. Observational notes describe the events experienced through watching and listening. Personal notes were also taken which are reflections of the reactions and experiences of the researcher (de Vos 2005:33). A connection was made with many of the adolescents and their reactions matched their stories. Hope was not all lost as I watched these adolescents tell their stories. Clearly most of them were struggling but one could see the determination in some.

This research project also gave the researcher a learning opportunity with the adolescents at the BBCCCOE to understand why some adolescents behaved the way they do while on ART. The challenge with adolescents has always been why sometimes there is no behaviour change related to adherence even if after undergoing counselling. This resistance to behaviour change sometimes even occurs in situations where the adolescents have succumbed to ill-health with opportunistic infections as a result of poor adherence.

The group was diverse and really shared their experiences while taking their ART with the researcher. Diversity of the adolescents was seen through the age range, the duration of their ART as well as the different family environments they all came from. Some may have found it difficult to share the factors influencing adherence to retroviral drugs with the researcher.

In order to collect adequate and relevant information, the researcher had to build a trusting relationship with the adolescents who are HIV positive and are on antiretroviral drugs. First contact was made with the adolescents coming for their routine follow ups at the clinic work where the researcher is a consulting medical doctor. The adolescents were approached and the studies explained to them and asked if they would be interested. At all times the adolescents were given a choice to participate or not to participate, coercion was avoided at all costs. Those who were interested were asked to bring their parent/caregiver for the consenting and



assenting process. Most adolescents at the BBCCCOE do not come to the clinic anymore but no separate appointment was given. The potential study participants still had to come on their next routine visit to the clinic. These two contacts gave ample time for the study participants and parents/caregivers to decide whether to participate or not in the study. The BBCCCOE also provided a safe environment for the study participants because it is the same place for their routine follow ups where the interviews were conducted.

Adolescents with adherence challenges have complex family and social settings and they would have undergone several individual or family counselling sessions at the clinic. Participating in a study on ART adherence factors meant that they may be discussing the same issues they discussed during counselling sessions. Particular attention was paid to adolescents with unacceptable adherence and reassurance was given and the purpose of the study explained. More time was taken with these adolescents even prior to consenting to ensure they are comfortable with the study.

#### **4.5 CONCLUSION**

The in-depth individual interviews conducted with 8 adolescents at the BBCCCOE revealed themes that facilitate adherence as well as barriers to adherence. These adolescents had been on ART for periods ranging from 4 to 9 years and therefore they provided rich experiences with their ART over the years. Themes that emerged from this study were related to knowledge and positive beliefs about ART; the need for support which can be from family, friends or society; a difficult treatment because it is life-long treatment as well as the type of medication; having a regular doctor as well as psychosocial-emotional needs which are related to stressful life situations.

Chapter 5 will conclude the study as well as discuss limitations and make recommendations for practice and further research.

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

This chapter presents the conclusions, limitations and recommendations of this study. The study sought to describe the factors that influence adherence to ART among adolescents who contracted HIV through vertical transmission, attending the BBCCCOE. The knowledge of such factors would assist in ensuring that programmes for adolescents include specific measures to improve adherence to ART treatment in Botswana.

#### 5.2 RESEARCH DESIGN AND METHOD

The study was non-experimental and qualitative in nature with a descriptive phenomenology approach. Qualitative approach was used to develop a rich understanding of the phenomenon, adherence to ART among adolescents as it exists in the real world and as it is constructed by individuals within the context of that world (Polit & Beck 2006:212).

Most adolescents acquire HIV through mother to child transmission, high-risk behaviours such as unprotected sex or through infected injection needles. A limited but increasing number of HIV-positive adolescents are long-term survivors of HIV infection acquired through vertical transmission. Such adolescents have been on ART for a longer time than that of adolescents infected later in life hence the focus on them as study population. A non-probability sampling purposive method was used to select study participants who have experienced long-term ART and were likely to provide information about the phenomenon (adherence to ART) under investigation (Burns & Grove 2005:352). Adolescents who participated in the study had been on ART for a period of up to nine years.

Adolescents with poor adherence and those with good adherence were included in the study and they were identified from the electronic medical record system

(EMR) which documents adherence at every visit. The sample size was not specified, the principle of saturation of data was adhered to.

The interviews were conducted in a private consultation room; giving study participants privacy to share their experiences. They were conducted in English by the researcher. The participants were assured of confidentiality and anonymity. The consent to participate in the study was confirmed before the commencement of the interviews. With the permission of the participants, all the interviews were audio-recorded and notes were taken during the interview in order to capture all the information and/or non-verbal observations. Each interview session took about 30 minutes. A total of eight (8) adolescents were interviewed.

Thematic analysis of the data was according to Van Manen (1990) cited in Polit & Beck (2008:519) using the holistic and the selective approaches. Themes were identified and they reflected a description of factors influencing adherence in adolescents living with HIV on ART at a referral facility in Botswana.

### **5.3 SUMMARY AND INTERPRETATIONS OF THE RESEARCH RESULTS**

Factors influencing adherence to ART amongst adolescents attending the BBCCOE were identified in the different themes that emerged during the study. Themes that emerged from this study were related to knowledge and positive beliefs about ART; the need for support which can be from family, friends or society; a difficult treatment because it is life-long treatment as well as the type of medication; having a regular doctor as well as psychosocial-emotional needs which are related to stressful life situations.

#### **5.3.1 Knowledge and positive beliefs about ART**

Knowledge and positive beliefs about ART promote adherence to ART. The participants demonstrated substantial knowledge about the benefits of ART but the knowledge was not consistent with adherence levels. In this study, an adolescent who had awareness and acknowledged that living with HIV and being on ART was

a difficult experience was doing well with adherence. Even though it was difficult, but appreciating and acknowledging the difficulties seem to give an edge on these adolescents to go through the difficult experience. This was evident from the expressions which showed their belief in the benefits of ART.

### **5.3.2 Need for support**

Adolescents in this study demonstrated the need for support and this was in the form of family support, support from friends as well as support from the society. A good family support structure promoted adherence as revealed by adolescents with good adherence to ART who reported getting help from family members who reminded them to take their medication. Not only does support from family and friends enhance adherence, it also promotes disclosure of the HIV status.

### **5.3.3 Difficult treatment**

It was clear from the experiences of adolescents that committing to a lifelong treatment was not easy especially when it has to happen at an early age. Medication related factors such as the side-effects of ART, interference with daily activities/routine, size of pills, number of pills and many doses. The common side effects mentioned were vomiting and stomach cramps. The ideal ART regimen would be with minimum number of pills taken preferably once a day without interference of daily routines, small pills and few side-effects.

Forgetting to take ART was a common experience expressed by adolescents who had poor adherence. Adolescents with good adherence who admit to forgetting to take their ART usually have corrective measures such as taking immediately one remembers. Being forgetful in this study was addressed by the use of electronic gadgets as well as being reminded by family members.

### **5.3.4 Having a regular doctor (my own doctor)**

Maintaining a regular contact with specific health care workers especially a regular doctor may promote adherence as suggested in this study. This is not a new

finding since it has already been reported that a relationship with a specific medical provider promotes adherence (Curioso et al 2010:6).

### **5.3.5 Psychosocial-emotional needs**

Stressful life situations such as the loss of a parent may have a negative impact on adherence to ART in adolescents living with HIV. This was evident in adolescents who had lost one or both parents. Depression, anxiety as well as bereavement may play a role in influencing adherence in adolescents living with HIV. Depression has been reported in literature to affect adherence implying that an assessment of baseline depression would be important before initiation of ART (Murphy et al 2009:1102).

Fear of stigma and discrimination was evident in some of the adolescents who preferred to keep their HIV status their 'secret' especially to school teachers and friends.

Before initiating ART on children and adolescents it is important to make an assessment of the family situation to see if a support network exists. Disclosure of HIV status was an important element when considering the circles of support as there was need for disclosure if help was sort. This follows the findings in many studies that demonstrated the benefits of disclosure as reported in a Botswana study as well by Phalade et al (2009). Phalade et al investigated challenges faced by adolescents living with HIV in Botswana and found that HIV disclosure among other factors was associated with adherence. This means that disclosure and continued education of the adolescent about HIV and ART could impart the knowledge needed to sustain adherence. Obviously the fear of stigma and discrimination made it difficult for some of the adolescents to disclose their HIV status especially to school teachers and friends for fear of stigmatisation and possible discrimination.

Other factors that may affect adherence include lifestyle factors such as

homelessness, substance abuse, lack of education and mental illness (Chesney 2000:S173). Such factors did not come up in this study but should also be explored when faced with an adolescent with poor adherence.

#### **5.4 CONCLUSION**

The themes that emerged from this study (knowledge and positive beliefs about ART, need for support, difficult treatment, having a regular doctor, psychosocial-emotional needs) show that there is need for a baseline assessment of adolescents before initiation of ART. The baseline assessments would include psychological (depression screening) as well family support; knowledge of HIV and ART including disclosure. Such assessments would then be periodically conducted at every contact. Where possible a regular doctor as well as a simplified ART regimen would be recommended.

#### **5.5 RECOMMENDATIONS**

The recommendations emanating from the study are based on practice, education and further research as it pertains to adolescents and adherence to ART. The following outline recommendations made based on the experiences shared by adolescents in this study. The study participants also had an opportunity to share what they thought could be done for them and is also incorporated in the recommendations below.

##### **5.5.1 Recommendations with regard to practice of health professionals**

The findings from this study provide valuable information to facilities managing adolescents living with HIV. Before initiating ART on children and adolescents it is important to make an assessment of the level of knowledge about HIV and ART, the family situation, beliefs about and attitude HIV and ART and the motivation ( or lack thereof ) for commitment to ART. Disclosure of HIV status was an important element when considering the circles of support as there is need for disclosure. The implication for health professionals' practice is continued education of the adolescents about HIV and ART increase the knowledge needed to sustain

adherence.

All facilities dealing with adolescents should have specialized staff that deal with adolescents and understand their needs as well as how to communicate with them. Given the findings of this study, there is need for a friendly, supportive and non-judgmental attitude of all health care providers as well as convenient appointment scheduling and confidentiality.

Involvement of adolescents in their own care has shown benefits in this study. The adolescents made suggestions of how the government and health care providers could help improve their adherence to ART. They also made good suggestions of how they can help each other maintain adherence. Their suggestions included the use of electronic reminders, taking treatment to school and taking treatment as soon as it remembered in cases of forgetfulness. They also challenged the medical profession to find a cure for HIV

#### **5.5.2 Recommendations regarding the education of health care professionals**

A facility that takes care of adolescents should have standard operating procedures (SOPs) that clearly outline all areas that should be explored in an adolescent prior to initiating ART. The SOPs would outline what is required at screening, initiation as well as follow up of adolescents living with HIV.

Facilities managing adolescents living with HIV should have also have specially trained providers who follow up these adolescents. Continuity of care with constant providers may also build trust by the adolescents thereby making it easier to manage them.

#### **5.5.3 Recommendation regarding further research**

Further research is still required in the area of the psychological impact of HIV on

the wellbeing of people living with HIV as well as adherence to ART. While studies have documented factors influencing adherence to ART in different settings, there is need to investigate a package that can be implemented to assist people living with HIV who are on ART. Adolescents are an important but yet challenging group that needs to be further researched. Interventions that work would most likely be location specific hence these will need to be further tested in each locality before use.

### **5.6 LIMITATIONS OF THE STUDY**

The limitations of this study were mainly related to the research setting and the researcher. This study was conducted at a referral facility in Botswana. The profile of patients at this centre is mainly complicated cases from a clinical as well as psychological end. This means that patients with adherence challenges may be more complicated and at the same time patients with acceptable adherence may have been managed well enough to reach acceptable adherence levels. This facility would not be representative of other facilities in peripheral clinics, district hospitals as well as primary hospitals. The participants in this study may have demonstrated biased information which may not apply to other participants in other facilities.

The setting of the study is also a research facility which means that some of these participants may have participated in prior studies related to adherence and may have given biased information. It was however assumed that the participants would be honest and it was ensured that all participants in this study were not concurrently participating in other studies at the time of the interviews.

### **5.7 CONCLUDING REMARKS**

This study investigated factors influencing adherence to ART among adolescents living with HIV at the Botswana-Baylor Children's Clinical Centre of Excellence. The adherence factors identified in this study were related to the knowledge and positive beliefs about ART, need for support from family, friends and society,



difficult treatment related to lifelong treatment and type of medication, having a regular doctor and psychosocial-emotional needs. Adolescents require support while taking simplified ART regimens after an assessment of their psychological well being and periodic checks.

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**UNIVERSITY OF SOUTH AFRICA  
 Health Studies Research & Ethics Committee  
 (HSREC)  
 Faculty of Human Sciences  
 CLEARANCE CERTIFICATE**

Date of meeting: 9 November 2010

Project No: 43394329

Project Title: **Factors influencing adherence to antiretroviral therapy in adolescents at Botswana-Baylor children's clinical centre of excellence: A qualitative study**

Researcher: Tafireyi Marukutira

Supervisor/Promoter: Mrs. M Chauke

Joint Supervisor/Joint Promoter: Prof TR Mavundla

Department: Health Studies

Degree: Masters in Public Health

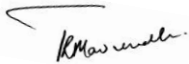
**DECISION OF COMMITTEE**

**Approved**

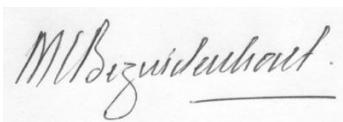


**Conditionally Approved**





**Prof TR Mavundla  
 RESEARCH COORDINATOR**



**Prof MC Bezuidenhout**

## **ANNEXURE 2: MOH APPLICATION FOR APPROVAL OF HUMAN RESEARCH**

Ministry of Health



Republic of Botswana

# **Application for Approval of Human Research**

### **Section A: Instructions**

1. For research/academic institutions or PHD students attach:
  - 14 copies of the Research Application form
  - 4 copies of the following:
    - i. Study proposal.
    - ii. Consent/authorization form or a request for waiver of consent/authorization- Setswana, English and back translation where applicable.
    - iii. Questionnaires to be used. Setswana, English and back translation where applicable.
    - iv. Curriculum vitae/ resume of each member of the Research team
    - v. Approval letter from other IRBs
    - vi. Grant approval letter
    - vii. Any other supporting materials i.e. recruitment scripts, brochures, flyers etc
2. For undergraduates and graduates attach one copy of the above listed items/ documents.

### **Section B: Application Details**

<b>1. Study Title: (Include Version number and date)</b> <b>FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERPAY IN ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE- A QUALITATIVE STUDY</b>	
<b>2. Date of submission: 16/12/2010</b>	
<b>3. Type of Research:</b> <ol style="list-style-type: none"> <li>i. Basic Science ( )</li> <li>ii. Public Health (X)</li> <li>iii. Clinical Research ( )</li> <li>iv. Human Biology ( )</li> <li>v. Other <u>  x  </u></li> </ol>	
<b>4. Principal Investigator( Name <i>&amp;and</i> Qualifications):</b>  <b>TAFIREYI MARUKUTIRA</b> <b>MBChB, Diploma HIV Management, Diploma Obstetrics</b>	<b>4(i). Local Contact Details</b> <b>Name: TAFIREYI MARUKUTIRA</b>
<b>Postal Address: P BAG BR 129, GABORONE</b>	<b>Postal Address: P BAG BR 129, GABORONE</b>

<b>Phone Number: 3190083</b>	<b>Phone Number: 3190083</b>
<b>E mail Address: tcmarukutira@yahoo.com</b>	<b>E mail Address: <a href="mailto:tcmarukutira@yahoo.com">tcmarukutira@yahoo.com</a></b>
<b>Name of affiliate Institution/Organization: BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE</b>	<b>Name of Institution/Organization: BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE</b>
<b>Department (If Government):</b>	<b>Department (If Government):</b>

<b>5. Other Investigators /Co-Principal Investigators</b>			
<b>Name:</b>	<b>Organization:</b>	<b>Email:</b>	<b>Telephone Number:</b>
<b>GADZIKANANI MONYATSI</b>	<b>BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE</b>	<a href="mailto:gmonvatsi@baylorbotswana.org.bw">gmonvatsi@baylorbotswana.org.bw</a>	<b>3190083</b>

<b>6. Key Personnel working with data that may be linked to human subjects:</b>			
<b>Name:</b>	<b>Organization:</b>	<b>Email:</b>	<b>Telephone Number:</b>
<b>VINCENT MABIKWA</b>	<b>BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE</b>	<a href="mailto:vmabikwa@baylorbotswana.org.bw">vmabikwa@baylorbotswana.org.bw</a>	<b>3190083</b>

**ANNEXURE 3: MOH LETTER: PERMISSION TO CONDUCT THE STUDY**

Telephone: (267) 3632000  
 FAX (267) 353100  
 TELEGRAMS: RABONGAKA  
 TELEX: 2818 CARE BD



MINISTRY OF HEALTH  
 PRIVATE BAG 0038  
 GABORONE

**REPUBLIC OF BOTSWANA**

REFERENCE No: PPME 13/18/ 1 PS Vol V (145)

5 January 2011

Health Research and Development Division (HRDD)

**Notification of IRB Review:** New application

Dr. Tafireyi Marukutira  
 Private Bag 129  
 Gaborone

<b>Protocol title:</b>	<b>Factors influencing Adherence to Antiretroviral Therapy in Adolescents at Botswana - Baylor Children's Clinical Centre of Excellence - A qualitative study.</b>
<b>HRDD Protocol number:</b>	HRU 00683
<b>Sponsor:</b>	N/A
<b>HRDD Review Date:</b>	December 29, 2010
<b>HRDD Review Type:</b>	Expedited review
<b>HRDD Review Determination:</b>	Approved
<b>Risk Determination:</b>	Minimal risk

Dear Dr. Marukutira

Thank you for submitting an application for the above referenced protocol to Health Research and Development Division for review and approval. The research application was reviewed on an expedited basis.

**Permission is therefore granted to conduct the above mentioned study.** This approval is valid for a period of 1 year effective January 5, 2011.

This approval includes the following:

1. Application form
2. Protocol
3. Interview guide
4. Both Setswana and English Consent forms
5. Both Setswana and English Assent forms.
6. University of South Africa Clearance certificate
7. Curriculum vitae of study investigators

The permit does not however give you authority to collect data from the selected site without prior approval from the management. The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be

submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hard copy and an electronic copy of the report to the Health Research and Development Division, Ministry of Health within 3 months of completion of the study. Copies should also be submitted to all other relevant authorities.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at [pkhulumani@gov.bw](mailto:pkhulumani@gov.bw), Tel +267-3914467 or Mary Kasule at [mkasule@gov.bw](mailto:mkasule@gov.bw) or [marykasule@gmail.com](mailto:marykasule@gmail.com) Tel +267-3632466 or Mr. Lemphi Moremi at [lamoremi@gov.bw](mailto:lamoremi@gov.bw) or [lemphim@yahoo.com](mailto:lemphim@yahoo.com) Tel +267-3632464.

#### **Continuing review**

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Application Form for approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research and Development Division office (HRDD), office No. 9A.10 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: [kmotlhanka@gov.bw](mailto:kmotlhanka@gov.bw) As a courtesy, the HRDD will send you a reminder e-mail about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Review Form.

#### **Amendments**

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDD approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from Health Research and Development Division office (HRDD), office No. 9A.10 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: [kmotlhanka@gov.bw](mailto:kmotlhanka@gov.bw). In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

#### **Reporting**

Other events which must be reported promptly in writing to the HRDD include:

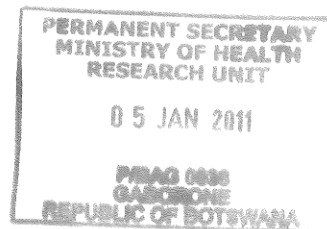
- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely



P. Khulumani  
**For Permanent Secretary**



## ANNEXURE 4: BCM LETTER: PERMISSION TO CONDUCT THE STUDY

July 07, 2011

NANCY R CALLES  
BAYLOR COLLEGE OF MEDICINE  
PEDIATRICS: RETROVIROLOGY



Baylor College of Medicine  
Office of Research  
One Baylor Plaza, 600D  
Houston, Texas 77030  
Phone: (713) 798-6970  
Fax: (713) 798-6990  
Email: [irb@bcm.tmc.edu](mailto:irb@bcm.tmc.edu)

**H-28973 - FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY IN  
ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE**

**APPROVAL VALID FROM 7/7/2011 TO 6/7/2012**

Dear Dr. CALLES

The Institutional Review Board for Human Subject Research for Baylor College of Medicine and Affiliated Hospitals (BCM IRB) is pleased to inform you that the research protocol named above was approved.

The study may not continue after the approval period without additional IRB review and approval for continuation. You will receive an email renewal reminder notice prior to study expiration; however, it is your responsibility to assure that this study is not conducted beyond the expiration date.

Please be aware that only IRB-approved informed consent forms may be used when written informed consent is required.

Any changes in study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participants' safety or willingness to continue in your study.

The BCM IRB is organized, operates, and is registered with the United States Office for Human Research Protections according to the regulations codified in the United States Code of Federal Regulations at 45 CFR 46 and 21 CFR 56. The BCM IRB operates under the BCM Federal Wide Assurance No. 00000286, as well as those of hospitals and institutions affiliated with the College.

Sincerely yours,

A handwritten signature in black ink that reads "Julie Pamela Katkin, M.D.".

JULIE PAMELA KATKIN, M.D.

Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals



**ANNEXURE 5: INFORMED CONSENT FORM: ENGLISH****Informed Consent Form**

**FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY IN  
ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE  
OF EXCELLENCE- A QUALITATIVE STUDY.**

**GUARDIAN CONSENT FORM**

My name is Dr Tafireyi Marukutira and I am a Masters of Public Health (MPH) student at the University of South Africa (UNISA). I am currently working for the Botswana-Baylor Children's Clinical Centre of Excellence, a partnership between Baylor College of Medicine and the Government of Botswana. I am doing a study to identify the factors that are associated adherence to ART among children aged 10 to 19 years of age.

The study has been approved by UNISA, the Ministry of Health of Botswana and I have been given permission by Baylor Clinic to do the study.

I would like to interview your child to discuss issues related to how he/she takes her medicine. A tape-recorder will be used during the interview. I also intend to get some information from the Electronic Medical (EMR) system at Baylor Clinic to assess his/her adherence. This information will be used to help health care workers to understand better why adolescents have poor or good adherence. It will help your child and other children once we understand the underlying factors.

The information gathered during this study will be kept completely confidential. Names and any other personal identifiers will not be published or made accessible to unauthorized persons. Your child does not have to answer any questions that he/she does not want to answer and she/he may discontinue answering the questionnaire, at any time she/he may choose. Your child will not be compelled to answer any questions they wish not to answer.

Neither you nor your child will be subjected to any physical risk of injury, pain or trauma and every effort has been made to ensure that any emotional stress or disturbance to study participants is minimized. Your child has access to a professional counsellor at the centre if needed.

The interview will take about *30 minutes to complete*.

If you agree for your child to participate, please indicate this by signing in the space below:

\_\_\_\_\_  
Name of Guardian

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of interviewer

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



**ANNEXURE 6: INFORMED CONSENT FORM: SETSWANA****SETSWANA INFORMED CONSENT****FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY IN ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE- A QUALITATIVE STUDY.****Tletla ya motsadi**

Leina lame ke ngaka Tafireyi Marukutira, ke moithuti kwa Mmadikolo ko Afrika Borwa (UNISA), mme ke bereka mo kokelong ya Botswana Baylor COE, e e leng bokopano gareng ga Baylor college of Medicine le goromente wa Botswana. Ke dira ditsheka-tsheko/patlisiso ka mabaka aa amangwang le go tsaya/nwa sentle kgotsa go sa ditsaya/nwa sentle diritibatsi mo baneng ba ba dingwaga tse di lesome go yak o go lesome le boferabongwe (10-19)

Patlisiso ee dumeletswe ke ba mmadikolo kwa Afrika Borwa (UNISA), le lephata la botsogo la Botswana. Godimo ga moo, ke filwe tetla ke ba kokelong ya Baylor go simolola tsheka-tsheko.

Ke kopa go botsa bana dipotso mabapi le ka fa ba tsayang/nwang melemo ya bone ka teng. Ke tla dirisa tape recorder. Mme gape ke tla lebelela ka fa ba ntseng ba dira ka teng mo molemong go tswa mo difaeleng (files) tsa bone tse di dirisiwang kwa kokelong ya Baylor. Se se tla thusa gore babereki ba botsogo ba tlhaloganye botoka gore ke eng bana ba ba fatlhogang bana a le bothata kgotsa ba sena bothata jwa go tsaya/nwa melemo. Go tla thusa gape ngwana wagago le babangwe fa re ka tlhaloganya mabaka a.

Sepe se se kgobokantsweng mo tsheka-tshekong e, e tlaa nna sephiri. Maina le ditshupetso tsotlhe di tla seke di gatisiwe kgotsa di bonwe ke ope fela yo o sa letelwang. Ngwana wagago ga a patelesege go araba potso epe e a sa batleng go e araba, gape o ka se tswelele ka patisiso fa a sa batle. Go ka nna le dingwe

tse bana ba ka se phuthologing go di bua fa pele ga motsadi, ka jalo re tlaa kopa go botsolosa bana ba le nosi.Mme le fa go ntsi jalo ngwana ga a patelediwe go araba potso ea sa batleng go e araba, gape o na le tshwanelo ya go kopa gore motsadi a nne teng fa potsoloso e ntse e tswelletse.

Tsheka-tsheko e, ga e na go baya ope, a ke motsadi kgotsa ngwana mo diphatseng dipe. Go ne ga tsewa kelelelo e kgolo go netefatsa gore go kgoberega maikutlo ga motsaa karolo mo tsheka-tshekong e go ko tlase kana ga goyo.Ngwana wag ago wa letelesega kgotsa o gololesegile go bona ba ba sedilang maikutlo mo kokelwaneng ya Baylor fa go tlhokega.Potsoloso e e tlaa tsaya magareng ga metsotso ee masome mararo.

Fa o dumalana gore ngwana wag ago o ka tsaa karolo mo patisisong e, supa ka go baya monwana fa:

.....  
Leina la Motsadi

.....  
Baya Monwana

.....  
Letsatsi

.....  
Leina la Mmotsolotsi

.....  
Baya Monwana

.....  
Letsatsi

**ANNEXURE 7: ASSENT FORM: ENGLISH****Assent form**

**FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY IN  
ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE  
OF EXCELLENCE- A QUALITATIVE STUDY.**

**ASSENT FORM**

My name is Dr Tafireyi Marukutira and I am a University of South Africa (UNISA) Masters of Public Health (MPH) student. I am currently working for the Botswana-Baylor Children's Clinical Centre of Excellence, a partnership between Baylor College of Medicine and the Government of Botswana. I am doing a study to find out factors that are associated with adherence to ART for children aged 10 to 19 years of age.

The study has been approved by UNISA and also by the Ministry of Health of Botswana. I have also sort permission from Baylor Clinic to do the study.

I would like to you to answer some questions related to how you take your medicine. A taper-recorder will be used during the interview. I will also get some information from the Electronic Medical (EMR) system at Baylor Clinic to assess your adherence as well. This information will be used to help health care workers to understand better why adolescents have poor or good adherence. It will help you and other children once we understand the underlying factors for good and poor adherence.

The information gathered during this study will be kept completely confidential. Names and any other personal identifiers will not be published or made accessible to unauthorized persons. You do not have to answer any questions that you do not want to answer and you may discontinue at any time you may choose.

You will not be subjected to any physical risk of injury, pain or trauma and every effort has been made to ensure that any emotional stress or disturbance to study participants is minimized. You will have access to a professional counsellor at the centre if needed during the process.

The interview should take about *30 minutes to complete*.

If you agree for to participate, please indicate this by signing in the space below:

\_\_\_\_\_  
Name of Adolescent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of interviewer

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**ANNEXURE 8: ASSENT FORM: SETSWANA****SETSWANA Assent Form****FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY IN ADOLESCENTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE- A QUALITATIVE STUDY.**

Leina lame ke ngaka Tafireyi Marukutira, ke moithuti kwa Mmadikolo ko Afrika Borwa (UNISA), mme ke bereka mo kokelong ya Botswana Baylor COE, e e leng bokopano gareng ga Baylor college of Medicine le goromente wa Botswana. Ke dira ditsheka-tsheko/patlisiso ka mabaka aa amangwang le go tsaya/nwa sentle kgotsa go sa ditsaya/nwa sentle diritibatsi mo baneng ba ba dingwaga tse di lesome go yak o go lesome le boferabongwe (10-19).

Patlisiso ee dumeletswe ke ba mmadikolo kwa Afrika Borwa (UNISA), le lephata la botsogo la Botswana. Godimo ga moo, ke filwe tetla ke ba kokelong ya Baylor go simolola tsheka-tsheko.

Ke kopa go go botsa dipotso mabapi le go tsaa/nwa melemo ga gago. Ke tla dirisa tape recorder. Ke tsile go lebele la mo faeleng ya gago ka fa o ntseng o dira/nwa melemo ka teng. Se se tsile go thusa badiri ba botsogo go tlhaloganya botuka gore ke eng bana ba ba fatlhogang ba sadire/nwa kgotsa ba dira/nwa diritibatsi. Se se tlaa thusa wena le babangwe fa re ka itse mabaka a.

Sepe se se kgobokantsweng mo tsheka-tshekong e, e tlaa nna sephiri. Maina le ditshupetso tsotlhe di tla seke di gatisiwe kgotsa di bonwe ke ope fela yo o sa letelelwang. Ga o patelesege go araba potso epe e o sa batleng go e araba gape o na le Tshwanelo ya go emisa tsheka-tsheko e nako ngwe le ngwe fa o batla. O tla bo o botsolotswa ntleng le motlhokomedi wagago, mme o na le tshwanelo ya go kopa gore a nne teng fa o botsolotswa.

Tsheka-tsheko e, ga e na go baya mo diphatseng dipe. Go ne ga tsewa kelelelo e kgolo go netefatsa gore go kgoberega maikutlo ga motsaa karolo mo tsheka-

tshekong e go ko tlase kana ga goyo.O gololesegile go bona ba ba sedilang maikutlo mo kokelwaneng ya Baylor fa go tlhokega.Potsoloso e e tlaa tsaya magareng ga metsotso ee masome mararo.

---

Leina la motsaa karolo

---

Baya Monwana

---

letsatsi

---

Leina la Mmotsolotsi

---

Baya Monwana

---

letsatsi

## **ANNEXURE 9: INTERVIEW GUIDE**

Thank you for taking time to meet with me today. My name is Tafireyi Marukutira and I would like to talk to you about your *experiences* taking ART. The interview should take about 30 minutes.

I will be tape recording the interview because I do not want to miss any of your important information and also because I cannot write fast enough to get everything you say. I will also be writing some notes. Please be sure to speak up because we are on tape and we do not want to miss anything

All your responses will be kept confidential; they will only be shared with the research team members. You do not have to talk about anything you don't want to and you may decide to end the interview at any time.

Are there any questions?

You are willing to take part in this interview and you have signed the assent form and your parents/ guardians have signed the consent form.

### **QUESTIONS FOR THE COMPLIANT CLIENT**

**1. For how long have you been on ART?**

*(The response to this question should be compared to the duration on the patient's record and if the client meets the criteria of '**must have been taking ART for at least 1 year**', then continue with the interview as follows*

***Our records show that you have been taking you treatment correctly and consistently as per doctor's prescription. Well done.***

- 2. How have you experienced taking ART for such a long time?**
- 3. What motivates you to continue taking your ART so consistently?  
What do you think helps you to take your ART correctly?**
- 4. What advice would you give to a friend who is struggling with adherence to treatment?**

5. ***What would you ask from the clinic or the government to help you maintain your levels of adherence to your medicines?***

**QUESTIONS FOR THE NON- COMPLIANT CLIENT**

- 1 ***For how long have you been on ART?***

*(The response to this question should be compared to the duration on the patient's record and if the client meets the criteria of '**must have been taking ART for at least 1 year**', then continue with the interview as follows*

***According to our records, you have not been taking your ART correctly and consistently as per doctor's prescription.***

2. ***How have you experienced taking ART for such a long time?***
3. ***Why don't take your ART according to the prescription?***
4. ***What do you think can be done to help you take your medicines correctly?***
4. ***What would you ask from the clinic or the government to help you take your medicines***

Is there anything you would like to add?

I will be analyzing the information you and others gave. I will be happy to share with you the report.

Thank you for your time, ke a leboga

## ANNEXURE 10: EMR LAYOUT

### EMR LAYOUT

This is how the home page for the Electronic Medical Records (EMR) looks like:



Username:

Password:

Then once you've logged in, it leads you to search for an existing patient by name or by using their CM numbers. OR it allows you to either create a new patient, or if you think the patient exists in the system, it allows you to list the entire database by searching the database:

[Create a new patient](#) | [Search for a patient](#) | [Bookings](#) | [Statistics](#) | [Account](#) | [Logout](#) **You are logged in as EDWIN MACHINE**

[debug info](#)

Search by one field below:

Chart Number:

Unique number:

First or last name:

[Create a new patient](#)



WHO Stage 3	<input type="checkbox"/> Unexplained moderate malnutrition	<input type="checkbox"/> Unexplained persistent diarrhoea	<input type="checkbox"/> Unexplained persistent fever
	<input type="checkbox"/> Persistent oral candidiasis	<input type="checkbox"/> Oral hairy leukoplakia	<input type="checkbox"/> Acute necrotizing ulcerative gingivitis/periodontitis
	<input type="checkbox"/> Lymph node TB (current)	<input type="checkbox"/> Pulmonary TB (current)	<input type="checkbox"/> Severe recurrent bacterial pneumonia
	<input type="checkbox"/> Symptomatic LIP	<input type="checkbox"/> Chronic lung disease including bronchiectasis	<input type="checkbox"/> Unexplained anaemia, neutropenia or chronic thrombocytopenia
	<input type="checkbox"/> Unexplained severe weight loss		
WHO Stage 4	<input type="checkbox"/> Unexplained severe wasting, stunting or severe malnutrition	<input type="checkbox"/> Pneumocystis pneumonia	<input type="checkbox"/> Recurrent severe bacterial infections
	<input type="checkbox"/> Chronic HSV infection	<input type="checkbox"/> Extrapulmonary TB	<input type="checkbox"/> Kaposi sarcoma
	<input type="checkbox"/> Oesophageal candidiasis	<input type="checkbox"/> CNS toxoplasmosis	<input type="checkbox"/> HIV encephalopathy
	<input type="checkbox"/> CMV infection	<input type="checkbox"/> Extrapulmonary cryptococcosis (including meningitis)	<input type="checkbox"/> Disseminated endemic mycosis
	<input type="checkbox"/> Chronic cryptosporidiosis (with diarrhoea)	<input type="checkbox"/> Chronic isosporiasis	<input type="checkbox"/> Disseminated non-tuberculous mycobacteria infection
	<input type="checkbox"/> Cerebral or B cell non-Hodgkin lymphoma	<input type="checkbox"/> Progressive multifocal leukoencephalopathy	<input type="checkbox"/> HIV-associated cardiomyopathy
	<input type="checkbox"/> HIV-associated nephropathy	<input type="checkbox"/> Acquired HIV-associated rectal fistula	<input type="checkbox"/> HIV wasting syndrome
	<input type="checkbox"/> Recurrent septicaemia	<input type="checkbox"/> Invasive cervical carcinoma	<input type="checkbox"/> Atypical disseminated leishmaniasis
	<input type="checkbox"/> Recurrent bacterial pneumonia		

**Assessment and Plan**

Details

New diagnoses / issues for followup

Nutritional Assessment: Within normal limits

WHO Stage: I

Are you changing the WHO Stage?  yes  no

**ANNEXURE 11: LETTER OF REQUEST OF THE ASSISTANCE OF THE  
PSYCHOLOGIST**



**BOTSWANA BAYLOR CHILDREN'S CLINICAL  
CENTRE OF EXCELLENCE**

Princess Marina Hospital • 1863 Hospital Way • P/Bag BR 129

Gaborone • Botswana

Tel 3190083 • Fax 3190079 • Website [www.baylorbotswana.org.bw](http://www.baylorbotswana.org.bw)



---

20 May 2011

Onkemetse Phoi  
Psychologist  
Baylor Clinic

**RE: REQUEST FOR AVAILABILITY DURING IN-DEPTH INTERVIEWS**

A request is hereby submitted to you asking for your availability during the conduct of in-depth interviews for my research project. The research is a qualitative research on factors influencing adherence in adolescents and in-depth interviews will be conducted. This is a minimal risk research but in the event of psychological instability during the conduct of the interviews, these research participants may be referred to you for further management.

The interviews are planned for mainly July and August 2011.

Thank you

**DR TAFIREYI MARUKUTIRA**

**ANNEXURE 12: APPROVAL LETTER: PSYCHOLOGIST**



**BOTSWANA BAYLOR CHILDREN'S CLINICAL  
CENTRE OF EXCELLENCE**  
Princess Marina Hospital • 1863 Hospital Way • P/Bag BR 129  
Gaborone • Botswana  
Tel 3190083 • Fax 3190079 • Website [www.baylorbotswana.org.bw](http://www.baylorbotswana.org.bw)



---


25 July 2011

Dr Marukutira

RE: REQUEST FOR AVAILABILITY DURING IN-DEPTH INTERVIEWS

Thank you for your letter and I would like to confirm that I will be available during the planned interviews.

Thank you

  
Onkemetse Phoi  
Clinical Psychologist

**ANNEXURE 13 : TRANSCRIPT**

AN EXAMPLE OF TRANSCRIPT

TRANSCRIPTIONS 1

18 yr old female

AHDERENCE CLASS: GOOD/ACCEPTABLE ADHERENCE)

Interviewer: Thank you for taking time to meet with me today. Good morning.

Interviewee: Morning

Interviewer: How are you today?

Interviewee: I am ok.

Interviewer: My name is Tafireyi Marukutira and I would like to talk to you about your experiences taking ART. The interview should take about 30 minutes.

Interviewee: Ok

Interviewer: I will be tape recording the interview because I do not want to miss any of your important information and also because I cannot write fast enough to get everything you say. I will also be writing some notes. Please be sure to speak up because we are on tape and we do not want to miss anything. Is that ok with you?

Interviewee: That's fine

Interviewer: All your responses will be kept confidential. This information will only be shared with the research team members. Is that ok?

Interviewee: Yes

Interviewer: And let me also tell that you do not have to talk about anything you don't want to and you may decide to end the interview at any time. Do you have

any questions so far?

Interviewee: No

Interviewer: Let me also remind that you agreed to participate in this study and you signed the assent form. However you are free to stop me from continuing at any time. And your caregiver signed for you to participate in this study. But all the same its still up to you. Is that ok with you?

Interviewee: Yes

Interviewer: Can we continue?

Interviewee: Yes

Interviewer: How long have you been on ART?

Interviewee: Umm, since 2004.

Interviewer; And how old are you now?

Interviewee: I was born in 1996

Interviewer: So that makes you 18 years this year?

Interviewee: Yes

Interviewer: So that means you were about 8 years when you started you ART?

Interviewee: ....ummm, yes.

Interviewer: Your clinic records show that so far you have been doing well with your medications, taking them as prescribed. That's good. 8 years taking your ART is a long time and yet you have done well, can you tell me how it has been for you over the years?

Interviewer: Aah, it's not easy....ah.

Interviewer: I understand that, can you share with me your experiences, how it has been like for you so far?

Interviewee: Ah, I think for me it's been difficult even though somehow I have managed. Ever since my parents died, my grandmother has had to take care of me. I have a sister who also helps me but my grandmother has really helped.

Interviewer: I am sorry to hear about your parents. Did that affect you?

Interviewee: I was very young then but I still remember. Then it was my grandmother that we were staying with.

Interviewer: How many siblings do you have?

Interviewee: 1

Interviewer: And that's your sister?

Interviewee: Yes

Interviewer: And how does your sister help you take meds?

Interviewee: Yes she does help me, she reminds me.

Interviewer: What has been the difficult part taking of taking your meds?

Interviewee: Having to wake up and make sure that I take my tablets before going to school. Sometimes I forget especially if my grandmother is not around.

Interviewer: What do you use to remind you?

Interviewee: My grandmother helps and I also have an alarm clock.

Interviewer: So with those two things how do you forget your morning doses?

Interviewee: Because....ah, my grandmother will wake me up and then even if my alarm clock rings, I will be so busy preparing to go to school as well...umm, so if I

don't take them immediately my grandmother tells me then sometimes I forget.

Interviewer: So even though you sometimes forget to take in the morning, you have done well. What helps you to take your medicines correctly?

Interviewee: I now have a trick, I take my medicines to school. So I always keep some tablets in my school bag.

Interviewer: That's clever of you. And how do you take them at school? Does anyone get to see you when you take them?

Interviewee: I just take them....ah. No one cares.

Interviewer: Have you told anyone at school that you take ART?

Interviewee: My friend and my guidance teacher knows.

Interviewer: What else helps you take your ART?

Interviewee: I think there is no cure for HIV and this is all there is....Unless if there is something now?

Interviewer: No, that's the best treatment so far. So what did you tell yourself what about ART?

Interviewee: Well, I told myself that if I don't take my tablets I will be sick.

Interviewer: Have you been sick before because you did not take your meds?

Interviewee: Yes.

Interviewer: What happened?

Interviewee: I don't remember but I was admitted mo Marina for some days. I remember those days I was not taking my ART

Interviewer: How old were you then?

Interviewee: I don't remember maybe 14?

Interviewer: And then what happened?

Interviewee: Then they changed my tablets and after that I always make sure I take my tablets.

Interviewer: How many tablets were you taking before they changed them?

Interviewee: 4

Interviewer: And now?

Interviewee; 6

Interviewer: That's a lot?

Interviewee; Yes but what can I do?

Interviewee; Well, I guess not much but I should congratulate you for taking that number of tablets every day. Is that what you take in the morning only?

Interviewee: 6 in the morning and another 6 in the evening.

Interviewer: What advice would you give if your friend was not doing well taking ART?

Interviewee: Ahh, I don't know.

#### ADVISE TO A FRIEND

Interviewer: If I ask you to talk to someone because you have done well with your ART what would you tell them?

Interviewee: Well, if they don't take ART they will be sick. Don't wait until you are sick. Like what happened to me.

#### ASSISTANCE FROM CLINIC/GOVERNMENT



Interviewee; And what would you ask the clinic or government to help you maintain your adherence?

Interviewee: Well, I don't know. There are many doctors here at the clinic and they are always changing.

Interviewer: So you want a few doctors?

Interviewee: I want my doctor....(laughing)

Interviewer: And would you ask anything from the government?

Interviewee: I don't know.

Interviewer: Thank you very much for your time. We are finished. Do you have any questions?

Interviewee; No

Interviewer: Is there anything you would like to add?

Interviewee: No

Interviewer: I will be analyzing the information you and others gave. I will be happy to share with you the report. Thank you for your time, ke a leboga