

**Adherence to antiretroviral therapy by adolescents in
Maseru: influencing factors and social work support**

by

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DECLARATION

I declare that ADHERENCE TO ANTIRETROVIRAL THERAPY BY ADOLESCENTS IN MASERU: INFLUENCING FACTORS AND SOCIAL WORK SUPPORT is my own work and and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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29 FEBRUARY 2016

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ABSTRACT

Adherence to long-term medications has remained a problem among adolescents worldwide. Antiretroviral therapy adherence is a wide-reaching challenge among HIV positive adolescents. The aim of this study is to explore and describe poor ART adherence among HIV positive adolescents in Maseru: influential factors and the need of social work support.

Qualitative approach was used, following an explorative, descriptive and contextual research design. The research was conducted at BCMCOE Lesotho. Data was collected by using semi-structured in-depth interviews and purposive sampling was applied to select a sample of adolescents who are HIV positive and who have poor adherence to ART. Data was analysed according to the framework provided by Tesch (in Creswell 2003). Guba's model (in Krefting 1991) was employed for data verification. Conclusions were drawn and recommendations were made about factors influencing adherence of adolescents to ART and support needed from social workers.

Key concepts

Adherence, anti-retroviral therapy, adherence counselling, adolescents, social work, support, HIV/AIDS

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CHAPTER 1

INTRODUCTION AND PROBLEM FORMULATION

This chapter presents the introduction of the study including the problem statement as well as the rationale for the study.

1.1 INTRODUCTION

The Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome (HIV/AIDS) is a global pandemic (Cohen, Hellmann, Levy, De Cock, Lange 2008:1244). The World Health Organisation (WHO) (2012:9) stated that since the beginning of HIV/AIDS epidemic, almost 70 million people have been infected with the virus and about 35 million of those infected had died of AIDS. Globally, 35.3 million of people (31.4-35.9 million) were living with HIV at the end of 2012 (WHO 2013:4). An estimate of 0.8% of adults aged 15-49 worldwide are living with HIV, although the burden of the epidemic continues to vary considerably between the countries and regions. Sub-Saharan Africa remains most severely affected, with nearly 1 in every 20 adults (4.9%) living with HIV (WHO, 2012:9). The Joint United Nations Programme on AIDS (UNAIDS 2010:35) estimated that over two million children under the age of 15 are living with HIV/AIDS worldwide, with about 80% of these children living in sub-Saharan Africa.

HIV/AIDS is a disease of the human immune system. It is caused by infection with the human immunodeficiency virus. The virus interferes with the immune system and it makes a person much more susceptible to infections, including opportunistic infections and tumors that do not usually affect people who have a working immune system (Sepkowitz 2001:1768). In a person's body there are many germs – bacteria, fungi and viruses (NACOSA 2013:40). The immune system controls these germs when it is working, but when the immune system is weakened by the HIV disease, these germs can get out of control and cause health problems. The opportunistic infections cause diseases like thrush that is fungal infection of the mouth, throat or vagina. A person can suffer from oral herpes (cold sores) or genital herpes. Pneumonia and tuberculosis are further examples of opportunistic infections. Tuberculosis is a bacterial infection that attacks the lungs and can cause meningitis (NACOSA 2013:40).

Genetic research indicates that HIV originated in West Africa during the early twentieth century (Sharp & Hahn 2011:1). HIV/AIDS has had a large impact on society, both as an

illness and as a source of discrimination. The disease also has a significant economic impact worldwide (Kallings 2008:335). HIV stigma and discrimination by family members and friends are the major causes of the deteriorating condition among people who are living with HIV (Biadgilign, Deribew, Amberbir & Deribe 2008:55). In a study conducted in Brazil, HIV stigma was characterised by the subjective feelings of embarrassment associated with social discrimination which affected young people's identity (Marukutira 2012: 18).

South Africa has the largest population of HIV-positive people of any country in the world at 5.9 million (UNICEF 2011:3). The first case of HIV/AIDS in Lesotho was reported in 1986 and since then, the epidemic had spread rapidly throughout the country's population. According to Nyanguru (2005:11), HIV/AIDS is changing the demographic structure of households and people are dying young.

Lesotho has the second highest prevalence rate of HIV/AIDS in the world, with approximately 23.1% of the population between 15-49 years of age infected with the disease (Elizabeth Glaser Pediatric AIDS Foundation 2014:1). The Ministry of Health (2014:20) stated that according to the latest statistics, there are about 363 526 orphans and vulnerable children (OVC) in Lesotho and more than 200 000 of the OVCs have lost parents due to HIV/AIDS. Over 38 000 of these OVCs are reported to be living with the disease.

The Lesotho government has taken concrete actions to address the HIV epidemic through the declaration of HIV/AIDS as a national disaster, development of the National AIDS Strategic Plan, and the establishment of the Lesotho AIDS Programme Coordinating Authority (LAPCA) under the Prime Minister's office (USAID 2005:29). The LAPCA which was introduced in 2001 for the purpose of coordinating the multi-sectoral response to HIV/AIDS, was hindered from fulfilling its strategic role by several factors, thus undermining its effectiveness and adversely affecting the national response (USAID 2005:29). In 2005, the Lesotho government passed the bill establishing the semi-autonomous National AIDS Commission (NAC) and National AIDS Secretariat (NAS) to coordinate and support the strategies (USAID 2005:29).

According to the Ministry of Health (2014:11), Lesotho's HIV epidemic continues to be fuelled by inter-relationships between both behavioural and structural drivers such as multiple and concurrent sexual partnerships, inadequate frequency of condom use across all sexually-active population groups, high rates of alcohol use, poverty and food insecurity and barriers to access to health care services.

In 2010, the Lesotho government approved some strategies that would be used to improve the prevention of transmission of HIV through sex. Those strategies are behavioural change communication (BCC), the male circumcision campaign, condom promotion and distribution and intervention for adolescents and youth, just to mention a few (Ministry of Health 2014:11). As part of the BCC strategy, multi-media materials were released which targeted adolescents. The Ministry of Health (2012:11) indicated that in 2011, the male circumcision campaign started and a policy was formulated which indicated the importance of both cultural and medical circumcision of males. Multi-sectoral partners came to the conclusion that the spread of HIV in Lesotho had increased due to inconsistent use of condoms by sexually active men and women. Condoms were not readily available in the communities, and condom distribution has been introduced to expand networking and to increase the reliability of condom supplies at every distribution point. The multi-sectoral partners targeted adolescents and youth both in and out of school with innovative and youth- driven HIV prevention interventions (Ministry of Health 2014:12).

The most important strategy to respond to HIV is the use of anti-retroviral therapies (ART). ARTs are medicines that are given to people who are infected by HIV to suppress the virus in their blood. Anti-retroviral therapy is the combination of three drugs which are used to suppress HIV and to prevent the virus from replicating into person's CD4¹ cells (Western Cape Government 2011:7).

Adherence to ART has been correlated strongly with HIV viral suppression, reduced rates of resistance to medication, an increase in survival and improved quality of life (Moore, Boyer & Safren 2011:135). In the absence of specific treatment, around half of those who are HIV-positive develop AIDS within 10 years (United States Department of Health and Human Services 2010:2). ART increases the person's CD4 cells and decreases the replication of HIV in the human cells. The benefits of HIV treatment include a decreased risk of progression to AIDS and a decreased risk of death (Vogel, Schwarze-Zander, Wasmuth, Spengler, Sauerbruch & Rockstroh 2010:508).

In the developing world, HIV treatment improves physical and mental health (Vogel, et al 2010:508). There is a 70% reduced risk of acquiring Tuberculosis when an infected person is on treatment (Beard, Feeley & Gosen 2009:1344). It is very important to be on HIV treatment because it also reduces the risk of transmission to sexual partners and decreases

¹ CD4 cells or T-helper cells are a type of white blood cell that fights infection. Their count indicates the stage of HIV or AIDS in a patient.

the chance of mother-to-child transmission (WHO 2010:19). The WHO (2010:20) points out that the effectiveness of treatment depends to a large extent on compliance. ART also reduces the risk of developing additional opportunistic infections.

Adherence to long-term therapy for chronic diseases is a worldwide problem; it severely compromises the effectiveness of treatment making this a critical issue both from the perspective of quality of life and health economics (Haynes, 2001:20). Adolescents often struggle to maintain adherence to chronic medications such as ART. According to Murphy, Belzer, Durako, Sarr, Wilson and Muenz (2005:36), a significantly smaller proportion of adolescents adhere well to ART compared to adults. Studies regarding poor adherence among adolescents were conducted in various countries such as Brazil, United States, Uganda, Zambia Kenya and Botswana. The studies conducted by Murphy et al (2001:37) and Nachega, Hislop, Nguyen, Dowdy, Chaisson, Regensberg, Cotton and Maartens (2009:66) compared ART adherence between adults and adolescents and the results showed that adherence of adolescents was lower than that of adults. According to Chesney (2006:S150), in the past few years, ART regimens have been greatly simplified. Although newer regimens include more fixed-dose combination products and offer once-daily dosing, adherence remains challenge especially among adolescents.

A study was conducted by Wagner and Ryan (2004:385) at chosen hospitals in Brazil which followed 120 adolescents who were on ART. The results showed that only 24% of those patients maintained good adherence with low viral loads over a period of 9 months. According to WHO (2003:7), adherence to long-term therapy for chronic illness in developed countries is 50%. The rates of adherence in developing countries are even lower (WHO 2003:7).

The ART medications are very expensive for governments to obtain and this impacts the economy worldwide. Wood (2012:10) stipulated that lower rates of adherence to medications increase health care costs, unnecessary hospitalisation, poor health conditions and deaths. Poor adherence to long-term therapy is caused by various factors. Belzer, Fuchs, Gallitt, Luftman and Tucker (1999:317) conducted a pilot study in a clinic for HIV-positive adolescents, between the ages of 12-19 years, who were on ART. They (adolescents) reported that factors associated with poor adherence included depression, pill burden, advanced HIV status, alcohol use and dropping out of school. The results also showed that only 39% of the adolescents complied well with treatment. The most common reason given by adolescents for not taking medication was that they had to take too many pills.

Research was also conducted in the USA in a clinic for chronic diseases. The results showed that people who have chronic diseases like diabetes, hypertension and HIV adhere poorly to medication because of side effects that are caused by the medications they are taking (Wood 2012: 201). Williams, Storm, Montepiedra, Nichols, Kammerer, Sirois, Farley and Malee (2006:e1748) found in their study on predictors of adherence to ART in children and adolescents who are living with HIV, the worst adherence levels were among the older adolescents aged 15-18, while Murphy et al (2005:768) found that the younger age group was associated with poorer adherence in their study. Therefore, demographic factors such as age and gender were concluded to be inconsistent in predicting adherence in adolescents.

A study was conducted by Marukutira (2012:70) at Botswana-Baylor Children's Clinical Centre of Excellence on factors influencing adherence to antiretroviral therapy in Botswana. The results showed that adolescents face major challenges in adhering to ART. According to Marukutira (2012:16), there are many factors that influence poor adherence among adolescents. Such factors are demographic factors, psycho-social factors and medication-related factors. Marukutira (2012:70) stated that adolescents need support from family, friends and society at large to improve adherence. Marukutira (2012:70) claimed that in Botswana stressful life situations such as the loss of a parent have a negative impact on adherence to ART by adolescents. Depression, anxiety as well as bereavement also play a role in influencing adherence to ART by adolescents (Marukutira 2012:70). Stigma and discrimination were evident in adolescents who preferred to keep their HIV status "secret" from school teachers and friends and they needed psycho-social support (Marukutira 2012:70).

School-aged children often develop the capacity to understand concepts of the illness and the need for treatment; however, they are often unaware of their infection (Wasti, Van Teijlingen, Simkhada, Randall & Baxter 2011:71). It was found that these children (adolescents) typically want to fit in with their peers and may wonder why they are taking medicine every day while other children are not (Wasti et al 2011:71). This implies that another factor that affects proper ART adherence is non-disclosure of HIV status to adolescents by caregivers. It is also noteworthy that HIV infection rates are still arising among adolescents (Sethi, Celentano, Gange, Moore & Gallant 2003:1114).

Developing countries are faced with different challenges for achieving and maintaining ART adherence as they scale up paediatric ART programs (WHO, 2008: 2272). The main goal of ART is to suppress the human immunodeficiency virus (HIV) replication sustainably.

Marukutira (2012:1) stated that “ART is administered in the form of highly active antiretroviral therapy (HAART), which is a combination of at least three different class drugs”. Lack of adherence to ART is one of the main causes for treatment failure worldwide and one of the main concerns when providing ART to developing countries (Filho, Nogueira, Machado, Abreu de Oliveira, Evangelista & Hofer 2008:1). Inadequate adherence to treatment is associated with detectable viral loads, declining CD4 counts, disease progression, episodes of opportunistic infections and poor health outcomes (Ugwu & Eneh 2012:13).

Making ART available to people living with HIV is not enough, as strict adherence is required for treatment success (Stevens, Kaye & Corrah 2004:280). Poor adherence can lead to treatment failure and the spread of multi-drug resistant forms of virus, resulting in a public health calamity. High levels of adherence to ART are required in order to achieve the benefits of HAART (Ding, Wilson, Modjarrad, McGwin, Tang & Vermund 2009: 1101). Several studies that were conducted globally indicate that adolescents face many challenges when it comes to compliance with chronic medication regimes. Though yet to be evaluated in research, adolescents’ developmental factors are believed to affect adherence. They may be easily distracted by issues of daily life.

The goal of this study is to determine factors influencing ART adherence by adolescents in Maseru and to explore and describe how social workers can support adolescents to improve ART adherence. Nachega, et al (2009:67) implied that research in this area can be of help to design guidelines and intervention strategies for the targeted group to achieve or maintain high adherence rates. The research problem is discussed below.

1.2 STATEMENT OF THE PROBLEM

Adherence is the key to success of ART programmes and the survival of HIV-infected people but it appears that poor adherence to ART is a serious problem among HIV-positive adolescents (Nachega et al 2009:66). Strict adherence to treatment instructions is critical in order to achieve effective treatment and realise the benefits of ART (WHO 2004:11). Worldwide, regardless of the illness or treatment, many people do not take their medication correctly (Wood 2012:202; Murphy et al 2001:27). The lower rate of ART adherence by adolescents underscores the urgent need to identify risk factors which contribute to poor adherence in sub-Saharan Africa (Nachega et al 2009:67). This study builds on the research of Marukutira (2012) which was conducted in the medical field within Botswana. The researcher explores and describes factors influencing adherence to ART by adolescents in Maseru, Lesotho, and the support adolescents need from social workers in order to improve adherence to ART.

Baylor College of Medicine Center of Excellence (BCMCOE) is an out-patient clinic for HIV-positive children and their families as well as pregnant women who are HIV-positive in Maseru, Lesotho. This clinic cares for over 8758 exposed and HIV-positive children. More than 2500 of them are on ART. The total number of adolescents is 863 of whom 775 are on ART. Some of the adolescents face major challenges in regard to adherence to ART. Adherence is calculated through pill counts; this is checked as every patient has to submit his/her medication to be calculated before s/he can get a refill. Adherence that is below 95% is regarded as poor response to treatment (Reisner, Mimiaga, Skeer, Perkovich, Jonson & Safren 2009:14). This study focuses on adherence to ART by adolescents in BCMOCE Maseru, Lesotho.

The researcher was involved in a Teen Club (the psycho-social support group of adolescents who are Baylor patients) and worked as an educator at the clinic, using the cognitive behavioural therapy (CBT). Most of the cases that were referred to the researcher concerning adolescents were related to poor adherence to ART. From the researcher's practice observation, most of adolescents who are living with HIV and who are on ART, do not comply with treatment specifications which negatively influences their chances of successful treatment and living a functional and quality life.

The problem investigated in this study can thus be formulated as follows:

There is a gap in knowledge of factors that influence poor ART adherence by adolescents in BCMCOE, Maseru, and how social workers could help them to improve ART adherence for the betterment of adolescents' lives. The following paragraphs discuss the rationale for this study.

1.3 RATIONALE FOR THE STUDY

This study provides information on adherence to ART among adolescents in Maseru, it explores and describes the influential factors and the support needed from social workers to improve ART adherence among adolescents. The researcher is a social worker who worked at the BCMCOE, Maseru in Lesotho for approximately six years. Among the services that the researcher provided as a social worker at Baylor, was adherence counselling.

Adherence counselling can be described as the establishment of a relationship of confidence from the outset between the patient and the care team (WHO 2001:36). Adherence counselling takes place in one-on-one sessions which are provided to a client who is about to be initiated on ART. In adherence counselling, the patient is expected to attend sessions in which information will be given that include: definition of HIV/AIDS, its transmission

modes, prevention, care and treatment. The barriers that may challenge adherence are assessed and addressed. A social worker does readiness assessment of a client before s/he recommends the client be introduced to ART. Adequate time should be set aside for the counselling so that appropriate and informed decisions on therapy and its implications are made by the patient, based on the information given to him/ her that is accurate and as complete as possible (WHO 2001:36). Counselling is provided to a person who starts ART or already taking ART to assist them to make sound choices that support their treatment and enable them to adhere to medication (Saloner 2005:12). Adherence counselling is provided only by a person who had been trained in HIV/AIDS counselling skills (Saloner 2005:12). People living with HIV need psychosocial support (WHO 2001:36), which is usually rendered by a social worker in the medical team. A social worker, as a psychosocial supporter, uses group work in teen clubs and camps as a contribution to the improvement of adherence by adolescents.

The researcher could not find the literature on adherence to ART by adolescents who are HIV-positive in Lesotho; this implies that this is the first study which is conducted to explore and describe factors influencing ART adherence by adolescents in Lesotho. The findings of the study are useful to health-care providers and policy makers for planning interventions and effective strategies for maximising long-term adherence to ART for successful treatment of HIV and AIDS. The knowledge of factors influencing adherence to ART in adolescents will assist in ensuring that programmes for adolescents include measures to improve adherence to ART treatment. The health-care workers will be in a better position to deal with adolescents once they understand the factors that promote or hinder adherence to ART (Marukutira 2012:4). The social workers, as part of a multi-professional team, will be able to provide psycho-social support basing their interventions on the findings of this study.

1.4 THEORETICAL FRAMEWORK

Theory can be defined as an objective, educated guess about a set of assumptions (Babbie [sa]: 1). On the other hand, Creswell (2014:86) theory is “a set of constructs interrelated and formed into propositions or hypotheses to specify a relationship among variables”. In qualitative research, theory is used as a broad explanation for behaviour and attitudes (Creswell 2014:98). According to Swanson (2013:1), theoretical framework is “the structure that can hold or support a theory of a research study. It introduces and describes the theory that explains why the research problem under study exists”. A theoretical framework is defined by Imenda (2014:189) as a set of concepts which are drawn from the same theory for an explanation of an event, or to shed some light on a particular phenomenon.

The systems theory points out that the whole of a system is greater than the sum of its parts and stresses the need to assess the interconnection and interdependence of systems and how these interactions feed into the presenting problem (Barbra 2014:36). The goal of systems theory is to intervene in one or more systems to alleviate the presenting problem and return the client to a state of equilibrium (Barbra 2014:36). On the other hand, Leighninger (2014:452) indicates that the most appealing aspect of systems theory is the encouragement to look at things as a whole. It allows the user to relate micro-social problems to macro-social forces.

The researcher applied family system theory in this study to gain knowledge of how the whole family is affected by living with an adolescent who is HIV-positive and is on ART treatment. The main purpose of family systems theory is to provide the “understanding and interpretation of the cognitive, social and emotional functioning of individuals in the society” (Dore 2008:435). Family systems theory emphasises that family should be treated as a whole when treating a deviant family member (Taylor-Sutphin, McDonough & Schrenkel 2013:503). The researcher interviewed adolescents as well as their guardians in order to gather more information on factors influencing ART adherence by adolescents in Maseru. When family systems theory is applied in a particular family, individual family members are viewed in the context of the whole family and the focus remains on the relationships between family members (Taylor-Sutphin et al 2013:503).

The use of systems theory is applicable to this study, as it allows the researcher to focus on understanding adolescents and their systems (families) and how these systems are influenced and affected by other systems (communities, schools, churches) in the environment. The researcher chose systems theory because it enables the user to widen his/ her views of the client’s problem and many other systems that could be contributing to the problem (Barbra 2014:23). Systems theory allowed the researcher to explore and describe the interaction between various factors contributing to sub-optimal ART adherence by adolescents in Maseru.

1.5 RESEARCH QUESTIONS, GOALS AND OBJECTIVES

Research questions, goals and objectives of the study will be discussed thoroughly below.

1.5.1 Research Questions

Creswell (2008:129) stipulated that, in qualitative research, the intent is to explore the complex set of factors surrounding the central phenomenon and present the varied perspectives or meanings that participants hold. Boeije (2010:24), on the other hand,

describes the research question as the central question which the researcher wants to answer by conducting the research project. According to Maxwell (2005:258), research questions in qualitative study serve several purposes: they help to focus the study, they offer some guidance on how to conduct the study and they shape the research design. The researcher used the above definitions to guide the formulation of the research questions.

To shape the research design in qualitative research, questions can be exploratory (those that investigate a phenomenon that is little understood), explanatory (those that explain a phenomenon), descriptive (those that seek to describe a phenomenon) and emancipatory (those that are meant to engage in social action around a phenomenon) (Marshall & Rossman 2006:142). In this study, the research questions were exploratory and descriptive.

The research questions which guided this study were:

- What are the factors influencing adherence to antiretroviral therapy by adolescents in Maseru?
- What social work support is needed to improve adherence to antiretroviral therapy by adolescents in Maseru?

The researcher had a dream of what she wanted to achieve by conducting the study. For the dream to be fulfilled, the researcher had to set the goals and the objectives of the study, which are discussed below.

1.5.2 Goals and Objectives of the Study

A research goal can be defined as a broad statement of desired outcomes or the general intentions of the study. It is the overall purpose of the study Varkevesser, Pathmanathan and Brownlee (2003:9). The research goal is more specific and reflects more precisely what the research wants to find out. Objectives are defined as the steps that a researcher should take in order to accomplish the goals of a study (Varkevesser et al 2003:9). The objectives of the research project summarise what should be achieved by the study. A goal is a dream and the objectives are to do lists of steps that should be followed and are clearly stipulated in order to achieve the goal.

The goals of this study were:

- To develop an in-depth understanding of the factors influencing adherence to antiretroviral therapy by adolescents in Maseru.

- To develop an in-depth understanding of social work support needed to improve adherence.

In order to attain the aforesaid goals of the study, the following objectives were formulated:

- To obtain a sample of adolescents in Maseru with poor adherence to ART
- To conduct semi-structured interviews to explore factors influencing adherence to ART by adolescents in Maseru as well as social work support needed to improve adherence.
- To sift, sort and analyse data using Tesch's eight steps for qualitative data analysis as cited in Creswell (2003:192).
- To describe factors influencing adherence to ART by adolescents in Maseru
- To draw conclusions about factors influencing adherence to ART by adolescents in Maseru as well as social work support needed to improve adherence.
- To make recommendations about what can be done to improve the adherence to ART by adolescents in Maseru.

The next paragraph focuses on a brief discussion of research methodology.

1.6 RESEARCH METHODOLOGY

A brief discussion on research methodology that the researcher planned to use in this research is provided in this section. A detailed discussion of the methodology and how it was applied is described in chapter 2. According to Kumar (2008:5), a research method is "a systematic way to solve the research problem". Camarinha-Matos (2012:3) stated that research methodology refers to the rationale and philosophical assumptions that underlie a particular study. The common research methodologies are quantitative, qualitative and mixed methods. This study adopted a qualitative approach as the researcher was more interested in experiences of adolescents who were undergoing life-long treatment; she was not interested in testing a hypothesis on this phenomenon.

1.6.1 Qualitative Approach

Using the qualitative approach, a researcher seeks to establish the meaning of a phenomenon from the views of participants (Creswell 2008:16). The researcher's aim is to understand how people make sense of their world and experiences they have in the world (Merriam 2009:13). Bryman (2012:392) indicated that the qualitative approach often provides significant amounts of descriptive detail which allows for the contextual understanding of social interactions, whereby social behaviour can be understood in terms of the environment in which it operates.

Various characteristics of the qualitative research paradigm have been defined by different authors such as Sargeant (2012:3), Creswell (2009:175-6), Kellydubose (2010:1), Brooker (2013:5) and Denzin and Lincoln (2011:3). The following are elements that characterise qualitative approach:

- Qualitative research is conducted in a natural setting: qualitative research emphasises a holistic approach, it is the detailed recording processes occurring in the natural setting that provides the basis for understanding the setting, the participants and their interactions. In this study, the research was conducted in the field and that allowed direct interaction between the researcher and people who were being studied in their context.
- Qualitative researchers are seen as primary instruments for data collection and analysis: the researcher collected data herself, semi-structured interviews were used as the data collection tool and an interview guide was used as an instrument to collect data.
- Qualitative data are descriptive: data in the form of interview notes, recordings and field notes are the basis for analysis and interpretation. During the interviews, participants were interviewed and were recorded; the researcher also took field notes.
- Qualitative data are analysed inductively: patterns and relationships are developed from collecting or observing multiple specific instances. As the data are analysed, the researcher often builds patterns, categories and themes from the bottom up. The researcher and an independent coder during data analysis developed themes, sub-themes, categories and sub-categories that emerged from the data.
- Interpretive inquiry: the researcher interprets what is seen, heard and understood. The researcher interpreted what she heard and understood from the participants and their reactions and gestures towards the questions were also interpreted.
- Complex picture: the researcher tries to develop a complex picture of the problem or issue by reporting multiple perspectives and identifying multiple factors involved. In this study, the researcher tried to develop a complex picture by identifying various factors that influence ART adherence by adolescents.

The above-mentioned characteristics of qualitative research motivated the researcher to conduct qualitative research to investigate factors which influence ART adherence by adolescents in Maseru. In the following section, the research design is briefly discussed.

1.6.2 Research Design

A research design is defined by Polit and Beck (2012:222) as “the basic strategies that the researchers adopt to answer their questions”. It is a logical structure of inquiry. According to Boeije (2010:19), a research design refers to the overall approach that should be followed

when the study is conducted, the plan should indicate the participants will be and clarify the location where the study will be conducted. Research design, according to Moniz (2010:10), is a “specification of methods and procedures for collecting, analyzing and interpreting the data”.

In planning this study, the researcher formulated research questions, goals and objectives of the study. The researcher clarified the importance of conducting this research study. Participants who were considered appropriate to participate in the study were identified. Data collection methods were indicated. The researcher stated how data will be analysed and verified. An explorative, descriptive and contextual research design was adopted.

1.6.2.1 Exploratory research design

Exploratory research seeks to explore what is happening and to ask questions about it. This kind of study is particularly useful when little is known about the phenomenon and when the research purpose and questions are uncertain (Gray 2014:36; Creswell 2013:18). The researcher uses an exploratory design in order to familiarise himself/ herself with the research topic (Babbie 2013:94).

The researcher in this study chose to employ an exploratory design in order to satisfy her curiosity and desire for better understanding of factors influencing ART adherence by adolescents in Maseru and how social work support may help them improve adherence.

1.6.2.2 Descriptive research design

A descriptive research design seeks to provide a picture of what is happening to the poorly-understood phenomena which do not lend themselves readily to quantification (Dadoniene, Zagminas & Berzanskyte 2013:38). The purpose of a descriptive study is a comprehensive summary of specific events experienced by individuals or group of individuals (Toury 2012:16). The key elements of descriptive studies are place, time and group of people (Dadoniene et al 2013:30).

A descriptive study is used to describe variables rather than to test a predicted relationship between variables (Creswell 2013:18). The researcher employed a descriptive design in order to describe in-depth the factors influencing ART adherence by adolescents and how social workers may help them to improve adherence. In the present study, a descriptive design was appropriate because an accurate and authentic description of the experience of adolescents who were on a life-long treatment was required.

1.6.2.3 Contextual research design

According to Holtzblatt and Beyer (2011:1), a contextual research design is a “structured, well defined user-centred design process that provides methods to collect data about users in the field, interpret and consolidate that data in a structured way, use the data to create and prototype product and service concepts and iteratively test and refine those concepts with users”. The key element of a contextual design is that in order for a researcher to understand participants’ lives or behaviour, s/he must go to their environment where they live and talk with them.

Contextual inquiry is used to capture detailed information about people in their natural setting. The researcher chose to use a contextual design in order to explore how participants interacted and behaved when they were in the environment from which they obtained their medication and where social workers were working as it was believed that participants’ behaviour may be influenced by their environment. In this study, BCMCOE Maseru was the context in which study was conducted. The following paragraph focuses briefly on the research method that was used in this study.

1.6.3 Research Method

Research methods set out the logical process that should be followed during the application of methods and techniques when a particular phenomenon is investigated (Polit & Beck 2006:15). According to Creswell (2009: 15), the research method refers to the forms of data collection, analysis and interpretation that the researcher has proposed to use for the study.

The following are discussed under this sub-heading:

- Population, sampling and sampling techniques.
- Methods of data collection, data analysis and data verification.

1.6.3.1 Population, sampling, and sampling techniques

Population is an entire group of elements or individuals about whom some information is required to be ascertained (Banerjee, Janaki, Chakrabarta & Chaudhury 2012:61). A research population can be defined as a large collection of individuals or objects that is the main focus of a scientific query. It can also be defined as collection of individuals who have common characteristics (Castillo 2009:231). According to the researcher's point of view, the study population is a group of individuals who have similar characteristics and who live in a particular geographical area. Samples were drawn from the population. A sample is a subset of the population selected, the sample must not be biased and must be representative of the larger population (Suresh, Thomas & Suresh 2011: 288). The goal of sampling is to

ensure that the sample group represents the entire population without errors. The purposive sampling technique was used to select sample. The purposive sampling technique is the deliberate choice of informants due to the qualities they possess (Tongco 2007: 147). The decision concerning individuals who should be included in the sample is taken by the researcher. The decisions are based on variety of criteria which may include knowledge and experiences of individuals (Tongco 2007: 147). Sample size is determined by data saturation within the qualitative paradigm.

The researcher planned to consult two populations during the study. The first was HIV-positive adolescents who were attending clinic at BCMCOE in Maseru. Adolescents who were chosen to participate in the study were those who knew their HIV status and who were struggling with optimal ART adherence.

The inclusion criteria for a sample from the first population were as follows:

- adolescents who were between the ages of 12-19 years;
- adolescents who received ART from the BCMCOE Maseru, Lesotho;
- adolescents who did not adhere to treatment (skipping medication more than once a week and those whose adherence was below 95% according to the pill count);
- adolescents who were aware of their HIV status;
- adolescents who were willing to participate; and
- adolescents whose caregivers had given permission.

The exclusion criteria for the sample from the first population were as follows:

- adolescents who were former clients of the researcher;
- adolescents who did not know their HIV status;
- adolescents who had good ART adherence;
- adolescents whose caregivers did not consent to participate in the study;
- adolescents who had not started taking ART; and
- adolescents who were younger than 12 years or older than 19 years.

The second population was the guardians of the adolescents who participated in the study. This group of people was chosen because the researcher believed that the guardians might give a different perspective on why their adolescents defaulted in adherence to ART.

The inclusion criteria for the sample from the second population were as follows:

- the guardians of the adolescents who were willing to participate.

The exclusion criteria for the sample from the second population were as follows:

- guardians who were former clients of the researcher;
- guardians who did not give consent; and
- guardians whose adolescents were younger than 12 years or older than 19 years.

1.6.3.2 Data collection

Data collection can be defined as planning for and obtaining useful information for a research project (Business Dictionary 2007: sv data collection). For the data to be collected, the researcher must first identify the key quality characteristics that s/he needs to measure, how they will be measured and what will be done with the collected data (Business Dictionary 2007: sv data collection). In the next paragraph, the researcher discusses the preparations that were made for data collection.

a. Preparation for data collection

The researcher obtained entrance to the institution by writing a request letter to the management and the Institutional Review Board (IRB) of BCMCOE Maseru for the permission to conduct the study at the clinic (see Appendix 4). The researcher planned to conduct the research interviews in English but the clinic management made her aware that the interviews should be conducted in Sesotho as the participants were not fluent in English.

She requested the names of adolescents who have poor ART adherence from the medical staff (doctors, nurses and social workers) of the clinic. The researcher then contacted the guardians of these adolescents and met the adolescents and their guardians at BCMCOE Maseru and the research topic was explained. Participants were requested to sign consent forms (see Appendix 2 and 3). By signing the consent forms, the participants indicated their voluntary agreement to participate in the research study (Albala, Doyle & Appelbaum 2010:7). Data was collected by the researcher and adolescents and guardians were interviewed separately.

b. Pilot study

A pilot study is defined by Leon, Davis and Kraemer (2011:626) as “a requisite initial step in exploring a novel intervention or innovative application of an interaction”. Its results can inform feasibility and identify modifications which are needed in the design of a larger presumed study (Leon et al 2011:626). A pilot study is conducted with the purpose to examine the feasibility of an approach that is intended to be used in a larger scale study.

The researcher conducted a pilot study in order to see if questions were clear enough for participants to be able to answer them and to test if the questions would help the researcher to answer the research question.

c. Methods of data collection

Data collection methods which are commonly used in qualitative research are individual or group interviews (including focus groups), observation and document review (Sargeant, 2012:1). It is essential to select the most appropriate method of data collection in order to ensure the credibility of data analysis (Graneheim & Lundman 2004:105). In-depth interviews were used as the method of data collection in this study. An in-depth interview is typically a one-on-one interaction between the researcher and participant (DiCicco-Bloom & Crabtree 2006: 314). Interviews are important in qualitative research because they allow for the exploration of individual experiences and perceptions in great detail (DiCicco-Bloom & Crabtree 2006:314; Bradley, Curry, Ramanadhan, Rowe, Nembhard & Krumholz 2009:1445). Bradley et al (2009: 1445) indicated that an in-depth interview allows the participant to give direction to the course of discussion as much as possible, thus allowing the participants to identify and describe concerns or concepts that may not have been anticipated or considered by the researcher. The researcher used in-depth interviews as she conducted face-to-face interviews with the participants, sharing their unique experiences of the use of ART.

Semi-structured interviews were used to collect data in this study and an interview guide was used as an instrument for data collection. The researcher used semi-structured interviews because they are flexible; questions may not follow on exactly as they are outlined in an interview guide (David & Sutton 2004:87). Open-ended questions were used in this study during the interviews. The importance of open-ended questions is that participants' responses are rich and explanatory in nature and the answers are not channelled as they are in closed ended questions (Gray 2004:217). The interviews were recorded and field notes were taken during interviews. Two interview guides were formulated, one for interviews with adolescents and another for interviews with the guardians (Appendix 2 & 3):

Interview guide for the interviews with adolescents

1. General information
 - (a) How old are you?
 - (b) Are you a male [] or a female []
2. Antiretroviral therapy
 - (a) According to your understanding what is ART?

- (b) How long have you been taking ART?
- (c) What are the reasons for you to take ART?
- (d) How were you prepared to take medication (ART)?
- (e) What happens when you do not take the medication (ART)?
- (f) What helps you to take the medication?
- (g) What makes it difficult for you to take the medication (ART)?
- (h) How do you feel about taking medication?
- (i) What support are you receiving to assist you to take the medication (ART)?
- (j) What support can a social worker give you to assist you to take the medication every day e.g. individual counselling, group counselling, other support?

Interview guide for the interviews with guardians

1. General information

- (a) How old are you?
- (b) Are you a male ☐ or a female ☐

2. Antiretroviral therapy

- (a) According to your understanding what is ART?
- (b) How long has the adolescent you are caring for been on ART?
- (c) What are the reasons for your adolescent to take the medication (ART)?
- (d) How were you prepared to give your adolescent medication (ART)?
- (e) What makes it difficult for your adolescent to take medication (ART)?
- (f) What can help your adolescent to take medication (ART)?
- (g) Do you always supervise your adolescent when s/he takes her/his medication (ART)?
- (h) Who else supervise him/her to take medication when you are not around?
- (i) What support has you or your adolescent received to assist him/her to take the medication (ART)?
- (j) What support can a social worker give you to assist the adolescent under your care to take medication every day e.g. individual counselling, group counselling, other support?

Although it wasn't planned initially, the researcher interviewed six health care professionals (one doctor, two nurses, two social workers and one pharmacy technician). This was done to further enrich the data. The following questions guided these interviews:

- (a) What is the adolescents' understanding of ART?
- (b) How are the adolescents being prepared to take ART?
- (c) What are the difficulties that the adolescents experience in taking medication?
- (d) What kind of support do health care professionals provide to adolescents who are on ART?

(e) What do you think are the factors that influence ART adherence by adolescents in Maseru?

The following paragraph discusses methods which were used in the study for data analysis.

1.6.3.3 Methods of data analysis

Qualitative data analysis is the process whereby the mass of words which were generated by interviews or observational data needs to be described and summarised (Lacey & Luff 2009:6). Data analysis is defined by Lodico, Spaulding and Voegtle (2010:301) as “an inductive process, that is, numerous small pieces of data are collected and gradually combined or related to a broader, more general descriptions and conclusions”.

The data were collected and were categorised into themes according to their shared commonality and according to Tesch’s (1990) framework (as cited in Creswell 2003:192), which includes the eight steps for data analysis. The researcher:

- Read all the transcribed interviews and field notes to make sense of what participants said, paying attention to the meaning and general impression of all the participants.
- Decided on one interview (the most appealing), keeping in mind its fundamental meaning and summarised the whole meaning by writing comments in the margin.
- Compiled the list with all the topics identified. Similar topics were grouped together into columns and were arranged as major topics, unique topics and leftover topics.
- The compiled list of topics was re-checked with the data collected by the researcher. The topics were abbreviated as codes, and these codes were written next to the appropriate sections of the text. This provided the opportunity to see if new categories emerged.
- Identified descriptive words for topics and to reduce the total list, clustered related topics together.
- The abbreviations for each topic were used and the codes were placed in alphabetical order.
- Related data in each category was assembled in one area to perform a preliminary analysis.
- The existing data was recoded.

The next paragraph discusses data verification briefly.

1.6.3.4 Data verification

The advantage of qualitative research lies in the richness of the collected data which need to be interpreted and coded in a valid and reliable way (Moretti, van Vliet, Bensing, Deledda, Mazzi, Rimondini, Zimmermann & Fletcher 2011:420). Verification strategies are very important in qualitative research because they help the researcher to identify when to continue researching, stop or modify the research process in order to achieve the validity and reliability and ensure rigor (Morse, Barrett, Mayan, Olson, & Spiers 2002:10).

Guba and Lincoln (1994) as cited in Shenton (2004:63), proposed four criteria for data verification within qualitative research, which are credibility, transferability, dependability and conformability.

Table 1.1: Guba's model of trustworthiness

Traditional criteria for judging quantitative research	Alternative criteria for judging qualitative research
Internal validity	Credibility
External validity	Transferability
Reliability	Dependability
Objectivity	Conformability

Source: (Shenton 2004:63)

Table 1.1 above shows the four criteria that were adopted and used by the researcher for pursuing a trustworthy study which corresponds to the criteria used by the quantitative researchers (Shenton 2004:63). The researcher used Guba's model to verify data. In this section, the researcher discusses what is understood by these criteria and how she planned to use them in her study. In Chapter 2, she describes how she applied the criteria.

Credibility: This concept replaces the idea of internal validity in quantitative research. In this concept, Guba and Lincoln focussed on the degree to which the findings make sense. They recommended that the researcher should give participants their interview transcripts to read though and the research reports so that they can agree/ disagree with the researcher's findings (Tobin & Begley 2004:390).

Credibility involves establishing that the research results are credible or believable from the perspective of the participant in the research (Trochim 2006:7). The purpose of using this criterion in this study was to understand adherence among adolescents and their life experiences of being on lifelong treatment.

True-value establishes how confident the researcher is with the truth of the findings based on the research design, participants and the context. The following measures were planned by the researcher to promote confidence in the research findings related to the phenomena under scrutiny:

- Triangulation of the data: By interviewing participants from both populations (adolescents and guardians) individual viewpoints and experiences could be verified against others and the rich picture of the attitudes, needs or behaviours of adolescents with poor adherence could be constructed based on the contributions of a range of people (Shenton 2004:66).
- Tactics to help ensure honesty in informants when contributing data: This can be done by giving participants the opportunity to choose to participate or not, in order to ensure that the data collection sessions involved only those who were genuinely willing to participate in the study (Shenton 2004:66).
- Background, qualifications and experiences of the researcher increases a credibility of a study.

Transferability: The aim of transferability is to provide enough information to the readers so that they can be able to judge if the findings can be applicable to other settings (Tobin & Begley 2004:391). A research study complies with the criterion when a detailed description of research methods is provided.

Dependability: This concept is concerned with whether the researcher would obtain the same results if s/he could observe the same thing twice (Trochim 2006:7). The researcher is responsible for ensuring that the process of research is logical, traceable and clearly documented (Schwandt 2001:32).

Confirmability: This concept is concerned with establishing that data and interpretations of the findings are not figments of the researcher's imagination, but they are clearly derived from the data (Tobin & Begley 2004:391). It was stipulated by Shenton (2004:72) that steps must be taken to ensure that the research findings are the results of the experiences and ideas of the participants not the preferences and characteristics of the researcher.

1.7 ETHICAL CONSIDERATIONS

In any research study, participants must be protected. Fouka and Mantzorou (2011:1) pointed out that "research ethics involve requirements on daily work, the protection of dignity

of subjects and the publication of the information in the research". It is the researchers' responsibility to consider whether any type of harm could occur when they plan their research and to ensure that mechanisms are instituted to avoid it (Polonski 2004:53). The following ethical principles are discussed: informed consent, anonymity and confidentiality, avoiding harm/ beneficence and debriefing.

1.7.1 Informed Consent

Informed consent can be described as "the invisible act of evaluating information and making a decision, and visible act of signifying the decision" (Anderson & Morrow 2011:101). On the other hand, WHO (2013:21) clarified that informed consent involves "informing potential participants, through document and discussion, of the purpose, procedures, risks, potential benefits, voluntary nature of the proposed research and documenting the participant's agreement". Informed consent is a process of three interactions namely: the researcher provides information to participants; participants are given information in a way that they clearly understand it, and then participants respond to it (Cocks 2006:265).

The purpose of the research, the benefits and risks of it were clearly discussed with participants in this study. They were told that participation was voluntary and that they could withdraw from the study at any time. The researcher provided participants with the information about the research project; the information was clear and understandable. They were able to make an informed and voluntary decision about whether they wanted to participate or not (Jupp 2006:43). The information letter and consent forms were given to adolescents and guardians (see Appendix 2 & 3) to be signed as the agreement of voluntary participation.

1.7.2 Anonymity and Confidentiality

Anonymity is a process of not disclosing the identity of research participants. Confidentiality is the process of not disclosing to other parties the opinions or information gathered in the research process (Clark 2006:4). According to Polonski (2004:60), anonymity means that the researcher does not know the participants and confidentiality means that participants are known but their identity would not be revealed in any way in the report. Whelan (2007:2) indicated that anonymity is the degree to which identifying information is not shared by the participant; therefore, the information shared cannot be traced back to the participant. Confidentiality pertains to "the treatment of information that an individual has disclosed in a relationship with a trust and the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure without permission" (WHO 2013:25).

The researcher was sensitive to the information obtained from minors and vulnerable people as is suggested by Polonski (2004:61). The researcher took precautions to protect confidentiality of participants' data by removing the identifying information from the study findings. The researcher did not reveal the identifying information about the individual in written or verbal communication (Aurelius 2011:78). Codes were used when the transcripts were made; this was done so that not even the independent coder could know the identity of participants.

It is our responsibility as researchers and especially as social workers, to protect the privacy of human subjects in our research (Synder 2002:71). The researcher kept the recorder and field notes in a safe place to which only she was the only one who accessed this place. The identifying information will be destroyed after the completion of final research report.

1.7.3 Avoiding Harm/ Beneficence

It is important in any study to consider ways in which participants could be harmed when participating in a study (Bechhofer & Paterson 2000:70). Participants can be harmed in a number of ways during the research process. They can be harmed physically, psychologically, emotionally and they can be caused embarrassment (social harm), just to mention a few (Polonski 2004:61). Therefore, researchers must identify any potential for harm that can affect the participants before they start the project and must indicate the solution for the foreseen harm.

Participants were assured that they would not be involved in any situation which could harm them (Aurelius 2011:54). According to Du Toit (2013:1), regardless of how knowledgeable the participant seems to be, if the researcher senses that participants can be at risk of any harm by participating, they should not be allowed to participate. Powerful emotions could be provoked by sensitive topics during qualitative interviews. Therefore, the researcher has to organise a referral source for professional help should referral be necessary (Du Toit 2013:1). Due to the sensitive nature of the topic, participants could have been affected emotionally, therefore the researcher arranged with the BCMCOE Maseru social workers for the referrals of such participants for counselling.

1.7.4 Debriefing

At the end of the study, participants should be thoroughly debriefed: they must get the general idea of what the researcher was investigating and why it was investigated. Their participation in the research should be explained and if they were deceived during the

research, they have a right to know and it should be explained how they were deceived (McLeod 2007:52).

The researcher discussed with the participants their experiences of the research for the purpose of monitoring any unforeseen negative effects or misconceptions. Debriefing focuses on the well-being and the rights of participants not the research itself. It is the closure of the research which, if done effectively, will make participants feel that they had made a valued contribution to the research and will leave with a positive mind (UCL Research Ethics Committee 2012). At the end of every interview, the researcher did debriefing with participants to formally terminate the relationship that was built during the interview.

1.8 DEFINITION OF KEY CONCEPTS

In the following paragraphs key concepts which were used in this research study are defined.

1.8.1 Adherence

Adherence is defined as taking at least (95%) of medicines the right way and at the right time (Paterson, Swindels, Mohr, Brester, Vergis, Squier, Wagner & Singh 2000:22). Longan, Burks, Velegol, Paramanova, Lindenmuth and Feick (2003:2366), defined adherence as “the extent to which the patient’s behaviour coincides with medical or health advice”. Adherence describes how faithfully a person sticks to and participates in a HIV prevention, care and treatment plan (Chesney 2006:S43). According to the researcher’s point of view, adherence is the degree to which a patient follows a prescribed treatment regimen and complies with its instructions.

Adherence to care means to enter into and to continue a lifelong care and treatment plan, to attend appointments as scheduled and to take medicines to prevent and treat opportunistic infections. It also includes participating in ongoing education and counseling (La Greca & Bearman 2003:119). UNAIDS (2010:49) stipulated that adherence to treatment includes taking or giving ART correctly as prescribed for the whole of the person’s life even if the person feels healthy. Non-adherence includes missing or skipping doses more than once, taking medicines at the wrong time and not returning to health facilities on agreed dates. In this study, poor adherence is referred to as skipping ART medication more than once in a week and which is below 95% according to the pill count.

1.8.2 Adherence Counselling

Adherence counselling can be defined as the establishment of a relationship of confidence from the outset between the patient and the care team (WHO 2001:36). Adherence counselling involves one-on-one sessions which are provided to a client who is about to be introduced to ART. A social worker does adherence counselling in Baylor, and the patient is expected to attend sessions in which information will be given that include: definition of HIV/AIDS, its transmission modes, prevention, care and treatment.

The barriers that may challenge adherence are assessed and addressed. A social worker does readiness assessment of a client before s/he recommends the client be introduced to ART. Adequate time should be set aside for the counselling so that appropriate and informed decisions on therapy and its implications are made by the patient, based on the information given to him/ her that is accurate and as complete as possible.

Counselling is provided to people who start ART or are already taking ART to assist them to make sound choices that support their treatment and enable them to adhere to medication (Saloner 2005:63). Adherence counselling is provided only by a person who had been trained in HIV/AIDS counselling skills (Saloner 2005:12).

1.8.3 Adolescent

Adolescence is defined by Kaplan (2004:218) as a transition stage between childhood and adulthood. Many researchers and developmental specialists in America use the age span 10-24 to define adolescence (American Academy of Child and Adolescents Psychiatry 2008:17). According to the Medical Dictionary for health Consumers (2007, sv adolescence) adolescence is a period between puberty and the completion of physical growth, roughly from 12 to 19 years of age. In this study, adolescents are considered as anybody between the ages of 12 and 19 as described by Erikson's developmental life stages (Erikson, as cited in Swartz, De La Rey, Duncan & Townsend 2011:126).

1.8.4 Antiretroviral therapy (ART)

Anti-retroviral therapies are medicines that are given to people who are infected by HIV (Human Immunodeficiency Virus) to suppress the virus in their blood. Anti-retroviral therapy is the combination of three drugs which are used to suppress HIV and to prevent the virus from replicating into a person's CD4 cells (Western Cape Government 2011:7). Anti-retroviral therapy is the main type of treatment for HIV; it is not a cure but it can stop people from becoming ill for many years. The treatment consists of drugs that have to be taken every day for the rest of a person's life (Avert 2006:4). In this study, ART is used to describe the medications which adolescents take to suppress HIV and to prolong their lives.

1.8.5 Factor

Factor is defined as one of the elements which contribute to a particular result or situation (Oxford English Dictionary 2008 sv factor). Factor is defined by Cambridge Business English Dictionary (2011:317 sv factor) as one of the several things that affect or influence a situation. The study focuses on factors which contributed to sub-optimal adherence to ART by adolescents in Maseru.

1.8.6 Influencing

It means the capacity to have an effect on the character, development, or behavior of someone or something, or the effect itself (Oxford English Dictionary 2010 sv influencing). Influencing is also 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 sv influencing). In this study, the same definition applies.

1.8.7 Social work

Social work is a professional and academic discipline that seeks to improve the quality of life and wellbeing of an individual, group or community by intervening through research, policy crisis intervention, community organising, direct practice and teaching on behalf of those afflicted with poverty or any real perceived social injustices and violations of their civil liberties and human rights (Agnew 2004:88, Bulter & Gwenda 2004:117). In this study, social work refers to the techniques used to provide HIV-infected patients with psychosocial support through counseling.

1.8.8 Support

Support is defined by the Free Dictionary (2008 sv support), as to bear all or part of the weight of, or to hold up. It is also defined as to give assistance to somebody. Support is “to agree and give encouragement to someone or something because you want them to succeed” (Cambridge Business English Dictionary 2011: 901 sv support). In this study, the latter two definitions apply.

1.9 DISSEMINATION OF RESEARCH RESULTS

The research results will be presented in report form. Recommendations based on the research could be submitted to the Ministry of Health Lesotho, BCMCOE and to the guardians who participated so that they can contribute to the interventions that will be necessary for the well-being of the adolescents.

1.10 STRUCTURE OF THE RESEARCH REPORT

Chapter 1: This chapter serves as an introduction to the study; it gives an overview of the study.

Chapter 2: Chapter 2 covers the research approach, research design, research method, data analysis, data verification, ethical considerations and potential limitations of the study in detail.

Chapter 3: The research findings and literature control are discussed in this chapter.

Chapter 4: This chapter covers the study conclusions and recommendations.

1.11 CHAPTER SUMMARY

The introduction and problem statement were introduced in this chapter. Research questions, objectives of the study as well as the significance of the study have been stated. The research methodology was briefly discussed and key concepts of this study were defined. The next chapter focuses on the application of the research methodology.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 INTRODUCTION

In the previous chapter, the problem statement, research questions that the research findings should answer, goals and objectives that the research needed to achieve, as well as the key concepts were discussed. This chapter explains the methodology that was used to explore and describe adherence to antiretroviral therapy by adolescents in BCMCOE Maseru, as well as the social work support they need to improve their adherence in more detail. The research approach, the study design, research method, population, sampling techniques, research instruments, data collection, data quality control, data analysis and interpretation, data verification, as well as ethical issues taken into consideration during the study, are discussed.

2.2 RESEARCH METHODOLOGY

Research methodology can be defined as “a systematic way to solve the research problems” (Kumar 2008:5). The procedures whereby researchers go about their work of describing, explaining and predicting phenomena are called research methodology. It can also be defined as “the study of methods by which knowledge is gained” (Rajasekar 2006:2). Research methodology refers to the rationale and philosophical assumptions that underlie a particular study (Camarinha-Matos 2012:3).

This section describes the research methodology which was used to develop an in-depth understanding of adherence to ART by adolescents in Maseru. The study focused mainly on the influencing factors and social work support. The study was conducted to answer the following questions:

- What are the factors influencing adherence to ART by adolescents in Maseru?
- What social work support is needed to improve adherence to ART by adolescents in Maseru?

The following paragraph will discuss the research approach which was used in this study.

2.2.1 Research Approach

The research approach which the researcher used is the qualitative approach. The qualitative approach according to Burns (2000:9) is “an interactive process in which the

persons studied teach the researcher about their lives. Qualitative research implies a direct concern with experience as it is “lived” or “felt” or “undergone”. Therefore, it then, has the aim of understanding experience as nearly as possible as its participants feel it or live it”. The aim of qualitative research is to understand experience as unified (Burns 2000:9-10). Merriam (2009:13) clarified that the “qualitative researcher is interested in understanding the meaning people have constructed, that is, how people make sense of their world and the experiences they have in the world”. With the qualitative approach, the focus is on the meaning not on the numerical data (Brooker 2013:1).

In qualitative research, subjective narrative data are systematically collected and analysed in an organised and intuitive fashion to identify the characteristics and the significance of human experience (Holloway 2005:47). The qualitative research uses an inductive form of reasoning; concepts, insights and understanding are developed from patterns in the data. It uses the “emic” perspective of inquiring, meaning that it derives meaning from participants’ perspective (Burns & Grove 2003:357).

The qualitative approach is used when the researcher wants 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). Qualitative approach is more flexible and it allows the genuine perspectives of participants to be revealed (Denzin & Lincoln 2005:8). This method was chosen because the researcher wanted to explore and describe factors influencing adherence to ART by adolescents in Maseru from their own perspective as not much was known about their experiences in this regard. The researcher also chose to use the qualitative approach for the in-depth understanding of how social workers can support adolescents who are taking ART for the improvement of ART adherence. The researcher developed a trusting relationship with participants in order to obtain a valid participant perspective. Participant perspectives are important because each participant could understand things differently and do things differently from another because there are multiple realities.

Qualitative research is especially effective in obtaining culturally specific information about the values, opinions, behaviours and social contexts of particular populations (Burns 2000:10). Qualitative research is characterised as developmental and dynamic with regard to the generation of knowledge. It does not use formal structured instruments (Holloway 2005:4).

The qualitative approach is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that makes the world visible (Denzin & Lincoln 2011:3). These practices transform the world; they turn the world into a series of presentations, including field notes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that a researcher who uses a qualitative approach studies things in their natural settings in an attempt to make sense of or to interpret phenomena in terms of the meanings people bring to them.

The qualitative research method allows a researcher to have deeper insight into individual behaviours and meanings associated with phenomena; this approach allows the researcher to see through the eyes of the people who are being studied (Bryman 2012:377). The researcher was able to transcribe and interpret the field notes which were taken during the interviews. The themes and categories were derived from the transcribed interviews by the researcher to make sense of the whole interviews. It is further indicated by Bryman (2012:392) that the qualitative approach often provides significant amounts of descriptions and this descriptive detail allows for contextual understanding of social interactions, whereby social behaviour can be understood in terms of the environment in which it operates.

In this study, the factors that contribute to sub-optimal ART adherence by adolescents were investigated. Participants were interviewed in their own natural setting; the environment was conducive for them to give information. One of the social worker's offices at the BCMCOE Maseru, where the participants usually received their medication and interacted with the social worker, was used as a private room for the interviews. Participants were not forced to participate in the study; they volunteered to participate. The events and ideas which emerge from qualitative research can represent the meaning given to real life events by the people who live them (Yin 2012:8). Qualitative research covers the social, institutional and environmental conditions within which people's lives take place. These contextual conditions may strongly influence all human events (Yin 2012:8).

One key characteristic of qualitative research is direct data collection (Kellydubose 2010:1). In this research, narrative data was collected by interviewing participants and data was analysed using the interpretive technique. The researcher personally collected data and interpreted what data meant and why. Participants were recorded as they were interviewed and field notes were also taken by the researcher during the interviews. Summary statements were made in the margin of a note pad after each day of data collection. The researcher used direct data collection in order to obtain a rich understanding of the factors

that contribute to poor ART adherence by adolescents in Maseru, and how social workers could support them in regard of adherence improvement. The researcher applied empathetic neutrality and mindfulness. An empathetic stance in interviewing seeks various understandings without judgement by showing openness, sensitivity, respect, awareness and responsiveness (Patton 2002:40).

Another key characteristic of qualitative research is inductive data analysis (Kellydubose 2010:1). An inductive reasoning process is commonly involved in qualitative research (Brooker 2013:5). It emphasises the qualities of entities, processes and meanings that are not experimentally examined or measured in terms of quantity, amount, intensity or frequency (Denzin & Lincoln 2005:8). After data was collected and summarised, the researcher looked for the relationships among the categories and the patterns that suggested generalisations and conclusions. Findings were interpreted by the researcher based on the data collected.

Purposeful sampling is another key characteristic of qualitative research which was used in this study. Participants who were selected in this study were selected because they were believed to be information rich, and illuminative, that is, the researcher believed that they would offer useful manifestations of the phenomenon under investigation (Kellydubose 2010:1).

Qualitative research explores open-ended questions rather than testing hypotheses. During the interviews, participants were asked open-ended questions in order to allow them to give information without restrictions and without being channelled in any specific direction. Open-ended questions allow participants to tell a story as it happened or was lived. This allowed the researcher to get in-depth understanding of the phenomenon being investigated (Denzin & Lincoln 2005:8).

2.2.2 Research Design

A research design is an indication of how the study will be conducted in order to maximise control over factors which could interfere with the validity of the findings (Burns & Grove 2005:211). To quote De Vaus (2001:9), "the purpose of research design is to ensure that the evidence obtained enables the researcher to answer the initial question as unambiguously as possible". A research design is defined by Van Wyk (2012:4) as an overall plan for connecting the conceptual research problems to the potential and achievable empirical research. In other words, the research design articulates what data is required, what methods are going to be used to collect data and analyse data, and how all of this is going to

answer research question. On the other hand, Cheek (2008:761) defines research design as “the way in which a research idea can be transformed into a research project or plan that can then be carried out in practice by a researcher or research team”.

The researcher used an exploratory, descriptive and contextual design in this study to explore factors which influence ART adherence among adolescents in Maseru and to create an understanding of how social workers can support these adolescents to improve ART adherence.

2.2.2.1 Explorative research design

The explorative design places emphasis on gaining ideas and insights (Free eBooks Download 2011:27 sv explorative research). Explorative research provides greater understanding of a concept or crystallises a problem rather than providing precise measurement or quantification (Allsop & Saks 2007:120). The purpose of explorative research is intertwined with the need for a clear and precise statement of the recognised problem. According to Allsop and Saks (2007:120), researchers conduct explorative research for three interrelated purposes which are: assessing a situation, assessing alternatives and discovering new ideas. It also helps to set priorities for research.

It came to the attention of the researcher during her practice at BCMCOE Maseru that adolescents were not complying with their ART medication. This motivated the researcher to conduct research of this kind to identify the factors that influence optimal ART adherence. This study adopted an exploratory research design in order to assess the situation of sub-optimal ART adherence by adolescents and to gain more insights in this matter as little was known about the influencing factors of ART adherence in BCMCOE, Maseru. Through the study, alternative social work interventions could also be explored. The researcher chose an explorative research design because it allows for the better understanding of a phenomenon about which little is known.

An explorative research design was used because it is sufficiently flexible to offer opportunity for considering various elements of a problem under a study (Wei 2014:140). It was used as the researcher’s tool to understand the influencing factors of ART adherence by adolescents more thoroughly. This approach also requires a natural setting; therefore, the researcher had to build a rapport with participants so that they could freely share their experiences in an environment known to them.

2.2.2.2 Descriptive research design

The descriptive research can be defined as a study that has as its main objective the accurate portrayal of the characteristics of people, situations or groups (Polit & Beck 2004:716). Description is useful in describing variables rather than testing predicted relationship between variables. It aims at understanding the relevance of a phenomenon and describing the incidence of a phenomenon in a population (Wei 2014:10). The descriptive research design does not aim at developing a theory, despite the facts described providing useful hints which may lead to theory building and theory refinement (Karlsson 2009:1). The descriptive research design does not answer the questions about how/when/why the characteristics occurred; rather it addresses “what” the characteristics of the studied population or situation are (Shields & Rangarajan 2013:1). This kind of a research attempts to discover facts or to describe reality in an accurate way as it exists naturally in order to gain an overview of the current status of a situation (Mertnes 2009:145).

The descriptive design was used to describe the characteristics of the phenomenon under study. In this study, the researcher began with a well-defined topic, and conducted research to describe the phenomenon accurately. Information was gathered by the researcher about the factors influencing poor ART adherence by adolescents in Maseru. A dense description of the phenomenon was given in order to gain deeper meanings of adolescents’ experiences of taking ART on a daily basis. The researcher avoided bias in this study by being personally detached from participants through using interview guides to collect data.

2.2.2.3 Contextual research design

Contextual research is “a technique of studying users in their own natural environment, to get under their skin, be it in their place of home or work life, understanding what makes them tick”. Holtzblatt and Beyer (2011:231) confirmed that contextual research design is a structured and well-defined user-centred design process which provides methods to collect data about users in the field interpret and consolidate that data in a structured way, use the data to create and prototype product and service concepts, and iteratively test and refine those concepts with users.

The researcher went out to the field (BCMCOE Maseru) and talked to the participants within their own environment about their life experiences of being on and not adhering to ART as well as parenting adolescents experiencing difficulty in adhering to ART. Through the interviews, participants were involved in discussions and reflections on their own actions, intents and values. The research method which was used in the study is discussed thoroughly below.

2.2.3 Research Method

Research method refers to techniques and procedures which are used in the process of data gathering. The techniques are used as a basis for inference and interpretation of data (Cohen, Manion & Morrison 2007:47). Research methods prescribe the logical process that should be followed during the application of scientific methods and techniques when a particular phenomenon is investigated (Polit & Beck 2006:15). According to Creswell (2009: 15), the research method refers to the forms of data collection, analysis and interpretation that the researcher proposes to use for the study. Clarke (2005:24) clarified that “research methods are used to reveal the existence of, identify the ‘value’, significance or extent of, and represent semantic relationships between one or more concepts identified in a model from which statements can be made”.

The research method must be appropriate for the objectives of the study. The sample must be selected from the appropriate population, that is, the sample must be selected from the population that has rich information about the topic which the researcher is willing to investigate (Clarke 2005:24). According to the researcher, research method refers to the processes and procedures that are followed in the scientific investigation of a phenomenon. In the following sections the researcher describes in detail how the population of the study was identified, entry was negotiated, data collected, analysed and verified.

2.2.3.1 Population

Population is defined as a collection of elements about which the researchers wish to make inference (Scheaffer, Mendenhal & Ott 2006:8). Jacobs (2013:4), on the other hand, clarified that population is a larger group from which individuals are selected to participate in a study. According to the researcher, the population entails all individuals who have particular characteristics that are of interest to a researcher.

This study was conducted at BCMCOE in Maseru district Lesotho. BCMCOE is an out-patient clinic for HIV-positive children and their families as well as pregnant women who are HIV-positive. The centre started operating on 1 December 2005. It was the first centre which was opened specifically for paediatric HIV in the entire country. The centre served as the referral centre for paediatric HIV children. In the first year of operation, (from 2005/12/01-2006/11/30), 781 patient files were opened. This clinic is now caring for over 8 758 exposed and HIV-positive children only in the Maseru district. More than 2 500 of them are on ART. The total number of adolescents is 863 of which 775 are on ART. Baylor has opened satellite clinics in five other districts (Butha-Buthe, Leribe, Mokhotlong, Mphahle's Hoek and Qachas' Neck). Some of the adolescents treated in the clinic face major challenges in regard

to ART adherence. Adherence is calculated through pill counts; every patient has to submit his/her medication to be calculated before he/ she can get a refill. Adherence that is below 95% is regarded as poor response to treatment (Reisner, Mimiaga, Skeer, Perkovich, Johnson & Safren 2009:14).

BCMCOE has an Institutional Review Board (IRB). An IRB is a review body which is established by the organisation to protect the rights and welfare of research participants recruited to participate in research studies (Hansen 2013:1). The IRB's main role is to conduct some form of risk-benefit analysis in an attempt to determine whether or not research should be done (Office of Human Research Protection 2012:1). According to Mundy (2009:101), the priority of the IRB is to protect human subjects from physical or psychological harm. The researcher wrote a request letter to the management and the IRB of BCMCOE for the permission to conduct the study at the clinic (see Appendix 4). After the approval was given, the researcher approached Baylor doctors, nurses and social workers who were working with adolescents and talked to them for the referral of adolescents who were struggling with adherence. The staff members were approached individually.

Two populations were consulted during the study. The first population was all adolescents who were HIV-positive and received ART from the BCMCOE Maseru and who did not adhere well to their treatment. This population was identified as it came to the attention of the researcher that adolescents were facing challenges to adhere to ART and there was limited information about the factors that influence adherence to ART by the adolescents in Maseru. The second population was the guardians of the adolescents who participated in the study. This group of people was chosen because the researcher believed that the guardians might give a different perspective on why their adolescents defaulted with regard to ART. BCMCOE Maseru health-care providers (four social workers, three nurses, two pharmacy technicians and two doctors) were also interviewed during data collection. Health-care providers were not identified as a population in the research proposal, but they were interviewed in order to enrich the data through triangulation. The researcher interviewed only health-care providers who provided services to adolescents on a daily basis. Eleven health-care providers were randomly selected and interviewed.

2.2.3.2 Sample and sampling procedure

Sampling is the process of selecting participants from a population of interest so that, by studying the sample, the researcher could generalise the results back to the population from which sample was chosen (Trochim 2004:7). In qualitative research, the units/ participants are deliberately selected to reflect particular features of groups within the sampled

population (Robson 2002:79). A sample can be defined as a subset of the population (Degu & Yigzaw 2006:41). Individuals were selected to represent the study population as it would not be easy to study the entire population. Adolescents who met the inclusion criteria (discussed below) were selected using non-probability sampling.

Non-probability sampling is defined as the selection of sampling units from a population using non-random procedures (Polit & Beck 2006:505). It implies that not every element of the population stands a chance to be included in the sample (Burns & Grove 2001:804). This indicates that the results of this study cannot be generalised. Purposive sampling (which is a form of non-probability sampling) was used in this study. Purposive sampling is a sampling technique whereby the researcher selects the sample from the population which has appropriate information for the study (Tongco 2007:147). In purposive sampling, researchers sample with a purpose in mind. They usually have one or more specific predefined groups they are selecting (Sandelowski 2000:338). The sample for this study was selected with consideration of the characteristics that were assumed to be crucial for the study and was identified as adolescents who were living with HIV, who were on ART and who knew their HIV status.

The main goal of purposive sampling is to maximise the value of data for theory development by gathering data rich enough to uncover conceptual relationships (Merriam 2009:350). Purposive sampling was chosen in this study because its main goal is to obtain cases deemed information-rich for the purpose of study (Sandelowski 2000: 338). It was assumed adolescents would give information that would provide optimal insight on factors influencing ART adherence by adolescents in Maseru.

As stated in Chapter 1, paragraph 1.6.3.1, the inclusion criteria for the first population were as follows:

- adolescents who were between the ages of 12-19 years;
- adolescents who received ART from the BCMCOE Maseru; Lesotho;
- adolescents who did not adhere to treatment (skipping medication more than once a week and those whose adherence was below 95% according to the pill count);
- adolescents who were aware of their HIV status;
- adolescents who were willing to participate; and
- adolescents whose caregivers had given permission.

The exclusion criteria for the first population were identified:

- adolescents who were former clients of the researcher;

- adolescents who did not know their HIV status;
- adolescents who had good ART adherence;
- adolescents whose caregivers did not consent to participate in the study;
- adolescents who had not started taking ART; and
- adolescents who were younger than 12 years or older than 19 years.

The inclusion criteria for the second population were as follows:

- guardians of the adolescents who were willing to participate.

The researcher also clarified the exclusion criteria for the second population:

- guardians who were former clients of the researcher;
- guardians who did not give consent; and
- guardians whose adolescents were younger than 12 years or older than 19 years.

The researcher met with the participants and their guardians referred to the researcher by the medical staff. Based on the recommendations of the clinic management that the interviews should be conducted in Sesotho, the research letter and consent forms were translated in Sesotho. The research topic was explained and participants were requested to sign consent forms (see Appendix 2 and 3). By signing the consent form, the participants were indicating their voluntary agreement to participate in the research study (Albala, Doyle & Appelbaum 2010:7). Data were collected by the researcher and adolescents and guardians were interviewed separately.

The sample size in qualitative research typically relies on the concept of “saturation”. Saturation is the point at which no new information or themes emerge in the data (Guest, Bunce & Johnson 2006:189). According to Merriam (2009:351), data saturation is the point where new data and their sorting only confirm the categories, themes and conclusions that are already identified. The idea of saturation provides little practical guidance for estimating sample sizes, prior to data collection in the qualitative research, despite the fact that it is helpful at the conceptual level (Guest et al 2006:189). For the first population, saturation was reached after 16 adolescents were interviewed, and for the second population, saturation was reached after seven guardians were interviewed.

2.2.3.3 Data collection and instruments of data collection

Data collection is a systematic gathering of data for a particular purpose from various sources such as questionnaires, interviews, observation, existing records and electronic

devices. Data collection can be defined as planning for and obtaining useful information for a research project (Business Dictionary 2007 sv data collection). For the data to be collected the researcher must first identify the key quality characteristics that s/he needs to measure how they will be measured and what will be done with the collected data (Business Dictionary 2007 sv data collection).

a. Methods of data collection

Primary data collection was done through interviewing study participants (adolescents and guardians). Health care providers were also interviewed in order to enrich the data through triangulation. In-depth interviews were chosen as a method of data collection in this study because it was assumed that “critical truth” could be found through in-depth interviews pertaining to how adolescents who are HIV-positive and are on ART, cope and what their day-to-day experiences are in taking a lifelong treatment (Shenton 2004:66).

Semi-structured interviews were used with the adolescents who did not adhere to ART and their guardians. In semi-structured interviews, the order in which the various topics are dealt with and the wording of the questions are left to the interviewer's discretion. Within each topic, the interviewer is free to conduct the conversation as s/he thinks fit, to ask questions s/he deems appropriate in the words s/he considers best, to give explanations and ask for clarification if the answer is not clear, to prompt the participants to elucidate further if necessary and to establish his/ her own style of conversation (Corbetta 2003:270). A semi-structured interview is flexible because questions may not follow on exactly in the way outlined in the schedule, unlike the structured interview used in quantitative research where the questions should follow some sequence (David & Sutton 2004:87). Semi-structured interviews were used in this study because it gave the researcher opportunities to probe for views and opinions of the participants (Gray 2004:217).

b. Data collection instruments

Interview guides gave direction to interviews with both the adolescents and their guardians. An interview guide is a list of questions, topics and issues that the researcher wants to cover during the interview (Gray 2004:241). As part of the interview guide, open-ended questions were developed in advance along with prepared probes. The open-ended questions usually give responses that are rich and explanatory in nature, while probing is a way for the interview to explore new paths which were initially considered (Gray 2004:217). The topics that were covered in the interview guide were participants' understanding of HIV, ART and CD4 cells, discussions on adherence, the importance of optimal ART adherence and consequences of sub-optimal ART adherence. Another topic which was covered in the

interview guide was how psycho-social support could help adolescents to improve ART adherence. (See Chapter 1, paragraph 1.6.3.2).

c. Data collection process

The adolescents and their guardians were prepared for the interviews together, but when the interviews were conducted in Sesotho; guardians were interviewed first, immediately followed by the adolescents. The researcher spent about 30 minutes with the participants as a group, explaining the goal and objectives of the study; participants' rights were also discussed and consent forms were signed by those who agreed to participate. Participants were then interviewed one-by-one for about 45 minutes. Interviews were conducted in the office of a social worker to provide privacy.

The researcher built rapport with participants by greeting them and involving them in a brief conversation before starting the interview, introducing herself to them and explaining the purpose of the study. The researcher thanked each participant for their voluntary participation. Assurance was given to participants that their shared information would be treated with high standards of confidentiality; they were also assured that any information which could expose their identity would not be reported. Participants were then reminded of their rights and then consent forms were signed before interviews were started.

Interviews were audio-taped and notes were also taken by the researcher during interviews; this was done with the permission of participants. Many communication skills were applied during the interviews in order for the researcher to get as much information as possible from participants. The researcher applied communication theory during data collection. Communication can be defined as "a process by which people arrive at shared meanings through the interchange of messages" (Rubin, Rubin, Haridakis & Piele 2010:3). Social workers use a variety of communication skills in gathering information, gaining perspectives and providing the information needed by others (*Communication and partnership: The college of social work* [sa]). During the interviews, the researcher used three communication skills which are commonly used in research which are expressive skills, listening skills and managing the overall process. Expressive skills were applied to convey information to participants. When using expressive skills, the researcher ensured that she got full attention from participants, conveyed information to them and then checked their understanding of the information (*Resource papers in action: communication* [sa]). Listening skills were also applied in this study. Attentive listening, paraphrasing and probing were used to get in-depth and rich information from participants. Open-ended questions were asked in order to give the participants an opportunity to share their insights and experiences of being on a lifelong

treatment. The last communication skill was managing the overall process which was used to deal with issues as they arose; for example, during the interviews the researcher asked some participants if they wished to be referred to counselling as they showed emotional distress. At the end of each interview, participants were thanked for their time and were given a chance to ask questions. They were also given a chance to tell the researcher about their experiences during the interview. This was done to assess if there was a need for referral.

d. Pilot study

A pilot study can be described as a mini-version of a full-scale study or a trial run which is done in preparation for the complete study (Van Teijlingen and Hudley 2001:1). A pilot study is a pre-testing of research instruments such as questionnaires or interview schedules (Van Teijlingen & Hudley 2001:1). In this study, a pilot study is defined as a “try-out” of research techniques and methods. The researcher tested the questions in the interview guide with one guardian and one adolescent. The pilot study of this research is therefore defined as a feasibility study as well as pre-testing of instruments and interview.

The goal of a pilot study is to provide information, which can contribute to the success of the project research as a whole (De Vos, Strydom, Fouch & Delport 2011:237). The goal is thus to test the study on small scale first to sort out all possible problems that might lead to the failure of the research procedure. De Vos et al (2011:237) stated that pilot study has to take place in a setting which is convenient for the researcher and that resembles the one used for the intervention. In this study, the research procedure of the pilot study resembled the true study. The researcher used the two interview guides found in Appendix 2 and 3 when interviewing one guardian and one adolescent, receiving ART from BCMCOE. These participants were referred to the researcher by the social worker. After conducting a pilot study, the researcher added some questions as probes such as “Can you kindly tell me what HIV is?; Do you know the names of ARVs you are taking?; How often do you take them?; What are the soldiers doing in the body?; Do you always take meds every time you are reminded to take them?; I heard you say that you get support in the teen club: tell me more about teen club, what are you doing there?; Do you enjoy it at teen club?”. The questions were added in order to get richer information from participants. The researcher learnt that she had to listen attentively when a participant was responding to the question to avoid asking the participant a question more than once.

2.3 DATA ANALYSIS

Data analysis is “an attempt to comprehend the structure and the essence of the lived experiences of the phenomenon for a group of individuals” (Creswell 2013:54). Data analysis in qualitative research is an inductive process; that is, numerous small pieces of data are collected and gradually combined or related to form broader, more general descriptions and conclusions (Lodico, Spaulding & Voegtler 2010: 301).

As described in Chapter 1, paragraph 1.6.3.3, the researcher used Tesch's framework (as cited in Creswell 2003:192), which include the eight steps for data analysis. The researcher prepared the data for analysis by transcribing and translating the interviews and by typing field notes. The researcher then read through all the data to obtain a general sense of the information and reflect on its overall meaning (Creswell 2008:21). The researcher chose one interview (the most appealing), keeping in mind its fundamental meaning and the whole meaning was summarised by writing thoughts in the margin. The researcher compiled the list with all the topics identified. Similar topics were grouped together into columns and were arranged as major topics, unique topics and leftover topics. The compiled list of topics was re-checked with the data collected by the researcher. The topics were abbreviated as codes, and these codes were written next to the appropriate sections of the text. This provided the opportunity to see if new categories emerged. Descriptive words were identified for topics, the total list was reduced and related topics were clustered together. The abbreviations for each topic were used and the codes were placed in alphabetical order. Related data under each topic were assembled in one area to perform a preliminary analysis and the existing data were recoded.

The researcher and an independent coder analysed the data. Both independently derived at themes, sub-themes, categories and sub-categories. The researcher, supervisor and independent coder had a consensus conversation during which the themes, sub-themes, categories and sub-categories that were derived from the data by the two parties were compared. Both parties agreed on four themes which were derived from the data. The overlapping categories and sub-categories were merged, alterations were made and a conclusion was drawn on how themes, sub-themes, categories and sub-categories should be presented. However, when the researcher started with the literature control, she discovered that some categories and sub-categories still overlapped. It was a challenge for the researcher to merge the overlapping categories and sub-categories.

2.4 DATA VERIFICATION

Verification refers to “ensuring the accuracy of the identification of the things being recorded” (Trevor 2006:2). Verification strategies are very important in qualitative research because they help the researcher to identify when to continue researching, to stop or to modify the research process in order to achieve the validity and reliability and ensure rigor. (Morse et al 2002:10). Guba and Lincoln (1994) as cited in Shenton (2004:63) proposed four criteria for data verification within qualitative research, which are credibility, transferability, dependability and conformability. The researcher used Guba's model (as cited in Shenton 2004:63) to verify data.

In the following sections the researcher describes in detail how data was verified and how trustworthiness was tested.

2.4.1 Credibility (also referred to as true-value)

This concept replaces the idea of internal validity in quantitative research. In this concept, Guba and Lincoln (as cited in Shenton 2004:63) focussed on the degree to which the findings make sense. They recommended that the researchers should give participants their interview transcripts and the research reports so that they could check the researcher's findings (Tobin & Begley 2004:390).

Trochim (2006:7) confirmed that credibility involves establishing that the research results are credible or believable from the perspective of the participant in the research. The purpose of using this criterion in this study was to understand adherence among adolescents and their life experiences of being on lifelong treatment.

Credibility establishes how confident the researcher is with the truth of the findings based on the research design, participants and the context (Tobin & Begley 2004:390). The following measures as described by Shenton (2004:63) were employed by the researcher to promote confidence in the research findings related to the factors influencing ART adherence and social work support needed for the improvement of optimal adherence:

- Triangulation of the data: The researcher interviewed the adolescents who did not adhere to ART and their guardians. Health-care providers were also interviewed to gain more information. The individual viewpoints and experiences were verified against each other and a rich picture of the attitudes, needs or behaviours of adolescents with poor adherence were constructed based on contributions of a range of people (Shenton 2004:66).

- Tactics to help ensure honesty of participants when contributing data: Participants were not forced to participate in the study. They were given the opportunity to choose to participate or not; this was done in order to ensure that the data collection sessions involved only those who were genuinely willing to participate in the study. Participants who voluntarily agreed to participate in the study were requested to sign the consent forms as an agreement between them and the researcher (see Appendix 2).

During the interview, the researcher asked permission from the participants to record the interviews. It was explained to them that the recording would help the researcher to capture as much information as possible while participants were responding to the questions. The researcher also informed the participants that she would be taking notes as they were talking. Participants were reminded that they could withdraw from the study any time they wanted to and they were informed that by signing the consent forms, they did not sign their rights away. Interview guides were used and open-ended questions were asked.

- Background, qualifications and experiences of the researcher supported the credibility of this study because the researcher is a social worker by profession and had worked with the adolescents who do not comply with ART treatment for approximately six years.

2.4.2 Transferability (also referred to as applicability)

The aim of transferability is to provide enough information to the readers so that they can be able to judge if the findings can be applicable to other settings (Tobin & Begley 2004:391). This research study complied with the criterion by providing a detailed description of the place where the study was undertaken. The researcher provided a detailed description of research methods used in the study. Transferability was increased by the use of purposive sampling technique.

This study was conducted at BCMCOE Maseru which is the capital town of Lesotho and it is in the urban area. Most of participants were from the Maseru district, even though some participants pointed out that during school holidays they visited their relatives in the rural areas, but they spent much of their time in Maseru. The findings of the study revealed that factors influencing sub-optimal adherence by adolescents differ due to geographical locations. Participants stated that distance and weather are influencing poor adherence when they were in rural areas.

2.4.3 Dependability (also referred to as consistency)

This concept is concerned with whether the researcher would obtain the same results if s/he could observe the same thing twice (Trochim 2006:7). Schwandt (2001:32) points out that

the researchers are responsible for ensuring that the process of research is logical, traceable and clearly documented. The researcher clearly described the research plan in Chapter 1; the research process is described in detail in Chapter 2 and evaluated in Chapter 4. A voice recorder was used to capture data and at the same time the researcher took notes during the interviews. Data were transcribed and translated and field notes were typed. The findings were sent to an independent coder for analysis. The researcher, supervisor and independent coder sat down to compare coding done by the researcher and the independent coder. Similarities and differences were discussed and a consensus agreement was reached.

2.4.4 Confirmability (also referred to as neutrality)

Confirmability refers to establishing that data and interpretations of the findings are not figments of the researcher's imagination, but they are clearly derived from the data (Tobin & Begley 2004:391). Shenton (2004:72) stipulates that steps must be taken to ensure that the research findings are the results of the experiences and ideas of the participants not the preferences and characteristics of the researcher. Detailed methodological description is provided by the researcher in Chapter 1 and 2 in order to enable the readers to scrutinise research results. Triangulation of data sources (adolescents, guardians and staff members) also contributed to confirmability.

2.5 ETHICAL CONSIDERATIONS

Ethics can be defined as a method, procedure or perspective for deciding how to act and for analysing complex problems and issues (David & Resnik 2011:4). Ethics pertains to doing well and avoiding harm. Harm can be prevented or reduced through the application of appropriate ethical principles (Orb, Eisenhauer & Wynaden 2000:92). According to Punch (2014:36), research ethics is "a branch of applied ethics focused on the specific contexts of planning, conducting, communicating and following up the research". Ritchie, Lewis, Nicholls and Ormston (2014: 78) argued that the researcher must always protect participants in the research study by abiding with the following principles:

- Research should be worthwhile and should not make unreasonable demands on participants.
- Participation in research should be based on informed consent and it should be voluntary and free from coercion or pressure.
- Adverse consequences of participation should be avoided and risk of harm known.
- Confidentiality and anonymity should be respected.

In any research study, participants must be protected. It is the researcher's responsibility to consider whether any type of harm could occur when she plans her research and to ensure that mechanisms are instituted to avoid it (Polonski 2004:53). The following ethics are discussed below: informed consent, anonymity and confidentiality, avoiding harm/beneficence and debriefing.

2.5.1 Informed consent

Informed consent can be described as “the invisible act of evaluating information and making a decision and visible act of signifying the decision” Anderson and Morrow (2011:101). The WHO (2013:21), on the other hand, stated that informed consent involves “informing potential participants, through document and discussion, of the purpose, procedures, risks, potential benefits, voluntary nature of the proposed research and documenting the participant's agreement”. Informed consent is a process of three interactions, namely: the researcher provides information to participants; participants are given information in a way that they clearly understand it, and then participants respond to it (Cocks 2006:265). Participants have the right to know whom to contact if they have questions or queries regarding the study or their rights. Harriss and Atkinson (2011:820) indicated that participants should provide consent to participate in the research freely and it should ideally be in writing. For children to participate in the research; guardians must give consent and children also have to sign the assent form.

The purpose of the research, the benefits and risks of it were clearly discussed with participants in this study. They were told that participation was voluntary and that they could withdraw from the study at any time without consequence. The researcher provided participants with the information about the research project; the information was clear and understandable. They were permitted to make informed and voluntary decisions about whether they wanted to participate or not (Jupp 2006:43). The consent and assent forms were given to guardians and adolescents (see Appendix 2 and 3) to be signed as the agreement of voluntary participation.

2.5.2 Anonymity and confidentiality

Anonymity is a process of not disclosing the identity of research participants. Confidentiality is the process of not disclosing to other parties the opinions or information gathered in the research process (Clark 2006:4). According to Polonski (2004:60), anonymity means that the researcher does not know the participants and confidentiality means that participants are known but their identity would not be revealed in any way in the report. Whelan (2007:2) indicates that anonymity is the degree to which identifying information is not shared by the

participant; therefore, the information shared cannot be traced back to the participant. Confidentiality pertains to “the treatment of information that an individual has disclosed in a relationship with a trust and the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure without permission” (WHO 2013:25) The researcher is liable to provide the information about the steps she will take to ensure that any identifying aspects of the data will be held confidential (Gas 2005:23).

The researcher was sensitive to the information obtained from minors and vulnerable people as is suggested by Polonski (2004:61). The researcher took precautions to protect confidentiality of participants' data by removing the identifying information from the study findings. The researcher did not reveal the identifying information about the individual in written or verbal communication (Aurelius 2011:78). Codes were used when the transcripts were made; this was done so that not even the independent coder could know the identity of participants. The researcher kept the recorder and field notes in a safe place to which only she had access. The identifying information will be destroyed after the final research report. As Synder (2002:71) indicated, our paramount responsibility as researchers and social workers is to protect the privacy of human subjects.

2.5.3 Avoiding harm/ beneficence

The researcher is expected to minimise the risk of causing harm to participants, to carry out a worthwhile and potentially beneficial job and to distribute any benefits and risks non-discriminatorily throughout a research project and beyond (Punch 2014:49). It is important in any study to consider ways which can be harmful to participants when participating in a study (Bechhofer & Paterson 2000:70). Participants can be harmed in a number of ways during the research process. They can be harmed physically, psychologically, emotionally and they can be caused embarrassment (social harm), just to mention a few (Polonski 2004:61). Therefore, the researcher must identify any potential for harm that can affect the participants before s/he starts the project and must indicate the solution for the foreseen harm.

Participants were assured that they would not be involved in any situation which could harm them (Aurelius 2011:54). According to Du Toit (2013:1), regardless of how knowledgeable the participant seems to be, if the researcher senses that he can be at risk of any harm by participating he should not be allowed to participate. Powerful emotions could be provoked by the sensitive topics during qualitative interviews. Therefore, the researcher had organised a referral source for professional help should referral be necessary (Du Toit 2013:1). Some adolescents were upset, especially when they talked about the death of their parents and

their home situations. The researcher offered to refer them to health-care providers for counselling, but they pointed out that they were already being seen by either a social worker or psychologist.

2.5.4 Debriefing

At the end of the study, participants should be thoroughly debriefed, and must get the general idea of what the researcher was investigating and why it was investigated (McLeod 2007:52). The researcher discussed with the participants their experiences of the research for the purpose of monitoring any unforeseen negative effects or misconceptions. Debriefing focuses on the well-being and the rights of participants not the research itself. If the closure of the research is done effectively, a participant will feel that he had made a valued contribution to the research and will leave with a positive mind (UCL Research Ethics Committee 2012). At the end of every interview, the researcher did debriefing with participants to formally terminate the relationship that was built during the interview. Most of the participants, especially guardians, pointed out at this stage that they hoped all stakeholders who were involved in wellbeing of their children would plan and employ intervention strategies to address the discussed factors which inhibit optimal adherence among adolescents.

2.6 POTENTIAL LIMITATIONS OF THE STUDY

Limitations are “matters, weaknesses and occurrences that arise in a study which are out of the researcher’s control (Simon 2011:2; Simon & Goes 2013:1). Adolescents who participated in this study were from the villages which were in the capital city of Lesotho; therefore, the findings cannot be generalised because the factors influencing adherence to ART by adolescents in towns could differ from those which adolescents in the remote areas face.

Adherence in this study was calculated based on pill counts and self-reports only. Participants were only adolescents whose adherence was below 95% when it was calculated. Those who had good adherence were not included. Sometimes adolescents hide or throw away medications (called pill tossing) and this can only be seen by the detectable viral load. A combination of adherence assessment tools could be very important for future research in this setting in order to gain an in-depth understanding of adherence and to explore the factors that influence adherence to ART by adolescents.

Participants were interviewed once; they were not observed over a longer period of time and this may have caused overestimation. However, adherence is a dynamic process that may

change over time. Multiple interviews with participants could have provided more information than once-off interviews. This study is gender-biased as adult participants (guardians) were only females. Males were difficult to reach; even those who were found were reluctant to participate in the study. Due to the sensitive nature of the topic which could have prevented participants from providing all information, the researcher assured participants of confidentiality. The fact that guardians and adolescents were interviewed could have made adolescents cautious that the researcher would tell their guardians what they had said. The researcher tried to prevent this limitation by interviewing guardians first and then adolescents.

2.7 CHAPTER SUMMARY

In this chapter, the researcher provided a detailed description on how the study was conducted. The research design and methods were stipulated, as well as how data was verified. The ethical principles which were applied in the study were discussed. The following chapter focuses on the presentation of findings and discussions based on a literature review.

CHAPTER 3

RESEARCH FINDINGS AND LITERATURE REVIEW

3.1 INTRODUCTION

This chapter presents the findings of the research, which emerged during data analysis and was verified by means of literature control. Data which were obtained from the participants during the interviews were compared with the relevant literature. Burns and Burns (2008:47) stated that “the purpose of literature control in qualitative research is to review what has been done by previous researchers, pulling disparate strands together and identifying relationship and contradictions between previous findings”. Burns and Burns (2008:49) further indicated that literature should be used inductively in qualitative research, unlike in quantitative research whereby it is used deductively.

3.2 RESEARCH RESULTS

The research results will be discussed below. Demographical data of participants will be presented and discussed themes, sub-themes, categories and sub-categories which emerged from the study will also be presented in a table followed by a discussion. Findings will be narrated and supported by the story lines quoted from the participants’ transcribed interviews. Relevant literature will be used as literature control to support or oppose the findings.

3.2.1 Demographical data

Semi-structured interviews were conducted and 23 participants were interviewed (16 adolescents and seven guardians). All adolescent participants were on ART and experienced difficulties in complying with the medication. All adult participants were caring for adolescents who were on ART.

Table 3.1: Profile of participants

PARTICIPANTS	GENDER	AGE	TOTAL BY GENDER
ADOLESCENTS	F	16	FEMALES=10
	F	15	
	F	17	
	F	14	

	F	14	
	F	17	
	F	16	
	F	14	
	F	16	
	F	17	
	M	16	MALES=6
	M	13	
	M	12	
	M	18	
	M	12	
	M	15	
GUARDIANS	F	43	ALL FEMALES=7
	F	67	
	F	23	
	F	57	
	F	38	
	F	69	
	F	70	

The first population of this study was adolescents who were patients at BCMCOE Maseru. Participants were between the ages of 12-19 according to Erikson's theory of adolescence stage (Erikson, as cited in Swartz, De La Rey, Duncan & Townsend 2011:126). Both males and females were included in the study as the researcher aimed at gaining in-depth understanding of factors which influence ART adherence by all adolescents, irrespective of gender, in BCMCOE Maseru and the support that social workers can provide to improve ART adherence.

Six males and 10 females were interviewed. Two were 12-year old males, one was a 13-year old male, three were 14-year old females, two were 15 years old (a male and a female), four were 16 years old (one male and three females), three were 17-year old females and one was an 18-year old male. Many studies have been conducted globally pertaining to ART adherence by adolescents. Almost all the findings point out that, regardless of the fixed doses which were anticipated to make it easy for adolescents to adhere to ART, and regardless of adolescent-user friendly services which are provided in many countries, adolescents are still facing challenges when it comes to ART adherence (Chesney

2006:150; Marukutira 2012:70; Murphy et al 2005:37; Nachega et al 2009:66; Wagner & Ryan, 2004: 385 & Williams et al 2006:1748)

The second population of the study was caregivers who were taking care of adolescents who were BCMCOE patients on ART and who were struggling with ART adherence. Adult participants were only females as males were reluctant to participate in the study. Male caregivers who were identified were too busy and they could not spare their time to be interviewed. Another reason why adult respondents were only females was that most of the adolescents were taken care of by their grandmothers.

There were seven adults who were interviewed, their ages ranging between 23 and 70 years. Adult participants were included in this study because the researcher hoped to get a broader understanding of the factors influencing ART adherence by adolescents. Guardians could provide in-depth information because they were caring for adolescent participants on a daily basis. According to the literature, a strong parental relationship with adolescents may improve adherence. Caregivers need to provide on-going support to and maintain open communication about HIV and ART with adolescents to improve ART adherence (Bikaako-Karuja, Luyirika, Purcell, Downing, Kaharuza, Mermin, Malamba & Bunnell 2006:S93).

3.2.2 Discussion of themes, sub-themes, categories and sub-categories

There were four themes that emerged during data analysis which were further divided into sub-themes, categories and sub-categories. The themes were identified by the researcher, independent coder and research supervisor. The table below provides the summary of the themes, sub-themes, categories and sub-categories that emerged during data analysis. Clear discussion of each theme follows which is supported by literature control. For some categories and sub-categories adequate literature control could not be found, the researcher confirmed this with the subject librarian. It was however decided to include these categories as it contributed to a detailed description of the participants' experiences.

Table 3.2: Summary of themes, sub-themes, categories and sub-categories

THEME 1: LIFE EXPERIENCES OF ADOLESCENTS ON ART	
Sub-themes	Category
1.1: Adolescents on ART had various difficult life experiences	1.1.1: Adolescents on ART had lost parents
	1.1.2: Adolescents on ART experienced a lack of care from family from whom it was expected
	1.1.3: Adolescents on ART experienced other illnesses
	1.1.4: Adolescents on ART had other experiences: orphanage, religious abuse
	1.1.5: Adolescents on ART experienced disillusionment when realizing that taking ART is a lifelong sentence
1.2: Other experiences of adolescents on ART	1.2.1: Adolescents on ART engaged in sexual risk behavior
	1.2.2: Adolescents on ART engaged in irresponsible behaviour
THEME 2: ADOLESCENTS' UNDERSTANDING AND KNOWLEDGE OF HIV AND ART	
Sub-theme	Category
2.1: Adolescents on ART had various understandings of HIV and ART	2.1.1: Adolescents on ART explained their understanding of HIV in medical and metaphorical terms
	2.1.2: Adolescents on ART described their understanding of ART using medical and metaphorical terminologies
	2.1.3: Adolescents on ART differed in their knowledge of the names of the medication
2.2: Adolescents on ART differed in their knowledge of how long they had been on ART	2.2.1: Some adolescents on ART knew exactly how long they had been on treatment while others did not know
	2.2.2: Adolescents on ART had different recollections of adherence counseling as a means of understanding their treatment
2.3: Adolescents on ART explained the reasons for taking ART in different ways	2.3.1: Some adolescents took ART to make the HIV to sleep and the soldiers in their bodies/ CD4 cells strong and to prevent the illness progressing to the stage of AIDS
	2.3.2: Some adolescents took ART to prolong their lives, live a normal life and follow their dreams
2.4: Adolescents on ART clearly understood the consequences of not adhering to treatment	
2.5: Adolescents on ART clearly understood when and how	

medication should be taken	
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THEME 3: VARIOUS FACTORS INFLUENCED ADHERENCE TO ART BY ADOLESCENTS IN MASERU		
Sub-themes	Category	Sub-category
3.1: Various factors positively influenced adherence to ART by adolescents	3.1.1: Factors in the self positively influenced adherence to ART	3.1.1.1: Taking responsibility for themselves to keep-track of time/watching the clock
		3.1.1.2: Having a dream about the future
		3.1.1.3: Believing that the medication helps
	3.1.2: Adolescents experienced receiving various forms of support that positively influenced adherence to ART	3.1.2.1: Experiencing support at home
		3.1.2.2: Experiencing support outside home
	3.1.3: Adolescents experienced different types of social work support that positively influenced adherence to ART	3.1.3.1: Adolescents experienced support from social workers through individual counselling that increased adherence to ART
		3.1.3.2: Adolescents experienced support from social workers through support groups that increased adherence to ART
3.2: Various factors negatively influenced adherence to ART	3.2.1: Factors related to poverty negatively influenced adherence to ART	3.2.1.1: Adolescents did not take the medication due to a lack of food: they believed it is not healthy to take medication on an empty stomach
		3.2.1.2: Adolescents were unable to fetch medication from the clinic due to lack of money for transport
	3.2.2: Various factors related to fear of stigmatisation, discrimination and marginalisation negatively influenced adherence to ART	3.2.2.1: Adolescents found it difficult to take medication in the presence of friends
		3.2.2.2: Adolescents found it difficult to take ART when they had visitors at home
		3.2.2.3: Adolescents were afraid of being found out and discriminated against
	3.2.3: Medication-related factors negatively influenced ART adherence	3.2.3.1: The medication was difficult to swallow and too big
		3.2.3.2: The medication consisted of too many different tablets /were too many
		3.2.3.3: The medication made them nauseous and dizzy
	3.2.4: Negative emotions related to taking ART negatively affected adherence	3.2.4.1: Adolescents experienced reluctance towards taking ART (didn't want to)
		3.2.4.2: Adolescents were tired of taking ART

		3.2.4.3: Adolescents felt overwhelmed by the fact that taking ART was a lifelong sentence
	3.2.5: Poor patient-provider relationships had a negative influence on adherence by adolescents	
	3.2.6: The difficult home conditions affected adherence negatively	
	3.2.7: Various factors that were intended to influence adherence to ART didn't seem to improve adherence	
	3.2.8 Factors related to religious beliefs negatively influenced adherence	

THEME 4: ADOLESCENTS MADE EXPLICIT AND IMPLICIT SUGGESTIONS ON HOW SOCIAL WORK SERVICES CAN IMPROVE ADHERENCE TO ART BY ADOLESCENTS IN MASERU	
Sub-theme	Category
4.1: Some adolescents had no suggestions on how social work services could improve adherence to ART	
4.2: Adolescents on ART made explicit suggestions on how social work services could improve adherence to ART	4.2.1: Adolescents suggested group and individual counselling by social workers to improve adherence to ART
	4.2.2: Adolescents suggested home visits from social workers to improve adherence to ART
	4.2.3: Adolescents suggested that social workers should motivate them to take the medication
	4.2.4: Adolescents suggested that social workers should facilitate education on HIV and ART especially to other children and people in the community who do not know how to treat someone with HIV
	4.2.5: Adolescents suggested that social workers should advocate their needs to parents and caregivers
	4.2.6: Adolescents suggested group and individual counselling by social workers to deal with other issues that are not directly related and may or may not impact on adherence to ART
4.3: Adolescents on ART implied suggestions on how social work services could improve adherence to ART	4.3.1: Adolescents implied that social workers should facilitate family support including empathic interest instead of only controlling and supervising taking of medication

3.2.2.1 Theme 1: Life experiences of adolescents on ART

The first theme which was identified in the study is “life experiences of adolescents on ART”. Two sub-themes, which reflected various aspects of life experiences of adolescents on ART, emerged from the first theme, and they were as follows:

- Adolescents on ART had various difficult life experiences,
- Other experiences of adolescents on ART.

Sub-theme 1.1: Adolescents on ART had various difficult life experiences

Adolescents pointed out during the interviews that they had faced challenges and hardships in life. Most of them had experienced loss of a parent; some had even lost both parents and were taken care of by extended family members. Adolescents pointed out that some extended family members were not taking good care of them and they (adolescents) felt that they lacked a sense of belonging. Some adolescents had experienced other illnesses due to the progression of the virus in their blood.

This sub-theme unfolded into the following categories:

- Adolescents on ART had lost parents;
- Adolescents on ART had experienced lack of care from family from whom it was expected;
- Adolescents on ART had experienced other illnesses;
- Adolescents on ART had other experiences: orphanage, religious abuse; and
- Adolescents on ART experienced disillusionment on realizing taking ART is a lifelong sentence.

Category 1.1.1: Adolescents on ART who have lost parents

Some of the participants indicated that they were staying with one parent due to their loss of another parent; others mentioned that they were staying with extended families. According to the researcher’s observation, most of the adolescents who participated in the study, were prenatally infected by the virus (they contracted the HIV virus from their mothers), and lost their mothers after their birth. When they were asked who attended ART adherence sessions with them before they were initiated to ART, their responses were as follows:

“(Eh) I attended those sessions with my mother while she was still alive, we were told what HIV is and how to drink our ART. I only remember that” (16-year old female).

“I don’t know [if someone attended it on my behalf] I think it was my mother. My grandmother accompanied me after my mother passed away” (17-year old female).

“I think they were taking ART properly when their mother was still alive. After the death of their mother, no one cared for them”. (38-year old female who cares for a 13-year old male and 15-year old female).

The findings of this study also revealed that most of the participants (12 out of 16, which is 75%) had lost both parents and that they stayed with their relatives who were sometimes too old to follow up and monitor the adherence of adolescents. One counsellor, Ms Khesa (2014), who was working at BCMCOE Maseru indicated during an interview that some adolescents were living with their step-parents who did not give them support. Ms Khesa further pointed out that such adolescents lacked social and emotional support and they behaved like they had given up in life. The following were the responses which were taken from the transcribed interviews of the participants:

“I am always sad because both my parents are no more. My aunt does not support me; she always tells me that I am taking ART for my own good and if I don’t take them I will die like my parents” (16-year old female).

“I am not quite sure because she started taking ART while her mother was still alive... He (the father of an adolescent) also died in 2010” (43-year old female).

This finding is supported by the study of Agwu and Fairlie (2013:5) on antiretroviral treatment, management challenges and outcomes in prenatally HIV-infected adolescents. The study showed that a high percentage of HIV-infected adolescents had experienced the loss of a primary caregiver. The study further indicated that parents who are still alive are frequently prone to depression and psychological distress which may impact children’s adherence to ART.

According to the US President’s Emergency Plan for AIDS Relief (PEPFAR) (2012:349), many children in Sub-Saharan Africa have lost one or both parents, a caretaker, relative or other sibling to HIV and this loss, resulting in bereavement, can impact their transition from paediatric to adult or adolescent care. The findings of a study that was conducted in the Western part of Kenya reveal that some children who had lost a parent due to AIDS-related infections often take significant care responsibilities such as preparing food, cleaning, other house chores as well as providing physical and moral support for their surviving ill parent

(Daniel 2010:160). Skodval (2010:98) further demonstrates that in some situations, children are frequently obliged to earn some cash in order for them to provide for their sick parents. In Botswana, Marukutira (2012:67) found that adolescents who lost their parents were the most non-adherent to ART. These adolescents showed the elements of bereavement and depression which caused adolescents not to adhere to their medications.

A study that was conducted in Rwanda found that adolescents who lost their parents were cared for by foster families or orphanage homes. The study further indicated that the foster families and some orphanages were not taking good care of those adolescents and they suffered from depression and anxiety due to the loss of their parents (Mutwa, Nuil, Kateera, Kestelyn, Vyankandondera, Pool, Ruhirimbura, Kanakuze, Reiss, Geelen, van de Weijgert & Boer 2013:5).

Category 1.1.2: Adolescents on ART experienced lack of care from family from whom it was expected

Some participants revealed that they had poor adherence due to the ignorance of the guardians; they indicated that some guardians were not committed to caring and they did not feel that the adolescents' lives should take priority. Some adolescents indicated during the in-depth interviews that they lacked parental care and guidance. From the researcher's observation, adolescents who were between the ages of 15-18 were the ones who did not receive care from their guardians. Some guardians were so busy that they forgot that their adolescents were living with this stressful virus and that they needed their guardians' care. Some adolescents were living in homes where peace and stability were not known. Some parents were fighting in front of their children; the fighting parents became so consumed with their own life situation that they even stopped caring for their children.

Some grandparents were too old to provide care for adolescents; due to old age they also needed to be cared for. Some adolescents found themselves in a situation where they had to provide care for their old grandparents. Ms Makhalanyane (2014), an outreach nurse at Baylor, pointed out during an interview that HIV is one of the diseases which are discriminatory and some people, especially those who still lack knowledge about the disease, do not want to be associated with people who are HIV-positive. Ms Makhalanyane explained that it came to their attention that some adolescents were forced to stay with people who were not prepared to receive them; some relatives did not want to stay with HIV-positive children because they were afraid of what the community would say. The following quotes were responses of adolescents indicating that they were not receiving appropriate care from their family members:

“My father does not give us money for transport when we have to come to the clinic” (15-year old female).

“Many things. When I was still staying with both my parents, they were always fighting. My father, when he is drunk is very violent, he beats everybody in the house. Sometimes he would beat us and we would run away and I would not be able to take meds because I would be sleeping at the neighbour’s house” (17-year old female).

“I have to take care of my younger cousin and my grandmother who is sick, so most of the times I forget that I haven’t taken my meds”.

“My brother was saying that I have to use my own cup, plate and basin. I don’t have to share dishes with them because I will infect them. No, [does not support me] he even refused to go to Baylor to sign the Teen Club consent form”.

This finding is supported by the study of Reda and Biadgilign (2012:2) that was conducted in Ethiopia in 2012. The study showed that a lack of knowledge of ART and beliefs about ART reduced the guardian’s ability to provide proper care for the child, thereby affecting the necessary adherence over time. The findings of the study that was conducted in Rwanda showed that adolescents, who lost their parents and were cared for by foster parents, were less cared for and the foster parents cared less about them taking their medication. Adolescents further stated that foster parents lacked involvement in their care (Mutwa et al 2013:5).

Category 1.1.3: Adolescents on ART experienced other illnesses

Participants indicated that they experienced illnesses other than HIV. Some even experienced social discrimination due to the illness they had. Some adolescents shared that they had to take medications other than ART for treating other illnesses. They indicated that they found it very difficult to take ART together with other medication; as a result, ART adherence was affected. Ms Makhalanyane (2014) (Baylor outreach nurse) mentioned that many adolescents who have various illnesses do not adhere well to ART medicine. She pointed out that adolescents who have HIV plus TB or HIV plus pneumonia, end up taking one drug for one illness; and they end up choosing to take medication for opportunistic infections and abandoning their HIV medication. The following quotes demonstrate that adolescents had other illness:

"I had TB and I was supposed to take ART and TB tablets at the same time. They were many and I couldn't take all of them at the same time, so I decided to take only TB tablets and hide the ART. Even when I am sick suffering from other diseases, I don't take ART. I take the medication for that disease only, when they are finished, I then take ART" (15-year old female).

"I had sores all over my body and I had [litlapedi] (ring worms) all over my head. I had rash that was very itchy on my hands" (12-year old male).

"Yes. [My friends know that I am taking pills.] My grandmother told them that even if we are busy playing, they have to remind me to come home early so that I can take my TB meds, they only think that I have TB and they told me that I don't have to take those meds because now I am not sick" (16-year old male).

Category 1.1.4: Adolescents on ART had other experiences: orphanage

Some participants explained that they had other experiences in life such as staying in orphanages. This finding was supported by the study of Mutwa et al (2013:6). They indicate that due to the mortality rate of people with HIV/AIDS, some adolescents stay in orphanages. Two 12-year old males clarified that after the death of his parents, they had to stay in the orphanage.

"People from the orphanage took [me]. So that they could help me. They are still helping me now, they buy clothes for me, they pay for my fees and they buy books for me. They even pay for my boarding fee".

"No. I was staying in the orphanage at that time. Now I spend most of the time at school. I am staying in the boarding school and when the schools are closed like now, I stay with my grandmother and grandfather".

Another study shows that across Ethiopia, there are orphanages which care for about 500 HIV/AIDS orphans (Hadassah Medical Center 2014). Many non-governmental and faith-based organisations in India are funding orphanages to care for children orphaned by AIDS (Kumar, Varghese, Chaturvedi, Agrawal, Fating & Makkad 2012:207).

When children had lost their parents and extended families are unable to care for them, they are left with only one option which is institutional care and orphanages (Close [sa]:326). Sherr, Verrall, Mueller, Richter, Wakhweya, Adato, Belsey, Chandan, Drimie, Haour-Knipe, Kimou, Madhavan, Mathambo and Desmond (2008:527) pointed out that institutionalised

children are not as happy as those who are living in their homes. Van Blerk and Ansell (2007:870) also found that there was an inability of orphanages to meet children's emotional and physical needs. Close ([sa]:326) stated that "some orphans may not have family members to stay with after their parents' death. They may try to survive by living on the streets or may be forced to stay in an orphanage or institution". Close ([sa]:326) further illustrated that in most cases, institutions fail to provide for the physical and psycho-social needs of children, and they cost more than direct monetary assistance to families that foster orphans.

Category 1.1.5: Adolescents on ART experienced disillusionment when realizing that taking ART is a lifelong sentence

Most young people with HIV have seen many family members and friends die of AIDS and most of them struggle with knowing that they have a disease that cannot be cured (United Nations 2014:44). This made them experience disillusionment when they realised that they have to take ART while HIV is not curable. The following storylines were the responses the researcher got from participants:

"They told me that ART do not cure HIV, it is the life-long treatment and they are taken at the same time every day" (43-year old female caring for 16-year old female).

"Yah it is very important, I couldn't accept that I am HIV-positive and I will live with this virus for as far as it is not curable" (18-year old male).

"In teen club they say that HIV cannot be cured; it only sleeps if we drink our medicines correctly. How long am I going to drink ART? Does it mean even when I am a father, I will be taking them?" (13-year old male).

The negative perception of ART may be a barrier for ART adherence. Wasti, Van Teijlingen, Simkhada, Randall and Baxter (2011:12) indicated that one participant in their study stated that she had stopped taking ART after she was initiated into the treatment. She pointed out that she did not see any use to take the pills because the fact remained that HIV-positive people would die eventually, whether they were taking or not taking ART. Adolescents claim that sometimes they do not feel like taking ART because that reminds them of their HIV infection (MacDonell, Naar-King, Huszti and Belzer 2013:86). Supportive and non-judgmental attitudes of the health-care providers can help adolescents not to consider ART as a life sentence, but rather to understand that they have a chronic disease which can only be controlled by optimal ART adherence.

Sub-theme 1.2: Other experiences of adolescents on ART

The second sub-theme which emerged from the first theme was 'other experiences of adolescents on ART'. Some adolescents reported that they had engaged in irresponsible behaviour, some even reported that they had been engaged in sexual risk behaviour. The sub-theme unfolded into the following categories:

- Adolescents on ART engaged in sexual risk behaviour;
- Adolescents on ART engaged in irresponsible behaviour

Category 1.2.1: Adolescents on ART engaged in sexual risk behaviour

Sexual risk behaviour is defined by Hoque (2011:1) as sexual activities that may expose an individual to the risk of infection with HIV and other Sexually Transmitted Infections (STIs). These include unprotected sex, early sexual debut, taking drugs or alcohol before sexual intercourse, multiple partners and forced or coerced sexual intercourse for a reward. Lack of knowledge about HIV/AIDS and poverty are regarded as risk factors that increase the chances of young people engaging in risky sexual behaviour (Ayodele 2009:12).

Adolescents are more likely to be engaged in risky sexual behaviour due to their developmental stage. They like to explore things, and this behaviour is influenced by strong peer group relationships. Adolescents are more exposed to media and social networks nowadays; they watch pornographic movies and they are keen to practise what they have seen in such movies. They also want to fit into society, so they start practising sexual activities in early adolescence (Chandler & Ngoksin 2013:34). The following responses indicate that participants engaged in sexual activities:

"No". [friends must not know of HIV status] "No". [must not know about the medicine] "Because they will tell my boyfriends and they will discriminate me. They will no longer want to play and hang out with me and they will tell many people in the village" (14-year old female)

"Two". [boyfriends]. "Yes" [she does have sex with them]. "Sometimes" [uses condoms] (14-year old female)

"Yes". [knows HIV is transmitted through unprotected sex] "I think so because I know that I will infect them but I do not want to tell them that I am HIV-positive" (14-year old female).

Studies show that many adolescents, whether HIV positive or negative, are involved in sexual intercourse with multiple partners prior to marriage (Ayodele 2009:12; Hoque 2011:1; Traore 2005:22). Adolescents in general, are at risk of engaging in sexual intercourse.

Hoque (2011:1) stipulates that urbanisation, poverty, exposure to conflicting ideas about sexual values and behaviour, and encouraging premarital sexual activity among adolescents, may be the factors which contribute to early sexual initiation of young people globally.

Youth seem to ignore the campaigns and programmes which offer education about reducing the incidence of HIV transmission among youth. Free condoms are distributed and STI treatment programmes are there, but they continue to engage in risky sexual behaviour (Traore 2005:22).

There are psychosocial factors which repeatedly contribute to unprotected sex among HIV positive people, this include: blaming others for acquiring HIV, believing that safer sex reduces sexual pleasure and experiencing emotional distress (Rice, Batterham & Rotheram-Borus 2006:164). In Ethiopia, it was found that peer pressure was the most important factor associated with risky sexual behaviour among school adolescents (Alamrew, Bedimo & Azage 2013:5).

Category 1.2.2: Adolescents on ART engaged in irresponsible behaviour.

Some adolescents had been on ART treatment as long as they could remember. Some were becoming rebellious and no longer wanted to take their medication (Ndiaye, Nyasulu, Nguyen, Lowethal, Gross, Mills & Nachega 2013:892). The findings of this study show that some adolescents pretended to be taking medication while in actual fact they were pill-tossing. Some lied about taking medication when they were reminded by their caregivers to take medication. The following quotes were the responses of participants when they were asked “what makes it difficult for you to adhere to your medication?”

“No”. [not taking medicine now] Last week when I arrived at home I threw them away; I will start taking them again today if they will be given to me” (14-year old female).

“There are some children who he is hanging out with, I have a feeling that they discourage him from taking his meds. I say this because he was taking meds very well all this while before he was hanging out with those boys, but now he has many stories when it comes to meds” (67-year old female caring for 16-year old grandson).

“I left home with my friends the other day to town and I stayed in town for three days without meds. When I came back I feared to go back home after spending those three days away, I

went to my grandmother's house which is not far from home and I was not taking my medication because I left them at my home" (14-year old female).

Males are more likely to have suboptimal adherence than their female counterparts. This may be due to the rebelliousness of male adolescents (Ndiaye et al 2013:894). Some adolescents deny their HIV status and become rebellious. These adolescents rebel against their disease because they want to be normal (Michaud, Suris, Thomas, Gnehm & Cheseaux 2010:250).

Substance abuse is regarded as another important co-morbidity for HIV-positive adolescents. Failure to identify and address this issue may prevent adolescents from successfully coping with their illness as well as ART adherence (Naswa & Marfatia 2010:6). One caregiver also suspected that her grandson was using drugs. She said:

"I really don't like them and I told him many times that I don't like his friends. Some of these so-called friends are older than him and they smoke dagga. I have the feeling that they have introduced him to dagga..." (67-year old female caring for 16-year old grandson).

In the REACH study that was conducted in the US, 14% of female participants and 25% of male participants reported that they had drunk alcohol during the previous three months. It was also found that 7% of females and 20% of males reported using hard drugs during the same period. These practices of drugs are regarded as irresponsible behaviours. These behaviours put the lives of the adolescents in more danger and they are less likely to comply with their ART. Refusing medication may be an act of rebellion for adolescents, or a way of expressing their autonomy. This behaviour may also be a response to feeling depressed or frustrated with taking ART every day (Chandler & Ngoksin 2013:32).

3.2.2.2 Theme 2: Adolescents' understanding and knowledge of HIV and ART

The second theme which emerged during data analysis is 'adolescents' understanding and knowledge of HIV and ART'. The findings showed that adolescents vary according to their understanding and knowledge of HIV and ART. Some participants described HIV and ART in medical terminology while others described it using metaphorical terminology. Adolescents between the ages of 15-18 and who were in the secondary schools (10 out of 16, which is 63%), were able to demonstrate their knowledge and understanding using medical terminology. The findings of the study also indicated that adolescents who were in primary school used metaphorical terminology to demonstrate their understanding and knowledge of HIV. Most of the adult participants, who were interviewed, indicated that their highest level of

education was primary school; one indicated that she never attended school. These participants also used metaphorical terminology to describe HIV and ART.

Under this theme the researcher describes adolescents' understanding and knowledge of HIV and ART with the focus on the following five sub-themes:

- Adolescents on ART had various understandings of HIV and ART;
- Adolescents on ART differed in their knowledge of how long they had been on ART;
- Adolescents on ART explained the reasons for taking ART in different ways;
- Adolescents on ART clearly understood the consequences of not adhering to treatment;
- Adolescents on ART clearly understood when and how medication should be taken

Sub-theme 2.1: Adolescents on ART had various understandings of HIV and ART

From the researcher's perspective, adolescents on ART were knowledgeable about issues concerning HIV; they only differed on how they understood the information.

The sub-theme was divided into the following categories:

- Adolescents on ART explained their understanding of HIV in medical and metaphorical terms;
- Adolescents on ART described their understanding of ART using medical and metaphorical terminologies; and
- Adolescents on ART differed in their knowledge of the names of the medication

Category 2.1.1: Adolescents on ART explain their understanding of HIV in medical and metaphorical terms

After HIV was declared as a pandemic disease worldwide, children were taught about it in schools and learners started to become more knowledgeable about HIV/AIDS (Matsika 2011:17). The findings of the study showed that some guardians also talked with their children at home about the HIV/AIDS. One guardian indicated that Baylor clinic had made it easy for them to talk about HIV with the adolescents under their care, because those adolescents were already being taught about HIV in the teen club.

Some adolescents and most of the adult participants used metaphorical terms to demonstrate their understanding of HIV. This is how they were taught. Ms Khesa (2014), a counsellor at Baylor, confirmed that when they did ART adherence counselling they also assessed the level of education of the individuals. For people who were not educated, they used language that was easily understood. She also indicated that they used age appropriate language with adolescents. Some participants referred to HIV as a monster and

others referred to the immune system as soldiers of the body. The researcher asked participants the following question: *'According to your understanding, what is HIV?'* The responses were as follows:

"HIV is the virus that lives in people's blood and it eats up CD4 cells and if the person does not test and take ART s/he can have AIDS and can die. AIDS is (um, eh), when the CD4 cells are very weak to fight the diseases and many diseases enter the person's body, s/he becomes very sick suffering from many sicknesses and dies" (16-year old female).

"HIV stands for Human Immunodeficiency Virus. This is the virus that only survives in human beings' blood. It destroys the CD4 cells in the body. Let me try, I think CD4 cells are part of red blood cells which helps the body to fight illnesses that attack the body. The main work of CD4 cells is to protect the body against viruses" (18-year old male).

"I was told that it is the monster because it eats our body soldiers" (12-year old male).

"The monster arises from sleeping and destroys my soldiers". {If I don't take my medicine} (12-year old male).

King Letsie III of Lesotho declared HIV/AIDS as the country's disaster in 1996 and since then, the government ministries started to implement HIV prevention strategies working together with NGOs (USAID 2005:30). Free primary education was introduced in 2000 in Lesotho, and since then, children have been taught about life skills and HIV/AIDS (USAID 2005:30).

In Zimbabwe, the Ministry of Education, Sports and Culture together with UNICEF initiated an in-service training scheme for primary and secondary schools in 2006. NGOs started using a number of different means to convey the messages about HIV. They used radios, television and pamphlets and children were given age appropriate information about the disease (Matsika 2011:17).

The finding is confirmed by the study that was conducted at Baylor college of Medicine Children's clinic Botswana by Marukutira (2012:47). One of the respondents [15-year old male] in that study said: *"I know if I don't take them {ART} properly my soldiers will go down and the bad guy {HIV} will wake up and I will be sick"*. According to Barrero and Larusso (2006:43), it is very important for the health-care providers to be aware that providing developmentally appropriate information about HIV/AIDS that matches children's illness experiences at all ages could eliminate the need for disclosure and reduce children'

emotional distress. This implies that if children are given age appropriate information about HIV, they will understand their illness and there will be no need for them to go through a disclosure process which causes children's emotional distress.

Ms Khesa (2014) explained that adolescents learned metaphorical terms during partial disclosure. She explained that partial HIV disclosure was done for children between the ages of 8 to 10 years. Botswana Guidelines for Teen Club (2012:6) explained that partial disclosure is the process whereby guardians are encouraged to start talking about HIV to their children. Guardians are guided by clinicians to disclose HIV status to their children and it is through this process that age appropriate words such as soldiers (CD4 cells) and the bad guy (HIV) are used to provide information to children (Botswana Guidelines for Teen Club 2012:6).

From the researcher's point of view, in communities, some community members are now taking the responsibility to convey the messages about the disease. It is no longer taken as the responsibility of only health care providers to teach people about HIV. It is the responsibility of every member of society: teachers, priests, traditional healers, health-care providers and even parents at home.

Category 2.1.2: Adolescents on ART described their understanding of ART using medical and metaphorical terminologies

Medical terms were used by some participants to define ART: they said ART is important because it boosts the immune system, it increases CD4 cells, it suppresses the HIV virus and some described it as treatment, pills, tablets, medicines or drugs. Adolescents mentioned that they had learnt all this information in the teen club. Some participants used various metaphorical terms to describe ART. Some described it as pills that make the monster sleep; some said it is pills that stop HIV from eating soldiers and some said ART collects the HIV and arrests it so that it cannot multiply in the body. The researcher asked the following question to the participants: *'According to your understanding, what is ART?'* Participants' responses were as follows:

"... according to my understanding, ART is a combination of drugs that are given to a person who is HIV-positive and whose CD4 count is less than 350. (Eh), they increase CD4 count and they prevent HIV from replicating so that a person cannot progress to the stage of AIDS" (18-year old male).

“(Um, um), [ART are] tablets or medicines that drug the virus of HIV so that CD4 can increase and be strong again to fight the diseases that want to attack my body” (16-year old female).

“It is ART. They are pills which are taken by people who suffer from HIV. They increase soldiers of the body and they make HIV to sleep” (13-year old male).

“They collect HIV and arrest it together so that it cannot multiply in the body” (14-year old female).

The immune system can be defined as the cells of the body which protect the body from disease (Van Aswegen, Banhegyi, Crafford, Kleynhans, Markham, Meyer, Moerdyk, O'Neill, Nel, Schlechter, Train, Dale-Jones, Southey & Pilbeam 2008:42). The main job of the immune system is to recognise and respond to antigens which include bacteria, viruses, fungi and parasitic worms. Participants in the study demonstrated their knowledge of how the immune system works in the body.

Adolescents seemed well-informed about their medication in this study, but there was no association between knowledge and good adherence. This finding was confirmed by Marukutira (2012:47) in the study that was conducted in Botswana that adolescents have a substantial knowledge about ART. The findings of that study show that adolescents demonstrated understanding of how beneficial ART is. However, their knowledge was not consistent with adherence level.

The findings pointed out that even patients who are considered as knowledgeable and who had demonstrated more understanding on the benefits of ART, still had poor ART adherence due to some factors such as stigma which inhibited adherence. Nyambura (2009:53) indicated that poor adherence cannot be associated with lack of understanding of the benefits of ART among patients. On the other hand, poor adherence among adolescents in Asia Pacific was associated with a lack of knowledge. According to Chandler and Ngoksin (2013:33), adolescents demonstrated lack of knowledge and understanding of ART regimens. Therefore, it cannot be generalised that poor adherence is caused by a lack of knowledge of ART or that knowledgeable adolescents are the ones who have worse adherence.

Some adolescents mentioned that they heard about HIV/AIDS care and treatment for the first time at school, so they said when they received the same information again in the clinic,

it became easy for them to grasp the medical terms because it was not the first time they were taught about HIV.

Studies have shown that adolescents can describe ART using medical terms, but little is known about adolescents using metaphorical terms to describe ART. It came to the researcher's attention during the interviews that most of adolescents who used metaphorical terms to describe HIV-related issues are not members of the teen club. They used terms which best expressed their feelings about the whole issue of being HIV-positive and being on ART. One of BCMCOE Maseru doctors, (Dr Molapo-Hlasoa 2014) mentioned that adolescents seemed to be knowledgeable when it comes to medication. During the interview Dr Molapo-Hlasoa (2014) said *"If you ask them about the importance of ART, most of them will describe in their own words how important the medications are, they know why they have to take medications every day, but surprisingly, their adherence levels contradict with the knowledge they have and this implies that they lack understanding of the whole issue"*. The findings of the study revealed that guardians also use metaphorical terms when they talked with their adolescents at home pertaining to the importance of ART.

Category 2.1.3: Adolescents on ART differed in their knowledge of the names of the medication

Most of the adolescents knew the names of their ART, 63% (10 out of 16) of them were able to mention the names of their ART. For adults, only 29% (2 out of 7) were able to mention the names of the ART their children were taking. Adolescents who were able to mention the names of their medications were teen club members. Those adolescents indicated that in teen club they were told that they must know their medications by their names and they were told that it is very important to know the names of the medications and to be able to differentiate between ART medications and other medications. One 15-year old female who was responsible for dispensing medication to her brother, was very knowledgeable; she knew the names of her ART medication as well as that of her brother's.

It was found during the interviews that some adults could not read the names of the ART because they were written in English; most of guardians were illiterate.

The following quotes were the responses of adolescents when they were asked if they knew the names of their ARTs:

"Yes, they are AZT, 3TC and Kaletra". "Yes, they are AZT, 3TC, and EFV" [brother's medicine] (15-year old female).

“They are AZT, 3TC and EFV. I am also taking multivitamins” (12-year old male).

“I only know multivitamins” (17-year old female).

“No”. [do not know the names of the medicine] (14-year old female).

“Hahahahahaha (laughing). Those names are written in English and I did not go to school. I can’t read English. Really I don’t know their names but he knows them. He told me but I can’t remember those difficult names, I think it is ok because the person who is taking them knows their names” (67-year old female, taking care of a 16-year old male).

This finding of this category was supported by the study that was conducted by Gawa (2011:26) in Malawi. Children between the ages of 7-15 years were interviewed in Malawi, out of 36 respondents, 20 of them knew the names of their medications (Gawa 2011:26). Some studies indicate that adolescent peer support groups play a vital role in educating adolescents about HIV-related issues. The studies show that in adolescent peer support groups, peer educators are used to educate other adolescents about HIV, ART and the names of drugs they are taking (Kerrissey 2008:12; UNICEF 2012:2). Botswana Guidelines for Teen Club (2012:20) also confirm that in Botswana adolescents are taught the names of their medication in teen club meetings.

On the contrary, the study that was conducted in Asia Pacific clarifies that many adolescents who participated in that study did not know the names of their treatment regimens, and that few of them demonstrated the understanding of how ART affects their bodies (Chandler & Ngoksin 2013:33).

Sub theme 2.2: Adolescents on ART differed in their knowledge of how long they had been on ART

Adolescents demonstrated various levels of knowledge of how long they have been on ART. Some of them reported that they were diagnosed while they were still very young and they had to start ART at a very young age that is why they did not know how long they had been on ART. Other adolescents started to take medication recently, so they knew exactly how long they had been on ART. Other adolescents referred to incidents that happened when they started to take ART, but they did not know when those incidents happened.

The sub-theme unfolded into the following categories

- Some adolescents on ART knew exactly how long they had been on treatment while others did not know;
- Adolescents on ART had different recollections of adherence counselling as a means of understanding their treatment.

Category 2.2.1: Some adolescents on ART knew exactly how long they had been on treatment while others did not

A few adolescents (5 out of 16, which is 31%) knew exactly when they started to take medication. Some adult participants (3 out of 7, which is 43%) also knew when the adolescents under their care started medication. Others had no idea when they started to take medication. This group of adolescents was those who started while they were still very young. Some adolescents remembered the incidents which happened at the time they were initiated to ART. They could not remember when exactly those incidences happened. Their expressions were as follows:

“Since 2012. Yes” [when she was 12] (14-year old female).

“Since 2006” [I was] 8 (16-year old female).

“I don’t know but I was told that I started a long time ago” (16-year old male).

“Since I was attending clinic at Queen Elizabeth II hospital before it was closed” (15-year old female).

The findings are supported by the letters which were written by adolescents living with HIV which were published by UNICEF (2014:5) in Latin America and the Caribbean. One adolescent mentioned that she had been on ART as long as she could remember; she indicated that she had no idea when she started to take medication; she could only remember that when she was young she was taking ART in the form of syrup, and she started taking pills when she was 9 years old (UNICEF 2014:5).

In Argentina, a 23-year old male elaborated that he had been taking ART medications all his life, and he found out only when he was 12 years old that he was taking medications all this while because he was HIV-positive (UNICEF 2014:6). The above literature demonstrated that adolescents were prenatally infected by HIV and that is why they started to take medication in the early years of their lives.

In Brazil, an adolescent mentioned that he contracted HIV when he was 15 years old after sharing injectable drugs (UNICEF 2014:9). Another adolescent from Brazil indicated that he had been living with HIV since he was born and he started taking ART at the age of 6 (UNICEF 2014:10).

Sub-theme 2.2.2: Adolescents on ART had different recollections of adherence counselling as a means of understanding their treatment

Every person who is HIV-positive has to attend pre-ART adherence counselling sessions before s/he could be initiated to ART (WHO 2013:8). According to the researcher's experience, adherence counselling sessions are held for the preparation of a patient to start ART. The sessions are held to provide in-depth information about HIV, its care and treatment, patients are assessed if they are ready to start the treatment, and possible barriers to treatment which may inhibit adherence in the long run are also assessed and discussed. In BCMCOE, Maseru, guardians are expected to attend adherence counselling sessions on behalf of their children. Adolescents are expected to attend such sessions together with their guardians. From the researcher's experience, some guardians do not want their children to be informed about their HIV status so such guardians choose to attend adherence counselling sessions alone and not with the adolescents.

As mentioned earlier, guardians reported that adolescents in the study were prenatally infected with the virus. Some of them started taking ART in the early years of their lives. Therefore, they did not attend adherence sessions; someone else attended the sessions on their behalf. During the interviews, some adolescents were not sure whether they attended adherence counselling or not, some were definitely sure that they attended those sessions. The findings reveal that those who attended adherence sessions were the ones who were diagnosed in early stage of adolescence. The following quotes were participants' responses:

"I think I did not attend them because I was young" (16-year old female).

"(Eh), I remember very well that we attended three sessions in which we were given information on what HIV is, how it can be transmitted, how it can be prevented and why I had to start meds. My CD4 was very low even though I can't remember the exact number of my CD4 cells at that time but I know it was lower than 250. We were told how ART works in the body and how important it is to take them at the same time. I was with my grand-mom" (18-year old male).

“I attended something like a training here at Baylor” (67-year old female who is taking care of 16-year old male).

Guardians are encouraged to disclose to adolescents their HIV status before they start taking ART. This is done so that adolescents can be involved in ART adherence counselling sessions as a way of encouraging optimal ART adherence (Nabukeera-Barungi, Kalyesubula, Kekitiinwa, Byakika- Tusiime & Musoke 2007:16). National AIDS Control Programme Tanzania (2013:29) pointed out that adolescents should go through adherence counselling sessions before they are initiated to ART.

In South Africa, adolescents who are eligible to take ART have to attend three preparation sessions before they can begin ART. They are initiated to the medication after completing the counselling sessions which are scheduled at weekly intervals (Patten, Wilkinson, Conradie, Isaakidis, Harries, Edginton, De Azevedo & Van Cutsem 2013:5).

Some studies revealed that adolescents who were infected prenatally are less likely to attend pre-ART adherence counselling sessions because they are initiated while they are still very young. Their guardians are the ones who attend the sessions on their behalf (Mutwa et al 2013:10; Nabukeera-Barungi et al 2007:13).

Sub-theme 2.3: Adolescents on ART explained the reasons for taking ART differently

Participants shared their various reasons why they are taking ART. They showed the knowledge and understanding of the importance of ART in the body. All the responses they provided indicated that adolescents understood that their good health depends on taking medication properly.

Two categories were identified within this sub-theme:

- Some adolescents explained that they took ART to make the HIV “sleep” and the soldiers in their bodies/ CD4 cells strong and to prevent the illness progressing to the stage of AIDS.
- Some adolescents took ART to prolong their lives, live a normal life and follow their dreams.

These categories link with Category 2.1.1 and 2.1.2 referring to the language adolescents used to describe their illness and the medication they take. The focus of the following categories is, however, the adolescents’ understanding of why they take ART.

Category 2.3.1: Some adolescents explained that they took ART to make the HIV “sleep” and the soldiers in their bodies/ CD4 cells strong to prevent the illness progressing to the stage of AIDS

As indicated earlier, adolescents understood that for HIV to be suppressed and the CD4 cells to be increased, they have to take ART. Participants pointed out that they took ART to prevent HIV from progressing to the stage of AIDS. ART has dramatically slowed down the progression of HIV, reduced the death rate from AIDS and transformed the infection from a fatal illness to a more manageable chronic illness (WHO 2012:43). Examples from the interviews are:

“I am drinking ART so that they can increase the soldiers in my body. I drink them to make HIV go to sleep” (13-year old male)

“I am taking ARVs because I don’t want to progress to the stage of AIDS. I want HIV to be drugged so that my CD4 cells can be strong enough to protect my body” (16-year old female).

“I was very sick before I started drinking ART, I was not able to play with my friends and I was not able to go to school. I don’t want to become that sick again” (12-year old male).

Category 2.3.2: Some adolescents took ART to prolong their lives, live a normal life and follow their dreams

Some adolescents showed a positive attitude towards life regardless of their HIV status. They showed the belief that if they take their medication, they could lead a normal life and follow their dreams. They understood that this could only happen if they took their medications every day as prescribed. The following statements were made:

“..... He also takes them to prolong his life” (69-year old female).

“I want to attend school so that I can be a doctor” (12-year old male).

“When a person takes ART s/he becomes healthy and does not have the signs that s/he has HIV” (16-year old female).

The findings of this study revealed that despite the knowledge and understanding of adolescents in regard of the importance of ART, they still face many challenges when it comes to ART adherence. They demonstrated knowledge and understanding that as long as HIV is not curable; their lives depend solely on the medications.

The findings discussed in this sub-theme were supported by the study of Marukutira (2012:45) in Botswana which reveal that adolescents mentioned that ART suppresses HIV and stops the progression of HIV to AIDS. A 14-year old adolescent in the study that was conducted by Kourrouski and de Lima (2009:4) in Brazil pointed out that if one desires to live longer, s/he has to take his or her medications correctly so that he/ she could live longer and have his or her own children someday. Adolescents in Brazil reported that medication adherence is a way to live and survive HIV because medication helps avoid diseases and death which would bring suffering to people with whom they live (Kourrouski & de Lima 2009:4).

Adolescents acknowledged the benefits of ART as to control the disease and improve their quality of life, however, many of them were non-adherent to ART and they justified this behaviour by the non-acceptance of the disease (Kourrouski & de Lima 2009:4).

Sub-theme 2.4: Adolescents on ART clearly understood the consequences of not adhering to treatment

Participants clearly understood the consequences of not adhering to treatment. Almost all participants were well informed about the consequences of poor adherence. They knew that non-adherence causes HIV to replicate in the body and destroy CD4 cells. They also knew that poor ART adherence increases the likelihood of the detectable viral load, which may contribute to a resistant virus. The following are representative of their opinions:

“When you have HIV, and you don’t take ART you become thin, you have ring worms and you can have TB” (16-year old female).

“HIV awakes and destroys many CD4 cells and that person can become weak and sick” (15-year old female).

“You become sick and HIV eats your soldiers and you can’t be cured and then you die. HIV cannot be cured, it only sleeps” (17-year old male).

The above findings are supported by the WHO (2013:8) by confirming that adolescents who understand their HIV status clearly understand the consequences of non-adherence to ART. The findings of the study revealed that some adolescents take medication to reduce the chances of having signs and symptoms of AIDS. WHO (2013:8) confirmed that adolescents take medication so that others may not know that they are sick. Adolescents have the understanding that poor ART adherence contribute to high rates of morbidity and mortality;

they also know that for a viral load to be undetectable, and for HIV not to progress to AIDS, there should be optimal ART adherence (Marukutira 2012:45).

Non-adherence to ART is associated with repeated hospital admissions, opportunistic infections and poor quality of life (Adefolalu & Nkosi 2013: 21; Graham, Masese, Gitau, Jalalian-Lechak, Richardson, Peshu, Mandaliya, Kiarie, Jaoko & Ndiya-Achola, Overbaugh & McClelland 2010:1540; Nachega et al, 2006:74). In Rwanda, one adolescent indicated that he stopped taking ART and his CD4 dropped to only 37 and after being re-initiated to ART again the CD4 cells increased to 200 (Mutwa et al 2013:9). This implies that adolescents know that there are consequences to be faced for suboptimal ART adherence.

Sub-theme 2.5: Adolescents on ART clearly understood when and how medication should be taken

All participants were well informed on when and how medications should be taken. They knew that medications should be taken at the same time once or twice a day depending on which treatment one is taking. During the interviews they pointed out that ART should be taken at the same time so that the HIV could not replicate in the body. They stated:

“I look at the watch and when it’s six I know I have to take them” (16-year old male).

“At 6:00 in the morning and at 6:00 in the evening” (16-year old male).

“After meals I wash my teeth and my step mom always tells us that after washing our teeth we have to drink our ART” (13-year old male).

“Once. Only in the evenings” (17-year female).

The findings of the study were supported by studies which were conducted in Botswana, Tanzania and Rwanda. In Rwanda, one adolescent mentioned that he started taking his medication regularly at the right time after his status was disclosed to him (Mutwa et al 2013:9). In Botswana, adolescents demonstrated a clear understanding of when and how medications should be taken. They pointed out that ART should be taken every day in the morning and evening (Marukutira 2012:46).

Participants acknowledged that even though it is crucial to take medication at the same time every day, it is not an easy task to do especially because ART interferes with their daily activities. Most of the participants in this study also pointed out that their guardians reminded

them to take medications. The findings of the study revealed that due to treatment fatigue that adolescents are experiencing, even though they know when and how they should take their treatment, sometimes they just ignore taking them. Sometimes they pretend as if they had already taken ART when they are reminded by their caregivers to take them. The following statements were made:

“Nowadays when I ask her if she has taken medication she would say yes even when she hasn’t taken it” (43-year old female).

“... I think she is tired of taking them...” (23-year old female).

“... Sometimes she ignores the alarm when it rings” (38-year old female).

According to Guest, Namey and Mitchell (2013:2), adolescents are informed on when and how to take their medications. Other adolescents reported that they were reminded by their caregivers to take ART when it was time to take medication (Guest, Namey & Mitchell 2013:2).

Treatment fatigue is described by Levin (2014:25) as “a condition which occurs over time to chronically ill patients who have to take a lot of medication, in which the patient stops taking pills because of the stress and monotony of constant pill swallowing”. Treatment fatigue may be caused by obstacles such as too many pills, side effects, food restriction and frequency of having to take the pills just to mention a few. Agwu and Fairlie (2013:5) point out that adolescents, especially those who were prenatally infected with HIV, are more likely to experience treatment fatigue. For them, taking ART every day becomes so monotonous that they decide to hide medication instead of taking them.

3.2.2.3 Theme 3: Various Factors influenced Adherence to ART by Adolescents in Maseru

Participants reported that there were various factors which influenced ART adherence both positively and negatively. Adolescents indicated that even though ART adherence was a challenge to them, they did not give up on life. They tried to take their medication. Adolescents indicated that they were in control of their lives; they said they were taking responsibilities such as taking medication on their own. Some acknowledged that they were forced by their life situations to take such responsibilities. Participants pointed out that support is crucial for a person who is HIV-positive. They argued that all kinds of support they were receiving motivated them to take ART every day even though it was not an easy thing to do.

Participants also acknowledged that there were factors which inhibited them from taking medication. They mentioned that factors such as lack of transport, insufficient food, size of the pills, taste of the pills, difficult home situations and negative attitudes of some staff members at BCMCOE Maseru affected their optimal adherence to ART.

Sub-theme 3.1: Various factors positively influenced adherence to ART by adolescents

Participants shared factors which influenced ART adherence positively. They stated that the support and encouragement they got from their families and care health providers helped them to improve ART adherence.

The sub-theme was divided into the following categories

- Factors in the self that positively influenced adherence to ART;
- Adolescents experienced receiving various forms of support that positively influenced adherence to ART;
- Adolescents experienced different types of social work support that positively influence adherence to ART.

Category 3.1.1: Factors in the self that positively influenced adherence to ART

Participants shared that they were taking responsibility for their lives by taking their medication. They mentioned all sorts of the reminders they used to track time so that they could take medication at the right time. Adult participants confirmed during the interviews that adolescents were the ones who were taking responsibility to take medication on time.

Some adolescents shared their dreams about the future. They acknowledged that although HIV is not curable, they still demonstrated hope that they would live a normal life and achieve some of their goals in life. They showed a positive attitude towards ART by acknowledging that if they could adhere well to ART, their lives would be prolonged and they would live a normal life.

This category can be divided into the following sub-categories:

- Taking responsibility themselves to keep track of time/watching the clock;
- Having a dream about the future;
- Believing that the medication helps.

Sub-category 3.1.1.1: Taking responsibility themselves to keep track of time/watching the clock

It was found that some adolescents were took full responsibility for taking medication. Guardians were there just to supervise them, not to dispense to them. Some guardians pointed out that they had stopped giving medication to adolescents because they wanted them to be responsible for their own medication. The following quotes are the examples of participants' expressions that show that they were tracking time themselves in order to take medication on time:

"I have an alarm watch" (12-year old male).

"I have a watch and when it is seven o'clock I take them" (17-year old female).

"I have a cell phone. No, I look at the time and take meds, I used an alarm for the first months of taking meds, now I am used to taking them, I don't need any alarm to remind me" (18-year old male).

Sub-category 3.1.1.2: Having a dream about the future

Adolescents demonstrated that they still had hope in life; they shared their dreams about the future. The following storylines were serves as proof of this:

"I want to grow up so that I can be a doctor and I want to help sick children" (16-year old male).

"I don't want to become that sick again. I want to attend school so that I can be a doctor. I want to help sick people" (12-year old male).

"I want to grow up and have children and family" (17-year old female).

Sub-category 3.1.1.3: Believing that the medication helps

Some adolescents (5 out of 16, which is 31%) showed a positive attitude towards ART. They acknowledged that medication helps them. Their opinions were as follows:

"I like them because they help me to live" (17-year old female).

"[I take ART] to suppress HIV and to prevent it from advancing to AIDS of course. I think the above reason is the main reason why I am taking them" (14-year old female).

The findings revealed that even though adolescents were not complying with their medication, they were taking some responsibility for their lives. According to Close ([sa]:328), health care providers should teach and empower adolescents to manage their medication. Family together with health-care providers should assist adolescents to be medically independent.

Kourrouski and de Lima (2009:951) found that “factors that favour medication adherence among adolescents may be subject to belief in its benefit for life and survival, to be aware that not taking medication can aggravate the illness, the desire to live and to have a future”.

Category 3.1.2: Adolescents experienced receiving various forms of support that positively influence adherence to ART

The study findings revealed that some adolescents received support in various ways. They received support inside and outside their homes. The category can be divided into the following sub-categories:

- Experiencing support at home;
- Experiencing support outside home

Sub-category 3.1.2.1: Experiencing support at home

Adolescents indicated that they received support from some family members at home. They indicated that some of the family members were always reminding them to take medication. Some were even given medications by the family members. The following remarks confirmed this:

“My sister reminds me. Sometimes she gives me sometimes she brings them to me and I take them myself” (13-year old male).

“My step mom always supports us, she told me that she wants me to be a lawyer when grow up and she said she wants my brother to be a doctor, so she said we will be those professionals only if we take our meds correctly every day. We get no other support” (15-year old female).

“I get support from my grandmother” (12-year old male).

Sub-category 3.1.2.2: Experiencing support outside home

The findings of the study revealed that adolescents also received support outside their homes. Some who were staying in the orphanages and in boarding schools pointed out that they received some form of support from the institutions. They shared as follows:

“[Not staying at the Orphanage anymore] ...because now I am staying in the boarding school. Boarding master [took care of the medicine] I think people from the orphanage told him because my meds were staying with him when I started staying in the boarding. He was the one who was giving me meds” (12-year old male).

“My aunt and the community health worker [give me support]. She is one (lady) who is living near our house and she was identified by Baylor staff member to help me to take meds. She always tells me that if I drink my ARTs I will grow up like her” (14-year old female).

“I was encouraged by a nurse from Baylor to look for a treatment supporter who can help me to give the child ARTs, that was helping me a lot because she was making sure that when I am not around my grandchild takes her ARVs but now that woman has relocated and I haven’t looked for another person who can help me while I am not around” (57-year old female taking care of 16-year old male).

Marukutira (2012:70) stated that adolescents need support from family, friends and society at large to improve adherence. Close ([sa]:328) indicated that support could help adolescents to overcome life challenges and to recover from the devastating loss of parents and the loved ones. Proper support may also help adolescents living with the virus of HIV to progress through the appropriate developmental stages and grow alongside their peers. Reda and Biadgilign (2011:2) clarified that family support plays a very important role in the improvement of ART adherence among PLWHA.

Category 3.1.3: Adolescents experienced different types of social work support that positively influenced adherence to ART

Some adolescents pointed out that they were receiving professional support from social workers and psychologists which has helped them to improve their ART adherence. The category is divided into the following sub-categories:

- Adolescents experienced support from social workers through individual counselling that increased adherence to ART;
- Adolescents experienced support from social workers through support groups that increased adherence to ART.

Sub-category 3.1.3.1: Adolescents experienced support from social workers through individual counseling that increases adherence to ART

Some adolescents pointed out that individual counselling had helped them to improve their ART adherence. They stated that social workers were supporting them through individual counselling. Some pointed out that they were being helped by psychologists. Their expressions were as follows:

“I am having sessions with the social worker and the psychologist. I am no longer sad because they told my aunt that her children are teasing me and they are the ones who told other children. The social worker said if I take ARTs correctly I will be healthy like those kids who are teasing me and I will not have AIDS” (14-year old female).

“I am seeing a psychologist. A social worker helped me by going to my place and he took my father to the hospital, he was admitted and now he is much better. The social worker also called my aunt and told her that her brother is very sick and my aunt came to help my father. He is much better now and I feel better also” (17-year old female).

Sub-category 3.1.3.2: Adolescents experienced support from social workers through support groups that improve adherence to ART

Adolescents stated that they were receiving support from social workers in the teen club. The majority of them (12 of 16 which is 75%) said that they were teen club members and they pointed out that they were enjoying being members of that support group. They mentioned that they got much information about HIV/AIDS in teen club meetings. Even those who were not members of teen club at the time of the interview wanted to be helped to join the support group. The following storylines serves as evidence:

“Yes [adolescents meet at the club]. They always teach us in teen club that we have to take our meds so that we cannot become sick. Yes, they say if we do not take our ARTs we will be sick. Yes I enjoy going to teen club” (16-year old male).

“They always advise us in the teen clubs that we have to take our meds correctly; they say we are taking meds for our own good not theirs” (17-year old female).

“Teen club is something like a support group for Baylor patients especially adolescents who are between the ages of 12-18. I did not like it at first because it is on Saturdays. When I had to hang out with my friends, they would always ask me where I was going and I had to make some excuses. I ended up not attending teen club. But I realised that I needed that support

from other adolescents who have the same problem like me so now I really enjoy going there” (18-year old male).

Psychosocial support (PSS) is crucial to adolescents and their caregivers who are infected and affected by HIV because these people need to be empowered to face any challenges related to the disease (Department of Social Development [sa]:2). PSS is the intervention that helps the child and adolescent live and copes with life stressors. It helps build resilience, and it is an on-going process (DSD [sa]:2). In the health-care setting, PSS focuses on factors such as emotional factors that are HIV-related issues like disclosure, adherence and treatment literacy, social factors which include stigma and discrimination, physical health, mental health and well-being and spiritual experiences (DSD [sa]:2). There are many activities for adolescents in the health-care settings such as support groups, individual counselling sessions, life skills coaching and peer educator programmes just to mention a few (DSD [sa]:3).

Adolescents often need repetitive education around daily living with the virus and how it will mould decisions that they make in their social lives. Family-centred family stressors and cultural factors impact on families with adolescents living with HIV. The therapeutic intervention with such families must begin with the concept of empowerment (Vranda & Mothi 2013:20).

Sub-theme 3.2: Various factors negatively influenced adherence to ART by adolescents

It was found that there were various factors which contributed to suboptimal ART adherence by adolescents in Maseru. Participants shared the contributing factors to non-adherence.

The sub-theme unfolded into the following categories:

- Factors related to poverty negatively influenced adherence to ART by adolescents;
- Various factors related to fear of stigmatization, discrimination and marginalization negatively influenced adherence to ART by adolescents;
- Medication-related factors negatively influenced ART adherence;
- Negative emotions related to taking ART negatively affected adherence;
- Poor patient-prprovider relationships had a negative influence on adherence by adolescents;
- The difficult home conditions affected adherence negatively; and
- Various factors that were intended to influence adherence to ART don't seem to improve adherence.
- Factors related to religious beliefs negatively influenced adherence to ART

Category 3.2.1: Factors related to poverty negatively influenced adherence to ART by adolescents

Participants shared that poverty was one of the challenges which contributed to suboptimal ART adherence. They mentioned that food insecurity and lack of transport money inhibited them from taking their medication. The findings of the study revealed that most of the adolescents who participated in the study were staying with their grandmothers who were not working. The only income they earned was the old age pension which was too small to meet basic needs. Some adolescents who were staying with their parents also experienced poverty. Adolescents reported that their caregivers were unemployed due to employment scarcity. Some guardians were employed in factories and their income was not enough to cover daily basic needs. The category unfolded into the following sub-categories:

- Adolescents did not take the medication due to a lack of food;
- Adolescents were unable to fetch medication from the clinic due to lack of money for transport / lack of transport.

Sub-category 3.2.1.1: Adolescents did not take the medication due to a lack of food

Adolescents preferred not to take medication if there was no food in their homes. Some adolescents mentioned that their guardians claimed that medication was not taken on an empty stomach; therefore, they were discouraged by their guardians to take medication if there was no food. These are the examples of their statements:

“Sometimes there is no food in the house and I don’t take them because grandmom said they are not taken on empty stomach” (16-year old male).

“Sometimes we don’t have food in the house so I don’t want to take them on empty stomach” [on question if someone told her not to drink medicine on an empty stomach]. “No”. (16-year old female).

“Sometimes there is no food in the house and I have to skip them because if I take them without food, I feel uncomfortable in the stomach and my stomach becomes painful” (17-year old female).

Sub-category 3.2.1.2: Adolescents were unable to fetch medication from the clinic due to a lack of money for transport

According to participants, ART medication has been subsidised by the government of Lesotho to make them accessible for everybody who needs them. The health services in Lesotho have been decentralised so that they can be easily reached. Despite the

decentralisation of the health services and the subsidised medication, some patients still have to use transport to go to the clinics, and due to high unemployment rate, participants reported that sometimes they were unable to go to the clinic due to a lack of money. They stated:

“Yes. Sometimes grandmother does not have transport money for me to go to the clinic. So I end up defaulting” (17-year old female).

“I forget to take them especially those that are taken in the morning. When the school closes I visit my grandmother who is staying in the mountains and you will find that she does not have transport money for me to go to the clinic. Even my aunt sometimes does not have money for transport and I miss appointments” (14-year old female).

“I have been staying with many people in many places, sometimes you would find that I don’t have transport money to come to the clinic for the refill” (17-year old female).

Poverty is one of the factors which contribute to suboptimal adherence among adolescents (Haberer & Mellins 2009:197; Nassen, Donald, Walker, Paruk, Vujovic, Duncan, Loughton & Moos 2014:93). In Uganda, some adolescents especially those who were staying in rural areas had poor adherence due to lack of transport money. Some were afraid to start ART because they believed that their appetite would improve and they would not have enough food (Nabukeera-Barungi et al 2007:16). In Nigeria, it was found out the most prevalent factor and major barrier to ART adherence was cost. Even though ART is heavily subsidised in the Nigeria, patients are expected to pay for their travelling costs to and from health centres to collect their medication as well as the cost of their laboratory testing. Therefore, poverty was found to be a strong determinant of suboptimal adherence in Nigeria (Monjok, Smesny, Okokon, Mgbere & Essien 2010: 71 & 74).

Category 3.2.2: Various factors related to fear of stigmatisation, discrimination and marginalisation negatively influenced adherence to ART by adolescents.

During the interviews, participants pointed out that in their communities, there were still people who lacked knowledge about HIV. Some of these people, who did not have a clear understanding of how HIV is transmitted, tended to stigmatise and discriminate against people living with HIV. Some adolescents experienced discrimination in their families and communities and some feared that they would be discriminated against.

The following sub-categories could be distinguished:

- Adolescents found it difficult to take medication in the presence of friends;
- Adolescents found it difficult to take ART when they had visitors at home;
- Adolescents were afraid of being found out and discriminated against.

Sub-category 3.2.2.1: Adolescents find it difficult to take medication in the presence of friends

Some participants clarified that they were not free to take their medication in the presence of their friends, because they had not disclosed their HIV status. They indicated that they had not disclosed their status to avoid stigmatisation and discrimination. Their statements were as follows:

“I don’t want to take them when I am in the boarding because I don’t want other children to know that I am taking them” (12-year old male).

“Sometimes she [mother] calls me when I am with my friends so I do not want them to know that I am taking ARTs” (14-year old female).

“Sometimes when we have taken school trips I don’t take them in front of other students because I do not want them to know that I am living with HIV” (16-year old male).

Sub-category 3.2.2.2: Adolescents found it difficult to take ART when they have visitors at home

The study revealed that even family members discriminated against other family members who were living with HIV. Some caregivers indicated that they had not disclosed the status of adolescents they were caring for to other family members because they felt they would be discriminated against. From the researcher’s observation, caregivers, especially mothers of adolescents, had not disclosed the HIV status of their children because they knew they would be disclosing their own HIV status. The following storylines attest to this:

“Even when there are visitors at home I don’t take them” (16-year old male).

“When there are visitors at my place, I feel ashamed of taking ARTs so I don’t take them” (16-year old female).

Sub-category 3.2.2.3: Adolescents were afraid of being found out and discriminated against

Participants indicated that fear of being discriminated against was the reason why they did not disclose their HIV status. From the researcher's experience, non-disclosure of HIV status is one of the major challenges when it comes to optimal adherence. Patients opt for missing doses when they are around people rather than taking medications. Some people saw HIV-infected patients being discriminated against, so they did not want to go through that discrimination and they decide not to disclose their status. This is clear from the following statements of participants:

"One day I was with my friends playing soccer, grand mom called me. I knew it was time for meds but I did not go because I did not want to explain to my friends that I am taking ARTs" (16-year old male).

"They will discriminate me and won't want to play with me again. No- body [should tell them], I don't want them to know" (16-year old male).

"If the alarm keeps on ringing at the same time every day other children will ask me about it and they will realise that I am drinking ARTs and they will know that I have the monster in my body" (12-year old male).

Recent studies reveal that regardless of the general knowledge of the population about HIV/AIDS and ART treatment, stigma is still a barrier to ART adherence in sub Saharan countries (Nash, Wu, Elul, Hoos & El Sadr, 2011: 1533; Ramadhani, Thielman, Landman, Ndosi, Gao, Kirchherr, Shah, Shao, Morpeth, McNeil, Shao, Bartlett & Crump 2007: 1492; Simoni, Montgomery, Martin, New, Demas & Rana 2007: e1371). Family and community members sometimes contribute to poor ART adherence by severely stigmatising children and adolescents who are living with HIV (Reda & Biadgilign 2012:2).

In Rwanda, it was reported that stigma, both perceived and experienced, hampered adolescents from both obtaining and taking their medication. Adolescents reported that they avoided going to an ART centre to collect medication because they did not want community members to see them. They also reported that sometimes they asked their family members to collect medication for them but they refused due to the fear of being seen and being labeled as living with HIV (Mutwa et al 2013:3).

According to Wolf, Halpern-Felsher, Bukusi, Kawango, Cohen and Auerswald (2014:4), most HIV-positive youths had experienced HIV-related stigmatisation from family members. This

is sometimes caused by the misinformation about HIV that leads to discrimination and poor mental health outcomes. Some family members separate the utensils used in the house if one family member had been diagnosed with HIV (Wolf et al 2014:4). In Zimbabwe, it was found that some adolescents reported stigma and discrimination both at school and at societal level. They opted for staying at home, not attending school to avoid stigma and discrimination (Macherera, Moyo, Ncube & Gumbi 2012:87).

Category 3.2.3: Medication-related factors negatively influenced ART adherence

It was revealed during the interviews that adolescents experienced poor ART adherence due to medical-related factors such as the size of the pills, number of the pills, taste of the pills, side effects and treatment fatigue. Some adolescents reported that the pills were too big to be swallowed; some said medication made them nauseous and some pointed out that they were expected to take too many pills. The category is divided into the following sub-categories

- The medication was difficult to swallow and too big;
- The medication consisted of too many different tablets /were too many; and
- The medication made them nauseous and dizzy.

Sub-category 3.2.3.1: The medication was difficult to swallow and too big

Adolescents pointed out that some of the pills they were expected to swallow were too big and they could not swallow them. They stated that they did pill-tossing because they were expected to swallow such big pills. One pharmacy technician, Ms Thafeng (20014) confirmed this during the interview with the researcher, said stated: *“the size of meds again is the problem; they say they can’t swallow them”*. Adolescents provided the following information:

“Sometimes I don’t want to take them because I can’t swallow them” (16-year old female).

“I do not want to take them anymore. Because they are too big to be swallowed.....” (15-year old male).

“Sometimes I don’t want to take them because I can’t swallow them. They are too big” (12-year old male).

Sub-category 3.2.3.2: The medication consisted of too many different tablets / were too many

It was found that too many pills also affect ART adherence. Ms Makhwanyane (2014) confirmed that adolescents who are taking many pills are less likely adherent than those who are taking few pills. She said:

“It has come to my attention that patients, especially adolescents who are on a single drug combination are more adherent than those who take three different pills of ART. People who have many illnesses also do not adhere well, for example, adolescents who take ART plus TB meds or ART plus pneumonia end up taking one drug for one illness”.

The adolescents expressed their experience as follows:

“I had TB and I was supposed to take ARVTs and TB tablets at the same time. They were many and I couldn’t take all of them at the same time, so I decided to take only TB tablets and hide the ARTs” (15-year old female).

“Sometimes I don’t want to take them because they are too many” (15-year old female).

Ms Sephaka, a nurse (2014) pointed out that *“due to pill burden, adolescents hide their meds and they lie to their caregivers about taking them especially if a caregiver is a grandparent”.*

Sub-category 3.2.3.3: The medication made them nauseous and dizzy

Some adolescents stated that there were some side-effects such as nausea and being dizzy, which were difficult to bear so they sometimes chose not to take medication, instead of taking them and facing side-effects afterwards. Baylor staff members who were interviewed clarified that side-effects and pill burden are the determinants of pill-tossing among adolescents in Maseru. The following information was taken from the transcriptions of participants:

“Sometimes I feel nausea after taking them, sometimes I feel dizzy. I don’t like them, I feel like vomiting after taking them” (15-year old male).

“They are hard to be swallowed and they are smelly. I sometimes feel dizzy after taking them” (16-year old female).

“I do not want to take them anymore. Because they are too big to be swallowed and I feel dizzy after taking them and I feel pain in my stomach” (12-year old male).

These findings were confirmed by the study of Reda and Biadgilign (2012:3), which indicated that there were medication-related factors contributing to suboptimal ART adherence. Medication taste, palatability, size of pills and adverse effects have been reported as determinants of poor adherence among adolescents in Ethiopia (Reda & Biadgilign 2012:3). Adolescents in Ethiopia reported that ART is a very complicated medication to comply with because it needs daily administration, regular dosing and dietary restrictions. It was found that pill burden (too many pills) also contributed to their non-adherent behaviour (Reda & Biadgilign 2012:3).

Some studies, however, argue that side-effects could not be associated with suboptimal adherence. Hansana, Sanchaisuriya, Durham, Sychareun, Chaleunvong, Boonyaleepun and Schelp (2013:8) argued that even though half of the adolescents they interviewed reported signs and symptoms of adverse reactions to their treatment, further analysis did not identify side-effects as being significantly related to non-adherence.

Category 3.2.4: Negative emotions related to taking ART by adolescents negatively affected adherence

Even though participants acknowledged that their good health depend solely on treatment, they demonstrated negative attitudes towards ART. Some demonstrated the feeling that to take ART is like punishment to them. Some adolescents showed some reluctance when it comes to taking medications, they pointed out that they were tired of taking medication and they did not want to continue to take it. Others felt so overwhelmed by the fact that taking ART was a lifelong sentence. All these negative emotions impacted on optimal ART adherence. The category was divided into the following sub-categories

- Adolescents experienced reluctance about taking ARTs;
- Adolescents were tired of taking ARTs;
- Adolescents felt overwhelmed by the fact that taking ARTs was a lifelong sentence.

Sub-category 3.2.4.1: Adolescents experienced reluctance toward taking ART (didn't want to)

Some participants mentioned that sometimes they just did not want to take medication; they avoided to take it even when they had remembered that they had to take it. They

experienced taking ARTs as a punishment. The following statements are representative of their opinions:

“You know, it is like a punishment, I have to be home before 7 so that I can take them. I have to come to Baylor to collect them every month. Why can’t we be given the supply of at least 6 months? When we were collecting them at Baylor before we were moved to Queen Mamohato Memorial Hospital, I did not want to go to Baylor for services because there I was meeting with neighbours and relatives who talk too much. Everybody knows that Baylor is for HIV positive children (18-year old male).

“When I have taken a school trip with other children I just ignore to take them because I don’t want them to know that I am positive” (18-year old male).

“I don’t want to go the clinic to collect ARTs every month; I want to be given three months’ supply. I have taken them long enough....” (16-year old female).

Sub-category 3.2.4.2: Adolescents were tired of taking ARTs

Ms Sekese (2014), a social worker at Baylor, indicated that their patients seemed to understand that HIV does not have a cure, but they were tired of taking their medication every day. She pointed out that some adolescents even asked if they would get medication which they could take once a month. Mr Ntlai (2014), outreach nurse, added that adolescents experienced treatment fatigue because they had started to take medication at a very young age and that was why they were tired of taking them. They verbalised this fatigue as follows:

“Sometimes I don’t want to drink them. Because my friends are not taking them, it is only me and my sister who are taking them. I am tired of taking them” (13-year old male).

“You know, tablets are tiring, for the fact that I was told that I have to take them for the rest of my life. I hate them, I really do, but I understand that I don’t have any other option but to take them” (18-year old male).

“I forget them. (Hai)! (sighing), honestly I am tired of taking them. I just feel tired of taking meds every day” (17-year old female).

Sub-category 3.2.4.3: Adolescents felt overwhelmed by the fact that taking ARTs was a lifelong sentence

Participants shared their sadness of knowing that they would be on ART as long as they were living. Their feelings were expressed as follows:

“They told me that ARTs do not cure HIV, it is the life-long treatment and they are taken at the same time every day” (43-year old female).

“Does it mean even when I am a father I will be taking them?” (13-year old male).

“[Hai!] ouch! (shaking his head). I can’t take them that long; I am tired of taking them” (13-year old male).

Marukutira’s findings in Botswana confirms that some adolescents have negative attitudes towards ART and that contribute to non-adherence (Marukutira 2012:45). In Cuba, adolescents mentioned that they had a belief that ART does more harm than good in person’s body. Some argued that they do not believe that it is important to be strict about taking medications (Aragones, Fraisl, Baes & Carmeliet 2009:20).

Adolescents whose parents are HIV-infected sometimes experience trauma of caring for a parent and perhaps, watching that parent die of AIDS. They tend to have a profound mistrust of the ART regimens, associating them with the death or illness of a parent (*Helping adolescents with HIV to adhere to HAART [sa]*) Adolescents have a belief that taking medication is as normal as not taking them (Rodriguez 2009:97).

Category 3.2.5: Poor patient-provider relationships had a negative influence on adherence by adolescents

It was found that some adolescents had been ill-treated by the health-care providers. Adolescents stated that the kind of treatment they sometimes received from health-care providers, demotivated them from coming to the clinic. Adolescents pointed out during interviews that they were no longer children, they were youth, and they would appreciate being treated with respect.

BCMCOE has introduced an adolescent user-friendly service in which adolescents are seen alone. But the findings revealed that even though the clinic is trying everything to reach out to this group of the population by offering adolescent user-friendly services, adolescents experienced ill-treatment from staff members and that demotivated them from seeking health

services at the centre. Mrs Sephaka (2014) confirmed this by saying: *“adolescents are afraid of staff members. When they have other diseases like STIs, they choose to default rather than coming to the clinic to seek help”*. The following are the comments of participants:

“They [social workers] have to talk to me nicely and the nurses, they don’t have to shout at me when I did not come for appointments or when I have not taken my ARTs. They have to encourage us not to shout at us. I know they are counted when we arrive at Baylor and if you have not taken them correctly, they shout at us [that is why she hides the ARTs when she had not taken them]. (16-year old female).

Baylor staff members [shout at us]. Not all of them, some of them” (15-year old female).

ART adherence is affected by the poor relationship between the patient and the provider. Aspects which positively affect adherence may include the patient’s opinion of the provider’s competence; the provider’s willingness to include the patient in the decision-making process; the affective tone of relationship (warmth, openness and cooperation); and the adequacy of referrals (Machtinger & Bangsberg, 2007:50).

Peralta, Belzer, April and Palmer (2007:6) pointed out that “research has demonstrated that adherence can be facilitated when a patient-provider relationship incorporates trust, good communication, adequate education about medications and an overall perception of caring, including a culturally and linguistically appropriate approach to the relationship”.

Health-care providers’ characteristics and clinical settings affect patients’ adherence. Overall patient satisfaction with the level of care is more likely to increase ART adherence (Gauchet, Targuinio & Fischer 2007:141). Long waiting times, poor staff attitudes and lack of confidentiality were found to be factors negatively influencing ART adherence in some studies (Adefolalu & Nkosi 2013:23; Simoni, Pearson, Pantalone, Marks & Grepaz 2006:S23). In this study, adolescents mentioned that they do not wait a long time at the clinic and that the service is very fast. They also stated that their information is kept confidential.

Category 3.2.6: The difficult home conditions affected adherence negatively

Participants pointed out that some conditions in their homes contributed to suboptimal adherence. Some mentioned that they were living with violent parents, some felt neglected by their parents and others had to take care of their sick grandparents and younger siblings. All these conditions affected ART adherence in one way or the other. The following are their expressions:

“When I was still staying with both my parents, they were always fighting. My father when he is drunk is very violent; he beats everybody in the house. Sometimes he would beat us and we would run away and I would not be able to take meds because I would be sleeping at the neighbour’s house” (17-year old female).

“I have to take care of my younger cousin and my grandmother who is sick, so most of the times I forget that I haven’t taken my meds” (17-year old female).

“These children have gone through a lot in life; I even don’t know where to start when relating their story which is very sad. I think they were taking ARTs properly when their mother was still alive. After the death of their mother, no one cared for them” (38-year old female).

A child’s adherence is strongly influenced by caregiver(s) and family functioning which may change over time (Haberer & Mellins 2009:198). Some adolescents are forced by circumstances to have multiple caregivers; this is sometimes caused by the death of biological parents. Caregivers may also change because of other commitments and adherence may when alternate caregivers take over (Fassinou, Elenga, Rouet, Laquide, Kouakoussui, Timite, Blanche, & Msellati 2004:1905).

Studies showed that some adolescents are forced by family circumstances to take care of their family members and some live in homes that are unstable. These factors influence suboptimal adherence by adolescents (Agwu & Fairlie 2013:5). It has been stated in some studies that poor general family functioning and greater family conflicts hinder ART adherence by adolescents. Lack of communication in the family causes family disruption which may hinder ART adherence (Avani, Modi, Pai, Hommel, Korey, Hood, Marisa, Hilliard, Guilfoyle & Gray 2012:e478).

Category 3.2.7: Various factors that were intended to influence adherence to ART didn’t seem to improve adherence

From the researcher’s point of view, there are factors which were intended to increase the levels of ART adherence by adolescents but they didn’t seem to improve adherence consistently. Although these factors are mentioned as having a positive influence on adherence (see Category 3.1), they did not always lead to improved adherence. Adolescents had alarms set, their caregivers reminded them to take medication, they had been warned about the consequences of poor adherence, but they still did not adhere well to their medications.

Adolescents pointed out that they had alarm clocks; others had cell phones on which alarms were set to remind them to take medication. They also indicated that they were reminded by their family members to take medication.

“There is an alarm in the house which reminds me when it is the time for medications. No. Sometimes it rings while I am outside playing” (15-year old female).

“[Why we changed from 7 to 6 o’clock] my stepmom said because we go to school early we have to change the time so that we can be able to take meds in the morning and in the evening. My stepmom. [bought the alarm] No. Sometimes I ignore the alarm, especially if there is something I am busy with. Sometimes I take them but sometimes I forget to take them especially if my stepmom is not around to remind me” (15-year old female).

“When you have HIV, and you don’t take ARTs you become thin, you have ring worms and you can have TB. HIV becomes awake and eats up CD4 cells and then you can become sick and die” (16-year old female).

“Yes. [I lie to my mother when she reminds me to take medicine] She forces me to drink them even when I don’t want to” (14-year old female).

Many studies recommend the use of programmable electronic medication reminders to minimise forgetfulness and improve adherence. Watch alarms, cell phone alarms, phone calls and SMS reminders are used in some countries to remind adolescents to take their medication but they ignore them and have poor adherence (Ludicello, Woods, Weber, Dawson, Scott, Carey, Grant, & HIV Neurobehavioural Research Centre (NRHC) Group 2008:799; Puccio, Belzer, Olson, Martinez, Salata et al, 2006:373; Woods, Moran, Carey, Dawson, Ludicello, Gibson, Grant & HIV Neurobehavioural Research Centre (NRHC) Group 2008:258).

In Asia Pacific, a 79-year old caregiver who was caring for a 15-year old grandson reported that she supervises him to take ART every day, but the grandson sometimes lies; he tells the grandmother that he had already taken his medication (Chandler & Ngoksin, 2013:32). The findings of Marukutira’s study show that adolescents demonstrated understanding of how beneficial ART is. However, their knowledge was not consistent with adherence level (Marukutira 2012:47).

3.2.8 Factors related to religious beliefs negatively influenced adherence

In this study, some caregivers of adolescents confirmed that the adolescents were somehow misled by religious beliefs. The following responses indicate that religion can mislead adolescents:

“She did not ask me when she wanted to join the church; she was invited by her friends who convinced her that she will be healed. She didn’t want to hear anything from anybody about ART at that time when she was still going to that church” (57-year old female caring for 15-year old granddaughter).

“Some churches preach that people are healed after being prayed for. This discourages adolescents from taking their medications, so they start rebelling against their ART. We had a case where an adolescent threw away her medication and refused to come to the centre; she was claiming that her pastor told her that she was healed...” (Ms Khesa 2014).

One outreach nurse (Mr Ntlai 2014) who was interviewed said:

“While I am doing outreach, it came to my attention that some religious caregivers do not support adolescents to take medications. Their understanding is that once the pastor has prayed for you, you become healed. So this religion issue is very complicated, but it is one of the challenges which lead into poor ART adherence by adolescents in Baylor clinic”.

Cultural activities, especially religious activities such as fasting, were found to be barriers to ART adherence in some studies. Wasti et al (2012:70) showed that religious beliefs are complex concepts and are part of the basic assumptions which shape people’s identities and strongly affect their decision-making such as taking medication on fasting days.

The findings of a study which was conducted at Makerere University, Uganda, indicated that 12% of patients discontinued ART because of a belief in spiritual healing (Wanyama, Castelnovo, Wandera, Mwebaze, Kambugu, Bangsberg & Kamya 2007:1486).

In the study that was conducted by Agyekum and Suapim (2013:141), it was revealed that a number of high school girls who were participants believed strongly that HIV/AIDS and, in fact, all opportunistic infections arising from this could be cured through anointed men of God. The girls even shared the testimonies they had heard on radio and seen on television of people who had been cured of HIV/AIDS. One girl shared her belief that her relative who tested positive was cured after receiving spiritual treatment. She confirmed that she was certain her relative was cured because the relative tested negative after going through a spiritual ceremony (Agyekum & Suapim 2013:141).

2.2.4 Theme 4: Adolescents made explicit and implicit suggestions on how social work services could improve adherence to ART by adolescents in Maseru

In this last theme, adolescents made some suggestions concerning social work services in BCMCOE Maseru. Social work as defined by IFSW (2014:1) is “a practice-based profession and academic discipline that promotes social change and development, social cohesion and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social science, humanities and indigenous knowledge, social work engages in people and structures to address life challenges and enhance wellbeing”.

Spies (2007:127) explained the role of the social worker with pediatric HIV care stating that the social worker works within the scope of a multi-disciplinary team in which all members are working together to achieve one goal, which is to provide a patient with a comprehensive service. The social worker's main role in this context is to support a patient psycho-socially for the improvement of patient's quality of life. The professional capacity of the social worker in HIV/AIDS care and treatment is to be: counsellor, negotiator, advocate, activist and coordinator, administrator and educator, researcher and programme developer (Sambo 2009:143). This theme was divided into the following sub-themes:

- Some adolescents had no suggestions on how social work services could improve adherence to ART;
- Adolescents on ART made explicit suggestions on how social work services can improve adherence to ART; and
- Adolescents on ART implied suggestions on how social work services can improve adherence to ART.

Sub-theme 4.1: Some adolescents had no suggestions on how social work services can improve adherence to ART

From the researcher's experience, some adolescents, even adults in Lesotho do not understand the role of a social worker in their day-to-day lives. Their responses were as follows:

“Nothing”. [no need] (16-year old male).

“No”. [for further support of social worker] (13-year old male).

“They cannot help me because I am not staying with them” (12-year old male).

The researcher was unable to find literature which supports or opposes the fact that adolescents had no suggestions on how social work services can improve adherence to ART.

Sub-theme 4.2: Adolescents on ART made explicit suggestions on how social work services can improve adherence to ART

Some adolescents made explicit suggestions on how social work services can help them to have optimal adherence to ART. They suggested many services which they hope would help them to increase ART adherence. The following categories were found under this sub-theme:

- Adolescents suggested individual and group counselling by social workers to improve adherence to ART;
- Adolescents suggested home visits from social workers to improve adherence to ART;
- Adolescents suggested that social workers should motivate them to take the medication;
- Adolescents suggested that social workers should facilitate education on HIV and ART especially to other children and people in the community who do not know how to treat someone with HIV;
- Adolescents suggested that social workers should advocate their needs to parents and guardians; and
- Adolescents suggested individual and group counselling from social workers to deal with other issues that are not directly related and may or may not impact on adherence to ART.

Category 4.2.1: Adolescents suggested individual and group counselling by social workers to improve adherence to ART

Some adolescents suggested individual counselling with social workers for the improvement of adherence, while others suggested group counselling. Those who suggested individual counselling stated that they were uncomfortable to speak their minds while they were in a group. So they thought one-on-one sessions would help them and they would be free to speak. The following were their comments:

“They can provide us with group counselling and individual counselling” (15-year old female).

“I am not sure about group counselling but I say individual counselling so that I can be able to be free to talk. I don’t want to talk in front of other children” (15-year old female).

“I think individual counselling can help us adolescents a lot. In teen clubs they do group counselling for us; in the group some of us are not free to talk about what is bothering us. But if there could be a time when they hold individual counselling for us it will be much better. We meet social workers only when we have not taken ARTs, I think it would be nice if we can also meet them even when we have 100% ART adherence” (18-year old male).

HIV/AIDS care, treatment, management and counselling has become a core element with psychological and emotional support which is recognised as being integrated to patient management and being essential at all stages of the HIV infection (Naidoo 2011:176). Reda and Biadgilign (2012:3) implied that both in developed and developing countries ART adherence may be influenced positively by the availability of counselling, enhancing family, as well as psychological support.

This finding was supported by the study of Ndiaye et al (2013:892) in Botswana. The Botswana study found that adolescents, who faced ART adherence challenges, were sent to a head nurse, psychologist or a social worker for individual counselling. Adolescents who knew their HIV status in Baylor Botswana joined the adolescents' support group from which they received group counselling about the virus (Ndiaye et al 2013:892).

Category 4.2.2: Adolescents suggested home visits from social workers to improve adherence to ART

Adolescents suggested home visits from social workers to improve adherence to ART. They pointed out that social workers must do home assessment to see where they lived and how they lived. One adolescent mentioned that sometimes health-care providers thought they were not telling the truth when they said that sometimes they missed medication due to lack of food. She said home assessment would help them and health care providers would understand their life conditions. These are their suggestions:

“They have to visit us in our homes so that they can see how we are living. My father does not give us money for transport when we have to come to the clinic, and they have to talk to him” (15-year old female).

“Social workers also must visit us in our homes to see how we are living and to show some support” (16-year old female).

The researcher was unable to find the written studies which support or oppose the fact that social workers' home visits and home assessment improve adherence to ART among

adolescents. From the researcher's experience, home visits are very important in the social work profession because a social worker is able to find the information that may be hidden when patients are at the health centre. The researcher found during her practice that some caregivers intended to hide the truth of their family conditions from the health-care providers. Sometimes they exaggerated the condition and sometimes they hid the conditions that might hinder optimal adherence. For the social worker to find out what exactly the family situation is, she has to conduct home visits to such families.

Category 4.2.3: Adolescents suggested that social workers should motivate them to take the medication

Participants acknowledged that to be on a lifelong treatment is not easy. They pointed out that they needed motivation from social workers so that they could be encouraged to take their medications every day. The following opinions were expressed:

"They have to motivate us now and then because, hey, we meet many life challenges out there. Lastly social workers should be friendlier so that we can feel free to approach them when we have problems" (14-year old female).

"They {social workers} should keep on reminding me to take meds when I am at the clinic" (14-year old female).

The focus of social workers who provide services to HIV patients should be on the provision of information in order to ensure the development of insight with regard to treatment and also interventions that motivate, support and promote adherence (Spies 2007:89). The social worker can motivate and provide ongoing emotional support to adolescents by employing various techniques such as clarification, catharsis, confrontation, interpretation, and offering advice (Spies 2007:97). The social worker must also explain, reflect and summarise the information that may lead to adolescents being guided successfully with respect to the development of insight into their treatment (Spies 2007:97).

Category 4.2.4: Adolescents suggested that social workers should facilitate education on HIV and ART especially to other children and people in the community who do not know how to treat someone with HIV

Participants mentioned that they needed support from social workers; they acknowledged that to be infected with HIV is very stressful, especially when the community discriminates against infected and affected families. Therefore, social workers should provide support to such families so that they (family members) could be able to conquer the discrimination

related to HIV/AIDS. They stated that the stigma and discrimination they went through would be minimised if communities could be taught about the issue of HIV. One adolescent mentioned that he did not disclose his status to his friends because he did not want to be treated like he had leprosy. The findings revealed that there were still people in the communities who lacked knowledge about HIV related issues. So the discriminated against people who are living with HIV. This was how they shared their views:

“... the social worker said if I take ARTs correctly I will be healthy like those kids who are teasing me and I will not have AIDS. He said I am lucky because I know my status, some of those children have not tested and they do not know their HIV status” (14-year old female).

“They have to go to school to teach other children about HIV so that we would easily take our medication without discrimination” (16-year old female).

From the researcher's experience, social work interventions can make a difference in combating social stigmatisation, marginalisation and discrimination. Social workers should leave their offices and go to the communities and schools to address community members about the issue of HIV/AIDS-related stigmatisation and discrimination.

Social workers should work to dispel the myths and stereotypes about HIV/AIDS. They should provide accurate information about how HIV is transmitted (Tomaszewski 2012:4). Primary and secondary education and prevention, political action and research may help social workers to combat discrimination against people living with HIV. Tomaszewski (2012:4) states that “given the high incidence of HIV, the global social work profession must take an active stance to mitigate the overwhelming psychological and social effects, including the inequality of access to medical care and lack of education and prevention of HIV/AIDS”.

Category 4.2.5: Adolescents suggested that social workers should advocate their needs to parents and guardians

It was found that some guardians do not understand the importance of a support group for adolescents. During the interview, one grandmother indicated that support groups are for adults not children, and she pointed out that during the weekend her grandson was supposed to do other family chores, not go to support groups. Adolescents expressed their feelings in the following manner:

[On what support can a social worker give]: “They can talk to aunt so that I can join teen club. I want to be the member of teen club like other children of my age and I want to go to camp” (16-year old female).

“They can convince my grandmother so that I can join teen club” (15-year old male).

It is crucial to give adequate attention to providing support to parents and guardians of adolescents living with HIV (ALWH) so that they can support adolescents (UNICEF 2013:11). Guardians should be supported continuously by being given counselling and education in order to ensure that the best interest of adolescents, and adolescents’ needs/ rights are given precedence over the preferences of parents/ guardians in all interactions and joint problem-solving (UNICEF 2012:11).

In South Africa, the Department of Social Development ([sa]:9) found that the needs of children and adolescents who are infected and affected by HIV/AIDS must be prioritised and be addressed. The study revealed that collective efforts are needed for the provision of comprehensive services which include psychosocial support (PSS) that is relevant to individual needs, particularly for children and adolescents.

Category 4.2.6: Adolescents suggested group and individual counselling from social workers to deal with other issues that were not directly related and may or may not impact on adherence to ART

Adolescents shared that sometimes they needed to talk to social workers about their problems. They stated that it would help them if social workers could have group and individual counselling with them to deal with other issues that were not directly related and may or may not impact on adherence to ART. They stated:

“I want them to convince my mother to go to my father because we really miss him and mom is not coping to take care of us alone” (17-year old female).

“They have to help us identify treatment supporters who will help the child with treatment. I think they can also help me by approaching this pastor who is misleading people. Many people will not be as lucky as my grandchild, they will die. This pastor needs to be stopped before many people die” (57-year old female).

[Needs] “Individual counselling. Sometimes I just feel that I want to talk, so if we can be allowed to talk to social workers every time we feel like talking I think it would do me good” (17-year old female).

The study revealed that adherence may be affected by other social factors. Adolescents pointed out the importance of being given time by the social workers so that they can address other issues which trouble them in their daily lives. They clarified that sometimes they feel like talking to social workers about their problems, so they have to be given the opportunity to do that every time they feel like talking.

From the researcher's observation, adolescents are scared to talk about their problems in the clinic, because they are not sure whether it is the right place to reveal one's social problems. It is the duty of all health-care providers to provide holistic care to these adolescents. They have to know that every time they are in the clinic, they have a right to talk to social workers at any time.

Sub-theme 4.3: Adolescents on ART implied suggestions on how social work services could improve adherence to ART

The findings of the study revealed that there were some ways which if applied by the professional social workers, may help adolescents improve their ART adherence. They indicated that family support, community awareness campaigns about social discrimination and social workers' advocacy for their emotional needs among health-care providers may improve ART adherence. The sub-theme unfolded into the following categories:

- Adolescents implied that social workers should facilitate family support including empathic interest instead of only controlling and supervising taking of medication;
- Adolescents implied that social workers should facilitate awareness and understanding among health workers of adolescents emotional needs related to HIV and ART.

Category 4.3.1: Adolescents implied that social workers should facilitate family support including empathic interest instead of only controlling and supervising taking of medication

The study revealed that family support may increase ART adherence. Adolescents illustrated that they needed empathy from their family members; they also felt that social workers should address community members about HIV/AIDS issues to reduce stigma and discrimination. Adolescents pointed out that social workers should advocate for their emotional needs among health care providers. The following were the opinions of participants:

“Social workers only [visit] when we have not taken ARTs, I think it would be nice if we can also meet them even when we have 100% ART adherence. They have to motivate us now and then because, hey, we meet many life challenges out there. Lastly social workers should

be friendlier so that we can feel free to approach them when we have problems” (18-year old male).

“I was send to psychologist and social worker and they told me that it is very important for me to take them so that I cannot have AIDS. I already receive their support in the counselling sessions and in teen club” (14-year old female).

Some adolescents pointed out that their caregivers were not supporting them to take ART. They felt controlled and pointed out that it would be helpful if social workers could facilitate family support which includes empathic interest instead of only controlling and supervising them to take medication.

Psychosocial support is very important to children, adolescents and their caregivers who are infected and affected by HIV. Some adolescents may be cared for by disabled or mentally handicapped primary caregivers and that may result in their being victims of various kinds of abuse (National Department of Health South Africa 2010:2). A social worker should work with a caregiver to achieve holistic psychosocial support to children and adolescents. This is particularly important when a social worker is facilitating issues such as HIV disclosure (Natioanal Department of Health South Africa 2010:2).

Category 4.3.2: Adolescents implied that social workers should facilitate awareness and understanding among health workers of adolescents emotional needs related to HIV and ART

Some participants clarified that they really needed emotional support from health-care providers. They demonstrated that there were many challenges that they met in day to day life. They needed encouragement and motivation to face such challenges. Their feelings were expressed as follows:

“I really thank some Baylor staff members who are supporting me to take care of these children. There was a time when I felt that I couldn’t support them anymore, their father would not give them transport money for their check-ups. He would say he doesn’t have money, he wouldn’t buy food in the house and I had to do everything. But Baylor staff encouraged me to continue to support them” (38-year old female).

3.3 CHAPTER SUMMARY

Four themes emerged in this study during the interviews. Themes, sub-themes, categories and sub-categories were discussed in this chapter and were supported by the interviews and literature. Participants shared their views pertaining to ART adherence. Various factors which influenced ART adherence positively and negatively were thoroughly discussed. Participants also made some suggestions on how social work services could help them improve ART adherence. The following chapter will discuss the conclusions and recommendations of the study.

CHAPTER 4

CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

The researcher outlined the research problem, goal and objectives of the study in Chapter 1. Key concepts were also defined and the methodology was briefly discussed. Chapter 2 provided a detailed description of research methodology which was applied in the study. The findings of the study which were analysed and verified by the means of literature control were discussed in Chapter 3. This chapter provides the conclusions and the recommendations of the study. Suggestions for further research will also be discussed in this chapter.

4.2 CONCLUSIONS

In this section the researcher summarises the research methodology, process and findings and draw conclusions about the process. This study was undertaken to gain an in-depth understanding of factors influencing ART adherence by adolescents in Maseru and ways in which social workers can support adolescents to increase their adherence to ART. Current evidence published in this regard is limited in Lesotho, therefore it is hoped that this study will provide crucial information to policy makers and health care providers. It is also assumed that favourable measures and interventions will be implemented.

4.2.1 Conclusions relating to the Qualitative Research Process

The goal of this study was to develop an in-depth understanding of the factors influencing adherence to antiretroviral therapy by adolescents in Maseru and their needs in relation to social worker support. In order to attain this goal, the following objectives were formulated:

- To obtain a sample of adolescents in Maseru with poor adherence to ART
- To conduct semi-structured interviews to explore factors influencing adherence to ART by adolescents in Maseru as well as social work support needed to improve adherence.
- To sift, sort and analyse data using Tesch's eight steps for qualitative data analysis as cited in Creswell (2003:192).
- To describe factors influencing adherence to ART by adolescents in Maseru
- To draw conclusions about factors influencing adherence to ART by adolescents in Maseru as well as social work support needed to improve adherence.
- To make recommendations about what can be done to improve the adherence to ART by adolescents in Maseru.

In order to reach the above goals, the researcher used the qualitative approach in this study for the in-depth understanding of factors influencing ART adherence by adolescents in Maseru. A qualitative approach allowed the researcher to explore the experiences of adolescents who were taking life-long medication and how social work support may help them to improve ART adherence from their frame of reference as well as from the perspective of the guardians caring for them. The qualitative approach has the aim of understanding experience as nearly as possible as research participants feel it or live it, therefore it was the appropriate approach to be used in this study. The researcher chose the qualitative approach because it is especially effective in obtaining culturally specific information about the values, opinions, behaviours and social contexts of particular populations. An exploratory, descriptive and contextual research design was employed in the study. The chosen research design worked very well in this study; the explorative design was used to provide greater understanding of the topic, the descriptive design helped the researcher to describe the factors which influenced adolescents not to adhere to their life-long treatment and the contextual design was useful because participants were studied in their own natural environment. It is concluded that the research design used during the qualitative research was suitable to the goal and objectives of the study. The researcher was able to categorise and interpret the participants' narratives in order to understand their experiences.

Purposive sampling was employed as a sampling technique in this research. The researcher used the purposive sampling technique to select participants who had characteristics which fitted the sampling criteria and who could share their experience of using ART. The sampling method used was appropriate because it provided information-rich and illuminative data. The sample size was determined by the data saturation.

Semi-structured interviews were used as a data collection tool. Semi-structured interviews were chosen by the researcher due to their flexibility, and this gave the researcher the opportunity to probe for views and opinions of participants. An interview guide was used as data collection instrument in order to give directions to interviews. It can be concluded that the semi-structured interviews, with the use of an interview guide, worked effectively to provide structure, yet flexibility to the researcher to gain the information which provided answers to the research question. The researcher used Tech's framework (as cited in Cresswell 2003:192) which include the eight steps for data analysis. As part of triangulation, the researcher obtained the information from adolescents, guardians and medical staff. The input of the independent coder enriched the study as patterns and themes were identified from more than one frame of reference. The researcher took steps to follow ethical

guidelines. She obtained approval from the management and the Institutional Review Board (IRB) of BCMCOE Maseru to conduct study on their premises. The researcher also obtained informed consent from participants before they participated in the study.

Based on the findings produced by following the above research process, the researcher believes that the goals and the objectives of the study were reached.

4.2.2 Conclusions relating to the Research Findings

This section describes conclusions drawn from the findings of the study according to the themes that emerged during data analysis. Four themes emerged during data analysis of this study and they will be discussed below.

4.2.2.1 Theme 1: Life experiences of adolescents on ART

The findings of this study revealed that adolescents had faced many challenges in life. It was found during the interviews that most of adolescents who were participating in the study were prenatally infected by the virus (they got HIV virus from their mothers). Some had experienced loss of one or both parents due to HIV/AIDS. Those who had lost both parents indicated that they were being taken care of by their extended family members. Some participants pointed out that their extended family members were not taking good care of them and they felt they lacked a sense of belonging. Some staff members at BCMCOE Maseru confirmed that some adolescents were not receiving good care and support in their homes. Various factors contributed to this, e.g. some relatives were not ready to live with adolescents who were diagnosed HIV positive because they were afraid of what community members would say when they found out that they were housing adolescents who were living with HIV. In some instances, adolescents were living with their stepmothers who were very ignorant about the illness. Some adolescents experienced living in orphanages due to loss of parents. Other participants stated that they were being taken care of by their grandparents who were also in need of care. They shared that their role in their families had shifted; instead of their being cared for, they were the ones who were taking care of their siblings and old grandparents.

A number of guardians were not committed to caring for the adolescents. In some families, parents were very busy or in conflict with each other, neglecting the adolescent with his/her specific needs. Adolescents stated that living with violence was very traumatising. They pointed out that some parents were fighting in front of them and sometimes they had to skip their medications because they were forced by their home situation to sleep in their neighbours' homes.

Adolescents revealed that they did not feel motivated to take their medication, due to the fact that some of their family members died of AIDS and they saw taking ART as a lifelong sentence; this led them to sub-optimal ART adherence. Most of participants had lost loved ones to HIV/AIDS. Most of them experienced disillusionment when they realised that they had to take ART for the rest of their lives while HIV is not curable. Participants shared that they experienced other illnesses apart from being HIV-positive and this caused them not to adhere to ART. They pointed out when they had other illnesses; they preferred to take treatment for the other diseases and abandoned their ART medication.

Some guardians indicated that their adolescents had poor adherence due to “religious abuse”. They stated that there were pastors from some churches who claim that they cure HIV by prayer. Adolescents abandoned their medication and went to such churches. Some adult participants clarified that adolescents were rebellious; they did not want to take their medication when they were reminded to take it, and sometimes they would pretend as if they had taken medication while they had not taken it. The findings of the study revealed that some adolescents engaged in risky sexual behaviour. Participants acknowledged that even though they were aware that unprotected sex was risky, they were practising it.

It can thus be concluded that adolescents on ART were influenced by various difficult life experiences, including their family structure, absence of understanding and support of caregivers; difficult financial circumstances; having other diseases; their own risky sexual behaviour; “abuse” by religious leaders and having lost family members to AIDS, leading to the feeling that ART is a lifelong sentence.

4.2.2.2 Theme 2: Adolescents’ understanding and knowledge of HIV and ART

The findings revealed that participants’ understanding and knowledge of HIV and ART differed. Some participants defined HIV and ART in medical terminology while others used metaphorical terminology to define HIV and ART. Adolescents who were in secondary schools used medical terms to describe HIV and ART while those who were in primary schools used metaphorical terms to describe HIV and ART. Most of adult participants who mentioned that their level of education was primary school also used metaphorical terms.

The findings of the study revealed that participants were knowledgeable about the issues concerning HIV and ART; they only differed on how they understood the information. They were able to define HIV, how it is transmitted, what it does in the body and how it can be prevented. They were also able to describe ART, how ART should be taken and the importance of ART. The researcher concluded from the interviews that in some

communities, some people such as parents, teachers and church members were taking the responsibility of conveying messages about HIV/AIDS. It is no longer the responsibility of only health-care providers to teach the community members about HIV. Caregivers stated that BCMCOE Maseru had made it easy for them to talk to adolescents about HIV because they were already being taught about the disease at the clinic during teen club meetings.

The findings also revealed that assessment of education level is crucial before information about HIV/AIDS is conveyed to another person. Social workers involved in ART adherence counselling, first have to assess patients' and their family members' level of education in order for them to provide information in a way that is appropriate to them. The study revealed that in schools also, teachers use age appropriate words to convey messages about HIV.

Participants' knowledge on how long they had been on ART differed. The study revealed that most participants were prenatally infected by HIV. Some were diagnosed at a very young age and they started to take medication while they were still young, which was why they did not know how long they had been on ART. Other adolescents were initiated to ART recently; therefore, they knew exactly how long they had been on ART. Other adolescents referred to incidents that happened when they started to take ART, but they did not know when those incidents happened.

Adolescents varied in their knowledge of the names of the medication they were taking. Some knew the names of ART they were taking, and stated that in teen club meetings, they were taught the names of their medication. They also mentioned that they were taught how to differentiate between ART treatment and other medication. Adolescents who were not members of teen club did not know the names of their medication. They were unable to differentiate between ART and other medication. Most of the adult participants also did not know the names of ART medication their adolescents were taking.

Participants shared their various reasons why they were taking ART treatment. They pointed out that they were taking ART to suppress HIV and to increase their CD4 cells. They clarified that in order for them not to progress to the stage of AIDS; they had to be on treatment. They also stated that they wanted to prolong their lives. Adolescents showed that they also wanted to live normal lives; they did not want to always be sick which was why they were taking their medication. Like any other person, adolescents also had their dreams which they wanted to pursue as they grow up. Some stated that they wanted to have families while

others indicated that they wanted to be doctors when they grew up so that they could help sick people.

From this theme, the researcher concluded that information pertaining to HIV/AIDS should be conveyed in language that is understood according to the person's level of education. The researcher also concluded that the adolescents' support group (teen club) had played a vital role in adolescents' lives. Adolescents who stated that they were members of teen club seemed more knowledgeable than those who were not members of the support group. Another conclusion drawn from this theme was that there does not seem to be a correspondence between the participants' level of understanding of the disease and its treatment and their adherence level. They knew how HIV is transmitted, how it can be managed and how dangerous sub-optimal adherence could be; however, they still did not always adhere to treatment. Even though adolescents were given the information about HIV and ART, their ART adherence was still sub-optimal.

4.2.2.3 Theme 3: Various factors influenced adherence to ART by adolescents in Maseru

Participants reported that there were various factors which influenced ART adherence both positively and negatively.

The adolescents identified positive factors inside themselves and in their environment. A number of adolescents indicated that even though ART adherence was a challenge to them, they did not give up on life. They indicated that they were in control of their lives; they mentioned that they were taking some responsibilities such as tracking time and taking medication on their own. Adolescents illustrated various reminders they were using to track time so that they could take medication at the same time every day. As indicated under the first theme, some adolescents were staying with old grandparents who could not care for them, and were thus forced by their life situations to take such responsibilities.

Adolescents acknowledged that support is very important to a person who is living with HIV. They pointed out that they received various kinds of support (support in their homes, outside their homes and from health-care providers). They shared that the kind of support they got strengthened them to take medication every day, though it was not an easy thing to do. Adolescents demonstrated that they still had hope in life and showed a positive attitude towards ART. They acknowledged that medication was helping them by preventing some opportunistic infections. They shared their dreams about their future. This showed that adolescents understood that optimal adherence prolongs their lives and they could have bright future like any other person.

Adolescents pointed out that in their homes, some family members reminded them to take their medication. Some indicated that they were given medication by their family members. Some adolescents who were staying in the orphanages and in boarding schools shared that they were also receiving support from these institutions. Other adolescents stated that they were receiving professional support from social workers and psychologists which helped them to improve their ART adherence. They pointed out that social workers provided them with individual and group counselling.

Factors such as poverty, stigma and discrimination, medication-related factors, negative emotions, poor relationship between health care providers and patients as well as difficult home conditions were mentioned as inhibitors of optimal ART adherence. Many of the participants experienced poverty, staying with parents without an income or a granny with an old-age pension. It was reported that some adolescents had to drop out of school due to financial pressure. Participants shared that food insecurity and lack of transport money inhibited them from taking their medication. They pointed out that when there was no food in their homes, they did not take their medication. They claimed that if they took medication on empty stomachs, they felt stomach pains. Some shared that they missed their appointments due to lack of transport money. Most of the interviewed participants claimed that their guardians were not working; most of them were staying with grandparents who were getting old-age pension. One adult participant pointed out that she was working in a factory and getting low wages and she was sometimes unable to give the adolescent under her care money for transport.

It was revealed during the interviews that in some communities, HIV stigma and discrimination still exists. This caused adolescents to experience sub-optimal adherence because they were afraid to take medication in front of other people, especially friends and visitors, because they did not want to disclose their status due to fear of stigma and discrimination. The study revealed that even some family members discriminated against other members who were living with HIV/AIDS. One 12-year old male participant indicated that his brother told him that he was supposed to use his own utensils and dishes because he was living with the virus. One adult participant stated that she did not want to disclose her daughter's status to other family members because she knew they would discriminate against her. Participants also mentioned that they missed doses when there were visitors at their homes. Research indicates that non-disclosure of HIV status is one major challenge to optimal adherence.

Participants indicated that medication-related factors such as the size of the pills, number of the pills, taste of the pills, side effects and treatment fatigue contributed to poor adherence. They stated that some pills were too big to be swallowed; some claimed that some pills tasted bad and they were smelly. Participants indicated that side effects such as nausea made them stop taking their medication. They pointed out they would feel nauseous every day after taking medication; therefore, they chose not to take medication. Others claimed that they were taking too many pills and they were tired of taking medication every day. As was indicated under the first theme which is 'life experience of adolescents on ART', some adolescents had illnesses other than HIV. They preferred to take medication for the other illness and defaulted on ART. One nurse at BCMCOE Maseru confirmed that adolescents were pill-tossing and had sub-optimal adherence due to pill burden.

Even though participants acknowledged that their good health depended solely on ART treatment, some still demonstrated a negative attitude towards ART. They claimed that taking ART was like punishment to them; they even said to take ART is a life sentence. Some showed reluctance when it came to taking medication and stated that they were tired of taking medication and they did not want to continue to take it. These negative emotions affected ART adherence. One of the health care providers pointed out during an interview that some adolescents were experiencing treatment fatigue because they started to take medication while they were still very young.

The findings of the study revealed that another factor which influenced poor adherence was poor provider/patient relationships. A few adolescents pointed out that some staff members were rude to them. One nurse confirmed that adolescents tend to hide other illnesses like STIs due to the rudeness of other staff members. Adolescents pointed out they were no longer children, and they would appreciate if they were treated with some respect. Others indicated that they sometimes became reluctant to go for their check-ups due to the rudeness of staff members.

Some shared that their home situations affected their adherence. They stated that they were staying in violent homes which contributed to poor adherence. Some felt neglected by their parents; one adolescent pointed out that sometimes her father did not want to give them money for transport to go for their check-ups even though the father had money. He always claimed that he did not have transport money. Other adolescents indicated that they were taking care of their siblings and grandparents, so this inhibited their optimal adherence as the roles had shifted in their homes.

It can be concluded that adolescents were trying to take charge of their lives by taking medication on their own even though they met some challenges. Another conclusion drawn from the above theme is that there were many inhibitors of optimal adherence including poverty, stigma, discrimination, adolescents' negative emotions, poor provider/patient relationships and difficult home situations.

4.2.2.4 Theme 4: Adolescents made explicit and implicit suggestions on how social work services could improve adherence to ART by adolescents in Maseru

The research findings revealed that some participants did not understand the role of a social worker in their day-to-day lives. They were not able to make suggestions because they did not understand social work services. They stated that social workers could not help them to improve adherence because the social workers were not staying with them. Some participants made explicit suggestions on how social workers could help them to improve their ART adherence. They suggested many services which they hoped would assist them with optimal adherence. They suggested that social workers should provide individual counselling. Participants pointed out that some of them were shy and felt uncomfortable to speak in a group, and suggested individual counselling. Other participants suggested group counselling. It was found during the interviews that most of adolescents who suggested group counselling were not members of the teen club.

Participants suggested that social workers should do home visits. Participants stated that health-care providers did not know the conditions they lived in, so they thought home visits would give social workers insight into their home situations. One adolescent said that social workers sometimes did not believe that they skip their medication due to food insecurity. She indicated that home assessment would help social workers to understand their home situations. From the researcher's personal work experience, some patients exaggerated about their home situations while others hid information which, in the long run, inhibited optimal ART adherence.

Adolescents suggested that social workers should always motivate them to take their medication properly. They acknowledged that to be on a lifelong treatment was not easy; therefore, they needed occasional encouragement from social workers. Participants also suggested that social workers should facilitate community education on HIV. They mentioned, as was previously indicated that some community members still discriminated against people who were living with HIV and that made them uncomfortable to disclose their HIV status and thus led to sub-optimal adherence.

Adolescents suggested that social workers should advocate for their needs to their guardians. Some adolescents pointed out that they wanted to join the teen club but their guardians did not want them to join. It was indicated during the interviews that some guardians did not understand the importance of a support group. They did not think it would benefit their children if they allowed them to join the teen club.

Participants also suggested that social workers should provide them with individual and group counselling pertaining to social issues. They pointed out that social workers should be friendlier so that they could feel free to approach them if they were facing some difficulties in life. Participants also stated that social workers should be approachable; they pointed out that sometimes they faced social challenges but they were afraid to approach social workers for advice.

Participants indicated that social workers should facilitate family support including empathetic interest. Adolescents illustrated that they needed empathy from their family members. They pointed out that if guardians could receive support from social workers, they would be able to support the adolescents and that would improve ART adherence. They implied that social workers should also facilitate awareness and understanding among other health-care providers of their emotional needs related to HIV and ART. Some participants clarified that they really needed emotional support from health care providers, not criticism. They pointed out that they were already being discriminated against in their communities and they were not expecting to be criticised at the clinic as well. They pointed out that they were shouted at by some staff members when they had missed their doses.

From the above theme, it can be concluded that social workers at BCMCOE Maseru do not do home visits nor do they do home assessment before a patient is initiated to ART medication. As mentioned earlier, through the researcher's practical experience, some patients exaggerated about their home conditions while others hid the information which could hinder optimal adherence. It can also be concluded that the suggestions made by the participants during the interviews implied that the social work department at BCMCOE Maseru should improve their services so that they could help patients to improve their ART adherence. Even though findings on the role of social workers in improving the adherence of adolescents on ART cannot be generalised, it can serve as a guideline to social workers working with adolescents with HIV/AIDS in other environments.

4.3 RECOMMENDATIONS

This section provides recommendations relating to the research process, the research findings as well as further research regarding the phenomenon under study. The goals of this study were to develop an in-depth understanding of the factors influencing adherence to antiretroviral therapy by adolescents in Maseru, as well as how social workers may help them to improve adherence. In the previous paragraphs, the researcher drew conclusions based on the findings of the study. Recommendations based on these conclusions are discussed below.

4.3.1 Recommendations pertaining to the Qualitative Research Process

From the researcher's point of view, the qualitative research approach is suitable to investigate factors which influence social behaviour (in this context, factors influencing ART adherence by adolescents and their needs for social work support) as participants could describe their behaviour and share their experiences from their own frame of reference. It is recommended to qualitative researchers consult various texts on the qualitative paradigm to have in-depth understanding of the principles of this approach (Polit & Beck 2006:212). As indicated in Chapter 4, paragraph 4.2.1, the exploratory, descriptive and contextual research design is recommended as a valuable framework when a specific focus is needed in terms of specific situation in a specific context (Bryman 2012:392). This research design is appropriate when the researcher investigates people's subjective experiences of their situations from which the researcher wants to gain an in-depth understanding and gather rich information.

The purposive, non-probability sampling technique is recommended for similar studies because participants who are selected to participate in the specific study are able to provide insights into lived experiences and data gathered would be information-rich (Sandelowski 2000:338). The use of semi-structured interviews is recommended as it is flexible and allows the researcher for more probing until data has reached the point of saturation (David & Sutton 2004:87; Gray 2004:217). An interview guide is recommended as it provides a direction from which the researcher could obtain information while focusing on answering the research questions and addressing the problem. Tech's framework for data analysis as described by Creswell (2003:192) is functional as its eight steps help the researcher to analyse data, interpret and draw conclusions based on the findings. Guba's model of data verification is recommended to be used as it allows the researcher to test the credibility, transferability, dependability and conformability. The researcher has to adhere to the ethical guidelines in order to protect participants.

4.3.2 Recommendations pertaining to Guardians

As Barbra (2014:36) stated that as family members are interconnected with and interdependent on one another, one problem can affect the entire family. The purpose of systems theory is to intervene in one or more systems in order to alleviate the existing problem. The findings of this study revealed that adolescents made suggestions of how their guardians could help them to improve ART adherence.

4.3.2.1 Empathic understanding of adolescents' experiences

It was revealed during the research that HIV stigma and discrimination still exists within communities, but also within families and peer groups. Knowledge of the challenges being on a life-long treatment, taking medication on a daily basis and coping with factors such as the size of the pills, number of the pills, taste of the pills, side effects and treatment fatigue could contribute to guardians having more empathy for the adolescents' experiences and to accept them unconditionally. The findings indicated that many participants suffered from depression due to loss of their parents. They often had to carry additional responsibility in looking after grandparents. A real understanding of the fear, shame and frustration experienced by adolescents will enable guardians to better support their adolescents to take responsibility for their treatment instead of trying to control them.

4.3.2.2 Working on a good trusting relationship and a sense of belonging

As mentioned in the conclusions, some adolescents were being taken care of by their extended family members who were not always ready to do so and who were ignorant of HIV/AIDS. Some participants pointed out that their extended family members were not taking good care of them and they felt they lacked a sense of belonging. Conflict and even violence in the family often lead to neglect of the adolescent with his/her specific needs. Knowledge about own HIV/AIDS status, the adolescent's status, the experience of having HIV/AIDS as well as proper intake of ART could form the basis of a trusting relationship, where the adolescents on life-long treatment can feel accepted, can talk openly about their challenges and feel that they belong to their family. A family where conflict is managed would create a safe environment for adolescents to adhere optimally to ART. Guardians should also motivate their adolescents to dream and set goals for themselves.

4.3.2.3 Showing interest in the adolescents' health

The conclusions indicated that not all guardians take an interest in the adolescents' health. It is recommended that guardians should understand the disease, how ART works, know the names of the medication the adolescents need to take, when and how medication should be taken. They should encourage a proper diet, provide money for transport to the clinic and

motivate them to go for regular check-ups. Whenever possible guardians could accompany the adolescents to the clinic and communicate with health care providers.

4.3.3 Recommendations pertaining to Health Care Providers

Health-care providers could help adolescents to improve their ART adherence. This include friendly, supportive and non-judgmental attitude of all health care providers. Peralta et al (2007:6) point out that “adherence can be facilitated when a patient-provider relationship incorporates trust, good communication, adequate education about medications and an overall perception of caring, including a culturally and linguistically appropriate approach to the relationship”. The following are recommendations pertaining to health care providers.

4.3.3.1 Maintaining a positive attitudes towards adolescents

The research findings indicated that ART adherence is affected by the poor relationship between the patient and the provider. Based on the feedback of participants it is recommended that health care providers treat adolescents with respect, as young people and not as children. Participants emphasised that health care providers should not shout at them. The relationship should be distinguished by warmth and openness. Adolescents should be included in decision making. Quick service delivery and confidentiality contribute to a positive relationship with the adolescents on ART and make a positive contribution towards adherence.

4.3.3.2 Explaining the role of HIV and ART educational level according to appropriate

It was concluded that adolescents who were in secondary schools used medical terms to describe HIV and ART while those who were in primary schools used metaphorical terms to describe HIV and ART. Most of adult participants who mentioned that their level of education was primary school also used metaphorical terms. It is recommended that health care providers take the educational level of both adolescents and their guardians into account when explaining the role of HIV and ART. Educating guardians will ensure that they are the primary sources of information about HIV transmission, prevention, care and management.

4.3.3.3 Preparing adolescents on what to expect during the use of ART

Health care providers should inform adolescents and their guardians in detail on what is expected during treatment e.g. knowing the names of medication they are taking, the size and taste of the medication as well as possible side-effects e.g. dizziness and nausea. Adolescents who have other opportunistic infections e.g. HIV plus TB or HIV plus pneumonia, should be informed of the importance of taking medication for HIV as well as the

other illnesses. The attitude with which this information is provided is important, so that taking ART is not portrayed as a life sentence.

4.3.3.4 Monitoring adherence through e.g. pill counts and drawing blood

Health care providers should encourage adolescents to go for regular check-ups and to monitor adherence through pill counts and blood tests before refilling prescriptions. Poor adherence should be understood and not punished. Suggestions could be made as to how adolescents can improve adherence e.g. by setting an alarm clock or having a family member reminding him/her of taking the medication at the same time of the day.

4.3.4 Recommendations pertaining to Social Workers

A social worker should work with the guardian to achieve holistic psychosocial support to adolescents. This is particularly important when a social worker is facilitating issues such as HIV disclosure and adherence to ART (Department of Health South Africa 2012:2). In the next paragraphs recommendations pertaining social workers are discussed.

4.3.4.1 Individual and group counselling

Some participants did not know what the role of a social worker can be. It is recommended that these adolescents be informed of what a social worker can do to assist them and their families.

As was explained in Chapter 1 (paragraph 1.3) adherence counselling is one-on-one sessions which are provided to a client who is about to be initiated on ART. In adherence counselling, the patient is expected to attend sessions in which information is provided on HIV/AIDS, its transmission modes, prevention, care and treatment. The barriers that may challenge adherence are assessed and addressed. A social worker does readiness assessment of a client before s/he recommends the client be initiated to ART. It is recommended that this kind of counselling is done, not only before treatment is started, but at regular intervals with both adolescents and their guardians to refresh their knowledge. It could be meaningful to develop an Individual Adherence Plan together with the adolescent in which individual and situational strengths, as well as challenges are identified and addressed.

Participants often referred to the importance of the teen club at BCMCOE Maseru. Peer groups or youth clubs can assist adolescents to feel accepted and motivate them to adhere to ART. Individual counselling is recommended to focus on issues e.g. bereavement where adolescents lost a parent or depression.

4.3.4.2 Home visits

The social worker should understand the adolescent in his or her context. Doing a home visit will enable the social worker to make an informed decision on the adolescent's readiness for ART and assess and ensure support from the family system. The social worker can also identify factors in the adolescent's environment which negatively affect adherence e.g. poverty, a lack of food or money for travelling to the clinic. Poor family relationships or conflict can also be observed. Judgemental attitudes and practices e.g. not allowing adolescents to eat with the same utensils than the family can be addressed. Practical support can be provided e.g. application for a public assistance or utilisation of community resources. Social workers should also advocate for the needs of adolescents with their guardians.

4.3.4.3 Community awareness raising

In this study, some guardians of adolescents indicated that the adolescents were misled by religious beliefs. They were convinced that praying without taking medication can heal them. This led to poor adherence to ART. Adolescents also did not want to take their medication in front of peers and family members feared to disclose the adolescents' HIV status.

It is recommended that communities should not only be informed of HIV but awareness should be raised on the experiences of individuals with HIV and their families as well as the importance of optimal adherence to ART.

4.3.4.4 Ongoing adherence motivation

Various factors were identified which positively influenced adherence to ART e.g. adolescents taking responsibility for setting an alarm, believing that medication works, utilising support inside and outside the home, as well as setting their own goals. It is recommended that social workers celebrate the adolescents' strengths and successes with them.

4.3.5 Recommendations pertaining to the Content of Adherence Programmes

When developing adherence programmes for group activities e.g. teen clubs the following should be included:

- Shared experiences e.g. adolescents who experienced negative consequences of not adhering to ART should be allowed to share with others, thus using peer education.
- Accurate information on HIV and ART

- Strategies to keep to optimal adherence e.g. taking medication at the same time every day, eating before taking medication, setting an alarm
- Relationships with guardians, their support system and the community
- Focusing on their dreams or goals.

4.3.6 Recommendations pertaining Further and Future Research

Further research is recommended on the topic of adolescents and optimal adherence to ART. This research was conducted among a small sample of adolescents in Maseru, the findings can thus not be generalised. Therefore, a further study which will involve adolescents in all districts of Lesotho will be meaningful.

Further research on the effectiveness of intervention strategies for the improvement of ART adherence by adolescents in Lesotho and elsewhere will further enrich service delivery. A cohort study, observing adolescents' adherence to ART over a number of years is recommended as adherence can vary according to the development needs and age-specific experiences of adolescents.

Further research is also recommended to understand the needs of guardians and to assess the coping mechanisms of family members whose adolescents are HIV positive. The attitude of community members towards such adolescents taking ART could also be further investigated.

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APPENDIX 1: LETTERS OF PERMISSION TO CONDUCT RESEARCH

**Ethical Declaration
Department of Social Work
University of South Africa**



Declaration

We the undersigned, hereby declare that the Masters proposal of the student named below has received ethical clearance from the Departmental Ethics Committee on the 01 October 2013.

Title of proposal:

**ADHERENCE TO ANTIRETROVIRAL THERAPY BY ADOLESCENTS IN MASERU:
INFLUENCING FACTORS AND SOCIAL WORK SUPPORT**

Student name: **MAFUSI CLAUANA BOOPA**

Student number: **4530-762-8**

Signature: _____

Name of supervisor: **Ms P Botha**

Signature: 

Date: 22/11/13

Chairperson of Departmental Ethics Committee
Prof. AH Alpaslan

Signature: 

Date: 29/11/13

The Chairperson of the Department of Social Work
Prof. L. Qalinge

Signature: 

Date: 29/11/13



University of South Africa
Pretoria School of Management & Public Governance
PO Box 9503, UNISA, 0003 South Africa
Telephone: +27 12 429 3011 Fax: +27 12 429 4135
www.unisa.ac.za



Ministry of Health
PO Box 514
Maseru 100

Date: 26 March 2014

Mafusi Claurana Boopa
Masters of Arts candidate
University of South Africa (UNISA)


Dear M.C. Boopa,

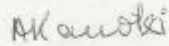
Re: Adherence to Antiretroviral therapy by adolescent in Maseru: influencing factors and social Support (ID44 -2014)

Thank you for submitting the above mentioned proposal. The Ministry of Health, Research and Ethics Committee having reviewed your protocol hereby authorizes you to conduct this study among the specified population. The study is authorized with the understanding that the protocol will be followed as stated. Departure from the stipulated protocol will constitute a breach of the permission.

We are looking forward to have a progress report and final report at the end of your study.

Sincerely,


Dr. Piet McPherson
Director General Health Services (acting)


Dr. A. Ranotsi
NH-IRB chairperson

APPENDIX 2: INFORMATION LETTER AND CONSENT FORM FOR ADOLESCENTS

Dear participants.

I Mafusi Boopa, the undersigned, am a master's student in Social Work at University of South Africa. In fulfillment of the master's degree, I have to undertake a research project and my focus will be on the following topic: **Adherence to antiretroviral therapy by adolescents in Maseru: influencing factors and social work support.**

In view of the fact that you are well informed about the topic, I hereby approach you with the request to participate in the study. I am going to give you information which will help you understand this project. The information I will provide will help you to decide whether you want to participate or not. I am going to explain to you the goal of this study and why it is crucial for this study to be undertaken. It will also be explained clearly to you how you are going to participate (i.e. what you will be asked/ or what you will be requested to do during the study, the risks and the benefits involved by participating in the research project, and your rights as a participant in the study).

This research project originated as a result of the noticeable poor adherence to ART by adolescents in Baylor Center of Excellence Lesotho and the goal is to explore and describe the factors influencing adherence to ART by adolescents as well as the role that social workers can play in improving the adherence to ART of adolescents. This kind of study is needed to be conducted so that possible solutions and interventions can be found. To participate, you must have started ART. Should you agree to participate, you would be requested to participate in an individual interview (face-to-face) that will be conducted at the Baylor Clinic from January to February 2014. The duration of the interview will be approximately one hour. The following questions will be asked:

1. General information

- (a) How old are you?
- (b) Are you a male ☐ or a female ☐

2. Antiretroviral therapy

- (a) According to your understanding what is ART?
- (b) How long have you been taking ART?
- (c) What are the reasons for you to take ART?

- (d)How were you prepared to take medication (ART)?
- (e)What happens when you do not take the medication (ART)?
- (f)What helps you to take the medication?
- (g)What makes it difficult for you to take the medication (ART)?
- (h) How do you feel about taking medication?
- (i) What support are you receiving to assist you to take the medication (ART)?
- (j) What support can a social worker give you to assist you to take the medication every day e.g. individual counselling, group counselling, other support?

The interviews will be audiotaped with your permission. The recorded interviews will be transcribed word for word. The information you will provide is very important and therefore you are requested to be sincere in your responses. I assure you that the information you give, will be handled with total confidentiality and you will not be required to identify yourself by name. The information you will provide will be locked in the cabinet to which the researcher is the only one who has access to its key. The transcripts (without any identifying information) will be made available to my research supervisor, a translator (if necessary) and an independent coder for the purpose of guiding and assisting me with this study. My research supervisor, translator and independent coder will each sign an undertaking to treat the information shared by you in a confidential manner.

Upon the completion of the study, the audiotapes and transcripts will be destroyed. The identifying information will be deleted or be disguised in any subsequent publication and/ or presentation of the research findings. Your participation in this study is voluntary and you are not bound to participate if you do not want to. If you choose not to participate, this will not affect the health services you receive from the health facility. You will receive every service that was provided to you without any prejudice. Should you agree to participate and sign the information and informed consent document herewith, as a proof of your willingness to participate, please note that you are not signing your rights away.

You can change your mind at any time during the study if you feel like you do not want to continue to participate. You are free to withdraw this consent and discontinue participation without any loss of benefits. However, if you do withdraw from the study, you would be requested to grant me an opportunity to engage in informal discussion with you so that the research partnership that was established could be terminated in an orderly manner. As a researcher, I am also bound to dismiss you from the study if the study makes you to

experience emotions or anything that can put your life into danger. I am also bound to refer you to health care providers if during your participation you experience some distress (should you agree). Furthermore, if participating in the study at any time jeopardises your safety in any way, you will be dismissed.

You have the right to ask questions concerning the study at any time. If you have question and concerns about this study, please feel free to contact me at 0719216579.

This study has been approved by the Research and Ethics Committee of the Department of Social Work at UNISA. Without the approval of this committee, the study cannot be conducted. If you have questions and queries that are not directed to me as a researcher, you are more than welcome to contact the chairperson of the Research and Ethics Committee of the Department of Social Work at UNISA. His contact details are as follows: Professor AH (Nicky) Alpaslan, telephone number 012 429 6739, or email: alpaslah@unisa.ac.za.

If you have consulted the researcher and the chairperson of the Research and Ethics Committee in the Department of Social Work and you are still not satisfied by the answers provided, feel free to conduct the chairperson of Human Ethics Committee, College of Human Science, P.O. Box 392, UNISA, 0003.

Upon the information provided to you above, and being aware of your rights, you are requested to give your written consent should you want to participate in this research study by signing and dating the information and consent form provided herewith and initialing each section to indicate that you have read and understood the information and you agree to the conditions. Your signature below means that you voluntarily agree to participate in this research study.

_____	_____	_____
Name of adolescent	Signature	Date
_____	_____	_____
Name of the parent/guardian	Signature	Date
_____	_____	_____
Name of the researcher	Signature	Date

THANK YOU FOR YOUR PARTICIPATION.

LENGOLO LA TLHALOSO LE TUMELLANO EA HO NKA KAROLO

Mocha

'Na Mafusi Boopa, ea tekenneng mona, ke moithuti lekaleng la boiketlo ba sechaba Junifesithing ea Africa Boroa. E le phihlelo ea lengolo la ka la maemo a phahameng a li kharata, ke lokela ho etsa porojeke ea patlisiso ka sehloho se latelang: **Ho se noe litlhare tsa liARV hantle hoa bacha Maseru: Lit'susumetso le thuso ho tsoa ho basebeletsi ba boiketlo ba sechaba.**

Ka kutloisiso ea hore u se u hlalositsoe ka botlalo ka sehloho sa patlisiso, ke u atamela mona ka kopo ho nka karolo patlisisong ena. Ke tlo fana ka tlhaloso ka botlalo e tla u thusa ho utloisisa projeke ena. Tlhaloso eo ke tlo fana ka eona e tla u thusa ho etsa qeto ea ho nka karolo kapa ho se e nke. Ke tlo u hlaloesetsa bohlokoa ba patlisiso ena le bohlokoa ba hore e etsoe. Ke tla fana ka tlhaloso hore na u lebeletsoe hore u nke karolo joang (se lebeletsoeng hore u se etse nakong ea patlisiso), mathata le melemo eo u ka e fumanang ka ho nka karolo porojekeng ena ea patlisiso, le litokelo tsa hau u le motho ea nkang karolo patlisisong ena.

Patlisiso ena e tsoetsoe ke ha ke hlokomela hore bacha ba Baylor ha ba noe litlhare tsa ts'oaetso hantle, sepheo ke ho nyakurela le ho hlalosa ka botebo lintlha-kholo tse susumetsang bacha ho se ts'oarelle litlhare tsa bona, le karolo eo bahlabolli ba ka e bapalang ho thusa hore bacha ba ts'oarelle le ho noa litlhare tsa bona ka nepo. Mofuta ona oa patlisiso oa hlokahala ho etsoa ele ho fumana litharollo.

Hore u nke karolo, u tlameha u be u qalile ho noa litlhare, u be u lumetse ho nka karolo, u tla koptjoa ho nka karolo puisanong ea bo mong e tla ts'oareloa setsing sa bophelo Baylor Maseru ho tloha Mots'ehanong ho fihlela Phupjane selemong se holimo. Puisano e hakanyetsoa ho nka hora. 'Me lipotso tse latelang li tla botsoa:

1. Tlhaloso kakaretso

(a). U lilemo li kae?

(b). Botona [] Bots'ehali []

2. Litlhare tsa ts'oaetso.

(a) Ho ea ka kutloisiso ea hau li ARV keng?

(b) Ke nako e kae u noa litlhare tsee?

- (c) Mabaka ao u noang li ARV ka ona ke afe?
- (d) U ile oa lokisetsoa joang ho noa litlhare?
- (e) Ho etsahalang ha u sa noe litlhare?
- (f) Keng se u thusang ho noa litlhare?
- (i) Ke ts'ehetso efe eo u e fumanang ha u noa litlhare?
- (j) Ke ts'ehetso efe eo mosebeletsi oa boiketlo ba sechaba aka u fang eona hore u noe litlhare letsatsi le letsatsi? Mohlala: tlhabollo ka bo mong, tlhabollo ea sehlopha, ts'ehetso e nngoe?

Lipuisano li tla hatisoa ka tumello ea hau. Lipuisano tse hatisitsoeng li tla ngoloa fats'e lentsoe ka lentsoe. Litaba tseo u tla fana ka tsona li bohlokoa haholo 'me u koptjoa ho fana ka maikutlo a phethahetseng likarabong tsa hau. Ke u ts'episa hore litaba tsa hau li tla nkoa le ho bolokoa ka lekunutu le leholo, hape u ke ke oa koptjoa ho itsebisa ka lebitso. Litaba tsa hau li tla bolokoa sebakeng se bolokehileng moo senotlolo sa teng se ts'oaroang ke ralipatlisiso feela. Lipampiri (tse senang litaba tse nang le boitsebiso) li tla fumants'oa motsamaisi oa ralipatlisiso le toloko (haeba ho hloka) ka sepheo sa ho ho thusa le ho tataisa ralipatlisiso patlisisong ena. Motsamaisi oa ka le toloko bat la tekena tumellano ea ho boloka litaba ka lekunutu.

Qetellong ea tumellano ena likhatiso li tla senngoa. Litaba tse nang le boitsebiso li tla hlakoloa kapa ho sebelisoa boikhakanyo phatlalatsong ea sephetho sa patlisiso ena. Ho nka karolo patlisisong ena ke boithaopo 'me ha u qobelloe ho nka karolo haeba u sa batle. Haeba u khetha ho se nke karolo, seo se ke ke sa ama lits'ebeletso tsa bophelo tseo u li tholang setsing sa bophelo. U tla nne u thole ts'ebeletso e fe kapa efe e fanoang setsing ntle ho ts'itiso ea letho. Haeba u lumela ho nka karolo, u koptjoa ho tekena tlhaloso le tokomane ena ea tumellano e le bopaki ba hore u ithaopetse ho nka karolo u sa qobelloa. Ho tekena mona ha se ho beha litokelo tsa hau kotsing.

U ka fetola maikutlo neng kapa neng nakong ea patlisiso haeba u ikutloa u se u sa batle ho nka karolo. U lokolohile ho hula tumellano ena le ho emisa ho nka karolo ntle ho tahlehelo ea melemo. Le ha ho le joalo, haeba u hula tumellano ena, ke tla u kopa ho mpha monyetla oa ho buisana le uena hore re khaole maqhama ao re neng re a thehile patlisisong ena. Ke le ralipatlisiso ke tlameha ho u lokolla patlisisong ena haeba patlisiso e u ts'oara habohloko maikutlong kapa, e beha bophelo ba hau kotsing. Hape ke tlameha ho u fetisetsa ho basebeletsi ba tsa bophelo nakong ea patlisiso haeba u ba le

bothata (haeba u ka lumela). Haeba ho nka karolo ho beha ts'ereletso ea hau kotsing ka tsela efe kapa efe, u tla llokolloa.

U na le tokelo ea ho botsa lipotso mabapi le patlisiso ena nako eohle. Haeba u na le potso kapa tlhahiso mabapi le patlisiso u ka ntetsetsa mohala nomorong ena: 071 921 6579. Patlisiso ena e lumeletsoe ke komiti ea lipatlisiso le melaoana ea boits'oaro lekaleng la tlhabollo Junifesithing ea Africa Boroa. Ntle ho tumello ea komiti ena, patlisiso e ke ke ea etsoa. Haeba u na le lipotso le litletlebo tse sa lebiseng ho nna ke le ralipatlisiso, u amohelehile ho letsetsa molula-setulo oa komiti ea lipatlisiso le melaoana ea boits'oaro lekaleng la tlhabollo Junifesithing ea Afrika Boroa. Eena ke Professor Alpalslan (Nicky), nomoro ea mohala ke 012 429 6739.

Haeba u letselits molula-setulo oa komiti ea lipatlisiso le melaoana ea boits'oaro lekaleng la tlhabollo 'me ebe ha oa khotsofalla likarabo tseo u li thotseng, u na le bolokolohi ba ho fetisetsa lipotso tsa hau ho molula-setulo oa komiti ea melaoana ea boits'oaro kolecheng ea mahlele a botho, aterese ke: P.O. Box 392, UNISA, 0003.

Ho ea ka tlhaloso eo u e fumaneng kaholimo, ebile u hlokomelitsoe litokelo tsa hau, u koptjoa ho fana ka tumello ka mongolo haeba u lakatsa ho nka karolo patlisisong ena ka ho tekena le ho ngola letsatsi la khoeli , u koptjoa ho ngola litlhaku tse qalang tsa mabitso a hau leqephe ka leng ele ho pakahatsa hore u balile oa ba oa utloisisa tlhaloso, hape u lumellana le lipehelo tsa patlisiso ena. Tekeno ea hau mona ke bopaki ba hore u lumela ho nka karolo ka boithaopo patlisisong ena.

-----	-----	-----
Mocha	Tekena	Letsatsi
_____	_____	_____
Motsoali/mohlomeli	Tekena	Letsatsi
-----	-----	-----
Ralipatlisiso	Tekena	Letsatsi

APPENDIX 3: INFORMATION LETTER AND CONSENT FORM FOR GUARDIANS

Dear participants.

I Mafusi Boopa, the undersigned, am a master's student in Social Work at University of South Africa. In fulfillment of the master's degree, I have to undertake a research project and my focus will be on the following topic: **Adherence to antiretroviral therapy by adolescents in Maseru: influencing factors and social work support.**

In view of the fact that you are well informed about the topic, I hereby approach you and your adolescent with the request to participate in the study. I am going to give you and your adolescent information which will help you understand this project. The information I will provide will help you to decide whether you and your adolescent want to participate or not. I am going to explain to you the goal of this study and why it is crucial for this study to be undertaken. It will also be explained clearly to you and your adolescent how you are going to participate (i.e. what you will be asked/ or what you will be requested to do during the study, the risks and the benefits involved by participating in the research project, and your rights as a participant in the study).

This research project originated as a result of the noticeable poor adherence to ART by adolescents in Baylor Center of Excellence Lesotho and the goal is to explore and describe the factors influencing adherence to ART by adolescents as well as the role that social workers can play in improving the adherence to ART of adolescents. This kind of study is needed to be conducted so that possible solutions and interventions can be found. To participate, your adolescent must have started ART. Should you agree to participate, you would be requested to participate in an individual interview (face-to-face) that will be conducted at the Baylor Clinic from January 2014. The duration of the interview will be approximately one hour. The following questions will be asked:

3. General information

(a) How old are you?

(b) Are you a male ☐ or a female ☐

2. Antiretroviral therapy

(a) According to your understanding what is ART?

(b) How long has the adolescent you are caring for been on ART?

(c) What are the reasons for your adolescent to take the medication (ART)?

- (d) How were you prepared to give your adolescent medication (ART)?
- (e) What makes it difficult for your adolescent to take medication (ART)?
- (f) What can help your adolescent to take medication (ART)?
- (g) Do you always supervise your adolescent when s/he takes her/his medication (ART)?
- (h) Who else supervise him/her to take medication when you are not around?
- (i) What support has you or your adolescent received to assist him/her to take the medication (ART)?
- (j) What support can a social worker give you to assist the adolescent under your care to take medication every day e.g. individual counselling, group counselling, other support?

The interviews will be audiotaped with your permission. The recorded interviews will be transcribed word for word. The information you will provide is very important and therefore you are requested to be sincere in your responses. I assure you that the information you give, will be handled with total confidentiality and you will not be required to identify yourself by name. The information you will provide will be locked in the cabinet to which the researcher is the only one who has access to its key. The transcripts (without any identifying information) will be made available to my research supervisor, a translator (if necessary) and an independent coder for the purpose of guiding and assisting me with this study. My research supervisor, translator and independent coder will each sign an undertaking to treat the information shared by you in a confidential manner.

Upon the completion of the study, the audiotapes and transcripts will be destroyed. The identifying information will be deleted or be disguised in any subsequent publication and/ or presentation of the research findings. Your participation in this study is voluntary and you are not bound to participate if you do not want to. If you choose not to participate, this will not affect the health services you or the adolescent under your care receive from the health facility. You or the adolescent under your care will receive every service that was provided to you or him/her without any prejudice. Should you agree to participate and sign the information and informed consent document herewith, as a proof of your willingness to participate, please note that you are not signing your rights away.

You can change your mind at any time during the study if you feel like you do not want to continue to participate. You are free to withdraw this consent and discontinue participation without any loss of benefits. However, if you do withdraw from the study, you would be

requested to grant me an opportunity to engage in informal discussion with you so that the research partnership that was established could be terminated in an orderly manner.

As a researcher, I am also bound to dismiss you from the study if the study makes you to experience emotions or anything that can put your life into danger. I am also bound to refer you to health care providers if during your participation you experience some distress (should you agree). Furthermore, if participating in the study at any time jeopardises your safety in any way, you will be dismissed.

You have the right to ask questions concerning the study at any time. If you have question and concerns about this study, please feel free to contact me at 0719216579.

This study has been approved by the Research and Ethics Committee of the Department of Social Work at UNISA. Without the approval of this committee, the study cannot be conducted. If you have questions and queries that are not directed to me as a researcher, you are more than welcome to contact the chairperson of the Research and Ethics Committee of the Department of Social Work at UNISA. His contact details are as follows: Professor AH (Nicky) Alpaslan, telephone number 012 429 6739, or email: alpaslah@unisa.ac.za.

If you have consulted the researcher and the chairperson of the Research and Ethics Committee in the Department of Social Work and you are still not satisfied by the answers provided, feel free to contact the chairperson of Human Ethics Committee, College of Human Science, P.O. Box 392, UNISA, 0003.

Upon the information provided to you above, and being aware of your rights, you are requested to give your written consent should you want to participate in this research study by signing and dating the information and consent form provided herewith and initialing each section to indicate that you have read and understood the information and you agree to the conditions. Your signature below means that you voluntarily agree to participate in this research study.

_____	_____	_____
Name of the parent/guardian	Signature	Date
_____	_____	_____
Name of the researcher	Signature	Date

THANK YOU FOR YOUR PARTICIPATION.

LENGOLO LA TLHALOSO LE TUMELLANO EA HO NKA KAROLO

Motsoali

'Na Mafusi Boopa, ea tekenneng mona, ke moithuti lekaleng la tlhabollo Junifesithing ea Africa Boroa. E le phihlelo ea lengolo la ka la maemo a phahameng a li kharata, ke lokela ho etsa porojeke ea patlisiso ka sehloho se latelang: **Ho se noe litlhare tsa ts'oaetso hantle hoa bacha Maseru: Lit'susumetso le thuso ho tsoa ho basebeletsi ba boiketlo ba sechaba.**

Ka kutloisiso ea hore u se u hlalositsoe ka botlalo ka sehloho sa patlisiso, ke u atamela mona ka kopo ho nka karolo patlisisong ena. Ke tlo fana ka tlhaloso ka botlalo e tla u thusa ho utloisisa projeke ena. Tlhaloso eo ke tlo fana ka eona e tla u thusa ho etsa qeto ea ho nka karolo kapa ho se e nke. Ke tlo u hlaloesetsa bohlokoa ba patlisiso ena le bohlokoa ba hore e etsoe. Ke tla fana ka tlhaloso hore na u lebeletsoe hore u nke karolo joang (se lebeletsoeng hore u se etse nakong ea patlisiso), mathata le melemo eo u ka e fumanang ka ho nka karolo porojekeng ena ea patlisiso, le litokelo tsa hau u le motho ea nkang karolo patlisisong ena.

Patlisiso ena e tsoetsoe ke ha ke hlokomela hore bacha ba Baylor ha ba noe litlhare tsa ts'oaetso hantle, sepheo ke ho nyakurela le ho hlalosa ka botebo lintlha-kholo tse susumetsang bacha ho se ts'oarelle litlhare tsa bona, le karolo eo bahlabolli ba ka e bapalang ho thusa hore bacha ba ts'oarelle le ho noa litlhare tsa bona ka nepo. Mofuta ona oa patlisiso oa hlokahala ho etsoa ele ho fumana litharollo.

Hore u nke karolo, u tlameha u be u qalile ho noa litlhare, u be u lumetse ho nka karolo, u tla koptjoa ho nka karolo puisanong ea bo mong e tla ts'oareloa setsing sa bophelo Baylor Maseru ho tloha Mots'ehanong ho fihlela Phupjane selemong se holimo. Puisano e hakanyetsoa ho nka hora. 'Me lipotso tse latelang li tla botsoa:

3. Tlhaloso kakaretso

(a). U lilemo li kae?

(b). Botona [] Bots'ehali []

4. Litlhare tsa ts'oaetso.

(a) Ho ea ka kutloisiso ea hau li ARV keng?

(b) Ke nako e kae mocha ea boikarabellong ba hau a noa litlhare tsee?

(c) Mabaka ao mocha ea tlasa tlhokomelo ea hau a noang li ARV ka ona ke afe?

- (d) U ile oa lokisetsoa joang ho thusa mocha ho noa litlhare?
- (e) Keng se etsang hore ho be thata ho mocha ho noa litlhare?
- (f) Keng se ka thusang mocha ho noa litlhare?
- (i) Ke ts'ehetso efe eo uena le mocha le e fumaneng hore a noe litlhare?
- (j) Ke ts'ehetso efe eo mosebeletsi oa boiketlo ba sechaba aka u fang eona hore u thuse mocha ho noa litlhare letsatsi le letsatsi? Mohlala: tlhabollo ka bo mong, tlhabollo ea sehlopha, ts'ehetso e nngoe?

Lipuisano li tla hatisoa ka tumello ea hau. Lipuisano tse hatisitsoeng li tla ngoloa fats'e lentsoe ka lentsoe. Litaba tseo u tla fana ka tsona li bohlokoa haholo 'me u koptjoa ho fana ka maikutlo a phethahetseng likarabong tsa hau. Ke u ts'episa hore litaba tsa hau li tla nkoa le ho bolokoa ka lekunutu le leholo, hape u ke ke oa koptjoa ho itsebisa ka lebitso. Litaba tsa hau li tla bolokoa sebakeng se bolokehileng moo senotlolo sa teng se ts'oaroang ke ralipatlisiso feela. Lipampiri (tse senang litaba tse nang le boitsebiso) li tla fumants'oa motsamaisi oa ralipatlisiso le toloko (haeba ho hloka hahala) ka sepheo sa ho thusa le ho tataisa ralipatlisiso patlisisong ena. Motsamaisi oa ka le toloko bat la tekena tumellano ea ho boloka litaba ka lekunutu.

Qetellong ea tumellano ena likhatiso li tla senngoa. Litaba tse nang le boitsebiso li tla hlakoloe kapa ho sebelisoa boikhakanyo phatlalatsong ea sephetho sa patlisiso ena. Ho nka karolo patlisisong ena ke boithaopo 'me ha u qobelloe ho nka karolo haeba u sa batle. Haeba u khetha ho se nke karolo, seo se ke ke sa ama lits'ebeletso tsa bophelo tseo u li tholang setsing sa bophelo. U tla nne u thole ts'ebeletso e fe kapa efe e fanoang setsing ntle ho ts'itiso ea letho. Haeba u lumela ho nka karolo, u koptjoa ho tekena tlhaloso le tokomane ena ea tumellano e le bopaki ba hore u ithaopetse ho nka karolo u sa qobelloa. Ho tekena mona ha se ho beha litokelo tsa hau kotsing.

U ka fetola maikutlo neng kapa neng nakong ea patlisiso haeba u ikutloa u se u sa batle ho nka karolo. U lokolohile ho hula tumellano ena le ho emisa ho nka karolo ntle ho tahlehelo ea melemo. Le ha ho le joalo, haeba u hula tumellano ena, ke tla u kopa ho mpha monyetla oa ho buisana le uena hore re khaole maqhama ao re neng re a thehile patlisisong ena. Ke le ralipatlisiso ke tlameha ho u lokolla patlisisong ena haeba patlisiso e u ts'oara habohloko maikutlong kapa, e beha bophelo ba hau kotsing. Hape ke tlameha ho u fetisetsa ho basebeletsi ba tsa bophelo nakong ea patlisiso haeba u ba le bothata (haeba u ka lumela). Haeba ho nka karolo ho beha ts'ereletso ea hau kotsing ka tsela efe kapa efe, u tla llokoloea.

U na le tokelo ea ho botsa lipotso mabapi le patlisiso ena nako eohle. Haeba u na le potso kapa tlhahiso mabapi le patlisiso u ka ntsetsa mohala nomorong ena: 071 921 6579. Patlisiso ena e lumeletsoe ke komiti ea lipatlisiso le melaoana ea boits'oaro lekaleng la tlhabollo Junifesithing ea Africa Boroa. Ntle ho tumello ea komiti ena, patlisiso e ke ke ea etsoa. Haeba u na le lipotso le litletlebo tse sa lebiseng ho nna ke le ralipatlisiso, u amohelehile ho letsetsa molula-setulo oa komiti ea lipatlisiso le melaoana ea boits'oaro lekaleng la tlhabollo Junifesithing ea Afrika Boroa. Eena ke Professor Alpalslan (Nicky), nomoro ea mohala ke 012 429 6739.

Haeba u letselits molula-setulo oa komiti ea lipatlisiso le melaoana ea boits'oaro lekaleng la tlhabollo 'me ebe ha oa khotsofalla likarabo tseo u li thotseng, u na le bolokolohi ba ho fetisetsa lipotso tsa hau ho molula-setulo oa komiti ea melaoana ea boits'oaro kolecheng ea mahlele a botho, aterese ke: P.O. Box 392, UNISA, 0003.

Ho ea ka tlhaloso eo u e fumaneng kaholimo, ebile u hlokomelitsoe litokelo tsa hau, u koptjoa ho fana ka tumello ka mongolo haeba u lakatsa ho nka karolo patlisisong ena ka ho tekena le ho ngola letsatsi la khoeli , u koptjoa ho ngola litlhaku tse qalang tsa mabitso a hau leqephe ka leng ele ho pakahatsa hore u balile oa ba oa utloisisa tlhaloso, hape u lumellana le lipehelo tsa patlisiso ena. Tekeno ea hau mona ke bopaki ba hore u lumela ho nka karolo ka boithaopo patlisisong ena.

_____	_____	_____
Motsoali/mohlomeli	Tekena	Letsatsi
-----	-----	-----
Ralipatlisiso	Tekena	Letsatsi

APPENDIX 4: REQUEST TO CONDUCT RESEARCH: BAYLOR COLLEGE OF MEDICINE

MAFUSI BOOPA
P.O. BOX 1483
REITZ PARK
WELKOM 9460
2013-08-05

THE DIRECTOR
BAYLOR COLLEGE OF MEDICINE LESOTHO
PRIVATE BAG A191
MASERU 100
LESOTHO

Dear Dr Mohapi

RE: Permission to conduct a research study

I hereby request permission to conduct a research study at your institution. I am currently enrolled in the Master's of Social Work programme at the University of South Africa and am in the process of writing my Master's thesis. The study is entitled: **Adherence to antiretroviral therapy by adolescents in Maseru: influencing factors and social work support**. The research questions of the study are:

- What are the factors influencing adherence to antiretroviral therapy by adolescents in Maseru?
- What social work support is needed to improve adherence to antiretroviral therapy by adolescents in Maseru?

I worked for BCMCOE for approximately 6 years as a social worker and I interacted with many adolescents in teen clubs and during camps. I identified that adherence to ART among adolescents is a big challenge. I identified the need for this study to be conducted as the study will provide information on why adolescents do not adhere to ART and what social work support is needed to improve adherence to ART by adolescents in Maseru.

I hope that the Baylor management will allow me to recruit adolescents who are between the ages of 12-19 years and who are not adhering to their ART to conduct individual interviews with them. I would also like to interview the guardians of these adolescents as they might provide a different view on the topic.

Interested adolescents, who volunteer to participate, will be given a consent form to be signed by them and their guardians (copy enclosed) to be returned to the researcher during the interview. Guardians who volunteer to participate will also sign the consent forms.

If approval granted, the participants will be interviewed at BCMCOE Maseru in a quiet setting on the clinic site. The interviews will be conducted on the appointment dates of participants. I humbly request the permission to interview participants when they are waiting to see the doctor. The interview is anticipated not to take longer than an hour. Information obtained during interviews will be used to identify themes and individual participants will remain anonymous while information shared, would not be linked to a specific participant. This will also apply should this study be published. No costs will be incurred by either Baylor or the individual participants.

Your approval to conduct this study will be greatly appreciated. I will follow up this letter with a telephone call in two weeks' time and would be happy to answer any questions or concerns that you may have at that time. You may contact me at: mafusiboopa@gmail.com/
mafusiboopa@yahoo.com or 0719216579/ 0722806998.

If you agree, kindly sign below and return the signed form in the enclosed envelop and I will collect the letter. Alternatively, kindly insert a signed letter of permission on your institution's letterhead acknowledging your consent and permission for me to conduct this study at your institution.

Sincerely,

Mafusi C. Boopa

Approved by

Name and title

Signature

Date

APPENDIX 5: PERMISSION TO CONDUCT RESEARCH: BAYLOR IRB

MAFUSI BOOPA
EDU- COLLEGE REITZ PARK
27 RD PHAMBILI STREET
WELKOM 9460
2013-08-05

To: Baylor IRB

RE: Permission to conduct research study

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If you agree, kindly sign below and return the signed form in the enclosed envelop and I will collect the letter. Alternatively, kindly insert a signed letter of permission on your institution's letterhead acknowledging your consent and permission for me to conduct this study at your institution.

The following documentation is provided in support of my application.

The researcher understands and accepts the following obligations to protect the rights and welfare of research subjects in this study:

- I recognise that as the researcher it is my responsibility to ensure that this research and the actions of all the project personnel involved in conducting this study will conform to the IRB requirements/ policies.
- I recognise that it is my responsibility to ensure that valid informed consent (unless explicitly waived by the IRB) has been obtained from all research subjects or their legally authorised representatives.
- I will not initiate any change in protocol without IRB approval.
- I will maintain all required research records on file: and I recognise that the IRB is authorised to inspect these records at any time.
- I will immediately inform the IRB chair and NPS Dean of Research of any untoward event or injury that involves a research participant.
- I understand that in the absence of a continuing review and approval, this research may not continue beyond the end of the approval period.
- At the completion of this project, an End- Experiment Report will be submitted.

- I will not commence this research, including subject recruitment, until I have received my NPS IRB application approval letter.

Sincerely,

Mafusi C. Boopa

Approved by

Name and title

Signature

Date

APPENDIX 6: TRANSCRIPT 9 (CODE: 009)

18-year old male

ADHERENCE AND INFLUENCING FACTORS

Interviewer: Thank you very much for your time to meet me today. How are you?

Interviewee: Um good.

Interviewer: My name is Mafusi Boopa I wish to talk to you about ART adherence, barriers for adherence and how social workers can help you to improve adherence.

Interviewee: Ok.

Interviewer: The information you are going to give me is very important; I don't want to miss anything you tell me. But very unfortunately I cannot write as fast as you talk, that is why I have brought this voice recorder to record everything you say if it is okay with you. Please speak up so that everything can be captured. I will also take some notes while you are speaking. Is that ok with you?

Interviewee: Yah.

Interviewer: The information you are about to give me will be kept confidential and it will only be shared amongst research team. Is that ok with you?

Interviewee: Yah.

Interviewer: You are not bind to communicate anything you don't want to talk about and can end the interview anytime. Do you have questions or you want clarities?

Interviewee: No.

Interviewer: Let me take this opportunity to remind you that you agreed to participate in this study and you signed the assent form. However, you are free to stop me from continuing with the interview anytime.

Interviewee: Cool.

Interviewer: Can we continue now if you still don't have questions?

Interviewee: Sure.

Interviewer: How old are you?

Interviewee: 18.

Interviewer: According to your understanding, what is ART?

Interviewee: Eh, according to my understanding ARVs are combination of drugs that are given to a person who is HIV positive and whose CD4 count is less than 350.

Interviewer: Ok. What do the ARVs do in people's bodies?

Interviewee: Eh, they increase CD4 count and they prevent HIV from replicating so that a person cannot progress to the stage of AIDS.

Interviewer: Tell me more about HIV, what is it?

Interviewee: HIV stands for Human Immunodeficiency Virus. This is the virus that only survives in human beings' blood. It destroys the CD4 cells in the body.

Interviewer: What is CD4 count?

Interviewee: Eish will I know to define this one? Hahahahaha (laughing). Let me try, I think CD4 cells are part of red blood cells which helps the body to fight illnesses that attack the body. The main work of CD4 cells is to protect the body against viruses.

Interviewer: Ok. Can you also define AIDS for me please?

Interviewee: This is Biology class straight! Eh, AIDS stands for Acquired Immunodeficiency Syndrome, it is the last stage of HIV. When the HIV virus has destroyed many CD4 cells, the body is left unprotected and many illnesses can attack the person. That person can even die.

Interviewer: Ok. How long have you been on ART?

Interviewee: I started taking ARVs in 2010 when I was 14years old, so yah, I have 4 years since I started meds.

Interviewer: Can you kindly tell me the names of ARVs you are taking?

Interviewee: Eh, I am taking TDF, 3TC and EFV.

Interviewer: How often do you take them?

Interviewee: The ones I am taking are only taken once per day.

Interviewer: At what time do you take them?

Interviewee: At 7:00 p.m.

Interviewer: What are the reasons for you to take ART?

Interviewee: To suppress HIV and to prevent it from advancing to AIDS of course.

Interviewer: Anything else why you are taking ART?

Interviewee: I think the above reason is the main reason why I am taking them.

Interviewer: Ok. How were you prepared to take medications?

Interviewee: I don't understand.

Interviewer: Let me rephrase my question, before you started medications, did you attend adherence sessions?

Interviewee: Sure.

Interviewer: Do you remember what you were told in those sessions?

Interviewee: Yah

Interviewer: What were you told?

Interviewee: Eh, I remember very well that we attended three sessions in which we were given information on what HIV is, how it can be transmitted, how it can be prevented and why I had to start meds. My CD4 was very low even though I can't remember the exact number of my CD4 cells at that time but I know it was lower than 250. We were told how ARVs work in the body and how important it is to take them at the same time.

Interviewer: With whom did you attend those sessions?

Interviewee: I was with my grandmother.

Interviewer: I see. What happens when you do not take your medications?

Interviewee: HIV becomes awake and rapidly replicate in the body and it destroys many CD4 cells.

Interviewer: What helps you to take medications?

Interviewee: I have a cell phone.

Interviewer: Have you set the alarm as a reminder for you to take meds?

Interviewee: No, I look at the time and take meds, I used alarm for the first months of taking meds, now I am used to taking them, I don't need any alarm to remind me.

Interviewer: What else helps you?

Interviewee: Grandmom.

Interviewer: Ok. What makes it difficult for you to take medications?

Interviewee: I forget them sometimes.

Interviewer: What else make it difficult for you to take medications?

Interviewee: Nothing, it is just that I sometimes forget them.

Interviewer: But earlier you said you don't need alarm to remind you to take them, now you say sometimes you forget them. Do you really forget them?

Interviewee: Yes I do forget them. You know, tablets are tiring, for the fact that I was told that I have to take them for the rest of my life I hate them, I really do but I understand that I don't have any other option but to take them. When I have taken a school trip with other children I just ignore to take them because I don't want them to know that I am positive.

Interviewer: Do you make sure that you are in the house at 7:00 every day?

Interviewee: No. Sometimes you will find that I am hanging out with my friends and I arrive home very late so I forget to take them.

Interviewer: Do your friends know that you are taking ARVs?

Interviewee: No!!!!

Interviewer: Do you think it would be wise if they knew that you are taking ARVs?

Interviewee: I don't want them to know.

Interviewer: Why?

Interviewee: I think they will treat me differently.

Interviewer: What do you mean they will treat you differently?

Interviewee: There are still people out there who still do not understand HIV. They treat people who are positive like they have leprosy.

Interviewer: Earlier you said your grandmother reminds you to take your meds?

Interviewee: Sure.

Interviewer: Do you take them every time she reminds you to take them?

Interviewee: Sometimes I take them but sometimes I lie and tell her that I have already taken them.

Interviewer: Why do you lie?

Interviewee: (kept quite).

Interviewer: How do feel about taking meds?

Interviewee: You know, it is like a punishment, I have to be home before 7 so that I can them. I have to come to Baylor to collect them every month, why can't we be given the supply of at least 6 months? When we were collecting them at Baylor before we were moved to Queen Mamohato Memorial Hospital, I did not want to go to Baylor for services because there I was meeting with neighbours and relatives who talk too much. Everybody knows that Baylor is for HIV positive children. It would be much better if there was like, eh, eh, injection which is taken for may be after every 3 months.

Interviewer: What support are you receiving to assist you to take meds?

Interviewee: I get the support from my aunt (who is a doctor at Universtas Bloem) even though I am not staying with her. She calls me every time she gets the chance and motivates me. She is my number one supporter. Grandmother also is always there for me. She took care of me when I was very sick. In teen club we support each other.

Interviewer: What support can a social worker give to assist you to take meds every day? E.g. Individual counselling, group counselling, other?

Interviewee: I think individual counselling can help us adolescents a lot. In teen clubs they do group counselling for us; in the group some of us are not free to talk about what is bothering us. But if there could be a time when they hold individual counselling for us it will be much better. We meet social workers only when we have not taken ARVs, I think it would be nice if we can also meet them even when we have 100% ART adherence. They have to motivate us now and then because, hey, we meet many life challenges out there. Lastly social workers should be more friendly so that we can feel free to approach them when we have problems.

Interviewer: Tell me more about teen club.

Interviewee: Teen club is something like a support group of Baylor patients especially adolescents who are between the ages of 12-18.

Interviewer: Ok. What do you guys do in teen club?

Interviewee: We are given more education about HIV/AIDS, ARVs and many other diseases. We are taught about life in general. We do many things in teen club.

Interviewer: How often do you go to teen club?

Interviewee: We go there every 3rd Saturday of the month.

Interviewer: Do you enjoy going to teen club?

Interviewee: I did not like it at first because it is in Saturdays when I have to hang out with my friends, they would always ask me where I was going and I had to make some excuses. I ended up not attending teen club. But I realised that I needed that support from other adolescents who have the same problem like me so now I really enjoy going there.

Interviewer: Can you encourage other teenagers who are not teen club members to join it?

Interviewee: Yah it is very important, I couldn't accept that I am HIV positive and I will live with this virus for as far as it is not curable. But now even when sometimes I don't take meds correctly, I have accepted my status and it was because of the motivation I got in teen club.

Interviewer: Thank you very much for your time. We are done. Are there any questions you have for me?

Interviewee: No

Interviewer: the information you shared with me will be analysed and it will be my pleasure to share the report with you. Thank you once again for you time.