

Barriers to highly active antiretroviral therapy amongst HIV-infected adolescents in a government hospital in Botswana

by

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A mini-dissertation submitted in partial fulfilment of the requirements for a

Masters of Social Work degree (Health Care)

MSW (HEALTH CARE)

in the

Department of Social Work and Criminology

Faculty of Humanities

University of Pretoria

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December 2015

Declaration of originality

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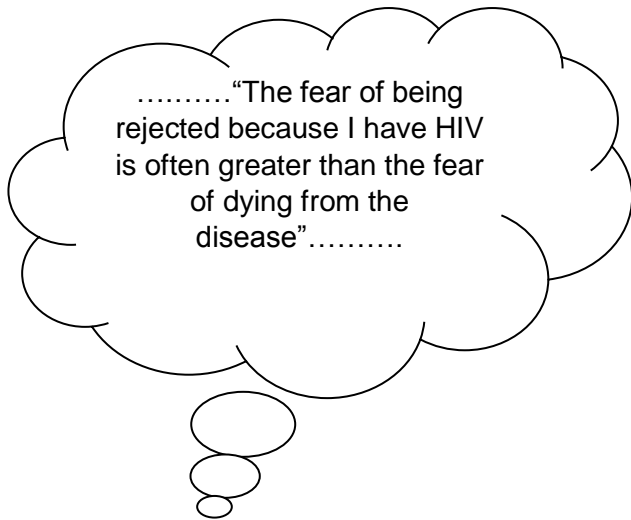
Date: 07/12/2015

Dedication

This mini-dissertation is dedicated to the Lord for the love and guidance he provided me with throughout my academic journey.

My family, my wife **Neo Judith Lemme** and our son **Omolemo Emmanuel Lemme**.

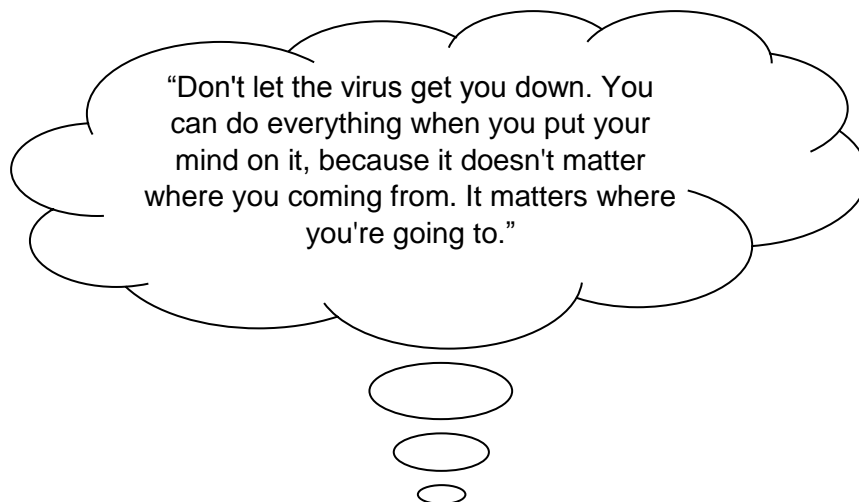
It also goes to all HIV-infected adolescents. May God give them strength and determination to live a meaningful, purposeful and prosperous life.



The voice of a 15-year-old girl living with HIV and AIDS.



The voice of a 12-year-old living with HIV and AIDS.



The voice of a 17-year-old girl living with HIV and AIDS.

Acknowledgements

Profound gratitude and appreciations are conveyed to the following:

- **Almighty God** for making everything possible.
- My supervisor, **Dr Charlene Carbonatto**, for her excellent and dedicated guidance and professional support.
- My family, **Neo Judith Lemme and Omolemo Lemme**, who have supported me throughout this academic journey.
- My sister, **Segomotso Lemme**, for translating the informed consent letter and assent letter from English to Setswana.
- Hospital management and staff of the government hospitals that took part in the pilot and the main study.
- The adolescents themselves and their parents or guardians who consented and assented to the interviews.
- **W.K. Kellogg Foundation** for their financial support in my studies.
- Research Ethics Committees from the Faculty of Humanities, **University of Pretoria** and the **Ministry of Health, Botswana** and the government hospital CEO for granting permission for the study to be conducted.

Abstract

Candidate: Thato A. Lemme.

Title: Barriers to highly active antiretroviral therapy amongst HIV-infected adolescents in a government hospital in Botswana.

Degree: MSW (Health Care).

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The emergence of the Human Immuno-Deficiency Virus (HIV) and Acquired Immuno-Deficiency Syndrome (AIDS) has resulted in many children being perinatally-infected. Some die before reaching adolescence, while others survived into adolescence due to the introduction of Highly Active Antiretroviral Therapy (HAART). Amongst countries of sub-Saharan Africa, Botswana has the highest estimated prevalence rate of HIV and AIDS which is 18.5% of a total population of 2 038 228. In 2002, Botswana became the first country in sub-Saharan Africa to launch a free national HAART programme in the public health sector. The country has achieved more than a 96% coverage rate of HAART. Despite availability of HAART, adolescence is a complex developmental phase marked with psychological, behavioural, physiological and cognitive changes. Hence, the goal of the study has been to identify barriers to HAART adherence amongst HIV-infected adolescents in a government hospital, in Botswana.

A qualitative research approach and a phenomenological research design have been utilised to explore and describe factors that inhibit HIV-infected adolescents from adhering appropriately to HAART. The study participants are twelve HIV-infected adolescents (males and females) aged 13 to 17 years who receive HAART from a government hospital in Botswana. Simple random sampling had been used to select these study participants. Unstructured, one-on-one interviews had been conducted utilising an interview schedule and the data that had been collected from the interviews has been transcribed and thematically analysed using Tesch's framework. A bio-ecological perspective has been applied to enhance understanding of this phenomenon.

The following themes emerged from the study: knowledge about HIV and AIDS and the importance of HAART adherence, contextualising and conceptualising HAART adherence amongst adolescents, factors contributing towards non-adherence to HAART amongst HIV-infected adolescents, coping strategies and recommendations.

The study findings reveal that participants displayed adequate knowledge regarding HIV and AIDS, its transmission, prevention and treatment. However, participants showed inadequate knowledge regarding the myths of HIV and AIDS. The study findings reveal further that participants are knowledgeable of the benefits of HAART adherence, methods that are being utilised to assess adherence and consequences of non-adherence. Hospital, school, home, radio, television, pamphlets, teen club and church are the major sources of information for the knowledge displayed. The results of the study show that a significant number of participants started treatment at a younger age and have been on treatment for lengthier periods. The main barriers to HAART adherence are individually-related factors, regimen or medication side effects, social stigma from school and community, and lengthy waiting times in the health facility during medication refills. However, disclosure of HIV positive status, support from family, teen club or peers, hospital, school, church and various individual strategies were utilised as coping mechanisms.

Moreover, majority of the participants were adamant that continuous education on the importance of HAART adherence by healthcare workers and caregivers is essential. They also added that medication supervision is a key strategy in enhancing adherence amongst non-adherent HIV-infected adolescents.

Recommendations include the imperativeness of a multi-sectoral approach towards strengthening education on HIV and AIDS, including the importance of HAART adherence, as well as addressing stigma and discrimination surrounding HIV and AIDS. Last of all, future research should include caregivers and healthcare workers particularly, in studies of this nature to strengthen the findings. It should also consider the effectiveness of initiatives that have been outlined to promote HAART adherence.

Key words: Adherence, adolescent, AIDS, antiretrovirals, barriers, Botswana, HAART, HIV, hospital.

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Abbreviations and acronyms

HIV: Human-Immuno-Deficiency Virus

AIDS: Acquired-Immuno-Deficiency Syndrome

HAART: Highly Active Antiretroviral Therapy

ART: Antiretroviral Therapy

ARV: Antiretroviral

WHO: World Health Organisation

UNICEF: United Nations Children's Fund

VCT: Voluntary HIV counselling and testing

MCP: Multiple concurrent partners

Cd4: Cluster of Differentiation

MOH: Ministry of Health, Botswana

TDF: Tenofovir

FTC: Emtricitabine

3TC: Lamivudine

EFV: Efavirez

AZT: Zidovudine

CTX:Co-trimoxazole

CHAPTER ONE: GENERAL INTRODUCTION

1.1. Introduction

The burden of the Human Immuno-Deficiency Virus (HIV) and Acquired Immuno-Deficiency Syndrome (AIDS) is a global problem particularly in sub-Saharan Africa. According to the United Nations Children's Fund (UNICEF), in 2012 there had been approximately 2.1 million adolescents aged between 10 and 19 years living with HIV and AIDS worldwide and about 1.5 million of them resided in sub-Saharan Africa (UNICEF, 2013:3). The introduction of Highly Active Antiretroviral Therapy or Antiretroviral Therapy which involves multi-drug combinations (nucleoside reverse transcriptase inhibitors–NRTIs, non-nucleoside transcriptase inhibitors–NNRTIs and protease inhibitors–PIs) has led to increased cluster of differentiation 4 (CD4) cell counts, decreased incidence of opportunistic infections (OIs), improved growth and development, delayed mortality and improved morbidity amongst HIV-infected adolescents (Merzel, Van Devanter & Irvine, 2008:977; Haberer, Cook, Walker et al., 2011:1). However, high levels of sustained HAART adherence are required to achieve these benefits. It is also imperative to note that failure to adhere as prescribed will lead to emergence of treatment resistant HIV strains, HIV mutations and poor virological and immunological outcomes (Merzel et al., 2008:977; Haberer et al., 2011:1).

Among the countries in sub-Saharan Africa, Botswana has the highest estimated prevalence rate of HIV and AIDS. Of a total population of 2 038 228 the prevalence rate is about 18.5% of which adolescents account for 5% (UNAIDS, 2012:32; Statistics Botswana, 2013:24). In January 2002, Botswana became the first country in sub-Saharan Africa to launch a free national HAART programme in its public health sector. Since then, the country has achieved among the world's highest coverage rates for HIV treatment delivering to more than 96% of those who need anti-retrovirals (ARVs). Consequently, many people who are HIV positive have the opportunity to live longer (UNAIDS, 2012:32). However, despite the availability of HAART, adolescence is a complex developmental phase marked with psychological, behavioural, physiological and cognitive changes and all these affect adolescents from maintaining sound HAART adherence (Rudy, Murphy, Harries et al., 2009:185). Merzel et al. (2008:984) and Li, Jaspán, O'Brien et al. (2010:755) reveal that survival amongst HIV-infected adolescents is significantly higher for those who adhere to the treatment than those who do not. The aim of this study is to identify the barriers to HAART adherence amongst HIV-infected adolescents in a government hospital in Botswana.

1.2. Clarification of key concepts

1.2.1. Human Immuno-deficiency Virus (HIV)

HIV is a virus that attacks the immune system of a person, rendering it helpless and too weak to fight illnesses. It is acquired through unprotected sexual intercourse, using or sharing unsterile syringes (behaviourally acquired) and mother-to-child transmission of HIV through pregnancy, birth and breastfeeding (perinatally-acquired) (Ross & Deverell, 2010:91). In this study, HIV-positive adolescents referred to adolescents who acquired HIV perinatally or behaviourally.

1.2.2. HIV-infected

HIV-infected refers to a person who has been diagnosed as being HIV-positive through the utilisation of HIV testing devices such as Rapid HIV antibody test, Deoxyribonucleic Acid polymerase chain reaction test (DNA-PCR), mainly used on children born to HIV-infected mothers, and Enzyme-linked immunosorbent assay (ELISA) (Ministry of Health (MOH), 2012:22-25). In this study HIV-infected will refer specifically to adolescents who are infected with the virus.

1.2.3. Adolescent

An adolescent is defined by the World Health Organisation (WHO) as a person who is between 10 and 19 years old (UNICEF, 2013:26). In this study, adolescent will refer to a person between 13 and 17 years of age in Botswana.

1.2.4. Barriers

Barriers are circumstances or obstacles that keep people or things apart, or something that prevents progress (Stevenson, 2010:134). Barriers in this study will refer to any obstacles or circumstances experienced by HIV-infected adolescents regarding their adherence to Highly Active Antiretroviral Therapy (HAART), in a government hospital in Botswana.

1.2.5. Adherence

Adherence means taking medication exactly as prescribed and at the correct times (Ross & Deverell, 2010:95). This study will refer to adherence in the context of adolescent patients with HIV and their adherence to HAART in a government hospital in Botswana.

1.2.6. Highly Active Antiretroviral Therapy

Highly Active Antiretroviral Therapy (HAART) is a treatment for people infected with HIV. The standard treatment consists of a combination of at least three drugs that suppress HIV replication, reduces mortality and morbidity, and improves quality of life. The standard first line regimen for post-pubertal adolescents and adults is NRTIs which consists of tenofovir

(TDF) + emtricitabine (FTC) or lamivudine (3TC) + NNRTIs which consists of efavirenz (EFV) as a single dose combination (MOH, 2012:38). This study will refer to HAART and adolescents on this treatment regimen in a government hospital in Botswana.

1.3. Contextualisation of topic

While contextualising the topic, the following are spelt out: knowledge amongst HIV-infected adolescents about HIV and AIDS, the importance of HAART adherence and contextualising and conceptualising HAART adherence amongst adolescents.

1.3.1. HIV and AIDS

There have been limited studies that explored the knowledge about HIV and AIDS amongst HIV-infected adolescents (Fernet, Proulx-Boucher, Richard et al., 2007:101). According to Manji, Pena and Durrow (2007:990-993), Van Dyk (2008:192) and Fernet et al. (2007:102-107) adolescents demonstrated general knowledge of HIV and AIDS. Some adolescents mentioned modes of HIV transmission such as unprotected sexual intercourse, unscreened blood transfusion, sharing of syringes especially among drug users, sexual abuse or rape and mother-to-child transmission. In contrast, participants in a study by Mahat and Scoloveno (2006a:587) did not know about the non-sexual modes of HIV transmission such as oral sex or finger play.

1.3.2. Prevention of HIV and AIDS

The adolescent participants in the studies conducted by Fernet et al. (2007:106) and Mahat and Scoloveno (2006a:587), talk about condom use as the main prevention method for HIV and AIDS. Yet some of the participants demonstrated a lack of coherence with regards to utilising condoms. On the other hand, some adolescents mentioned inconsistent condom use because they feared that disclosing their status to their partners could lead to a negative reaction and rejection. Moreover, abstinence or delayed sexual intercourse and avoidance of multiple partners are additional preventive measures (Fernet et al., 2007:107; Botswana-Baylor Children's Clinical Centre of Excellence, 2011:76).

1.3.3. Treatment and adherence to HAART

UNICEF indicates that as HIV-infected adolescents grow older, their treatment care and support needs also change and they face new challenges in adhering to medications as well as taking on greater responsibility for their own health (UNICEF, 2013:4). In a study by Botswana-Baylor Children's Clinical Centre of Excellence (2011:137), participants indicated that there is no cure for HIV and AIDS. Nonetheless, there are ARVs which should be taken as prescribed to suppress the virus and boost the immune system.

The following aspects relate to knowledge of the importance of antiretroviral treatment and adherence to HAART.

1.3.3.1. Benefits of adherence

Holele (2012:22) argues that exploring the level of knowledge on the significance of HAART adherence among HIV-infected adolescents has been minimal. Rosso, Biagio, Maggiolo et al. (2012:57) revealed that the utilisation of a one-pill, fixed-dose treatment enables participants to attain an adherence rate of 97 to 99% because it is tolerable, convenient and simple. It also reduces the number of pills that need to be taken each day. Mutwa, Van Nuil, Assimwe-Kateera et al. (2013:2-3), Van Dyk (2008:95) and Spies (2007:65) identified the following benefits of HAART adherence:

- viral load will decrease to undetectable levels;
- quality of life will improve;
- CD4 count cells will increase and remain above the baseline;
- chances of developing opportunistic infections (OIs) will be reduced;
- HIV-related illness and deaths will be reduced;
- HIV transmission will be reduced; and
- chances of drug resistance will be reduced.

1.3.3.2. Consequences of non-adherence

The shift to the utilisation of HAART for HIV and AIDS has led to increasing complex drug regimens. HAART presented significant challenges for patients and healthcare workers with regards to adherence (Van Dyk, 2008:101). Rao, Kekwaletswe, Hoske et al. (2007:28), Nglazi, Kranzer, Holele et al. (2012:2), Mutwa et al. (2013:2-3), Ross and Deverell (2010:95) and Spies (2007:79) indicate that if one is non-adherent the following virological, clinical and immunological outcomes will result:

- HIV will develop resistance to one or more drugs;
- viral load will increase and become detectable and
- CD4 count cells will decrease and the immune system will become defenceless or easily attacked by HIV-related illnesses such as Tuberculosis (TB), pneumonia, meningitis and many more.

Moreover, Agwu and Fairlie (2013:5) mentioned that the primary factors contributing to non-adherence to HAART, which may lead to severe consequences for the individual, are: pill burden or fatigue and medication side effects. However, Arrive, Dicko, Amghar et al. (2012:3) indicate that in order to deal with the consequences of non-adherence to HAART medications, healthcare workers should provide ongoing adherence support to help

adolescents who are on treatment to identify specific challenges, help them resolve these challenges or refer them to peer support groups, social workers or counsellors. Other efforts such as telephonic follow-ups and home visits are helpful in assisting adolescents to achieve positive clinical outcomes.

1.4. Rationale and significance of study

The burden of HIV and AIDS is a global problem particularly in sub-Saharan Africa (UNICEF, 2013:3). The introduction of HAART involving multiple-drug combinations has proven to be effective in reducing the mortality rate and improving the morbidity rate amongst HIV-infected adolescents (Merzel et al., 2008:997). Even though, HAART requires strict adherence to avoid poor immunological and virological outcomes, non-adherence to HAART amongst HIV-infected adolescents is a major concern that necessitates investigation (Yeap, Hamilton, Charalambos et al., 2010:1102; Merzel et al., 2008:997; Li et al., 2010:752). There have been an increasing number of HIV-infected adolescents in Botswana who are defaulting their HAART. In addition, there has been limited research to establish the main barriers to treatment adherence (Mmatli, 2010:7; Kambale, 2012:2). Rao et al. (2007:28) show that barriers to HAART adherence have been studied extensively with HIV-infected adults but not adolescents. Furthermore, Holele (2010:8) indicates that most of the studies done amongst HIV-infected adolescents are in European countries.

Moreover, other studies that have been conducted focus on the caregiver's point of view, experiences and challenges regarding the care of an HIV-infected adolescent (Holele, 2010:8). Given the increase in survival of HIV-infected adolescents due to HAART, it is becoming increasingly important to identify barriers to adherence in this population in order to design appropriate and effective interventions (Holele, 2010:8). Consequently, the researcher hopes the study at hand, will identify barriers to HAART adherence amongst HIV-infected adolescents in a government hospital in Botswana from their own point of view.

1.5. Research question

The research question that will be addressed by this study is: *What are the barriers to HAART adherence amongst HIV-infected adolescents in a government hospital in Botswana?*

1.6. Goal and objectives

The main goal of the research study is to identify the barriers to HAART adherence amongst HIV-infected adolescents in a government hospital, in Botswana.

1.6.1. Research objectives

The research objectives for this study are:

- To explore and describe the knowledge of HIV-infected adolescents regarding HIV and AIDS and the importance of adherence to HAART.
- To contextualise and conceptualise HAART adherence amongst adolescents.
- To identify and describe factors contributing to non-adherence to HAART amongst HIV-infected adolescents.
- To identify and describe coping strategies amongst HIV-infected adolescents on HAART.
- To make suggestions on measures to increase HAART adherence based on the research findings.

1.7. Overview of research design and methodology

A qualitative research approach has been utilised to establish the barriers to HAART adherence from the viewpoint of HIV-infected adolescents (Maree, 2007:78; Leedy & Ormrod, 2013:142; Kumar, 2011:64), as the topic is of a sensitive nature. A phenomenological research design has been utilised because the study at hand aims to collect rich data from adolescents telling the stories of their adherence challenges (Creswell, 2013:76; Fouché & Shurink, 2011:316). The research design has enabled the researcher to understand the phenomenon under investigation regarding the participants (what they experienced). It has also assisted the researcher in providing a description of how participants have experienced HAART adherence (Fouché & Shurink, 2011:317). The study's population are HIV-infected adolescents aged 13 to 17 years old who receive HAART in a government hospital in Botswana. The probability simple random sampling had been applied to select a sample of twelve participants (Strydom, 2011a:228).

A pilot study had been conducted in a different government hospital using two participants. Unstructured, one-on-one interviews were conducted to gather data using an interview schedule (Greeff, 2011:347-348). A digital voice recorder had been used to capture these interviews with the permission of the participants (Braun & Clarke, 2013:92) and the data has been thematically analysed using Tesch's framework (Tesch, 1990:113). Last of all, trustworthiness of data has been ensured through the following constructs: credibility, transferability, dependability and conformability (Schurink, Fouché & De Vos, 2011:419). The research design and methodology is discussed in detail in Chapter 3.

1.8. Ethical considerations

Ethical guidelines serve as standards and the basis upon which each researcher ought to evaluate his or her own conduct (Strydom, 2011b:113; Babbie, 2011:477; Braun & Clarke, 2013:61). Participations had been informed of the overall purpose of the study without any dishonesty to ensure voluntary participation. Informed consent had been obtained from participants' parents or legal guardians before the interviews were conducted, while assent had been obtained from the participants. Participants had been given codes such as 01 or 02 as pseudonyms to ensure confidentiality. After the interviews, the participants were debriefed to clarify any uncertainties yet none of them showed the need to be referred to the social worker for supportive counselling. Ethical considerations will be explicated more in Chapter 3.

1.9. Limitations of the study

The following limitations have been identified in the study.

- Recruitment of participants took longer than anticipated because a significant number of them were reluctant to partake in the study, and others declined after agreeing to be part of the study. In addition, recruitment also depended on the ARV refill dates that had been set by the hospital. Therefore, it was difficult to recruit or set appointments separate from these dates since the majority of the participants are school-going. Furthermore, most of the participants are learners and interviews had to be done within the limited time they had been granted by the school authorities to attend clinic visits. As a result, a significant number of interviews took a shorter period of time than planned and some issues were not explored adequately. However, member-checking had been possible for most of the interviews, and issues could be clarified further.
- Some of the participants were not forthcoming in revealing their non-adherence and the researcher had to probe. Others may have altered or provided incorrect information regarding their non-adherence in order to please the researcher. In this way, true data may have not been achieved and this proves to be a limitation.
- The study utilised unstructured, one-on-one interviews which were time consuming to conduct and transcribe into Setswana, the vernacular language of all interviewees. An English translation had to be provided.
- The data analysis process was time consuming as large amounts of data had to be reduced to themes and sub-themes.

- Due to the qualitative nature of the study, the sample size and variability in meaning attributed to the unique experiences of participants, implying that the findings cannot be generalised to a greater population.
- Last of all, the study did not include interviews with either healthcare workers or caregivers and such information could have strengthened the findings.

1.10. Chapter outline

Chapter one: General Introduction

This chapter provides the introduction of the study, clarification of concepts, contextualisation of topic, rationale and problem formulation, research question, goal and objectives, overview of research design, methodology and ethical issues, limitations of the study and chapter outline.

Chapter two: Literature study

This chapter focusses on literature that is relevant to the study: the bio-ecological perspective underpinning the study, knowledge amongst HIV-infected adolescents about HIV and AIDS and the importance of HAART-adherence, contextualising and conceptualising HAART adherence amongst adolescents, factors contributing to non-adherence to HAART amongst HIV-infected adolescents, coping strategies and measures to increase HAART adherence.

Chapter three: Research methodology and empirical study

In this chapter, research design and methodology is covered in detail, together with the ethical considerations. Empirical results are discussed according to a thematic analysis.

Chapter four: Conclusions and recommendations

This chapter will bring the study to a close. Conclusions and recommendations will be drawn from key findings that have emerged from the study.

The next chapter will present the literature study to enhance understanding of the research topic.

CHAPTER TWO: LITERATURE STUDY

2.1. Introduction

This chapter will detail a literature study of the topic and field of study. Emphasis will be predominantly placed on the following areas: knowledge about HIV and AIDS and the importance of Highly Active Antiretroviral Therapy (HAART) adherence amongst HIV-infected adolescents, contextualising and conceptualising HAART adherence amongst adolescents, factors contributing to non-adherence amongst HIV-infected adolescents, the participants' coping strategies and recommendations to address non-adherence problems. A bio-ecological perspective will be deliberated to facilitate a better understanding of the research topic.

2.2. Theoretical framework

According to Gray and Webb (2013:175-178) the critics of general systems theory and its perceived lack of practical application for frontline social work practice, several social work theorists began to introduce ideas from the field of ecology into social work theory. Ecological theories have been popular in the fields of sociology, anthropology and psychology prior to their introduction into social work. One of the most significant influences on the ecological perspective of social work is the work of Urie Brofenbrenner, in the 1970s. Brofenbrenner's bio-ecological perspective examines the complex interactions and relationships between an individual and his or her multiple social and physical surroundings. Brofenbrenner postulated that these surroundings are in constant interaction with one another and together they shape the human development. These surroundings are: individual system or organism, microsystem, mesosystem, exosystem, macrosystem and chronosystem (Nash, Munford & O'Donoghue, 2005:36).

The bio-ecological perspective has been chosen because it will allow the researcher to examine how complex interactions and relationships between HIV-infected adolescents on HAART and their multiple social and physical surroundings play a significant role in adherence to HAART medication. The interactions that individuals have with others as well as with the various environments are seen as key to human development (Nash et al., 2005:36).

2.2.1. Individual system or organism

An individual system refers to an individual as a client system or as an individual organism (Nash et al., 2005:37). Adolescence is a complex developmental phase marked with psychological, behavioural, physiological and cognitive changes. It is also characterised by deviation from expected or prescribed behaviour, experimentation, risk taking and significant

peer influence and all these are significant contributors of non-adherence (Nglazi et al., 2012:2; Rudy et al., 2009:185).

According to Kagee, Remien, Berkma et al. (2011:78), Midtbo, Shirima, Skovdal et al. (2012:262) and Agwu and Fairlie (2013:5) for many adolescents living with HIV and AIDS and the pressure to comply with a treatment regimen is indisputably stressful. As a result, Kamau, Kuria, Mathai et al. (2012:840) identify major depression and anxiety disorders as mental health illnesses among these adolescents. Mutwa et al. (2013:5) and Wagner, Goggin, Remien et al. (2011:353) add that these mental health illnesses disrupt the social functioning and daily living activities of a person. They affect the motivation to do anything including taking medication which may lead to a weak immune system and high viral load. Hence, Kamau et al. (2012:841) and Tanney, Naar-King, MacDonnel et al. (2011:304) recommend that HIV-infected adolescents are at risk of experiencing mental illnesses and centres providing care to them should routinely screen for these mental health disorders and intervene early with treatment options before the conditions worsen.

On the other hand, Nicastro, Continisio, Storange et al. (2013:364) find that disclosing to the child his or her HIV-positive status has been associated with good medication-taking, self-efficacy, resilience, positive expectation on medication, social support, reduced perceived stigma and fewer emotional problems as opposed to those who had not been informed of their positive status. Haberer et al. (2011:5), Mutwa et al. (2013:4) and Arrive, Dicko, Amghar et al. (2012:2) state that while disclosure is essential for secondary prevention of HIV transmission, it may heighten emotional and behavioural disorders amongst adolescents, and familial conflicts or social stigma perception may increase and these may jeopardise confidentiality. Additionally, the anger in some cases may lead to adolescents being less adherent, sometimes in an attempt to punish their parents or due to confusion about why this happened to them and not to others.

Adolescents are also confronted with numerous challenges to maintain a sound adherence. Chandiwa, Koenig, Sill et al. (2012:243), Ndiaye, Nyasulu, Nguyeni et al. (2013:894) and Agwu and Fairlie (2013:5) cite that forgetting to take medication is an issue amongst adolescents and this is attributable to a lack of motivation to prioritise medication, substance abuse, poor planning, and a busy and varying or chaotic schedule rendering them unable to integrate medication into their daily schedules. Furthermore, older adolescents mentioned that HIV medication interrupted their social life, for example when being asked for sleepover parties and having to bring their medication. Others mentioned that taking HIV treatment is overwhelming or in other words it is a 'hassle'. On the other hand, taking treatment everyday reminds these adolescents that they are 'different' and they find the thought depressing.

Some added that adolescence is a stage for one to negotiate heterosexual relationships and being HIV-positive makes it difficult as one has to disclose his or her status to the partner. Therefore, these factors may complicate an adolescent's transition towards taking responsibility in managing their illness and HAART adherence.

Haberer et al. (2011:6) and Agwu and Fairlie (2013:2) add that the influence of age and sex on adherence is notable. Older age has consistently been related to poor adherence in both resource-rich and limited countries, with adolescents above 15 years of age having a greater risk of non-adherence in comparison to younger adolescents. Girls had poorer adherence than boys. Despite the challenges alluded to earlier, Van Dyk (2008:107) identifies some routine activities to which taking medication can be linked – taking HAART when brushing teeth in the mornings and evenings; and using a radio or television programme as a reminder but it should be a programme that the patient always watches or listen to and it should start or end at the time he or she has to take the medication. Lowenthal, Jibril, Sechele et al. (2014:146) add that adherence counselling is crucial because it enlightens HIV-infected adolescents about the importance of treatment and it should be an ongoing part of clinical care appointment for early identification of non-adherence issues.

Balthip and Purnell (2014:33) and Veinot, Flicker, Skinner et al. (2006:265) add that determination, accepting oneself as being HIV-positive and accepting that dying and death are part of life are some of the important elements in finding meaning and purpose in life to cope with being HIV-positive. Some adolescents mention that they have utilised medication diaries, pill box and alarm clocks to deal with some of the above mentioned challenges (Park & Nachman, 2010:559; Orban, Stein, Koenig et al., 2010:424-425; Mutwa et al., 2013:5-6). Some participants mention that they have lived for more than 10 years while taking ART to prolong life. They know that taking care of themselves will prolong their lives.

Campbell, Skovdal, Mupambireyi et al. (2012:128) and the MOH (2012:36) indicate that a treatment 'buddy' or partner plays an important role in providing the patient with ongoing support for adherence to care and treatment. This person is usually someone close to the adolescent – a family member, teacher, friend or caregiver – and should accompany him or her to the clinic visits. Therefore, it is important for healthcare workers to ensure that treatment buddies have the necessary information on HIV and AIDS and HIV medication. Despite the availability of mediating factors, the reality is that the transition from childhood to adolescence is characterised by numerous challenges which make it problematic for HIV-infected adolescents to adhere appropriately to HIV medication (Chandiwani et al., 2012:243; Agwu & Fairlie, 2013:5).

2.2.2. Microsystem

The microsystem refers to the small, immediate or direct environment in which an HIV-infected adolescent on HAART operates within (Nash et al., 2005:37). Examples of elements in such environments are family, peers, classmates, teachers, neighbours and other people who have direct social interactions with these adolescents and they are included in the microsystem.

Social stigma in the schools, family settings, peer interaction and the community play a significant role in non-adherence to HAART amongst HIV-infected adolescents. Calabrese, Martin, Wolters et al. (2012:4), Kamau et al. (2012:841), Kimani-Murage, Manderson and Norris (2013:745) and Mutwa et al. (2013:3) found that some HIV-positive children and adolescents maintain secrecy about their diagnoses, some reported some degree of medication hiding or skipping medication due to perceived and experienced stigma. Some describe how they would avoid going to the clinic to obtain their drugs because they did not want community members to see them. At times, family members who had been asked to fetch the medication refused, fearing being seen and labelled as living with HIV. Some caregivers of HIV-infected children choose to attend clinics far from their local clinic to avoid being seen or identified as HIV-infected. On the other hand, unconditional love and support from family, peers and community are well-known for influencing adherence by creating an environment that enables HIV-infected adolescents to adjust to new drug-taking routines and cope with side effects. Receiving support boosts the HIV-infected adolescents' drive, strengthens their minds and enhances their self-worth and this shows them that, they still have a place in society (Mburu, Ram, Oxenham et al., 2014:15; Veinot et al., 2006:265; Balthip & Purnell, 2014:32).

Moreover, Mutwa et al. (2013:5) demonstrate that HIV-infected adolescents, particularly those in boarding schools, are faced with the challenge of finding a safe place to keep and take their medication. Some feel that they have to hide their pill bottles from other students. In addition, students' medication schedule sometimes conflicts with their class schedule and as the teachers would not allow them to leave the class, they were forced to take their medication in front of other students to avoid unintentionally disclosing their status. These situations have led to students becoming uncomfortable, isolated and non-adherent.

Nevertheless, HIV-infected adolescents in a study by Botswana-Baylor Children's Clinical Centre (2011:53) mention that despite missing classes due to ill-health and medical check-ups, they were assisted with notes by their teachers and other classmates and as result their stress levels were reduced. Others adolescents add that when they were on educational

tours their teachers or trip facilitators assisted them in taking their HIV medication. In general, support from classmates and teachers towards HIV-infected adolescents minimise isolation and depression and increase a sense of self-competence and medication adherence. Petersen, Bhana, Myeza et al. (2010:973) also highlight that despite fears of being stigmatised, disclosure to trusted peers and class teachers may serve as a form of support which could also lead to better coping and improve adherence. Over and above, microsystems such as the school environment, family settings and the community play a significant role in the adherence to treatment by HIV-infected adolescents.

2.2.3. Mesosystem

The mesosystem comprises the linkages and processes taking place between two or more settings. For example, the linkage between the home and school environments or between the home and the community (Nash et al., 2005:37). The above microsystems– school environment, family and community – did not enable adolescents to adhere well to treatment. For example, peer interactions in schools were affected as many HIV-infected adolescents kept their HIV-positive statuses secret and therefore would not take their treatment in front of their peers, to avoid unnecessary attention. In addition, interactions between teachers and these adolescents were sometimes unpleasant and this affected their adherence.

The home environment plays a significant role as well because many families do not want to be associated with HIV and AIDS due to the AIDS-related stigma. Additionally, disclosure of a child's HIV-positive status may expose their biological parents and raise questions about other family members, if mode of infection is revealed or assumed (Mutwa et al., 2013:4; Calabrese et al., 2012:4; Kagee et al., 2011:87). The aforementioned scenarios reveal that the link between home and school plays a significant role in non-adherence. In addition, the link between family and community is also affected as these adolescents find it difficult to go for their refills because of the negative attitude from the community towards people living with HIV and AIDS (PLWHA). Likewise, some of the family members are reluctant to collect treatment for their children as they do not want to be labelled as HIV-infected (Kagee et al., 2011:87). Therefore, the linkages between the mentioned mesosystems clearly show that they have a negative impact on adherence to HAART amongst HIV-infected adolescents.

2.2.4. Exosystem

The exosystem links a social setting, for which the individual does not have an active role in his or her immediate context, to its contribution to the development of the individual (Nash et al., 2005:37). According to Rajaraman, Earle and Heymann (2008:1) a number of caregivers

had to balance the demands of a job with that of providing care for those who have become ill or orphaned by HIV and AIDS. Moreover, a study by Yeap et al. (2010:1104) in South Africa discovered that some working caregivers had difficulty getting time off to attend the child's clinic appointments or to collect medication. As a result, the needs of HIV-infected children, including medication supervision, are not fulfilled due to demanding and multiple household chores and lack of time off from work. Rajaraman et al. (2008:13) recommend that it is a matter of urgency to develop, evaluate and monitor workplace programmes and policies that enable employees to continue to work and care for their family members.

Facility-related factors are the exosystem which HIV-infected adolescents do not play an active role in and this is the only place they could get their medication refills. Campbell et al. (2012:125), Kagee et al. (2011:86) and Mburu et al. (2014:16) cite poor service, long waiting times, impatient and unsympathetic healthcare workers, staff burn-out, work dissatisfaction, level of confidentiality, poor communication between service users and providers, severe shortage of trained staff, lack of youth-friendly health services and shortage of consultation rooms as deterring adolescents from adhering to ART. Consequently, health facilities should be well equipped and staff members should be supported and trained to manage their workload in order to produce quality health services. Despite these facility-related challenges, HIV-infected adolescents revealed that healthcare professionals are a primary source of support. The main reason for this is that they provide access to counselling services, education and help the adolescents develop positive strategies early in the disease process to facilitate setting the stage for long-term adherence (Chandiwani et al., 2012:249; Balthip & Purnell, 2014:33). The above exosystems shows that HIV-infected adolescents do not have an active role in them, hence why they play a significant role towards adherence.

2.2.5. Macrosystem

The macrosystem consists of the overarching patterns of microsystem, mesosystem and exosystem characteristics of a given culture, its subculture with particular reference to the belief systems, bodies of knowledge, material resources, customs, lifestyles, and policies that are embedded in each of these broader systems (Nash et al., 2005:37).

Campbell et al. (2012:125) and Skovdal, Campbell, Madanhire et al. (2011:956-957) reveal that some of the HIV-infected children and adolescents are cared for by their elderly parents who likely live in poverty. In addition, immobility, deteriorating memory and poor comprehension of complex treatment regimens mean some of these caregivers battle to ensure optimal adherence by their children and adolescents. Immobility, lack of transport money, insufficient food security or nutritional support, distance to health facilities and high clinic attendance fees are some of the factors that prevent some of the caregivers from

taking their children for monthly consultations which are crucial for optimal HAART monitoring and distribution. In general, unemployment or poverty is a serious problem and some guardians mention that they are reluctant to borrow money because they will struggle to repay it. However, communities do play an important role in mitigating factors that cause non-adherence amongst children and adolescents. Some community members in Zimbabwe volunteered to care for HIV-infected children in order to assist with adherence (Campbell et al., 2012:126). Furthermore, some non-governmental organisations (NGOs) facilitate an adherent competent context through their community-based counselling services. Households which are in need are given food parcels by these NGOs. This is helpful as some HIV-infected children live with elderly guardians who are unable to provide for them (Campbell et al., 2012:127; Mburu et al., 2014:15).

Religion is a macrosystem that could either become a barrier or a mediating factor towards HAART adherence. Vermeulen (2011:72-73) mentions that some churches forbid members to take their HAART because they have been 'cured' by the power of God through a healing prayer and therefore some end up not taking their treatment. In contrast, Park and Nachman (2010:560-561), Lyon, Garvie, Kao et al. (2011:633), Kremer, Ironson and Porr (2009:132) and Sopena, Evangeli, Dodge et al. (2010:1257) argue that religious organisations play a crucial role in patients' lives as they strengthen patients' ability to cope with illness and promote self-worth, thereby increasing compliance to treatment. The aforementioned shows that poverty or low socioeconomic circumstances and religion play significant roles in non-adherence amongst HIV-infected adolescents.

2.2.6. Chronosystem

Chronosystem is the pattern of environmental events, transitions and shifts in the lifespan of an individual. This may also involve the socio-historical contexts that influence an individual (Nash et al., 2005:37). According to Agwu and Fairlie (2013:1-2) stigma and discrimination have been prominent ever since the discovery of HIV and AIDS. These elements are still prevalent in the current climate and have become major impediments to adherence to HIV treatment. A recent study by Mburu et al. (2014:15) found some acts of stigma and discrimination against HIV-infected students in schools. Instances of teachers hinting at the presence of students living with HIV in a manner that had been interpreted as a warning not to associate with them had been reported. As a result, some HIV-infected students mention that other students did not want to share plates or cups with them. Furthermore, respondents in a study by Nwezeh (2008:390) indicate that HIV-infected students should be dropped from school and some add that they will terminate their relationship with a friend that has been diagnosed with HIV. Additionally, Tanney et al. (2011:300) highlight high rates of depression

amongst HIV-infected adolescents which is exacerbated by AIDS-related stigma and discrimination.

Midtbo et al. (2012:264) and Petersen et al. (2010:973) report different incidences of HIV stigma experienced by HIV-infected adolescents. Some adolescents mention that they are called degrading names, while others feel that people gossip about their HIV statuses. On the other hand, some adolescents feel uncomfortable when people talk negatively about people living with HIV and AIDS (internalised stigma). Some feel discriminated against or rejected by friends and family members (externalised stigma). In addition, Mutwa et al. (2013:3) cite that stigma is a major issue amongst HIV-infected adolescents who live in congested households, boarding schools and foster care homes. Many of them do not want their siblings, friends and others to see them taking HIV medication. This is mainly exacerbated by the lack of a private place to keep medication, and therefore adherence is significantly affected. Furthermore, some participants in a study by Beyers and Nkoane (2012:661) reveal that after disclosing their status to family members, their parents had asked them to keep it quiet and not tell any more people. The participants said this reaction made them feel cast out which leads to anger and frustration.

However, Calabrese et al. (2012:4) state that despite stigma and discrimination, some adolescents found ways to deal with it. They mention that disclosing their statuses to a larger circle of friends corresponds with less medication hiding which offers them immunological benefits and better coping. Moreover, Rao et al. (2007:32) reaffirm that HIV stigma and discrimination emerge as an important factor that drives non-adherence. Hence, development of effective stigma reduction programmes in schools, families and communities may be vital to improving adolescents' adherence. It will also contribute to positive health outcomes as well as protect broader public health by limiting the emergence of treatment resistant HIV strains. In conclusion, the above examples on stigma and discrimination clearly play a significant role in the non-adherence to treatment amongst HIV-infected adolescents.

2.3. Knowledge about HIV and AIDS

This section will cover what knowledge adolescents have demonstrated regarding HIV and AIDS.

2.3.1. HIV and AIDS

Wagbatsoma and Okojie (2006:81) reveal that students are aware of HIV and AIDS but have insufficient knowledge of its aetiology. Some students had mentioned that AIDS is caused by a bacteria or evil spirits, and others said it is caused by HIV. However, adolescents with high self-esteems had demonstrated adequate knowledge of HIV and AIDS. In addition, the

knowledge of HIV and AIDS improves with age, especially between the ages of 12 and 19 years (Botswana-Baylor Children's Clinical Centre of Excellence, 2011:76-77; Van Dyk, 2008:192). Similarly, Dawood, Bhangwanjee, Govender et al. (2006:4-5) has assessed the knowledge of HIV and AIDS amongst adolescents with mild mental retardation (MMR) and results show that general awareness of HIV and AIDS and STIs is high, although a significant minority of persons with MMR from the younger age group are still unaware of the existence of the virus. The possible explanation may be that the participants are unable to differentiate between HIV infection and AIDS because the two terms seems identical.

A study by Manji et al. (2007:993) in the United States of America (USA) discovered a drastically limited knowledge of HIV and AIDS amongst out-of-school adolescents as opposed to their school-going counterparts. On the contrary, a recent study in China, reveals poor knowledge and awareness of HIV and AIDS, and safe sex amongst senior high school students (Cai, Ye, Shi et al., 2013:5). Consequently, Manji et al. (2007:993) and Cai et al. (2013:5) propose that a multi-component approach in dissemination of information about HIV and AIDS and safe sex must reach adolescents in-and-out-of-school. Moreover, programmes based in schools, communities, health facilities and mass media has the greatest chances of success.

2.3.1.1. Transmission of HIV and AIDS

According to Kadivar, Garvie, Sinnock et al. (2006:544), Espada, Orgiles, Morales et al. (2012:504), Wagbatsoma and Okojie (2006:82) and Nwezeh (2008:389) the most common route of HIV contraction amongst adolescents is through unprotected sexual intercourse. Ganczak, Baron-Kaczmarek, Leszczyszyn-Pynka et al. (2005 :11), Kadivar et al. (2006:54) and Nwezeh (2008:389) add that sex with multiple or older partners is a major contributing factor to the rapid transmission of HIV. Hutchinson, Jemmott, Wood et al. (2007:41) affirm that in Jamaica, young girls are sleeping with older men or drug lords for material gains such as clothes and money. In most instances, these girls have no power to negotiate for condom use. In contrast, these girls' male counterparts sleep with different girls to prove to their fathers that they are 'men' and not homosexuals. As a consequence, these acts make them vulnerable to either contracting or spreading HIV or other STIs.

In addition, Wagbatsoma and Okojie (2006:82), Tung, Ding and Farmer (2008:401), Mahat and Scoloveno (2006b:415), Van Dyk (2008:40) and Nwezeh (2008:389) mention other common routes of HIV transmission:

- unscreened blood transfusion;

- sharing needles or sharp objects; and
- mother-to-child transmission of HIV during pregnancy, delivery and breastfeeding.

Furthermore, Mahat and Scoloveno (2006b:419) discovered that the knowledge of HIV and AIDS transmission amongst adolescents is generally low but after an educational intervention there had been great differences. However, participants in a study by Dawood et al. (2006:5) demonstrated gaps in knowledge as well as erroneous information regarding HIV transmission – they mentioned that HIV is transmitted by insects. Moreover, in other studies, adolescents are able to identify three or four STIs such as gonorrhoea and syphilis which are contracted through unprotected sexual intercourse (Hutchinson et al., 2007:41; Nwezeh, 2008:388). The researcher is of the view that more robust interventions such as education is necessary, especially in this era in which there is an assumption that many people including adolescents are conscious of the dangers of HIV and AIDS. These interventions should accommodate adolescents living with different disabilities too.

2.3.1.2. Prevention of HIV and AIDS

The following aspects relate to the adolescents' knowledge of the prevention of HIV and AIDS.

- **Abstaining, being faithful and using condoms**

The participants in studies by Perez, Barrales, Jara et al. (2008:505), Ganczak et al. (2005:10) and Botswana-Baylor Children's Clinical Centre of Excellence (2011:76) suggest, that in the era of HIV and AIDS, it is important to stick to one partner and use a condom at all times during sexual intercourse. However, Ganczak et al. (2005:9) cite that some conservative forces and the Catholic Church are actively opposing sex education and family planning, such as the distribution of condoms, in school. Their campaign promotes abstinence as the only method of HIV and AIDS prevention. Even though, their campaign is valuable, mentioning condoms especially in the context of protection against HIV and AIDS should be included to accommodate those who do not choose to abstain. Nonetheless, Kabiru and Azeh (2007:125) found that some adolescents abstain from sexual intercourse due to lack of a partner, postponement of sex until marriage which is normally guided by moral and religious beliefs, fear of pregnancy and avoidance of STIs.

Further on the abstinence debate, adolescents cite that their parents and teachers encourage them to abstain from sex until they get married despite their peers, magazines and the media offering contradicting messages from the ones conveyed by their parents and teachers (Malinga, 2010:64). Contrary to above, female participants in a study by Malinga (2010:64) report that maintaining virginity is unhealthy and could lead to 'virgin disease' or

affect one's chances of procreation. Others participants say it could lead to the reduction of the size of the birth canal or make it difficult for one to have children in future. Their male counterparts, indicate that failure to engage in sex could lead to erectile problems (Malinga, 2010:64-65). When reconciling the debates on abstinence, Malinga (2010:67) reiterates that sexual abstinence has been introduced as a component of the ABC prevention approach (Abstain, Be faithful and Condom use) which has been adopted by WHO in the fight against HIV and AIDS. Programmes should therefore be designed in a way that will address the issues and myths or misconceptions that adolescents struggle with.

The use of a condom is another prevention method that is surrounded by controversies; some related to culture, religion and limited coherent knowledge of condom use amongst adolescents. Consequently, these controversies have resulted in constant condom use (Hutchinson et al., 2007:40). In a study by Hutchinson et al. (2007:41) and Alemu, Marian, Belay et al. (2007:348) a group of adolescents make reference to the Rastafarian belief that condoms take something away, condoms are embarrassing to use and they also agree that sex feels unnatural when a condom is used. Other participants of the study believe that using a condom is unnecessary if they are already using another form of contraception. Female participants mention the following fears about using a condom: one will have allergies; they do not want rubber inside their vagina; and are scared that it will tear the vagina. The researcher is of the view that when designing messages of HIV prevention, including advocacy for condom use, the involvement of important stakeholders such as religious and cultural leaders is crucial in disseminating these messages to young people. As a result, young people may avoid using religious or cultural ideologies and lack of knowledge as scape goats for low condom use.

Guiella and Madise (2007:193) and Vujovic, Struthers, Meyersfeld et al. (2014:125) state that there is inconsistent and low condom use amongst adolescents and some adolescents indicated that condom use resembles lack of trust in your sexual partner. Guiella and Madise (2007:194) add that a possible interpretation for the low use of condoms amongst adolescents, despite high levels of awareness of HIV and AIDS, is that the majority of adolescents do not plan to have sex. Some adolescents had disclosed that these unplanned sexual behaviours take place at social gatherings such as weddings, birthday parties, music festivals and many more. The researcher's point of view is that campaigns on condom use should be reinforced to encourage condom use.

Despite the controversies that have been alluded to on condom use, some adolescents have shown some knowledge that condoms help prevent STIs, HIV and AIDS, and pregnancy. In

addition, adolescents had been able to identify different places where condoms can be acquired from, which include: health facilities; pharmacies; and some shops. However, obtaining male condoms from health facilities is often embarrassing for young boys who do not want people to know that they are sexually active (Vujovic et al., 2014:125; Hutchinson et al., 2007:41; Nwezeh, 2008:391). Moreover, in Uganda it has been discovered that healthcare workers have refused to give adolescents condoms because they believe this encourages them to have sex, especially as premarital sexual intercourse is prohibited (Ybarra, Kiwanuka, Emenyonu et al., 2006:7). Nevertheless, Guiella and Madise (2007:194) and Cai et al. (2013:6) advocate that HIV prevention programmes can contribute to higher use of both male and female condoms by focusing on increasing adolescents' self-efficacy and life skills, especially for females. Promoting positive attitudes towards condoms and motivating adolescents to take responsibility for their own safety are also important strategies for increased use of condoms.

- **Prevention of mother-to-child transmission of HIV (PMTCT)**

According to Van Dyk (2008:41) mother-to-child- transmission (MTCT) of HIV is one of the major causes of HIV infection in children. Nonetheless, the Government of Botswana had launched a National Prevention of Mother-to-Child Transmission (PMTCT) Programme in 2001 in order to increase the survival of children born to an HIV-positive mother. In 2011, the prevalence rate of the Human Immunodeficiency Virus (HIV) amongst pregnant women in Botswana was about 30.4%. High coverage rates of HIV testing and antiretroviral prophylaxis have reduced the rate of MTCT of HIV from as high as 30.4% with no prophylaxis to <4% in 2013. Currently, the national coverage rate of PMTCT in Botswana is at 96% (Motswere-Chirwa, Voetsch, Lu et al., 2014:158-159).

Motswere-Chirwa et al. (2014:158-160) affirm that in order to reduce or eradicate MTCT the following should be done adequately.

- Pregnant mothers should be encouraged to register with health facilities in order to utilise various antenatal services. For example, a pregnant mother should undergo an HIV test after counselling, if she is HIV-positive a blood sample should be collected to check her CD4 count. If the CD4 cell count is less than 350, initiation on HAART utilising Atripla must be done at 14 weeks into gestation. But if the CD4 count is above 350, initiation on HAART should be done in order to reduce transmission risks to the foetus.
- Babies who have been exposed to HIV should be given prophylactic treatment to reduce the transmission rate. The mothers should be counselled on two breastfeeding methods being exclusive breastfeeding for 6 months or exclusive formula feeding. Mothers who

choose exclusive formula feeding are provided with free infant formula until the baby is 12 months of age.

- Infants who have been exposed to HIV should be tested six weeks after birth utilising polymerase chain reaction (PCR) testing on dried blood spot specimens (DBS). Confirmatory test should be done immediately if the child tests positive. If the test is negative, a repeat test should be done at 18 months. However, all HIV-positive infants whether symptomatic or not should be referred to the ARV programme for Anti-Retroviral (ART) services.

- **Voluntary HIV Counselling and Testing (VCT)**

Van Dyk (2008:134) points out that Voluntary HIV counselling and testing (VCT) has emerged as a major strategy in the prevention of HIV and AIDS. VCT services should be a key component of any prevention and care programme that is offered to people. According to Espada et al. (2012:12), Straub, Pomputus, Boyer et al. (2007:105), Van Dyk (2008:134) and the Centre for Disease Control and Prevention (CDC) (2007:665), adolescents declare that HIV testing is the only way for one to know his or her HIV status. Early diagnosis of HIV infection also facilitates medical interventions and enables infected persons to reduce high-risk behaviour and the likelihood of further HIV transmission. CDC (2007:666) finds that prevalence of HIV testing is higher amongst female students than male students because the female adolescents show greater knowledge about HIV and AIDS in comparison to their male counterparts. The results show that students who have been taught about HIV and AIDS in schools are more likely to have an HIV test than those who have not been taught about it. Therefore, CDC (2007:668) recommends that in order to decrease the number of undiagnosed HIV infections amongst adolescents and promote HIV prevention, healthcare providers should offer HIV screening as part of routine medical care. Van Dyk (2008:134) emphasises that wider access to VCT services may also lead to greater openness about HIV and AIDS, raise awareness and reduce stigma and discrimination.

- **Avoid multiple, concurrent partners**

Multiple, concurrent sexual partnerships (MCP) has emerged as a critical factor that contributes to young people's vulnerability to contracting HIV and AIDS, as well as STIs. Poverty or low socio-economic status has been attributed to a high rate of MCP. For example, poor people especially young women are more likely to engage in particular practices such as early onset of sexual activity or occasional transactional sex, which may increase their risk of infection. On the other hand, wealthy people may find that their wealth permits greater social and sexual networking or allows them to have a higher number of

regular, sexual partners especially with young girls or boys; a behaviour which may place both of them at risk. This is referred to as cross-generational sex (National AIDS Coordinating Agency, 2009:16-17). In 2009, the MCP prevalence rate in Botswana had been estimated around 44%. Nonetheless, the following strategies have been adopted to address it: multisectoral approach in sensitising the public on behaviour change, including addressing the social and environmental factors that drive MCPs; as well as advocacy for supportive policy interventions and changes, especially on the empowerment of young women (National AIDS Coordinating Agency, 2009:17).

2.3.1.3. HIV treatment and adolescent myths about HIV and AIDS

HIV-infected adolescents have stated in previous studies that although there is no cure for HIV and AIDS, it is important to adhere to clinic appointments and ART regimens. They have realised that it is important to take responsibility for their own health and play an active role in their own care. This has helped HIV-infected adolescents remain healthy and at the same time, achieve self-reliance and self-growth (Balthip & Purnell, 2014:34-35; Nwezeh, 2008:389). Botswana-Baylor Children's Clinical Centre for Excellence (2011:78) state that 70% of the participants have knowledge about ART and half of them correctly knew the names of their ARVs. Additionally, Veinot et al. (2006:263) state that most adolescents have obtained information about HIV medication from healthcare workers and some have researched it on the internet.

Despite the above sentiments, in the study by Veinot et al. (2006:263) some adolescents express misperceptions and uncertainties about the purpose and value of HAART. Many of them did not understand why they should have treatment that cannot cure them and consider treatment to be meaningless. Others allege that HAART degrades their quality of life which is why they have pursued other alternatives, such as homeopathy (Veinot et al., 2006:263). Furthermore, participants in a study by Dawood et al. (2006:5) believe that traditional or faith healers can cure HIV and AIDS. A possible explanation for this is that traditional or faith healers are seen as resource persons who are widely utilised and accepted by some communities as interpreters of what constitutes health and illness, especially in the African context.

According to Espada et al. (2012:504), Hutchinson et al. (2007:41-42), Nwezeh (2008:389), Mahat and Scolovon (2006a:585) and Tung et al. (2008:401) the following are some of the myths and beliefs about HIV and AIDS.

- HIV and AIDS can be transmitted through sharing the same food, cup and spoon with some who is HIV-infected;

- HIV and AIDS can be transmitted from a moist toilet seat;
- HIV and AIDS can be cured by showering after unprotected sexual intercourse; and
- HIV and AIDS can be spread through swimming pools, sharing cigarettes, sneezing and coughing or hugging an HIV-infected person

Furthermore, Van Dyk (2008:192) finds that in South Africa, participants have mentioned the myth that having sexual intercourse with a virgin, namely 'virgin cleansing', will cure HIV and AIDS. The researcher is of the opinion that sexual myths and misconceptions interfere with safe sex initiatives. As a result, engaging adolescents in discussions to find out why they believe in these myths and misconceptions is vital so that they can discover for themselves that these myths are untrue. Interestingly, a myth amongst Jamaican adolescents about condoms is that "the USA government has sent AIDS to Jamaica by putting it inside condoms" (Hutchinson et al., 2007:504). As a result, these misconceptions and inaccurate knowledge on the modes of transmission of HIV and AIDS are key factors that hinder the prevention of HIV and AIDS (Hutchinson et al., 2007:42). In conclusion, Nwezeh (2008:393) and Espada et al. (2012:504) reaffirm that continuous awareness about HIV and AIDS is necessary to eradicate these myths and misconceptions in order to save more adolescents from being infected by HIV.

2.3.2. Sources of information dissemination on HIV and AIDS

Providing information about HIV and AIDS in face-to-face sessions has been effective in reaching people in small groups but given the continuing high rate of HIV infection amongst adolescents, innovative approaches in providing prevention information are needed. More adolescents are reachable through technology and mass media (Cornelius, Dmochowski, Boyer et al., 2013:257).

A significant number of authors such as Ganczak et al. (2005:7-8), Wagbatsoma and Okojie (2006:82), Nwagwu (2012:14) and Nwezeh (2008:392) find that for many adolescents, the main sources of information on HIV and AIDS has been through television, radios, newspapers, billboards, schools and medical personnel especially doctors and nurses. However, Wagbatsoma and Okojie (2006:82) mention that television or newspapers may provide information which is ambiguous or sometimes negative or unbelievable. This may contribute to misconceptions about people living with HIV and AIDS (PLWHA) and the modes of HIV transmission.

Over and above, Wagbatsoma and Okojie (2006:82), Nwagwu (2012:14) and Dawood et al. (2006:7) point out that television had been the main source of information on HIV and AIDS

for their study population. The justification is that television is an engaging multimedia facility that utilises a combination of audio, voice and images to communicate information. Many experts have suggested that it is a powerful tool in information communication (Wagbatsoma & Okojie, 2006:83; Nwagwu, 2012:15). Although, there is positive feedback about the utilisation of television, Wagbatsoma and Okojie (2006:82-83) and Nwagwu (2012:15) highlight that lack of affordability of television sets by some families, lack of electricity in some places especially in rural areas, and repeated power interruptions are major impediments to this important source of information. Similarly, Nwezeh (2008:393) adds that radio is the main source of information because many homes have access to it. Even those in rural areas without electricity can use battery-operated radios. Wagbatsoma and Okojie (2006:83), Nwagwu (2012:15) and Nwezeh (2008:393) recommend that the utilisation of these mediums for health education should be encouraged for this age group.

The researcher agrees with the above authors – Botswana television (Btv) is currently airing a live educational programme called “Talk Back” every Tuesday at noon and the repeat is on Saturdays at 11am. The programme discusses issues affecting HIV-infected and affected adolescents. It is interactive as professionals are invited to discuss numerous issues and viewers are also allowed to call in to contribute during the programme. In addition, Botswana Radio Stations one and two (R.B 1 & 2) are airing a radio drama entitle *Makgabaneng* which also tackles issues around HIV and AIDS that affects all the age groups. The researcher believes that these programmes are contributing tremendously towards disseminating information on HIV and AIDS that is tailored to adolescents and other important stakeholders.

Nwagwu (2012:14) has discovered that handbills or pamphlets are another major source of information about HIV and AIDS. Handbills are common for distributing information, education and communication materials by many non-governmental organisations and the targeted groups usually include students in primary and secondary schools. Handbills or pamphlets are relatively cheap to produce and they can be freely distributed to the users, making their distribution largely infrastructure-independent. This is not the case with electronic resources such as radio and television which would often require electric power to function. The researcher’s understanding is that even though pamphlets can be distributed to many adolescents, the question that remains is whether the adolescents read them? In order to deal with this impediment, it is imperative to ensure that message in pamphlets or handbills are written in vernacular languages to broaden the audience and capture the audience’s attention.

Moreover, peer education has been labelled as the most important strategy for effective communication of information to adolescents. Studies have shown that contact with peer educators is associated with greater spontaneous knowledge of modern contraceptives, symptoms of STIs and greater use of condoms in adolescents. This is because peer educators and adolescents relate better as they share common interests, sentiments and beliefs. Peer educators can pass on information to adolescents through formal and informal means to bring about change in their risky sexual behaviours (Simba & Kakoko, 2009:100; Mahat, Scoloveno, Leon et al., 2008:362; Nwagwu, 2012:17). Bloemen (2011:3) indicates that teen clubs for HIV-infected children and adolescents play an enomours role in their lives. It exposes them to teachings about HIV and AIDS, treatment adherence, confronting stigma, disclosure issues as well as coping strategies.

Hutchinson et al. (2007:42) find that most adolescents have discussed information about sex, condom use, HIV and AIDS with their mothers. However, it is believed that some parents may not have enough or accurate information on HIV and AIDS or some cultural practices do not permit them to talk to their children about sex. Lastly, Moore, Onsomu, Timmons et al. (2012:871-873) indicate that the church has served as an institution of spiritual guidance and is now a place to obtain health information. In addition, pastors have become change agents in the health sector especially after the discovery of HIV and AIDS. By creating high levels of awareness about HIV and AIDS, churches have utilised different platforms such as church services, church health fairs, youth camps and health seminars to provide information on HIV and AIDS. Moreover, some church leaders have encouraged their members to take an HIV and AIDS test and there are some church leaders who have used themselves as examples. The goal has been to help church members learn their HIV and AIDS status in order to reduce the stigma. Finally, church leaders have agreed that the church should be an advocate for those infected with the disease and it should be at the forefront of HIV and AIDS education (Moore et al., 2012:873).

2.3.3. Highly Active Antiretroviral Therapy (HAART) and the importance of adherence

The following aspects relate to HAART and the importance of adherence.

2.3.3.1. Benefits of adherence

Wiens, MacLeod, Mussiime et al. (2012:331) and Agwu and Fairlie (2013:6-7) emphasise that adherence to antiretroviral (ART) medications is amongst the most important factors to ensure immunological, viral and clinical response in the treatment of HIV. Amongst the numerous treatment groups, adolescents are often labelled as high risk with respect to adherence. Dietz, Clum, Chung et al. (2010:278) and Garvie, Wilkins and Young (2010:504)

reveal that the utilisation of HAART has greatly improved health and decreased the mortality rate amongst HIV-infected adolescents. Adherence to HAART does not mean remembering to take prescribed medication only but following strict dosage instructions, timing intervals and dietary guidelines are also essential.

A recent study in Botswana by Ndiaye et al. (2013:893) finds that HIV-infected adolescents with an excellent pill count of HAART adherence have had a satisfying virological suppression and this demonstrates that excellent treatment outcomes can be achieved if one adheres as prescribed. Longitudinal investigations by Patel, Hernan, Williams et al. (2008:1755) and Resino, Resino, Micheloud et al. (2006:868) find that there has been a significant increase of CD4+ count cells and a decrease of viral load after HAART initiation amongst children and adolescents and that is sustained for at least five years if the child adheres correctly. Nonetheless, Resino et al. (2006:868) find that during the last four years of receiving HAART, there is a significant decrease in viral load but not an increase in CD4+ cell percentage because CD4+ cell percentage reaches its peak after the second year.

According to Mutwa et al. (2013:2) some HIV-infected adolescents state that the medication had given them not only physical health such as making them grow or gain weight but also hope and the ability to lead a 'normal' life. Adolescents have emphasised the wish to continue living on par with their HIV uninfected peers. The personal experiences of health improvement, including evidence of increased CD4 levels, encourages them to remain adherent to their medication schedules. Yet, some adolescents despite adhering well may fail to respond as expected because sometimes it takes a longer time period for viral replication to be controlled by ART. In such cases, it is imperative to conduct further clinical investigations in order to identify the problem(s) (Mutwa et al., 2013:3).

2.3.3.2. Methods of assessing adherence

Non-adherence to HAART is a common problem amongst HIV-infected adolescents. A >90-95% (high adherence rate) is required to achieve optimal viral suppression and prevention of the development of drug-resistance HIV (Veinot et al., 2006:265; Kumar de & Dalui, 2012:253). Haberer et al. (2011:6), Garvie, Wilkins and Young (2010:508), Bangsberg (2008:274) and Parsons et al. (2006:276) mention that outpatient strategies to improve adherence in a paediatric patient are crucial. Pill count, self or caregiver reports, standardised questionnaires, medication charts, medication diaries and records of pharmacy visits are some of the adherence measures mentioned by participants. Nonetheless, subjective reports to adherence are easy to collect but at times patients may overestimate the adherence. Similarly, clinic pill counts are relatively easy to perform, although patients

may manipulate pills to appear more adherent. In addition, unannounced home-based pill count is another measurement of adherence which can be effective because patients or caregivers have little opportunity for pill manipulation; yet it is resource intensive (Haberer et al., 2011:6).

Moreover, Glikman, Walsh, Valkenburg et al. (2007:1146) indicate that hospital-based, directly observed therapy (DOT) as is utilised with TB patients is considered to be the most accurate adherence measurement for children and adolescents who are faced with non-adherence. The results show a significant decline in participants' viral load. Hospital-based DOT also provides the patient with a relaxed, unhurried atmosphere in which problems associated with non-adherence could be discussed and addressed. Glikman et al. (2007:1147) propose that short hospital-based DOT be considered for patients with poor virological control and for whom outpatient interventions have failed.

Haberer et al. (2011:7) and Wiens et al. (2012:334) state that a Medication Event Monitoring System (MEMS) is generally accepted as the industry gold standard for adherence measurement, even though it is expensive compared to other traditional methods. MEMS has less evidence of higher estimates in comparison to other measures and has a significant association to viral load. MEMS data may show distinct morning and evening peaks, which may reflect true pill taking. Additionally, HIV and AIDS Treatment Guidelines (MOH, 2012:48) stipulate that laboratory tests such as viral load and CD4 cell count are additional reliable measures of adherence. For children and adolescents, laboratory tests should be done every three months until the age of 18 years as a way of assessing adherence or any other clinical indications which need to be attended to. However, the tests follow-up period may change depending on the clinical outcome of the patient. In conclusion, Bangsberg (2008:273) advises that more accurate adherence monitoring systems may help clinicians to better gauge the impact of treatment over time, in order to guide decisions on whether regimens need to be modified to improve adherence and prevent viral rebound.

2.3.3.3. Consequences of non-adherence to HAART

Kagee et al. (2011:83) and Parsons, Sibery, Parsons et al. (2006:275) allude to adherence as a major problem in the care of paediatric patients with an HIV infection, particularly in adolescents. Wiens et al. (2012:332) indicate that >80-89% resembles when the patient is non-adherent while <80% resembles very poor adherence. Garvie et al. (2010:504) indicate that anything less than perfect adherence, such as missing doses or taking medication at wrong times, can undermine the individual's response to treatment. As a consequence, the following will result: decreased CD4 count and percentage, increased viral load which could

lead to detectable viral load, increased risk of HIV transmission, increased risk for developing resistance to ART medications and the risk of developing opportunistic infections (IOs). Kagee et al. (2011:83) point out that it is imperative to adhere to ART as prescribed because if patients develop drug resistance as a result of non-adherence they will need to be switched to second line regimens, which are more expensive than first line regimens.

Additionally, Arrive et al. (2012:2) and Parsons et al. (2006:280) note that virological failure has been observed amongst adolescents and this could lead to poor treatment outcome, advanced immunosuppression and HIV-related deaths. Agwu and Fairlie (2013:6) add that older adolescents, who are non-adherent, comprise the majority of perinatally-infected children who are normally hospitalised and who have the highest rates of morbidity and mortality. Furthermore, non-adherence to HAART does not only have clinical implications for the patient, it has economic implications for many countries because the costs of procuring ART are high, especially when it is distributed for free. The economic cost of non-adherence could be the total value of all direct and indirect resources utilised or spent on the individuals. However, since the concept of adherence is inclusive, the true cost might never be accurately determined. The researcher's understanding is that the above sentiments are reiterating the significance of adherence to HIV medication.

2.4. Contextualising and conceptualising HAART adherence amongst HIV-infected adolescents

The emergence of HIV and AIDS has resulted in many children being perinatally-infected. Some children die before reaching adolescence, while others survive into adolescence as a result of HAART. Yet, the number of behaviourally-infected adolescents continues to be a great concern (Naswa & Marfatia, 2010:5). Over two million adolescents worldwide are living with HIV and AIDS, 90% of whom reside in sub-Saharan Africa (UNICEF, 2013:3).

It is worth noting that as HIV-infected adolescents grow older they gain a greater sense of independence and adherence to HAART becomes a major concern. Adolescence is a complex developmental phase that is characterised by deviation from expected behaviour, experimentation, risk taking and significant peer influence. In addition, the demand to cope with an HIV-positive status complicates this developmental stage (Nglazi et al., 2012:1-2). A study by Nachega, Hislop, Nguyen et al. (2009:68) reveals that HAART-adherence amongst HIV-infected adolescents aged 15-18 years is significantly lower than HIV-infected adults, which leads to the adolescents displaying poorer virological and immunological outcomes. On the contrary, an in-depth study by Haberer et al. (2011:4) in Zambia which followed perinatally-infected children and adolescents for two years, finds high levels of adherence as

a result of one-pill, fixed dose. In 2012, Botswana introduced the one-pill, fixed dose (Atripla), a fixed dose combination of TDF + FTC (or 3TC) (Truvada), and a fixed dose combination of AZT + 3TC (Combivir) (MOH, 2012:38). Henceforth, the researcher is of the opinion that one-pill, fixed dose plays a significant role towards improving adherence amongst adolescents and other countries should invest in it.

A study by MacDonell, Naar-King, Huszti and Belzer (2013:89) assessed medication adherence amongst perinatally- and behaviourally-infected adolescents and finds that the following barriers to treatment are similar within the two groups: medication side effects and fatigue (especially perinatally-infected); stigma and discrimination; and forgetting. Insufficient knowledge on HIV and AIDS, a lack of belief in the effectiveness of HIV medication, socio-economic circumstances, anger due to living with HIV and AIDS (especially perinatally-infected), lack of self-esteem and lack of disclosure are additional barriers (Naswa & Marfatia, 2010:8; Holele, 2012:34; Agwu & Fairlie, 2013:5). However, it has been observed that good adherence is associated with a low pill burden, such as two or less pills per day or all drugs combined into one pill with once-a-day dosing (Agwu & Fairlie, 2013:5; Naswa & Marfatia, 2010:8).

Agwu and Fairlie (2013:5) argue that one of the obstacles to adherence amongst HIV-infected adolescents, particularly in resource-limited settings, is an inadequate number of healthcare professionals (medical care providers, support staff, psychologists, social workers and counsellors) who are experienced in adolescent healthcare management (Agwu & Fairlie, 2013:5). Holele (2012:35) concludes that despite the challenges of living with HIV adherence being the greatest one, most young adolescents have good insights and genuine motivation to remain adherent to HAART.

In summary, Naswa and Marfatia (2010:8) and Agwu and Fairlie (2013:6) indicate that it is crucial for clinicians who are caring for adolescents to understand that for the eventual success of treatment it is critical to manage the 'whole' adolescent within the context of his or her own economic, cultural, psychological and family environment. Moreover, providing adolescents with psychosocial support including creating non-stigmatising or discriminatory environments will enable them to conquer challenges that may confront them on this journey.

2.5. Factors influencing non-adherence amongst HIV-infected adolescents

This section will look at factors that contribute towards non-adherence to HAART amongst HIV-infected adolescents.

2.5.1. Mental health

According to Midtbo et al. (2012:262), Agwu and Fairlie (2013:5), Petersen et al. (2010:972), Rudy et al. (2009:168) and Kagee et al. (2011:87) living with HIV and AIDS and the pressure to comply with treatment regimen is indisputably stressful. Life events such as the loss of loved ones due to HIV and AIDS can negatively affect functioning of or psychological adjustment (outlook) amongst HIV-infected adolescents. However, adolescents vary greatly in the manner in which they cope with loss and death. Coping depends on their attachment to the deceased, past experiences and developmental stages.

A recent study by Kamau et al. (2012:840) in Kenya finds that the most common mental health disorders amongst HIV-infected adolescents are major depression and anxiety. Major depression is significant amongst the males even though this is in contrast to what many other studies have found; depression more prevalent in females. It has been discovered that a low CD4 count of <350 cells/mm³ and virological treatment failure is significantly associated with major depression. Furthermore, Tanney et al. (2011:300) indicate that high rates of depression amongst HIV-infected adolescents may be exacerbated by AIDS-related stigma and discrimination. Ramiro et al. (2013:186) find that females score higher in depression than males and are more likely to abuse drugs as well as engage in risky sexual behaviours.

Mutwa et al. (2013:4) and Wagner et al. (2011:353) reiterate that depression disrupts social functioning and activities of daily living and it can also affect motivation to do anything, including adhering to healthy lifestyles. Mutwa et al. (2013:4) point out that HIV-infected adolescents are less motivated to take their ART which leads to immune suppression. This is mainly perpetuated by anger and confusion amongst these adolescents, questioning why they became infected while their siblings are not. Furthermore, Kamau et al. (2012:841) note an increase in attempted suicide or ideation with age and the prevalence is lowest in the youngest age group and highest in the oldest age group. It is important to understand that suicidal ideation or attempt can be a manifestation of depression.

Malee, Tassopoulos, Huo et al. (2011:1533), Kagee et al. (2011:87) and Scharko (2006:442) reveal that some of the signs of mental health problems amongst perinatal-infected adolescents include: attention or behavioural problems; and hyperactivity. Regarding this, Kamau et al. (2012:841) and Tanney et al. (2011:304) highlight that HIV-infected adolescents are at risk of experiencing mental illness, therefore centres providing care to them should routinely screen for mental health disorders. Intervention should be provided early before the condition worsens because these disorders play a significant role in non-adherence to HIV medication.

2.5.2. Social stigma

The negative stigma and labelling attached to being HIV-positive and consequent risks associated with being HIV-positive have caused HIV-infected adolescents to be selective about revealing their diagnosis to family and friends. The disclosure by these adolescents may expose the HIV status of their biological parents and raise questions about family members' if the mode of infection is revealed or assumed (Mutwa et al., 2013:4; Calabrese et al., 2012:4; Kagee et al., 2011:87). Lowenthal et al. (2014:144) add that due to the associated stigma, children are often given untrue information about why they are taking HAART. Caregivers often describe feeling both emotionally unprepared as well as unable to answer questions about HIV and AIDS. Once these children are told the truth, they find it difficult to deal with disclosure which significantly affects their adherence.

Calabrese et al. (2012:4), Kamau et al. (2012:841), Kimani-Murage et al. (2013:745) and Mutwa et al. (2013:3) find that some HIV-positive adolescents continue to maintain secrecy around their diagnosis and some report hiding their medication due to perceived and experienced stigma. Adolescents have described how they would avoid going to the clinic to obtain their drugs because they did not want community members to see them. At times, family members who have been asked to pick up the medication have refused, as they fear being seen and labelled as living with HIV. Kagee et al. (2011:87) point out that some caregivers of HIV-infected children choose to attend clinic appointments at a clinic which is far from from them to avoid being seen or identified as HIV-infected. However, lack of transport monies may become a hindrance in clinical visitations. Furthermore, some participants in a study by Beyers and Nkoane (2012:661) reveal that after disclosing their status to family members, their parents asked them to keep it quiet and not tell anyone else. They said that this reaction made them feel cast out which lead to anger and frustration.

Additionally, Mutwa et al. (2013:3) cite that stigma is a major issue amongst HIV-infected adolescents who live in congested households, boarding schools and foster care homes. Many of them do not want their siblings, friends and others to see them taking HIV medication. This is exacerbated by a lack of a private place to keep medication, as therefore adherence is significantly affected. Nevertheless, Mutwa et al. (2013:7) recommend that support structures for HIV infected adolescents should be in place at health facilities, schools and foster care families.

Midtbo et al. (2012:264), Vermeulen (2011:67) and Petersen et al. (2010:973) report different incidents of HIV stigma experienced by HIV-infected adolescents. Some adolescents have mentioned that they are being called degrading names, while others have felt that people have gossiped about their HIV status. Furthermore, Muller, Bode, Myer et al.

(2011:136) cite that the consequences of stigma have made some caregivers feel compelled to hide their children's medications to avoid unwanted attention and this may result in skipping doses. They felt uncomfortable when people spoke negatively about people living with HIV and AIDS (internalised stigma) and some felt discriminated against or rejected by friends and family members (externalised stigma). Midtbo et al. (2012:264) indicate that maintaining secrecy of being HIV-positive became increasingly difficult for older adolescents as they negotiate future heterosexual relationships. Some have felt that disclosing their HIV-positive statuses may result in them being abandoned by their partners. However, Calabrese et al. (2012:4) state that despite stigma and discrimination, some adolescents have come up with ways to deal with it. They have mentioned that disclosing their status to a larger circle of friends meant less medication hiding, which offered them immunological benefits and they coped better.

2.5.3. School environment

Botswana-Baylor Children's Clinical Centre of Excellence (2011:42) reveals that HIV affected social interactions in schools had separated HIV-infected adolescents from their peers. In studies by Li et al. (2010:753) and Rao et al. (2007:31) participants spoke about keeping their HIV statuses secret from their friends or class teachers. Many of them admitted to skipping doses because they feared that their friends might discover their HIV-positive status, which would result in stigmatisation. Additionally, an insufficient level of knowledge about HIV and AIDS in schools has posed an obstacle in the fight against non-adherence to medication as well as the spread of HIV amongst adolescents (Kushima, de Castro, Amarante et al. 2008:126). In Zambia, Mburu et al. (2014:15) find some acts of stigma and discrimination against HIV-infected learners in schools. Instances of teachers hinting at the presence of learners living with HIV in a manner that had been interpreted as a warning not to associate with them have been reported. As a result, some HIV-infected learners have mentioned that other learners did not want to share plates or cups with them. Some even made derogatory comments towards HIV-infected learners. Similarly, respondents in a study by Nwezeh (2008:390) indicate that HIV-infected learners should be dropped from school and some added that they will terminate their relationship with a friend who has been diagnosed with HIV. The researcher is of the opinion that these comments resemble stigma and discrimination towards those living with HIV and AIDS.

Mutwa et al. (2013:5) show that HIV-infected adolescents particularly those in boarding schools are faced with the challenge of finding a safe place to keep and take their medication. Some have had to hide their pill bottles from other students but other learners would sometimes search through their belongings making it difficult to keep the medication

hidden. Spies (2007:67) indicate that establishing medication storage is a vital psychosocial consideration before one commences with treatment because it can be a major obstacle towards adherence (Mutwa et al., 2013:2-3). Furthermore, these HIV-infected adolescents report that some teachers knew about their status yet had been unaccommodating in assisting them, affecting their adherence. For example, learners sometimes had conflicts with their medication schedule and their class schedule. The teachers would not allow them to leave the class, consequently they would be forced to take their medication in front of other learners to avoid unintentionally disclosing their status. The situation has led to learners becoming uncomfortable, isolated and non-adherent (Mutwa et al. 2013:3).

Rao et al. (2007:32) reaffirm that HIV stigma and discrimination has emerged as an important factor of non-adherence. Hence, development of effective stigma reduction programmes in schools, families and communities may be vital in improving adolescents' adherence. It might also contribute to positive health outcomes as well as protect broader public health by limiting the emergence of treatment resistant HIV strains.

2.5.4. Home environment

According to Rajaraman et al (2008:1) families are the primary caregivers to the tens of millions of people who are HIV-infected and affected in Africa. Little research exists, though, on how caregivers balance the demands of holding a job, while providing care to those who have become ill or orphaned by HIV and AIDS. Rajaraman et al. (2008:6) mention that caregivers in Botswana live in large households and are caring for a great number of children who are mostly of school-going age. As a result, the needs of HIV-infected children including medication supervision are not fulfilled because of multiple household demands. The study indicates that HIV caregivers have had to frequently take extended, unpaid leave to care for their sick family members. In many cases, this has led to job loss and resulted in serious consequences for household economic security. Rajaraman et al. (2008:13) recommend that the role of the caregiver does not appear to have been addressed formally in any workplace policies in the region, despite the growing burden of HIV care-giving on employees, as a result of the HIV and AIDS epidemic. It is therefore, a matter of urgency to develop, evaluate and monitor workplace programmes and policies that enable employees to continue to work and care for their family members.

Similarly, a study by Yeap et al. (2010:1104) in South Africa, discovered that some caregivers who had jobs had difficulty getting time off to attend to their child's clinic appointments. Therefore, Yeap et al. (2010:1106) proposes that since many caregivers have to work long hours and are not given time off to attend to their children's health, secondary caregivers become an important source of physical and emotional support. Coordination

amongst caregivers is important and failure to do that may be detrimental to the child's quality of care.

Yeap et al. (2010:1104) and Haberer, Kiwanuka, Nansera et al. (2012:4-5) add that the role of caregivers in establishing a medication-taking routine is crucial. The association of a caregiver with alcohol use may disrupt this routine when the caregiver is intoxicated. A similar association between a caregiver's alcohol use and poor adherence for the child is evident in a recent study conducted in South Africa. Campbell et al. (2012:125) and Skovdal et al. (2011:956-957) reveal that some of the HIV-infected children and adolescents in Zimbabwe are cared for by their elderly parents who likely live in poverty. In addition, immobility, deteriorating memory and poor comprehension of complex treatment regimens has meant that some caregivers have battled to ensure optimal adherence by children and adolescents. Some guardians have forgotten to dispense drugs when the child appears healthy and this has frustrated healthcare workers and compromised the quality of relation between the two.

Over and above, immobility, lack of transport money, insufficient food security or nutritional support, distance to health facilities and high clinic attendance fees have prevented some from attending monthly consultations which are crucial for optimal HAART monitoring and refilling (Campbell et al., 2012:125; Skovdal et al., 2011:957). In contrast, Sikstrom (2014:52) adds that despite these challenges, some grandparents play a pivotal role in the lives of their HIV-infected grandchildren's care. To conclude, Kamau et al. (2012:841) reiterate that caregivers' needs, especially the elderly guardians, should be addressed to facilitate even better care of the HIV-infected children which may contribute towards better adherence.

2.5.5. Individual factors

It has been discovered that adolescents are at risk given their typical developmental route which involves behavioural experimentation, engagement in risk-taking behaviours, as well as difficult and complex choices regarding independence from families, romantic relationships, sexual behaviour, substance abuse and identity formation (Thurston, Bogart, Wachma et al., 2014:191; Arrive et al., 2012:1; Kidia, Mupambireyi, Cluver et al., 2014:1; Van Dyk, 2008:185). Snyder, Wallace, Duby et al. (2014:115) add that HIV-infected adolescents need to cope with compounded issues such as stigma, medication regimens, clinic appointments, fears of life expectancy and sickness. These developmental and social hurdles are particularly challenging to HIV-infected adolescents because optimal adherence requires them to independently manage their illness, while continuing to balance being a 'normal teenager'.

Kadivar et al. (2006:846), Dietz et al. (2010:282), Kagee et al. (2011:84) and Agwu and Fairlie (2013:5) reveal numerous adolescent-related factors that have a negative impact on adherence: alcohol use; smoking of tobacco and marijuana, cocaine or crack – acts prevalent amongst male adolescents. Furthermore, urine toxicology tests have been conducted on the participants and results have shown evidence of substance use. The utilisation of the substances has been cited as a major contributing factor towards missing clinical visits and non-adherence. Alemu et al. (2007:348) mention that substance abuse does not only affect medication adherence, it also diminishes the judgement of these HIV-infected adolescents who end up indulging in unsafe and risky sexual behaviours that facilitate transmission of HIV and AIDS. Shockingly, adolescents in a study by Mutwa et al. (2013:5) indicate that if they did not accept their status, they resort to casual substance use which is associated with forgetting to take HIV medication. Dietz et al. (2010:282) emphasise that regular attendance of medical appointments is necessary for medical treatment, behavioural interventions, and monitoring of CD4 count cells and viral load. Consequently, health facilities must follow up with adolescents who have missed their clinic appointments either by phone, short messaging service (SMS) or home visits.

Chandiwa et al. (2012:243), Ndiaye et al. (2013:894) and Agwu and Fairlie (2013:5) mention that forgetting to take medication is a significant independent predictor of self-reported non-adherence among respondents. Forgetting has been attributed to lack of motivation to make medication a priority, poor planning, busy and varying or chaotic schedules because they were unable to integrate medication into their daily schedules. According to Haberer et al. (2011:6) and Agwu and Fairlie (2013:2) the influence of age and sex on adherence has been notable. Older age has consistently been related to poor adherence in both resource-rich and -limited countries, with adolescents above 15 years of age having a greater risk of non-adherence than younger adolescents. In addition, older adolescents have mentioned that HIV medication interrupts their social life – being asked for sleepover parties means that they have to bring their medication (Veinot et al., 2006:264). Others adolescents have mentioned that taking HIV treatment is overwhelming or in other words a ‘hassle’. Some have added that taking treatment everyday reminds them that they are ‘different’ and the thought is depressing (Veinot et al., 2006:264). Hence, many have been reluctant to take their medication or will take it when they feel like it. The aforementioned illustrates that transition from childhood to adolescence has had some challenges for medication adherence.

Fernanda, Kourrouski, Aparecida et al. (2009:950), Naswa and Marfatia (2010:7-8) and Beyers and Nkoane (2012:660) highlight that there is no cure for HIV and AIDS. This causes some adolescents to retaliate by indicating that there is no need to adhere to HIV

medication, instead they said death will be the fastest way to solve their problems. Naswa and Marfatia (2007:8) add that the above is a result of denial, stigmatisation, misinformation, fear and lack of belief in the effectiveness of medications, and low self-esteem. In contrast, some adolescents who took part in the study, have mentioned that medication adherence is a way to live and survive HIV, as it boosts the immune system (Naswa & Marfatia, 2007:9; Fernanda et al., 2009:951).

2.5.6. Regimen factors

The principal factors associated with non-adherence amongst adolescents appears to be medication or regimen complexity, pill burden, side effects, dosing frequency and palatability of ART (Chandiwani et al., 2012:243; Agwu & Fairlie, 2013:5). Caregivers in studies by Biadgilign, Reda, Deribew et al. (2011:91) and Wrubel, Moskowitz, Richards et al. (2005:2427) mention that they found it difficult to administer ARV medications to children they cared for. Some of the problems cited had been the spitting out of medication due to taste, resistance and refusal. With regards to medication side effects, the following have been cited by caregivers: nausea, vomiting, stomach cramps, diarrhoea, rash, sleeplessness and sedative effect. These have resulted in a dilemma to caregivers of whether to continue administering treatment to their children or not. Furthermore, Veinot et al. (2006:264) note that some adolescents did not take their HIV medication due to fear of side effects that they heard about from others, while some mentioned that the HIV treatment increased their body fat, hence they stopped taking it. Agwu and Fairlie (2013:5) also add that some long-term toxicity such as lipodystrophy may also be a reason for non-adherence.

To the contrary, Bangsberg (2008:273) mentions that some adolescents tolerated side effects without missing doses, even though a slight number occasionally missed doses. The National HIV and AIDS Treatment Guidelines (MOH, 2012:40) stipulate that all adverse side effects of ART or any other medication utilised to treat HIV patients should be properly reported on the Adverse Reactions Reporting Form (attached as **Appendix I**). Additionally, HIV clinicians are aware of what needs to be done to manage side effects which include stopping all ARVs including cotrimoxazole (CTX) or admission for in-patient care and monitoring patients closely.

Chandiwani et al. (2012:249) propose that with the availability of fixed-dosing combinations and single-dose regimens options, it may be easier for providers to explore the possibility of simplifying adolescents or youth's regimens to decrease pill burden. This may also increase their perceptions that they can effectively manage their medications. Rosso, Biagio, Maggiolo et al. (2012:57) and Harberer et al. (2012:5) note that the use of one-pill, fixed-dose has enabled participants to achieve a positive clinical outcome and it is also associated

with sustained improvements of several symptoms commonly related to HIV infection or ART.

Lastly, the HIV and AIDS Treatment Guidelines (MOH, 2012:38) has provisions for fixed doses. For example, standard first line regimens for post-pubertal adolescents and adults: TDF + FTC (or 3TC) + EFV (it is a single dose combination referred as Atripla); TDF + FTC (or 3TC) is also available as a fixed dose combination known as Truvada; and AZT + 3TC as fixed dose combination known as Combivir. Lastly, Haberer et al. (2012:5) point out that the utilisation of CTX may assist children and adolescents in developing effective routines applicable to ART adherence. CTX also helps to prevent opportunistic and other infections in the months prior to starting ART.

2.5.6.1. Available HAART medications in Botswana

The figure below shows the different HAART medications available in Botswana.

Figure 2.1: Different HAART medications available in Botswana



Nevirapine



Combivir



Atripla



Efavirenz



Aluvia



Truvada

Source: www.cdc.gov/hiv (accessed 2014/1014)

2.5.7. Facility-related factors

Campbell et al. (2012:125), Yeap et al. (2011:1103), Vermeulen (2011:27), Nglazi et al. (2012:6) and Kagee et al. (2011:86) state the following institutional factors which act as barriers to adherence: poor service, long waiting times, impatient and unsympathetic

healthcare workers, staff burn-out, work dissatisfaction level of confidentiality and poor communication between service users and providers. Mburu et al. (2014:16) add that severe shortage of trained staff, lack of youth-friendly health services and shortage of consultation rooms have been reported to be deterring adolescents from accessing appropriate services. Kagee et al. (2011:87) indicate that some patients, in an attempt to deal with facility-related problems, would decrease their doses so that their supplies would last longer and this has led to suboptimal adherence. Yeap et al. (2010:1105) has postulated that negative attitudes from staff members may result from low morale attributable to working in an overburdened environment. Henceforth, health facilities should ensure that staff members are well supported and trained to manage their workload in order to produce quality services.

Ross and Deverell (2010:95), Agwu and Fairlie (2013:4), MOH (2012:36) and Fernandez, Hosek, Warren et al. (2011:1497-1498) reveal that the success of adherence or failure to adhere to HIV medication depends on the kind of adherence counselling offered. This process gives one the opportunity to identify potential obstacles regarding adherence and disclosure as well as brainstorming practical solutions. It also enables the healthcare worker to assess the patient and the caregivers' understanding and knowledge of HAART and inform them about potential medication side effects. Fernandez et al. (2011:1497) indicate that assessing the readiness of an adolescent to start HAART is vital. A tool has been developed and has been well accepted by adolescents, which enables them to honestly report their concerns and readiness to start HAART medication. Furthermore, the tool has guided the physicians in deciding the optimal time to start HAART and identify those in need of intervention services. Moreover, adherence counselling should be a continuous process and must be done during each clinic visit. In conclusion, it is important to show HIV-infected adolescents, that long-term adherence to HAART is of key importance for positive clinical outcomes and treatment efficacy.

2.6. Coping strategies

This section will look at coping strategies utilised by HIV-infected adolescents to deal with their HIV status and adherence to HAART.

2.6.1. Disclosure of HIV-positive status

According to Haberer et al. (2011:5) and Arrive et al. (2012:2) disclosure to children and adolescents of their HIV-positive status is a process that is documented in sub-Saharan Africa. Little is known of whether it has influenced clinical response to HAART or coping ability. Nonetheless, Lowenthal et al. (2014:144), Midtbo et al. (2012:262) and Nicastro et al. (2013:364) find that disclosing a child's status to him or her has been associated with good

medication-taking, self-efficacy, resilience, positive expectation of medication, social support, reduced perceived stigma and fewer emotional problems in comparison to those who are not aware of their HIV-positive statuses.

Balthip and Purnell (2014:32) add that with support from family, many participants have been able to have the courage to disclose their HIV-positive status to trusted people, after taking time to consider the implications. Botswana-Baylor Children's Clinical Centre of Excellence (2011:78), Merzel et al. (2008:978), Holele (2010:24), Vaz, Corneli, Dulyx et al. (2008:844-848), Oberdorfer, Puthanakit, Louthrenoon et al. (2006:283) and Lesch, Swartz, Kagee et al. (2007:815) indicate that the process of disclosure should start much earlier at an average age of 3 to 5 years for perinatally-infected children (partial disclosure). Full disclosure should be done by the time an adolescent is 10 or 12 years old or when he or she starts asking questions about his or her illness. The disclosure process should be done in a way that builds on the child's strength and assessing the readiness of the child or an adolescent for partial or full disclosure is crucial. Haberer et al. (2011:5), Mutwa et al. (2013:4) and Arrive et al. (2012:2) state that while disclosure is also essential for secondary prevention of HIV transmission, it may heighten emotional and behavioural disorders amongst adolescents, familial conflicts or social stigma perceptions and these may jeopardise confidentiality. Additionally, this anger in some cases may lead to adolescents being less adherent, sometimes in an attempt to punish their parents or due to confusion about why this happened to them and not to others.

A study by Kidia et al. (2014:3) finds that adolescents prefer a health care setting in which to be told of their HIV-positive status. The main reason is that in a health care facility, they have access to accurate information from healthcare workers as well as an environment that makes the illness seem more real. This means that healthcare workers should empower caregivers well before their children reach adolescence to prepare for disclosure. Lowenthal et al. (2014:144) mention that in recent years, healthcare workers' training programmes have been implemented in several settings to increase their knowledge and capability in order to provide psychosocial support to children, including post-disclosure and on-going support. In Botswana, the training programmes are National KITSO AIDS training and Paediatric KITSO AIDS training (Lowenthal et al., 2014:144).

2.6.2. Personal coping strategies

The utilisation of medication-taking reminders such as alarm clocks, beepers, calendars, pill boxes, drug identification charts and daily schedules are some of the strategies utilised by HIV-infected adolescents to adhere to HIV and AIDS medication (Thurston et al., 2014:192; Van Dyk, 2008:107; Kagee et al., 2011:84; Park and Nachman 2010:559; Orban et al.,

2010:424-425). Others have relied on their caregivers for their medication and that has been found in other studies as a reliable strategy towards adherence (Naswa & Marfatia, 2010:8).

Van Dyk (2008:107) identifies some routine activities to which taking medication can be linked and these are: taking HAART when brushing teeth in the mornings and evenings; utilising a radio or television programme that coincides with the time the patient should take the medication and that the patient watches or listens to regularly as a reminder. Balthip and Purnell (2014:33) and Veinot et al. (2006:265) add that determination, accepting oneself as being HIV-positive and accepting that dying or death is part of life are some of the important elements in finding meaning and purpose in life to cope with being HIV-positive. In addition, these elements resemble positive living. Some participants have mentioned that they have lived for more than 10 years while taking ART to prolong life. They knew that taking care of themselves would extend their lives.

Campbell et al. (2012:128) and the MOH (2012:36) indicate that a treatment ‘buddy’ or partner plays an important role in providing the patient with ongoing support for adherence to care and treatment. This person is usually someone close to the adolescent, a family member, teacher, friend or caregiver and should accompany the patient to the clinic visits. Henceforth, it is important for healthcare workers to ensure that treatment buddies have the necessary information on HIV and AIDS including HIV medication. However, not having a treatment buddy or partner should not act as a barrier to any patient who is being initiated on HAART. Lastly, HIV-positive adolescents have reported that they keep quiet about their HIV-positive status so that people around them would not know they live with it. The participants have done this to protect themselves from the community that looks negatively upon those who live with HIV and AIDS (Thupayagale-Tshweneagae, 2010:262; Botswana-Baylor Children’s Clinical Centre of Excellence, 2011:55; Beyers & Nkoane, 2012:660; Orban et al., 2010:425; Mutwa et al., 2013:5-6).

2.6.3. Family and peer support

Unconditional love and support from family and peers have been evident as a positive influence to adherence as it creates an environment that enable HIV-infected adolescents to adjust to new drug-taking routines and cope with side effects. Receiving support has boosted the drive of HIV-infected adolescents, strengthened their minds and enhanced their self-worth and all these have shown them that they still have a place in society (Mburu et al., 2014:15; Veinot et al., 2006:265; Balthip & Purnell, 2014:32). Mburu et al. (2014:15) find that due to love and support from family members, adolescents’ especially older ones have felt that their families had become over-protective of them since their HIV diagnosis.

Brown, BeLue and Airhihenbuwa (2010:452) establish that family units in South Africa are often a strong source of social support and they remain the strongest source of support of caring for people who are living with HIV and AIDS (PLWHA). Research has shown that disclosing one's status can yield even greater social and emotional support for PLWHA and foster a sense of trust among family members. This is an important element of coping with the stress of living with HIV and AIDS as well as maintaining trust and mutual respect within the family. In addition, disclosing to family members can also provide another channel through which information is shared. For example, family members can solicit medical advice and treatment options from doctors on behalf of the PLWHA. However, family relations do not always embody the type of emotional support and physical care that PLWHA require. By keeping the patient's status a secret may imply that the family is ashamed and such perceptions are reinforced by negative enablers that may prevent PLWHA from getting the necessary assistance including adherence to treatment.

Mburu et al. (2014:16), Pettitt (2010:79), Kidia et al. (2014:5) and Marino, Simoni and Silverstein (2007:74-76) indicate that peers who have been living with HIV feature prominently as a source of psychosocial support, improved self-esteem, friendship and ART adherence. The main reason is that experienced adolescents are capable of using age-appropriate terminology to explain important concepts of HIV and AIDS to those who have been diagnosed recently. Additionally, adolescents have reported that through such peer connections, they could share coping strategies, make each other feel valued and accepted as well as offer each other a sense of identity. This has reduced the sense of isolation and maintained motivation and commitment to HIV care and treatment. Some adolescents have mentioned that peer support is an excellent resource for making decisions about disclosing their statuses to their families, especially behaviourally-infected adolescents. Adolescents in a study by Kidia et al. (2014:4) explain that by attending peer support groups and youth clubs or youth friendly centres they have become more knowledgeable about HIV and AIDS. In return, they are able to teach others about the importance of adherence to medications, avoiding risky behaviours and staying healthy.

Pettitt (2010:79) notes that including activities such as drama, pool parties, safari trips, art sessions, teachings on personal finance management, preparing for college and goal setting is vital in youth or teen clubs. This provides HIV-infected adolescents with the opportunity to normalise their social experiences and improve their outlook on life. In summary, Pettitt (2010:79) restates that support groups or teen clubs for HIV-infected children generally provide a health-enabling 'safe space' which helps to create important networks and social

bonds. These will ultimately lead to improved clinical and mental outcomes as well as healthy transitions into adulthood.

2.6.4. Support from schools

Schools play a major role in educating learners about HIV and AIDS as well as medication adherence (Kushima et al., 2008:126). Research has shown that school-based sexuality programmes play a significant role in reducing HIV-related stigma and discrimination (Kushima et al., 2008:126). Additionally, educational materials make classroom work easy because there will be improved learning and better understanding of the subject. Researchers have developed audio-visual materials named kits for HIV and AIDS classes which contain a series of illustrated slides for utilisation in theoretical classes. Subsequently, these have played an important role towards improving learners' knowledge of HIV and AIDS and positive attitude towards HIV medication which has led to better adherence (Kushima et al., 2008:126).

Additionally, Botswana-Baylor Children's Clinical Centre of Excellence (2011:49) and Petersen et al. (2010:973) affirm that despite fears of stigma, disclosure to class teachers or guidance and counselling teachers has been reported to be beneficial. The reason being that these teachers are able to provide support and have an understanding of the learner's health situation. HIV-infected adolescents in a study by Botswana-Baylor Children's Clinical Centre (2011:53) mention that despite missing classes due to ill-health and medical check-ups, they had been assisted with notes by their teachers and other classmates. Others have added that when they were on educational tours their teachers or trip facilitators assisted them with taking their HIV medication. In general, support from classmates and teachers minimised isolation, depression and stress levels amongst HIV-infected adolescents. It has also increased a sense of self-competence and medication adherence.

Mears, Charlebois and Holl (2006:52) add that school-based clinics have become an important model towards medication adherence amongst school-going adolescents. However, the researcher is of the view that it is an area of research that needs further exploration in relation to adherence to HAART.

2.6.5. Spiritual support

Park and Nachman (2010:560-561), Sopena et al. (2010:1257) and Li et al. (2010:754) note that with the focus of HIV moving away from being an incurable illness to a chronic disease, infected patients and their families have had to develop lifelong coping mechanisms. One outlet for confronting their issues and perhaps seeking help is through religion and spirituality. Lyon et al. (2011:633) and Kremer et al. (2009:132) find that adolescent

spirituality is associated with lower levels of anxiety and depression, optimism about the future and coping with treatment side effects. In fact, those who have believed that spirituality is helpful in coping with side-effects also reported fewer symptoms that are common to the illness and its treatment. Lyon et al. (2011:635) note that adolescents with high spirituality have adhered well to HAART medication and this is significant amongst perinatally-infected adolescents. High spirituality in the family has generally played a major role amongst HIV-infected adolescents in medication adherence. On the contrary, those who have believed that being HIV-positive is a punishment from God have had poor HAART-adherence. Moreover, Vermeulen (2011:72-73) finds that some churches forbid members to take their HAART because they have been cured by their faith in God and a healing prayer. Consequently, many of them have stopped taking treatment and have become very ill and experience stress again. However, Mutwa et al. (2013:5) reiterate that discussions regarding religious support and practices are important strategies in overcoming religious barriers to HAART-adherence.

2.6.6. Support from the health facilities

Petersen et al. (2010:974), Sopena et al. (2010:1257) and Botswana-Baylor Children's Centre of Excellence (2012:11) point out that the provision of services from health facilities such as counselling services, serves as a mediator in a number of issues faced by HIV-infected adolescents. Additionally, HIV-infected adolescents have revealed that healthcare professionals are a primary source of support. The main reason is that they provide access to counselling services, education and help adolescents to develop early positive strategies to set the stage for long-term adherence (Chandiwani et al., 2012:249; Balhithip & Purnell, 2014:33). Veinot et al. (2006:266) also point out that patients' understanding of their medical conditions and treatment recommendations has been a strong predictor of treatment adherence. A study by Lowenthal et al. (2014:145-146) that had been conducted in Botswana indicates that adherence should be done in a developmentally appropriate manner. In the beginning the child is taught that the medication (ARVs) keeps him or her healthy. When he or she is sick, it will help him or her to get better. In addition, teaching the child how to take medications at the appropriate time and the appropriate amount is vital. Teach the child that as long as he or she takes medication, he or she will become strong and healthy. Simple drawings are also utilised to reinforce these concepts.

The intermediate steps include teaching the child the names of the medications. Once children know the alphabet and can count, they are considered ready to learn the names of ARVs and should be taught the simplest three letter abbreviations. (e.g. AZT, 3TC). Teach the child about CD4 cells in an age-appropriate way. (In Setswana, CD4 cell translates as

“soldier of the body”. The BDF (Botswana Defence Force) is well-known by children who recognise that the soldiers of the BDF ‘protect Botswana’. In Botswana, it is relevant to teach that just as soldiers of the BDF protect Botswana, there is a part of our bodies that protects us from getting sick. When we get sick, this part of our bodies helps us fight sickness so that we can get better. As a result it protects us, and we call it the soldiers of the body. Teach that the ARVs help to keep the soldiers strong and also help to make new soldiers. Teach that as long as the soldiers are strong and healthy, the child can do whatever he or she wants in life.

Advanced steps include teaching the child the necessity of taking medicines because something in his or her body is making the CD4 cells (soldiers) weak. Teach that medicines work by keeping the ‘bad guy’ asleep so that it cannot attack the CD4 cells. Incorporate an understanding of medication resistance prevention. If the ‘bad guy’ stays asleep, he cannot become ‘tricky’ and learn to get away from the medicines. Introduce the proper names of CD4 cells and HIV. Explain the difference between HIV and AIDS. Ensure that the child understands how HIV is transmitted. Re-assess understanding at each visit following disclosure of HIV status (Lowenthal et al., 2014:145-146). Refer to **Appendix J** for some drawings which have been adapted from Botswana-Baylor Children’s Clinical Centre of Excellence.

Lowenthal et al. (2014:145) mention that where the study took place, before an HIV-infected child is initiated on HAART, all adults involved in his or her care are required to attend a group learning session (adherence class) which last an hour. The session focusses on basic HIV concepts, disclosure and adherence education. This is to equip caregivers with skills and knowledge to care for their children. In addition, older children who are aware of their HIV status are also welcome to accompany their caregivers during these classes. However, for attendees who have difficulties comprehending, there will be further one-on-one discussions with a nurse or a social worker. Home visits are incorporated when some adult caregivers such as aged grandparents are unable to attend clinic-based sessions. Rao et al. (2007:32) have emphasised the importance of developing a collaborative doctor-patient relationship, one that provides adolescents and young people with a mutual understanding and acceptance that might encourage them to discuss adherence with their providers. Chandiwani et al. (2012:249) and Lowenthal et al. (2014:146) reaffirm that adherence counselling should be an ongoing part of clinical care for early identification of non-adherence issues.

McIntosh (2010:60) indicates that it is important to make clinic visits more enjoyable and educational for HIV-positive children. A study has been carried out at Botswana-Baylor

Children's Clinical Centre of Excellence and shows that structured play, reading, arts and culture appreciation, hygiene promotion and guided reading has enabled these children to interact. Consequently, these activities facilitate an overall positive clinical experience for children and improve health outcomes. The researcher is of the view that this is an admirable initiative to address some of the facility-related factors. Hence, it could be extended to government health facilities, even though it is resource intensive.

2.7. Summary

The chapter has reviewed relevant literature that supports this study. A bio-ecological perspective has shown that individual system, microsystem, mesosystem, exosystem, macrosystems and chronosystem play significant roles in non-adherence to HAART, amongst HIV-infected adolescents as they interacted with multiple social and physical environments. Furthermore, the literature has highlighted the level of knowledge HIV-infected adolescents have about HIV and AIDS and the importance of adherence to HAART. Additionally, a number of direct and indirect causes to non-adherence amongst HIV-infected adolescents have been covered comprehensively. On the other hand, the literature has revealed different strategies being utilised by HIV-infected adolescents for coping with being HIV-positive as well as HIV-medication. The researcher will put forward recommendations that will ensure adherence to HAART as proposed by the participants during the study.

The next chapter will cover the research methodology and design, and empirical results.

CHAPTER THREE: RESEARCH METHODOLOGY AND EMPIRICAL STUDY

3.1. Introduction

This chapter will describe the methodology utilised in this research study. It will cover the research approach, type of research, research design, study population and sampling procedures. It will describe the data collection methods and the methods of data analysis, as well as trustworthiness of results. Moreover, this chapter will describe the pilot study and how it was conducted in order to test the research instruments, as well as the ethical considerations that guide this study. The empirical results will be presented by means of themes and sub-themes that had been identified during data analysis and will be supported by verbatim quotes from interviews and substantiated with literature.

3.2. Goal and Objectives

3.2.1. Goal

The main goal of the research study is *to identify barriers to HAART adherence amongst HIV-infected adolescents in a government hospital in Botswana.*

3.2.2. Objectives

To attain the goal of the research study, the following objectives have been set.

- To explore and describe the knowledge of HIV-infected adolescents regarding HIV and AIDS and the importance of adherence to HAART.
- To contextualise and conceptualise HAART-adherence amongst adolescents.
- To identify and describe factors contributing to non-adherence to HAART amongst HIV-infected adolescents.
- To identify and describe coping strategies amongst HIV-infected adolescents on HAART.
- To make suggestions on measures to increase HAART-adherence based on the research findings.

3.3. Research approach

The researcher has utilised the qualitative research approach which enables the researcher to gain an understanding in identifying barriers to HAART adherence from the point of view of HIV-infected adolescents' (Maree, 2007:78; Leedy & Ormrod, 2013:142; Kumar, 2011:64). Through the qualitative research approach, the researcher has managed to collect data in the natural setting of the HIV-infected adolescents. In addition, it has allowed the researcher

to report on the multiple perspectives of HIV-infected adolescents in order to create a larger picture regarding barriers to HAART adherence (Creswell, 2013:46). Moreover, the qualitative research approach has assisted the researcher in making results appear in the form of words as well as in the natural language of participants (Fouché & Delport, 2011:66).

Some of the advantages of qualitative research approach include enabling the researcher to keep a focus on learning the meaning that participants hold about the problem and not on the meaning that the researcher brings to the research or writes from literature. The participants' meanings further suggest multiple perspectives on a topic and diverse views. Also, it is emergent, meaning the initial plan for research cannot be tightly prescribed as the process may change after the researcher enters the field to begin data collection (Creswell, 2013:47).

3.4. Type of research

Applied research places a strong emphasis on application and solving problems in practice (Fouché & de Vos, 2011:95). This research is applied because it focusses on a specific problem in practice, namely barriers to HAART-adherence amongst HIV-infected adolescents in a government hospital in Botswana. The research findings will assist healthcare workers, caregivers, teachers and other relevant stakeholders in gaining an in-depth understanding of barriers to HAART adherence amongst HIV-infected adolescents (Fouché & de Vos, 2011:95). In addition, the research outcomes will definitely assist the selected government hospital at which the study is being conducted to come up with various measures to address this problem. Furthermore, the applied research approach has given HIV-infected adolescents an opportunity to express themselves and share their experiences regarding their adherence to HAART (Fouché & de Vos, 2011:95). Last of all, the nature of the study is exploratory and descriptive. The researcher managed to explore, describe and gain a comprehensive understanding of non-adherence to HAART amongst HIV-infected adolescents (Fouche & de Vos, 2011:95).

3.5. Research design

The research design that is being utilised is phenomenology (Creswell, 2013:76; Fouché & Shurink, 2011:316). Due to the sensitive nature of the research topic, a phenomenology research design is most appropriate. Phenomenological research design has accorded the researcher an opportunity to gain a deep understanding of the barriers to HAART-adherence amongst HIV-infected adolescents. It has too allowed the researcher to describe these barriers to HAART-adherence as accurately as possible by refraining from any pre-given frame and adhering to the facts (Creswell, 2013:76; Fouché & Shurink, 2011:316). The

researcher has been able to understand the phenomenon under study from the participants' perspectives (what they experience) to be able to provide a description of how they experience it (Fouché & Shurink, 2011:317). Moreover, a phenomenological research design has enabled the researcher to set aside any personal experience with participants in order to focus on their experiences in an open-minded way (Creswell, 2013:76; Fouché & Shurink, 2011:316-317).

3.6. Research methodology

The researcher has utilised the research methods discussed in this section.

3.6.1. Study population

The study population are HIV-infected adolescents (males and females) aged 13 to 17 years old who receive HAART at a government hospital in Botswana. The hospital has been purposely selected because it is one of the health facilities that has children and adolescents on HAART and that is accessible to the researcher. It is situated in a town called Lobatse in the southern part of Botswana and serves a population of approximately 29 007 people, from Lobatse and surrounding areas (Statistics Botswana, 2012:A1). The ARV-Infectious Disease Care Clinic (IDCC) at the hospital was launched in April, 2004 as a special clinic dedicated to the care of adult and paediatric outpatients with HIV and AIDS. The clinic has trained staff members such as medical officers, nurses, counsellors and facilities such as a pharmacy and laboratory to provide different HIV and AIDS care services. Currently, the hospital's ARV-IDCC has about 5 258 patients on HAART (www.hiv.gov.bw accessed 2014/04/02).

3.6.2. Sampling

The researcher had requested a list of potential participants who meet the inclusion criteria, from staff members who work in the hospital's ARV-IDCC. The staff then informed the potential participants and their parent or legal guardian about the study, utilising an information letter. The simple random sampling technique had been utilised to select the sample size for the study because it reduced the researcher's bias in the selection of participants. According to Strydom (2011a:228), in probability simple random sampling each individual case in the population theoretically has an equal chance of being selected for the sample. The selection criteria is listed below.

Participants should:

- be on HAART at the selected government hospital's ARV-IDCC;
- be on HAART for at least six months or more;
- be an HIV-infected adolescent, who is aware of his or her HIV status;

- be between the ages of 13 and 17 years old;
- have a parent or legal guardian who is aware of the adolescent's HIV status; and
- have a parent or legal guardian who is willing to give their informed consent for their adolescent to take part in the study.

Twelve participants (four males and eight females) had been interviewed for this study. These participants opted to be a part of the study after an identified healthcare worker from the hospital's ARV-IDCC informed them of the study using the information letter. This had been provided to them as they came for their clinic appointments. All those who were interested in taking part in the study, together with their parent or legal guardian, were given an opportunity to clarify everything before they made their final decisions. Once informed decisions had been made by the parents and/or legal guardians and participants, the names of the potential male participants were put in a box. From the box, six names had been randomly drawn and these adolescents comprised the sample population. This same method had been applied to the potential female participants (Strydom, 2011a:231-232). However, after the sample population from the males had been drawn only four agreed to take part in the study and the other two declined. The researcher had attempted to recruit two more males to ensure equal representation but his efforts proved fruitless. As a result, the number of female participants had been increased to eight. The selected participants and their parents or legal guardians signed the letters of informed consent and assent before the study commenced.

3.6.3. Data collection

The topic that is being investigated is sensitive, hence the decision had been taken to conduct unstructured, one-on-one interviews. According to Greeff (2011:347-348), an unstructured, one-on-one interview is also referred to as in-depth interview. The purpose of this interviewing technique is to gain understanding into the experiences of other people and the meaning they derive from those experiences. It is not to get answers to questions, nor test or evaluate a hypothesis. Unstructured interviewing is also commonly utilised when investigating sensitive issues.

In order to establish the meaning participants' link to their experiences, the researcher must define what information is required. Thereafter, the interview is comprised of three main types of questions which guide the conversation and when responses lack sufficient detail, depth or clarity, probing is important and follow up questions which are based on answers provided to the main questions can be addressed to the participants (Greeff, 2011:349). The researcher had interviewed the twelve HIV-infected adolescents on HAART and this

technique is suitable for such a sample size (Greeff, 2011:350). The primary and secondary questions for the unstructured interviews had been constructed by the researcher and is attached as **Appendix H**.

The letter of informed consent which had been discussed with the parents or legal guardians of the adolescent first, are available in English and Setswana (**Appendix D**: English version and **Appendix E**: Setswana version). Once the parents or legal guardians' consented to the adolescents taking part in the study, they signed the letter of informed consent. All the parents or legal guardians preferred the Setswana letter to the English letter. Once they signed, the letter of assent had been read to the adolescent, which is also available in English and Setswana (**Appendix F**: English version and **Appendix G**: Setswana version). Once the adolescent agreed to voluntarily take part in the study and had signed the assent letter, the interview commenced or an appointment was made to conduct the interview at a later stage. Participants preferred the Setswana assent letter.

Regarding the data collection apparatus, the researcher had utilised a digital voice recorder to record all the interviews, with the permission from the participants and their parents or legal guardians (Braun & Clarke, 2013:92). The digital voice recorder is user-friendly and assisted the researcher in capturing these HIV-infected adolescents' responses, language and concepts they utilised when narrating the challenges they are facing with regards to HAART-adherence. It permitted the researcher to transcribe everything that transpired during the interviews (Braun & Clarke, 2013:92). During the interviews, the researcher also wrote down brief field notes on a note pad. The interviews had been conducted in a government hospital in Botswana.

3.6.4. Data analysis

Data was thematically analysed using Tesch's framework (Tesch, 1990:113).

- Verbatim transcriptions were done for all twelve interviews that were conducted, first in Setswana, the vernacular language, which was then translated into English.
- The researcher printed and read through each interview slowly trying to gain a deeper understanding of what the participant said and the same procedure applied to other transcriptions.
- The researcher selected one interview and started to make notes in the margins as the researcher identified some 'topics' which arose from the data. The researcher labelled those topics or gave them a name and continued writing in the margins.
- Once the researcher had gone through the entire interview with coloured pens, the researcher started grouping these descriptive labels under a common 'theme' or

'category'. The researcher took research objectives into consideration when doing the analysis.

- One broad 'theme' may have several categories and a category may have sub-categories.
- The researcher continued refining his analysis by thinking through the categories and sub-categories.
- The researcher developed a preliminary table that sets up the main themes, categories/sub-categories and utilised this as a framework for discussing the findings. This is called 'first order' analysis in which categories of meaning are derived from the participants' responses.
- The framework had been set up for discussions and analysis to take place through utilising the actual quotes of participants and engaging in further 'second order' analysis. The researcher has utilised his own concepts or typologies found in literature and quotes are linked to other authors' observations found in the literature review.

3.6.5. Trustworthiness

The researcher had ensured that findings of the study are worth paying attention to or worth taking account of by considering and addressing the following concepts (Schurink, Fouché & De Vos, 2011:419).

3.6.5.1. Credibility

Credibility is an alternative to internal validity, and the goal is to demonstrate that the study has been conducted in a manner that ensures that participants are accurately identified and described (Schurink et al., 2011:419-420). The researcher had interviewed twelve HIV-positive adolescents on HAART from a selected government hospital in Botswana. The researcher had checked and verified their clinical records, with the permission of the staff, to make sure that participants who meet the criteria are taking part in the study. A digital voice recorder had been utilised during the twelve interviews, which were guided by an unstructured interview format. In addition, all the interviews have been transcribed verbatim in Setswana, the vernacular language of the participants. This is important as it enables anyone to take a transcribed interview and match it with what has been recorded to test the credibility and trustworthiness of the data. The transcribed Setswana interviews have been translated into English. The quotes utilised in the thematic analysis later in the chapter, are presented in Setswana and then in English to ensure trustworthiness.

Moreover, issues around HIV and AIDS may have different meanings, therefore during the interviews the researcher sought to clarify any issues to ensure that both the researcher and participant understood the phenomenon in the same way. After the interviews had been transcribed, the researcher engaged with the participants again to verify and explore some issues further (member checking). The researcher took care not to lead participants to providing answers that the researcher wanted (reflexivity). Lastly, Dr. Thato Molefi, a Clinical Psychologist employed at Botswana Harvard AIDS Institute Partnership (BHP), acted as a peer debriefer throughout the study (Schurink et al., 2011:419).

3.6.5.2. Transferability

Transferability refers to the extent to which findings can be applied to other contexts or to other participants (Schurink et al., 2011:420). The researcher has utilised a qualitative research approach and the study findings cannot be generalised due to the variability in meaning attributed to the unique experiences of each HIV-infected adolescent and the small sample size. However, the findings could be generalised in theory or with a similar group of people and not in a representative population (Schurink et al., 2011:420).

3.6.5.3. Dependability

Dependability means the research process is logical, well-documented and it can be audited (Schurink et al., 2011:420). The researcher has utilised an unstructured interview format to ensure some level of uniformity in how the interviews unfolded. Since all interviews have been recorded with a digital voice recorder, the extent of uniformity is evident and this shows in the researcher's transcriptions. As a result, the evidence is sufficient to prove that the researcher did not fabricate data. The researcher is confident that even if the same study is repeated with the same participants, in the same or similar context the findings will be similar (Schurink et al., 2011:420). All transcriptions have been done in Setswana and thereafter translated into English to ensure dependability.

3.6.5.4. Conformability

Conformability refers to whether the findings of the study can be confirmed by another study, even though this is problematic in qualitative research (Schurink et al., 2011:420). Nonetheless, the role of peer debriefing as well as supervision are crucial in reducing the bias and subjectivity of the researcher. The researcher has kept a diary and written down his feelings and experiences in order to remain in touch with his feelings in striving toward objectivity to avoid any bias (reflexivity). The voice recordings and verbatim transcriptions have enabled the supervisor to assess whether the researcher is biased or not (Schurink et al., 2011:421).

3.7. Pilot study

A pilot study had been conducted to test the overall feasibility, appropriateness and applicability of the study (Strydom & Delpont, 2011:284). The researcher had executed a pilot study in the same manner as is planned for the main investigation. However, the pilot study has been conducted in another government hospital that is situated in the Kgalagadi District in Botswana. Probability simple random sampling had been utilised to select the sample size. A total of two HIV-infected adolescents on HAART between the ages of 13 and 17 years were interviewed, based on the unstructured one-on-one interview technique. The researcher is of the opinion that the data collection method is appropriate, as it provided responses to the research question and provided opportunity for the real experiences of the participants to be voiced. There were no amendments necessary particularly on the interview schedule. The data that has been gathered is not included in the final dissertation. Lastly, the researcher has chosen a different hospital because it is situated in a different part of Botswana. This has made it impossible for participants who had been interviewed during the pilot study to meet with potential participants of the main study, as this could have had an impact on the research outcomes.

3.8. Ethical considerations

The study has been based on morality, mutual trust and well accepted conventions which are important in research (Strydom, 2011b:113; Babbie, 2011:477; Braun & Clarke, 2013:61). The following are some of the ethical considerations the study has adhered to.

3.8.1. Voluntary participation

The researcher had given the parents/guardians and the participants adequate information to enable them in making a voluntary informed decision to take part in the study. The researcher did not force or deceive anyone into participating in this research study (Strydom, 2011b:116; Babbie, 2011:478). Participants had been informed that they could withdraw during the course of the research if they wished to do so and that there would be no consequences and their data would be discarded.

3.8.2. Deceptions of subjects/respondents

The researcher has not mislead participants, misrepresented facts or withheld information in order to ensure the participation of the respondents (Strydom, 2011b:118; Babbie, 2011:484; Braun & Clarke, 2013:63). Adequate information regarding what the study entails had been provided to participants in a written format, namely a letter of informed consent for the parents/guardians and an assent letter for the adolescent participants. This had been

designed to enable potential participants together with their parent or legal guardian to read and understand, and make informed decisions.

3.8.3. Informed consent

The researcher has utilised HIV-infected adolescents between the ages of 13 and 17 years as participants. The researcher has prepared a letter of informed consent for the parent or legal guardian in English and Setswana and an assent letter for the adolescents also in English and Setswana. Parent or legal guardians of potential adolescent participants had been given the letter of informed consent which outlined the purpose of the study, what is expected from participants, potential risks and discomfort, their rights, potential benefits and confidentiality, as well as the fact that the data will be stored in a safe at the Department of Social Work and Criminology, at the University of Pretoria for 15 years, as required by the University.

The document had been written in English and Setswana. Thereafter the letter of assent had been given to the adolescents and the researcher went through it with them. The researcher had given them adequate time to internalise and ask for clarity where they did not understand, to enable them to make informed decisions. (Strydom, 2011b:117; Babbie, 2011:480-481; Kumar, 2011:244). All parties signed letters of informed consent and letters of assent before the study commenced. Parent or legal guardian's letter of informed consent is attached as **Appendix D** (English version) and **Appendix E** (Setswana version). Letter of assent for adolescents is attached as **Appendix F** (English version) and **Appendix G** (Setswana version).

3.8.4. Violation of anonymity and confidentiality

The researcher guaranteed the participants that their privacy and confidentiality will be maintained (Strydom, 2011b:119; Braun & Clarke, 2013:63). In this regard, the researcher used unstructured one-on-one interviews which were recorded. Participants were assured of confidentiality and privacy at the beginning and after the interviews. Participants were given a code as pseudonym, for example 01 or 02 and their personal details were stored under this code to ensure confidentiality. Access to collected data was also controlled, and will continue to be controlled, as the tapes will be stored in a safe at the Department of Social Work and Criminology, at the University of Pretoria for 15 years, thereby restricting access to the data.

3.8.5. Avoidance of harm

The fundamental ethical rule of social research is that it must bring no harm to participants. In addition, participants can be harmed in a physical and or emotional manner (Strydom,

2011b:115; Babbie, 2011:479). The study at hand, was investigating a sensitive topic and emotions could have been evoked. The researcher dealt with the interview in a very professional and sensitive manner, so as to avoid any harm as far as possible. Arrangements were made with the hospital social worker where the study took place to be referred any participants that might need counselling. However, there were no participants who needed counselling.

3.8.6. Debriefing of participants

The diversity around HIV and AIDS may have different meanings. The researcher after the interviews debriefed each participant on the issues raised to make sure that both the researcher and the participant understand it the same (Strydom, 2011b:122), and to clarify any uncertainties or determine if further counselling is needed.

3.8.7. Providing incentives or compensation

There was no remuneration for participants to partake in the study and this was covered in the letters of assent and informed consent (Kumar, 2011:245; Strydom, 2011b:121).

3.8.8. Action and competence of researcher

The researcher is adequately skilled as a social worker and has research and interviewing skills and experience that made him competent to undertake the study. The researcher completed research at BSocSci (SW) Honours degree level and passed the Research Methodology (MWT 864) module at Master's degree level (Strydom, 2011b:123). Researcher also was guided by his supervisor.

3.8.9. Release or publication of the findings

The researcher will introduce findings of the study to the public in written form. The researcher will provide a CD version of the mini-dissertation, which will be available on the University of Pretoria Thesis and Dissertations portal (UPeTD), to be freely accessible on the Web-www.upet.up.ac.za and other search engines. The findings will be presented to the selected government hospital staff where the study took place and the office of the Ministry of Health (Strydom, 2011b:126). A brief research report will be compiled for the participants and their parents or legal guardians.

3.9. Empirical findings

This section will present, analyse and interpret the qualitative data that was collected. The biographic profile of participants will be presented, as well as the framework for discussing findings. The findings will be presented by means of different themes and sub-themes

generated from the data, with quotes from the interviews to illustrate these themes and literature to substantiate these findings.

3.9.1. Biographic profile of participants

The biographic information of the participants is described in Table 3.1.

Table 3.1: Biographic profile of participants

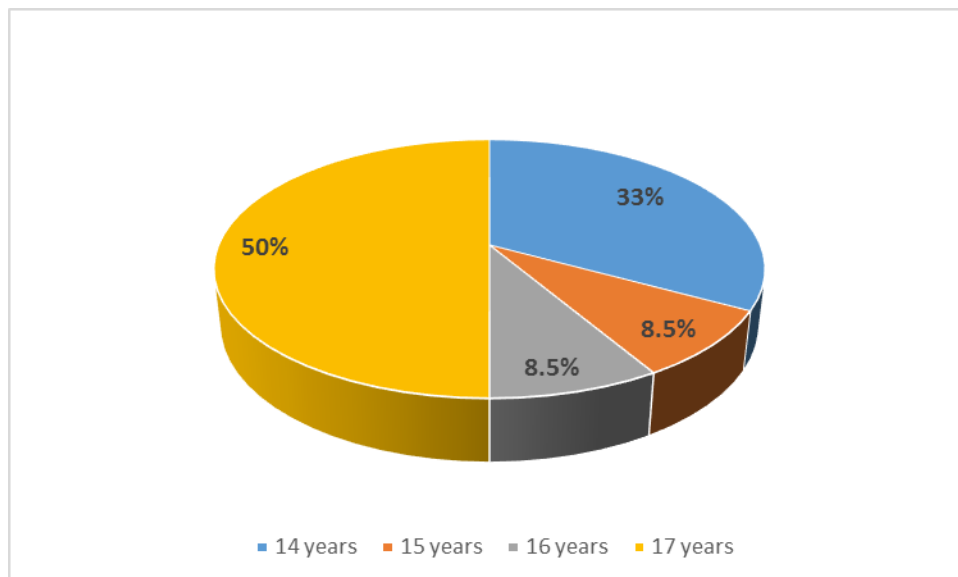
Code assigned to the participant	Age	Gender	Educational level	Day scholar, boarding or out-of-school	Caregiver (Biological or relative)	Length of period on HAART	Aware of HIV status
01	17 years	Male	Form 3	Day scholar	Biological parent	10 years	Yes
02	16 years	Male	Form 2	Day scholar	Relative	8 years	Yes
03	14 years	Female	Form 1	Day scholar	Biological parent	10 years	Yes
04	17 years	Male	Form 3	Day scholar	Relative	10 years	Yes
05	14 years	Male	Standard 7	Day scholar	Relative	7 years	Yes
06	17 years	Female	Form 5	Day scholar	Biological parent	4 years	Yes
07	17 years	Female	Finished Form 3	Out-of-school	Relative	10 years	Yes
08	17 years	Female	Form 5	Day scholar	Relative	7 years	Yes
09	14 years	Female	Form 1	Day scholar	Biological parent	10 years	Yes
010	17 years	Female	Form 5	Day scholar	Biological parent	1 year & 8 months	Yes
011	14 years	Female	Form 1	Day scholar	Biological parent	10 years	Yes

012	15 years	Female	Form 1	Day scholar	Relative	11 years	Yes
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The above table shows that twelve participants took part in the study. Their ages ranged from 14-17 years and most of them were females. In addition, the majority of them are learners except for one participant. Furthermore, all participants knew their HIV status and a significant number of them have been on HAART for a lengthier period. Lastly, some participants are being cared for by their biological parents, while other are taken care of by their relatives.

The discussions and pie charts to follow will provide a comprehensive analysis on these biographic details of participants.

Figure 3.1: Ages of participants

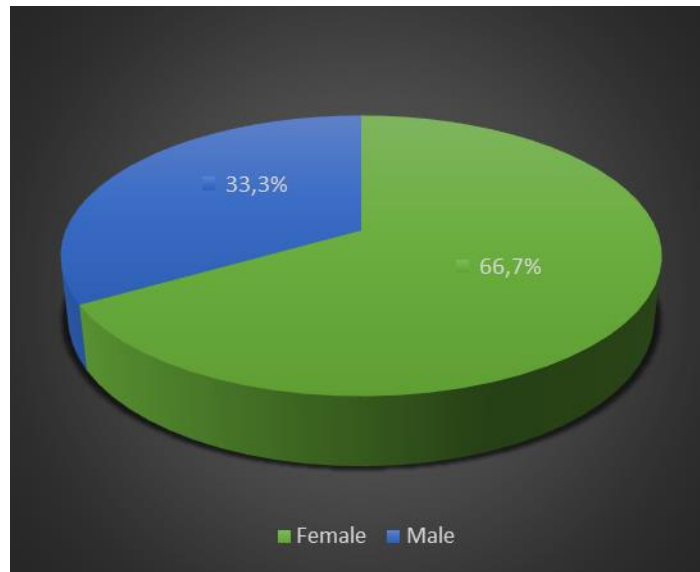


n=12

The above figure of the biographic profile of participants indicates that their ages ranged between 14-17 years. The majority were those who are 17 years old constituting 50% followed by 14 year olds with 33% and those who were 15 and 16 years old constituted 8.5% respectively.

Subsequently figure 3.2 will represent the gender of participants.

Figure 3.2: Gender of participants

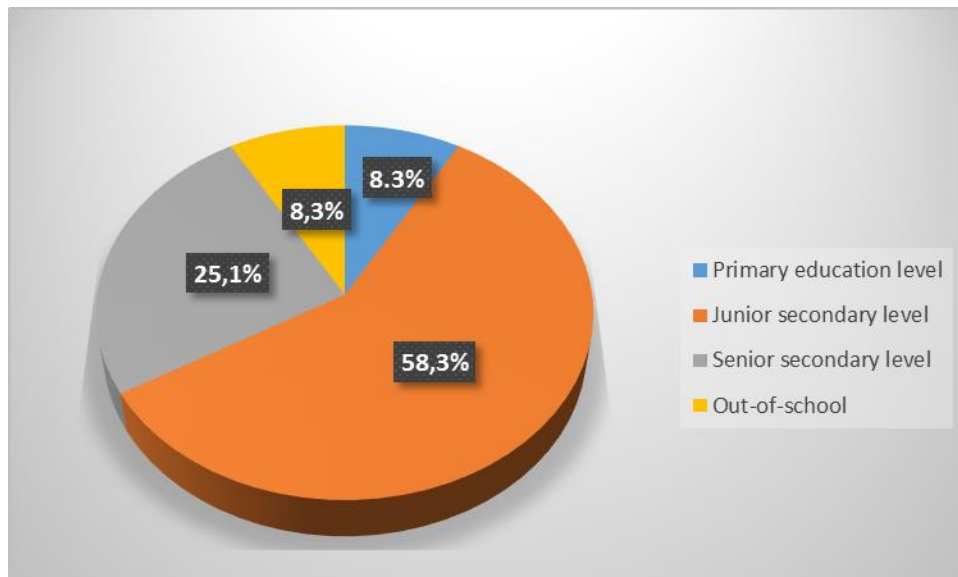


n=12

The figure shows that the majority of the participants were females and constituted 66.7%, while their male counterparts constituted 33.3%. The study targeted 50% representation of each gender, but more females showed interest to partake in the study compared to males.

Figure 3.3 will present educational level of the participants.

Figure 3.3: Educational level of participants



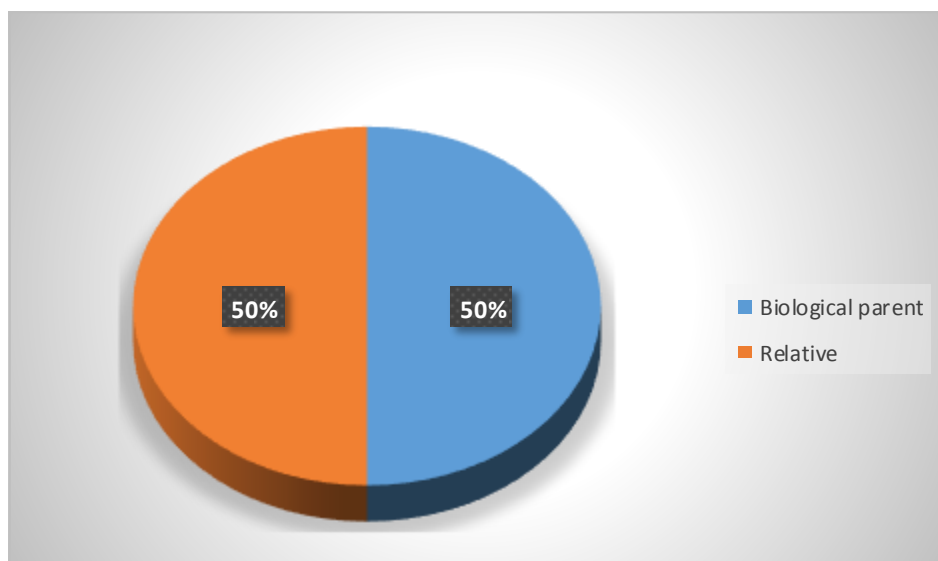
n=12

The figure illustrates that participants came from different educational levels according to Botswana's educational system. The first phase is primary which is from standard 1-7,

followed by junior secondary phase which runs from form 1-3 and lastly senior secondary phase which is form 4-5. The majority were those in the junior secondary phase by 58.3% followed by the senior secondary phase with 25.1% and the primary phase constituted 8.3% which is similar to out-of-school representation. The study targeted participants who are between the ages of 13-17 years and majority of them are found in the junior secondary phase. Furthermore, the majority of the participants were day scholars with 91.7% and out-of-school representation was 8.3%. There were no participants in boarding facilities.

Figure 3.4 will present caregivers of participants.

Figure 3.4: Caregivers of participants

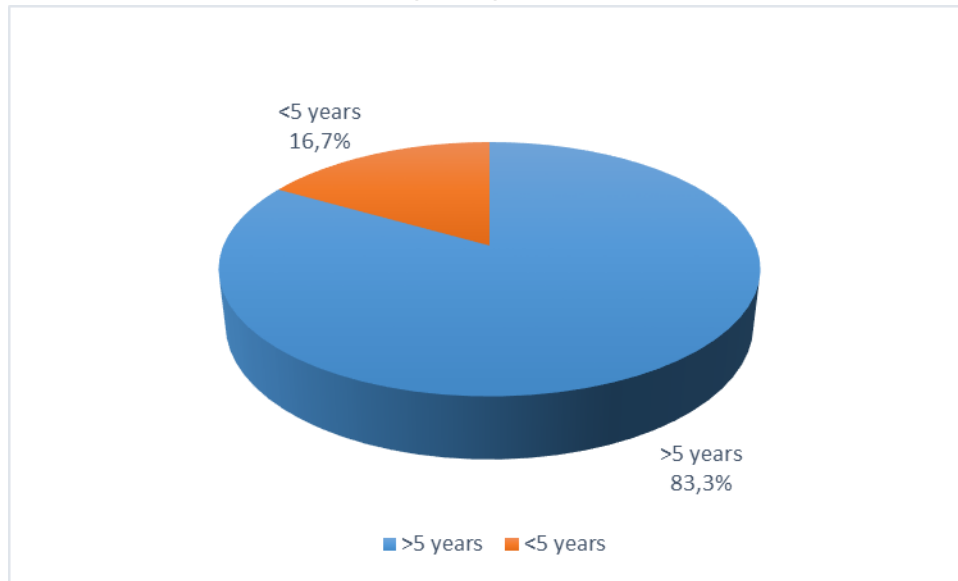


n=12

The figure shows that the number of participants, who are cared for by their biological parent, was equal to those who were cared for by their relatives. Although, Skovdal, Campbell, Madanhire, *et al.*, (2011:956-957) and Botswana-Baylor Children's Clinical Centre of Excellence (2011:58) indicated that due to AIDS-related deaths, most of HIV-infected children are cared by their grandparents or relatives. Rajaraman, Earle and Heymann (2008:1) also alluded that a significant number of families provide most of the care to the tens of millions of HIV-infected and affected in Africa.

Figure 3.5 will present participant's length of period on HAART.

Figure 3.5: Length of period on HAART of participants



n=12

The figure of the biographic information on the length of period on HAART shows that a significant number of participants started HAART at a young age and have been on treatment for a lengthier period. Those who have been on treatment for <5 years constituted 16.7%, while those with >5 years constituted 83.3%. Naswa and Marfatia (2010:5) revealed that the emergence of HIV and AIDS has resulted in many children being perinatally-infected. Some died before reaching adolescence, while others survived into adolescence due to the introduction of HAART. Furthermore, all participants knew their HIV status. On the other hand, there were no participants with any form of disability which could have made it difficult to disclose their HIV status to them.

Thus the biographic details show that majority of the participants were females. In addition, most of the participants were those who are 17 years old followed by those who are 14 years of age. The biographic details also revealed that majority of the participants were learners with the majority from the junior secondary phase. Moreover, all of the participants knew their HIV status and have been on treatment for a lengthier period. Lastly, the number of participants who are cared for by their biological parents was equal to those who were cared by their relatives.

3.9.2. Thematic analysis

Research findings will be discussed according to the themes and sub-themes that were identified during the data analysis. All interviews were conducted in Setswana, the vernacular language of Botswana and as a result the verbatim quotes from the interviews supporting

the themes, will be firstly provided in Setswana, whereafter the English translation will be provided, thus ensuring trustworthiness. This has also contributed to the length of this chapter being longer as a result. The themes will be further substantiated with literature from chapter two. Table 3.2 provides an overview of the themes and sub-themes generated from the research.

Table 3.2: Themes and sub-themes

Themes	Sub-themes
Knowledge about HIV and AIDS and importance of HAART adherence	<ul style="list-style-type: none"> • HIV and AIDS • Transmission of HIV and AIDS • Prevention of HIV and AIDS • HIV treatment and adolescents' myths about HIV and AIDS • Sources of information dissemination on HIV and AIDS • Benefits of HAART-adherence • Methods of assessing adherence • Consequences of non-adherence
Contextualising and conceptualising HAART adherence	<ul style="list-style-type: none"> • Perinatal and behavioural infection • Medication adherence • Challenges regarding medication adherence
Factors contributing towards non-adherence amongst HIV-infected adolescents	<ul style="list-style-type: none"> • Individual factors • Social stigma from school and community • Regimen factors • Facility-related factors • Home environment • Mental health
Coping strategies	<ul style="list-style-type: none"> • Disclosure of HIV positive status

	<ul style="list-style-type: none"> • Support from the family or relatives • Teen club or peer support • Support from the hospital • Spiritual support • Individual strategies
Recommendations	<ul style="list-style-type: none"> • Continuous education on HAART-adherence combined with medication supervision are key.

Subsequently each theme with its sub-themes will be discussed.

3.9.2.1. Theme 1: Knowledge about HIV and AIDS and the importance of HAART adherence

This theme concentrated on exploring the knowledge of participants on HIV and AIDS and the importance of HAART-adherence. It has been divided into eight sub-themes and these include: information about HIV and AIDS, transmission, prevention, treatment and myths of HIV and AIDS, sources of information dissemination, benefits of HAART-adherence, methods of adherence assessment and consequences of non-adherence.

Sub-theme 1.1: HIV and AIDS

All participants showed adequate knowledge about HIV and AIDS. They revealed that HIV is a virus that causes AIDS. They went further to mention that HIV attacks the human immune system which makes it susceptible to be attacked by numerous illnesses. Others explained that AIDS is a collection of diseases. The following quotations highlight their responses:

“HIV o emetse Human Immuno-Deficiency Virus. E thasela masole a mmele.” (Participant 05)

Translation: HIV stands for Human Immuno-Deficiency Virus and it attacks the immune system.

“HIV ke mogare o o thaselang mmele wa motho kana o dira gore mmele o nne bokowa mme motho a thaselwe ke malwetsi a mantsi.” (Participant 012)

Translation: HIV is virus that attacks the body or makes the body weak to be attacked by different illnesses.

“Re rutilwe gore HIV e ja masole a mmele, e bile o baka bolwetsi jwa AIDS. Re ne ra rutiwa gape gore AIDS ke malwetsi a a farologaneng.” (Participant 07)

Translation: We were taught that HIV attacks the immune system and causes AIDS. They also told us that AIDS is a collection of diseases.

“HIV ke mogare o o dirang gore masole a mmele a ye ko tlase o bo o felalela o tsaya treatment.” (Participant 04)

Translation: HIV is a virus that attacks the immune system which results reduction of CD count cells. This will lead to be enrolled on ARV's.

"HIV ke mogare. Fa AIDS yone e le bolwetsi jo bo bakiwang ke mogare wa HIV." (Participant 06)

Translation: HIV is a virus and AIDS is a disease that is caused by HIV.

"HIV ke mogare o o tlhaselang masole a mmele, mme o dire gore mmele o nne bokowa. AIDS ke bolwetsi." (Participant 03)

Translation: HIV is a virus that attacks the immune system and makes it weak. AIDS is a disease.

The above findings illustrate that participants displayed adequate knowledge regarding HIV and AIDS. These findings are partially supported by Wagbatsoma and Okojie (2006:81) who revealed that students were aware of HIV and AIDS, but had insufficient knowledge of its aetiology. Some mentioned that AIDS is caused by bacteria or evil spirits, others said, it is caused by HIV. Furthermore, the above quotations are contrary to a recent study by Cai et al. (2013:5) in China, which showed poor knowledge and awareness of HIV and AIDS and safe sex amongst senior high school students.

Sub-theme 1.2: Transmission of HIV and AIDS

The participants were probed on various ways in which one can be infected by HIV and AIDS. The most prominent findings were unprotected sexual intercourse and mother-to-child transmission of HIV (MTCT). The following quotes depict their views:

"HIV e ka go tsena fa o tlhakanela dikobo o sa itshireletsa." (Participant 01)

Translation: You can get HIV if you have unprotected sex.

"Mogare o ka tswa ko go mmaagwe-ngwana mme wa fetela ko ngwaneng fa mmaagwe a le moimana, nako ya pelegi kana ka kamoso ka lebele. E bile mogare wa HIV o ka go tsena fa o tlhakanela dikobo mme o sa dirise sekausu." (Participant 08)

Translation: HIV can be transmitted through mother-to-child transmission during pregnancy, labour or breast feeding as well as through unprotected sex.

"O ka tsenwa ke mogare fa o tlhakanela dikobo le motho yo o nang le mogare go sena tiriso ya sekausu." (Participant 010)

Translation: You can get HIV by having unprotected sexual intercourse with someone who is HIV-infected.

"Mosadi yo o nang le mogare wa HIV o ka o fitisetsa ko ngwaneng wa gagwe ka nako ya boimana kana nako ya pelegi." (Participant 012)

Translation: An HIV positive mother can transmit HIV to her unborn child during pregnancy or delivery.

"O ka tswenwa ke mogare fa o tlhakanela dikobo le motho yo o nang le mogare mme go sa dirisiwe sekausu. Mmangwana yo o itsholofetseng mme a na le mogare o ka o fitisetsa ko ngwaneng wa gagwe ka nako ya boimana." (Participant 03)

Translation: You can get HIV by having unprotected sexual intercourse with someone who is HIV-positive. An unborn baby can get HIV from the mother who is HIV-positive during pregnancy.

The above findings are fully supported by Kadivar et al. (2006:544), Espada et al. (2012:504), Wagbatsoma and Okojie (2006:82) and Nwezeh (2008:389) who indicated that the most common route of HIV contraction amongst adolescents is through unprotected sexual intercourse. Wagbatsoma and Okojie (2006:82), Tung et al. (2008:401), Mahat and Scoloveno (2006b:415), Van Dyk (2008:40) and Nwezeh (2008:389) supported the findings further by mentioning that mother-to-child transmission of HIV during pregnancy, delivery and breastfeeding is another most common route of HIV and AIDS transmission.

A significant finding from four participants was that HIV and AIDS can be transmitted through sharing of unsterile sharp objects especially a razor blade. Two participants added that having multiple sexual partners may also put one at risk of contracting HIV and AIDS. The quotations below highlight their responses:

“O ka tswena ke mogare wa HIV fa o tlhakanela didirisiwa tse di bogale jaaka legare le motho yo o nang le mogare wa HIV.” (Participant 06).

Translation: You can contract HIV by sharing sharp objects such as razor blade with someone who is HIV-infected.

“Mogare o ka go tsena fa o tlhakanela didirisiwa tse di bogale jaaka legare le motho yo o nang le mogare mme wena o sena one.” (Participant 08)

Translation: An HIV negative person can contract HIV and AIDS through sharing sharp objects such as a razor blade with someone who is HIV-infected.

“Fa lo tlhakanela didirisiwa tsa di bogale jaaka legare o ka tsenwa ke mogare.” (Participant 012)

Translation: You can also get it by sharing sharp objects such as razor blade.

“.....kana e ka go tsena fa o na le bakapelo ba le bantsi.” (Participant 02)

Translation: Multiple sexual partners may put one at risk of contracting HIV and AIDS.

The above quotations are similar to the findings by Wagbatsoma and Okojie (2006:82), Tung et al. (2008:401), Mahat and Scoloveno (2006b:415), Van Dyk (2008:40) and Nwezeh (2008:389) who mentioned that other routes of HIV and AIDS transmission include sharing needles or sharp objects. Ganczak et al. (2005:11), Kadivar et al. (2006:54) and Nwezeh (2008:389) also added that sex with multiple or older partners was a major contributing factor to the rapid transmission of HIV. Hutchinson et al. (2007:41) revealed that in Jamaica, young girls were sleeping around with older men or drug lords for material gains such as clothes and money. In most instances, these girls had no power to negotiate for condom use, whereas their male counterpart slept with different girls to prove to their fathers that they are “men” and not homosexuals. As a consequence, these acts made them vulnerable to either contracting or spreading HIV or other STIs.

It was evident that throughout the interviews participants displayed adequate knowledge regarding transmission of HIV and AIDS. These findings are contrary to Dawood et al. (2006:5) who found that participants showed inadequate knowledge regarding HIV transmission by indicating that HIV and AIDS is transmitted by insects.

Sub-theme 1.3: Prevention of HIV and AIDS

Study participants mentioned different prevention methods, but emphasised mostly condom use. The majority of them especially older ones went further by indicating that condoms are readily available in places such as clinics, hospitals and some shops. This is reflected by the following responses:

“Re tshwanetse go dirisa sekausu ka nako ya tlhakanelo dikobo.” (Participant 03)

Translation: We must ensure condom usage during sex.

“Dikhondomo ke ntlets-ntlets fela.” (Participant 06)

Translation: Condoms are widely and readily available.

“Our teacher o ne a bua gore boimana jwa bana ba ko sekolong bo ile magoletsa, mme moo go supa gore sekausu ga se dirisiwe. Mme e bile o ne a supa gore the chances tsa gore bangwe ba bone ba bo ba tsenwe ke mogare di ko godimo ka gore ba ne ba sa dirise sekausu.” (Participant 08)

Translation: Previously our teacher mentioned that pregnancy rate at school has increased. This shows that condoms are not being utilised. She also indicated that since they did not use condoms, there is a high possibility that some may have contracted HIV and AIDS.

“Dikhondomo di bonwa gongwe le gongwe mo dikokelong le mo dipateleng, e bile di tsewa mahala.” (Participant 010)

Translation: Condoms are widely and freely available in different places such as clinics and hospitals.

“Re tshwanetse go dirisa sekausu ka nako tsothe fa go na le tlhakanelo dikobo.” (Participant 01)

Translation: We must use condoms at all times during sexual intercourse.

“Dikhondomo di bonwa mo mafelong a mantsi jaaka ko dikokelong mme ga ke itse gore a bankane bame baa di dirisa kana ba itse gore e dirisiwa jang.” (Participant 07)

Translation: Condoms are widely available in different health facilities, but I do not know if my age mates are using them or they even know how to use them.

Similarly, participants in studies by Perez et al. (2008:505), Ganczak et al. (2005:10) and Botswana-Baylor Children’s Clinical Centre of Excellence (2011:76) alluded that in the era of HIV and AIDS, it is important to use a condom at all times during sexual intercourse. Some adolescents showed some knowledge that condoms help to prevent STIs, HIV and AIDS and pregnancy (Vujovic et al., 2014:125; Hutchinson et al. 2007:41; Nwezeh, 2008:391). In addition, adolescents were able to identify different places where condoms can be acquired which included: health facilities, pharmacies and some shops. But then again, obtaining male condoms from health facilities was often embarrassing to young boys who did not want

people to know that they are sexually active (Vujovic et al., 2014:125; Hutchinson et al., 2007:41; Nwezeh, 2008:391).

Furthermore, majority of the participants reiterated that it is imperative for expectant mothers to know their HIV status so that those who will be diagnosed HIV-positive may be enrolled on the prevention of mother-to-child therapy (PMTCT). Moreover, four participants' especially older ones indicated that it is also vital for the new-borns to be tested for HIV as well so that those who found to be infected can be enrolled on ARVs. However, they did not know at what age these new-borns should be tested. This is what they said:

".....bo mmabana ba ba nang le mogare e bile ba sena go belega ba tshwanetse go amusa ka tami gore mogare o seka wa fetela ko ngwaneng ka kamuso ka lebele." (Participant 011)

Translation: HIV-infected mothers who have given birth should bottle feed their infants instead of breast feeding to prevent transmission of HIV and AIDS.

"Nna ke utlwile gotwe ngwana yo o tshotsweng ke motsadi yo o nang le mogare o tshwanetse go tthatlhobelwa mogare, jaanong ga ke itse gore ao tthabiwa immediately a sena go tsholwa kana jang." (Participant 08)

Translation: I heard that a child who has been born to an HIV-infected mother should be tested for HIV and AIDS, but I am not sure when the test should be done, whether immediately after birth or few days after."

"Mme yo o itsholofetseng o tshwanetse go ya sepatela gore a itthatlobele mogare wa HIV gore fa go fitlhelwang ana le one a kgone go tsenelela lenaneo la thibelo mogare go tswa ko go mmaagwe ngwana go ya ko ngwaneng yo o iseng a tsholwe." (Participant 05)

Translation: It is important for a pregnant woman to visit the hospital so that she can be tested for HIV. If tested HIV-positive, it is vital for her to be enrolled on the prevention of mother-to-child treatment to protect the unborn child.

"Go bua boammaaruri ga ke sure gore ba tthatlhobelwa mogare morago ga nako e kae, mme fela se ke se itseng ke gore they should be tested for HIV gore ba ba fitlhelwang ba na le one ba bo ba fiwa treatment." (Participant 010)

Translation: To be honest I am not sure of when they should be tested, but what I am aware of is that they should be tested so that those who are infected can be enrolled on the ARV programme.

"Bomme ba ba itsholofetseng ba tshwanetse go buisana le dingaka gore ba ba nang le mogare ba fiwe kalafi gore mogare o seka wa fetela ko ngwaneng yo iseng a tsholwe." (Participant 07)

Translation: Pregnant mothers should talk to the doctors so that those who are HIV-positive can be given treatment to ensure that the virus does not pass to the unborn child.

The above findings are fully supported by Motswere-Chirwa et al. (2014:158-160) who affirmed that in order to reduce or eradicate MTCT the following should be done adequately:

- Pregnant mothers should be encouraged to register with health facilities in order to utilise various antenatal services. For example, a pregnant mother should undergo an HIV test after counselling, if she is HIV positive a blood sample should be collected to check CD4 count. If the CD4 count cells are less than 350, initiation on HAART using

Atripla must be done at 14 weeks of gestation. But if the CD4 count is above 350, initiation on HAART should be done in order to reduce transmission risks to the infant.

- HIV exposed infants should be tested at six weeks after birth using polymerase chain reaction (PCR) testing on dried blood spot specimens (DBS). Confirmatory test should be done immediately if child tested positive. If negative, repeat test should be done at 18 months. However, all HIV positive infants whether symptomatic or not should be referred to the ARV programme for Anti-Retroviral (ART) services.

In addition, the abovementioned prevention strategies, three participants talked about avoidance of multiple sexual partners. Another four participants emphasised the importance of knowing your HIV and AIDS status. These are their responses:

“.....motho gaa tshwanela go tlhakanela dikobo le bakapelo ba le bantsi.”
(Participant 02)

Translation: A person should avoid having sexual intercourse with multiple partners.

“Gape ga goa siama go tlhakanela dikobo le batho ba le bantsi.” (Participant 03)

Translation: It is improper to have sexual relationships or contact with numerous partners.

“Go bothokwa gore o bolelele mokapelo wa gago fa e le gore o tshela le mogare wa HIV le bolwetsi jwa AIDS gore lotlhe lo itse seemo sa lona.” (Participant 04)

Translation: It is important to inform your partner if you are living with HIV and AIDS so that both of you are knowledgeable about each other's HIV status.

“Go bothokwa gore ba itse seemo sa bone nako e le teng gore ba kgone go thusiwa ka treatment. Lebaka ke gore fa mogare o fitlhelwa o setse o le bogale treatment e ka nna ya seke e bereke sentle.” (Participant 07)

Translation: It is important so that you can be assisted. Sometimes when you know your status late you may realise that treatment is worthless because already the CD4 count cells very low and the viral load may be high. Therefore treatment may not be effective.

“.....go bothokwa gore mongwe le mongwe a itse seemo sa gagwe sa mogare pele a akanya ka tlhakanelo dikobo. Ba ka itlhatlhobela mogare ko dikokelong, dipateleng le ko Tebelopele.” (Participant 010)

Translation: It is important for everyone to know their status before they think about having sexual intercourse. Testing services can be found at the clinics, hospitals or Tebelopele Testing Centre.

“Nna le bangwe ba di classmates tsame we decided gore re ye Tebelopele re ye go itlhatlhoba morago ga gore batle ko sekolong go re ruta ka mosola wa go itse seemo sa gago.” (Participant 06)

Translation: My classmates and I decided to go and test after an information session with staff members from Tebelopele Voluntary counselling and testing centre on the importance of knowing your HIV status.

The study results show similarities with the findings of other studies cited in literature. For example, Perez et al. (2008:505) and Botswana-Baylor Children's Clinical Centre of Excellence (2011:76) alluded that in the era of HIV and AIDS, it is important to stick to one

partner. Multiple concurrent sexual partnerships (MCP) have emerged as a critical factor contributing to young people's vulnerability to HIV and AIDS including STIs. Poverty or low socioeconomic status has been attributed to high rate of MCP. For example, poor people especially young women in some settings are more likely to engage in particular practices such as earlier onset of sexual activity, or occasional transactional sex which may increase risk of infection. On the other hand, wealthy people in some settings may find that their wealth permits greater social and sexual networking, or allows them to have a higher number of regular sex partners especially with young girls or boys, a behaviour which may place them at risk as well. This is normally referred as cross generational sex (National AIDS Coordinating Agency, 2009:16-17). In 2009, the MCP prevalence rate in Botswana was estimated around 44%. Nonetheless, the following strategies have been adopted to address it: multisectoral approach in sensitizing the public on behaviour change including addressing the social and environmental factors that drive MCPs as well as advocacy for supportive policy interventions and changes especially on the empowerment of young women (National AIDS Coordinating Agency, 2009:17).

The findings are further supported by Van Dyk (2008:134), who also pointed out that Voluntary HIV counselling and testing (VCT) has emerged as a major strategy for the prevention of HIV and AIDS. In addition, adolescents declared that HIV testing was the only way for one to know his or her HIV status. As a result, early diagnosis of HIV infection also facilitates medical interventions and enables infected persons to reduce high-risk behaviour and the likelihood of further HIV transmission (Espada et al., 2012:12; Straub et al., 2007:105; Van Dyk, 2008:134; CDC, 2007:665). Moreover, results showed that students who had been taught about HIV and AIDS in schools were more likely to have an HIV test than those who had not been taught about it (CDC, 2007:665).

The participants mainly talked about other prevention methods, but when they were probed on abstinence. This is what they said:

"Abstinence ya pala nowadays ke sone se o bona palo tsa banana ba ba itsholofetseng di le ko godimo. Ke palo e e potlana ya banana e e ikgapang mo tlhakanelo dikobo. Re ne re bolelelwa gore mo sekolong sa rona boimana bo ko godimo and mo go supa gore ga ba ikgaphe e bile ga ba dirise sekausu." (Participant 08)

Translation: Young people find it difficult to abstain from sexual intercourse that is why there is high rate of pregnancy amongst young people. There is a handful number of young people who abstain. We were informed that pregnancy rate in our school is alarming and this shows that they do not abstain nor use a condom.

"Nna rra kea ikgaphe mo tlhakanelo dikobong gape le ko kerekeng re rutilwe gore tlhakanelo dikobo pele ga lenyalo ke bolele. Le ko sekolong re tlhola re bolelela mosola wa teng." (Participant 010)

Translation: I abstain from sex. We have been taught at church that pre-marital sex is a sin, even at school teachers always emphasise it.

“Eish bana sekolo ba palelwa ke go itshwara morena ke sone se o bonang boimana bo le ko godimo mo dikoleng ka go farologana.” (Participant 01)

Translation: Students are unable to abstain that is why there is high pregnancy rate in different schools.

“Nna ga ke itse gore go pala fa kae tota gore banana ba ikgaphe mo tlhakanelo dikobong.” (Participant 06)

Translation: I am not sure what is difficult for young people to abstain from sex.

Similarly, Ganczak et al. (2005:9) cited that some conservative forces and the Catholic Church are actively opposing school sex education and family planning such as distribution of condoms. Their campaign promotes abstinence as the only method of HIV and AIDS prevention. Kabiru and Azeh (2007:125) found that some adolescents abstained from sexual intercourse due to lack of a partner, postponement of sex until marriage which is normally guided by moral and religious beliefs, fear of pregnancy and avoidance of STIs. Malinga (2010:67) reiterated that sexual abstinence has been introduced as a component of ABC prevention approach (Abstain, Be faithful and Condom use) which was adopted by WHO in the fight against HIV and AIDS.

The above findings show that participants were knowledgeable of different prevention methods, although condom use and PMTCT were the most common amongst all. Furthermore, the findings showed that older participants were able to elaborate further some aspects of HIV and AIDS prevention especially on the PMTCT programme as well as issues around condom availability and abstinence.

Sub-theme 1.4: HIV treatment and adolescents' myths of HIV and AIDS

Adolescents in a study by Balthip and Purnell (2014:34-35), Nwezeh, (2008:389) and Botswana-Baylor Children's Clinical Centre for Excellence (2011:78) stated that although there is no cure for HIV and AIDS, with the presence of ART, it is important to adhere to clinic appointments and ART regimens. They realised that it was important to take responsibility for their health and have an active role in their own care. All these helped HIV-infected adolescents to be healthy and at the same time, they were able to achieve self-reliance and self-growth. The above findings were highly evident in the current study:

“Nna rra se ke se itseng ke gore AIDS ke bolwetsi jaaka malwetsi a mangwe, mme fela yone ga bona kalafi ke sone se re nwang dipilisi go ritibatsa mogare.” (Participant 01)

Translation: I know that AIDS is a disease which is not curable, that is why we are taking ARV's to suppress the virus.

“Ke tshwanetse go tsaya dipilisi tsa mogare jaaka ke laetswe ke ba bongaka, e bile ga ke a tshwanela go di emisa.” (Participant 04)

Translation: It is imperative to adhere to treatment as told by the healthcare workers and one should not stop taking it.

“Re rutilwe gore HIV le AIDS di ka go bolaya fa o sa tseye dipilisi sentle.” (Participant 02)

Translation: We were taught that if you do not take your medication as prescribed you will die of HIV and AIDS.

A study by Veniot et al. (2006:263) found that some adolescents expressed misperceptions and uncertainties about the purpose and value of HAART. Many of them did not understand why they should take treatment that cannot cure them and saw treatment as meaningless. Others alleged that HAART degrades quality of life. These findings by Veniot et al. (2006:263) stand in stark contrast with the findings of the current study.

Furthermore, it was significant from the findings that everyone was knowledgeable of the names of their prescribed ARVs. The knowledge was attributed to the healthcare workers. This is what they said:

“Ee rra ke itse dipilisi tse ke di tsayang. Ke tsaya nevirapine le combivir. I was taught by the nurse.” (Participant 03)

Translation: Yes I know my medication. I am on nevirapine and combivir. I was told by the nurse.

“Ke tsaya atripla. Ke rutilwe ke ba botsogo.” (Participant 010)

Translation: I am taking atripla. I was told all this by the healthcare workers.

“Nna ke tsaya efavirenz le combivir. Ke boletswe ke dingaka.” (Participant 08)

Translation: I am taking efavirenz and combivir. I was told by the healthcare workers.

The above quotes are partly supported by Botswana-Baylor Children’s Clinical Centre for Excellence (2011:78) who discovered that 70% of the participants had knowledge about ART and half of them correctly knew the names of their ARV’s. The only difference is that in the findings by Botswana-Baylor Children’s Clinical Centre for Excellence (2011:78) half of the participants knew the names of their ARV’s, while in the current study everyone knows his or her treatment. Furthermore, the above findings are supported by Veinot et al. (2006:263) who indicated that most of adolescents obtained information about HIV medication from healthcare workers.

Four participants revealed that there were instances in which they were not adhering to treatment as prescribed due to various reasons such as forgetfulness, side effects, laziness and lack of commitment towards treatment. Nonetheless, they are currently adhering because they realised the importance of treatment. With regards to myths of HIV and AIDS, the majority of the participants displayed inadequate knowledge towards myths, except for two participants. This is what they said:

“Nna gaise ke utlwe go buiwa sepe ka di-myth tsa HIV le AIDS.” (Participant 03)
Translation: I have not heard anything regarding myths of HIV and AIDS.

“Eish nna ga ke di itse.” (Participant 04)
Translation: I do not know them.

“Nna gaise ke utlwe go buiwa ka tsone.” (Participant 08)
Translation: I have never heard about them.

“Ijoo ga ke di itse.” (Participant 12)
Translation: I have no idea.

The above findings on myths of HIV and AIDS are contrary to Espada et al. (2012:504), Hutchinson et al. (2007:41-42), Nwezeh (2008:389) and Tung et al. (2008:401) who indicated the following as some of the myths of HIV and AIDS:

- HIV and AIDS can be transmitted through sharing the same food, cup and spoon with some who is HIV-infected;
- HIV and AIDS can be transmitted from a moist toilet seat;
- HIV and AIDS can be cured by showering after unprotected sexual intercourse; and
- HIV and AIDS can be spread from swimming pools, sharing cigarettes, through sneezing and coughing or hugging an HIV-infected person.

Furthermore, Van Dyk (2008:192) found that in South Africa, participants mentioned the myth that having sexual intercourse with a virgin, namely-‘virgin cleansing’ will cure HIV and AIDS. The researcher is of the opinion that sexual myths and misconceptions interfere with safer sex initiatives. As a result, engaging adolescents in discussions to find out why they believe in these myths and misconceptions is vital, so that they can discover for themselves that these myths are untrue.

Sub-theme 1.5: Sources of information dissemination on HIV and AIDS

Delivering information about HIV and AIDS in face-to-face sessions have been effective in reaching people in small groups, but given continued high rate of HIV infection amongst adolescents, innovative approaches in delivering prevention information are needed. Henceforth, more adolescents can be reachable using technology and mass media (Cornelius et al., 2013:257). This was evident throughout the interviews because all participants showed that they encountered a source(s) of information regarding HIV and AIDS. The following were common amongst participants: hospital, school, home, television and radio. This is what different participants said:

“Nna ke utlwile ka HIV le AIDS ko sekolong, mo lapeng le mo sepateleng.”
(Participant 03)
Translation: I heard about HIV and AIDS at school, home as well as in the hospital.

“Nna ke utlule go buiwa ka HIV le AIDS mo sepatela, mo thelebishineng le radio.”
(Participant 04)

Translation: I heard about HIV and AIDS in the hospital, on television and radio.

“Nako e ntsi re rutiwa ka HIV le AIDS ko sekolong. Nako tse dingwe re kgona go lebelela di-programme tse di tshwanang le bo ntwakgolo gore re ithute go le gontsi.”
(Participant 8)

Translation: In most instances, we are taught about HIV and AIDS at school. Sometimes we watch programmes like “*ntwakgolo*” to learn more about HIV and AIDS.

“Nna ke utlule go buiwa ka HIV le AIDS ko sekoleng, mo sepatela le ko lapeng.”
(Participant 06)

Translation: I got this information on HIV and AIDS at school, hospital and home.

“Nna ke utlule go buiwa ka yone mo radiong le mo thelebishineng.” (Participant 02)

Translation: I heard about it from the radio and television.

“Nna ke utlwile ka HIV and AIDS ko sekoleng le mo TV.” (Participant 09)

Translation: I heard about HIV and AIDS at school and on television.

A significant number of authors Ganczak et al. (2005:7-8), Wagbatsoma and Okojie (2006:82), Nwagwu (2012:14) and Nwezeh (2008:392) support the above findings by indicating that for many adolescents, the main sources of information dissemination on HIV and AIDS was through schools, medical personnel especially doctors and nurses, television and radio. In addition, Wagbatsoma and Okojie (2006:82), Nwagwu (2012:14) and Dawood et al. (2006:7) also found that television was the main source of information with regards to HIV and AIDS. The justification is that television is an engaging multimedia facility that uses a combination of audio, voice and images to communicate information. Many experts have also suggested that it is a powerful tool in information communication (Wagbatsoma & Okojie, 2006:83; Nwagwu, 2012:15). On the other hand, Nwezeh (2008:393) added that radio was the main source of information because many homes have access to it. Even those in rural areas without electricity can use battery-operated radios. Furthermore, Hutchinson et al. (2007:42) found that most adolescents discussed information about sex, condom use, HIV and AIDS with their mothers. Even though, it is believed that some parents may not have enough or accurate information on HIV and AIDS or some cultural practices do not permit them to talk to their children about sex. Three participants talked about getting information about HIV and AIDS from the teen club and at times they are given some pamphlets on HIV and AIDS and treatment for further reading. While, two participants acknowledged their churches for the information.

“.....ko teen club go monate ka gore rea rutiwa ka HIV and AIDS, e bile rea rutana re le bana ba tshelang ka mogare ga mmogo le go bua ka dikgetlho tse re kopanang le tsone. Nako tse dingwe ba re fa mokwalonyana mo dipampiring gore re ipalele ko gae.” (Participant 012)

Translation: The teen club is enjoyable because we are being taught about HIV and AIDS. In addition, as children living with HIV and AIDS we are able to share experiences as well as challenges that we encounter. At times they give pamphlets so that we read further when get home.

“Go na le teen club ya bana ba ba tshelang ka mogare. Gantsi re kopana ka di-weekend fa e le gore baeteledipele ba rona ba na le sengwe se ba batlang re se dira. Re nna re rutwa ka HIV and AIDS le bomosola jwa go nwa dipilisi tse di ritibatsang mogare. Ba re fa melaetsa e e kwadilweng mo dipampiring gore re rute ba re nnang le bone ko malwapeng. Gape le ko kerekeng re rotloediwa go itse seemo sa rona sa mogare gore re fokotse kanamo ya one. E bile ba nna ba rotloetsa gore ba ba tsayang dipilisi ba seka ba di emisa.” (Participant 07)

Translation: There is a teen club for children living with HIV and AIDS. We normally weekends if our coordinators have something to be done. At the teen club we are being taught about HIV and AIDS as well as the importance of treatment. They also give us pamphlets so that we are able to educate our families. At church they sometimes encourage us to know our HIV status so as to reduce the transmission rate. They also encourage those who are on treatment to continue taking their treatment.

“Teen club e re thusa fela thata ka gore dithuto ka HIV and AIDS re di rutiwa thata gone kwa e bile ba rotloetsa gore se re se ithutileng re se arogane le ba re nnang le bone.” (Participant 01)

Translation: Teen club plays a vital part in our lives because that is where we get more information on HIV and AIDS. They also encourage us to share what we have learnt with others at home.

“Gantsi ko kerekeng mogolo jang youth activities rea rutiwa ka dikgang tse tsa HIV le AIDS. Re rotloediwa gore re ikgaphe mo tlhakanelong dikobo ka gore e ka tlisetsa motho malwetsi a dikobo a a farologaneng kana boimana.” (Participant 010)

Translation: At church especially during youth activities we are being taught a lot about HIV and AIDS. We are being encouraged to abstain from sexual intercourse because it will put one at risk of contracting sexually transmitted infections or one will become pregnant.

The above findings are similar to those observed by Bloemen (2011:3) who indicated that teen clubs for HIV infected children and adolescents plays an enormous role in the lives. It exposes them to teachings about HIV and AIDS, treatment adherence, confronting stigma, disclosure issues as well as coping strategies. Furthermore, Nwagwu (2012:14) also discovered that handbills or pamphlets were another major source of information about HIV and AIDS. Handbills are commonest information, education and communication materials distributed by many non-governmental organizations that are working on HIV and AIDS and the targeted groups usually include students in primary and secondary schools. Handbills or pamphlets are relatively cheap to produce or they can be freely distributed to the users and their usage is largely infrastructure-independent. This is not the case with electronic resources such as radio and television which would often require electric power to function.

The above findings are further supported by Moore et al. (2012:871-873) who indicated that in the beginning the church has served as an institution of spiritual guidance and now is a place to get health information. In addition, pastors have become change agents in the health sector especially after the discovery of HIV and AIDS. In creating high levels of

awareness about HIV and AIDS, churches have utilised different platforms such as church services, church health fairs, youth camps and health seminars. Moreover, some church leaders have encouraged their members to take an HIV and AIDS test and there were some church leaders who used themselves as examples for their church members. The goal was to help church members to learn their HIV and AIDS status in order to reduce the stigma. Lastly, church leaders have agreed that the church should be an advocate for those infected with the disease and it should be at the forefront of HIV and AIDS education (Moore et al., 2012:873).

The findings of the current study reveal that hospital, school, home, television, radio, teen club, pamphlets and churches were significant sources of information on HIV and AIDS. In relation to the bio-ecological perspective school and home are sources of information that makes up microsystem which these HIV-infected adolescents have direct interaction with (Nash et al., 2005:37). In addition, hospital, teen club, pamphlets, television and radio constitute their exosystem. This is whereby the individual does not have an active role in his or her immediate context, even though that social setting contributes to their development (Nash et al., 2005:37). Two participants talked about church as a source of information and it forms part of their macrosystem. Consequently, these microsystems, exosystems and macrosystem have played a significant role towards the enormous knowledge that has been displayed by the participants regarding HIV and AIDS. Moreover, the linkages between the above mentioned settings (mesosystems), clearly shows that they convey similar messages regarding HIV and AIDS.

Sub-theme 1.6: Benefits of HAART-adherence

Wiens et al. (2012:331) and Agwu and Fairlie (2013:6-7) emphasised that, adherence to antiretroviral (ART) medications is amongst the most important factors to ensure immunological, viral and clinical response in the treatment of HIV. But, amongst the numerous treatment groups, adolescents are often labelled as high risk with respect to adherence. Dietz et al. (2010:278) and Garvie et al. (2010:504) revealed that the use of HAART has greatly improved morbidity and delayed mortality amongst HIV-infected adolescents. Adherence to HAART does not mean remembering to take prescribed medication only, but then again following strict dosage instructions, timing intervals and dietary guidelines are also essential. The study findings revealed that almost all of the participants were knowledgeable of the benefits of HAART-adherence. They mainly talked about suppression of HIV, improved CD4 count cells and prolonged lives. The participants expressed the following views:

“Go botlhokwa ka gore di-ARV di oketsa botshelo jwa motho.” (Participant 06)

Translation: It is important because ARV’s prolongs one’s life.

“Nna ke itse gore di-ARV’s di ritibatsa mogare.” (Participant 011)

Translation: I know that ARV’s suppresses HIV.

“.....mme fa o tsaya di-ARV jaaka o boleletswe ke dingaka, masole a mmele a tlaa oketsega.” (Participant 01)

Translation: If ARV’s are taken as prescribed by the doctors, the CD4 count cells will increase.

“Bo nurse ba mpoleletse gore ke nwe dipilisi tsame ka nako gore mogare o kgone go ritibale ka gore fa ke ka seke ka dira jalo bokete jwa mogare bo tlaa oketse ka gore masole a mmele a tlaabo a le ko tlase.” (Participant 010)

Translation: I was told by the nurses that I should take my medication on time so as to suppress the virus or else the viral load will increase due to decreased CD4 count cells.

“Go botlokwa ka gore di-ARV di kokobetsa mogare. E bile di thusa gore motho a itekanele batho ba seka ba bona gore o tshela le mogare wa HIV.” (Participant 05)

Translation: It is important because ARV’s suppresses HIV. It also helps one to be fit so that people may not notice that he or she is living with HIV.

These findings are consistent with a recent study in Botswana by Ndiaye et al. (2013:893) who found that HIV-infected adolescents with excellent pill count of HAART-adherence had a satisfying virological suppression and this demonstrated that excellent treatment outcomes can be achieved if one adheres as prescribed. The findings further correlate with a longitudinal investigation by Patel et al. (2008:1755) and Resino et al. (2006:868) who found that there was a significant increase of CD4+ count cells and a decrease of viral load after HAART initiation amongst children and adolescents and that was sustained for at least five years if the child was adhering correctly. Mutwa et al. (2013:2) also added that some HIV-infected adolescents stated that the medication gave them not only physical health such as making them grow or gain weight but also hope and the ability to lead a “normal” life. Adolescents emphasized the wish to continue living as their HIV uninfected peers. The personal experiences of health improvement, including evidence of increased CD4 levels, encouraged them to remain adherent to their medication schedules.

Sub-theme 1.7: Methods of assessing adherence

Non-adherence to HAART is a common problem amongst HIV-infected adolescents. A >90-95% (high adherence rate) is required to achieve optimal viral suppression and prevention of the development of HIV drug resistance (Veinot et al., 2006:265; Kumar de & Dalui, 2012:253). Henceforth, Bangsberg (2008:273) advised that more accurate adherence monitoring systems may help clinicians to better gauge the impact of treatment outcome over time, in order to guide decisions on whether regimens need to be modified to improve adherence and prevent viral rebound. There were three main methods of adherence which were mentioned by the study participants. Their responses are as follows:

“Re tsewa madi go tswa foo, ba tlaabo ba mpolelela gore a mme ke tsaya melemo ka fa tshwanelong kana jang.” (Participant 02)

Translation: They collect blood samples in order to assess whether I am adherent or not.”

“Nako tse dingwe ba bala dipilisi go tlhola gore a ga ke a tlhodisa go nwa tse dingwe. Fa gongwe ba botsa mama gore a mme ke nwa dipilisi sentle.” (Participant 09)

Translation: Sometimes they count number of pills to assess if I am adherent. In other instances they will ask my mother if I am adherent.

“Ke ba neela mabotlolo a dipilisi gore ba bone gore ke feditse dipilisi. Nako tse dingwe baa mpotsa gore a ke di tsaya sentle kana ba botsa mmamane.” (Participant 04)

Translation: They will check my medication in the bottles if I have finished the pills or there are some which are left. They will also ask me or my aunt if I am taking my treatment as told.

“Everytime fa ke tsile for refill nurse o bala dipilisi tse di sentseng go bona gore a di tsamaelana le malatsi a ke ne ke tshwanetse go di tsaya ka one. Nako tse dingwe ba ntsaya madi go tlhola gore bokete jwa mogare bo selekanyo se se kae kana gore a masole a mmele a a oketsegile kana a fokotsegile.” (Participant 06)

Translation: When I come for refills, the nurse will count the remaining pills to check if I took them as told. Other times, they collect blood samples to check the viral load and CD4 count cells.

“Gantsi ba ntsaya madi go tlhola gore masole a mmele a selekanyo se se kae. Kana ba botsa nkuku gore a mme ke tsaya dipilisi sentle.” (Participant 05)

Translation: They will either collect blood samples to assess the CD4 count cells or they will ask my grandmother if I am adherent.

The study findings revealed that laboratory tests were the main method followed by self or caregiver reports and lastly pill count. Similarly, MOH (2012:48) stipulated that laboratory tests such as viral load and CD4 cell count are reliable measures of adherence. For children and adolescents, laboratory tests should be done every three months until the age of 18 years as a way to assess adherence or any other clinical indications which need to be attended. In addition, Haberer et al. (2011:6), Garvie et al. (2010:508), Bangsberg (2008:274) and Parsons et al. (2006:276) found that pill count and self-reports or caregiver reports were some of the adherence measures mentioned by participants. Nonetheless, subjective reported adherence is easy to collect, but at times patients may overestimate adherence. Similarly, clinic pill counts are relatively easy to perform, although patients may manipulate pills to appear more adherent.

Sub-theme 1.8. Consequences of non-adherence

Kagee et al. (2011:83) and Parsons et al. (2006:275) alluded that adherence is a major problem in the care of paediatric patients with HIV infection, particularly in adolescents. Wiens et al. (2012:332) indicated that the following measures >80-89% resembles that the patient is non-adherent while <80% resembles very poor adherence. The findings clearly show that participants had appropriate knowledge with regards to the consequences of non-

adherence. All of the participants acknowledged that if one does not take HAART as prescribed will result decreased CD4 count cells, weakened immune system, increased viral load and all these will result death. One participant talked about the risk of developing opportunistic infections (IOs). The following are verbatim responses from participants in this regard:

“Fa motho a sa tseye dipilisi tsa gagwe sentle masole a mmele a wela ko tlase, se se dire gore a lwale mo ko pheletsong o ka felela a tlhokafala.” (Participant 01)

Translation: Treatment adherence is important and failure to adhere as told will result decreased CD4 count cells, weakened body and eventually death.

“Tota fa o sa tseye dipilisi sentle bokete jwa mogare boa oketsega, masole a mmele le one a fokotsega o be o fitlhela o lebagane le loso fela.” (Participant 08)

Translation: If one is non-adherent, the viral load will increase, CD4 count cells will go down and you might die.

“Fa o sa tseye dipilisi sentle mmele o nna bokowa mme o nne mo diphatseng tsa go tsenwa ke malwetsi a a farologaneng jaaka kgotlholo e tona.” (Participant 06)

Translation: The immune system will become weak which makes you vulnerable to be attacked by different illnesses such as TB.

“Go botlhokwa go tsaya dipilisi sentle ka gore fa o ka seke o dire jalo o tlaa lwala, e bile masole a mmele a tlaa ya ko tlase.” (Participant 05)

Translation: It is important to be adherent because if not you will become sick and the CD4 count cells will drop.

“Ba bo ba bua gape gore masole a mmele a kgona go ya ko tlase fa o sa tseye dipilisi sentle.” (Participant 02)

Translation: They mentioned that the CD4 count cells will decrease if one does not take medication as told by the nurses or doctors.

The above mentioned quotes are supported by Garvie et al. (2010:504) who indicated that anything less than perfect adherence such as missing doses or taking medication at wrong times can undermine the individual's response to treatment. As a consequence, the following will result: decreased CD4 count and percentage, increased viral load which could lead to detectable viral load, increased risk of HIV transmission and increased risk for developing resistance ART medications as well as the risk of developing opportunistic infections (IOs). Additionally, Arrive et al. (2012:2) and Parsons et al. (2006:280) discovered that virological failure has been observed amongst adolescents and this could lead to poor treatment outcome, advanced immunosuppression as well as HIV-related deaths.

3.9.2.1.1. Key findings of theme 1

The participants showed great knowledge with regards to HIV and AIDS. They were able to define both HIV and AIDS. They also revealed different routes of HIV transmission which includes: unprotected sexual intercourse, mother-to-child transmission of HIV, sharing unsterile sharp objects particularly razor blade as well as engaging in multiple sexual

partners. The findings also showed that a significant number of older participants were knowledgeable regarding condoms, PMTCT and avoidance of multiple partners as prevention strategies. Others added the importance of HIV and AIDS testing. With regards to abstinence, some suggested that nowadays young people are failing to practice it, hence there is high teenage pregnancy in schools. As a result they are susceptible to contract HIV and AIDS.

Furthermore, participants showed that there is no cure for HIV and AIDS, therefore treatment adherence is key. Although, four participants cited incidents of skipping their HAART due to various reasons such as forgetfulness, medication side effects, laziness and lack of commitment towards treatment. However, they are currently adhering as told by the healthcare workers and they have found the importance of treatment. Moreover, all of them knew the names of their prescribed HAART. With regards to myths of HIV and AIDS, the majority showed poor knowledge except for two participants. Regarding sources of information on HIV and AIDS, the following were the main ones: hospital, school, home, television and radio. Three participants added teen club, pamphlets and two mentioned church. Their knowledge on the importance of HAART adherence was also satisfactory. All of them showed that the benefits of treatment adherence include: increased CD4 count cells, decreased viral load and consequently lives are prolonged. The participants indicated that laboratory tests, pill count and self or caregiver reports were the main methods used to assess their adherence. Participants indicated that if one is not adherent, the outcomes will be as follows: decreased CD4 count cells, increased viral load and all these will result in death.

In relation to bio-ecological perspective school and home are sources of information that makes up microsystem of these participants. In addition, hospital, teen club, pamphlets television and radio constitute their exosystem. Two participants talked about the church as a source of information which forms part of their macrosystem. It is evident that these microsystems, exosystems and macrosystem have played a significant role towards the enormous knowledge that has been displayed by the participants regarding HIV and AIDS and the importance of HAART adherence. Moreover, the linkages between the above mentioned settings (mesosystems), clearly shows that they have positively contributed towards the participants' knowledge.

3.9.2.2. Theme 2: Contextualising and conceptualising HAART-adherence amongst adolescents

This theme is putting into context HAART-adherence amongst HIV-infected adolescents. Perinatal or behavioural infection, treatment adherence and challenges facing adherence are the major sub-themes that will be deliberated.

Sub-theme 2.1: Perinatal or behavioural infection

The findings show that ten participants started ARV's at an early age. One participant showed some evidence of behavioural infection, while the other participant's mode of infection was not clearly defined.

"Nna ke simolotse go nwa dipilisi ke bala standard one." (Participant 02)

Translation: I started taking treatment when I was doing standard one.

"Ke simolotse go nwa dipilisi ke santse ke le monnye. O kare ke ne ke dira standard two. Tota fa ke sale ke di simolola gaise ke kopane le bothata bope yo bo ka dirang gore ke seka ka nwa sentle." (Participant 04)

Translation: I started taking ARV's at a younger age and I was doing standard two. Ever since I started them I have not experienced any challenge that would have prevented one from adhering correctly.

"Ga ke gakologelwe gore dipilisi ke di simolotse leng mme fela e rile ke le dingwaga di le 10, ke be le lemoga gore ke nwa dipilisi." (Participant 05)

Translation: I am not sure when I started taking my ARV's, but when I was 10 years old that is when I realised that I am taking HIV medication.

"Ga ke gakologelwe ka gore go supega gore ke di simolotse ke le monnye." (Participant 011)

Translation: I do not remember because it seems I started taking ARV's at an early age.

"Ga ke sure gore ke di simolotse leng mme e rile ke bala standard five ke be le lemoga gore go na le dipilisi dingwe tse ke di tselang ko kokelong phakela ke ya sekoleng le fa ke bowa." (Participant 09)

Translation: I am not sure when I started treatment, but I realised when I was doing standard five that there is certain medication I should take in the morning and after school at the clinic.

"Ga ke sure gore a ke simolotse ka 2003 or 2004, mme fela nkuku o poleletse gore ke na le mogare ka 2003." (Participant 07)

Translation: I am not sure whether I started in 2003 or 2004, but I know that my grandmother disclosed to me that I am HIV positive in 2003.

These findings are supported by Naswa and Marfatia (2010:5) who indicated that the emergence of HIV and AIDS has resulted in many children being perinatally-infected. Some died before reaching adolescence, while others survived into adolescence due to the introduction of HAART (Naswa & Marfatia, 2010:5). Nonetheless, Naswa and Marfatia (2010:5) cited that the number of behaviourally-infected adolescents continue to be a great concern. In addition, UNICEF (2013:3) alluded that over two million adolescents worldwide are living with HIV and AIDS, 90% of whom reside in sub-Saharan Africa (UNICEF, 2013:3).

Sub-theme 2.2: Treatment adherence

The findings regarding treatment adherence varied. A significant number of participants reported a satisfactory adherence. In addition, ten participants indicated that their treatment is scheduled for twice a day (morning and evening), while two participants take their ARVs once a day. Furthermore, it was also evident that these ten participants are on two pills per day, while the other two participants are on one pill fixed dose which is taken once a day. This is what they said:

“Ke tsaya nevirapine le combivir. Ke di nwa ka 7am le 7pm.” (Participant 03)

Translation: I take my medication at 7am and 7pm. I am on Nevirapine and Combivir.

“Ke tsaya atripla. Ke nwa ka 9pm.” (Participant 010)

Translation: I am taking atripla and I take it at 9pm.

“Ke tsaya efavirenz le combivir. Ke di nwa ka 6am le 6pm.” (Participant 08)

Translation: I am taking efavirenz le combivir at 6am and 6pm.

“Nna ke tsaya nevirapine le combivir. Ke di nwa ka 6am le 6pm.” (Participant 02)

Translation: I am currently taking nevirapine and combivir and I take them at 6am and 6pm.

“Ke tsaya aluvia, ABC and 3TC. Ke di nwa ka 7am and 7pm.” (Participant 09)

Translation: I take aluvia, abacavir and 3TC (Lamivudine). I take them at 7am and 7pm.

The above findings are similar to those observed by Agwu and Fairlie (2013:5) and Naswa and Marfatia (2010:8) who alluded that good adherence is associated with a low pill burden. For example, two or less pills per day or all drugs combined into one pill with once-a-day dosing. Furthermore, an in-depth study by Haberer et al. (2011:4) in Zambia which followed perinatally-infected children and adolescents for two years, found high levels of adherence and this was as a result of one-pill fixed dose. In 2012, Botswana also introduced one pill fixed dose (Atripla), Truvada a fixed dose combination of TDF + FTC (or 3TC) as well as Combivir which is also a fixed dose combination of AZT + 3TC (MOH, 2012:38).

Sub-theme 2.3: Challenges regarding adherence

UNICEF (2013:4) indicated that children living with HIV, when they grow older, their treatment care and support needs also change and they face new challenges in adhering to medications as well as taking greater responsibility for their own health. Four participants indicated that they experienced some medication side effects for a short period especially vomiting, forgetfulness and experiencing weird dreams, but did not stop their treatment. On the other hand, four participants mainly females talked about the challenges they experienced which were mainly medication side effects, forgetfulness, stigma and lack of commitment towards treatment.

“Fa ke dira standard 6 le 7 ke ne ke kgona go ya go tshameka ke bo ke lebala gore ke tshwanetse go tsaya dipilisi. Mme fela mo bogompienong ke di nwa sentle.” (Participant 012)

Translation: When I was doing standard 6 and 7 I used to forget to take my medication because I will be playing with my friends. But, at the moment I am adherent.

“Ka 2012 go na le nako e ke kileng kabo ke nwa dipilisi ka go di tludisa. Ke belaela gore ke ne ke dirwa ke botshwakga fela le go lebala.” (Participant 06).

Translation: In 2012 I used to skip my doses and I suspect that it might have been laziness and forgetfulness.

“Ke ne ke tsaya dipilisi sentle mme fela fa ke sale ke chenchelwa ke fiwa aluvia le combivir, ga di ntseye sentle e bile le wena wa bona gore masole a mmele a ya ko tlase le bokete jwa mogare bo ko godimo. Ke boletse ba bongaka gore ke batla ba nchenchele aluvia baa gana. Ke na le about 2 months ke sa tseye dipilisi sentle because of di-side effects tsa aluvia. Gone kea itse ditlamorago tsa go tlhoka go tsaya dipilisi sentle. Fa seemo same se ka baakanngwa ke tlaa nwa dipilisi sentle.” (Participant 07)

Translation: I used to be adherent before my medication was changed to alluvia and combivir. I am experiencing problems with regards to the new medication as you can see my CD4 count has decreased and the viral load has increased. I have informed the healthcare workers about this problem, but are refusing to change my medication. I have about 2 months without taking my medication due to side effects from aluvia. Of course I know the consequences of being non-adherent, but if my problem can be addressed I will adhere appropriately.

The above findings are supported by Nglazi et al. (2012:1-2) who noted that as HIV-infected adolescents grow older, they gain a greater sense of independence and adherence to HAART becomes a major concern. Adolescence is a complex developmental phase that is characterised by deviation from expected behaviour, experimentation, risk taking and significant peer influence. In addition, the demand to cope with HIV positive status complicates this developmental stage. Furthermore, a study by Nachega et al. (2009:68) showed that HAART-adherence amongst HIV-infected adolescents aged 15-18 years was significantly lower compared to HIV-infected adults, which led to poorer virological and immunological outcomes. Moreover, a study by MacDonell et al. (2013:89) assessed medication adherence amongst perinatally-and-behaviourally-infected adolescents and found that the following barriers to treatment were similar amongst the two groups: medication side effects and fatigue, forgetfulness, stigma and discrimination.

Nonetheless, Naswa and Marfatia (2010:8) and Agwu & Fairlie (2013:6) indicated that for clinicians caring for adolescents, it is crucial to understand that for the eventual success of treatment, it is critical to manage the ‘whole’ adolescent within the context of his or her own economic, cultural, psychological and family environment. Moreover, providing adolescents with psychosocial support including creating non-stigmatising or discriminatory environments will enable them to conquer challenges that may confront them in this journey.

3.9.2.2.1. Key findings of theme 2

The findings showed that a significant number of participants started ARVs at an early age which contributed to their survival. The findings further indicated that a significant number of participants reported satisfactory adherence, while other mentioned incidents of skipping their HIV medication. Some participants reported medication side effects such as vomiting, forgetfulness and weird dreams, which they experienced for a short period, although they did not stop taking their medication. On the contrary, other participants highlighted the following reasons for their occasional non-adherence: medication side effects, forgetfulness or lack of commitment towards the medication as well as stigma.

In relation to the bio-ecological perspective it is evident from the findings that there were individual system, macrosystem and chronosystem factors which contributed towards some of the participants' non-adherence. However, for some participants, it is clear that their interaction with these systems did not deter them from achieving sound adherence.

3.9.2.3. Theme 3: Factors contributing towards non-adherence to HAART amongst HIV-infected adolescents

This theme will explore factors that inhibit HIV-infected adolescents from adhering appropriately to HAART. Six sub-themes have been identified and are as follows: individual factors, regimen factors, social stigma from school and community, facility-related factors and home environment. However, the study findings did not reveal mental health as a factor contributing towards non-adherence.

Sub-theme 3.1: Individual factors

It has been discovered that adolescents are at risk given their typical developmental route which involves behavioural experimentation, engagement in risk taking behaviours, as well as difficult and complex choices regarding independence from families, romantic relationships, sexual behaviour, substance abuse and identity formation (Thurston et al., 2014:191; Arrive et al., 2012:1; Kidia et al., 2014:1; Van Dyk, 2008:185). Snyder et al. (2014:115) added that HIV-infected adolescents must also cope with compounded issues such as stigma, medication regimens, clinic appointments, fears of life expectancy and sickness. These developmental and social hurdles are particularly challenging to HIV-infected adolescents because optimal adherence requires them to independently manage their HIV, while continuing to balance being a "normal teenager."

The findings in the current study shows that there are some participants who experienced certain individual-related factors which contributed towards their non-adherence, while others observed these factors from their friends. The most notable was forgetfulness which

was coupled with lack of commitment towards treatment. This was alluded by three participants:

“Fa ke dira standard 6 le 7 ke ne ke kgona go ya go tshameka ke bo ke lebala gore ke tshwanetse go tsaya dipilisi. Mme fela mo bogompienong ke di nwa sentle.” (Participant 012)

Translation: When I was doing standard 6 and 7 I used to forget to take my medication because I will be playing with my friends. But, at the moment I am adherent.

“Ka 2012 go na le nako e ke kileng kabo ke nwa dipilisi ka go di tludisa. Ke belaela gore ke ne ke dirwa ke botshwakga fela le go lebala.” (Participant 06).

Translation: In 2012 I used to skip my doses and I suspect that it might have been laziness and forgetfulness.

“Fa ke dira standard 7 go na le nako e ke ne ke sa tseye dipilisi sentle ka gore ke ne ke nna ke lebala. Ka nako eo mama o ne a robaditse ko sepatela jaanong go sena yo o nkgakololang. Ke ne ke nna le mmangwane le fa a ne a chaise bosigo ko a ne a berekela teng.” (Participant 09).

Translation: When I was doing standard 7 I used to forget taking my medication. At the time my mother was hospitalised and there was no one to remind me to take medication. I was staying with my aunt who used to come late from work.

The above findings are consistent to Chandiwa et al. (2012:243), Ndiaye et al. (2013:894) and Agwu and Fairlie (2013:5), who mentioned that forgetting to take medication was a significant independent predictor of self-reported non-adherence among respondents. Forgetting was attributed to lack of motivation to make medication a priority, poor planning, busy and varying or chaotic schedule because they were unable to integrate medication into their daily schedules. Haberer et al. (2011:6) and Agwu and Fairlie (2013:2) added that the influence of age and sex on adherence was notable. Older age has consistently been related to poor adherence in both resource-rich-and-limited countries, with adolescents above 15 years of age having a greater risk of non-adherence compared to younger adolescents. The aforementioned illustrates that transition from childhood to adolescent stage had some challenges towards medication adherence.

An additional individual-related factor was alcohol intake. None of the participants who talked about it have experienced it, instead it is a prominent factor amongst older adolescents. Furthermore, one participant attributed forgetfulness to alcohol intake:

“Go nwa bojalwa ke nngwe ya mabaka a a ka dirang gore ba bangwe ba seka ba nwa dipilisi sentle. Ke sone go leng bothokwa gore fa motho a simolola dipilisi e le thaka tsa rona a gokololwe gore bojalwa le dipilisi ga di tsamaelane.” (Participant 01)

Translation: Alcohol intake is another factor that can contribute towards non-adherence amongst my age mates. That is why it is an important aspect that is always included into adherence counselling.

“Ba bangwe ba lebadisiwa dipilisi ke gore baabo ba ile majalweng ko dibareng jaana. O fitlhela gore motho o tlaa bosigo mo lapeng fa nako ya gagwe ya gore a tseye dipilisi e sa bolo go heta.” (Participant 08)

Translation: One of the reason why some people are non-adherent is because of alcohol intake as well as visiting liquor stores. As a result they come home late and cannot take their medication because the time has passed.

“Ke na le tsala ko teen club yo o neng a mpohelela gore o nwa bojalwa, mme ka mo gakolola gore bojalwa ga bo a siama e bile motho a tsaya dipilisi.” (Participant 012)

Translation: I have a friend at the teen club who told me that she takes alcohol and I advised her that when someone is on ARV's should not take alcohol.

These findings are similar to those observed by Kadivar et al. (2006:846), Dietz et al. (2010:282), Kagee et al. (2011:84) and Agwu and Fairlie (2013:5) who revealed numerous adolescent-related factors that have a negative impact on adherence and these include: alcohol use, smoking of tobacco and marijuana, cocaine or crack and all these were prevalent amongst male adolescents. The use of the substances has been cited as a major contributory factor towards missing of clinical visits and non-adherence. Alemu et al. (2007:348) mentioned that substance abuse does not only affect medication adherence, it also diminishes the judgement of these HIV-infected adolescents who end up indulging in unsafe and risky sexual behaviours that facilitate transmission of HIV and AIDS. Shockingly, adolescents in a study by Mutwa et al. (2013:5) indicated that if they did not accept their status, they will resort to casual substance use, which was also associated with forgetting to take HIV medication. Dietz et al. (2010:282) restated that regular attendance of medical appointments is necessary for medical treatment, behavioural interventions and monitoring of CD4 count cells and viral load. Consequently, health facilities must follow up adolescents who missed their clinic appointments either by phone, short messaging service (SMS) or home visit.

The above mentioned individual-related factors form part of the individual system as postulated by the bio-ecological perspective. It is evident that these individual systems make it difficult for these HIV-infected adolescents to maintain a sound adherence.

Sub-theme 3.2: Regimen factors

According to Chandiwani et al. (2012:243) and Agwu and Fairlie (2013:5) the principal factors associated with non-adherence amongst adolescents appear to be medication or regimen complexity, pill burden, side effects, dosing frequency and palatability of ART. Nonetheless, medication side-effects was the main factor contributing to non-adherence. Firstly, four participants indicated that they experienced some medication side effects, but did not stop their treatment. On the other hand, one participant admitted that she stopped treatment due to side effects. While two participants' acknowledged skipping dosages due to side effects. One participant talked about pill burden as a factor which could lead to non-adherence. This is what they said in this regard:

“Di- side effects tse ke di itemogetseng ke go heroga sebete le mathe a ne a nna motlhofo mo ganong. E rile ke bolelela ba bongaka ba bo bare ke e tsenye mo metsing, mme seemo se ne sa se fetoge. Ba mpolelela gore ke tseye pilisi e ka soft drink mme ga seka ga fetoga sepe gape. Ke ne ke tsaya dipilisi sentle mme fela fa ke sale ke chenchelwa ke fiwa alluvia le combivir, ga di ntseye sentle e bile le wena wa bona gore masole ame a mmele a ya ko tlase le bokete jwa mogare bo ko godimo. Ke boletse ba bongaka gore ke batla ba nchenchele alluvia baa gana. Ke na le about 2 months ke sa tseye dipilisi sentle because of di-side effects tsa alluvia. Gone kea itse ditlamorago tsa go tlhoka go tsaya dipilisi sentle. Fa seemo same se ka baakannngwa ke tlaa nwa dipilisi sentle.” (Participant 07).

Translation: The side effects that I noticed firstly were vomiting and weak saliva. I reported all these to the healthcare workers and I was told to put it inside water. There was no change and reported back. I was told to take it with a soft drink but nothing changed. I used to be adherent before my medication was changed to alluvia and combivir. I am experiencing problems with regards to the new medication as you can see my CD4 count has decreased and the viral load has increased. I have informed the healthcare workers about this problem, but are refusing to change my medication. I have about 2 months without taking my medication due to side effects from alluvia. Off course I know the consequences of being non-adherent, but if my problem can be addressed I will adhere appropriately.

“Two months ke sena go simolola dipilisi ke fa ke nna le rash mmele otlhe, ke nna ke selelega go sa batle ke ja sepe. I know there was a time ke ne ka di emisa selekanyo sa beke e le gore ke tshaba tsone di-side effects.” (Participant 06)

Translation: Two months after starting the treatment, I developed rash all over the body and at times I felt like vomiting. I could not eat anything. There was a time I stopped taking treatment for a week fearing these side effects.

“Sengwe se ke se itemogetseng ke gore bontsi jwa rona ko teen club go supega re na le lobaka lo lo leele re le mo dipilising. Go supega o kare bangwe ba lapisitswe ke go tsaya dipilisi letsatsi le letsatsi tse le fa re tlhola re gakololwa gore dipilisi tse re ya go di tsaya botshelo jwa rona jotlhe.” (Participant 01)

Translation: It is evident at the teen club that many of us started ARV's at a younger age. It seems some are tired of taking their treatment everyday, even though we have been taught that this is a life treatment.

“Nna tota di ne di sa ntseye sentle o ne o fitlhela o kare ke ka kgwa fa ke sena go dinwa le ko sekoleng di ne di okotsedisa. Fa gongwe ke ne ke itira o kare kea dinwa fa ke tswela fa ntle ba sa mpone kea dingwa.” (Participant 09)

Translation: I used to feel like vomiting as well feel drowsy at school after taking this medication. At times I will pretend as if I have taken them and will spit them out in a hidden place.

“Di siame fela, mme e rile ke di simolola e be e nna e kare fa ke fetsa go di nwa go be gore ke kgwe.” (Participant 02)

Translation: They are fine, but there were some times when I finished taking them I felt like vomiting.

“E rile ke di simolola eish di ne di nkotsedisa gore ko sekoleng, mme legale ga keaka ka di emisa ka gore ba mpoleletse bo-nurse gore di dira jalo.” (Participant 010)

Translation: When I started the treatment I used to feel drowsy at school, but I did not stop it because the nurses made me aware of such side effects.

The findings show that the most prominent medication side-effects were vomiting, rash, drowsiness and pill burden. Similarly, caregivers in studies by Biadgilign et al. (2011:91) and Wrubel et al. (2005:2427), mentioned that they found it difficult to administer ARV medications to children they cared for. Some of the problems cited were spitting out medication due to taste, resistance and refusal. With regards to medication side effects, the

following were spelt out by caregivers: nausea, vomiting, stomach cramps, diarrhoea, rash, sleeplessness and sedative effect and diarrhoea and vomiting. These resulted in a dilemma to caregivers whether to continue administering treatment to their children or not. Furthermore, Veinot et al. (2006:264) discovered that some adolescents did not take their HIV medication due to fear of side effects they heard from others, while some mentioned that the HIV treatment increased their body fat, hence they stopped taking it. On the contrary, Bangsberg (2008:273) mentioned that some tolerated side effects without missing doses, even though a slight number occasionally missed doses.

Chandiwani et al. (2012:249) added that with the availability of fixed-dosing combinations and single-dose regimens options, it may be easier for providers to explore the possibility of simplifying adolescents or youth regimens to decrease pill burden. This may also increase their perceptions that they can effectively manage their medications. Rosso et al. (2012:57) and Harberer et al. (2012:5) discovered that the use of one-pill fixed-dose enabled participants to achieve a positive clinical outcome and it was also associated with sustained improvements of several symptoms commonly related to HIV infection or ART. However, MOH (2012:40) has single dose combination referred as atripla, truvada and combivir. In addition, it has been stipulated that all adverse side-effects of ART or any other medication used to treat HIV patients should be properly reported on the Adverse Reactions Reporting Form (refer to **Appendix I**). Furthermore, HIV clinicians are aware of what needs to be done to manage side effects which include stopping all ARVs including cotrimoxazole (CTX) or admission for in-patient care and monitoring patients closely (MOH, 2012:40).

The issue on regimen or medication complexity is a policy-oriented issue which forms part of the macrosystem of these participants. Treatment guidelines are determined by policy-makers and HIV-infected people at times are not consulted, instead what is required of them is sound adherence. As a result, the findings clearly showed that medication side effects played a significant role in non-adherence.

Sub-theme 3.3: Social stigma at school and community

According to Mutwa et al. (2013:4), Calabrese et al. (2012:4), Kagee et al. (2011:87) negative stigma and labelling attached to being HIV-positive and consequent risks associated with being HIV positive, have made HIV-infected adolescents to be selective about revealing their diagnosis to family and friends. Botswana-Baylor Children's Clinical Centre of Excellence (2011:42) revealed that HIV affected social interactions in schools, as it separated HIV-infected adolescents from their peers. In studies by Li et al. (2010:753) and Rao et al. (2007:31) participants spoke about keeping their HIV status secret from their friends or class teachers. It was evident throughout the interviews that social stigma from the

school and community was a major impediment towards adherence. The following quotations are a testimony on this issue:

“Last year I heard that go ne go le mosimane o mongwe next to our class o ne a tsaya dipilisi tsa gagwe ka 7pm, jaanong ka gore reabo re le mo evening study gatwe fa nako e le 1850hrs he will leave the class and di classmates tsa gagwe di tlaabo di mo tsega. Go lebega gore ba ne ba tlhola ba mo lebeletse, jaanong dilo tse di tshwanang le tse di ka dira gore motho a seka a tsaya dipilisi sentle ka gore gaa battle go tshagiwa ke di-classmates. Tota bana ba ba mo boarding ba tshela le mogare ba tshela bokete tota fa go tsena kgang ya dipilisi and o ka nna wa fitlhela gore dipalo tse di ko godimo ke tsa bana ba ba sa tseye dipilisi sentle ke ba ba mo boarding. Nna ke ne ke thusiwa ke gore ke ne ke nwa ka 9pm evening study yaabo e fitile.” (Participant 010)

Translation: I was told that last year there was one student in our school who used to leave the evening study at 18:50hrs so that he can take his medication at 7pm. The classmates observed him and whenever he leaves at that time they will mock at him. As a result, acts like this one could lead to non-adherence. To be honest boarding students who are living with HIV and AIDS as well taking treatment suffer a lot of stigma. You might realise that the number of non-adherent students mostly are in boarding facilities. For me I was better because I took medication at 9pm.

“E rile ke bolelelwa gore ke na le mogare ke ne ka ipotsa gore a ke a go amogelesega mo sechabeng ka gore there is stigma and discrimination towards batho ba ba tshelang le mogare. Right now ke tseela dipilisi tsame mo sepateleng se, ka gore ga ke batle go di tseela ko sepateleng se se bapileng le sekolo sa rona e le yone kgang ya stigma. Mme nna ka ke na le madi a go pagama go tla kwano, jaanong yo o tshabang go tseela ko sepateleng se a bapileng le sone mme a sena madi ka ga re lekane, go raya gore dipilisi gaana go di tsaya sentle.” (Participant 08)

Translation: When I was disclosed my status, I asked myself if the community or people in large will accept me due to the prevailing stigma and discrimination towards people living with HIV and AIDS. Currently I am taking treatment in this hospital instead of the hospital where my school is situated to avoid stigma. At least for me I have resources to come here, therefore someone who fears to refill in their own hospital due to stigma may not have transport money and their adherence will be definitely affected.

“Nako tse dingwe fa go twe re tle ka 7am ko sekolong ke tsena late ka gore keabo ke emetse go tsaya dipilisi tsame. Ngwaga o o fitileng ga kea kgona go ya triping ko sekolong ka gore ke tsaya dipilisi. Fa ke ne ke tsamaile go nwa dipilisi e ne ya go nna bothata ka gore ga ke batle ope a itse seemo same. Ke dumela gore fa go ka direga gore go nne le dipilisi tse re di tseelang ko sekolong ba le bantsi ga re na go di tsaya sentle.” (Participant 04)

Translation: There are some instances whereby were are told to come at 7am at school, but since I take medication at 7am, it means on those days I will be late. Last year I could not be part of the school trip due to the fact that I am taking ARV's and I do not want anyone to know my status at school. I am of the opinion that should some medication be taken at school a number of us will default.

“Ga ke batle go hiwa label ya motho yo o tshelang ka mogare, akanya jaanong o tsaya dipilisi ko sekolong go ne go ya go nna worse.” (Participant 012)

Translation: I do not want to be labelled as someone living with HIV and AIDS. Imagine if we had to take medication at school, treatment adherence would become problematic.

“Bana ba sekolo ba dingalo rra fa ba ka itse baya go go opela. Akanaya jaanong fa go ne go na le dipilisi tse re di tseelang ko sekolong go ne go ya go nna le bothata because bana ba sekolo ke mathata.” (Participant 06)

Translation: Should students know that one is HIV positive, you will be mocked at. Imagine one has to take her medication at school, definitely it will not work out due to stigma.

“Nna ke siame ba ntse ba sa itse seemo same. Kana jaanong fa ba ka bona ke tsaya dipilisi letsatsi le letsatsi ko sekolo ba ya go ntsoetsa modumo and go ka dira gore motho a seka a tsaya dipilisi sentle. Kana morutabana a lebetse a bo a go botsa gore ao nole dipilisi ba ya go ipotsa gore ke tsa eng.” (Participant 05)

Translation: It is much better if other students do not know my HIV status. Now if there were to see me taking medication at school everyday, definitely everyone would be curious and that might affect adherence. In some instances the teacher may forget and ask you in front of other students if you took your medication.

The study findings are supported by Calabrese et al. (2012:4), Kamau et al. (2012:841), Kimani-Murage et al. (2013:745) and Mutwa et al. (2013:3), who found that some HIV-positive adolescents continued to maintain secrecy surrounding their diagnosis and some reported hiding their medication due to perceived and experienced stigma. In addition, in Zambia, Mburu et al. (2014:15) found some acts of stigma and discrimination in schools against HIV-infected learners. There were instances reported of teachers hinting at the presence of learners living with HIV in a manner that was interpreted as a warning not to associate with them. As a result, some HIV-infected learners mentioned that other learners did not want to share plates or cups with them. Some even made derogatory comments towards HIV-infected learners.

Moreover, Mutwa et al. (2013:3) supported the above findings by citing that stigma was a major issue amongst HIV-infected adolescents who lived in congested places such as boarding schools. Many of them did not want their friends and others to see them taking HIV medication. This was mainly exacerbated by lack of a private place to keep medication, as a result adherence was significantly affected. Moreover, Midtbo et al. (2012:264) and Petersen et al. (2010:973) reported different incidents of HIV stigma which were experienced by HIV-infected adolescents. Some mentioned that they are being called degrading names, while others felt that people gossiped about their HIV status. Moreover, Kagee et al. (2011:87) pointed out that some caregivers who cared for HIV-infected children choose to attend clinic appointments to a clinic which is far from their local clinic to avoid being seen or identified as HIV-infected. However, lack of transport monies may become a hindrance towards clinical visitations. Rao et al. (2007:32) reaffirmed that HIV stigma and discrimination emerged as an important factor driving non-adherence.

Stigma and discrimination forms the chronosystem of these participants as stipulated in the bio-ecological perspective. It is evident that stigma and discrimination is still an impediment towards medication adherence amongst people living with HIV and AIDS.

Sub-theme 3.4: Facility-related factors

It was evident that throughout the interviews the mostly mentioned facility-related problem was long awaiting time. The results showed that over-booking as well as the high number of patients who are referred to the medical officer, contribute to long waiting time. The following are verbatim responses from four participants:

“Dikgwetlho tse ke kopanang le tsone ke gore ke tsaya nako e ntsi mo sepatela. Nna rra se ke sa se itumeleleng ka sepatela ke gore re tsaya nako e ntsi kwano. Fa gongwe go tlaabo gotwe o ye go bona ngaka and ngaka wa IDCC o nosi fela golo moo go dira gore re nne lobaka mo sepatela. Jaanong golo mo go ka felela go dira gore re seka ratla di check-up ka gore ga re batle go salela ko morago ka dithuto tsa rona.” (Participant 01)

Translation: The only problem with the hospital is the amount of time that we spend there during refills. There is one medical officer who has been assigned to ARV-Infectious Disease Care Clinic (IDCC) and many patients will be referred to him, hence more time is spent at the hospital. As a result, all these could demoralise one to come for medical check-ups because of the amount of time spent at the hospital. In addition, this contributes a lot towards falling behind in our academic work.

“Nna ke se se itemogetseng ke gore o fitlhela re le bantsi bana baabo ba tsile refill, ke sone se se dirang gore re tseye lobaka mo sepatela. I know someone o kile a tsamaela ruri ka gore go ne sa le gotwe re emele ngaka and o tsamaile a sa tsaya dipilisi.” (Participant 010)

Translation: I have realised that there is a large number of us who normally come for refills which makes us to wait long. I know someone who left without having her refill because we spent some time waiting for the doctor.

“Eish fa re tsile for refill re nna nako e ntsi mo sepatela because o fitlhela re le bantsi. Ee seemo se se ka kgoba motho marapo bogolo jang rona bana ba sekolo ka gore ko morago dithuto dia re siama le fa gone go le botlhokwa gore re tle di-refill. Gone re boleletse bo-nurse ka seemo se, bare ba tlaa se baakanya.” (Participant 08)

Translation: We spent more time in the hospital during our refills due to large numbers of children and adolescents that have been booked for that date. Off-course one can be demoralised by this especially students who know that they are falling behind in their school work. We have reported to the nurses who promised to address the situation in due course.

“Problem e nngwe ke gore re nna nako e ntsi ko sepatela nako fa re ile go tsaya dipilisi tsa rona.” (Participant 06)

Translation: The only worry is that we spend more time in the hospital especially during medication refills.

The above findings are supported by Campbell et al. (2012:125), Yeap et al. (2011:1103), Vermeulen (2011:27) and Nglazi et al. (2012:6) and Kagee et al. (2011:86) who stated that the following institutional factors which act as barriers to adherence include: poor service, long waiting times, impatient and unsympathetic healthcare workers, staff burn-out, work dissatisfaction, level of confidentiality and poor communication between service users and providers. Mburu et al. (2014:16) added that severe shortage of trained staff, lack of youth-friendly health services and shortage of consultation rooms have been reported to be deterring adolescents from accessing appropriate services. Kagee et al. (2011:87) indicated

that some patients in an attempt to deal with facility-related problems would decrease their doses so that their supplies would last them longer and this led to suboptimal adherence.

Ross and Deverell (2010:95), Agwu and Fairlie (2013:4), MOH (2012:36) and Fernandez et al. (2011:1497-1498) revealed that the success of adherence or failure to adhere to HIV medication depends on the kind of adherence counselling offered. This process gives one the opportunity to identify potential obstacles regarding adherence and disclosure as well as brainstorming practical solutions. It also enables the healthcare worker to assess the patient and the caregivers' understanding and knowledge of HAART and inform them about potential medication side effects. However, the findings of the current study did not show any evidence on lack of inadequate adherence counselling which was provided by the healthcare workers.

In relation to the bio-ecological perspective, it is evident that certain aspects of the hospital setting as an exosystem play a significant role towards medication adherence amongst these HIV-infected adolescents.

Sub-theme 3.5: Home environment

According to Rajaraman et al. (2008:1) families provide most of the care to the tens of millions of HIV-infected and affected in Africa. Though, little research exists on how caregivers balance the demands of holding a job, while providing care for those who have become ill or orphaned by HIV and AIDS. A significant number of participants did not show that home environment is a factor that contributed towards their non-adherence. However, one participant indicated it as a factor which contributed towards her non-adherence. This is what she said:

“Fa ke dira standard 7 go na le nako e ke ne ke sa tseye dipilisi sentle ka gore ke ne ke nna ke lebala. Ka nako eo mama o ne a robaditse ko sepatela jaanong go sena yo o nkgakololang. Ke ne ke nna le mmangwane le fa a ne a chaise bosigo ko a ne a berekela teng.” (Participant 09)

Traslation: When I was doing standard 7 I used to forget taking my medication. At the time my mother was hospitalised and there was no one to remind me to take medication. I was staying with my aunt who used to come late from work.

Similarly, a study by Yeap et al. (2010:1104) in South Africa, discovered that some caregivers who had jobs had difficulty getting time off to attend their child's clinic appointments. Therefore, Yeap et al. (2010:1106) proposes that since many caregivers have to work long hours and are not given time out to attend to their children's health, this necessitates the involvement of secondary caregivers as an important source of physical and emotional support. Coordination amongst caregivers is important and failure to do that may be detrimental to the child's quality of care.

Haberer et al. (2012:5), Yeap et al. (2010:1104) and Haberer et al. (2012:4-5) added that the role of caregivers in establishing medication taking routine is crucial. The association of caregiver alcohol use may disrupt this routine when the caregiver is intoxicated. A similar association between caregiver alcohol use and poor adherence for the child was evident in a recent study carried in South Africa. On the other hand, Campbell et al. (2012:125) and Skovdal et al. (2011:956-957) revealed that in Zimbabwe some of the HIV-infected children and adolescents were cared for by their elderly parents who were likely to live in poverty. In addition, immobility, deteriorating memory and poor comprehension of complex treatment regimens meant some battled to ensure optimal adherence by children and adolescents. On the contrary, these aforementioned factors did not come out in the current study as inhibitors of HAART-adherence.

Sub-theme 3.6: Mental health issues

According to Midtbo et al. (2012:262), Agwu and Fairlie (2013:5), Petersen et al. (2010:972), Rudy et al. (2009:168) and Kagee et al. (2011:87) living with HIV and AIDS and the pressure to comply with treatment regimen is indisputably stressful. Life events such as loss of loved ones due to HIV and AIDS can greatly affect functioning or result in poorer psychological adjustment (outlook) amongst HIV-infected adolescents. Kamau et al. (2012:841) and Tanney et al. (2011:304) highlighted that HIV-infected adolescents are at risk of experiencing mental illness, therefore centres providing care to them should routinely screen for mental health disorders. Intervention should be provided early before the condition worsens because these disorders play a significant role in non-adherence to HIV medication. A significant number of participants indicated that they were deeply hurt after discovering their HIV positive status. Nonetheless, the results did not show any evidence of non-adherence which came as a result of sadness. This is what participants said:

“Ke ne ka lela gore mme fela go ikamogela ke nngwe ya di coping strategies tse di nthusang thata ke sone se o bona ke tsaya treatment sentle.” (Participant 08)

Translation: I cried a lot, but accepting one’s HIV status is one of the coping strategies that helps me a lot to be adherent.

“Nna ke ikamogetse the way ke ntse ka teng.” (Participant 010)

Translation: I have accepted the way I am.

“Go ne go le thata mme fela ke ne ka ipolelela gore ga se bofelelo jwa botshelo.” (Participant 04)

Translation: It was difficult at first, but I told myself that it is not the end of life.

“Ke ne ke utlwile botlhoko tota. Counsellor ya ko Tebelopele o ne a mpha dikgakololo mme moo ga dira gore ke amogele seemo same le fa go ne go se motlhofo. Gape ke ne ka lemoga gore ga se bofelelo jwa lefatshe.” (Participant 06)

Translation: I was deeply sad, but after receiving counselling I was much better. I told myself that it is not the end of the world.

The above findings are contrary to a recent study by Kamau et al. (2012:840) in Kenya who found that the most common mental health disorders amongst HIV-infected adolescents were major depression and anxiety disorders. It was discovered that low CD4 count of <350 cells/mm³ and virological treatment failure was significantly associated with major depression. Mutwa et al. (2013:4) and Wagner et al. (2011:353) reiterated that depression disrupts social functioning and activities of daily living of a person and it can also affect the motivation to do anything including adhering to healthy lifestyles. Mutwa et al. (2013:4) pointed out that HIV-infected adolescents were less motivated to take their ART which led to immune suppression. This was mainly perpetuated by anger and confusion amongst these adolescents, questioning why they became infected while their siblings were not. Furthermore, Kamau et al. (2012:841) noted an increase of suicidal attempt or ideation with age and the prevalence was lowest in the youngest age group and highest in the oldest age group. It is important to understand that suicidal ideation or attempt can be a manifestation of depression.

3.9.2.3.1. Key findings of theme 3

The findings show that there were a number of factors which contributed towards non-adherence amongst some of the participants. On the other hand, some of the participants talked about factors which they observed from their friends who are HIV-infected. Individual-related factors mainly forgetfulness, lack of commitment towards treatment and alcohol intake were the most prominent inhibiting factors revealed. Additionally, other participants cited the following medication side effects as contributory towards non-adherence: vomiting, developing rash, drowsiness and pill burden. Social stigma from school environment and community was also a factor which was dominant. Furthermore, other participants mentioned long waiting time as a major facility-related factor which could demoralise HIV-infected adolescents from coming for their refills more so that many of them are learners and do not want to fall behind in their school work.

Home environment especially multiple roles that are facing caregivers was another factor because medication supervision role was not fulfilled. Moreover, literature indicated that HIV-infected adolescents are susceptible towards developing mental illnesses especially major depression and anxiety (mental health issues) and these could contribute towards non-adherence. Nonetheless, a significant number of participants indicated feelings of sadness when they were disclosed their status, but the sadness did not deter them from adhering correctly.

In terms of the bio-ecological perspective, the above mentioned inhibiting factors toward adherence, consists of individual system, microsystem, exosystem, macrosystem and

chronosystem. As a result, all these have had a significant role towards non-adherence amongst these HIV-infected adolescents.

3.9.2.4. Theme 4: Coping strategies

This theme explored various coping strategies that are being utilised by participants. The following sub-themes will be explicated: disclosure, support from family, support from teen club, support from the hospital, spiritual support, individual strategies and support from school.

Sub-theme 4.1: Disclosure of HIV-positive status

Disclosure as a coping strategy was a prominent factor throughout the interviews. Six participants knew their HIV-positive status after being told by the healthcare workers at the hospital, five were disclosed to at home, while one knew her status after seeking voluntary HIV and AIDS counselling and testing services. The findings also show that ten participants were disclosed to during their primary school era. The following quotations confirm that indeed disclosure is an important factor in coping with living with HIV and AIDS:

“E ne yare re tsena ko sepatela ka isiwa ko go social worker mme a mpaya fa fatshe a mpotsa pele gore a ke itse gore dipilisi tse ke di nwang ke di nwela eng. Ka gore ke ne ke sa itse o ne a mpolelela gore ke na le mogare wa HIV ke sone se ke nwang dipilisi tse, ka gore di ritibatsa mogare. O ne a nkgothatsa gore ke di tseye ka fa ba bongaka ba ntaetseng ka teng. Le fa ke ne ke utlwile botlhoko go utlwa gore ke na le mogare wa HIV, mme fela ke lebogela ka fa a ntlhaloseditseng ka teng.” (Participant 01)

Translation: We went the hospital and I was referred to the social worker. She found out if I am aware that I'm taking ARV's. Since I did not know, she informed me that I am HIV positive, hence I am taking ARV's to suppress the virus from multiplying in. She encouraged me to adhere to treatment as told my healthcare workers. Although, I was deeply sad, at least I liked the way she explained everything to me.

“Nna ke boleletswe mo sepatela ke nurse ke sena go dirwa tlhatlhobo ya HIV. Ke ne ke dira standard 6. Ke ne ke na le monna wa ga mmagwane fa ke bolelelwa. Rra ke ne ka lela gore fa ke sena go bolelelwa gore ke na le HIV ka gore ke ne ke sa itse gore ke e tsaya kae. Le fa e ne ya re ko morago ka bolelelwa gore mama o tlhokafetse a na le yone. Mme fela mo tsamaong ya nako ke ne ka amogela seemo and e bile dipilisi ke di nwa sentle.” (Participant 08)

Translation: I was disclosed my HIV status by the nurse after an HIV test. I was doing standard 6 and I was with my aunt's husband. I cried a lot after being told because I didn't know where I got it, although later I was told at home that my late mother had it. As time goes on I accepted myself and I am very adherent.

“Ke boleletswe ke nurse gore ke na le mogare. Ke ne ke dira standard 5. Ka nako eo ke ne ke tseela dipilisi tsame ko kokelong pele ga ke ya sekolong le fa ke tswa sekolong.” (Participant 09)

Translation: I was told by the nurse at the clinic and I was doing standard 5. At the time, I used to get my ARV's at the clinic before and after school.

“Ke boleletswe seemo same sa mogare ke mmagwane, ke ne le dingwaga di le lesome. Ka nako eo ke ne ke sa thaloganye gore mogare go tewa eng, mme e rile ke ntse ke gola gape re rutiwa ko sekolong ke bo ke kgona thaloganya.” (Participant 012)

Translation: I was told my HIV status my aunt and I was 10 years at the time. Though, I did not understand what she meant by saying I have HIV. As I grew up more so that were we taught about HIV at school I started to understand.

“Ke boleletswe seemo same sa HIV ke mama ke sena go mmotsa gore ke nwelang dipilisi. E ne e ka nna ka 2008. (Participant 03)

Translation: I was told by my mother that I am HIV positive after asking her the reason why I am taking ARV's. It might have been around 2008.

“Nna ke boleletswe ke nkuku I think ke ne ke le dingwaga di le 10 ka gore ke ne ke bala standard 3.” (Participant 07).

Translation: I was told by my grandmother. I might have been 10 years because I was doing standard 3.

“Nna ke boleletswe ko Tebelopele ke sena go itlhatlhobela mogare. Ke ne ke utlwile bothoko tota. Counsellor ya ko Tebelopele o ne a mpha dikgakololo mme moo ga dira gore ke amogele seemo same le fa go ne go se mothofo. Gape ke ne ka lemoga gore ga se bofelelo jwa lefatshe. Motho yo ke neng ka mmolelela ke mama.” (Participant 06)

Translation: I was told my HIV status at Tebelopele HIV and Testing centre. I was deeply sad, but after receiving counselling I was much better. I told myself that it is not the end of the world. The person I told my status was my mother.

The above quotes are supported by Lowenthal et al. (2014:144), Midtbo et al. (2012:262) and Nicastro et al. (2013:364) who found that disclosing to the child his or her HIV-positive status has been associated with good medication-taking, self-efficacy, resilience, positive expectation on medication, social support, reduced perceived stigma and fewer emotional problems compared to those who had not been disclosed to. Botswana-Baylor Children's Clinical Centre of Excellence (2011:78), Merzel et al. (2008:978), Holele (2010:24), Vaz et al. (2008:844-848), Oberdorfer et al. (2006:283) and Lesch et al. (2007:815) indicated that the process of disclosure should start much earlier at an average age of 3-5 years for perinatally-infected children (partial disclosure). Full disclosure should be done by the time an adolescent is 10-12 years old or when he or she starts asking questions about his or her illness. The disclosure process should be done in a way that builds on the child's strength and assessing the readiness of the child or an adolescent for partial or full disclosure is crucial.

Furthermore, a study by Kidia et al. (2014:3) found that adolescents preferred a health care setting to be told their HIV-positive status. The main reason is that in a health care facility, they have access to accurate information from healthcare workers, as well as an environment that makes the illness seem more real. However, this finding was not significant from those who were disclosed their status at the hospital. Moreover, the findings of the current study are contrary to Haberer et al. (2011:5), Mutwa et al. (2013:4) and Arrive et al. (2012:2), who stated that while disclosure is also essential for secondary prevention of HIV transmission, it may heighten emotional and behavioural disorders amongst adolescents, familial conflicts or social stigma perceptions and these may jeopardise confidentiality.

Additionally, this anger in some cases may lead to adolescents being less adherent, sometimes in an attempt to punish their parents or due to confusion about why this happened to them and not to others.

The study findings shows that a hospital, home and a testing centre were the most prominent places where disclosure took place. In relation to bio-ecological perspective, it is evident that these micro and exosystems played a meaningful role in helping the participants to cope with their HIV positive status which also enabled them to cope with treatment.

Sub-theme 4.2: Family support

The quotations below confirm that indeed family support played an immense role in their lives:

“Bontsi jwa batho ba ba mo lwapeng baa itse ka seemo same sa mogare go simolola ka mama, mmangwane le bo nkgonne tota. Ke bone ba ba nthusang gape go gakologelwa gore nako e chaile ya gore ke tseye dipilisi. E bile mama ke nna ke tsamaya le ene fa ke ya sepateleng go ya go tsaya melelo.” (Participant 03)

Translation: Most of my family members and relatives know about my status. At times, they will remind me to take my medication. In addition, I am always accompanied by my mother for medication refill at the hospital.

“Bontsi jwa batho ba ko lapeng ba itse ka seemo same bo mmagwane, le banna ba bone and the support from them is amazing.” (Participant 08)

Translation: Most of my relatives know my HIV status especially my aunts and their husband. They are supportive.

“Sengwe se se nthusang ke support go tswa ko go ba lolwapa lwame bogolo jang nkuku le bo mmangwane.” (Participant 04)

Translation: One element that keeps me going is the support I get from my family members and relatives especially my grandmother and aunts.

“Mama ke ene motho yo e leng gore fa go na le bothata bongwe ka nna kea mmolelela. Le go tla sepatela ke nna ke tla le ene.” (Participant 011)

Translation: My mother is my source of support and if there is something bothering me I will let her know. In addition, she always go with me for medication refill.

“Nkuku le bo nkgonne ke bone ba mphang thotloetso jaaka ke le motho yo o tshelang le mogare.” (Participant 05)

Translation: As someone who is living with HIV and AIDS, I get most of the support from my grandmother and other siblings.

These findings are supported by Mburu et al. (2014:15), Veinot et al. (2006:265) Balthip and Purnell (2014:32) who indicated that unconditional love and support from family were eminent to influence adherence positively by creating an environment that enabled HIV-infected adolescents to adjust to new drug-taking routines and cope with side effects. Receiving support boosted the drive of HIV-infected adolescents, strengthened their minds and enhanced their self-worth and all these showed them that they still have a place in the society. Brown et al. (2010:452) established that family unit in South Africa is often a strong source of social support and it remains the strongest source of support for caring for those

who are PLWHA. Research has shown that disclosing one's status can yield even greater social and emotional support for PLWHA and foster a sense of trust among family members. This is an important part to cope with the stress of living with HIV and AIDS, as well as maintaining trust and mutual respect within the family.

Furthermore, the study findings indicated that participants got support from various family members and relatives. These results are contrary to the findings by Brown et al. (2010:452) who indicated that family relations do not always embody the type of emotional support and physical care that PLWHA require. Therefore, keeping their status a secret may imply that the family is ashamed and such perceptions are reinforced by negative enablers that may prevent PLWHA from getting the necessary assistance including adherence to treatment.

In relation to bio-ecological perspective, family support is a microsystem that plays a pivotal role in the lives of these HIV-infected adolescents to live positively.

Sub-theme 4.3: Support from the teen club or peers

Three participants talked about the importance of a teen club. Other participants have heard about the teen club, but they have never been part of it. The three participants indicated that it gives them support to share their experiences with others who are also HIV positive, they play different games and most importantly they are being taught about HIV and AIDS and importance of treatment adherence. This is what they said:

“Teen club e bothokwa fela thata ka gore e re fa sebaka re le bana ba ba tshelang le mogare gore re kopane re bue ka dikgwetlho tse re kopana le tso. E bile re nna re rutwa thata ka HIV and AIDS. Ko sepatela o fitlhela gore nako ya teng e nnyenyane gore re re rutiwe but ko teen club re nna le nako e ntsi ya go rutiwa.” (Participant 01)

Translation: Teen club plays an important part in our lives because it gives children living with HIV and AIDS an opportunity to meet and discuss the challenges they are faced with. At the teen club we are being taught about HIV and AIDS. I realised that at the hospital the time is limited to be taught on HIV and AIDS as compared to at the teen club.

“Ko teen club re ithuta go le gontsi mo go ba bangwe, e bile re rotloediwa gore re tseye dipilisi tsa rona sentle ka gore ke botshelo jwa rona. Go bua nnete o fitlhela go le monate ko teen club.” (Participant 012)

Translation: We learn from others at the teen club. In most instances we are encouraged to be adherent to our treatment. To be honest being at the teen club gives one happiness.

“Teen club ea thusa fela thata e bile rea rutiwa mme le rona re tla re rutana. Gape fa re le ko teen club re tshameka di-game ka go farologana jaaka koi, dibeke, bolo le go bina tota. Last year re ne re isitswe ko Mmololodi gore re ye go bona diphologolo, go ne go le monate gore.” (Participant 07)

Translation: We learn a lot at the teen club because we are able to share our experiences. In addition, when we are at the teen club we play different games such as *koi, dibeke*, football and we also dance a lot. Last year we embarked on a trip to Mmololodi Nature Reserves to view natural beauty and we really enjoyed.

The above quotes are supported by Mburu et al. (2014:16), Pettitt (2010:79), Kidia et al. (2014:5) and Marino et al. (2007:74-76) who indicated that peers who were living with HIV featured prominently as a source of psychosocial support, improved self-esteem, friendship and ART adherence. The main reason is that experienced adolescents are capable of using age-appropriate terminology to explain important concepts of HIV and AIDS to those that have been recently diagnosed. Additionally, adolescents reported that through such peer connections, they could share coping strategies, make each other feel valued and accepted, as well as offering each other a sense of identity. Thus, reducing a sense of isolation and maintaining motivation and commitment to HIV care and treatment. Some mentioned that peer support was an excellent resource for making decisions about disclosing their status to their families, especially behaviourally-infected adolescents. Adolescents in a study by Kidia et al. (2014:4) explained that by attending peer support groups and youth clubs or youth friendly centres, they became more knowledgeable about HIV and AIDS. In return, they were able to teach others about the importance of adherence to medications, avoiding risk behaviours and staying healthy.

Pettitt (2010:79) noted that including activities such as drama, pool parties, safari trips, art sessions, teachings on personal finance management, preparing for college and goal setting is vital in youth or teen clubs. This gives HIV-infected adolescents the opportunity to normalise their social experiences and improve their outlook on life. In summary, Pettitt (2010:79) restated that support groups or teen clubs for HIV-infected children generally provide a health-enabling “safe space” which helps to create important networks and social bonds. These will ultimately lead to improved clinical and mental outcomes as well as healthy transitions into adulthood.

The study findings and literature shows that teen club is an exosystem that plays a tremendous role in the lives of these HIV-infected adolescents towards coping with treatment adherence, as well as being HIV-infected.

Sub-theme 4.4: Support from the hospital

Petersen et al. (2010:974), Sopena et al. (2010:1257) and Botswana-Baylor Children’s Centre of Excellence (2012:11) pointed out that the provision of services from health facilities such as counselling services, serves as a mediator in a number of issues faced by HIV-infected adolescents. During the interviews it became evident to the researcher that the hospital where all of the participants got their medication, played an enormous role towards their treatment adherence. Activities such as adherence and supportive counselling are being done. It also became clear that almost all of the participants knew the names of their ARV’s and this knowledge was attributed to healthcare workers.

“Pele ga ke simolola dipilisi bo-nurse le bongaka ba ne ba mpotsa gore a ke ready go di simolola, mme go tswa foo ba nthalosetsa sengwe le sengwe ka tsone le di side effects tota. Mo bogompionong ke tsaya atripla.” (Participant 06)

Translation: Before I commenced treatment, the nurses and the doctors provided adherence counselling. They also talked about possible side effects. Currently, I am taking atripla.

“Sengwe se se neng se gatelelwa ke social worker ke gore dipilisi ga di batle go tlhakannngwa le bojalwa or else ga di na go bereka go bo go tshwana fela le motho yo o sa tseyeng dipilisi sentle.” (Participant 01)

Translation: The social worker emphasised that while on treatment one should avoid alcohol because it will reduce the efficacy of the treatment.

“Gantsi fa o sa tseye dipilisi sentle ba botsogo ba leka ka bojotle go go thusa. Go na le class ya Friday e e leng gore ba ba sa tseyeng dipilisi sentle ba tla sepatela gore ba tle go rutiwa.” (Participant 06)

Translation: If one is non-adherent, the healthcare workers will come up with different ways to assist. For example there is a class every Friday at the hospital for the defaulters to be taught about the importance of treatment.

“Ko sepatela le gone re rea rutiwa ka mogare le mosola wa go tsaya dipilisi.” (Participant 04)

Translation: At the hospital we are being taught about HIV and AIDS as well as the importance of treatment adherence.

“Maina a dipilisi tse ke di tsayang ke efaviranz and combivir. Kea rutilwe ke bo-nurse.” (Participant 02)

Translation: I am currently on efaviranz and combivir and I was taught by the nurses.

“Nako tse dingwe ba bala dipilisi go tlhola gore a ga ke a tlhodisa go nwa tse dingwe. Fa gongwe ba botsa mama gore a mme ke nwa dipilisi sentle.” (Participant 09)

Translation: Sometime they count the number of pills to assess if I am adherent. Other times they will ask my mother about my adherence.

The study findings are supported by Chandiwani et al. (2012:249) and Balthip and Purnell, (2014:33) who revealed that healthcare professionals were seen as the main source of support by HIV-infected adolescents. The main reason is that, they provide access to counselling services, education and help adolescents to develop early positive strategies in the disease process to set the stage for long-term adherence. Veinot et al. (2006:266) also pointed out that patient’s understanding of their medical condition and treatment recommendations was a strong predictor of treatment adherence.

A study by Lowenthal et al. (2014:145-146) conducted in Botswana indicated that adherence should be done in a developmentally appropriate manner. The early steps include: The child is taught that the medication (ARVs) keeps him or her healthy. When he or she is sick, it will help him or her to get better. In addition, teaching the child how to take medications at the appropriate time and appropriate amount is vital. Teach the child that as long as he or she takes medication well, he or she will become strong and healthy. Simple drawings are also utilised to reinforce these concepts. The intermediate steps include: teaching the child the names of the medications. Once children know the alphabet and can count, they are

considered ready to learn the names of ARV's and should be taught with the simplest 3 letter abbreviations. (e.g. AZT, 3TC). Advance steps include: Teach that the child needs to take medicines because something in his or her body was making the CD4 cells (soldiers) weak. Teach that medicines work by keeping the "bad guy" asleep so that it cannot attack the CD4 cells. Incorporate an understanding of medication resistance prevention. If the "bad guy" stays asleep, he can't become "tricky" and learn to get away from the medicines. Introduce the proper names of CD4 cells and HIV. Chandiwani et al. (2012:249) and Lowenthal et al. (2014:146) affirmed that adherence counselling is crucial because it enlightens HIV-infected adolescents about the importance of treatment and it should be an ongoing part of clinical care appointment for early identification of non-adherence issues.

The findings are evident that indeed a hospital setting which forms part of participants' exosystem plays a major role towards their coping ability.

Sub-theme 4.5: Spiritual support

Park and Nachman (2010:556) and Li et al. (2010:754) noted that with the focus of HIV moving away from an incurable illness to a more chronic disease, infected patients and their families have had to develop lifelong coping systems. One outlet for confronting their issues and perhaps seeking help is through religion and spirituality. Only two participants indicated that prayer and trust in God keeps them strong. This is what they said:

"Nna tota ke motho wa thapelo e bile ke dumela thata mo modimong ka gore support yotlhe ke e tsaya mo ene." (Participant 010)

Translation: I believe in God and that is where I get all my strength.

"Nako e nngwe moruti ko kerekeng o kopa botlhe ba ba lwalang go gatela ko pele gore a ba rapelela mme lenna kea tle ke rapelelwe. Tota thapelo e mpha moko e bile e nthusa gore ke tswelile ke tshela." (Participant 03)

Translation: At times in our church the pastor will invite those who are sick to come in front so that he can pray for them and at times I become part of them. To be honest prayer gives me strength and prolongs one's life.

The study findings are supported by Lyon et al. (2011:633) and Kremer et al. (2009:132) who found that adolescent spirituality was associated with lower levels of anxiety and depression, optimism about the future and coping with treatment side effects. In fact, those who believed that spirituality was helpful in coping with side effects, also reported fewer symptoms that are common due to the disease and its treatment. Lyon et al. (2011:635) discovered that adolescents with high spirituality, adhered well to HAART medication and this was significant amongst perinatally-infected adolescents. Generally, high spirituality in the family played a major role amongst HIV-infected adolescents to score high on spirituality and medication adherence.

These findings show that religion as a macrosystem, is helping these participants to develop a positive attitude towards their diagnosis and treatment adherence.

Sub-theme 4.6: Individual coping strategies

The participants mentioned different medication reminders. The main ones highlighted included: alarm clock or setting a reminder on the cellular phone, depending on family members and using a certain television programme which is showed at the time one has to take his or medication. One participant alluded that he has included medication taking on the study time table. The following quotes reflect these different strategies:

“Nna ke nwa dipilisi ka 7am le 7pm mme dinako tse tsotlhe ke di tsentse in my study timetable gore ke kgone go gakologelwe gore ke tseye dipilisi.” (Participant 01)

Translation: I take my medication at 7am and 7pm and all these times I have included them on the study timetable so as to remember taking my HIV medication.

“Fa mama a seo ke gakololwa ke mmagwane kana ke target dikgang tsa Btv tsa 7pm.” (Participant 03)

Translation: In my mother’s absence I am reminded by my aunt or I target the Botswana Television news bulletin at 7pm.

“Nkuku kana ba ke nna le bone baa nkgakolola fa nako e atumetse gore ke nwe dipilisi.” (Participant 04)

Translation: I will be reminded by my grandmother or siblings at home.

“Nna ke setela alarm ya phone gore e nkgakolo.” (Participant 05)

Translation: I normally set the alarm on the phone so that I remember.”

“Ke setela alarm kana mama wa nkgakolola gore e chaile ya go nwa dipilisi.” (Participant 06)

Translation: I set an alarm or my mother will remind me when time is up for medication.

“Gantsi nna ke setela alarm ya phone gore e lele 15 minutes before nako e ke tsayang dipilisi ka yone, fa godimo ga moo ke na le watch ya letsogo. Ke tsone tse ke di dirisang go ikgakolola.” (Participant 08)

Translation: I normally set an alarm on my phone so that it alerts me 15 minutes before the time for medication. In addition, I have a wrist watch and I use all of them as reminders.

“Re na le watch ya lebotana ko lapeng, gantsi ke bona nako mo go yone.” (Participant 09)

Translation: Normally I check time on the wall watch at home.”

“Ke lebelela nako on my phone kana fa dikgang tsa BTV di tsena tsa 6pm ke itse gore ke nako ya gore ke tseye dipilisi.” (Participant 012)

Translation: I use my cellphone to check time or I target Botswana Television news at 6pm so that I take my medication.

Similarly to the above quotes, the use of medication-taking reminders such as alarm clocks, beepers, calendars and daily schedules were some of the strategies used by HIV-infected adolescents to cope with HIV and AIDS medication (Thurston et al., 2014:192; Van Dyk, 2008:107; Kagee et al. 2011:84). Others relied on their caregivers for their medication and

that has been found in other studies as a reliable strategy towards adherence (Naswa & Marfatia, 2010:8). Van Dyk (2008:107) identified some routine activities to which taking medication can be linked to and these are: taking HAART when brushing the teeth in the mornings and evenings, using a radio or television programme as a reminder and it should be a programme that the patient always watches or listens to. It should start or end at the time he or she has to take medication.

Campbell et al. (2012:128) and MOH (2012:36) supported the findings further by indicating that a treatment “buddy” or partner plays an important role in providing the patient with ongoing support for adherence to care and treatment. This person is usually someone close to the adolescent, a family member, teacher, friend or caregiver and should accompany him or her to the clinic visits. Henceforth, it is important for healthcare workers to ensure that treatment “buddies” have the needed information on HIV and AIDS including HIV medication. But, not having a treatment “buddy” or a partner should not act as a barrier to any client that is being initiated on HAART.

An additional significant finding which was prominent amongst the participants was accepting oneself. This is what they said:

“Go ikamogela ke nngwe ya di coping strategies tse di nthusang thata ke sone se o bona ke tsaya treatment sentle.” (Participant 08)

Translation: Accepting one’s HIV status is one of the coping strategies that helps me a lot to be adherent.

“Nna ke ikamogetse the way ke ntse ka teng.” (Participant 010)

Translation: I have accepted the way I am.

“Maikutlo a ne a siame fela, e bile ke tsere tshwetso ya gore ke tlaa tswelala fela di tsaya dipilisi tsame ka fa ke laetsweng ka teng.” (Participant 04)

Translation: I was fine and I told myself that adhering to treatment as told is key

“Ke ne ke utlwile bothoko tota. Counsellor ya ko Tebelopele o ne a mpha dikgakololo mme moo ga dira gore ke amogele seemo same le fa go ne go se motlhofo. Gape ke ne ka lemoga gore ga se bofelelo jwa lefatshe.” (Participant 06)

Translation: I was deeply sad, but after receiving counselling I was much better. I told myself that it is not the end of the world.

The findings are supported by Balthip and Purnell (2014:33) and Veinot et al. (2006:265) who added that determination, accepting oneself of being HIV-positive and accepting that dying or death is part of life, were some of the important elements in finding meaning and purpose in life to cope with being HIV-positive. In addition, these elements resembled positive living. Some participants mentioned that, they have lived for more than 10 years while taking ART to prolong life. They knew that, taking care of themselves would extend their lives.

According to Thupayagale-Tshweneagae (2010:262), Botswana-Baylor Children's Clinical Centre of Excellence (2011:55) and Beyers and Nkoane (2012:660) HIV-positive adolescents reported keeping quiet about their HIV positive status so that people around them would not know they live with it. The participants did this to protect themselves from the community that looks negatively on those who live with HIV and AIDS. The findings show that ten participants kept their HIV status a secret especially at school. This is what they said:

"Ijoo bana ba sekolo ba rata go seba rra jaanong fa ba ka itse seemo sa motho ke mathata fela." (Participant 08)

Translation: Students have the tendency to gossip about other people's situation and should they know my HIV status that will be problematic.

"Ga ke batle go hiwa label ya motho yo o tshelang ka mogare." (Participant 012)

Translation: I do not want to be labelled as someone living with HIV and AIDS.

"Bana ba sekolo ba dingalo rra fa ba ka itse ba ya go go opela." (Participant 06)

Translation: Should students know that one is HIV positive, you will be mocked at.

The above mentioned individual coping strategies form part of their individual system or organism. It is evident that these participants use different individual systems to cope with being HIV infected, as well as treatment adherence.

Sub-theme 4.7: Support from the school

The findings showed that a number of participants acknowledged that the rich knowledge which they possess on HIV and AIDS was obtained at school. In addition, three participants indicated that the school management has never refused to give them permission to attend clinical visits even though they have not disclosed their illness. The findings further showed that only two participants indicated that there are some teachers who are knowledgeable about their HIV status. This is what they said:

"Ko ntle ga ba ko lapeng my class teacher le wa guidance ke bone ba ba itseng seemo same. Fa o ka lemoga re tla sepatela kgwedi le kgwedi nako tse dingwe re tsaya nako e ntsi mo sepatela mo go dirang gore dithuto tsa rona di salele ko morago, mme le gale ke na le tsala e gantsi e nthusang ka di notes." (Participant 01)

Translation: At the moment my class teacher and guidance and counselling teacher are the ones who knows my HIV status apart from my family. As you might have noticed we come to the hospital every month and at times we spend more time and as result we fall behind on our academics. Nonetheless, I have a friend who normally assist me with notes.

"Batho ba ba itseng seemo same ke morutabana wame wa Setswana, teacher wa guidance and le head of house wa rona. Nako tse dingwe teacher wa guidance o na le go re phuthela ko holong ya sekole rona bana ba ba tshelang le mogare a tla go re rut aka bomosola jwa dipilisi." (Participant 02)

Translation: My Setswana teacher, guidance and counselling teacher and our head of house are the ones who knows my status. At times as students living with HIV and AIDS we will gather in the school hall and our guidance and counselling teacher will teach us about the importance of treatment.

“Normally ke tla refill after three months mme ga gona nako e ko sekoleng ba kile ba gana go mpa permission go tla sepateleng le ntswa ba sa itse gore ke lwalang.”
(Participant 08)

Translation: I come for refill after every three months and there has never been an instance whereby the school management refused to give out permission, even though they do not know my illness.

“Go bua nnete ko sekoleng gagona ka nako epe e ba kileng ba gana ke tla sepatela.”
(Participant 012)

Translation: There has never been an instance whereby I was not granted permission to attend clinical visits.

Similarly, Kushima et al. (2008:126) indicated that schools play a major role in educating learners about HIV and AIDS as well as medication adherence. HIV-infected adolescents in a study by Botswana-Baylor Children’s Clinical Centre (2011:53) mentioned that despite missing classes due to ill-health and medical check-ups, they were assisted with notes by their teachers and other classmates. In general, support from classmates and teachers minimised isolation, depression and stress levels amongst HIV-infected adolescents. It also increased a sense of self-competence and medication adherence.

Furthermore, Botswana-Baylor Children’s Clinical Centre of Excellence (2011:49) and Petersen et al. (2010:973) affirms that despite fears of stigma, disclosure to class teachers or guidance and counselling teachers, was reported to be beneficial by HIV-infected adolescents and their caregivers. The reason being these teachers will be able to provide support and have an understanding of the child’s health situation. On the contrary, 10 participants indicated that no one knows their HIV status at school due to fear of being stigmatised. This is what they said:

“Ijo bana ba sekolo ba rata go seba rra jaanong fa ba ka itse seemo sa motho ke mathata fela.” (Participant 08)

Translation: Students have the tendency to gossip about other people’s situation and should they know my HIV status that will be problematic.

“Nako tse dingwe fa go ba bangwe ba ya trip ya sekolo go dingalo gore ke tsamaye ka gore ke mo dipilising. Tota ga ke batle ope a itse gore ke tsaya dipilisi.”
(Participant 04)

Translation: At times when other students will go for school trips, I will remain behind because I am on treatment. I do not want anyone of my schoolmates to know that I am taking ARV’s.

“Ga ke batle go hiwa label ya motho yo o tshelang ka mogare.” (Participant 012)

Translation: I do not want to be labelled as someone living with HIV and AIDS.

“Bana ba sekolo ba dingalo rra fa ba ka itse ba ya go go opela.” (Participant 06)

Translation: Should students know that one is HIV positive, you will be mocked at.

“Nna ke siame ba ntse ba sa itse seemo same.” (Participant 05)

Translation: I am fine with it if they do not know my HIV status.

The findings from the participants clearly show that the school plays a significant role towards educating them about HIV and AIDS. However, only two participants' status was known by some teachers in their respective schools, while the rest indicated that they have kept their status secret to everyone at school including teachers. With regard to the bio-ecological perspective the participants showed mixed responses regarding support from this microsystem.

3.9.2.4.1. Key findings of theme 4

The findings showed that participants utilised different strategies to cope with being HIV-infected as well as the HIV medication. The coping strategies which were dominant were disclosure of HIV positive status, support from family or relatives and support from the hospital. There were numerous individual coping strategies which were utilised: alarm clock or alarm on the cell phone, wrist or wall watch, dependant on caregivers, certain television programmes such as news, study timetable, accepting oneself and keeping quiet about one's HIV status.

Furthermore, few participants mentioned teen club as a major source of support, because it gives them a sense of belonging, hope, education as well as interaction with other children who are living with HIV and AIDS. Other participants alluded that their strength comes from spiritual support. Lastly, support from school was another coping strategy mentioned, although majority indicated that their friends or school management do not know about their status to avoid being stigmatised or discriminated.

In relation to bio-ecological perspective, the above-mentioned coping strategies form part of their individual system, microsystem, exosystem and macrosystem and all these help them to cope with treatment adherence.

3.9.2.5. Theme 5: Recommendations

Recommendations were solicited from the participants on what could be done to assist HIV-infected adolescents who are non-adherent to HAART. The majority of them suggested that continuous education on the importance of treatment adherence and medication supervision are key strategies. On the other hand, one participant added that every child who is HIV-infected must become part of the the teen club. While one participant indicated that healthcare workers should introduce medication reminders, such as sending short text messages (SMS).

“Nna ke akanya gore go tswelwe fela ba rutiwa ka botlhokwa jwa treatment. Ba lemotshiwe gore go botlhokwa go tsaya dipilisi ka nako and e bile ga wa tshwanela go di tludisa. E bile ba tshwanetse go gakololwa gore ba seka ba lebala go tla di-check-up tsa kgwedi le kgwedi.” (Participant 04)

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Translation: They should be give continous education on the importance of adherence. In addition, it is vital to show them that adhering to refill dates every month is also important.

“Nna ke akanya gore batsadi ba netefatse gore bana ba tsaya dipilisi sentle. Le mo sepatela ba botsogo ba tshwanetse go ba rotloetsa ka nako tse tsotlhe gore dipilisi di nowa sentle.” (Participant 05)

Translation: Caregivers should ensure medication supervision. The healthcare workers as well must provide continuous encouragement regarding the importance of treatment.

“Se se botlhokwa ke gore batsadi ba netefatse gore bana ba tsaya treatment ka fa tshwanelong.” (Participant 07)

Translation: It is imperative for parents to ensure medication supervision for their children.

“Go likilwe tse dintse bo-nurse, batsadi ba buile thata ka go tlhoka go tsaya dipilisi mme ga go na sepe se se fetogang. Go na le bo di teen club le tsone dia leka. Gongwe go botoka gore re tswelele ka go ba bontsha botlhokwa jwa dipilisi gongwe mo tsamaong ya nako ba tlaa itharabologelwa.” (Participant 08)

Translation: A number of efforts have been tried by parents and nurses to show them the importance of treatment and we have other iniatives such as teen club. May be continuous education may help them to change their mind set.

“Se se botlhokwa ke gore re tswelelele re ba rotloetsa re ba bontshe botlhokwa jwa dipilisi.” (Participant 011)

Translation: Continous encouragement and the importance of HIV treatment is key.

“Batsadi ba tshwanetse go bua le bone ba ba supegetse gore dipilisi tse ke botshelo jwa bone.” (Participant 012)

Translation: Parents should talk to them and show them that this treatment is part of their lives.

3.9.2.5.1. Key findings of theme 5

The findings clearly show that the majority of participants are advocating for continuous education on HIV treatment and treatment supervision. One suggested that it is imperative for every child who is living with HIV and AIDS to be incoorporated in the teen club. The other participant added that healthcare workers should introduce medication reminders such as sending short text messages (SMS) to children or adolescents who are non-adherent. In relation to the bio-ecological perspective, these two forms of support are regarded as the microsystem and exosystem of the participants. Therefore, they are vital with regards to sound adherence.

3.10. Summary

There was firstly a discussion of the research methodology, followed by the empirical findings. The findings revealed five themes which were discussed regarding barriers to HAART-adherence amongst HIV-infected adolescents in a government hospital in Botswana.

The first theme explored participants' knowledge about HIV and AIDS and importance of HAART-adherence. It was evident that majority of the participants were able to define HIV and AIDS, its transmission and prevention. However, a significant number of them showed inadequate knowledge regarding myths of HIV and AIDS. Additionally, participants revealed that there is no cure for HIV and AIDS, therefore treatment adherence is key. They showed great knowledge regarding the benefits of HAART-adherence, methods of HAART assessment and consequences of non-adherence. Last of all, a significant number of sources of information dissemination were recognised for their contribution towards participants' knowledge.

The second theme contextualised and conceptualised HAART-adherence amongst adolescents. The findings showed that a significant number of participants started treatment at an early age and have been on it for a lengthier period. In addition, a good number of them reported good adherence, while others acknowledged incidents of non-adherence.

The third theme explored factors that contribute towards non-adherence amongst HIV-infected adolescents. The results revealed that individual factors, regimen or medication factors, social stigma from school and community, long waiting period at the hospital (facility-related factor) and home environment were the main impediments towards non-adherence. Lastly, mental health issues was another factor which came up, but it was not an impediment towards adherence, although literature cited it as a hindrance.

The fourth theme explored coping strategies that are being utilised by participants. The results showed that disclosure of HIV positive status, support from family or relatives, teen club or peers, hospital and school, spiritual support and various individual strategies were the main coping strategies.

The last theme looked at the recommendations which participants suggested in order to increase HAART-adherence amongst HIV-infected adolescents. The majority indicated that continuous education by caregivers and healthcare workers and medication supervision are key.

The next chapter will focus on conclusions and recommendations of the study.

CHAPTER FOUR: CONCLUSIONS AND RECOMMENDATIONS

4.1. Introduction

The previous chapter had presented the empirical research findings obtained through a qualitative research approach. The aim of this chapter will be to provide a general summary of the research findings, draw conclusions and make recommendations regarding the barriers to HAART adherence amongst HIV-infected adolescents. In addition, the researcher will articulate to what extent the goal and objectives of the research study have been met. Conclusions drawn from the research study will be discussed. Lastly, recommendations will be put forward for practice and future research according to the themes.

4.2. Summary

The objectives and goal of the study and how they have been met will subsequently be discussed.

4.2.1. Objectives of the study

- To explore and describe the knowledge of HIV-infected adolescents regarding HIV and AIDS and the importance of adherence to HAART.
- To contextualize and conceptualise HAART-adherence amongst adolescents.
- To identify and describe factors contributing to non-adherence to HAART amongst HIV-infected adolescents.
- To identify and describe coping strategies amongst HIV-infected adolescents on HAART.
- To make suggestions on measures to increase HAART-adherence based on the research findings.

4.2.1.1. Objective 1: Knowledge about HIV and AIDS and importance of HAART-adherence

This objective was achieved through an in-depth literature review and empirical research conducted. Literature review revealed that some participants showed knowledge about HIV and AIDS, its transmission, prevention and treatment and myths, while others showed poor knowledge. However, empirical evidence revealed that participants displayed greater knowledge on the above concepts except on the myths of HIV and AIDS. Additionally, literature indicated a significant number of information sources which were attributed towards the knowledge amongst participants. Empirical results also showed that hospital, school,

home, television, radio, teen club, pamphlets and church played a tremendous role towards participants' knowledge on HIV and AIDS and the importance of HAART. In relation to the bio-ecological perspective, especially on the above mentioned sources, some form part of the participants' microsystem, exosystem and macrosystem and all these have played an immense role towards their knowledge. Lastly, literature provided benefits of HAART adherence, numerous methods that are being used to assess adherence and consequences of HAART adherence. The empirical results also showed that participants were knowledgeable of these concepts which were alluded to in the literature.

4.2.1.2. Objective 2: Contextualising and conceptualising of HAART adherence amongst adolescents

This objective was achieved through an in-depth literature review and empirical research. Literature indicates that the emergence of HIV and AIDS has resulted in many children being perinatally-infected. Some died before reaching adolescence, while others survived into adolescence due to the introduction of HAART. The empirical results also concurred with the literature, as many of the participants showed that they started HAART at an early age and have been on it for a lengthier period. Literature further indicated that as HIV-infected adolescents grow older, they gain a greater sense of independence and adherence to HAART becomes a major concern. A significant number of barriers to treatment have been cited. However, empirical results showed that some participants had excellent adherence, while others indicated that medication side effects, forgetfulness, lack of commitment towards treatment and stigma and discrimination were attributed towards their occasional non-adherence.

4.2.1.3. Objective 3: Factors contributing towards non-adherence to HAART amongst HIV-infected adolescents

This objective was also achieved through an in-depth literature review and empirical research conducted. The literature highlighted the following factors which are impediments towards adherence: mental health especially major depression, social stigma, school environment, home environment, numerous individual factors, regimen or medication factors and facility-related factors. On the other hand, the empirical results revealed the following factors which contributed towards non-adherence: individual-factors especially forgetfulness, lack of commitment towards treatment and alcohol intake, medication side effects such as vomiting, drowsiness and pill-burden, social stigma at school, as well as from the community and facility-related factors especially long waiting times, which is attributed towards over-booking or high number of patients and shortage of medical officers. Home-environment, especially lack of medication supervision due to multiple role of caregivers, was mentioned

to by one participant. In terms of the bio-ecological perspective, the above mentioned inhibiting factors towards adherence consist of individual system, microsystem, exosystem, macrosystem and chronosystem. As a result, all these have had a significant role towards non-adherence amongst these HIV-infected adolescents.

4.2.1.4. Objective 4: Coping strategies amongst HIV-infected adolescents on HAART

This objective was also achieved through an in-depth literature review and empirical research conducted. Literature suggested that HIV-infected adolescents utilised different coping strategies such as disclosure of HIV status, family support, support from teen club or peers, support from the hospital, spiritual support and individual factors. The empirical results revealed that disclosure of HIV positive status, family support, support from hospital and various individual strategies, were dominant amongst all participants. Others talked about spiritual support, support from the teen club and support from the school. In relation to bio-ecological perspective, the above-mentioned coping strategies form part of their individual system, microsystem, exosystem and macrosystem and all these help them to cope with treatment adherence.

4.2.1.5. Objective 5: Suggestions on measures to increase HAART-adherence based on the research findings

This objective was achieved through empirical research. The majority of the participants recommended that continuous education by caregivers and healthcare workers on the importance of HAART and medication supervision, are key strategies which could increase HAART-adherence amongst non-adherent HIV-infected adolescents. Furthermore, recommendations for practice, policy, future research as well as those in relation to the identified themes will be explicated more in the chapter.

4.2.2. Goal of the study

The goal of the study has been to identify barriers to HAART-adherence amongst HIV-infected adolescents in a government hospital in Botswana. This goal is achieved through the objectives, which in summary included the following:

The literature review contextualised HIV and AIDS by focusing exclusively on the knowledge of HIV and AIDS and importance of HAART-adherence. The following areas were deliberated: information on HIV and AIDS, its transmission, prevention, treatment and myths, sources of information dissemination, benefits of HAART adherence, methods of assessing adherence and consequences of non-adherence. In addition, HAART-adherence amongst adolescents was contextualised and conceptualised. Furthermore, factors contributing towards non-adherence, as well as coping strategies, were also described and clarified. A

bio-ecological perspective was the theoretical framework which was considered to enhance more understanding on this phenomenon.

From the empirical results, five themes were extracted and each theme had various sub-themes. The first theme was knowledge about HIV and AIDS and importance of HAART-adherence and was divided into eight sub-themes namely: information on HIV and AIDS, transmission, prevention, treatment and myths about HIV and AIDS, sources of information dissemination, benefits of HAART adherence, methods of assessing HAART-adherence and consequences of non-adherence. The second theme was contextualisation and conceptualisation of HAART-adherence amongst adolescents and was divided into three sub-themes namely: perinatal or behavioural infection, treatment adherence and challenges facing adherence.

The third theme was on factors contributing towards non-adherence amongst HIV-infected adolescents and was divided into six sub-themes namely: individual factors, medication or regimen factors, social stigma from school and community, facility-related factors, home environment and mental health. Coping strategies was the fourth theme which came out and was divided into six sub-themes namely: disclosure of HIV and AIDS, family support, support from the hospital, spiritual support, individual strategies, support from the teen club or peers and support from school. The last theme which came out was recommendations and was divided into one sub-theme namely: continuous education on the importance of HAART adherence combined with medication supervision.

4.2.3. Research question

In the context of this study, the following research question was asked:

What are the barriers to HAART adherence amongst HIV-infected adolescents in a government hospital in Botswana?

The data collected from unstructured one-on-one interviews with the participants' revealed themes and sub-themes relating to barriers to HAART-adherence amongst HIV-infected adolescents in a government hospital in Botswana. These themes and sub-themes were discussed comprehensively in chapter three. The research question was demarcated into specific areas which forms part of main themes of the study.

4.3. Conclusions

In the section the conclusions from the research methodology and the literature review will be discussed.

4.3.1. Conclusions from research methodology

This study was qualitative in nature and this approach enabled the researcher to gain an understanding in identifying barriers to HAART adherence from HIV-infected adolescents' point of view. It also enabled the researcher to collect data in the natural setting of these HIV-infected adolescents. Phenomenology was the appropriate research design because the research topic was sensitive. It also enabled the researcher to understand the phenomenon under study on the participants' own terms (what they experienced), in order to provide a description of how they experienced it. Applied research was the suitable type, because it focused on a specific problem in practice, namely barriers to HAART-adherence amongst HIV-infected adolescents in a government hospital in Botswana. The research findings will assist healthcare workers, caregivers, teachers and other relevant stakeholders, to have an in-depth understanding of barriers to HAART-adherence amongst HIV-infected adolescents. Probability simple random sampling was utilised to select study participants.

The researcher utilised unstructured one-on-one interviews with an assistance of an interview schedule (attached as **Appendix H**), because the research topic is sensitive. This technique accorded the researcher an opportunity to collect first-hand information from participants. It also enabled the researcher to understand the experiences of participants and the meaning they make with regards to barriers to HAART-adherence. In addition, all interviews were captured using a digital voice recorder. All these made data collection manageable. In addition, the recording of the interviews made the transcriptions easier. This helped the researcher to become familiar with the content of each interview, as well as in identifying themes and sub themes which came out.

Data was thematically analysed using Tesch's framework. Verbatim transcriptions were done for all twelve interviews that were conducted in Setswana, whereafter they were transcribed and translated into English. The researcher went through all the interview transcripts and made notes in the margins. The categories which emerged were labelled accordingly and themes and sub-themes were derived. The researcher developed a preliminary table that sets up the main themes and sub-themes which were used during discussions and analysis. Credibility, transferability, dependability and conformability as constructs were considered to establish trustworthiness of data, including strategies such as member checking, peer debriefing and reflexivity that were utilised. Lastly, all ethical considerations were adhered to throughout the study. It can be concluded that the indeed the research approach, design, type, data collection methods and data analysis framework used were appropriate to produce these findings.

4.3.2. Conclusions from literature study

The theoretical framework which was appropriate to enhance more understanding on this phenomenon was the bio-ecological perspective, because it examines the complex interactions and relationships between an individual and his or her multiple social and physical surroundings. It allowed the researcher to examine how complex interactions and relationships between HIV-infected adolescents on HAART and their multiple social and physical surroundings play a significant role towards adherence to HAART medication. The Bio-ecological perspective consists of systems being individual systems or organisms, microsystem, mesosystem, exosystem, macrosystem and chronosystem. All these systems are in constant interaction with one another and together they shape the human development. It became evident in the analysis that participants displayed adequate knowledge with regards to HIV and AIDS and HAART adherence. The knowledge was attributed to different sources of information which the participants have interacted with. The bio-ecological perspective enabled the researcher to match these information sources with the above mentioned systems and the role they played in equipping the participants with information. The same applied to the identified barriers to HAART adherence and coping strategies. Therefore, it can be concluded that bio-ecological perspective is an approach that was successfully used to understand the relationship between individuals and their environment.

The literature study has shown that in 2012, there were about 2.1 million adolescents aged between 10-19 years, living with HIV and AIDS worldwide and about 1.5 million of them resided in sub-Saharan Africa. The introduction of Highly Active Antiretroviral Therapy has led to improved growth and development and delayed mortality and improved morbidity amongst HIV-infected adolescents. Nonetheless, adolescence is a complex developmental stage and these complexities have affected adolescents from maintaining a sound HAART-adherence. Literature cited that mental health, social stigma, home environment, facility-related factors, regimen or medication factors, school environment and individual factors were the main barriers to HAART-adherence. On the contrary, literature revealed the following strategies that are being utilised by some adolescents to cope with treatment adherence and being HIV positive: disclosure of HIV positive status, personal strategies, support from family, peers, community, school and hospital and spiritual support. It can be concluded that indeed adolescents are faced with direct and indirect challenges to maintain high levels of HAART-adherence, although there are strategies which can be utilised to alleviate or eliminate this problem. It can be concluded that the literature study conducted was relevant and appropriate to the subject that was being investigated.

Subsequently the conclusions regarding the empirical findings will be presented according to the key findings and the conclusions and recommendations of each theme.

4.4. Key findings, conclusions and recommendations from the empirical study

The key findings, conclusions and recommendations from each theme in the findings will now be discussed.

Table 4.1 provides an overview of the themes and sub-themes that emerged from the empirical results.

Table 4.1: Themes and sub-themes

Themes	Sub-themes
Knowledge about HIV and AIDS and importance of HAART-adherence	<ul style="list-style-type: none"> • HIV and AIDS • Transmission of HIV and AIDS • Prevention of HIV and AIDS • HIV treatment and adolescents; myths about HIV and AIDS • Sources of information dissemination on HIV and AIDS • Benefits of HAART-adherence • Methods of assessing adherence • Consequences of non-adherence
Contextualising and conceptualising HAART adherence	<ul style="list-style-type: none"> • Perinatal and behavioural infection • Medication adherence • Challenges regarding medication adherence
Factors contributing towards non-adherence to HAART amongst HIV-infected adolescents	<ul style="list-style-type: none"> • Individual factors • Social stigma from school and community • Regimen factors • Facility-related factors • Home environment

	<ul style="list-style-type: none"> • Mental health
Coping strategies	<ul style="list-style-type: none"> • Disclosure of HIV positive status • Support from the family or relatives • Teen club or peer support • Support from the hospital • Spiritual support • Individual strategies • Support from school
Recommendations	<ul style="list-style-type: none"> • Continuous education on HAART-adherence combined with medication supervision are key

Recommendations for the research findings according to each theme will be discussed.

4.4.1. Theme 1: Knowledge about HIV and AIDS and importance of HAART adherence

This theme concentrated mainly on finding out the knowledge of participants about HIV and AIDS and importance of HAART-adherence.

4.4.1.1. Key findings

The participants were able to define both HIV and AIDS. They also revealed different routes of HIV transmission which included: unprotected sexual intercourse, mother-to-child transmission of HIV during pregnancy, birth and breast feeding, sharing unsterile sharp objects particularly razor blades, as well as engaging in multiple sexual partnerships. However, condom usage, enrolment of HIV-infected pregnant mothers on PMTCT programme, importance of HIV and AIDS testing and avoidance of multiple partners were the main prevention strategies. With regards to abstinence, some suggested that nowadays young people are failing to practice it, hence there is high teenage pregnancy in schools. As a result, they are susceptible to contract HIV and AIDS.

Furthermore, participants showed that there is no cure for HIV and AIDS, therefore treatment adherence is key. Although, some participants cited incidents of skipping their HAART due to various reasons such as forgetfulness, medication side effects, laziness and lack of commitment towards treatment. Moreover, all of them knew the names of their prescribed HAART. With regards to myths of HIV and AIDS, the majority showed poor knowledge.

Moreover, hospital, school, home, television, radio, teen club, pamphlets and church were alluded to as the main sources of information about HIV and AIDS. In addition, increased CD4 cell count and decreased viral load which prolongs one's life were the cited benefits of HAART-adherence. On the other hand, laboratory tests, pill count and self or caregiver reports, were the main methods used to assess participants' adherence. Last of all, participants indicated that decreased CD4 count cells, increased viral load and death will be the end results of non-adherence to HAART.

4.4.1.2. Conclusions

It can be concluded that participants were knowledgeable of HIV and AIDS and the importance of HAART-adherence. Although, a significant number of participants showed inadequate knowledge regarding myths of HIV and AIDS. In addition, it can be concluded that in terms of prevention, abstinence is still a challenge amongst young people and requires more attention. With regards to the bio-ecological perspective, it can be concluded that the above mentioned sources of information dissemination formed part of the participants' microsystem, exosystem, mesosystem and macrosystem. These systems have played a significant role towards the knowledge displayed by participants regarding HIV and AIDS and the importance of HAART-adherence.

4.4.1.3. Recommendations

- The information around myths of HIV and AIDS may seem outdated, but the researcher recommends that it is imperative to impart it to the adolescents, so that they are able to make informed decisions without the influence of any false information.
- Campaigns around abstinence amongst the youth should be reinforced by all relevant stakeholders such as school authorities, health facilities, churches, parents, community leaders and non-governmental organisations which deal with adolescents or youth health issues.

4.4.2. Theme 2: Contextualising and conceptualising of HAART-adherence amongst adolescents

This theme put into perspective HAART adherence amongst HIV-infected adolescents.

4.4.2.1. Key findings

The findings showed that a significant number of participants started ARV's at an early age, which contributed to their survival. The findings further indicated that a significant number of participants reported satisfactory adherence, while others mentioned incidents of skipping their HIV medication. Some participants reported medication side-effects such as vomiting,

forgetfulness and weird dreams, which they experienced for a short period, although they did not stop taking their medication. On the contrary, other participants highlighted the following reasons for their occasional non-adherence: medication side effects, forgetfulness or lack of commitment towards the medication, as well as stigma.

4.4.2.2. Conclusions

It can be concluded that a significant number of participants were perinatally-infected, compared to those who were behaviourally-infected and all have been on treatment. However, it still is evident that there are some incidents of non-adherence to HIV medication amongst HIV-infected adolescents. In relation to the bio-ecological perspective it was evident from the findings that there were factors which contributed towards some of the participants' non-adherence within the individual system, macrosystem and chronosystem. However, for some participants, it was clear that their interaction with these systems did not deter them from achieving sound adherence.

4.4.2.3. Recommendations

- The research findings showed that the majority of participants may have been perinatally-infected. With the introduction of PMTCT, a strong collaboration amongst all stakeholders is needed to educate the public at large on the importance of this programme in curbing or eliminating the number of children who are born HIV-infected. A similar approach is also needed to target teenagers and young people who normally contract HIV and AIDS behaviourally.
- With regards to non-adherence to treatment amongst HIV-infected adolescents, it is recommended that health facilities and the Ministry of Health, Botswana should review existing strategies which are meant to fight HAART non-adherence and strategies which are ineffective must be strengthened.

4.4.3. Theme 3: Factors contributing towards non-adherence amongst HIV-infected adolescents

This theme looked at various factors which have contributed towards non-adherence to HAART amongst HIV-infected adolescents.

4.4.3.1. Key findings

The findings show that there are a number of factors which contribute towards non-adherence amongst some of the participants. On the other hand, some of the participants talked about factors which they observed from their friends who are HIV-infected. Individual-related factors mainly forgetfulness, lack of commitment towards treatment and alcohol

intake, were the most prominent inhibiting factors revealed. Additionally, other participants cited the following medication side effects as contributory towards non-adherence: vomiting, developing a rash, drowsiness and pill burden. Social stigma from school environment and community was also a factor which was dominant. Furthermore, other participants mentioned long waiting time as a major facility-related factor, which could demoralise HIV-infected adolescents from coming for their refills, more so that many of them are learners and do not want to fall behind in their school work.

Home environment especially multiple roles that are facing caregivers, was another factor, because the medication supervision role was not fulfilled. Moreover, literature indicated that HIV-infected adolescents are susceptible towards developing mental illnesses, especially major depression and anxiety (mental health issues) and these could contribute towards non-adherence. Nonetheless, a significant number of participants indicated feelings of sadness when they were disclosed their status, but the sadness did not deter them from adhering correctly.

4.4.3.2. Conclusions

It can be concluded that there are direct and indirect factors which contributed towards non-adherence amongst HIV-infected adolescents. Lastly, literature concluded that mental illness especially major depression and anxiety, have been major factors towards non-adherence to HAART amongst HIV-infected adolescents. However, it can be concluded that, though it came out in the findings, it did not deter participants from adhering to treatment. In terms of the bio-ecological perspective, the above mentioned inhibiting factors toward adherence, consists of the individual system, microsystem, exosystem, macrosystem and chronosystem. It can be concluded that all these systems have had a significant role towards non-adherence amongst these HIV-infected adolescents.

4.4.3.3. Recommendations

- Medication side-effects is a major issue towards non-adherence, therefore the response by healthcare workers in addressing medication side effects need to be strengthened.
- In order to reduce long waiting times during medication refills, permission must be obtained from patients and their caregivers to refill at their nearest health facilities.
- To reduce medication non-adherence and stigma, HIV-infected persons who have been on treatment for a lengthier period should hold motivational talks in schools, hospitals and community places such as *kgotla*.

4.4.4. Theme 4: Coping strategies

This theme examined different strategies that are being utilised by HIV-infected adolescents to cope with HAART as well as being HIV-infected.

4.4.4.1. Key findings

The findings showed that participants utilised different strategies to cope with being HIV-infected as well as the HIV medication. The coping strategies which were dominant were disclosure of HIV positive status, support from family or relatives and support from the hospital. There were numerous individual coping strategies which were utilised: alarm clock or alarm on the cell phone, wrist or wall watch, dependant on caregivers, certain television programmes such as news, study timetable, accepting oneself and keeping quiet about one's HIV status.

Furthermore, few participants mentioned teen clubs as a major source of support, because it gives them a sense of belonging, hope, education as well as interaction with other children who are living with HIV and AIDS. Other participants alluded that their strength comes from spiritual support. Lastly, support from school was another coping strategy mentioned, although the majority indicated that their friends or school management do not know about their status, to avoid being stigmatised or discriminated.

4.4.4.2. Conclusions

It can be concluded that despite challenges with regards to adherence, there are strategies that a number of HIV-infected adolescents are utilising to cope. It can also be concluded that stigma and discrimination in schools is still a major problem. In relation to bio-ecological perspective, it can be concluded that the above-mentioned coping strategies formed part of their individual system, microsystem, exosystem and macrosystem and all these helped them to cope with treatment adherence.

4.4.4.3. Recommendations

Structures should be put in place in schools to tackle stigma and discrimination. In addition, disciplinary actions must be taken against students or teachers who discriminate against HIV-infected learners.

4.4.5. Theme 5. Recommendations

This theme mainly solicited suggestions from the participants on measures to increase HAART-adherence amongst HIV-infected adolescents who are non-adherent.

4.4.5.1. Key findings

The majority of the participants indicated that continuous education by caregivers and healthcare workers, as well as medication supervision are key.

4.4.5.2. Conclusions

It can be concluded that caregivers and healthcare workers can play an enormous role towards education and medication supervision in the effort to eliminate or address non-adherence to HAART amongst HIV-infected adolescents. In relation to the bio-ecological perspective, these two forms of support are regarded as the microsystem and exosystem of the participants. Therefore, it can be concluded that they are of importance with regards to sound adherence.

4.5. Recommendations

Subsequently the recommendations for future research and policy will be made.

4.5.1. Recommendations for future research

- The researcher discovered that there were instances whereby some of the participants were not truthful about their non-adherence, unless probed further. Therefore, the researcher recommends that future research should not concentrate on adolescents only, instead healthcare workers and caregivers should be included, to strengthen the findings.
- The research findings showed that significant progress has been made to eliminate various impediments towards HAART adherence. However, it is recommended that future research should look at the effectiveness of factors that promote adherence.

4.5.2. Recommendations for policy

- The findings showed that a significant number of participants take two pills a day, because the majority started treatment at an early age, before the introduction of one pill fixed-dose. The researcher recommends that the Botswana National HIV and AIDS guidelines on HIV should be amended so that these patients can be switched to one pill fixed-dose when possible in the context of their treatment regimen.
- The findings showed that there was low number of participants who are part of the teen club. The researcher recommends that protocols must be put in place, to enable many HIV-infected adolescents to access this important initiative that has been tailored for them.

4.6. Concluding remarks

HIV-infected adolescents on HAART are still facing direct and indirect challenges to maintain sound adherence. Much still needs to be done especially to address individual-related factors, social stigma and regimen or medication side-effects, which are the main contributors of non-adherence. A strong collaboration between relevant stakeholders such as healthcare workers, teachers, caregivers, non-governmental organisations and different religious institutions is imperative to eliminate these barriers. Lastly, support structures that are tailored for HIV-infected adolescents on HAART are also vital.

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