



**UNIVERSITY of the
WESTERN CAPE**

**ADOLESCENTS' PERCEPTIONS AND EXPERIENCES OF ANTI RETROVIRAL
THERAPY (ART) AT A TERTIARY HOSPITAL IN FRANCISTOWN, BOTSWANA**

By

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Supervisor: Dr. Jo-Celene De Jongh

KEY WORDS

Adolescents' perceptions and experiences of anti-retroviral therapy (ART) at a tertiary hospital in Francistown, Botswana

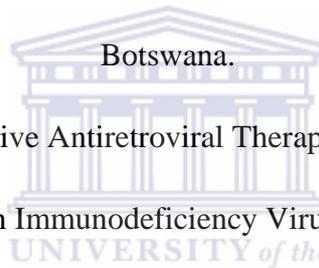
Acquired Immunodeficiency Syndrome (AIDS)

Adherence/Compliance

Anti-retroviral (ARV)

Anti-Retroviral Therapy (ART)

Adolescents



Highly Active Antiretroviral Therapy (HAART)

Human Immunodeficiency Virus (HIV)

Health Belief Model (HBM)

ABSTRACT

Botswana is experiencing high levels of HIV prevalence rate at 16.9% among the general population, 4.5% among adolescents aged 10-14 and 4.7% among adolescents aged 14-19. Adolescents are in a critically stage between childhood and adulthood and undergo a lot of developmental changes physically, psychologically and emotionally. The scourge of HIV/AIDS has also brought with it multiple challenges to adolescents as those who are HIV positive have to adhere to all the health requirements of being HIV positive and at the same time being pressurised by the societal expectations. Stigmatisation and discrimination are experienced as barriers against the fight towards HIV which is seen a major factor among adolescents. The aim of the study was to explore and describe adolescents' perceptions and experiences of anti-retroviral therapy at a tertiary hospital in Francistown, Botswana. The study followed a qualitative research approach with an exploratory descriptive research design. Purposive sampling was used to recruit participants. Participants were school going adolescents aged between 13 and 19 years, who are on antiretroviral therapy and going for reviews at a tertiary hospital in Francistown, Botswana. Data were gathered through face to face semi structured interviews with each of the 24 participants. Data were analysed thematically. The following four themes emerged during the analysis: i. "ARVs control but don't cure"; ii. "Why did it happen to me?-the reality of using ARVs"; iii. "I don't want to take them for the rest of my life"; and iv. "No man is an island", which addressed the research objectives. The findings led to the conclusion that, despite the fact that HIV has been around for over two decades and ARVs has been around for more than a decade, adolescents living with HIV still faces challenges such as stigmatisation due to social as well as clinical factors and adjusting to a lifelong treatment which made it difficult for them to adhere to their treatment. However, adolescents are happy as they are living a healthy and a fruitful life as a result of the ARVs. Ethical considerations were adhered too. Furthermore the findings of the study could assist the

Ministries of Health, Education, Local Government and Rural Development to address these challenges experienced by the adolescents in the development of social programmes to improve the livelihood of the adolescents living with HIV/AIDS.



CANDIDATE DECLARATION

I hereby declare that the thesis entitled, adolescents' perceptions and experiences of anti-retroviral therapy (ART) at a tertiary hospital in Francistown, Botswana is a result of my own research. I declare that all sources have been acknowledged and that this work has not been submitted for any other degree at any other university.

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Signed 
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Date: 16 November 2015

LIST OF ABBREVIATIONS

\leq	Greater than, less than or equal to
AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-retroviral
ARVs	Anti-retrovirals
ART	Anti-Retroviral Therapy
BAIS IV	Botswana AIDS Impact Survey IV
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HBM	Health Belief Model
IDCC	Infectious Disease Control Centre
μL	Millilitre
NACA	National AIDS Coordinating Agency
N. D	No date
PLWHA	People Living With HIV/AIDS
SCT	Social Cognitive Theory
SLT	Social Learning Theory
S-R	Stimulus Response
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

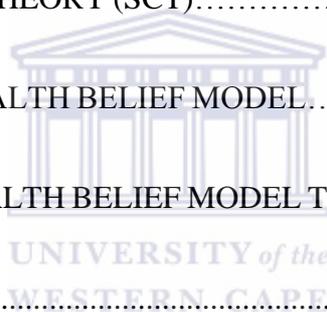
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This work is dedicated to the following people, my husband Tumisang Albert Kebuang who has been supportive throughout the journey of my postgraduate studies. My mother, Elia Ketshwantsitse, I am sincerely grateful to her as she took care of my baby Quinton Leatile Kebuang as young as three weeks old when I had to leave him in Botswana to study in Cape Town, South Africa. My late sister, for always believing in me from a young age. My mother in law and father in law for the continuous support that they have shown me throughout this journey. My siblings, my sisters and brother in law I am very grateful for the motivation that you gave me when the journey was getting tougher. I am sincerely grateful to the adolescents on ART at the tertiary hospital in Francistown, Botswana as well as their parents and guardians who agreed to take part in this study. Without them this study could not have been a success. The tertiary hospital IDCC staff members, they treated me like a fulltime staff member and therefore made the process of data collecting interesting. Mrs. Masego Lecha, a Social Worker at the tertiary hospital, a friend, and a motivator. When the journey seemed to be too long, she made it look shorter through her words of motivation. She gave me courage to persevere. Most importantly, my supervisor Dr. Jo-Celene de Jongh. She took me through the journey of the research proposal from an infancy stage, to a stage where I can call myself a researcher, completing the full thesis. Her patience and dedication in assisting me was very overwhelming and it motivated me to push hard even in difficult times. W.K. Kellogg Foundation who supported me financially is exclusively appreciated. Lastly, to God all might for the strength and guidance throughout this whole process.

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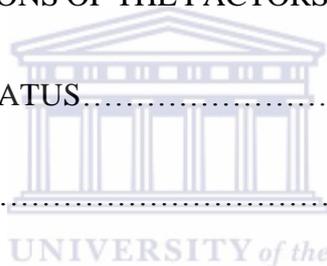
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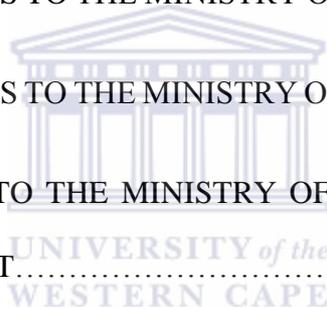
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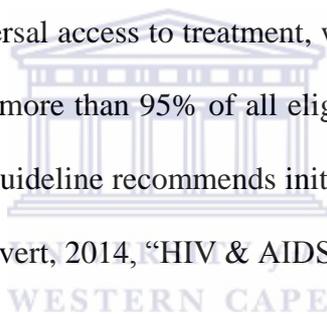
CHAPTER 1

1. INTRODUCTION

At its start, the Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) epidemic was accompanied by fear, ignorance, and denial leading to stigmatisation and discrimination against people living with HIV/AIDS and their family members (International Centre for Research on Women as cited in Letamo, 2004, p. 191). Sub-Saharan Africa is highly affected by Human Immunodeficiency Virus (HIV). In 2010, about 68% of all people living with HIV resided in Sub-Sahara, however, the region constitutes only 12% of the world's population (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2011). Botswana is one country in the Sub-Saharan region which has experienced a high percentage of people living with HIV and AIDS. Botswana AIDS Impact Survey IV (BIAS IV) estimated a national prevalence rate of 16.9% and an incident rate of 2.47 for population aged six weeks and over in Botswana (Statistics Botswana, 2013). It is further stated that the prevalence rate for the age group of 18 months to 64 years is estimated at 19.03%, compared to 17.6% realised in the 2008 BIAS III for the same age group. Prevalence is estimated at 4.5% for the age group 10-14 years, compared to 3.5% found in BIAS III and 4.7% among adolescents aged 15-19 compared to 3.7% among the same group in BIAS III (Central Statistics Office, 2014).

In 2012, an estimated 2.1 million adolescents (10-19 years) were living with HIV in low and middle income countries (UNAIDS, 2013); however, new infections are now declining worldwide as more people receive HIV treatment. In 2012, 9.7 million people in low and middle income countries received HIV treatment, representing 61% of all people who were

eligible under the 2010 WHO HIV treatment guideline and 34% (32%-37%) of the 28.6 million people eligible, using the 2013 WHO HIV treatment guideline (UNAIDS, 2013). High income countries had 875 000 eligible people who were receiving ARVs, making a total of 10.6 million people receiving ARVs as of December 2012 (UNAIDS, 2013). Between 2009 and 2010, antiretroviral coverage increased by 20% in Sub-Saharan Africa (UNAIDS 2011). New infections and AIDS-related deaths declined. The decline was achieved as a result of recognisable political agreement on the impact of the AIDS epidemic, which included among others the 2001 Declaration of Commitment on HIV/AIDS and the 2006 Political Declaration of HIV/AIDS which endorsed the goal of universal access to HIV prevention, treatment, care and support. This led to Botswana, Namibia and Swaziland implementing the declaration and thus they have achieved the universal access to treatment, which is defined as 80% or greater of ART coverage. Botswana has more than 95% of all eligible adults and children receiving treatment and its national AIDS guideline recommends initiation to HAART to people with a CD4 count of ≤ 350 cells/mm³, (Avert, 2014, "HIV & AIDS treatment in Botswana". Para 26)



As a Social Worker working in a hospital context, I first worked in a primary hospital for a year and half and thereafter in a tertiary hospital for four and half years. The tertiary hospital mainly operates as a referral hospital for the whole northern part of Botswana. I originally worked on a part-time basis in the Infectious Disease Control Centre (IDCC) which accommodates people living with HIV and AIDS (PLWHA) and their families. Since April 2013, I have been working as a fulltime Social Worker for the centre, doing intervention with adolescents from the paediatric as well as the adult clinics. Children with good adherence backgrounds were transferred to the adult clinic upon reaching 13 years of age. However, those with a poor adherence history remained in the paediatric clinic until their adherence was satisfactory, even if they were at an adolescent stage.

1.1 RATIONALE FOR THE STUDY

Increased availability of antiretroviral therapy in Sub-Saharan Africa has enabled a number of children who were perinatally infected with HIV/AIDS, to reach the adolescent stage. However, despite the fact that ARVs give PLWHA the ability to live longer, there are several barriers to the utilisation of care leading to suboptimal effectiveness of available treatment, such as shortage of staff to manage the antiretrovirals, delays in initiating HAART among HIV positive patients which lead to death, and at times drug shortage, particularly in Africa (Morolake, Stephens and Welbourn, 2009). Stigmatisation from neighbours, families and spouses have been identified in reducing the coping mechanisms of PLWHAs. Adolescents are no exception to stigmatisation which reduces their effectiveness in ARV programmes, thus leading to poor adherence to ART (Kitaka, Barungi, Nostlinger, Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, and Colebunders, 2008; Mutwa, Van Nuil, Asiimwe-Kateera, Kestelyn, Vyankandondera, and Geelen, 2013; Ndiaye, 2014; Rao, Kekwaletswe, Hosek, Martinez, and Rodriguez, 2007). Worth noting is that most of these adolescents are still going to school. In a study conducted in Uganda among adolescents who were perinatally infected with HIV, 70% were still attending school and those not at school were older adolescents. School-going adolescents on ART experienced self-imposed stigma from their school mates as well as from their teachers (Birungi, Obare, Katahoire and Kibenge, 2011). According to literature, adolescents need special attention and intensified formal support for them to be in a position to adhere correctly to the prescribed medication from parents, peers, and health care workers as well as from the educational sector (Birungi et al., 2011; Mutwa et al., 2013). From my experience working in a hospital, the Infectious Disease Control Centre (IDCC), we experienced high numbers of adolescents defaulting treatment and others failing in their regimen. They gave various reasons as to why they defaulted, ranging from psychosocial aspects to financial aspects. Even though most of them seemed to have adequate understanding

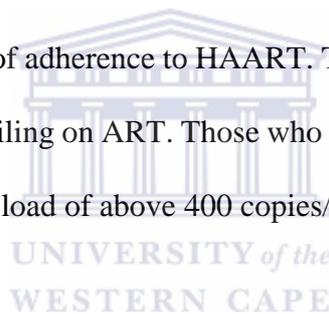
of ART, they still did not adhere to treatment. It is for this reason that I found it vital to do this study at the tertiary hospital in Francistown, Botswana so as to explore and describe the adolescents' perceptions and experiences of antiretroviral therapy. This study will yield valuable information in terms of understanding adolescents' perceptions and experiences of ART at a tertiary hospital in Francistown, Botswana. The information gathered will be used to make recommendations to the IDCC, Ministry of Education and Ministry of Health as well as the Ministry of Local Government and Rural Development, as to how to work with, and assist adolescents on ART.

1.2 THEORETICAL FRAMEWORK

The study is rooted in the Health Belief Model (HBM). Becker and Rosenstock (as cited in Turner, Hunt, DiBrezzo and Jones, 2004, p.116) noted that the HBM is a conceptual framework used to understand health behaviour and find explanations of why people do not comply with recommended health action. The model was used to explore and describe adolescents' perceptions and experiences of ART in a tertiary hospital in Francistown, Botswana. The application of the HBM assisted the researcher to gain new insight as well as broaden the understanding of adolescents' perceptions and experiences of using ART, following the six constructs, as discussed by Glanz, Rimmer and Viswanath (2008), of perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and perceived self-efficacy.

1.3 PROBLEM STATEMENT

The Infectious Disease Control Centre (IDCC) is an outpatient clinic caring for HIV positive people. It attends to people of all ages. The clinic has different types of specialised clinics. It has the paediatric clinic which cares for children from infancy to 12 years old, the adolescent clinic which is relatively new (started during 2014) and caters for adolescents aged 13 to 21 years and the adult clinic which cares for patients above 21 years of age. It also has two special clinics, one being the paediatric failure clinic which cares for all children below the age of 13 years who are failing ARVs, and one for adolescents above 13 years of age who would have been failing HAART when below the age of thirteen, treated in the clinic but who have not yet improved. Such adolescents are transferred to the adolescent clinic or the adult clinic when they show signs of improvement of adherence to HAART. There is also the adult failure clinic which caters for adults who are failing on ART. Those who are not responding to treatment are those who have a detectable viral load of above 400 copies/ml.



According to the clinic's statistics report of 13 February 2015, the department caters for a total number of 5104 patients (Nyangabgwe hospital IDCC, 2015a). 360 of them are aged between births to 9 years, 775 are aged 10 years to 19 years and 3969 are aged above 19 years. The department attends to about 72 adolescents per month aged 13 years to 19 years (Nyangabgwe hospital IDCC, 2015c). The IDCC monitoring and evaluation report of 30 January 2015, indicates that there were 41 children aged between birth and 19 years seen at the paediatric failure clinic (Nyangabgwe Hospital IDCC, 2015b). According to the nurse who covers the failure paediatric clinic, the failure is ascribed to poor adherence to medication as well as poor or lack of monitoring and supervision by parents or guardians.

From my experience of working in the tertiary hospital in Francistown, Botswana, I have learnt from doing monthly reviews of patients who were referred to the Social Work department for adherence counselling, and other social issues such as behavioural challenges among adolescents, that adolescents do not use ARVs as prescribed. Most of them report fear of stigmatisation and discrimination from their peers whilst others report lack of privacy to store and use their medication. Lack of privacy to store and use ARVs is mostly experienced by adolescents in institutions such as boarding schools, (Birungi et al., 2011; Mutwa et al., 2013). Poor or lack of monitoring and supervision were also identified in the monthly reviews of adolescents on ART as factors causing adolescents not to use their ARVS. Some of these adolescents would have been using their medication whilst very young under strict supervision of parents and guardians, but when given responsibility to act on their own, they do not take the medication. I noticed that this had a negative effect on their health as they usually fail in their regimen which then leads to frequent hospital visits for monitoring purposes thus spending a lot of their time in the hospital. Therefore, this study addressed the following research question: What are adolescents' perceptions and experiences of anti-retroviral therapy at a tertiary hospital in Francistown, Botswana?

1.4 RESEARCH SUB-QUESTIONS

- i. What are adolescents understanding of ART?
- ii. What are adolescents' experiences of using ARVs?
- iii. What are adolescents' perceptions of the factors related to their use of ARV?
- iv. What support is needed by adolescent on ART?

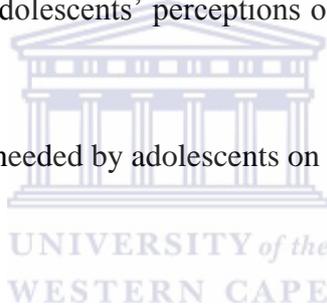
1.5 AIM OF THE STUDY

The aim of the study was to explore and describe adolescents' perceptions and experiences of antiretroviral therapy at a tertiary hospital in Francistown, Botswana.

1.6 OBJECTIVES

The objectives of the study were:

- i. To explore and describe adolescents' understanding of ARV therapy.
- ii. To explore and describe adolescents' experiences of using ARVs.
- iii. To explore and describe adolescents' perceptions of the factors related to their use of ARVs.
- iv. To determine the support needed by adolescents on ART.



1.8 SIGNIFICANCE OF THE STUDY

Several studies have been done amongst adolescents in Botswana; however, most of them were focused on adherence to ARVs. To mention but a few are Do, Phiri, Bussmann, Gaolathe, Marlink and Wester (2010); Kambale (2013); Ndiaye, Nguyen, Lowental, Gross, Mills and Nachenga (2013) and Weiser et al. (2003). This study therefore explored and described adolescents' perceptions and experiences of ART at a tertiary hospital in Francistown, Botswana. It is envisaged that the findings of the study could assist health care service providers to address identified gaps in service provision for adolescents on ART. Furthermore, the findings of the study can assist health care providers with strategies to deal with the barriers to ART experienced by adolescents, hence improving adherence. The findings of the study

could assist the Ministry of Education with guidelines to develop programmes that could be useful for adolescents at school, or those within their care, for optimal use of antiretroviral therapy. Lastly the findings of the study could inform the educational sector when developing HIV/AIDS policies for schools.

1.9 DEFINITION OF TERMS

Acquired Immunodeficiency Syndrome (AIDS): An advanced stage of infection with the human immunodeficiency virus (HIV) (Venes, 2013).

Adolescents: for this study, the term adolescents will be used to refer to people between the ages of 13 and 19, as defined by Baylor Centre of excellence in Botswana (Ndiaye, 2014).

Antiretroviral (ARV): An agent that acts against retroviruses such as HIV, (Venes, 2013).

Antiretroviral Therapy (ART): refers to the main type of treatment for HIV or AIDS. ART consists of the combination of at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of the HIV disease (World health Organisation, 2015, “Antiretroviral therapy”, para1)

Adherence: This is the preferred term today and is based on the therapeutic alliance between the patient and the physician and refers to responsibilities on both sides. World Health Organisation (WHO), defines adherence as: “The extent to which a person’s behaviour taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (Matthes and Albus, 2014).

Compliance: The process of complying with a regimen of treatment, (Merriam-Webster, 2015, “Compliance”, para1)

Experience: knowledge resulting from actual observation or from what one has undergone, (Simpson and Weiner, 2004).

Form: in Botswana, the term form is used to refer to a grade in secondary school. Free dictionary (n.d) defines form as a grade in a British secondary school or in some American private schools.

Health Belief Model (HBM): is a model used to predict health-related behaviour in terms of certain belief patterns (Glanz et al., 2008).

Highly Active Antiretroviral Therapy (HAART): is used to describe a combination of three or more anti-HIV drugs, (Foundcare, 2014 “what is combination therapy, what is HAART?”para 3)

Human Immunodeficiency Virus (HIV): refers to any of several retroviruses, and especially HIV-1, that infect and destroy the helper T cells of the immune system, causing a marked reduction in their numbers, which is a diagnostic of AIDS, (Merriam-Webster, 2015, “HIV”, para1”)

Perception: is a person’s primary form of cognitive contact with the world around him/her (Efron, 1969).

People Living with HIV/AIDS (PLWHA): refers to people infected with HIV/AIDS (Mushayabasa, 2014).

Seed bags: in this study, seed bag is a term used to refer to the plastic medicine envelopes that are used to dispense tablets in pharmacies and hospitals.

1.10 OVERVIEW OF CHAPTERS

Chapter One introduces the reader to the study on adolescents' perceptions and experiences of anti-retroviral therapy (ART) at a tertiary hospital in Francistown, Botswana. The chapter will give the rationale of the study, the study problem as well as the significance of the study. It will also look at the research questions, aims, objectives and definitions.

Chapter Two provides a theoretical framework of the study. The first part is aimed at presenting the Stimulus-Response (S-R) and Cognitive theories that the Health Belief Model (HBM) is derived from, as the HBM is the one used to frame this study. The second part of the chapter discusses the HBM theory and how it is applied in the study.

Chapter Three presents an overview of the literature and secondary data in relation to HIV and adolescents on ART to support and argue the study.

Chapter Four presents the research design, research approach, the research setting and data collection method as well as the analysis of the data. The study employed a qualitative approach with an exploratory descriptive design so as to achieve the objectives and the aim of the study. Thematic analysis was used to analyse the data.

Chapter Five presents the findings of the study and the common themes that were extracted from the data and the findings under each theme as a means to illustrate the experience and perceptions of adolescents on ART at a tertiary hospital in Francistown, Botswana.

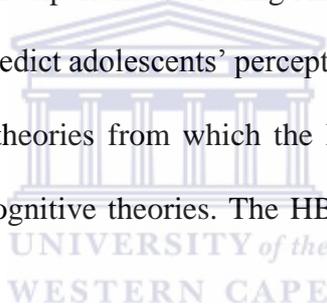
Chapter Six is a discussion of the findings, conclusion and recommendations made to various stakeholders. Furthermore, in this chapter the findings are linked to the secondary data from literature review as well as the theoretical framework.

CHAPTER 2

THEORETICAL FRAMEWORK

2.1 INTRODUCTION

This chapter discusses the theoretical concept that guides this study. Barker (2003) in De Vos, Strydom, Fouche and Delpont (2011) defines a theory as a set of interrelated hypotheses, concepts, constructs, definitions and propositions that present a systematic view of phenomena based on facts and observations, with the purpose of explaining and predicting the phenomena. The purpose of this chapter is to develop a theoretical understanding of adolescents on ARVs, how they perceive ARVs and their experiences of using ARVs. The Health Belief Model was used in the study to explain and predict adolescents' perceptions and experiences of ART. This chapter starts by presenting the theories from which the HBM was derived, which are the stimulus response theories and cognitive theories. The HBM is then presented in detail and applied to the study.



2.2 HEALTH BELIEF MODEL (HBM)

The HBM is a conceptual framework used to explain change and maintenance of health-related behaviour as well as for guiding health behaviour interventions in health behaviour research (Champion and Skinner, 2008, p.45). The HBM was developed in the 1950s by social psychologists who were trying to understand behaviours that grew from social learning theories, derived from two major sources: stimulus-response (S-R) theory (Hull; Thorndike; Watson, as cited in Rosenstock, Strecher and Becker, 1994, p.6)) and cognitive theory (Kohler;

Lewin; Lewin, Dembo, Festinger and Sears; Tolman, as cited in Rosenstock, Strecher and Becker, 1994, p.6).

2.3 STIMULUS RESPONSE (S-R) THEORY

There is no single S-R theory, but a cluster of theories resembling each other yet possessing distinctive qualities (Hall and Lindzey, 1970). According to Hall and Lindzey (1970, p. 417), the S-R theory is mainly concerned with the process whereby the individual mediates between an array of responses and the tremendous variety of stimulation (internal and external) to which he or she is exposed. The development of S-R theory was contributed to by Ivan Pavlov, John B. Watson and Edward L. Thorndike (Hall & Lindzey, 1978). The S-R theorists believe that learning results from events (reinforcements) which reduce physiological drives that activate behaviour (Rosenstock et al., 1994). Pavlov (as cited in Hall and Lindzey, 1970, p. 418) discovered a type of learning known as classical conditioning. Hall and Lindzey, (1970) argued that Pavlov demonstrated that through classic conditioning, the simultaneous presentation of an unconditioned stimulus and a conditioned stimulus, the conditioned stimulus will eventually elicit a response that originally could be elicited by the unconditioned stimulus. On the other hand, Watson (as cited in Hall and Lindzey, 1970, p. 418) proposed that psychology should study behaviour as other natural sciences, using the same types of objective techniques. He moved away from Pavlov's principle of conditioning and introduced a position of behaviourism (Hall and Lindzey, 1970). Behaviourism is an approach in psychology based on the assumption that behaviour can be researched scientifically without recourse to inner mental states (Cullata, 2011). Cullata (2011) noted that the behaviourist thought is that free will is deceptive, and that all behaviour is determined by the environment, either through association or reinforcement. Thorndike (as cited in Hall and Lindzey, 1970, p. 418) demonstrated the

importance of reward and punishment in learning process-law of effect. The “**Law of effect**” states that any behaviour that is followed by pleasant consequences is likely to be repeated, and any behaviour followed by unpleasant consequences is likely to cease (McLeod, 2007). Similarly, Skinner, (as cited in Rosenstock, Strecher and Becker, 1988, p. 176) formulated a hypothesis that the frequency of behaviour is determined by its consequences (also known as reinforcements). Skinner (as cited in Rosenstock et al., 1988, p. 176) termed such behaviours as operants as they operate in an environment which brings about change, resulting in reward or reinforcement. The other component that is an important concept in S-R theory, is that of habit as proposed by the theorists Dollard and Miller (Glanz et al., 2008). Glanz et al. (2008) noted that the theorists defined a habit as a link or association between stimulus (cue) and response. The unique events that individuals are exposed to determine their habits which influence their personalities.



2.4 COGNITIVE THEORIES

Cognitive theories are those theories that emphasise modification of cognitive patterns representative of the relationship in the environment (Hollan, 2008). Glanz et al. (2008, p. 46), argued that cognitive theorists emphasise the role of subjective hypothesis and expectations held by individuals, believing that behaviour is a function of the subjective value of an outcome and of the subjective probability, or expectation, that the particular action will achieve the outcome. HBM was influenced by Social-Psychological theory by Kurl Lewin (Hochbaum, Rosenstock and Kegels, 1952; Straub and Leahy, 2014) and the Social Cognitive theory by Albert Bandura (Hochbaum et al., 1952).

2.4.1 SOCIAL-PSYCHOLOGICAL THEORY

Allport (as cited in Chadee, 2011, p. 1) defines social psychology as “an attempt to understand and explain how the thoughts, feelings and behaviour of individuals are influenced by actual, imagined or implied presence of others”. In social psychology, it is believed that social behaviour is influenced by social, internal and cognitive occurrences (Chadee, 2011). Hochbaum et al. (1952) stated that social-psychology theory assumes that it is the world that determines what an individual will and will not do. Lewin (as cited in Straub and Leahy, 2014, p. 1517) argued that this theory uses the value expectancy approach. Value expectancy works on the assumption that the individual’s belief in an event is determined by the expected outcome. Lewin, (as cited in Straub and Leahy, 2014, p.1517) proposed that events were positively or negatively evaluated based on two variables. These are: whether the individual believed the event to be likely to happen (Lewin, as cited in Straub and Leahy, 2014, p. 1517) or the individual’s estimate of the likelihood that the given action will result in that outcome or the value placed by an individual on a particular outcome (Rosenstock; Janz and Becker, as cited in Straub and Leahy, 2014 p.1517)

2.4.2 SOCIAL COGNITIVE THEORY (SCT)

Social Cognitive theory was initially called Social Learning theory (SLT). The SLT came into being as a result of Albert Bandura, his colleagues’ and his students’ studies, designed to explain why children displayed aggressive behaviour (Denler, Wolters and Benzon, 2014). This was during the era when researchers such as Skinner, Hall, Spence and Tolman (Denler et al, 2014), explained human functioning, including classroom learning, by behavioural models (Denler et al., 2014). In the 1970s, these studies led to the development of a theory

initially called observational theory and then later called SLT (Bandura as cited in Denler et al., 2014, para. 5). According to Bandura (1971), SLT had three propositions. Its initial proposition was that behaviour is a product of response consequences. An individual can learn by observing other people's behaviour and its consequences. Bandura (1971) noted that an individual also observes the development of emotional affective reactions of others undergoing painful or pleasurable experiences. When an individual observes others engaging in feared activities without any adverse consequences, an individual can eliminate their fears and defensive behaviour and engage in those activities. The second fact proposed by Bandura (1971) determines how man is affected by his own experiences and develops future plans, which is man's superior cognitive capacity. Bandura (1971) proposed that the external influences experienced by people can be represented symbolically such as used later to guide actions and resolve problems as well as foreseeing probable consequences of different actions, thus modifying their behaviour accordingly. The third factor of the SLT was that an individual is capable of creating self-regulative influences. He referred to self-regulative influences as the capability of people to control their own behaviour by managing stimulus determinants of given activities and producing consequences of their own actions. As the theory evolved, in 1986 Bandura renamed it SCT. SCT hypothesises that learning occurs in a social context with a dynamic and reciprocal interaction of the person, environment, and behaviour (Denler et al. 2014). The SCT drew ideas from information-processing models of psychological functioning to describe the cognitive process that mediates learning. Denler et al. (2014) noted that SCT continues to emphasis that learning occurs in a social context and that much of what is learned is gained through observation.

According to Rosenstock et al (1994), the two major contributions to SCT in the HBM are in regard to the informative emphasis that there are several sources for acquiring expectations, stressing the role of reinforcement and observational learning/modelling of other people's

behaviour. The second major contribution is the concept of self-efficacy (efficacy expectations) as distinct from outcome expectation. Rosenstock et al. (1994) noted that outcome expectation is similar to the HBM concept of perceived benefits and is defined as the person's estimate that the given behaviour will lead to certain outcomes.

The 5 components of the SCT:

- i. **Observational learning/ Modelling** assumes that behaviours displayed by people are mostly learned, either intentionally or unintentionally, through the influence of examples (Bandura, 1971). Forms of models vary and include live demonstration by a person, say a teacher, to students in a class, verbal, or written descriptions; video or audio recordings are also forms of modelling (Denler et al., 2004). Denler et al. (2004) also noted that there are different types of models. There are mastery models which are proficient in demonstrating skills, coping models which struggle and make mistakes but eventually show proficiency; abstract modelling which conveys the message indirectly and cognitive modelling which occurs when a model verbalises her thoughts while demonstrating a cognitive process or skill. Bandura (1971) argued that modelling is guided by four interrelated processes. The processes are described as follows in Bandura (1971, pp. 7-8)
 - **Attentional processes:** for a person to learn by observation, he needs to attend to, or recognise the essential features of the model's behaviour.
 - **Retention process:** for a person to be influenced by a model there is a need for long-term retention of activities that have been modelled at one time or another.
 - **Motoric reproduction response:** this is a process whereby symbolic representations guide overt actions. When one has learned behaviour, he/she should be able to exhibit a correct new pattern of behaviour, but if the response components

are lacking, behavioural reproduction will be faulty. Bandura noted that in most cases, people usually achieve rough approximations of new patterns of behaviour by modelling and refine them through self-corrective adjustments as they receive feedback on their performances.

- **Reinforcement and motivational process:** this involves provision of positive incentives which activates unexpressed observational learning. Reinforcement affects the level of people's observational learning by controlling what people attend to and how they actively code and rehearse what they have seen. Reinforcements affect whether people would want to continue or not.

- ii. **Outcome expectations:** Outcome expectations reflect individuals' beliefs about what consequences are most likely to arise if particular behaviours are performed (Denler et al., 2014). In order to successfully perform a behaviour, a person must know what to do and how to do it. People learn from the consequences of their behaviour, which also affects the environment in which they live. The decisions that people make are shaped by the expected outcomes as they determine which actions one should take and which actions one should suppress. When a positive outcome is observed through certain behaviour, that behaviour is likely to be portrayed most of the time and if an unfavourable outcome is observed through certain behaviour, that behaviour is likely to be avoided.
- iii. **Goal setting** - Goals reflect cognitive representations of anticipated, desired, or preferred outcomes. (Denler et al., 2014). People set future goals, identify desired outcome and develop plans of actions to achieve the planned goals. Goals are an important prerequisite for self-regulation as they determine the route one needs to take and one can judge his/her achievement based on the set goals.

- iv. **Perceived Self-efficacy:** Perceived self-efficacy concerns people's belief in their capabilities to mobilise the motivational cognitive resources and causes of action needed to exercise control over events in their lives (Wood and Bandura, 1989, p364). Wood and Bandura (1989) argued that people with the same skill may perform differently or may behave differently depending on how self-efficacious they are. Perceived self-efficacy determines people's behaviour and choices of activities and efforts they will put in when faced with an obstacle (Bandura and Adams, 1977). Therefore, people with high self-efficacy cope better than those with low self-efficacy. People with high levels of perceived self-efficacy have greater choice, have more persistence, and have more effective strategy use than those with low self-efficacy (Bandura and Adams, 1977). This means that people who strongly believe in their own capabilities are likely to perform better than those who do not believe in themselves, as they are not let down by a single poor performance. Self-efficacy is viewed as a product of an individual's own past performances, the observation and verbal persuasion of others in the environment, and the individual's ongoing physiological state (Bandura, 1994).
- v. **Self-regulation:** Self-regulation assumes that people can control their own behaviour by managing the stimulus determinants of given activities and produce consequences of their own actions (Bandura, 1971). Though in other aspects, such as education it blossomed in the 1980s, it is a component that Bandura has since identified in the inception of SLT. Bandura emphasised that self-regulation has 3 sub-processes (Moore, 1999).
- **Self-observation** reflects that personal, individual human studies and their behaviour have the ability to keep track of their actions.

- **Self- judgement** is the process through which humans compare their observed actions with standards which can be self-set or societal set rules.
- **Self-response** is an evaluation of whether the actions meet the standards and where necessary modify their behaviour. Positive results are rewarded and if the result is negative, the person punishes herself/himself as a response.

(Wood and Bandura, 1989; Denler et al, 2014), argued that self-regulatory process works through people's belief in their self-efficacy. Denler et al. (2014) also noted that modelling also affects self-regulated learning in people.

2.5 DESCRIPTION OF THE HEALTH BELIEF MODEL

HBM was developed in the 1950s by social psychologists to explain the widespread effect of people to participate in programmes to prevent or to detect disease (Glanz et al., 2008). The HBM was later expanded to study people's response to symptoms (Kirscht, as cited in Glanz et al. 2008, p. 46) and to the behaviour in response to diagnosed illness, particularly compliance with medical regimens (Glanz et al., 2008). Hochbaum (as cited in Turner et al., 2004, p.31) argued that the underlying concept of the original HBM is that behaviour is determined by personal beliefs or perceptions about disease and strategies available to decrease its occurrence. The HBM suggests that if individuals think that they are susceptible to a condition, they believe that the condition has potentially serious consequences, and display a belief that there are options available for them to mitigate the potential consequences, they believe that the anticipated benefits outweigh the barriers (cost to) so are therefore likely to take a health action that they believe will reduce the risk (Rosenstock, Strecher and Becker, 1994). Rosenstock, et al. (1994,) argued that the HBM is a value expectancy theory. The value expectancy concepts

were reformulated and translated in the context of health-related behaviour as follows (Rosenstock et al., 1994):

- i. The desire to avoid illness or to get well (value).
- ii. The belief that a specific health action available to a person would prevent or (ameliorate) illness (expectation).

The HBM theory has six constructs which are: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action and self-efficacy. Table 1 below summarises the constructs, definitions and application examples of the HBM.

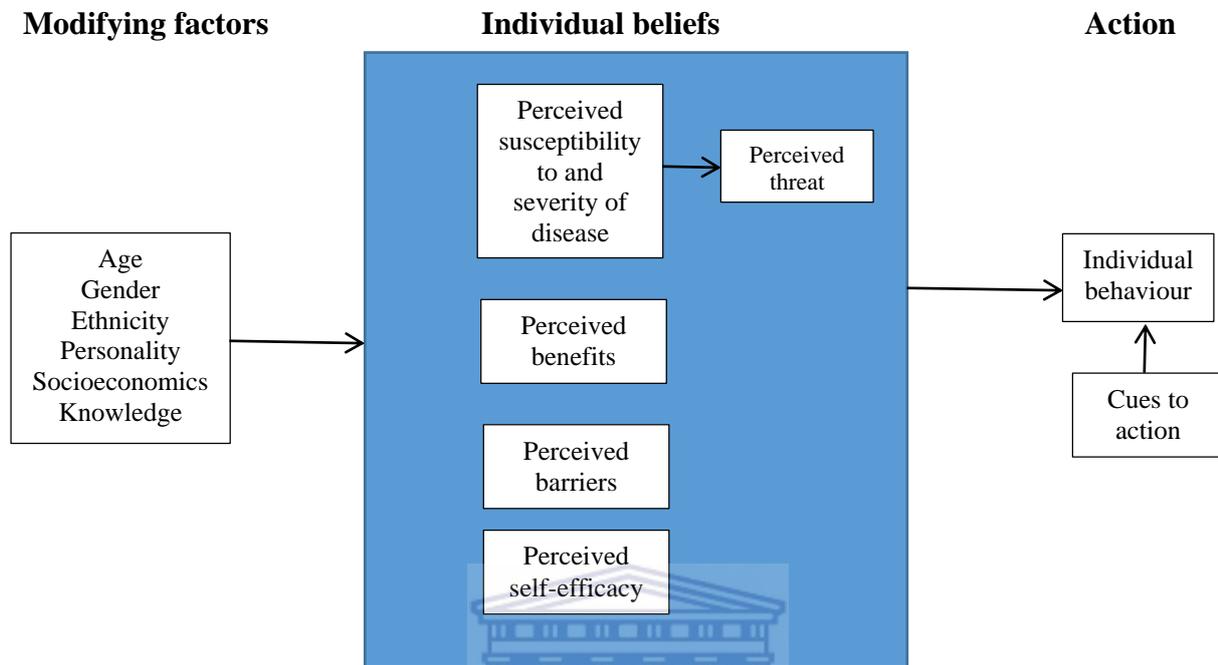
Table 2.1: Key concepts, definitions and applications of the Health Belief Model

Concept	Definition	Application
Perceived susceptibility	Refers to the belief about likelihood of getting a disease.	Define population(s) at risk Personalise risk based on a person's characteristics or behaviour such as age, gender and ethnicity. Make perceived susceptibility more consistent with individual's actual risk.
Perceived severity	Belief about the seriousness of the condition, or leaving it untreated and dealing with its consequences	Specify consequences of risks and conditions
Perceived benefits	These are individual opinions and beliefs in the efficacy of what a patient has been advised to do to reduce the risk and the impact	Define action to take: how, where, when; clarify the positive effects to be expected.
Perceived barriers	Belief about the possible undesirable aspects of the advised action	Identify and reduce perceived barriers through reassurance, correction of misinformation, incentives, assistance
Cues to action	These are strategies to stimulate the action.	Provide how-to information, promote awareness, use appropriate reminder systems
Self-efficacy	The belief that one can successfully execute the behaviour required to produce the outcomes	Provide training and guidance in performing recommended action Use progressive goal setting Give verbal reinforcement Demonstrate desired behaviours Reduce anxiety

Source: Glanz et al. (2008, p.48)

Figure 1 below illustrates the relationship amongst constructs of the HBM

Figure 1: Health belief components and linkages



Source: Glanz et al. (2008, p.49)



2.6 APPLICATION OF THE HEALTH BELIEF MODEL TO THE STUDY

To discuss and explain adolescents’ perceptions and experiences of ART, the six constructs of the model were applied. Participants in this study already have a condition which is HIV/AIDS. The theoretical constructs have been used to predict people’s behaviour in relation to preventing, screening or controlling their illness, (Glanz et al., 2008), therefore, for this study the constructs were used in relation to adolescents who participated in this study.

- (i) **Perceived susceptibility:** refers to the belief about the likelihood of getting a disease (Glanz et al., 2008). Participants in this study were adolescents who already have a health condition, namely HIV/AIDS.

- (ii) **Perceived severity:** refers to the belief about the seriousness of the condition, one's feeling or opinion and the consequences of leaving an illness untreated (Glanz et al., 2008). According to Mc Cormick-Brown, (as cited in Turner et al. 2004, p. 31), the perception of the seriousness of the illness is usually based on medical knowledge and information, personal belief influences and how adolescents perceive the seriousness of the illness. This means that, based on participants' belief on the seriousness of HIV and the effects of leaving it untreated will determine whether they will leave the condition untreated (use of ARVs) or not. Adolescents can perceive HIV as any other infection and not rely much on ARVs or they can perceive being HIV positive as a serious infection which lead to AIDS. If they perceive AIDS as a serious disease with severe consequences, then it can ignite the importance of taking ARVs so as not to develop AIDS.
- (iii) **Perceived benefits:** these are individual opinions and beliefs in the efficacy of what a patient has been advised to do to reduce the risk and the impact. Turner et al. (2004) argued that perceived benefits are the person's opinion of the value of the usefulness of new behaviour in decreasing the risks of developing a disease. The theory works on the assumption that a person can take a health-related action if he or she feels a negative condition can be avoided by treating it. Therefore, if adolescents have the knowledge and understanding that ARVs can prevent HIV escalating to AIDS they are likely to take the medication and adhere to the medication. This can assist them to make informed decisions and accept their health situation. It can help them understand how health can improve as a result of following recommended actions from health workers. This involves adhering to all the

recommendations involved with the ARV prescriptions, including the time factor, the daily consumption and going for their checkups. Following the recommended action from the health workers is also likely to reduce the number of hospital visits to the health facility for them, thus not having a negative effect on their school work and social life.

- (iv) **Perceived barriers:** these are potential obstacles to following the recommended behaviour. Taking ARVs might have potential obstacles such as stigmatisation and discrimination, lack of privacy and many others. This construct works on the assumption that when an individual is given a health option, he is likely to assess the expected benefits over the perceived barriers. If the adolescent feels that despite all the barriers, the action is more beneficial, he or she is likely to take the recommended action. Adolescents on ARVs can be faced with obstacles when using ARVs. However, whether adolescents can manage to overcome the barriers depends on how they perceive the threats as well as how they acknowledge the benefits of ARVs. As the theorists have identified, at times when obstacles are present, individuals fail to follow recommended health actions (Glanz et al., 2008).
- (v) **Cue to action:** these are strategies to stimulate the action. Through the HBM, adolescents can develop strategies to stimulate action (cues of action). Adolescents, who have the potential to identify what can best work for them to continue using ARVs, despite the difficult circumstances they are in, are likely to adhere well to ART. Worth noting is that the theory assumes that there are other factors that influence readiness to take action, such as cues to instigate action or environmental events Glanz et al. (2008). Adolescents can thus identify such cues or environmental factors to improve

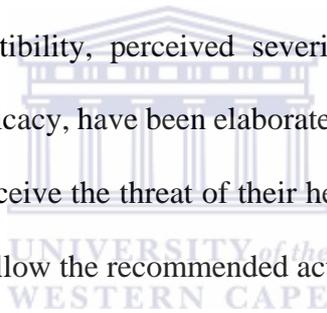
their condition so as to continue using ARVs. This may include identifying support systems within their schools as well as their communities, such as joining existing support groups or the formation of teen clubs to support each other. Adolescents can also learn from the health programmes broadcast on the radio or television as well as the information they are getting at the hospital.

- (vi) **Perceived self-efficacy:** Bandura (1994, p. 2) defines perceived self-efficacy as “people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives”. People with high self-efficacy can aim at doing something to change their situations. These are elements of behavioural change. As the theory proposes that for behaviour change to succeed, people must feel threatened by their current behavioural patterns (perceived susceptibility and perceived severity) and believe that a specific kind of change can result in a valued outcome at an acceptable cost (perceived benefit) (Glanz et al., 2008). Adolescents on ARV therapy need to feel that they are competent enough (self-efficacious) to overcome perceived barriers in order for them to take action. This can happen if these adolescents feel threatened by the outcome of not adhering to treatment (frequent hospital visits which can also lead to stigmatisation, failing to adhere to their regimen, which is likely to make them sick, and eventually their medication being increased and fear of death). If they believe that ARVs have the potential benefits exceeding stigma and discrimination, they are likely to find strategies to overcome the barriers to taking their ARVs. Therefore, adolescents with high self-esteem are likely to continue taking ARVs without fear of stigmatisation and

discrimination, lack of monitoring, lack of privacy and any other barrier, as ARVs are their key to a healthy and prolonged life.

2.7 CONCLUSION

This chapter has drawn on the Health Belief Model to provide the theoretical underpinning of the current study. The HBM is grounded on the Stimulus Response and Cognitive theories by Lewin and Bandura (Straub and Leahy, 2014; Hochbaum et al., 1952). According to the HBM, individuals have the desire to avoid illness or to get well and believe that a specific health action available to a person would prevent illness or improve the person's health. Six constructs of the theory: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action and self-efficacy, have been elaborated on in this chapter to explain how adolescents taking ARVs can perceive the threat of their health condition and the factors that can determine their decision to follow the recommended actions.



CHAPTER 3

LITERATURE REVIEW

3.1 INTRODUCTION

According to literature, a wealth of research has been done on adolescents living with HIV and on ART, but very limited research was done on adolescents' perceptions and experiences of using ARVs. There are various studies which have been carried out to address adolescents' aspects of HIV and adherence to ART globally and in Botswana (Mutwa, 2013, Ndiaye, 2014). Increased availability of anti-retroviral therapy in Sub Saharan Africa has enabled a number of children who were perinatally infected with HIV/AIDS to reach the adolescent stage. However, despite the fact that ARVs give PLWHA the ability to live longer, there are several barriers to the utilisation of care leading to suboptimal effectiveness of available treatment (Morolake et al., 2009). Stigmatisation from neighbours, families and spouses has been identified in reducing the coping mechanisms of PLWHAs. Adolescents are no exception to stigmatisation, which reduces their effectiveness in ARV programmes, thus leading to poor adherence to ART (Kitaka et al., 2008; Mutwa et al., 2013; Ndiaye, 2014; Rao, Kekwaletswe, Martinez and Rodriguez, 2007). Worth noting is that most of these adolescents are still attending school, thus experience academic as well as health-related stress due to the fact that they are living with HIV. This is a result of being burdened by lifelong medical treatments, eventually negatively affecting their academic performance (Birungi, Obare, Katahoire and Kibenge 2011; Mutwa et al., 2013). In a study conducted in Uganda among adolescents who were perinatally infected with HIV, 70% were still attending school and those not at school were older adolescents. School-going adolescents on ART experienced self-imposed stigma, as well as stigma from their school mates and from their teachers (Birungi et al., 2011). According to literature, adolescents need special attention and intensified formal support for them to be in a

position to adhere correctly to the prescribed medication and advice from parents, peers, health care workers and the educational sector (Birungi et al., 2011; Mutwa et al., 2013).

3.2 ADOLESCENTS

DiClemente, Wingood and Crosby (2003) state that adolescence is a crucial developmental period characterised by marked physical, emotional and intellectual changes as well as changes in social roles, relationships and expectations. Spiegel and Futterman (2009) supported DiClemente et al. (2003), and further noted that during adolescence, mental processes and sexual identity also evolve and mature. These changes are important for the development of the adolescent and provide a foundation for functioning as an adult. Spiegel and Futterman (2009) argued that, during this stage, adolescents have to satisfy the societal expectations and demands from families and peers. HIV therefore becomes a challenging experience for the adolescents as it is usually accompanied by depression, low self-esteem, fear of hurting and being rejected by families, friends and loved ones (Spiegel and Futterman, 2009). (DiClemente et al., 2003; Spiegel and Futterman, 2009) further indicated that the development of healthy adolescents is a complex and evolving process that requires supportive and caring families, peers and communities, access to high quality services such as health education, social and other community services. Sithole (2011) noted that, during the stage of adolescence, several risky behaviours are tried and tested, such as alcohol consumption, sexual intercourse and drug abuse. This poses a health hazard to adolescents as it is usually a result of depression and other pressures of living with HIV.

The change from childhood to adolescence is also characterised by changes in identity, self-consciousness and cognitive flexibility (Yurgelun-Todd, 2007; Pedlow and Carey, 2004). The adolescence stage is associated with emerging cognitive abilities such as the ability to think abstractly, foresee consequences of actions and to understand social context of behaviours, (Pedlow and Carey 2004). Veinot et al. (2006), noted that due to adolescents' cognitive, emotional and social development, adolescents live in the here and now. Giedd (2010) noted that, despite all these drastic changes during adolescence, they successfully manage to change from being dependent on their parents to being self-sufficient. With the HIV epidemic, the adolescence stage might be a challenge due to poor decision-making. When adolescents were infants, they depended on their parents for adherence purposes. However, during adolescence, adherence to HIV treatment might be lost as adolescents are mostly prioritising short term activities such as social/sexual relationships and overall identity development (Haberer and Mellins, 2009). Christie and Viner (2005, p.301) noted that, adolescence is known as “a period that poses specific challenges for treating disease and promoting health”. Due to adolescents' cognitive immaturity as well as their lack of experience, Pedlow and Carey (2004) alluded that it is vital to focus on skills development among adolescents when dealing with issues of HIV/AIDS and importance of ART. Venoit et al. (2006) further alluded that it is vital that adolescents are given developmental appropriate information of HIV treatment, as it will assist in overcoming knowledge-based barriers to HIV treatment.

According to Pettifor et al. (2013), the adolescence stage is marked by social transitions such as finishing school, finding employment, living independently, first sexual relationships, pregnancy and marriage. Pettifor et al. (2013) further noted that, at this stage, there is minimal parental supervision; however, adolescents usually have limited life skills such as self-confidence, have limited knowledge and usually make uniformed decisions which could put

their lives at risk. This was supported by Casey, Jones and Hare (2008, p.11) as they argued that adolescence is a developmental stage characterised by suboptimal decisions and actions that are associated with an increased incidence of unintentional injuries, violence, substance abuse, unintended pregnancy and sexually transmitted diseases. During adolescence, there is increased emotional reactivity. As noted by Pettifor et al. (2013), Christie and Viner (2005) also noted that, during the adolescence stage, independence is achieved. The adolescents do not value much the knowledge and advice they get from their parents. They believe that no person understands how they feel as young persons (Christie and Viner, 2005).

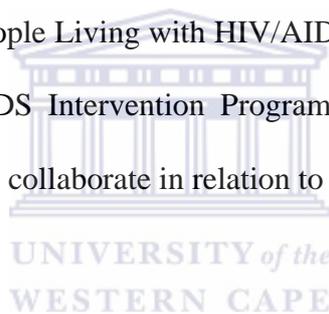
3.3 HIV AND AIDS

HIV/AIDS is a world concern as it has affected all world nations (Fauci, 2003). According to Fauci (2003), HIV/AIDS is ranked amongst the greatest infectious disease scourge in history. The world became aware of HIV in the summer of 1981, but has since spread almost unchecked around the globe (Fauci, 2003). Cumulatively, in 2003, about 60 million people around the world had been infected, of which over a third had died (Fauci, 2003). According to the Joint United Nations Programme on AIDS (UNAIDS, 2013), globally 35.3 (32.2-38.8) million people were living with HIV in 2012, an increase from previous years as more people are on ART. UNAIDS (2013), further reports that there was a 33% decline in new infections, from 3.4 (3.1-3.7) million in 2001 to 2.3 (1.9-2.7) million new infections in 2012. The number of AIDS deaths is also declining with 1.6 (1.4-1.9) million AIDS deaths in 2012 down from 2.3 (2.1-2.6) million in 2005 (UNAIDS, 2013). The UNAIDS (2010) report indicates that in the Sub-Saharan region, 1.9 million new people were infected with HIV, accounting for 67% of new infections world-wide. The increase in the number of people living longer is a result of

significant expansion of access to ARVs, which has led to the decline of AIDS-related deaths, especially in more recent years.

In Botswana, the first case of HIV was reported in 1985 and soon spread across the country (Hardon et al., 2006). Since HIV was identified, several strategies have been identified to combat the disease. There are three distinct phases that can be identified as a response to the HIV epidemic. There is the early phase which runs from 1987-1989. This phase mainly focused on screening of blood to eliminate the risk of transmission of HIV through blood transfusion (Hardon et al., 2006). Within the early phase, the government developed a short term plan to create awareness among health workers in clinical management of HIV/AIDS. The second phase was the period between 1989 and 1997. This is the period in which there was more concentration on information, education and communication programmes. The government also developed the five year medium term plan one (MTP1) which was aimed at containing the rapidly spreading virus, strengthening surveillance activities, and preventing sexual and perinatal transmission and transmission through blood products. It was in this period that Botswana developed the 1993 National Policy of HIV (Avert, 2014, “History of HIV and AIDS in Botswana”, para 38). Letamo, (2003) further argues that in 1998, the policy was revised to incorporate the Home Based Care (HBC) programme as the major component in the management of HIV. The period between 1997 and 2002 was the third phase. During this stage, the response to HIV/AIDS was expanded to include education, prevention and comprehensive care, including the provision of antiretroviral therapy (Hardon et al, 2006). This is the stage where the political leadership took an active role in combating the virus. Medium Term Plan two (MTP II) was developed in 1994 and it encompassed various stakeholders, such as non-governmental organisations, as well as the private sector. It was during this phase that HIV was not only recognised as a health or medical challenge but also accepted as a social and

political disease, as well as having cultural implications among people and the country at large. Letamo (2003) further noted that different institutions were established to combat the virus, which included the parliamentary select Committee of HIV/AIDS, and the AIDS/STD unit was formed which was initially called the National AIDS Control Programme in the 1987 and 1992 period. In 2002, the National AIDS Coordinating Agency (NACA) was established to coordinate and implement the multi-sectoral response to HIV and to provide policy guidance to other sectors. At the district and sub-district level, multi-sectoral AIDS Committees were established to coordinate and promote response programmes at local level. Private sectors and civil societies formed a coalition named the Botswana Business Coalition of AIDS to coordinate HIV/AIDS interventions. Civil society organisations also formed several networks, such as Botswana Network of People Living with HIV/AIDS, Botswana Network of Law and Ethics, Botswana Christians AIDS Intervention Programme and many others to support, promote, coordinate, network and collaborate in relation to HIV.



According to the Botswana 2012 global AIDS response report, national anti-retroviral therapy was introduced in 2002, followed by the introduction of routine HIV testing in 2004 (NACA, 2012). The expected benefits of introducing ARVs were:

- i. To enable people with HIV to live longer, healthier lives;
- ii. To offer an incentive for HIV testing, and to lower the rate of HIV transmission;
- iii. To decrease the number of children orphaned each year by AIDS; and
- iv. To maintain skills in the workforce necessary for economic development.

(Avert, 2014, “History of HIV and AIDS in Botswana”, para 44)

Botswana also introduced the National Orphan Care and Community Home Based Care programme in 2002 to provide support for HIV/AIDS infected and affected people (NACA,

2012). The Prevention of Mother to Child Transmission (PMTCT) HIV programme was also introduced in 1999 to prevent infections from mothers to children. The programme was aimed at improving the survival and development of children by reducing HIV-related morbidity and mortality. Its main objective was to reduce the number of new paediatric infections occurring through mother-to-child transmission (NACA, 2012). In 1999 the PMTCT was only launched in Gaborone and Francistown, but it has since been extended to 634 health care facilities providing ART. Continual revisions of PMTCT guidelines and improvements in clinical care have allowed the Botswana PMTCT programme to prevent HIV infection in over 13,000 HIV exposed infants annually (NACA, 2014).

3.4 HIV AMONG ADOLESCENTS

Adolescents living with HIV/AIDS can be divided into two groups. There are perinatal infected adolescents and behavioural infected adolescents (Spiegel and Futterman, 2009). In a study done among older children and adolescents in Southern Africa (Ferrand et al., 2009), it has been noted that in Southern Africa there are many children who live longer without HIV treatment and yet develop to the adolescence stage. These infants are called slow progressors. Research has shown that about 1/3 (one third) of infected African infants are slow progressors and their median life expectancy is 16 years (Ferrand et al., 2009). Therefore, many HIV positive infants reach the adolescence stage, and with the introduction of ART more and more children perinatal-infected with HIV reached the stage of adolescence (Ferrand et al., 2009; Spiegel and Futterman, 2009). Spiegel and Futterman (2009), state that, even though perinatal and behavioural infected adolescents might have some similar challenges, perinatal infected adolescents have their own challenges related to the prolonged use of ARVs. These might include resistance to medication as a result of poor adherence as well as pill fatigue, which

could lead to adherence challenges. Similarly, Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath, and Ferrand (2014) noted that some adolescents have long been living with HIV, from infancy, when their immune systems were not fully developed, and it has thus resulted in some distinctive chronic complications which cause severe morbidity. Lowenthal et al. (2014) further noted that adolescents living with HIV are faced with living with a chronic illness, challenged with issues of adherence to the HIV treatment, learning to engage in sexual relationships and at the same time rapidly changing both physically and psychologically.

According to Underwood, Skinner, Osman, and Schwandt (2011), in Sub-Saharan Africa, girls are three times more likely than boys to be living with HIV. The structural factors of insufficient economy, education and socio-cultural and legal support for the girl child are the root cause as these young girls are exposed to unprotected sexual relationships as well as intergenerational relationships. To address the HIV problems faced by these adolescent girls, Underwood et al. (2011) argued that the community proposed that structural interventions should be designed to protect the girl child both culturally, economically, legally and educationally. Communication between parents and the girl child should be enhanced.

In Botswana, adolescents are severely affected by HIV with a prevalence rate of 3.5% among adolescents aged 10-14 and 3.7% among adolescents aged 15-19 years (Statistics Botswana, 2013). It is reported that, in Botswana, HIV infection among boys and girls is almost the same (“Wise up campaign”, n.d). In a report from the Sunday Standard newspaper by Ontebetse (2015), she noted that in a study done by NACA presented at the National AIDS Council meeting, it was reported that the Botswana fight against HIV is under threat as HIV prevalence among adolescents aged between 10 and 14 years of age is high. It emerged from the meeting

that between 2004 and 2008, there was a decline of 0.2%; however, there was a sharp increase in prevalence of 6.6% between 2008 and 2013 among adolescents aged 10 and 14 years of age. Among adolescents aged 15 to 19 years in Botswana, between 2004 and 2008 prevalence increased from 6.5% to 12.3% and increased by 21.2% between 2008 and 2013. Ontebetse (2015) noted that it also emerged from the meeting that in Botswana new infections are still being recorded. Botswana adolescents, as in the rest of the world and in Africa, generally engage in risky sexual behaviour and do not consider themselves to be at risk of being infected with HIV (“Wise up campaign”, n.d). BIAS III (Statistics Botswana, 2009) estimated that 7% of people aged 15-19 had sex with people over 10 years older than themselves. Adolescents engage in intergenerational relationships as well as concurrent relationships. Adolescents are also said to be reluctant to participate in preventative strategies like safe male circumcision and condom use.



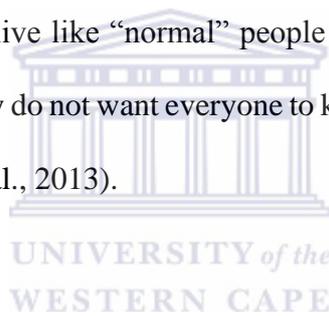
3.5 ANTIRETROVIRAL THERAPY (ART)

Anti-retroviral therapy helps prevent people living with HIV from dying from AIDS and from developing tuberculosis, becoming ill and transmitting tuberculosis and HIV (UNAIDS, 2013). UNAIDS (2013) further states that new science indicates that people should start on ART early to realise the benefits. WHO has provided new guidelines recommending starting treatment when individuals' CD4 count falls below 500 cells/ul and immediately for pregnant women. In Botswana, antiretrovirals have since been provided free of charge to every person who qualifies for treatment from 2002. The ART programme, known as MASA, involves a public private partnership. Initially the ART programme was launched in four sites in Botswana, two referral hospitals and two district hospitals. By the end of 2004 the programme had expanded to all 32 district and primary hospitals throughout the country (Hardon et al., 2006).

People have different perceptions and understanding of ARV therapy. On a study done on people's perceptions before HAART initiations, people expressed the need to take ARVs when they have HIV/AIDS-related symptoms (Horne, Cooper, Gellaitry, Date and Fisher, 2007). Therefore, when they do not show the symptoms of HIV, they feel that there is no need to take their ARVs. However, people who viewed HAART as a positive experience in their life indicated that they were adhering well to it. According to Horne et al. (2007), people's perception and understanding of ART are not consistent as a clinical imperative for ARV treatment.

ART is viewed as a life saver by some people living with HIV (Mutwa et al. 2013; Ndiaye, 2014). Research has revealed that some adolescents take ARVs to keep healthy as they have seen some positive changes in their growth after being initiated to HAART (Mutwa et al. 2013). Adolescents have reported to have gained weight and started growing up normally after HAART initiation. On the other hand, Ndiaye (2014) is of the opinion that there are some psychological factors, such as open communication between the caregiver and the adolescent as well as early disclosure of HIV status, which enable adolescents to use ARVs as prescribed. Open communication helps the caregiver to share all necessary information with the adolescent, including the benefits of adherence to medication, consequences of defaulting treatment and knowledge of risky sexual behaviour. Early disclosure of HIV status assists the adolescent to be mature and start questioning the medication, which gives the parents a platform to explain important details in relation to medication adherence and risky sexual behaviour (Merzel, Van Devanter and Irvine, 2008).

Though there are positives experiences of using ARVs, many barriers have been identified by different researchers. Adolescents identified stigmatisation as the main barrier to using ARVs (Kitaka, et al., 2008; Mutwa, et al., 2013). According to UNAIDS (2013), a survey conducted with People living with HIV revealed that stigmatisation and discrimination lead to intense psychological costs, resulting in feelings of guilt, shame and suicidal thoughts. According to Mutwa et al. (2013) adolescents' feelings on disclosing their HIV status and their perceived experience hindered them from taking their drugs, attending clinics and carrying treatment in public. For adolescents staying in institutions such as boarding schools and orphan care homes, privacy was non-existent. Lack of privacy in these institutions was identified as a major barrier to both keeping the medication safe as well as using it privately. Adolescents on ART reported that they want to be treated and live like "normal" people and not live a life where they are taking medication every day. They do not want everyone to know their HIV status and therefore treat them differently (Mutwa et al., 2013).



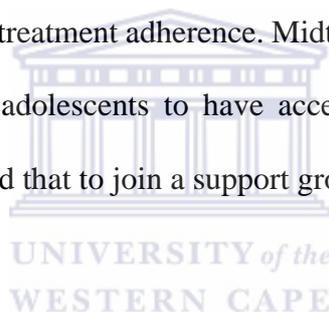
(Kitaka et al., 2008; Abadía-Barrero, and Castro, 2006) identified peer pressure, poverty, racism, ignorance by partners, alcohol use and desire to have children for older adolescents as barriers to good adherence to medication. Some adolescents lack specific behavioural skills such as how to disclose their HIV status to their partners as a barrier to taking ARVs because they fear that they will be rejected and stigmatised (Kitaka et al., 2008). Identified by (Nachega, et al., 2009), as barriers to ARVs are depression, pill burden, advanced HIV, alcohol, dropping out of school, side effects and complications of day-to-day routine. Restrictions of independence in daily life and family conflicts, low self-esteem, forgetfulness as well as a busy schedule of adolescent life affects their adherence to medication (Nachenga et al., 2009).

In his study, Ndiaye (2014) concluded that patients and family caregivers, demographic and psychological factors, including cognitive and behavioural problems and substance abuse, as barriers to good adherence to medication. Rao et al. (2007) supported Ndiaye (2014) that substance abuse and the identified depressive symptoms, the use of marijuana at a young age as well as concrete rather than abstract reasoning skills, are barriers to good adherence. Lack of motivation and “pill fatigue” were also identified by Marukutira (2012) as a barrier to good adherence to ART. Another factor identified by Ndiaye (2014) was the Health Care Delivery System. He argued that the way the institution operated had an impact on how adolescents adhere to treatment. He was of the opinion that an institution that solely addresses issues of HIV among paediatrics and adolescents has a strong monitoring system as compared to other institutions such as hospitals which supply ARVs. This is the reason why good adherence to medication by adolescents attending the clinic at Baylor Centre of Excellence is higher than those seen at other institutions. Rao et al. (2007), further stated that HIV stigmatisation, disclosure, family involvement, medication regimen complexity, side effects, lack of knowledge about HIV and relationship between the provider and the patient have been identified as barriers to taking ART.

3.6 COMPLIANCE (ADHERENCE) WITH ART

Different studies show the importance of being compliant and being non-compliant to ARVs, (Biadgilign, Deribew, Amberbir, and Deribe, 2008; Marukutira, 2012; Nam, Fielding, Avalos, Dickinson, Gaolathe, and Geissler, 2008; Gilbert and Walker, 2009; Thupayagale-Tshwenegae, 2010; Sithole, 2011). ARVs are regarded as lifesaving drugs and if adolescents understand this, then it motivates them to adhere to the ARVs. In South Africa, in a study done by Gilbert and Walker (2009), adolescents in Northwest showed commitment to ARVs due to

the value to life they attached to it. However, geographical locations limited other people access to it and even adhere to the treatment due to distance and financial issues. In a study done by Biadglin-Deribew et al. (2008), in Ethiopia, results revealed that children whose parents were paying for their treatment were more compliant with their ARVs and attended hospital appointments than those who received them free of charge. Biadglin-Deribew et al. (2008) further acknowledged that those adolescents whose family members had fully disclosed their status to them were fully adherent to ARVs as they had a better understanding of their health and had knowledge of the benefits of the ARVs, as compared to those adolescents to whom their HIV status was not yet disclosed. A similar sentiment was identified by Midtbo, Shirima, Skovdal and Daniel (2012) in a study they did in Botswana and Tanzania that disclosure of status contributes significantly to treatment adherence. Midtbo et al. (2012) further argued that disclosure of status also assists adolescents to have access to different HIV services; for example, in their study, they found that to join a support group, an adolescent needed to know his or her own status.



According to Bygrave, Mtangirwa, Ncube, Ford, Kranzer and Munyaradzi (2012), in a study among adolescents and youth in rural Zimbabwe, they found that challenges to compliance among adolescents are side effects, appointment schedules that interfere with daily schedules, depression, stigmatisation, fears about disease transmission, transfer to adults' HIV services and disclosure of HIV status. Growing up to adulthood was also mentioned by Bygrave et al. (2012) as a hindrance to compliance as these adolescents usually migrate to Botswana and South Africa to look for employment. The other trend noted in Zimbabwe among older adolescents as having a negative impact on adherence to treatment, was going to live with in-laws, either in marriage or after child birth, as is customary. To improve compliance in such a

setup, Bygrave et al. (2012) recommended that the challenge of mobility should be addressed by improving how the ARTs are provided and the use of monitoring and evaluation tools. Travel plans for work, education or social events should be discussed between patient and health care provider so as to provide drugs for a longer period and being flexible in treatment schedules.

In a study among adults over 20 years of age, Watt, et al. (2009) found that adherence to medication was influenced by the belief in the efficacy of the medication to improve health and prolong life. This was reported by people who have experienced debilitating illness and recovered from the illness as a result of using ARVs (Watt et al., 2009). Also identified by Watt et al. (2009), was the need for support by family as a motivator to adhere to treatment. In a study by Veinot et al. (2006), they found that understanding the medical condition and the prescribed treatment were positive factors to adhering to treatment. Veinot et al. (2006) argued that adolescents in their study were sceptical about taking treatment that does not cure the disease, and other adolescents did not know why they should take the treatment. A recommendation was then made that it is very important to educate youth on the specific questions that they have in order to address issues of compliance.

In Botswana, Sithole (2011) argued that adolescents are hindered from adhering to treatment because of their mobile life (going to school, visiting relatives and going for school trips). Adolescents usually go on school trips and also visit family members for various reasons. Their unwillingness to disclose their status hinders them from adhering, as usually there is limited privacy during the school trips and the family visits. Sithole (2011) argued that some of such

adolescents have devised coping mechanisms, such as the use of Smarties sweet boxes (multi colored small pill shaped chocolate sweets) to carry their medication so that they can continue taking their medication while, at the same time preventing premature disclosure of status. Nam et al. (2008) reported that acceptance, denial and self-stigmatisation played a significant role in adhering to medication. In a study conducted in Gaborone, Botswana, Nam et al. (2008) identified that people who had accepted their condition adhered well to their medication. In the study done by Thupayagae-Tswenegae (2010), in Gaborone, Botswana, she found that adolescents used different protective behaviours to comply with their medication. Adhering (taking medication as prescribed by the medical team) to medication was identified as the main method as it reduces the chance for someone else to know if you are HIV positive or not. If a person does not adhere, he or she is likely to be sick and therefore everyone could know his/her HIV status. Thupayagae-Tswenegae (2010), further argued that some adolescents on ART kept quiet about their status and just took their medication and treated it like any other illness. Other adolescents reported that they went immediately for medical attention, even if they experienced common conditions like influenza (Thupayagae-Tswenegae (2010)). Adolescents believed that if they took too long before going for treatment, people are more likely to link being ill with being HIV positive.

According to Kambale (2013) on his study on factors that affect adherence to antiretroviral therapy among adolescent patients at selected Palapye clinics in Botswana, poor processing of disclosure among adolescents, fear of stigmatisation, accessibility to health facilities, waiting time for being served and the nature of support that people receive from relatives, as well as feelings towards ARVs, were identified as having both positive and negative influences towards a person's compliance to ARV. Another study done in Botswana using Paediatric

Symptom Checklist (PSC), revealed that psychosocial dysfunction in older children and adolescents was common and therefore led to non-adherence (Lowenthal et al. 2012). Lowenthal et al. (2012) identified that non-adherence resulted in treatment failure as well as the development of a resistant virus.

3.7 SUPPORT NEEDED BY ADOLESCENTS ON ART

ARVs are lifetime drugs and need strong support and motivation for those who are using them. Adolescence is a crucial stage of human development which means adolescents need more support to enable them to continue using ARVs. Kitaka et al. (2008), recommend that adolescents need to be assisted to develop appropriate behavioural skills to improve their sexual behaviour. Kitaka et al. (2008) alluded that there is a need to develop appropriate intervention strategies specifically designed for adolescents. Structural interventions should address and reduce HIV-related stigmatisation and socio-economic need of young people living with HIV (Kitaka et al., 2008). Martinez and Chakraborty (2014) argue that there is a need for youth-friendly services that can assist in addressing issues of stigmatisation, confidentiality and privacy. Rao et al. (2007) suggest that patients who are depressed, need to be involved in support groups. Support groups are said to develop coping skills through sharing experiences and skills, thus building self-esteem among individuals living with HIV. Ndiaye (2014) found that in Botswana, Gaborone, most adolescents seen at Baylor Centre of Excellence are members of a teen club within the centre which is a support group. Therefore, his results showed a high level (75.6%) of adherence to ARVs by adolescents seen at this Centre. Midtbo, et al. (2012) noted that support group played a significant role among adolescents living with HIV as it made adolescents have a sense of belonging and developing relationships among themselves with people in a similar situation. Midtbo et al. (2012) further argued that

adolescents on ART need strong family support for them to be adherent to their HIV treatment. Supportive family environment was also noted by Williams et al. (2006) as vital for adolescent adherence to medication. Williams et al. (2006) noted that their findings revealed that having an adult supportive caregiver, even if the adult caregiver is not biological, and a friend to remind the adolescent to take the medication, improves adherence to ARVs. Also found by Williams et al. (2006), is that higher caregiver education assists in improving adherence to HIV treatment amongst adolescents.

3.8 GAPS IN LITERATURE

The literature highlights the challenges that are being faced by adolescents who are living with HIV and are on ART that hinders them to adhere well to the ARVs though they know and understand the benefits of the ARVs on their health. These include among others, complexity of the adolescent stage, dealing with the social pressures of being on ART such as peer pressure, lack of privacy in boarding institutions, pill burdening, school dropout to mention but a few (DiClemente et al., 2003; Kitaka et al., 2008; Mutwa, et al., 2013, Nachenga et al., 2009). The literature further highlight the factors that lead to good adherence such as paying own medical bills, disclosure, being a member of a support group, understanding the medical condition as well as the prescribed medication (Biadglin-Deribew et al., 2008; Midtbo et al., 2012; Veinot et al., 2006). However, the literature does not indicate how the adolescents should deal with all the challenges there are facing. There is a huge gap on the tangible things that the governments and the organisations that deal with adolescents who are on ARVs are doing to address the identified challenges. Literature further indicates how adolescents can benefit on peer support which is provided in form of support groups, however, most or all of the members of these support groups are HIV positive adolescents (Midbto et al., 2012; Ndiaye, 2014). Therefore,

there is a gap on how the adolescents who are on ARVs can positively live and associate with their peers who are not HIV positive with minimal or no stigmatisation and discrimination.

This study will therefore explore further and describe the adolescents perceptions and experiences of antiretroviral therapy with the aim of identifying feasible solutions to the challenges that the adolescents on ART faces on daily bases so as to improve their compliance. The study will also indicate the challenges that are faced by the adolescents on ART that different organisations and departments that deals with adolescents on ART need to address.

3.9 CONCLUSION

Since the introduction of antiretroviral therapy, HIV/AIDS is now seen by many as a chronic disease which is controllable, and not a death sentence. Antiretroviral therapy has been identified as a lifesaving drug by adolescents in different studies. ARVs are said to be increasing the life expectancy of people living with HIV. However, there are different factors identified that makes taking ARVs challenging to adolescents. This includes stigmatisation and discrimination, minimal privacy as well as side effects. For adolescents to adhere to ART they need the support of their families, their friends and the community at large. The next chapter addresses the research methodology used in the study.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 INTRODUCTION

This chapter describes the research approach and methodology used to explore adolescents' perceptions and experiences of antiretroviral therapy at a tertiary hospital in Francistown.

4.1.1 RESEARCH SETTING

The study was conducted at a tertiary hospital in the IDCC department in the Northern part of Botswana. The IDCC department attends to people living with HIV and AIDS. The department operates as an outpatient clinic, monitoring patients living with HIV. It offers HIV counselling services, ARV dispensation and monitoring and educational services on issues of HIV and AIDS to patients and their families. It attends to new clients as well as patients referred by other ARV sites within the Northern part of Botswana who are not doing well in HAART. As the IDCC is situated in a tertiary hospital which is staffed by all health professionals, it is linked to all the services that the tertiary hospital offers. The departments have a strong referral system with other departments in the hospital for conditions that affect people living with HIV. The researcher was given an office in the IDCC to use for the period of her study to conduct the interviews. However, one participant was interviewed at his home, due to his preference for being interviewed at home.

4.2 RESEARCH APPROACH

Research approaches are plans and the procedures for research that span the steps from broad assumptions to detailed methods of data collection, analysis, and interpretation (Creswell, 2013). A qualitative research approach was used in this study. Qualitative research is

concerned with the lived experiences of individuals and is thus well-suited for identifying and locating the significance people place on the events, processes and structures of their lives (Bailey, 1997). In qualitative research, the concern is with understanding with naturalistic observation the subjective exploration of reality from the perspective of an insider (Babbie and Mouton, 2014; De Vos et al, 2011). Qualitative research is a means for exploring and understanding the meaning that individuals or groups ascribe to a social or human problem, (Creswell, 2009). A qualitative research approach was used in the study as it aims to understand and interpret the meanings that subjects give to their everyday life (De Vos, Styrydom, Fouche and Delport, 2001). The aim of the study was to explore and describe adolescents' perceptions and experiences of ART. The use of a qualitative research approach was best suited as the adolescents were able to share their lived experiences from their own perspectives. According to Babbie and Mouton (2014), qualitative research is aimed at describing and understanding human behaviour.



4.3 RESEARCH DESIGN

An exploratory descriptive research design was followed in this study. An exploratory research design is conducted where a problem has not been clearly defined, thus breaking ground, and offering new insights and comprehension (Babbie and Mouton, 2014). Exploratory research is conducted to gain insight into a situation, phenomenon, community or individual (De Vos et al, 2011). It is done where there is a lack of basic information on a new area of interest or in order to get acquainted with a situation so as to formulate a probe or develop a hypothesis. Qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events (Swandelowski, 2000, p.336). Descriptive research presents a picture of the specific details of a situation, social setting or relationship and focuses on “how” and “why”

questions Kreuger and Neuman as cited in De Vos et al. (2011 p.96) In this study, the aim was to explore and describe adolescents' perceptions and experiences of ARV therapy at a tertiary hospital in Francistown, Botswana. The reason for using an explorative descriptive design in this study was that most research on adolescents in relation to HIV and ARVs is mostly concentrated on the bio-medical aspects of ART. Therefore, there is little research on the psychosocial aspects of adolescents on ART. An explorative descriptive design was thus best suited for this study as it gave the researcher new intuitions and understanding of the issues that are related to adolescents' experiences and perceptions of antiretroviral therapy.

4.4 PARTICIPANT RECRUITMENT AND SELECTION

Participants were recruited from the IDCC department at the tertiary hospital in Francistown, Botswana from the 2nd February 2015 to the 26th February 2015. The department caters for about 5104 HIV positive patients, of which 775 are aged between 10 to 19 years of age, in which the target group for the current study fell (Nyangabgwe hospital IDCC, 2015a). A study population or target population is defined as that aggregation of elements from which the sample is actually selected, (Babbie and Mouton 2014). Babbie and Mouton, (2014), further explain that it is the role of the researcher to ensure that every element meeting the theoretical definitions laid down actually has a chance of being selected in the sample. The population for this study was school going adolescents aged 13 to 19 years of age attending their reviews at the tertiary hospital IDCC in Francistown, Botswana.

Participants were recruited using purposive sampling. The logic and power of purposeful selecting lies in selecting rich cases for study in-depth (Patton, 2002). For this study, two

strategies of purposive sampling were followed. These are criterion sampling and purposely random sampling. Patton (2002) argued that purposely sampling strategy does not automatically eliminate any possibility of random selection of cases; however, purposely random sampling increases the credibility of the results as it reduces the suspicion about why certain cases were selected for the study. The logic of criterion sampling is to review and study all cases that meet the predetermined criterion of importance (Patton, 2002). According to Creswell (2013), criterion sampling works well when the individuals studied represent people who have experienced the phenomenon. Participants in this study were randomly selected purposively as they were HIV positive and seen at the tertiary hospital IDCC. The selected participants were then assessed as per the predetermined inclusion criteria. Those who did not meet the inclusion criteria were excluded from participating in the study. Welman, Kruger and Mitchell (2007, p. 69) indicated that in purposive sampling, researchers rely on their experience, ingenuity and or previous research findings to deliberately obtain units of analysis in such a manner that the sample may be regarded as being representative of the relevant population. Adolescents from the tertiary hospital IDCC paediatric clinic, adolescent clinic and adult clinic were selected on the following inclusion criteria:

- i. They had to be HIV positive
- ii. On ARVs for at least one year
- iii. School going adolescents
- iv. Aged between 13 years and 19 years old
- v. Attending their reviews at the tertiary hospital IDCC in Francistown, Botswana
- vi. Only participants who signed the written consent forms (appendix 5 & 6) and, for the minors who had signed the written assent forms (appendix 7 & 8) and their parents who had signed the parent/guardian written consent form (appendix 9 or 10), participated (The age of maturity in Botswana is 18 years as

per the amendment of the interpretation act of 1984 in 2010 by the Botswana Parliament on the 6th of July 2010), (Government of Botswana, 2010, “Maturity age reduced to 18” para. 1).

Participants were excluded on the following criteria:

- i. HIV negative adolescents
- ii. On ART for less than a year
- iii. Non-school going adolescents
- iv. Adolescents who did not consent, or minor adolescents without parental consent.

According to Babbie and Mouton (2014), it is appropriate for a researcher to sample on the basis of her own knowledge of the population, its elements and the nature of the research aim or say the purpose of the study when using a purposive sampling technique. Adolescents who did not meet all the above inclusion criteria were excluded.

In this study the participants were identified from the waiting queues for their doctors or queues to receive treatment refills. Some adolescents that the researcher missed in the queue were referred to the researcher by the attending health worker. All adolescents identified were further assessed to find out if they had met the selection criteria. This was done by asking them questions. Those who met the selection criteria were given the information sheet to read and the researcher explained it to them. All the participants were given an opportunity to ask the researcher questions for clarification. All their questions were responded to before they signed the consent forms. Those who wanted to continue with the interviews on the same day were interviewed. The other participants set different dates for the interviews as well as the venue

where the interviews would take place. All the participants above 18 years of age had to sign a consent form after the study had been explained to them and had voluntarily agreed to participate before the interview was conducted. Those below the age of 18 had to sign an assent form and the parent signed a parent/guardian consent form after the study had been explained to them, and the child had voluntarily agreed to participate and the parent had given him or her permission to participate before being interviewed. Those who agreed to participate but did not want to sign the consent form, assent form or the parents were not willing to sign the parents/guardian consent form, were excluded from participating in the study. However, those participants below the age of 18 years without their parents or caregivers present, were informed of the research and its purpose. Those participants who showed an interest in participating in the study, provided their parents' contacts details. Their parents were then contacted by the researcher and informed about the study and those who showed interest were met at a venue of their choice for further explanation with the adolescent; if they consented then the interview took place or a date for the interview was set, as per the participants' schedule. Twenty four participants voluntarily agreed to participate in the study and were selected for the study. Twenty four participants were interviewed until data saturation.

4.5 DATA GATHERING

According to Clamp, Gough and Land (2004) data collection refers to ways in which information can be obtained from the real world, recorded in a systematic way, quantified and/or explained. For this study, data was collected by means of individual, semi-structured interviews with the aid of an interview guide. All the interviews were conducted by the researcher and were all one-on-one-with each participant.

4.5.1 INTERVIEWS

An interview is a two-way conversation in which the interviewer asks the participants questions to collect data and to learn about the ideas, beliefs, views, opinions and behaviours of the participants, (Nieuwenhuis, 2013). Interviews help in constructing rich descriptive data that assist the interviewer in understanding the participant's construction of knowledge and social reality, (Nieuwenhuis, 2013). Semi-structured interviews are a verbal interchange where the interviewer asks the interviewee questions in an attempt to elicit information (Longhurst, 2003). Longhurst (2003) further expressed that, in a semi-structured interview, the researcher gives participants the chance to freely explore issues they feel are important. Semi-structured interviews are used by researchers to gain a detailed picture of a participant's belief or perceptions or accounts on a particular topic, (De Vos et al., 2011). According to Nieuwenhuis, (2013), in semi-structured interviews, the participant is required to answer a set of predetermined questions. The questions are flexible in nature, thus allowing the researcher to probe more and the participant to explicitly explain him/herself fully. Semi-structured interviewing differs from other types of interviews in that it is open, therefore allowing the object of study to speak for himself or herself rather than provide the respondent with a battery of predetermined hypothesis-based questions. In this study, the researcher conducted semi-structured interviews with each participant that lasted for 20 to 45 minutes each.

The researcher initially started by introducing herself. This included telling the participants and caregivers the researcher's name, where the researcher was studying, the purpose of the study and the reason they have been selected. The participants and parents/caregivers were also informed of the details of my supervisor so that, should they need clarity or were not happy they could contact her. This was done to establish rapport. Establishing rapport assists the

interviewer to gain information from participants as they are likely to be comfortable with him or her (De Vos et al., 2011). The researcher used open ended questions in the interviews. Welman et al. (2007), define open ended question as a procedure in which the interviewer asks a question without any expected set of answers. This gave the participants the opportunity to talk freely without limitations; probes were used by the researcher to encourage participants to talk more and clarify emerging themes. According to Welman et al. (2007, p.167), probes are usually used to clarify vague responses or to ask for elaboration of incomplete answers. Probes deepen the response to a question, increase the richness and depth of responses, and give cues to the participant about the level of response that is desired (Patton, 2002). Probes also allowed participants to be flexible in their responses and ask for clarity when they did not understand the question posed to them. Wording of questions is an important technique that was used during data collection. Questions were asked in such a manner that motivated the participants to answer completely and honestly (Berg, 2001). The important aspect that assisted the researcher was language, as the researcher was very conversant in Setswana language, which most participants preferred. Paraphrasing and reflections (De Vos et al., 2011) were used so as to get rich information from the participants. Berg (2001) noted that in paraphrasing, it is very important to use words wisely so that the participants can see that the interviewer is genuinely interested in his/her experience and not interested in something that is particularly sensational, particularly negative or especially positive.

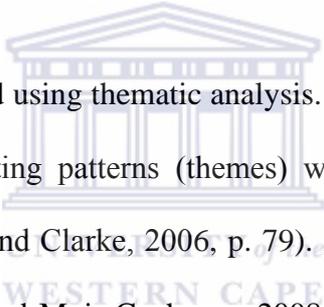
The researcher was using an interview schedule consisting of open-ended questions (Appendix 1). A research instrument is anything that the researcher uses to get the data that he or she is going to analyse (Hofstee, 2013). According to Annum (2015), the researcher is mandated to ensure that the instrument is valid and reliable. It should be appropriate to the study he/she is carrying out. An interview guide is, “a list of topics, themes or areas to be covered in a semi-

structured interview” (Mason, 2002, p.519). Semi-structured interviews allow the researcher to make use of audio recorders, take written notes as well as observe nonverbal cues from the participants which she uses to compile the field notes (De Vos et al., 2011). Field notes are written accounts of things the researcher hears, sees, experiences and thinks in the course of interviewing (De Vos et al., 2011). The written notes included participants’ responses, their expressed emotions, and emotions observed by the researcher during the interviews. Recording the interviews is very vital in a qualitative research. In this study, the interviews were audio taped. Permission to record was obtained from the participants and from the parents/guardians for those under 18 years. Smit (1995) stated that a tape recorder allows a much fuller record than notes taken during the interview. When using an audio recorder, the researcher pays full attention to the interview more than taking notes. Twenty two interviews were audio taped out of the twenty four interviews held. One interview was not audio taped due to technical problems experienced after the interview was conducted. The other interview was not audio recorded as the parents as well as the participant were not comfortable with being audio recorded. The reason being that they did not trust the confidentiality of the recording. They believed that, if exposure of the recordings take place, their son could be sabotaged and discriminated for the rest of his life because it is possible that someone could identify his voice. Interviews were conducted among all 24 participants until data saturation was reached. The data from all the twenty four interviews were transcribed verbatim.

Interview data collection limitations included telephonic interruptions as interviews were conducted in a consultation room in the IDCC. The telephone could not be disconnected and the researcher had to transfer all the calls to relevant officers during the interview. Interruptions destruct participants and thoughts are lost; and time is lost trying to get back on track (Field and Morse, cited in De Vos et al., 2011).

4.6 DATA ANALYSIS

Deductive thematic analysis was used to analyse data. In deductive analysis, data is read and reread to identify themes and categories (Pope, Ziebland & Mays, 2000). In deductive analysis, all the data relevant to each category are identified and examined using a process called constant comparison in which each item is checked or compared with the rest of the data to establish analytic categories (Pope et al, 2000). Pope et al. (2000) further argued that, furthermore, the categories are further refined and reduced in number by grouping them together, informed by the analytical and theoretical ideas developed during research. Key themes and categories are then selected for further investigation.



All transcribed data were analysed using thematic analysis. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within the data. “It organises and describes data in detail” (Braun and Clarke, 2006, p. 79). According to Daly, Kellehear and Glicksman (as cited in Fereday and Muir-Cochrane, 2008 p. 82) thematic analysis involves searching for themes that emerge as being important to the description of the phenomenon. In data analysis, the data is read and reread to identify themes and categories (Pope, Ziebland and Mays, 2000). All the data relevant to each category were identified and examined using a process called constant comparison in which each item is checked or compared with the rest of the data to establish analytic categories (Pope et al., 2000). Pope et al. (2000) further argued that the categories are further refined and reduced in number by grouping them together, informed by the analytical and theoretical ideas developed during research. Key themes and categories are then selected for further investigation. Thematic analysis allows for themes to emerge direct from the data. A theme can be described as “umbrella” constructs which are usually identified by the researcher before, after and during data collection (Cresswell, 2009).

According to Saldana, (2009), a theme refers to an outcome of coding, categorisation and analytic reflection, not something that is, in itself, coded.

In this study, the analysis was done by following the steps of analysis as suggested by Braun and Clarke (2008) as discussed below:

i. Step one was to **familiarise myself with the data**. This involved reading and re-reading to get meaning and patterns, taking notes for coding. It was at this stage that the recorded notes from the interviews were transcribed verbatim. The researcher went through the 24 transcribed interview sheets and listened to the 22 audio recordings of the interviews. This assisted the researcher in identifying the patterns of codes and the meaning of what the participants were saying.

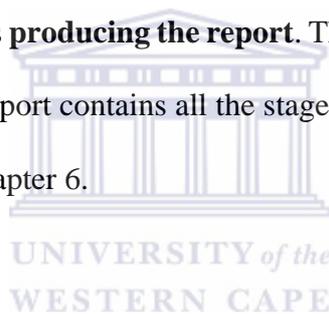
ii. The second step was to **generate initial codes**. This is where the codes were produced from the data. All the identified codes were listed in a note book. Codes identify a feature of the data that appeared interesting to the analyst, and referred to the most basic segment, or element of the raw data or information that could be assessed in a meaningful way regarding the phenomenon (Boyatzis, cited in Braun and Clarke, 2008, p. 88). Saldana, (2009, p. 3) defines a code in qualitative inquiry as “often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data”. Codes were produced from the transcribed data of the interviews that had specific meaning. This involved a vigorous activity in which the researcher went through all the 24 interview transcripts to get codes, being guided by the

objectives of the study. Many different codes were identified which were then used to develop categories and themes.

iii. The third step involved **searching for themes**. This is the stage where different categories were developed from the codes. The categories were then sorted into potential candidate themes and all relevant coded data was organised into main themes. At this stage, six themes emerged.

iv. The fourth stage involved **reviewing of themes**. Identified themes were relooked at and similar themes were merged and the unnecessary ones discarded. This involved two levels of reviewing and refining themes. In level one, the stage involved reading all the coded data extracts for each theme to identify if they formed a coherent pattern (Braun and Clarke, 2008). It was at this level that the researcher realised that the candidate themes identified did not form a coherent pattern. The themes were reworked. All the six themes identified in step three were discarded, some were deduced to categories and four new themes were emerged. Reworking of the themes was done until the researcher was satisfied that the new themes that emerged formed a coherent pattern. In level two, after the researcher ensured that the themes formed a coherent pattern, then the validity of the themes was assessed in relation to the data and the researcher ensured that the candidate's thematic map accurately reflected the whole data (Braun & Clarke, 2008). The four themes that emerged, formed a coherent pattern and they are representative of the whole data. The four themes will be presented in chapter 5.

- v. The fifth stage was to **define and name the themes**. This is a stage where the researcher defines and refines the themes after being satisfied with the thematic map of the data. By defining and refining, Braun and Clarke (2008), refer to identifying the ‘essence’ of what each theme is about and determining what aspect of data each theme captures. In this step, the researcher assessed the essence of each identified theme and related it to the data in order to determine what each theme captured in the data. As the researcher, I relooked at each category under each theme to assess if it really belonged to the theme which it is under. The purpose here was to ensure that each theme was grounded on the original data.
- vi. The final stage was **producing the report**. The report was written and produced in a full thesis. The report contains all the stages that the researcher went through, from Chapter 1 to Chapter 6.



4.6.1 DATA VERIFICATION

The analysis of the data was deduced from the data gathered during the data collection process at the tertiary hospital in Francistown, Botswana among adolescents who were on antiretroviral therapy and attended the IDCC. Audio recordings of the interviews were transcribed verbatim first into Microsoft word documents. Both the Microsoft word transcripts as well as the written notes gathered during the data collection process were used in the analysis of the data. Nieuwenhuis (2013) argues that in verifying and validating of data, the findings should be the essential outcome of the data analysis process.

4.7 RIGOUR AND TRUSTWORTHINESS

As this is a qualitative study, rigour needs to be ensured throughout the research process (Babbie and Mouton, 2014). Aroni (as cited in Fereday and Muir-Cochrane, 2008, p. 82) defined rigour as demonstrating integrity and competence within a study. Qualitative research employs differed techniques such as credibility, transferability, dependability and confirmability to ensure trustworthiness of the findings. These were employed as follows in the study:

Credibility is achieved by checking representativeness of the data as a whole (Thomas and Magilvy, 2011, p.152). This involved reviewing the transcripts for individual participants and looking for similarities. Thomas and Magilvy (2011) argue that some of the strategies to ensure credibility are reflexivity, member checking and peer debriefing, which were not applied in this study. According to Golafshani, (2003, p.600) in qualitative research, credibility depends on the ability and effort of the researcher. Credibility in this study was ensured through **prolonged engagement** (Babbie and Mouton, 2014). The researcher was in the field until meeting the required sample and satisfied that the research question had been answered, without her own bias. The researcher was observant to both the verbal and non-verbal cues which she used in producing a coherent report (**Persistent observation**). Credibility in this study was strengthened by using the transcripts whilst writing the final report and using participants' words. The interview techniques used by the researcher also strengthened the credibility of the study. **Triangulation** was done which is a plan of action for sociologists and other social science researchers above the personal biases that stem from single methodologies (Denzin, cited in Babbie and Mouton, 2014, p. 275). Patton (1999) proposed that the logic of triangulation is based on the premise that no single method ever adequately solves the problem of the rival causal factors. Patton (2002) then stated that, within a qualitative inquiry, triangulation can be attained by combining both interviewing and observations, mixing

different types of purposeful samples or examining how competing theoretical perspectives inform a particular analysis. In this study, triangulation was done by combining two purposeful samplings which were purposive random sampling and criterion sampling. Purposive random sampling strengthened the credibility of the study as all adolescents had a possibility of participating. Criterion sampling was used for quality assurance, as the only participants selected were those who met the inclusion criterion selection and were therefore information rich as they had adequate experience of using ARVs and thus helped in identifying gaps and suggesting ideas that could be used when dealing with adolescents on ART. To ensure the **referential adequacy**, field notes as well as tape recordings were used for future referral.

Transferability refers to the extent to which findings can be applied in other contexts or with other respondents (Babbie and Mouton, 2014). Transferability was ensured by use of thick descriptions as well as purposive sampling (Guba and Lincoln as cited in Babbie and Mouton, 2014, p. 277). The researcher gathered sufficient and concrete data and gave a detailed report of the findings for the readers to make judgments about transferability (Babbie and Mouton, 2014). As the researcher was using purposive sampling, it was easy to select respondents that were representative of the study population as the participants were purposely selected.

Dependability: According to Guba and Lincoln (as cited in Babbie and Mouton, 2014, p. 278), there is no credibility without dependability. Dependability was ensured by collecting data among participants that met the selection criteria. Only adolescents aged 13-19 years old, who were school-going and had been on antiretrovirals for more than a year and attended at the tertiary hospital in Francistown, Botswana, were selected. Participants' responses from the semi structured interviews were used to interpret the data. Research findings were used to write the final report.

Confirmability: Babbie and Mouton (2014, p.278) define confirmability as: “the degree to which the findings are the product of the focus of the inquiry, not the biases of the researcher”. The participants’ responses were used to interpret the data, draw conclusions and to make recommendations. Raw materials such as field notes and tape recordings were available for confirmation.

4.8 BRACKETING

Bracketing is a method used by some researchers to mitigate the potential deleterious effects of unacknowledged preconceptions related to the research and thereby to increase rigour of the project (Tufford and Newman, 2012). In bracketing, the researcher’s aim is to enhance the research process. In this study, the researcher already knew some of the participants as she had worked for IDCC before. To achieve rigour, the researcher used the concept of bracketing by cognitively putting aside her own beliefs about the participants and the study. The participants were given a chance to explicitly express themselves without being judged or prejudiced. The findings presented are solely the participants’ expressions.

4.9 ETHICS CONSIDERATIONS

Webster New World Dictionary (as cited in Babbie and Mouton, 2014, p. 520) defines ethics as conforming to the standards of conduct of a given profession. Babbie and Mouton (2014, p. 520) noted that ethics is usually linked with morality as both deal with right and wrong. Thus, the following ethical considerations were honoured by the researcher. Permission to conduct the research was obtained from the University of the Western Cape’s Senate and Faculty of Community and Health Sciences Research Committees (appendix 11), Ministry of Health-

Botswana (appendix 12) and the Superintendent of the tertiary hospital's Ethics Committees (appendix 13). Informed written consent was obtained from all the participants after they were informed about the significance and nature of the study (appendix 5 & 6) and after they had the opportunity to ask questions and discuss any queries they might have had about the study. As some participants were minors (below 18 years), written consent was sought from their parents and caregivers (appendix 9 & 10) and assent was obtained from the participants before their participation (appendix 7 & 8). In Botswana, the age of maturity is 18 years as per the amendment of the interpretation act of 1984 in 2010 by the Botswana Parliament on the 6th of July 2010, (Government of Botswana, 2010, "Maturity age reduced to 18" para. 1). Participants were assured of their confidentiality and anonymity. Anonymity was ensured by giving participants pseudo names and all personal information about participants was known only to the researcher. Even though consent was sought from the participants' parents and guardians, the interviews were held privately between the researcher and the participants to ensure confidentiality. Participation was on a voluntary basis; therefore, participants were informed that they were allowed to withdraw from the study at any time they wished to do so without being stigmatised or prejudiced. Participants in the study already were a vulnerable population in the society as literature has revealed due to stigma attached to their condition (Kitaka et al., 2008; Mutwa et al., 2013). The researcher therefore took into consideration their emotions and feelings so that they did not feel judged, which could possibly lower their self-esteem. Those who were identified as emotionally and psychologically disturbed, either from the study or from any other social situation, were informed of the available Social Work services in the hospital or were referred to the Social Workers for counselling after verbally consenting to the referral. The researcher tried at all times to offer a supportive environment where participants were free to express themselves. The data were analysed and a report was produced which included the findings of the study. The aim of the researcher was to be objective and adhere to

the standard requirements of data analysis and reporting. As this research is a requirement for the fulfillment of a Master's Degree in Child and Family Studies, the researcher is the only author of this study. All references used in the data were acknowledged throughout the report and listed in the bibliography at the end of the research. If this study can be published, the rule of no simultaneous submission of manuscript will be applied, which means that the report cannot be submitted to two or more journals for publication (Babbie and Mouton, 2014).

4.10 LIMITATIONS OF THE STUDY

Limitations are what separate doing one study is according to one's method from perfection (Hofstee, 2013). They affect either how far one is able to generalise the conclusion (scope) or how confident you can be about your conclusions (reliability), (Hofstee, 2013).

The following were limitations in the study

- i. Two participants' interviews were not audio recorded. The reason being the lack of the researcher's technical skills of using the tape recorder. It was only after the first interview was done that the researcher realised that the recording did not take place. However the hand written notes were available. The other interview that was not recorded was because the participant's father works for the defence force and therefore the father reported to have experienced a lot of negative outcome of recorded interviews in the force. He therefore did not trust the researcher preventing the audio recording from going viral. He believed that if it may happen that the audio recording was exposed, someone could identify the voice of his son and he would be stigmatised and discriminated for the rest of his life because of his HIV positive status.
- ii. Minor adolescents (under the age of 18 years) who were recruited in the absence of their parents/caregiver, came alone for the reviews and assented. When their parents

were telephonically contacted to explain the scope of the interview and asked to set up an appointment, some agreed to the appointment date but either postponed it or reported that they were not interested and did not want their children to participate.

- iii. Some minor adolescents were brought to check-ups by their mothers who, after recruitment and explanation of the purpose of the study, reported that the study is interesting but they would have to get permission from their husbands so that they could give consent for their child to participate in the study. When the researcher did the follow up, the mother would either report that the child was no longer interested in doing the interview or the father refused to consent to the child participating.

These limitations led the study to have a greater proportion of participants who fell into the 18 and 19 years age group than other age groups in the study.



CONCLUSION

This chapter outlined the methodology applied in conducting this research study. The actual procedures and measures adopted were discussed and explained from data collection, data analysis and rigour and trustworthiness. The ethics statement was also provided in this chapter. Despite the limitations of the study, the researcher successfully managed to access 24 participants who met the selection criteria. In the next chapter the findings of the study will be presented.

CHAPTER 5

FINDINGS

5. I INTRODUCTION

In this chapter, the findings of the study are presented. The findings emerged from the analysis of the transcribed semi-structured interviews and the researcher's observation and personal notes taken throughout the study.

5.2 RESEARCH RESULTS



5.2.1 SAMPLE DESCRIPTION

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Table 5.1, below gives a summary of the demographic details of the participants.

Table 5.1: Demographic details of the participants

Participant number	Age	Gender	Level of study	No. of years on ART
Participant A	15	F	Form 1	12 years
Participant B	16	M	Standard 7	4 years
Participant C	15	M	Form 2	11 years
Participant D	19	F	Form 5	8 years
Participant E	18	F	Form 5	12 years
Participant F	18	F	Form 3	4 years
Participant G	18	M	Form 3	8 years
Participant H	18	M	Form 5	10 years
Participant I	18	M	Form 4	3 years
Participant J	16	M	Form 1	8 years
Participant K	13	M	Standard 6	7 years
Participant L	16	F	Form 2	11 years
Participant M	17	F	Form 2	10 years
Participant N	18	F	Form 5	10 years
Participant O	18	M	Form 3	9 years
Participant P	16	M	Form 4	3 years
Participant Q	19	M	Form 5	12 years
Participant R	18	M	Form 4	10 years
Participant S	16	F	Form 4	9 years
Participant T	18	M	Form 5	9 years
Participant U	19	F	2 nd year tertiary student	7 years
Participant V	15	F	Form 3	9 years
Participant W	17	F	Form 3	10 years
Participant X	14	F	Form 1	4 years

5.2.2 THEMES

From the thematic analysis, the following four themes emerged (Table 5.2).

Table 5.2: Themes and Categories

Theme number	Themes	Categories (Subthemes)
1	“ARVs control but don’t cure” (5.2.2.1)	5.2.2.1a Knowledge of ART 5.2.2.1b Knowledge of ART regimen 5.2.2.1c Importance of adhering to treatment
2	“Why did it happen to me?- the reality of using ARVs” (5.2.2.2)	5.2.2.2a Positive experiences 5.2.2.2b Negative experiences 5.2.2.2b (i) Social challenges faced by the adolescents on ART 5.2.2.2b (ii) Clinical challenges faced by adolescents on ART
3	“I don’t want to take them for the rest of my life” (5.2.2.3)	5.2.2.3a Acceptance of HIV status 5.2.2.3b Non-compliance to treatment 5.2.2.3b (i) Causes of non-compliance 5.2.2.3b (ii) Strategies to address non-compliance 5.2.2.3c Stigmatisation and discrimination
4	“No man is an island” 5.2.2.4	5.2.2.4a Importance of social support 5.2.2.4a (i) Family support 5.2.2.4a (ii) Peer support 5.2.2.4a (iii) Hospital Support 5.2.2.4a (iv) School support

5.2.2.1 THEME 1: “ARVs CONTROL BUT DON’T CURE”

This theme captures participants’ understanding of HIV and ART use. It also captures participants’ knowledge of the importance of adherence to treatment. The theme highlights the well-known knowledge that ARVs do not completely destroy the virus, therefore they cannot kill it. The ARVs lowers the viral load and thus people are healthier with an increased life expectancy.

5.2.2.1a KNOWLEDGE OF ART

The majority of the adolescents interviewed were conversant on issues of HIV. Adolescents have knowledge that HIV is a virus that causes AIDS and that it is not curable but can be suppressed by the use of ARVs. They reported that ARVs only suppress the virus but do not cure it. Adolescents argued that when the virus is suppressed, it is unlikely that one can be attacked by opportunistic infections. However, the participants reported that one can live a healthy longer life, as quoted by the participant below:

“ it’s like they (ARVs) make the virus stable so that you don’t develop AIDS, because this is HIV; and at the end, if you use ARVs you just become HIV positive, so the use of ARVs is to prevent HIV from becoming AIDS”. (Participant T: male, 18 years old)

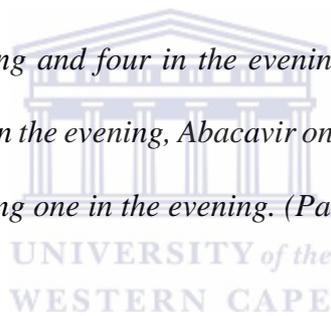
One participant reported that ARVs prevent transmission of HIV from the mother-to- child as quoted below:

“umm...I also understand that umm...ARVs they may also help in pregnant women, pregnant women can use ARVs to prevent from mother to child transmission” (Participant V: female, 15 years old)

5.2.2.1b KNOWLEDGE OF ART REGIMEN

From the findings, it was evident that of the 24 participants, 22 of them had excellent knowledge of their regimen. One participant had inadequate knowledge and one did not know anything at all. However, the participant reported that she was taking her ARVs every day. All the participants knew the names of their treatment regimen, and the instructions for using them. Some of the participants (13) were taking two drugs, nine participants were taking three different drugs, and only one participant was taking four different drugs whilst one participant did not know the names nor the number of drugs that she was taking. All the participants were on regimens that were taken twice a day, morning and evening at the same time as quoted below:

"I take four in the morning and four in the evening. Its Alluvia, Abacavir and AZT. Aluvia 2 in the morning 2 in the evening, Abacavir one in the morning one in the evening and AZT one in the morning one in the evening. (Participant W: female, 17 years old)



Another participant quoted:

"I take one Combivir morning and one in evening. Combivir I take it with EFV in the evening (Participant I: Male, 18 years)

All the participants knew their doses in the absence of the medication. The one participant who had inadequate knowledge about the ART regimen, knew the regimen by names but reported that he only knew how to take them when he is holding the bottles. This participant quoted as follows:

“I take ABC, D4T and Kaletra.....I only know how I take them when the tablets are here” (Participant G: male, 18 years old)

5.2.2.1c IMPORTANCE OF ADHERING TO TREATMENT

Most of the participants’ demonstrated correct knowledge that ARVs, when taken according to their prescriptions, can suppress the virus, prevent opportunistic infections, increase CD4 count in the body, prevent early death and lead to a long healthy life. The participants responded that they take their ARVs every day at the same time as per the prescribed regimen, so the virus will not become active. One participant quoted as follows:

“When you take them well, they make the virus to sleep. When you take them you are not attacked by opportunistic infections” (Participant F: Female, 18 years old).

Most of the participants noted that ARVs need not to be missed to prevent the HIV virus from becoming active. One participant stated:

“When you take them.....missing them, the virus can become active” (Participant J: male, 16 years old)

The majority of the participants noted that ARVs are taken every day for them to work well.

To demonstrate how the ARVs are taken, one participant said:

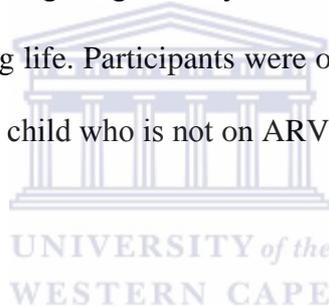
“I take them every day, morning and evening at 6 o’clock” (Participant V: female, 15 years old)

5.2.2.2 THEME 2: “WHY DID IT HAPPEN TO ME?-THE REALITY OF USING ARVs”

This theme highlights the participants’ experiences of using ARVs. It captures both the positive and the negative experiences of using ART. The negative experiences focuses on the social and clinical challenges that are faced by adolescents in their daily lives as they use ARVs.

5.2.2.2a POSITIVE EXPERIENCIES OF USING ARVS

All the participants reported that ARVs are the best thing that has ever happened in their lives. They referred to ARVs as “lifesaving drugs”. They were very excited at the fact that ARVs prolong life as well as normalising life. Participants were of the opinion that with ARVs they live a “normal” life like any other child who is not on ARVs. One participant said:



(Smiling) “I realised that this medication really helped me because it took me from one position to another, currently I am in a position that I am free among people. They stopped things such as discrimination; before it was like ahh, I am poor, I am sick, even my friends were discriminating me” (Participant I: male, 18 years old)

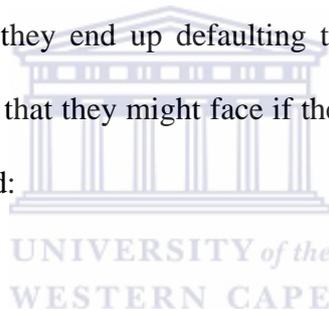
5.2.2.2b NEGATIVE EXPERIENCIES OF USING ARVS

The majority of the participants in this study reported negative experiences of using ARVs relating them to their daily life experiences as well as the side effects. The negative experiences of using ARVs were related to the social challenges and the clinical challenges faced by them. These experiences affected their self-esteem and mostly were a challenge to adhere to

treatment. The following are some of the experiences shared by the participants when using ARVs:

5.2.2.2b (i) SOCIAL CHALLENGES FACED BY PARTICIPANTS ON ART

All of the participants in this study were school-going adolescents and some stayed in boarding schools. They reported finding it difficult to take their medication consistently because of the situation they find themselves in. The ARVs are a lifelong drug and is taken every day. Therefore during trips, taking the medication is a challenge because there is minimal privacy during that time. Those who are staying at boarding facilities reported that there is no privacy at all in boarding schools, thus they end up defaulting treatment because of their fear of stigmatisation and discrimination that they might face if their roommates realise that they are HIV positive. One participant said:



“amm, I think, should I say it...because sometimes if you go for trips or everywhere because of confidentiality, sometimes it may be hard to take them in front of people and also being stigmatised and stuff like that” (Participant V: female, 15 years old)

Another participant said:

“The difficulty depends on the condition, like whom you are with. For example, I was a boarding student when I was doing form four, you know in boarding they will be about nine or ten of you sharing a room. So, for you to take them in the presence of

others it becomes a challenge. You will be fearing that they will tell others about your condition then your image will be tarnished” (Participant T: male, 18 years old)

One participant who was once a victim of stigmatisation and discrimination from her peers during a school trip, quoted as follows:

(Sad) “My experience is that, when I am on a school trip, some of my friends laugh at me saying I take ARVs, I have HIV” (Participant A: female, 15 years old)

Peer pressure is also a social challenge faced by most participants. Participants reported that it is really a challenge for them to be taking ARVs when their peers are not taking ARVs. They have to find different strategies to use every day so that they can leave their peers behind and go home early in order for them to take their ARVs. At times they have to satisfy their friends and just opt for missing the dose or taking them late. One participant said:

“Why me of all these people....Sometimes it’s peer pressure. Your friends will not be taking ARVs and it will only be you who is taking ARVs, you will think it’s not right” (Participant U. female, 19 years old)

Difficult life situations such as lack of food and lack of parental care also had an impact on participants’ adherence to medication. One participant reported that his mother did not care much about him; she could not pay for his school fees nor buy him clothes. Therefore, he felt

there is no need to take ARVs for his survival when no one takes care of you. One participant who has lost her parents reported that she at times misses the ARVs because there is no food. She used to be cared for by the Social Workers under the orphan care programme. However, the orphan care programme caters for children only up to 18 years of age. Upon reaching 18 years of age you are automatically removed from the programme despite your social situation. This participant said:

“I miss it when there is no food. When there is no food because when I take them on an empty stomach I feel dizzy” (Participant F: female, 18 years old)

5.2.2.2b (ii) CLINICAL CHALLENGES FACED BY PARTICIPANTS ON ART

Some of the participants reported that it is a challenge to take ARVs every day because they are not “sick”. Some of the participants are of the view that they are severely challenged by the fact that they are taking ARVs but there is no improvement, therefore they are failing their regimen. The majority of the participants reported that being on a “lifelong drug”, which must be taken every day, is also tiring to them. Participants were of the opinion that having to take the ARVs everyday also leads to pill fatigue for them. One participant said:

“Being healthy, feeling okay make it difficult...taking a pill knowing that you are not sick” (Participant E: female, 18 years old)

“Because my situation will not be improving” (Participant C: male, 15 years old)

ARVs are a lifelong drug, taken every day. Taking ARVs everyday poses a challenge as it is tiring to some of the participants. One participant noted that he was used to not taking medication every day; however, when initiated on ARVs, he had to start to take the ARVs every day. It therefore became very difficult for the participant to adhere to medication as prescribed, quoted as follows:

“I was not used to medication everyday.....I was getting tired of taking them every day, but it’s just fine” (Participant R: male, 18 years old)

Side effects were also experienced by many of the participants, mostly when they were being initiated on HAART. The common side effects reported were nausea and dizziness. Other side effects experienced by the participants included fatigue and painful throat. Two participants experienced the most adverse side effects. One participant reported that the colour of her nails changed and one male participant reported that he developed breasts upon initiation to ART and was quoted as follows:

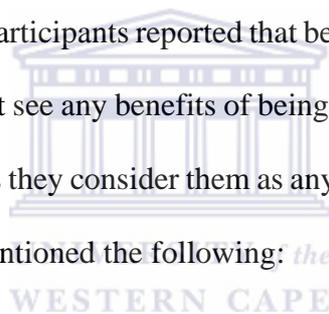
(Worried) “They can affect a person by changing his body shape. Mmhh, Imagine - I developed breast as a man and it led to me feeling like I am being discriminated as people were greeting me as if they are greeting a woman, mmhh! Saying dumela mma (hello madam). My self-esteem was very much crushed down” (Participant P: male, 16 years old)

5.2.2.3 THEME 3: “I DON’T WANT TO TAKE THEM FOR THE REST OF MY LIFE”

This theme focuses on factors that are related to the participants’ acceptance of their status. This theme relates to issues that lead participants not to comply to ARVs as well as how they work on towards improving their compliance to treatment. The theme also addresses the factors that are related to stigmatisation and discrimination, perceived and experienced by the participants on ART.

5 .2.2.3a ACCEPTANCE OF STATUS

Acceptance of status emerged as the best way for participants to improve or maintain good adherence to ARVs. Most of the participants reported that before they accepted their HIV status they were defaulting. They did not see any benefits of being on ART. Since they accepted their status taking ARVs is very easy as they consider them as any other drugs which is helping them to live longer. One participant mentioned the following: *the*



“They need an open heart, and you should have accepted yourself...you have to love them as they give you life” (Participant Q: male, 19 years old.

5.2.2.3b NON COMPLIANCE

5.2.2.3b (i) CAUSES OF NON COMPLIANCE

Non-compliance to ART was stated by most participants. Of all the 24 participants, only six indicated that they had never missed their doses. Five reported that they missed by months, two missed by days and eleven missed by dose. Participants who defaulted for months reported that they had not accepted their statuses after they were disclosed to them. Those who missed by

days, some of them informed the researcher that they had forgotten to pack their medications when going for trips. However, most of them take their medication late. Even those who reported that they had never missed their medications at all reported some episodes of taking them late and mostly it happens when they arrive late from school. One participant expressed the following:

“At first it was really hard for me to accept that I live with HIV to the extent that I withdraw from them. I really defaulted for quite a long time. For about 3-4 months without taking them, and...but then I had not accepted that this is who I am, I didn't choose to be like this” (Participant H: male, 18 years old)

Forgetfulness was the common reason expressed by most of the participants for missing doses. Most of the participants who reported to be missing doses reasoned that they usually miss the morning dose as they forget to take the medication when they are in a hurry to get to school. One of the participant said:

“At times I forget them, maybe in the morning when I go to school, then I remember when I am at school, then I take the evening dose” (Participant A: female, 15 years old)

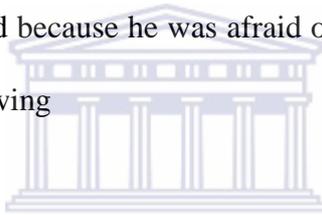
Another participant was not happy having to take ARVs for the rest of his life. One participant responded as follows:

“It is being made difficult by the thought of taking them for the rest of my life... why are they not curing at once?” (Participant P: male, 16 years old)

Non-compliance to medication was also reported by most of the participants to be prominent during school trips and at boarding schools due to lack of, or minimal privacy. Participants in these situations reported that it is either that they do not take the ARVs at all or take them late as they have to find a secret place to take them. One participant responded as follows:

“When you go for trips or everywhere, because of confidentiality, sometimes it may be hard to take them in front of people and also being afraid of being stigmatised and stuff like that” (Participant V: female, 15 years)

One participant who resides in a boarding facility, who defaulted treatment because of lack of privacy, reported that he defaulted because he was afraid of others. As a result, his viral load increased. He expressed the following



“It was last year when my viral load rise because I was afraid of taking them (ARVs) in the presence of others because they were always available.....At times I will take them late in secret, so when I came to check my results, the viral load was very high” (Participant T: male, 18 years old)

5.2.2.3b (ii) STRATEGIES TO ADDRESS NON COMPLIANCE

The majority of the participants discussed different strategies that could assist them not to miss taking their medication. The use of an alarm clock was mentioned by many as a gadget which can act as a reminder so that they do not forget when to take their medication. Some participants are already using the alarm to remind them. One participant responded as follows:

“I need a watch to set the alarm and I need my parents...my parents to remind me”

(Participant A: female, 15 years old)

Incorporating taking ARVs into daily life activities is another strategy that adolescents mentioned as vital for maintaining and improving their adherence. One of the participants responded as follows when asked about how she manages not to miss taking any of her medication:

“I eat at 5.30 so at 6 o’clock I remember that I should take my pills”. (Participant K:

male, 13 years old)

Use of seed bags, as opposed to the plastic containers, was also identified by one participant to assist in addressing compliance as they are easy to carry in one’s pocket and are not as noisy as the plastic containers. One participant said:

“I always ensure that I have a seed bag then put them (ARVs) in my pocket”

(Participant S: Female, 16 years old)

The findings also revealed that the participants, who take their ARVs during trips, are those ones whose medication is kept by their teachers. For those who are staying in boarding school, the situation improves when the medication is kept by the boarding master or the matron.

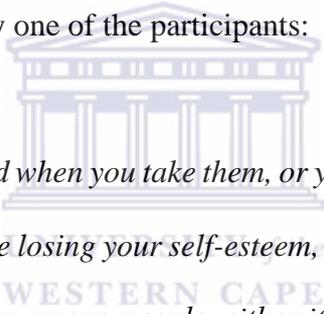
“I give them to my teacher to keep them for me” (referring to when on school trips)

(Participant N: Female, 18 years old)

“I ended up telling the boarding master and he took them and I started taking them from him” (Participant T: Male, 18 years old)

5.2.2.3c STIGMATISATION AND DISCRIMINATION

Fear of stigmatisation and discrimination was reported by most of the participants. They reported that they fear that if people know that they are on ART, they might stigmatise and discriminate against them. Participants also reported that when they are among people, they find a secret place to take their medication. The participants reported that if they do not find a secret place, they miss the dose because they do not want to risk taking it in public and being recognised as taking ARVs and then people might start to stigmatise them. The following is one of the statements expressed by one of the participants:



“Eish! At times you feel bad when you take them, or you become shy to take them among people, you feel like you are losing your self-esteem, asking yourself what people would say.....so I never take them among people, either it is during the day or night, I move away and take them secretly without anyone recognising” (Participant I: male, 18 years old)

The participants who stay in boarding facilities reported that because of minimal or lack of privacy they have been stigmatised and ill-treated by their roommates after they realised that they are HIV positive and are on ART. The roommates shared their statuses with their friends and it spread throughout the whole school. One of the participants, who is a boarding student, responded as follows:

(Sad) “It was not safe, the way they were treating me, I wasn’t having privacy, when someone is not having anything to say, they just gossip about my status with everyone at school or anywhere with anybody” (Participant S: female, 16 years old)”.

5.2.2.4 THEME 4: “NO MAN IS AN ISLAND”

This theme highlights the support that adolescents have been receiving and the support that they need from families, peers, hospital and schools to continue adhering with ART.

5.2.2.4.a IMPORTANCE OF SOCIAL SUPPORT

5.2.2.4a (i) FAMILY SUPPORT

Most of the participants expressed gratitude for the support they receive from family members. They reported that their family members encourage and motivate them to continue taking their medication. They remind them when it is time for medication and at times escort them to the hospital for check-ups. One participant said:

“Yah, no man can operate as an island, yah, I need support, and yah, they are giving me much support, obviously my mum, time and again she tells me how important this is, she keeps on reminding me how important this is...yes, and how does it benefit me and how it will benefit me in the future, because if I default now then it means all my dreams will be tarnished, so I have to keep on doing it for the sake of my happiness” (Participant H: male, 18 years old)

Participants reported that the support that they receive from their family members is encouraging and gives them hope for their future life. The family members inform them that

with the use of ARVs, they are less likely to be sick and therefore have a bright future ahead.

One participant said:

“So the support that I received was an encouragement to keep doing well in my medication so that I can become successful in life, not being disturbed by sickness and manage to continue learning at school” (Participant I: male, 18 years)

5.2.2.4a (ii) PEER SUPPORT

Only two of the participants mentioned that it is very vital that their peers be supportive to them. They reported that they need to love them and encourage them. This is what one participant said:

“There is need for love from roommates and friends and being encouraged here and there” (Participant S: female, 16 years old)



5.2.2.4a (iii) HOSPITAL SUPPORT

Most of the participants were thankful for the support they have received from the doctors and the nurses. They stated that the medical team usually offers them guidance and education on ART, and the importance of why they should continue with this. One of the participants pointed out as follows:

“Myself and other adolescents we need support and to always being taught about ARVs from the hospital and by our parents” (Participant P: male, 16 years old)

One participant was sceptical about how things are done in hospital in relation to people living with HIV. She stated that the two months period between check-ups is too short. According to this participant, they should be given at least six months in between each check-up. Her reasons were that these check-ups are delaying them as students because they miss a lot of school work at school. She argued that the doctors and nurses should assess case per case when giving dates for check-ups. Someone with good adherence like her should have very few check-up appointments. She quoted as follows:

“Yah, we are coming too frequently, more frequently, because two months is nothing.....at least six months because I think the doctors should look at how you take your tablets before they say...before they determine how many times you should come for check-up” (Participant V: female, 15 years old)

She also suggested that the other option can be to introduce weekend check-ups for students only, as it will also reduce the number of days they miss at school.

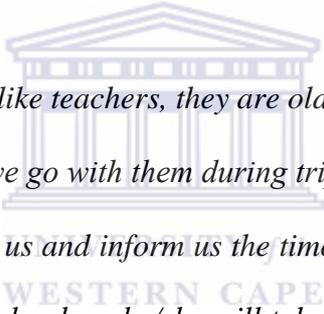
“Maybe the government should say there is Saturday check-ups so that people will be free on that time” (Participant V: female, 15 years old)

The findings also revealed the need for ARVs to be more accessible like all other medications in the hospital and clinics, not in IDCC where only HIV positive patients are attended to, as it is discriminatory. Normally ARVs are offered in a secluded place in the hospital and some clinics where only HIV positive patients are attended to.

“Ahh! Also ahh, beside ARVs, where we take them, I think they should be everywhere not in the IDCC only” (Participant V: female, 15 years old)

5.2.2.4a (iv) SCHOOL SUPPORT

The majority of the participants stated that it is important that their teachers, matrons and boarding master should protect them from being humiliated by their peers. During school trips, teachers should assist them by monitoring their medication and reminding them to take the medication. At the boarding facilities the boarding master, as well as the matron, can assist them by keeping the medication for them for confidentiality and safety purposes. The following expression was noted by one of the participants:



“I think parents at school, like teachers, they are old, maybe there are also affected we don't know, maybe when we go with them during trips, they should be informed of our status so that they support us and inform us the time for our medication, so that when it is time, the teacher can plan how he/she will take you privately for you to take your medication without other students recognising” (Participant I: male, 18 years old)

Another participant stated:

“At boarding school I think students should take their medications to the boarding master and the matron, because where they stay is not safe because there are so many in a room and it will be your secret if others do not know of it”. (Participant T: male, 18 years old)

5.3 SUMMARY

This chapter presented the findings of the study. The four themes that emerged were discussed in detail in this chapter which are “ARVs control but don’t cure”, which was basically discussing the knowledge that adolescents have on ART. Adolescents were found to have correct knowledge on issues of ARVs. The next theme discussed was “Why did it happen to me?-the reality of using ARVs”. This theme captured the experiences and challenges that are experienced by adolescents on ART. “I don’t want to take them for the rest of my life” is the third theme that was identified. The theme was looking at acceptance of HIV status, issues related to non-compliance to treatment as well as stigmatisation and discrimination among adolescents on ART. The fourth theme discussed was named “No man is an island”. This theme was basically looking at the support system that adolescents on ART need for them to continue adhering to treatment. Family support, peer support, hospital support and school support were discussed in relation to how they benefit the adolescents on ART and how they can be improved. The next chapter will discuss the findings of the study, supported by the latest literature and applying the findings to the theoretical framework of the Health Belief Model. It will also draw up the conclusions and the recommendations.

CHAPTER 6

DISCUSSION OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

6.1 INTRODUCTION

The study aimed to explore and describe adolescents' perceptions and experiences of anti-retroviral therapy at a tertiary hospital in Francistown, Botswana. The objectives addressed were: (i) to explore and describe adolescents' understanding of ARV therapy, (ii) to explore and describe adolescents' experiences of using ARVs, (iii) to explore and describe adolescents' perceptions of the factors related to their use of ARVs and (iv) to determine the support needed by adolescents on ART. Participants in the study were adolescents who are living with HIV, are receiving ART, and attending their reviews at a tertiary hospital in Francistown, Botswana. These were adolescents aged between 13 to 19 years of age who have been on ART for more than one year and they were all attending school. The participants provided information regarding their experiences and perceptions of antiretroviral therapy. Four themes emerged during the data analysis, as discussed in the previous chapter. Central to the study is that adolescents believe in ARVs, and that ARVs are a life saver, both for the participants who default treatment and those who adhere to treatment.

6.2 ADOLESCENTS' UNDERSTANDING OF ART

The findings revealed that the participants in the study had substantial knowledge of ART. Most of the participants (95%) knew that ART suppresses the virus, thereby controlling the progression of the disease. They had knowledge that ART is taken every day and that when one defaults treatment, one can die. These findings are in accordance with the findings of Nachenga et al. (2005), whom in their study on HIV/AIDS and Antiretroviral Treatment Knowledge, Attitudes, Beliefs, and Practices in HIV-Infected Adults in Soweto, South Africa,

found that 98% of their participants knew that ART can prevent disease progression. Nachenga et al. (2005) also reported that 90% of their participants agreed that ART prevents vertical transmission and 88% agreed that ART controls HIV. He also reported that 49% of his participants believed that ART could cure HIV. However, these findings are not in agreement with the findings of the current study as 23 (95%) of the participants knew that ARVs only control the HIV virus but does not cure. One participant did not have any knowledge on ART. However, it was not clear whether her lack of knowledge was ignorance or being in denial. The fact that this participant was on ART but did not know anything about it, poses serious threats to adherence. According to Nachenga et al. (2005), most participants knew that ART causes side effects as they had experienced it once. Only two participants in this study reported that ARVs do not cause side effects and that they had never experienced any side effects. Olowookere, Fatiregun and Adewole (2012) have found in their study on knowledge and attitudes regarding HIV/AIDS and antiretroviral therapy among patients at a Nigerian treatment clinic, that PLWHAs had a large amount of knowledge about ART but an unacceptable proportion did not have the basic knowledge of the purpose of the therapy, which is to improve the quality of life by increasing their CD4 count and reducing their viral load. Oguntibeju (2012) also supports the fact that ARVs improve quality of life. In his review on the quality of life of people living with HIV and AIDs and antiretroviral therapy, Oguntibeju (2012) noted that ARVs do not completely destroy the virus but it has proved to stop replication of the HIV. ARVs therefore lowers the viral load and thus increases people's life expectancy. Oguntibeju (2012, p. 119), defines improved quality of life as "the degree of excellence in a person's life at any given period that contributes to satisfaction and happiness of the person and benefits society".

6.2.1 ADOLESCENT KNOWLEDGE OF ART REGIMEN

The knowledge of ART regimen and how dosage is prescribed is an important element of adherence to ART. This is because ARVs are complex, have serious side effects, are not easy to be adhered to and have serious consequences of developing viral resistance because of non-adherence to the drug regimen or suboptimal levels of antiretroviral agent (Martin et al., 2007; Miller et al., 2003). Failing to reach maximum virologic suppression due to non-adherence, lead to viral replication thus losing the immunologic and clinical benefits of the intervention. (Conway, 2007; Dybul, Fauci, Bartlett, Kaplan & Pau, 2002). Participants in this study presented with excellent knowledge of their regimen by name and dosing. Only one participant had inadequate knowledge. This participant knew the names of the regimen but did not know how they are dosed in the absence of the medication containers. Only one participant did not have any knowledge at all. One of the reasons might be because these participants have been on ART for too long. Miller, et al. (2003) supported this finding of the study and found that poor knowledge of antiretroviral was common after a new regimen was prescribed. Participants in this study had been on ART for more than three years. However, the participants were all not asked of when they started on their regimen, which might have given a reason as to why one participant did not know his dosage and the other one did not have knowledge about it at all. However, with the ART regimen, most probably knowledge of the dosing is crucial to adherence as taking a wrong dose might lead to viral resistance.

6.2.2 THE IMPORTANCE OF ADHERING TO TREATMENT

Knowledge of the importance of adherence to treatment was remarkable among the participants in the study which is substantiating their knowledge of ART and this is very important for achieving high adherence to ART. Participants knew that they needed to take their ARVs every

day, at the correct time and take the correct dose, thus increasing the CD4 count in their body, suppressing the viral load, preventing early death and leading to prolonged healthy life. They knew that if they do not take their ARVs correctly, as prescribed by the clinicians, the virus will not be suppressed. The virus will attack all the CD4 cells and they will become sick with AIDS and could eventually die. Conway (2007) in his study on the role of adherence to antiretroviral therapy in the management of HIV infection, also argued that for the success of HAART, there is a need for good adherence. He argued that to optimise adherence, factors that affect good adherence such as pill burden, dosing frequency, food requirements and acute tolerability should be addressed adequately.

6.3 ADOLESCENTS' EXPERIENCIES OF USING ARVS

6.3.1 POSITIVE EXPERIENCIES OF USING ARVS

Antiretroviral therapy has brought lost hope to many HIV infected people. Before HAART was introduced, many people died of HIV/AIDS therefore leaving behind many orphans. With the introduction of ARVs many children perinatally infected with HIV reach the stage of adolescence and those who are horizontally infected also have access to ART (Ferrand et al., 2009; Spiegel and Futterman, 2009). ARVs are therefore seen as a life saver by many. In their study, Abadia-Barrero and Castro (2006) found that, though poverty and social inequality continue to dominate the lives of children living with HIV, access to HAART has assured survival and improved quality of life. According to Abadia-Barrero and Castro (2006), it became evident that HAART changes the social cause of AIDS and experiences of stigma when children reach adolescence.

The findings of this study revealed that HAART is a life saver and reduces stigmatisation. Some of the participants reported that they started HAART when they were really sick, some were even stigmatised and discriminated against by their friends. Since their initiation to HAART, they now look normal and live a healthy life. From the findings it was evident that the participants strongly believed in this medication and the happiness it brought to their lives, despite the challenges that they had to go through when taking the medication. Mutwa et al. (2013), support the findings of this study as their study on how living situations affect adherence among adolescents found that ART made students feel better and it also reduced infections. The participants in the study by Mutwa et al. (2013) reported poor health before HAART initiation. After HAART initiation, their health improved and they were able to resume their normal daily activities. Wolfe et al. (2008) also shared a similar sentiment as they reported that participants in their study believed that the availability of ART has decreased discrimination towards people living with HIV. ARVs are very effective and therefore transformed a deadly and often disfiguring disease into a manageable condition that is not necessarily visible to others.

6.3.2 NEGATIVE EXPERIENCIES OF USING ARVS

Despite the benefits that ARVs have brought to people living with HIV, participants in the study also reported negative experiences towards ART. These negative experiences reported by the participants were mainly in the areas of the social and the clinical challenges faced by the adolescents on ART.

SOCIAL CHALLENGES

It was evident from the findings that the lack of privacy or minimal privacy posed a social challenge for the participants on ART. They feared stigmatisation and discrimination from their

family members to whom their status has not been disclosed, their peers, and the community at large. Lack of or minimal privacy is therefore a threat to treatment adherence as at times adolescents would miss their dose or take the dose late when they were among other people. This was common during school trips and among participants who stayed in boarding schools. Mutwa et al. (2013) indicate that the lack of a private place to keep and take medication in boarding schools or for people staying in congested places hindered adolescents from taking their medication. Even those adolescents willing to take the medication, would opt to skip their medication among people in order not to disclose their status. Living like this was very stressful for these adolescents on ART as they were living with fear and always had to watch their backs, rather than enjoying their youthfulness like their peers who are HIV negative. In the study, due to the lack of privacy, one of the participants ended up moving out of the boarding facility to rent an apartment so that she could adhere to her treatment. This is extremely challenging for adolescents in boarding facilities as not all parents can afford to rent an apartment for their children. Renting an apartment also increases the financial burden for these adolescents who are on ART as they also need transport money for their monthly refills and check-ups.

The issue of privacy in boarding school needs a strategic approach of addressing it which is both structural and also social. HIV negative adolescents at boarding schools need to be educated on how to live in harmony with each other and devise tangible strategies that they can implement that can make living all enjoyable rather than stressful. They also need to be educated on how to behave and handle people living with HIV, being taught the challenges that adolescents living with HIV and on ART face, so that they can be supportive.

Difficult life situations such as lack of food due to poverty and lack of parental care results in poor adherence to ART. Adolescents are dependent on their parents for transport money for check-ups, food and clothes, and when a parent fails to provide food for them or fails to pay for their school fees it can be a reason enough to default treatment. Participants in the study reported that taking ARVs on an empty stomach lead to nausea. Not being cared for, such as your school fees not being paid for or not being provided with clothing, was reported by one participant to have affected his confidence; thus he lost hope in life and felt there was no need in continuing with ARVs. In Botswana, the orphan care programme and the destitute programmes are available to assist orphans and people who live in poverty respectively. However, the guidelines that are used to implement the orphan care programme and the destitute programme are not at times favourable to the orphans who still needs care when graduating from the orphan care programme at the age of 18 years, as they do not automatically graduate to destitution. This therefore means that an orphan can be removed from an orphan care programme and stay for months without receiving any assistance whilst still trying to access the destitution programme. An orphan is defined as any child below the 18 years of age who has lost either one parent (child of a single parent) or both parents (child of married parents), either biological or adoptive, (Ministry of Local Government, Department of Social Services, 2010). Married couples include those married in civil and traditional marriages. The orphan care programme provides assistance to adolescents until 18 years of age; however, at 18 years, some adolescents will still be in school and not yet independent but dependent on their guardians and or government. Most probably adolescents who are living with HIV are still in school mainly because they spent some years not attending school due to their illness. The destitute programme also caters for people who are not capable of working due to old age or disability. It therefore takes longer for adolescents who are still in school to get help after they are removed from the orphan care programme due to their age. One

participant who at times missed her doses because of lack of food, was assisted by providing her with a food basket, clothes and toiletry under the orphan care programme. As she turned 18 years of age, she was automatically removed from the programme without any arrangements made as to how she would be assisted in the future. Vervoort, Borleffs, Hoepelman and Grypdonck (2007) found similar results to the above argument when reviewing qualitative studies which were conducted on adherence in antiretroviral therapy as they established that several studies had identified that socioeconomic factors such as income, work, disability, homelessness and poverty negatively influences adherence to ARVs. Vervoort et al (2007) argued that it is important to address these factors amicably among patients on HAART.

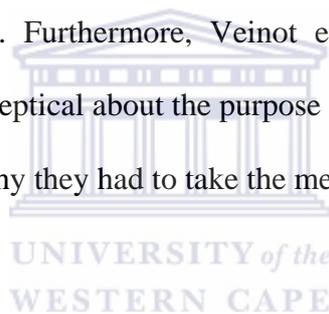
Most adolescents in Botswana who are on ART are orphans and cared for by their relatives and mostly by their unemployed grandparents, who only survive on the old age pension of P330.00 (R438.397) per month provided by the state. Removing an adolescent who is still at school from the orphan programme, does not only affect the adolescent's adherence due to the lack of food, but also affects the adolescent's education as it is difficult to concentrate with an empty stomach and other aspects of their social life such as being unable to pay for school trips or buying clothes. There is a need for the government of Botswana to develop a strategy of removing orphans on the orphan care programme. Age should not be the only determining factor of removing an orphan from the programme. Rather, as the orphan care programme caters for adolescents up to 18 years of age, those adolescents who are still at school and dependent on their guardians for their survival, need to be treated as special cases, and be transferred to the destitute programme where the benefits are equal.

CLINICAL CHALLENGES

Taking ARVs does not necessarily mean that there are visible symptoms that show that someone is sick. Many people are initiated on HAART whilst they are asymptomatic, but with a CD4 cell count ≤ 350 cells/ μ L (previously ≤ 250 cells/ μ L) (Ministry of Health, 2012). For some adolescents who were perinatally infected, some of them were initiated on HAART whilst they were sick and very young. By the time their status was disclosed to them, they were no longer sick. Not being sick can pose a challenge as it is likely to lead to denial of being HIV positive and therefore leads to poor adherence. One of the participants stated that it was difficult to take ARVs because she was not sick. This participant once defaulted treatment for months and was still not adherent as she reported that at times she just skipped the medication because she felt that it was tiring and that it was too much. She was the only participant who reported to be taking four different drugs in a day which might have led to her being pill fatigued. The other participant who defaulted treatment for months also argued that she defaulted because she was not sick and did not know why she had to keep on taking drugs. A similar finding was reported by Sanjobo, Frich, and Fretheim (2008) in a study on the barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia. In the study it was found that patients' feeling of improved health was a barrier to ART. When patients felt better, they stopped taking their medication. However, Sanjobo et al (2008), also found that for some patients, improved health motivated them to continue taking their ARVs, more especially those who started HAART when they were extremely sick.

Being on treatment and experiencing that one's status is not improving (virologic failure) also posed a challenge to participants taking ARVs. There was no motivating factor for some participants to continue adhering because their viral load was not suppressed and thus no benefits were noted of being on ART. Different factors might lead to virologic failure such as

poor adherence to treatment which might include missing doses and not adhering to time and missing appointments (Mugavero et al., 2009; Merzel et al., 2008). Such factors need to be identified well in advance and addressed adequately so that adolescents failing their treatment might be motivated to continue taking ARVs and enjoy the benefits like all other people on ART. In a study done on adherence to antiretroviral therapy, factors independently associated with reported difficulty taking antiretroviral therapy in a national sample of HIV-positive Australians by Grierson, Koelmeyer, Smith and Pitts (2011), findings revealed that personal attitudes such as not believing in the benefits of ART and concern about the effectiveness of ART in the future impacted on adherence to ART. A positive attitude towards the treatment is therefore necessary among adolescents living with HIV to enhance adherence so as to achieve the maximum viral suppression. Furthermore, Veinot et al (2006), also found that the participants in their study were sceptical about the purpose and value of HIV treatment. Many participants did not understand why they had to take the medication that does not cure.



Living on drugs is a challenge on its own as it is tiring and leads to pill fatigue. In a qualitative study done by Merzel et al. (2008) pill fatigue was reported to be a major challenge to older adolescents. Adolescents felt that as this is a life time drug, if they are tired of taking it they can skip one or two days. Merzel et al. (2008) noted that caregivers played a significant role in trying to ensure that adolescents do take the medication every day, even though it was difficult to monitor the grown up adolescents.

6.4 ADOLESCENTS' PERCEPTIONS OF THE FACTORS RELATED TO USE OF ARV

6.4.1 ACCEPTANCE OF STATUS

It is very important for people living with HIV to accept their status. Acceptance of their status proves to be resourceful in adherence to ART. It is unlikely for someone who has accepted his or her status to default treatment, and such people need minimal supervision from relatives and the medical personnel (Nam et al., 2008). For the six participants who reported that they had never defaulted treatment, all have accepted their statuses; other participants also reported that since they had accepted their statuses, they no longer default treatment as they used to and that they now appreciate the benefit of HAART. In a study by Nam et al. (2008) they found that acceptance of status was crucial to achieving adherence to antiretrovirals, whereas individuals experiencing adherence difficulties described aspects of denial. After accepting one's status, one does not internalise the issue of stigmatisation and discrimination but is interested in the positive outcomes of the medication (Nam et al., 2008). Nam et al (2008) argued that the patients who had accepted status managed to develop a therapeutic relationship with the medication. Patients in this study said HIV was "within me, how can I forget" (Nam et al. 2008, p. 303). Two participants who reported their adherence to treatment also explained that taking their ARVs is within them and their bodies react when it is time for their medication. Therefore, there is no way of forgetting to take their medication. Nam et al (2008) further noted that provision of support and care by someone close to you who shares the burden and the reality of HIV assists in one's acceptance of one's status and adherence to medication. One of the participants who used to default reported that she went for counselling at a Social Worker in the hospital, the emphasis being on her acceptance of her status. Her parents also played a significant role in emphasising the importance of accepting that she lives with HIV. Since she accepted her status, she no longer see any difficulties in taking ARVs and adheres well.

Olowokere et al. (2012), stated that, as much as most participants have a positive attitude to ART, there are some who have a negative attitude. About a third of their participants reported not to be convinced of their HIV status and did not think ART was necessary. Hence, they believed that this negative attitude might affect adherence as patients need to accept their status in order to take their medication.

6.4.2 NON COMPLIANCE

Adherence to HAART is key to boosting immunity by suppressing the virus and improving the CD4 count. For participants in the study, despite their correct knowledge that HAART works best only with good adherence to treatment, some found it difficult to adhere. Three main factors were identified that led to non-adherence. These were, forgetfulness, being a lifelong drug and lack of privacy during trips and in boarding schools. The most common reason for non-adherence was forgetting. Some studies have identified forgetting as the principal reason given for non-adherence of ART, (Mills et al., 2006; Vanthournout, Kelen, Elate, Goetghebuer Hainaut and Levy, 2013)

Other reasons for non-adherence that had been identified in various studies included being busy, being out of town, being asleep, being depressed, having adverse side effects, being too ill, size, taste, food restrictions as well as dosing times, lack of understanding of treatment benefits, complicated regimens (Ndiaye, 2013; Vanthournout et al, 2013; Mills et al, 2006)

Contrary to other studies, adverse side effects have not been identified as major factors which lead to non-adherence in the current study. Most participants have experienced the common side effects of ART which are dizziness and nausea but they did not link it to defaulting

treatment. Even the two participants who mentioned that side effects might lead to defaulting treatment, emphasised that their reasons for non-adherence was forgetting to take their medication. Those participants who reported adverse side effects such as developing breasts as a boy and change of the nail colour are among the six which had been reported to have never missed their doses, but only had minor episodes of taking them late, maybe once or twice in a year. This finding was supported by Watt et al. (2009) in a study done among adults aged 20 years of age and older in Tanzania. About one third of their respondents experienced side effects when they started ART, the common one being the abdominal symptoms, but the improvements of their health always over shadowed the side effects.

Other studies, (Sanjobo et al., 2008; Vervoot et al., 2007) found that side effects had an effect on compliance to antiretroviral therapy. Sanjobo et al. (2008, p. 36) noted that one of the participants in their study, a nurse, reported that in their clinic one patient had severe diarrhoea as a side effect to ART and wanted to stop because she could not cope with the diarrhoea. Another participant in their study reported the reason why she stopped taking ARVs was that it made her sexually aroused. Vervoot et al, 2007, suggest that patients should be informed of the expected side effects when being initiated on ART and how to manage them to minimise defaulting ART as a result of the side effects.

Being on a lifelong drug leads to pill fatigue. Some of the participants in the study believed that taking their HIV drugs every day had been their main challenge and that is why they defaulted treatment to give themselves a grace period. However, they understood that in ARVs there is no grace period; if you default there are adverse effects that you might encounter like being sick for a long time and eventually die. Conway, (2007) reported that there are studies;

(Cohen et al, 2005; Dybul et al, 2004) which have been done to allow for an “off day”, known as a forgiving period. The results of these studies have shown that, even with a viral suppression of <50 copies/mL, HIV RNA may remain undetectable for up to seven days after treatment is stopped (Conway, 2007:S16). One of the participants reported that the thought of taking the ARVs for the rest of his life made it very difficult for him to continue adhering. This participant questioned why the ARVs did not cure at once. Merzel et al. (2008) noted that in reduction of doses, for example, once-per-day-dosing may assist in improving and maintaining good adherence to ART.

The above mentioned factors that lead to non-compliance indicate that, as long as there is no cure for HIV/AIDS and there is no alternative to ARVs, people living with HIV will continue needing support from all stakeholders in the society so as to improve or maintain good adherence. People living with HIV will continue requiring emotional and financial support from their families as well as the community at large. They will also need the society to be understanding of the challenges that they face and therefore be supportive to them rather than being judgemental. The pharmaceutical industry also needs to continue developing friendly medication so as to reduce pill fatigue. One of the adherent adolescents was of the opinion that there is a need for injections that are taken at least after every month or two so as to reduce pill burden as the thought of taking the medication for the rest of her life was too much to bear.

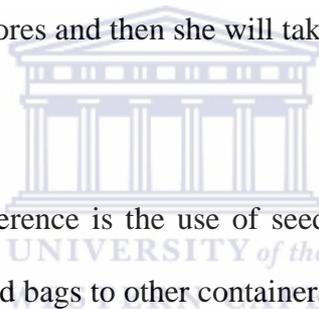
Lack of privacy is also a major challenge to adherence to treatment. Despite the benefits of ARVs mentioned by the adolescents, minimal or lack of privacy have an impact on adherence because adolescents want to keep their status a secret. Therefore, when they are among people, they are likely not take their medication, even if they have it with them. They fear to be labelled

as HIV positive by the public. This finding is supported by Golin, Isasi, Bontepi and Eng (2002) who stressed that participants in their study believed that taking ART was lifesaving, but missed doses because they feared that by taking them in public would reveal their status.

Different strategies to improve adherence have been employed and suggested by the participants in the study. The use of a watch/clock to set an alarm as reminders was the common method suggested by the participants. However, most of them reported not having a watch or a cell phone in order to set the alarm. This strategy therefore needs one of the relatives, who has a watch or cell phone, to be always available to be used by the adolescents to set the alarm. However, this is practically impossible as in many cases parents and guardians work and attend other community activities like meetings, funerals and weddings whereas the adolescents spend most of their times outside their homes. In a study done by Pop-Eleches et al. (2011) mobile phone technologies were used to improve adherence to antiretroviral treatment in a resource-limited setting. Message reminders on the cell phones were used to address barriers to adherence such as forgetfulness and lack of support. Patients were sent messages to remind them to take medication as well as for support. By the end of the study by Pop-Eleches (2011) patients who achieve more than 90% adherence to ART had increased by 13-16%. However, it should be noted that participants in this study were receiving the reminder messages from the clinic. This interventions shows that, if adolescents may use a form of reminder, for example, set an alarm to remind them, they can address the problem of forgetfulness and therefore enhance their adherence.

Incorporating taking ARVs into daily life activities is very important. One of the participants in the study said that she ensures that she eats at 5.30 am and p.m. every day, and at 6 o'clock

every morning and evening she will take her medication. Eating is a daily activity and if it is made regular then it works best for the person who is on ART to know when to eat every day. In a study by Castro, Gonzale and Perez (2015), a mother of two adherent children benefitted from a collaborative relationship in preparing and taking medication which may have contributed to their adherence success and reinforcement of behaviours and incorporation of it into their daily life. Watt et al (2009) also found that making a pill part of once-daily routine helps in adherence. One of her respondents in her study shared the same sentiments as the participant in the study by taking her medication at 10 a.m. and 10 p.m. She has a routine schedule of doing all house hold chores in the early morning and at 9.45 a.m. every day, she takes her breakfast and 10 a.m. she takes the medication. In the evening by 22.00 p.m., she will be done with all the household chores and then she will take her medication.



Another strategy to improve adherence is the use of seed bags as suggested by one of the participants. When comparing seed bags to other containers that are used to carry ARVs, seed bags are more user friendly as they are not noisy. Currently there is no stigma attached to seed bags as most medication for most illnesses are dispensed in seed bags and therefore taking your medication from a seed bag is not labelled as taking ARVs. However, ARVs are dispensed in large quantities and therefore it is practically impossible to dispense them in seed bags as the seed bag damages easily because they tear. So medication can still be dispensed in the plastic containers and the seed bags could be used for the convenience of the patient. A reasonable dose might be taken in a seed bag, maybe when going for trips or during family gatherings like weddings and funerals which are likely to compromise their privacy thus leading to defaulting treatment. For boarding students, they can also keep a reasonable dose in a seed bag which they can keep in their pockets and use at their convenience without having to open the noisy container everyday thus making their roommates suspicious. A study by Sithole

(2011) indicated that some adolescents used sweets boxes such as smarties sweets boxes (multi coloured small pill shaped chocolate sweets) to avoid being noticed whilst taking their medication. It is therefore vital to support adolescents in choosing strategies that can work best for each of them.

6.4.3 STIGMATISATION AND DISCRIMINATION

In the current study, stigmatisation and discrimination appear to have not directly affected most participants, but have been experienced by two participants who reside in boarding facilities. These two participants felt humiliated and eventually defaulted treatment. One participant who is a day scholar experienced stigmatisation at school. Participants reported that they feared to take their ARVs among people and during trips with their peers because they thought that if their peers/relatives or any other person might know their HIV status, they would be stigmatised. Therefore, these participants either took their ARVs late in privacy or missed them when they felt their privacy was being compromised. This finding shows that both perceived and experienced stigmatisation and discrimination are likely to equally lead to poor adherence to treatment. Similar to the study findings, in their analysis, Mutumba et al. (2014) found that stigma within schools in Uganda represents a serious challenge for adolescents living with HIV. Adolescents living with HIV in schools are stressed as they do not have safe places to keep their medication private as well as take their medication privately. They had a fear of premature disclosure to peers which might ignite stigmatisation and discrimination.

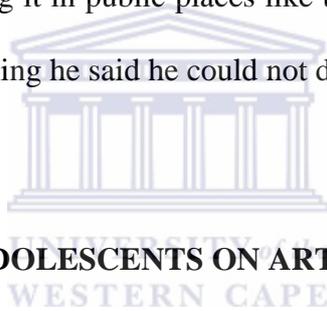
In a study done by Letamo (2003), he found that Batswana have discriminatory attitudes towards people living with HIV AIDs. Only 59.7% of the participants in his study reported that a teacher with HIV who is not sick should be allowed to teach and 39.9% reported that they

can buy food from an HIV positive person. However, an improvement in terms of discriminatory attitude towards PLWHA was reported 5 years later by Wolfe et al. (2008) in a study on “The impact of universal access to antiretroviral therapy on HIV stigma in Botswana”. 97% of their participants stated that a teacher with HIV who is not sick should be allowed to teach and 77% reported that they can buy food from an HIV positive person. Worth noting, is that, despite this improvement, Wolfe et al. (2008) noted that some people still have a discriminatory attitude. Wolfe et al. (2008) noted that 38% of the participants reported stigmatising attitudes and 70% of their respondents reported anticipated stigma.

In 2004, Letamo carried out a study on HIV/AIDS- related to stigmatisation among adolescents in Botswana who were aged 10-19 years of age. He found that most adolescents have discriminatory attitudes towards people living with HIV. Most adolescents in his study (68%) indicated that they would not buy vegetables from an HIV patient and about 54% argued that an HIV positive teacher should not be allowed to teach, even though he or she may not be sick. It is therefore not surprising to find participants at school, and mostly in boarding facilities being stigmatised and discriminated by their roommates and school mates. It is an indication that adolescents have negative or wrong perceptions towards people living with HIV/AIDS. Hence, it is central to being strategic as to how education on HIV/AIDS is being offered at schools and what it entails. HIV/AIDS and ART should be broad enough, not only to address how HIV is spread, how it is being prevented and how ARVs work, but it should also include all the psychosocial aspects that surround being HIV/AIDS and the difficulties of using lifelong drugs so as to reduce stigmatisation and discrimination and enhance peer support in schools. Mutumba et al. (2014) noted that stigma in schools might lead to non-adherence and affect adolescents’ academic performances. Mutumba et al. (2014) also noted that in Uganda the HIV/AIDS education at school should not only concentrate on imparting knowledge about

transmission and prevention. He suggested that HIV/AIDS education should be presented in such a way that it creates a context where youth may learn and question the social process of HIV/AIDS, produce or reinforce HIV/AIDS related to stigmatisation or understand the effect of stigmatisation on persons living with HIV/AIDS.

According to Watt et al. (2009), patients feared to miss their doses because of fear of stigmatisation and discrimination when one is sick. The participants carried the medication with them always so that they do not default and become sick. One of the participants in the study made an observation that adults usually carry their medication with them everywhere; and he often observed them taking it in public places like taxis, not fearing to be stigmatised and discriminated against, something he said he could not do.



6.5 SUPPORT NEEDED BY ADOLESCENTS ON ART

From the findings, participants highlighted the need for family and peer support, support from the hospital as well as support from the school. This support is expected to assist the participants to adhere to their HIV treatment.

6.5.1 SOCIAL SUPPORT

ARVs are life time drugs and people living with HIV in general and those who take ARVs need strong support and motivation from their relatives, friends and acquaintances. In Botswana, before initiation of ARVs, an HIV positive person needed to attend several counselling sessions with an adherence partner, (MOH, 2012). An adherence partner is an important person in the life of an HIV positive person as he/she is expected to be a motivator

of the person taking HAART and also remind him or her to take the medication and go for check-ups. Therefore the adherence partner should be included in all adherence discussions. The adolescent stage is a crucial developmental stage characterised by marked physical, emotional and intellectual changes as well as changes in social roles and expectations. Adolescents on ART require special treatment and care from their parents and relatives, the medical team, the educational team as well as from their peers. This support is crucial as these adolescents are in a treatment which requires a strong person who can make concrete decisions regarding his/her health. Kambale (2013) noted that adolescents on treatment need a treatment buddy because they are more likely to have a fragile mental state characterised by denial and fear of infection. Support might also assist avoidance of experiencing an attitude of low self-esteem.



6.5.2 FAMILY SUPPORT

Family plays a significant role in HIV/AIDS patient and ART. Family members motivate HIV patients to take their ART by reminding them when it is time for the medication and at times escorts them to their check-ups. In counselling they are the treatment adherence partners. According to Mutwa et al. (2013), adolescents living with their families felt that their family members (parents and siblings) generally provided a supportive environment, often reminding them to collect and take their medication. Kambale (2013) further noted that support by relatives was extremely important in his study. He found that adolescents who attended the facility accompanied by a direct relative, such as their mother, aunt or a sibling, were found to adhere better to their treatment than those were accompanied by a grandmother or those coming alone to the facility. Kambale (2013) noted that it is unfortunate that most adolescents stay with their grandmothers in rural areas, therefore contributing to a permanent issue affecting

adherence in the rural areas. Veinot et al. (2006) also noted that provision of support by trusted adults had a positive impact on adolescents on treatment. Their involvement on treatment and decision making as well as help to access HAART is very important for adolescents.

6.5.3 PEER SUPPORT

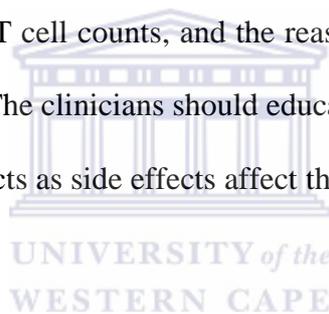
Adolescents spend most of their times with their peers, either at school or during play time hence the need of peer support for adolescence on ART. Unfortunately, most adolescents do not disclose their status to their peers due to fear of stigmatisation and discrimination. Participants in this study reported that, during school trips and in boarding facilities, they found it difficult to take their medication because they feared that their peers might know their status and start discriminating and stigmatising them. Sithole (2011) also shares a similar sentiment in that adolescents face multiple challenges in taking their medication on school trips and daily in school. Sithole (2011) argued that they do not want their peers to see them taking the medication and start questioning them about the medication they are taking as it might force them to prematurely disclose their status, thus risking stigmatisation. In this study, only one participant reported to have voluntarily disclosed her status to her friend. A female participant aged 16 years of age reported that her classmate found her medical card in her school bag, read it and then questioned her about the medication. She disclosed to her and the classmate started spreading news about her HIV status to her classmates and eventually to the school community. She eventually stopped taking the medication as she had lost hope that no one would ever accept her. Menon, Glazebrook, Campain, and Ngoma (2007), discovered that adolescents seem to be having particular problems with relationship with other young people. They thought that peer problems might be worsened by stigma associated with HIV.

Only two participants suggested that they needed support from their peers. One participant suggested that their peers need to provide them with love and support and the other one said they can assist them by reminding them to take their medication during trips. However, they are also not comfortable with disclosing their status to their peers. Most participants reported that they would never disclose their status to their peers. Peer support among adolescents is practically impossible as their friends do not know their status. It is very important to start addressing the issue of the relationship among HIV negative and HIV positive adolescents and devising strategies that adolescents who are not on ART might be appreciative and supportive of adolescents living with HIV without discriminating and stigmatising them. This is because many adolescents default treatment, mostly when they are with their peers, either at school, during sporting activities, during school trips and during outings. Also, adolescence is a stage where they start exploring with different things including sexual relationships. If adolescents are not comfortable with disclosing their status to their peers, they might find it difficult to disclose their status to their partner and thus pose as a health threat to both their partners and themselves. Adolescents living with HIV might infect their partners or be re-infected themselves thereby ending up with new infections among adolescents as well as a lot of adolescents who are resistant to treatment due to reinfections.

6.5.4 HOSPITAL SUPPORT

It was very evident from the study that the relationship between patient and the health care provider is very important and motivational for people on ART. The health care provider is very important in educating adolescents regarding their health and providing guidance to them. Vervoort et al. (2011) found that a good health care provider relationship can be a motivating factor to adherence to treatment. Health care providers' communication to patient should be of

good quality, the instructions in taking medication should be very clear and they should include the patients in decision making regarding their check-up schedules, as it is vital for treatment adherence (Vervoort et al., 2011). One participant in the study noted that their check-ups are too frequent, thus delaying them. It was not convenient for them to come to the hospital frequently, thus they were likely to miss the doctors' appointments or refill dates. Therefore, it was important to work with such a patient to develop a strategy that works best for her so that she does not relapse. It is crucial for the health care system to include patients in their decisions for optimal use and benefits of ART. According to Dybul et al. (2002), before HAART initiation, clinicians need to assess the readiness of the clients. When they educate them, they should include the goals of therapy, and include a review of expected outcomes that are based on baseline viral load and CD4^T T cell counts, and the reason for the adherence and the plan for the mechanics of adherence. The clinicians should educate patients on possible effects and what to do when having side effects as side effects affect their treatment adherence.



6.5.5 SCHOOL SUPPORT

Support from school by adolescents involves teachers' willingness to offer a parental role when adolescents are under their care by reminding them to take their medications. It also involves being assisted by the matron and the boarding master to keep medications safely for boarding students. This provides safety to the adolescent as well as increased privacy, thus improving adherence to medication. The finding is supported by Mutwa et al. (2013) who noted that supportive boarding school staff, like administrators, would keep medication in their offices to increase privacy and some boarding teachers would also assist the students in storing and taking their medication. As much as this might be a good strategy for privacy of adolescents' medication, the strategy can only work best when it is a team of administrators and teachers

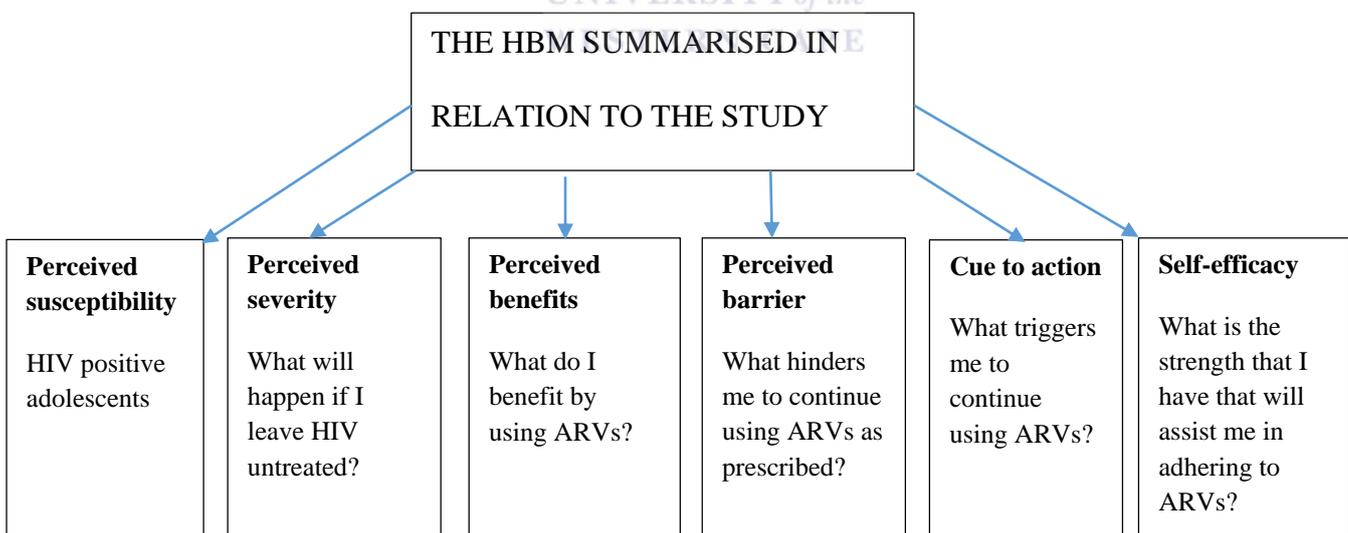
who are willing to keep the medication for adolescents, and each child being taken care of, by at least two people. This is because during the weekends, when teachers and the matrons are not on duty, they are likely to go outside school to attend social activities which might also hinder good adherence to medication. It can also work when those keeping the medication do not forget to give the adolescents extra doses to keep when they are outside the school.

6.6 APPLICATION OF THE FINDINGS TO THE HEALTH BELIEF MODEL

The Health Belief Model include six constructs as discussed in chapter 2 which are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy.

Figure 2 below illustrates how the constructs of HBM have been applied in the study

Figure 2: Application of HBM constructs to the study findings



6.6.1 PERCEIVED SUSCEPTIBILITY

This refers to the belief about likelihood of getting a disease (Glanz et al., 2008). Participants in this study were adolescents living with HIV/AIDS. These adolescents already have a health condition.

6.6.2 PERCEIVED SEVERITY

These are one's feeling or opinion and consequences of leaving an illness untreated (Glanz et al., 2008). From the findings it was evident that most participants believe that if HIV (which is a virus) is left "untreated" it manifests into AIDS, a disease which kills, having severe symptoms including the unbearable opportunistic infections like tuberculosis and cancer. The perceived severity of leaving HIV untreated made most participants use ARVs even though there were some who were defaulting the treatment. The findings of the study showed that adolescents used ARVs to suppress the HIV and to prolong life. The findings further showed that some participants used the ARVs to prevent being sick and being discriminated upon as they had a history of being discriminated due to being ill. Perceived severity of leaving HIV untreated therefore lead to the increased perceived benefits of using ARVs. This finding is consistent with the study done by Zhao et al. (2012) who found that perceived severity of HIV had a positive effect on condom use. Zhao et al. (2012) noted that the perceived severity led to increased perceived benefits of condom use. The findings also revealed that before accepting their status, most participants were defaulting on ARVs as they did not have an understanding of the condition they were living with, including its severity. A similar finding was reported by Kip, Ehlers and Van (2009) that people who do not perceive HIV as a severe condition, are likely to default HIV treatment and not use condoms consistently.

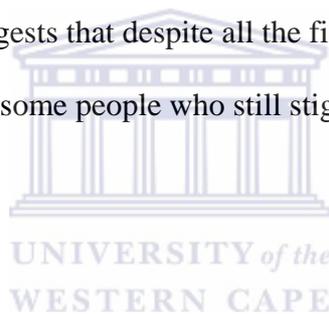
6.6.3 PERCEIVED BENEFITS

These are individual opinions and beliefs in the efficacy of what a patient has been advised to reduce the risk and the impact (Glanz et al., 2008). Therefore, participants who believe that they can successfully take a recommended health action can confidently take ARVs as prescribed despite stigmatisation and discrimination. The findings of the study revealed that most participants believe in the effectiveness of ARVs and the importance of adhering to the ARVs (perceived benefits). Despite some episodes of taking their doses late or missing doses at times by others, most participants showed commitment to ARVs as they believe that ARVs saves them and prolongs their lives. Participants now appreciate the quality of life, both mentally and physically, that has been brought by the ARVs. This is supported by Sharifirad, Entezari, Kamran and Azadbakht (2009) as they found similar information in a study where they used the HBM to determine the effectiveness of nutritional knowledge of diabetic patients. They found that the nutritional knowledge on the benefits of adhering to a diabetic diet, which is to control the fasting blood sugar, weight and lowering the cost of disease (perceived benefits), made the diabetic patients adhere to the recommended diet.

6.6.4 PERCEIVED BARRIER

These are potential obstacles to following the recommendations from the health team (Glanz et al., 2008). The findings of the study highlighted that lack of, or minimal privacy, forgetfulness and the fact that the ARVs are a long life drug as barriers to taking ARVs. These findings show that, though there was high perceived severity of fear of leaving the condition untreated, it did not encourage all participants to adhere fully to the ARVs as there are some who defaulted treatment. Some of the participants were defaulting because they felt that there is no need to take the medication when the virus is not being suppressed. These findings are

supported by Hounton, Carabin and Henderson (2005) whom, when analysing the determinants of behavioural change in their study population, found that though there was high-perceived vulnerability and perceived severity to being infected with HIV when not using condoms, the vulnerability and susceptibility did not encourage condom use. Hounton et al. (2005) reported that some of their participants did not believe in the efficacy of the condom, which acted as a barrier to condom use. The findings also showed that fear of stigmatisation acted as a perceived barrier to adhering fully to ARVs. Fear of stigmatisation as a perceived barrier to adhering to ARVs is consistent with findings by Nakigozi et al. (2013) who found that fear of stigmatisation hindered people to use HIV care services, when they did a study exploring barriers to entry into care from HIV positive clients, who had never enrolled in care and HIV care providers. This suggests that despite all the fight against stigmatisation amongst people living with HIV, there are some people who still stigmatise them.



6.6.5 CUE TO ACTION

These are strategies to stimulate the action. It is anything that can trigger a decision, (Burke, n.d). The findings of the study showed that for some of the participants, who once defaulted for months, started taking ARVs after several counselling sessions with the doctors, nurses and social workers. That is when they realised the need to continue with HAART. The messages from the counselling sessions are the ones which triggered their decision to take HAART. In a study by Do, Phiri, Bussmann, Gaolathe, Marlink and Wester (2010) on psychosocial factors affecting medication adherence among adults in Botswana, other than forgetfulness, ARVs' medication toxicity and complacency were identified to have an impact on poor adherence. To stimulate continuous use of ARVs, Do et al (2010) found that the adherence message to people who are being initiated on HAART should be greatly emphasised on the toxicity or the side

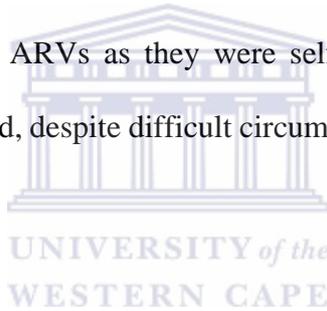
effects of HAART so that it can stimulate them to continue with HAART as they will have the correct knowledge. For those who have been in treatment for more than a year, communication should be more on complacency, as after being on treatment for a long period and having improved physically and mentally, patients tend to be less motivated to adhere to ARV medication. Do et al (2010) also suggested that personal testimonial of other patients should be used to motivate others to stay on ARVs.

6.6.6 PERCEIVED SELF EFFICACY

Bandura (1994, p. 2) define perceived self-efficacy as “people beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives”. People with high self-efficacy can aim at doing something to change their situations. The findings indicated that some participants in the study were self-efficacious. Most of the participants, despite the challenges (perceived barriers) that they went through as being HIV positive, take their ARVs as prescribed so as to suppress the virus and live a long, healthy life (perceived benefits). Some of the participants, though at some point in time they defaulted in their HIV treatment because of fear of stigmatisation, with counselling (cues to action) started taking their ARVs accordingly. A similar finding was found by Kip et al. (2009) as they found that almost all of their participants reported taking ARVs as prescribed and not sharing them with anyone. Almost all the participants in this study knew their regimen by name; only one participant did not know the regimen’s name. However, this finding is in contrast with the findings by Kip et al. (2009) as they found that about 46% of their participants could not name any ART drug.

6.7 SUMMARY OF THE APPLICATION OF THE HEALTH BELIF MODEL

Participants in this study were adolescents living with HIV. Perceived severity of leaving HIV untreated triggered participants to take ARVs due to the perceived benefits of adhering to ART which are: living a healthy and prolonged life. Several perceived barriers to good adherence such as forgetfulness, lack of privacy, it being a long life drug, hindered participants to fully adhere to the treatment. However, as the perceived benefits outweighed the perceived barriers, most participants believed in the efficacy of the ARVs. Communication from counselling services with the health team triggered the importance of medication adherence to those participants who defaulted treatment. Self-efficacy is an important element among people living with HIV. Most participants in the current study showed confidence in antiretroviral use and had good knowledge of the ARVs as they were self-efficacious. Participants tried to continue using ARVs as prescribed, despite difficult circumstances that they found themselves in.



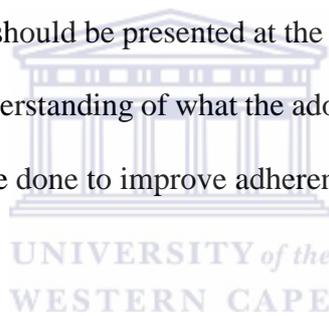
6.8 RECOMMENDATIONS

6.8.1 RECOMMENDATIONS TO THE MINISTRY OF HEALTH

- i. The finding of this study revealed that most of the participants' default treatment due to various reasons, despite the fact that they knew the consequences of defaulting treatment. Health workers should provide continuous education on the benefits of adherence to ART and the consequences of defaulting treatment at every hospital visit.
- ii. The time factor has been identified to be an issue in taking ARVs. All participants, even those who reported to have never missed a dose, reported to have at times taken their medication late. Counsellors need to emphasise the importance of tracking time and

encourage all parents to buy their children alarm watches for them to set reminders to take their medications.

- iii. The findings revealed that some participants, despite the fact that they are taking ARVs, are still failing on treatment (virologic failure). Failing on ARVs stresses the participants and demotivates them to continue with the medication. This therefore poses a threat to defaulting treatment and eventually developing resistance to the ARVs. It is therefore recommended that these adolescents be monitored closely by the health workers and offered education on the consequences of virologic failure on their health and be offered the knowledge and skills necessary to improve their overall health so as to suppress the virus.
- iv. The findings of the study should be presented at the IDCC so that the health workers at the IDCC have a clear understanding of what the adolescents are going through and the suggestions of what can be done to improve adherence to ARVs among adolescents.



6.8.2 RECOMMENDATIONS TO THE MINISTRY OF EDUCATION

- i. Discrimination and stigmatisation of adolescents living with HIV/AIDS have been identified to be experienced in school. In school, the HIV/AIDS education needs to be broadened to include the psychosocial aspects of HIV. Issues of how stigma and discrimination affect adherence to medication and the consequences of poor adherence should be included in the school curriculum (Life Orientation programme) so that adolescents can learn how to be supportive to each other when finding out that other scholars are on ARVs.

6.8.3 RECOMENDATIONS TO THE MINISTRY OF LOCAL GOVERNMENT AND RURAL DEVELOPMENT

- i. It was identified that some adolescents who are on ART are orphans who have been cared for under the orphan care programme, being assisted with food baskets. Upon reaching the age of 18 years these adolescents are removed from the orphan care programme as per the orphan care guideline and these adolescents default treatment due to lack of food. It is therefore recommended that the Ministry of Local Government and Rural development develop a policy of identifying orphans who exceed 18 years but who are still dependent on their guardians/parents and needy so that the ministry continues to take care of them until they finish school and are independent.



6.8.4 RECOMMENDATIONS FOR PRACTICE

- i. Lack of privacy in boarding facilities is a challenge to adherence. Participants staying in boarding facilities default treatment as a result of both experienced and perceived stigmatisation. The Ministry of Health and the Ministry of Education should work in collaboration to address the issues of lack of privacy in boarding facilities. The government should build private structures in the future, or develop the ones that they have to make the rooms a little more private where only few adolescents share the room, such as is done in universities whereby a room is shared by two people only. It is recommended that all learners should be provided with lockable cabinets so that they can keep their belongings privately and safely.

The researcher is aware that the sample used is little and mostly skewed on the 18-19 years old adolescents, and therefore does not represent the whole of Botswana. However, it is expected

that the findings of the current study could assist all the parties that are responsible for adolescents' life such as the Ministry of Health, Ministry of Education and Ministry of Local Government and Rural development and all other stakeholders, including non-governmental organisations that deal with adolescents living with ARVs to develop strategies, policies and training programmes that could be beneficial to adolescents living with HIV and on ART.

6.8.5 RECOMMENDATIONS FOR FURTHER RESEARCH

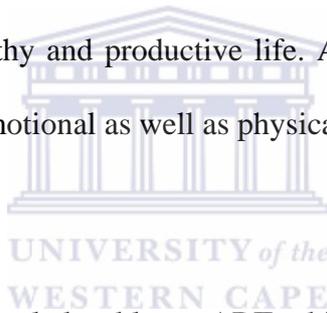
The following research studies should be considered in the future:

- i. The findings of the study show that peer support is very important among adolescents living with HIV. However, adolescents do not have peer support, despite the fact that they spend most of their time with their peers. Future research should include types of support groups that could assist adolescents living with ART. This is important because other studies have shown that support groups among HIV positive adolescents bring positive results as they all have a common condition. Peer support among all adolescents, either HIV positive or HIV negative is therefore important as all of these adolescents are in the same developmental stage and therefore understand each other better.
- ii. From the findings, adolescents who stayed in boarding schools experienced stigmatisation and discrimination because of lack of privacy. It is recommended that further research needs to be done to explore why adolescents in boarding facilities experience stigmatisation and discrimination and to develop strategies to deal with stigmatisation and discrimination in boarding facilities.
- iii. The findings also revealed that the use of seed bags can improve adherence. A longitudinal/experimental pilot study on the feasibility of the use of seed bags to address

defaulting due to lack of privacy needs to be done among adolescents in schools. Furthermore, research on exploring whether seed bags really contribute to improving adherence to ART or not should be undertaken.

6.7 CONCLUSION

HIV/AIDS is a world concern. Botswana has been highly affected with the HIV epidemic socially and economically. The introduction of ART has changed the HIV pandemic from a most feared disease to a controllable chronic disease. Children who were born with HIV have reached the stage of adolescence as a result of antiretroviral therapy. It is therefore vital to work with and support adolescents living with HIV who are on ARVs as they need strict adherence to ARVs for them to live a healthy and productive life. Adolescents are a fragile group of people as they undergo a lot of emotional as well as physical changes.



Adolescents have been found knowledgeable on ART which is vital for adherence to ART. Studies have shown that knowing the ARVs an individual is taking and how they are dosed, plays a significant role in adherence to ART. Having correct knowledge about ARVs among adolescents is an important element in managing HIV. In order for adolescents to adhere well to treatment, they need to have knowledge and understanding of the consequences of taking their medication. Having an understanding, helps the adolescents to make informed decisions regarding their treatment and their health. Adolescents need continuous health education and emotional support to be adherent to their medication. If the virus is not controllable, despite the fact that one is taking ARVs, it demotivates adolescents to continue taking the ARVs. Adolescents therefore need to be in control of how they take their treatment so that there is adherence to minimise an uncontrollable virus. It is vital to emphasise the importance of

adherence to treatment so that there are minimal cases of drug failures. Adolescents need to devise strategies or activities that will remind them that they have to take the ARVs every day without failure.

Participants in the current study have both positive and negative experiences of using ARVs. ARVs have brought lost hope to the participants and have restored their happiness through healthy living. Despite these positive outcomes of using ARVs, participants face daily challenges of coping with a lifelong treatment whilst they are adjusting to the psychosocial and physical challenges of the developmental stage. Participants' perceptions of ART are clinically relevant. Acceptance of HIV status is key to medication adherence and only good adherence can result in positive results of using ARVs. Social support is very important for adolescents on ART. Family plays a significant role in the care of an adolescent living with HIV. Educational support as well as motivation to continue taking ARVs by the health team is of utmost importance. The significant role played by the school and the boarding master contribute positively in terms of adherence to treatment. Peer support was also identified as vital, although not available, to most adolescents. Adolescents fear to disclose their status to their peers due to fear of stigmatisation and discrimination. This is a challenge to the health system as adolescents spend most of their time with their peers.

It can therefore be concluded that with adequate knowledge and support from all the relevant stakeholders, adolescents are likely to adhere to their treatment. HIV/AIDS have been around for over two decades and ARVs have been around for over a decade in Botswana. However, adolescents living with HIV still face challenges such as stigmatisation due to social as well as clinical factors and adjusting to a lifelong treatment which makes it difficult for them to adhere

to their treatment. ARVs have saved the lives of many people and therefore it can be termed as “the precious diamond in the era of HIV”. Many adolescents are happy as they are living a healthy and fruitful life as a result of the ARVs. Despite the challenges that adolescents living with HIV face, they are now hopeful and have future plans for their lives. A public presentation will be done at the tertiary hospital in Francistown, Botswana. It is hoped that the findings of the research will bring value to the work of the IDCC staff and health care at the hospital and elsewhere where they deal with adolescents living with HIV.



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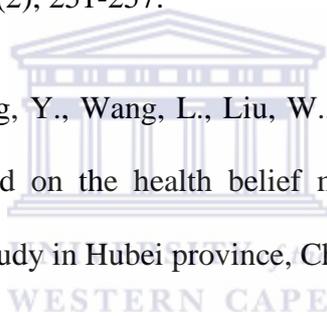
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APPENDICES



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APPENDIX 1

INTERVIEW SCHEDULE

Title of Research Project: Adolescents' perceptions and experiences of anti-retroviral therapy (ART) at a tertiary hospital in Francistown, Botswana

Name of Interviewer.....

Place of interview.....

Date of interview.....

Mini background of participant

Gender.....

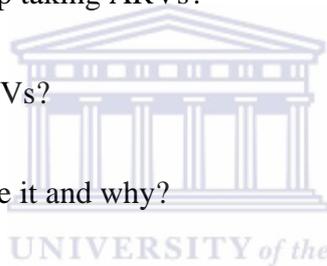
Age.....

Level of study.....

Date of ARV initiation.....

Questions

1. What is your understanding of the use of ARVs?
2. Tell me about your experiences of using ARVs.
3. What do you think the benefits are of using ARVs? (What is good about it?)
4. What do you think are the disadvantages of using ARVs? (What is bad about it?)
5. Do you take your ARVs every day?
6. What makes it difficult to keep taking ARVs?
7. What makes it easy to keep taking ARVs?
8. How do you take your ARVs?
9. Do you sometimes not take it and why?
10. What do you need to make sure that you use your ARVs as prescribed?
11. Is there any other thing that you would like to share with me in relation to anti-retroviral therapy?





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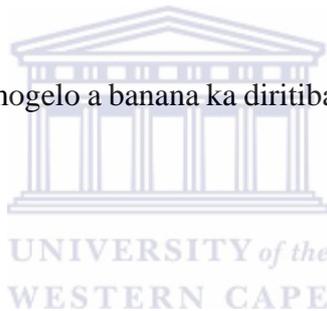
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APPENDIX 2

Lenaneo la potsoloso

Setlhogo: Dikakanyetso le maitemogelo a banana ka diritibatse tsa mogare mo kokelong kgolo mo Francistown, Botswana



Leina la mosekaseki:.....

Lefelo la potsoloso:.....

Letsatsi la potsoloso:.....

Ka ga gago

Bong.....

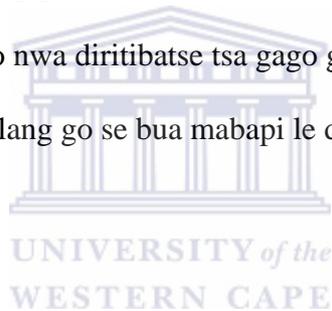
Dingwaga.....

O bala mang.....

Letsatsi le o simolotseng diritibatse.....

Dipotso

1. O tshaloganya eng ka ga diritibatse tsa mogare?
2. Maitemogelo a gago mo tirisong ya diritibatse tsa mogare ke eng?
3. O akanya gore mosola wa diritibatse tsa mogare ke eng? (ke eng se se molemo ka tsone)
4. Ke eng se se bosula ka go dirisa diritibatse tsa mogare?
5. A o nwa diritibatse tsa gago malatsi otlhe?
6. Ke eng se se dirang gore go nne thata go tswelera o nwa diribatse tsa mogare?
7. Ke eng se se go tlhofofaletsang gore o tswelere o nwa diritibatse tsa mogare?
8. O nwa jang diribatse tsa gago?
9. A gona le nako e o tlodisang go dinwa? (bua lebaka fa o e tle o tlodisa)
10. O tlhoka eng go tswelera o nwa diritibatse tsa gago go ya ka ditaelo tsa bongaka?
11. A gona le sengwe se o batlang go se bua mabapi le diritibatse tsa mogare?





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APPENDIX: 3

INFORMATION SHEET

Title of Research: Adolescents' perceptions and experiences of anti-retroviral therapy (ART) at a tertiary hospital in Francistown, Botswana

What is this study about?

This is a research project being conducted by myself, a post graduate Social Work student from the University of the Western Cape. I am inviting you to participate in this research project as you are an adolescent living with HIV/AIDS and you are on antiretroviral therapy. The aim of this research project is to explore adolescents' perceptions and experiences of antiretroviral therapy at a tertiary hospital in Francistown, Botswana.

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

You will be asked to participate in a semi-structured interview. Each individual interview is expected to take at least an hour. The interviews will be held at the tertiary hospital infectious disease control centre or at a venue of your choice. I will address questions based on your perceptions and experiences of anti-retroviral therapy.

Would my participation in this study be kept confidential?

Your personal information will be kept confidential. To help protect your confidentiality, all recording of the interviews will be kept in a locked cabinet and only the researcher will have access to these documents for the purpose of the study. To help protect your confidentiality, I will be using pseudonyms when reporting the study results. Therefore, none of the participants' real names will be used in the study. Thus, a code will be placed on the interview sheet in order to protect confidentiality and through the use of an identification key, the researcher will be able to link the interview sheet to your identity. However, only the researcher will have access to this key. If I write a report or article about this research project, your identity will be protected to the maximum extent possible.



What are the risks of this research?

There may be some risks from participating in this research study, such as eliciting emotional and personal experiences that you have encountered during your hospital visits. Within the interviews, the participants may be made to feel emotionally uncomfortable and this will be managed by the researcher by means of one- on- one debriefing with participants or participants will be referred to the Social Work department at the tertiary hospital for counselling.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the researcher to learn more about adolescents' perceptions and experiences of ART. I hope that, in the future, other people might benefit from this study by understanding adolescents who are receiving

ART. Recommendations will be made to assist the Infectious Disease Control Centre and the Educational sector in providing relevant services to adolescents.

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

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

Is any assistance available if I am negatively affected by participating in this study?

Counselling services from the tertiary hospital's Social Work department will be available as a resource to assist if emotional distress is experienced by the participants. The participants will also be provided with a list of contact details of relevant resources to provide them with various options.

What if I have questions?

This research is being conducted by myself, a post graduate social work student from the University of the Western Cape. If you have any questions about the research study itself, please feel free to contact my supervisor, Dr J de Jongh at: The Occupational Therapy Department at the University of the Western Cape at: 021 9592544 or email: jdejongh@uwc.ac.za. Should you have any questions regarding this study and your rights as a

research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department: Professor C. J Schenck

Department of Social Work

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Private Bag X17

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Ph: 021-959 2277

Dean: Prof. J. Frantz

Faculty of Community and Health sciences

University of the Western Cape

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Supervisor: Dr J. de Jongh

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This research has been approved by the University of the Western Cape's Senate Research Ethics Committee.



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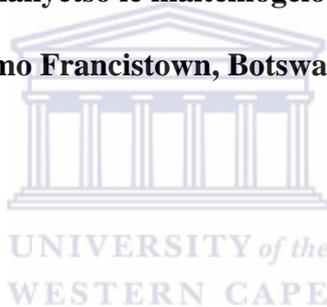
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APPENDIX: 4

Dintlha tsa bothokwa ka ditshekatsheko

Setlhogo sa tshekatsheko: Dikakanyetso le maitemogelo a banana ka tiriso ya diritibatse tsa mogare mo kokelong kgolo mo Francistown, Botswana



Tshekatsheko e ke ka ga eng?

Mona ke tshekatsheko e e dirwang ke nna Bongani Lebo Kebuang, moithuti ko sekolong se se golo se gotweng University of the Western Cape. Ke go laletsa go tsaya karolo mo tshekatshekong e ka o le monana yo o tshelang ka mogare wa HIV/AIDS ebile ole mo diritibatseng tsa mogare. Maikaelelo magolo a tshekatsheko e ke go batlisisa ka ga maitemogelo le dikakanyetso tse banana ba nang le tsone, tebang le tiriso ya diritibatse tsa mogare ko kokelo kgolo mo Francistown, Botswana.

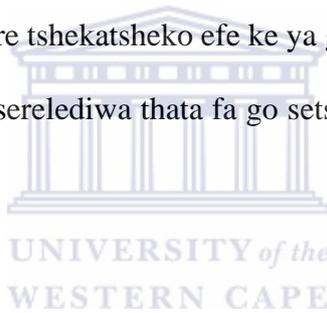
Ke tsile go botswa eng fa ke dumela go tsaya karolo?

O kopiwa go tsaya karolo mo potsolotsong. Go solofetswe gore potsolotso nngwe le nngwe eka tsaya oura. Ditshekatsheko di tlaabo di tshwaretswe mo lephateng la tlhokomelo malwetse

a a tshelanwang kgotsa ko felong le otlala le tlhophang. Dipotso tse di tlaa botswang di tlaabo di lebagane le maitemogelo le dikakanyetso tsa gago tebang le diritibatse tsa mogare.

A go tsaya karolo game mo tshekatshekong e go tlabo go sireletsegile?

Sengwe le sengwe ka ga gago setla sirelediwa. Dipotsolotso tsotlhe le tse di gatisitsweng di tla lotlelelwa mo kobotlong e e bulwang ke mosekaseki fela ele tsela ya go go sireletsa. Go go sireletsa, go tlaa dirisa maina a maitlhamelo fa go kwala mokwalo tshoboko. Ka jalo ga gona leina la motsaya karolo ope le le tla kwalwang mo pampering ya tshekatsheko. Pampiri nngwe le nngwe ya tshekatsheko etla direlwa sesupo se se tlaa thusang go go sireletsa, ka jalo mosekaseki o ka kgona go itse gore tshekatsheko efe ke ya ga mang. Mosekaseki ke ene fela a tlaabong ana le selotlolo. O tlaa sirelediwa thata fa go setse go kwala mokwalo tshoboko ka ga tshekatsheko e.



Bodiphatsa jwa tshekatsheko e ke eng?

Go tsaya karolo mo tshekatshekong e go ka nna le diphatsa tse di tshwanang go gogomoga maikutlo ka tse di go diragaletseng fa o ntse o tla kokelong. Fa se se ka diragala, mosekaseki o tla a buisana le wena kaga maikutlo a gago. Gape, o ka romelwa ko go bomaitsaanape ba tsa tshidilo maikutlo mo sepateleng.

Mosola wa tshekatsheko e ke eng?

Tshekatsheko e ga e dirwa gore e nne le mosola mo go wena ole mongwe fela, mme maduo a yone a ka thusa mosekaseki go ithuta gole gontsi ka dikakanyetso le maitemogelo a banana

tebang le diritibatsi tsa mogare. Ke solofela gore mo isagong tshekatsheko e e tla thusa ba bangwe ka go tshaloganya dikakanyetso le maitemogelo a banana ka diritibatse. Megopolo e tla fetisediwa ko go ba lephatha la tlhokomelo ya malwetsi a a tshelanwang le ba lephata la thuto go ba thusa go tlhoma mananeo le dithuso tse di maleba go ka itebaganya le dikgwetlho sa banana ba.

A ke patelesega go tsaya karolo?

Go tsaya karolo ga gago ke ka boithaopo. O ka tlhopha go sa tsaya karolo. Fa o ka tlhopha go tsaya karolo, o ka tlogela nako nngwe le nngwe fa o sa tlhole o batla go tswelela o tsaya karolo. O ka se otlhaiwe kgotsa ga kganelwa sepe se se ntseng se go lebagane fa o ka se tseye karolo kgotsa o ka emisa go tsaya karolo.



A gona le thuso nngwe e ke ka e fiwang fa ke ka amega ke go tsaya karolo mo tshekatshekong e?

Ba lephata la tshedilo maikutlo la sepatela ba teng go ka gofa dithuso tse di maleba fa o kgoberilwe maikutlo ke go tsaya karolo. Batsaya karolo batla fiwa molaetsa ka ga maphata otlhe a ba ka bonang thuso ko go one.

Ke dire jang fa kena le dipotso?

Kele moithuti mogolo wa lephata la Social Work mo sekolong sa University of the Western Cape, ke nna mosekaseki wa tshekatsheko e. Fa ona le dipotso ka ga tshekatsheko e, o ka botsa mookame di wame Dr J de Jongh at: The Occupational Therapy Department ko University of

the Western Cape mo: 021 959 2544 kgotsa email: jdejongh@uwc.ac.za. Fa ona le dipotso
tebang le tshekatsheko e kgotsa, ka ditshwanelo tsa gago kgotsa o batla go bolela bothata jo o
kopaneng najo mabapi le tshekatsheko e o ka bua le:

Head of Department: Professor C. J Schenck

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Dean: Prof. J. Frantz

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Supervisor: Dr J. de Jongh

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Tshekatsheko e e amogetswe ke komiti ya ditshekatsheko ya University of the Western Cape



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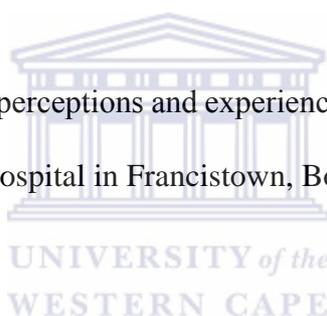
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APPENDIX 5

Consent Form-Interview

Title of Research: Adolescents' perceptions and experiences of anti-retroviral therapy (ART)
at a tertiary hospital in Francistown, Botswana



The study has been described to me by means of the Information Sheet, in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's Name: Participant's Signature:

Date:

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the researcher.

Researchers: Bongani Lebo Kebuang

Email: blselape@gmail.com

Cell: +27 723952152/+267 71290619

Should you have any questions regarding your rights as a research participant, you may also contact:

Supervisor: Dr J de Jongh

Email: jdejongh@uwc.ac.za

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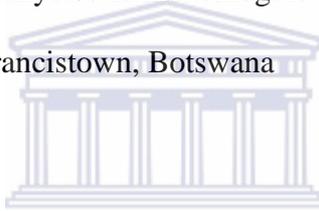
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E-mail: jdejongh@uwc.ac.za

APPENDIX 6

Fomo ya tumalano-Potsoloso

Setlhogo sa tshekatsheko: Dikakanyetso le maitemogelo a banana ka tiriso ya diritibatse tsa mogare mo kokelong kgolo mo Francistown, Botswana



Ke tthaloseditswe ka tshekatsheko e go dirisiwa mokwalo wa dintlha tsa botlhoka. Go tthalositswe ka teme e ke e tthaloganyang, ka jalo ke itlhaopela go tsaya karolo. Dipotso tsame kaga tshekatsheko e di arabilwe. Ke itse fa seriti same se tlaa serelediwa, go sena yo o ka bolelwang gore kene keke motsaya karolo. Nka nna ka emisa go tsaya karolo nako nngwe le nngwe mo go tseyeng karolo mo tshekatshekong e ke sa fe mabaka ape, mme seo se ka seke se nkame ka gope.

Leina la motsaya karolo.....

Monwana wa motsaya karolo.....Letsatsi.....

Fa o nale potso ka ga tshekatsheko e, kgotsa o amegile mabapi le tshekatsheko e, o ka bua le mosekaseke.

Mosekaseki: Bongani Lebo Kebuang

Email: blselape@gmail.com

Cell: +27 723952152/+267 71290619

Fa o nale potso tebang le ditshwanelo tsa gago o le mo tsaya karolo o ka bua le:

Mookamedi: Dr J de Jongh

Email:jdejongh@uwc.ac.za

Phone: 021-959 2544





UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2544 Fax: 27 21-959 1440

E-mail: jdejongh@uwc.ac.za

APPENDIX 7

Assent for participation in the study

(To be signed by the participants below 18 years. This form must be accompanied by signed parental/guardian consent form)



Title of Research: Adolescents' perceptions and experiences of anti-retroviral therapy (ART) at a tertiary hospital in Francistown, Botswana

I.....hereby acknowledge that the researcher has discussed with me all the aspects of the study, and how it will be carried out. I understand the purpose of the study and confirm that I have been allowed adequate opportunity to ask questions where I do not understand.

The decision to participate in the study is solely my own.

By signing my name I agree to participate in the study. I know and understand that participation is entirely voluntary and that I may choose to withdraw at any time without any punishment.

I have had the study explained to me and I am willing to participate at my own free will.

Participant's Name:

Participant's Signature:

Date.....

Should you have any questions regarding this study or wish to report any problems your child have experienced related to the study, please contact the researcher.

Researchers: Bongani Lebo Kebuang

Email: blselape@gmail.com

Cell: +27 723952152/+267 71290619



Should you have any questions regarding your rights as a research participant, you may also contact:

Supervisor: Dr J de Jongh

Email:jdejongh@uwc.ac.za

Phone: 021-959 2544



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

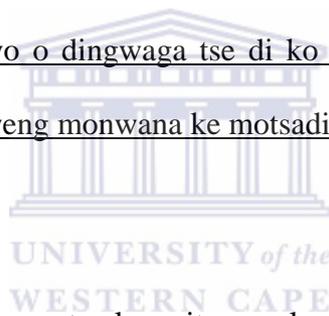
Tel: +27 21-959 2544 Fax: 27 21-959 1440

E-mail: jdejongh@uwc.ac.za

APPENDIX 8

Tumalano ya go tsaya karolo mo tshekatshekong

(E tladiwa ke mo tsaya karolo yo o dingwaga tse di ko tlase ga borobabobedi. Fomo e e tshwanetse go patiwa ke e e beilweng monwana ke motsadi kgotsa motlhokomedi.



Setlhogo sa tshekatsheko: Dikakanyetso le maitemogelo a banana ka tiriso ya diritibatse tsa mogare mo kokelong kgolo mo Francistown, Botswana

Kele.....ke rurifatsa fa ke buisantse le mosekaseki gotlhe ka ga tshekatsheko e le gore e tsile go dirwa jang. Ke tlhaloganya mosola wa tshekatsheko e mme ke dumela fa ke filwe nako go botsa dipotso fa ke sa tlhaloganyeng teng.

Ke itseetse tshwetso ya go tsaya karolo mo tshekatshekong e.

Ka go baa monwana wame, kedumela go tsaya karolo mo tshekatshekong e. Ke a itse ebile ke dumela fa go tsaya karolo game e le ka boithaopo le gore nka nna ka tlogela nako nngwe le nngwe ke sa kobiwe.

Tshekatsheko e ke e tlhaloseditswe mme ebile ke ithaopa go tsaya karolo ka bonna.

Leina la mo tsaya karolo:

Monwana wa motsaya karolo:

Letsatsi.....



Fa o na le potso ka ga tshekatsheko e, kgotsa o amegile mabapi le tshekatsheko e, o ka bua le mosekaseki.

Mosekaseki: Bongani Lebo Kebuang

Email: blselape@gmail.com

Cell: +27 723952152/+267 71290619

Fa o na le potso tebang le ditshwanelo tsa gago o le motsaya karolo o ka bua le:

Mookamedi: Dr J de Jongh

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E-mail: jdejongh@uwc.ac.za

APPENDIX 9

Parental/Guardian Consent Form– Interview

I am requesting permission from you to allow your child to participate in a research study that involves participating in an interview.



Title of Research: Adolescents' perceptions and experiences of anti-retroviral therapy (ART)
at a tertiary hospital in Francistown, Botswana

The study has been described to me by means of the Information Sheet, in a language that I understand. I freely and voluntarily grant permission for my child to participate in the study. My questions about the study have been answered. I understand that the identity of my child will not be disclosed and that he/she may withdraw from the study without giving a reason at any time and this will not negatively affect him/her in any way.

Parents/Guardian name:.....

Parent/Guardian Signature.....

Date:.....

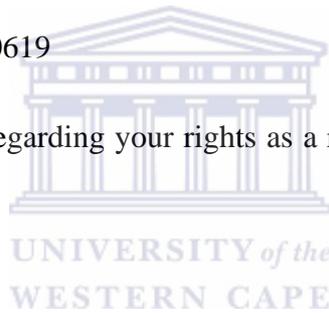
Should you have any questions regarding this study or wish to report any problems your child have experienced related to the study, please contact the researcher.

Researchers: Bongani Lebo Kebuang

Email: blselape@gmail.com

Cell: +27 723952152/+267 71290619

Should you have any questions regarding your rights as a research participant, you may also contact:



Supervisor: Dr J de Jongh

Email:jdejongh@uwc.ac.za

Phone: 021-959 2544



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E-mail: jdejongh@uwc.ac.za

APPENDIX 10

Tumalano ya go tsaya karolo ya motsadi/motlhokomedi-Potsoloso

Ke kopa gore ofe ngwana wa gago tetla ya go tsaya karolo mo tshekatshekong ka go botsolotswa dipotso



Setlhogo sa tshekatsheko: Dikakanyetso le maitemogelo a banana ka tiriso ya diritibatse tsa mogare mo kokelong kgolo mo Francistown, Botswana

Ke tthaloseditswe ka tshekatsheko go dirisiwa mokwalo wa dintlha tsa botlhokwa ka teme e ke e tthaloganyang. Keitlhaopa go go fa tetla ya gore ngwanake o ka tsaya karolo mo tshekatshekong e. Dipotso tsame ka ga tshekatsheko e di arabilwe. Ke dumela fa seriti sa ga ngwanake setla serelediwa le gore o kanna a emisa go tsaya karolo nako nngwe le nngwe asa fe mabaka mme seo seka seke se mo ame ka gope.

Leina la Motsadi/Motlhokomedi:.....

Monwana wa Motsadi/Motlhokomedi.....

Letsatsi:.....

Fa o nale potso ka ga tshekatsheko e, kgotsa ngwana wa gago a amegile mabapi le tshekatsheko e, o ka bua le mosekaseki.

Mosekaseki: Bongani Lebo Kebuang

Email: blselape@gmail.com

Cell: +27 723952152/+267 71290619



Fa o nale potso tebang le ditshwanelo tsa gago o le motsaya karolo o ka bua le:

Mookamedi: Dr J de Jongh

Email: jdejongh@uwc.ac.za

Phone: 021-959 2544



**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT**

4 November 2014

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Mrs BL Kebuang (Social Work)

Research Project: Adolescent' perceptions and experiences of anti-retroviral therapy (ART) at a tertiary hospital in Francistown, Botswana.

Registration no: 14/9/29

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

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*

TELEPHONE: 363 2766
FAX: 391 0647
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

Republic of Botswana

REFERENCE NO: PPME 13/18/1 PS V (340)

12 January 2015

Health Research and Development Division

Notification of IRB Review: New application

Bongani Lebo Kebuang
P.O. Box 301960
Francistown

Protocol Title:

**ADOLESCENTS PERCEPTIONS AND
EXPERIENCES OF ANTI-RETROVIRAL
THERAPY (ART) AT A TERTIARY
HOSPITAL IN FRANCISTOWN, BOTSWANA**

HRU Approval Date: 12 January 2015
HRU Expiration Date: 12 January 2016
HRU Review Type: HRU reviewed
HRU Review Determination: Approved
Risk Determination: Minimal risk

Dear Ms Kebuang

Thank you for submitting new application for the above referenced protocol. The permission is granted to conduct the study.

This permit does not however give you authority to collect data from the selected site without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

Continuing Review

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 7A.7 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomoitso Motlhanka, e-mail address: kgmmotlhanka@gov.bw As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 7A 7 or Ministry of Health website: www.moh.gov.bw or can be requested via e- mail from Mr. Kgomoitso Motlhanka, e-mail address: kgmotlhanka@gov.bw . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting

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

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

If you have any questions please do not hesitate to contact Mr. P. Khulumani at pkhulumani@gov.bw, Tel +267-3914467 or Lemphi Moremi at lamoremi@gov.bw or Tel: +267-3632754. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely



P. Khulumani
For Permanent Secretary



MINISTRY of HEALTH

Vision: Model of Excellence in Quality Health Services

Values: Botho, Equity, Timeliness, Customer Focus, Teamwork, Accountability



-Telephone : +2672411000
Fax : +2672416706



Republic of Botswana

Nyangabgwe Hospital
Private Bag 127
Francistown

Ethical Review of Proposed Study: Adolescents' Perceptions and Experiences Of Anti Retroviral Therapy (Art) At Tertiary Hospital in Francistown, Botswana

Name of Applicant: Bongani Lebo Kebuang
P.O.Box 301960
Francistown

Name of Site: Nyangabgwe Referral Hospital

Decision: **Approved**

Date of Decision: 04 February 2015

Expiry Date: 12 January 2016

Risk Determination: Minimal risk

The Institutional Review Board (Research and Ethics Committee) For Human Subjects Research of Nyangabgwe Hospital is pleased to inform you that the research protocol was approved.

The study involves collection of data at Nyangabgwe Hospital; no more than minimal risk. It is a non therapeutic research and doesn't involve the use of devices for which there is limited knowledge.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Hospital Research and Ethics Committee. In addition you are expected to submit at least one hard copy and an electronic copy of the report to the committee within three months of completion of the study.

Signed:-----

B.R.Munyere
Secretary
(Research and Ethics Committee)