AN INVESTIGATION INTO THE EXPERIENCES AND CHALLENGES OF ADOLESCENTS WHO WERE VERTICALLY INFECTED WITH HIV AND CURRENTLY RECEIVING TREATMENT AT DR GEORGE MUKHARI ACADEMIC HOSPITAL, GARANKUWA GAUTENG PROVINCE

by

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RESEARCH DISSERTATION

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2015
DECLARATION

I, ____________________________, with student number: 200603342 declare that the submitted work on ______________________ is my own work and that I have not used any other source than the permitted reference sources or materials nor engaged in any plagiarism. All references duly acknowledged by means of complete references. I further declare that the work has not been submitted for the purpose of academic examination, either in its original or similar form, anywhere else.

Signed: ______________________

Date: ______________________
DEDICATION

This dissertation is dedicated to my late great grandmother, Mrs Elizabeth Raesetja Mashabela, and my late brother, Solomon Maboyane Malatji. I dedicate this research to those adolescents who were vertically transmitted with HIV, especially those who participated in this study. Although it might be difficult living with a chronic illness, HIV/AIDS, I hope that psychologists might assist you in installing hope and impacting your lives positively.
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The journey of studying towards master’s degree was challenging both academically and personally. Although it was challenging, I’m grateful to the experience this journey has afforded me as it was also fruitful.

I’m grateful to being given every form of assistance during this journey. The assistance has motivated and helped me go through the process of completing this degree. Based on this, I’m expressing my deepest gratitude and appreciation towards everyone who assisted me.

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As I was on the journey of completing my master’s degree, I experienced a tremendous loss with the passing of loving late brother Solomon Maboyane Malatji. I am grateful to have shared my life and my studies with him. He encouraged and supported me. I will always cherish, love, and remember you ‘Nko’ ‘Kwashu!’

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This study aims to explore the experiences and challenges of adolescents who were vertically infected with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital. A qualitative research methodology was used, using semi-structured interviews to collect data. Eleven participants were purposively sampled. Content analysis was used to make meaning and extract themes from the participants’ experiences.

The results indicate that participants are exposed to experiences and challenges that may result in physical and psychosocial difficulties prior, during and after HIV disclosure. Furthermore, numerous participants are not receiving any psychosocial support putting them at risk of social isolation, stigmatisation and self-doubt, as well as difficulties in developing identity and unable to reach formal operational thinking. Based on the current study results, the stage of adolescence is a period where individuals are faced with numerous developmental challenges; yet having to cope with HIV/AIDS while going through this developmental crisis of adolescence can have a huge impact on the adolescent’s well-being. Furthermore, adolescents who were vertically infected with HIV are negatively affected by HIV as this leads to physical and psychosocial challenges. In addition, these adolescents need tailor-made multidisciplinary treatment in hospitals and clinics. In South Africa there is lack of and/or limitation of such treatments tailor-made for adolescents. Despite the light shed by the experiences of vertically HIV-infected adolescents, the results of this study cannot be generalised to a larger population. Therefore, a study with larger sample is recommended.

**Keywords:** Adolescence, Vertically infected, HIV, Challenges, Psychological, Social difficulties.
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CHAPTER 1
INTRODUCTION

According to Karim and Karim (2010), the human immunodeficiency virus (HIV) affects the human immune system. In South Africa, HIV was first discovered in 1983 (Wexler, 2013). Since then, the disease has spread rapidly resulting in a pandemic that has impacted every country in the world, affecting young, old, rich, poor, educated, uneducated, female, and male. Approximately 90% of all HIV-infected children live in Sub-Saharan Africa (Karim & Karim, 2010).

Wittenberg (2009) indicates that HIV infection in children occurs through Mother-to-Child-Transmission (MTCT) as vertical transmission (infection during birth) or after birth through breastfeeding and accounts for a large majority (more than 95%) of HIV infections in children. Other forms of transmission include sexual abuse of children by HIV-infected individuals and blood transfusions (Wittenberg, 2009).

In instances of vertical transmission of HIV, HIV has a direct and indirect impact on both mother and the child’s survival. In an indirect impact to the child, HIV-positive mothers are at an increased risk of death compared with HIV-negative mothers which places their infants at an increased risk of being orphans. Therefore, loss of a caregiver leaves a child confused, especially because the caregiver is often the only stable source of support in the family (Loubser & Müller, 2011).

On the other hand, HIV directly impacts on the physical well-being of the child. A study by Karim and Karim (2010) shows that 60% of HIV-positive infants manifest some symptoms of disease such as growth failure and developmental delay; respiratory system diseases like tuberculosis; neurological system diseases; cardiovascular system diseases; and renal disease. Thus, the medical problems place the infants at an increased risk of being dead. However, with the improvement of antiretroviral (ARV) medication, there has been a decrease in the mortality rates and HIV has transformed from an acute terminal illness into a chronic disease (Foster & Lyall, 2005; Rohlede, Swartz, & Kalichman, 2009; Swanepoel & Louw, 2011). The health of HIV positive adolescents is becoming a critical subject as ARV medications have significantly increased the chances of HIV-positive children to grow into adolescence and adulthood (Rohlede et al., 2009; Swanepoel & Louw, 2011).

The researcher has conducted a qualitative research study exploring and documenting the subjective lived experiences of adolescents receiving treatment at Dr George Mukhari Academic Hospital in Garankuwa, Gauteng Province. These adolescents were infected with HIV through vertical transmission. The qualitative research methodology of this study is comprehensively explained in chapter three of this research report. The research articulates a contextualised understanding of the experiences and challenges of adolescents infected with the human immunodeficiency virus (HIV). Furthermore, the research aims to explore the experiences and challenges of adolescents living with HIV, thus understanding how psychology as a discipline can better incorporate considerations of psychological treatment and preventative measures. The current chapter (chapter One) then introduces the reader to this study through discussing background to the research problem relating to adolescents who were perinatally infected with HIV, the problem statement, as well as giving an overview of the chapters contained in this study.

1.1 BACKGROUND OF THE RESEARCH PROBLEM
Adolescents living with HIV are exposed to experiences, thoughts, and challenges which may result in physical, psychological and social difficulties. A study conducted by Tanney, Naar-king, and
MacDonnel (2011) found that adolescents diagnosed with HIV and being exposed to stigmatisation are prone to develop depression.

This is further supported by research conducted by Gadow, Chernoff, Williams, Brouwers, Morse, Heston, Hodge, …, (2010) who found that HIV-positive adolescents experience limited social support, loss of family members as a result of HIV/AIDS, and are at a risk of developing behavioural and emotional disturbance. The experience of traumatic events and HIV-related stigmatisation has a direct contributory effect on depression among children affected with HIV/AIDS. Literature suggests that trusting relationships together with future orientation and perceived social support mediates positive outcomes of traumatic events and HIV-related stigmatisation (Wang, Li, Barnett, Zhao, Zhao & Stanton, 2012).

Fair, Connor, Albright, Wise, and Jones (2012) highlight the importance of supportive group (such as Youth Camps and Youth Support group) in the treatment of HIV-positive individuals. Furthermore, this type of intervention has a positive impact on individual growth and decrease isolation in adolescents living with HIV. In addition, Fawzi, Eustache, Oswald, Louis, Surkan, Scanlan, Hook, …, (2012) found that psychosocial support groups reduced the psychological symptoms, psychosocial difficulties, isolation and HIV-related stigma on HIV-positive adolescents. Furthermore, these types of intervention have shown positive changes in the adolescents support networks.

The aim of this study is to explore and document the subjective lived experiences of adolescents who were infected with HIV through vertical transmission and are now receiving treatment at Dr George Mukhari Academic Hospital.

1.2. PROBLEM STATEMENT
Over the past few decades, the field of psychology has evolved from focusing on the individual to understanding the importance of additional contributing factors to mental health. This paradigm shift includes acknowledging the importance of health psychology as a subspecialty of psychology which is aimed at promoting and maintaining health, while also preventing and treating illnesses (Gurung, 2010). Health psychologists incorporate a biopsychosocial approach with a specific focus on the importance of a biological constituent of health. Furthermore, this approach acknowledges the psychology of health, which is understood through exploring thoughts, feelings and behaviours, as well as the influence of society and culture on health. In addition, this approach can be used in promoting the health of individuals who are HIV infected (Gurung, 2010). For this study, the focus is on the individuals who are in adolescence stage and are vertically infected with HIV.

Adolescence is a developmental stage from the age of 12 years characterised by the transition from childhood to adulthood, the adolescent begins a process of establishing his/her identity as an individual with a sense of belonging to a certain group of individuals (Nolen-Hoeksem, Fredrickson, Loftus & Wagenaar, 2009). An HIV positive adolescent may be at an increased risk of experiencing anxiety, hopelessness, helplessness, shame and suicidal ideation (Gurung, 2010). These experiences may be linked to disclosure and nondisclosure of their HIV status. Chaudoir, Fisher and Simoni (2011) highlight the potential risks of disclosing ones HIV status. This may increase the risk of stigmatisation, social isolation, physical harm and social discrimination. Thus, the health of an individual is the end results of variables including biological characteristics, behavioural factors, and social factors (Marks, Murray, Evans, Willig, Wooddall, & Sykes, 2006).
A biopsychosocial approach to disease control, more specifically HIV, can be effective in managing and treating adolescents who were infected with HIV through vertical transmission. This approach suggests multiple interventions with specific focus placed on the biological, psychological and social factors contributing to disease management (Mark, et al., 2006). The researcher has identified limitations to the treatment which is tailor made for HIV-positive adolescents at Dr George Mukhari Academic Hospital. The researcher has identified a need for psychological intervention and management of HIV-positive individuals at this facility. Thus, the study aims to understand and explore the experiences and challenges of HIV-positive adolescents. The researcher aims to use this knowledge to improve and promote the importance of psychological interventions when treating and managing HIV-positive adolescents.

1.3. RATIONALE OF THE STUDY
The study results will inform healthcare providers about the experiences, challenges of HIV-positive adolescents and provide information on the current systems of HIV-positive adolescents at Dr George Mukhari Academic Hospital. Furthermore, the study results will generate debate around the importance of psychological interventions at tertiary hospitals in South Africa. The findings will also assist the healthcare providers with information to improve mental health of adolescents who are vertically infected with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital.

1.4. AIM AND OBJECTIVES

1.4.1. AIM OF THE STUDY
The aim of the study is to explore the experiences and challenges of adolescents who were infected with HIV through vertically transmission and are currently undergoing treatment at Dr George Mukhari Academic Hospital in Garankuwa, Gauteng Province.

1.4.2. OBJECTIVES OF THE STUDY
The research objectives are:

- To gain insight into the experiences and challenges faced by adolescents who were infected with HIV through vertical transmission.

- To explore the current coping resources given to adolescents who were infected with HIV through vertical transmission.

- To stimulate future research and generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

1.5. OVERVIEW OF METHODOLOGY
The methodological approach to an exploratory research design will be used to address the research question. The research seeks to explore and document the subjective lived experiences of adolescents who were infected with HIV through vertical transmission and are receiving treatment at Dr George Mukhari Academic Hospital. This was reached through adopting qualitative research method. This research method allows for a well-organized analysis of personal meaning, attached to the context of an individual’s social environment (Polgar & Thomas, 2008). Personal meaning is understood within the context of an individual’s subjective observation and the meanings attached to these experiences, actions and social environments (Punch, 2014).
The researcher used purposive sampling. This subtype of non-probability sampling is a technique in which the research participants are selected based on the researcher’s clinical judgement. This is based on the characteristics identified within the sample population (Polonsky & Waller, 2011; Punch, 2014). The sample frame was generated through the distribution of an information hand-out (Appendix C) requesting the nurse-in-charge of the Paediatric Clinic to identify, approach and refer possible candidates who meet to the inclusion criteria of the study. A mental healthcare practitioner informed possible research candidates about the role and aims of the research, allowing participants to agree to participation in the proposed research by completing and signing the consent form (Appendix A).

The study aims to explore and document the experiences of HIV-positive adolescents, aged between 15 and 18 years. The sample frame was taken from individuals attending the outpatient Paediatric clinic at Dr George Academic Mukhari Hospital. The sample size consists of 11 participants. As part of the inclusion criteria, only participants who have been infected with HIV through vertical transmission at birth were considered for the research. Participants and their parents who are unwilling or unable to provide written assent/consent were excluded in the study. No preference towards gender, race, and/or ethnicity was given. The participants must be willing to participate in the study. All interviews were conducted in English and/or Setswana which are the dominating languages used in Dr George Mukhari Academic hospital.

1.6 DEFINITION OF KEY CONCEPTS

1.6.1. Adolescence
Adolescence is the developmental stage between childhood and adulthood (Louw, Ede, & Louw, 1998). This life stage begins at ages between 11 and 13 years; the stage may vary between individuals (Papalia, Olds & Feldman, 2006; Jansen, Moeletsa, Neves, Soudien, Stroud, Swart, & Wild, 2012; Leifer & Fleck, 2013), and ends at the ages of 17 to 21 years (Jansen et al. 2012; Leifer & Fleck, 2013).

1.6.2. HIV
Human Immunodeficiency Virus (HIV) is a retrovirus that destroys the CD4 (which is a type of white blood cell that fights infection) of the immune system, leaving the body vulnerable to life-threatening infections (Evian, 2011; Van Dyke, 2012; Wexler, 2013).

1.6.3. HIV-positive
A person is HIV positive when the HIV antibodies are detected in his or her blood indicating that the person is infected with the virus (Evian, 2011; Van Dyke, 2012; Wexler, 2013).

1.6.4. AIDS
Acquired Immune Deficiency Syndrome (AIDS) is a group of different diseases resulting from a breakdown in the body’s immune system. This is not just one disease but it presents itself as a number of diseases that come about as the immune system fails. Hence, it is regarded as a syndrome (Evian, 2011; Van Dyke, 2012; Wexler, 2013).

1.6.5. Perinatally infection of HIV
Perinatally infection of HIV is the contraction of HIV from Mother-To-Child-Transmission at birth and through breastfeeding (Evian, 2011; Van Dyke, 2012; Wexler, 2013). Perinatal infection is also referred as vertical infection, therefore in this study the two words will be used interchangeably.
1.7. CHAPTER OVERVIEW
This section provides the reader with a brief outline of the chapters that follow and what they cover:

- Chapter one provided an introduction to the study and aimed at orientating the reader to the study.

- Chapter two presents a review of the relevant literature on the study topic. It is divided into two parts: part one focuses on adolescence and its theories, and part two focuses on adolescents who are vertically transmitted with HIV.

- Chapter three outlines the research methodology. The researcher discusses the design and method used in the study.

- In Chapter four the research results will be presented by using main themes and subthemes.

- Chapter five will detail a discussion of the results will be integrated with literature review of chapter 2, and provide a conclusion and recommendations drawn from the study’s findings.
CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION
The aim of the study is to explore the experiences and challenges of adolescents who were vertically infected with HIV. This literature review chapter is divided into two parts. The first part, section 2.2, focuses on how adolescence is defined based on the literature. The discussion also looks at the physical changes associated with adolescence and challenges associated with this stage. Furthermore, and a theoretical perspective on adolescents and the developmental tasks faced by adolescents are discussed. The second part, section 2.3, of the literature review will take a closer look at the experiences of adolescents who were vertically infected with HIV.

2.2. THE CONCEPT OF ADOLESCENCE
This part focuses on how adolescence is defined based on the literature. The stage of adolescence, physical changes associated with adolescence and the psychosocial changes of adolescence are discussed in this section. Likewise, the developmental tasks acquired by adolescents while moving through multiple changes and challenges are also discussed in this section. Lastly, conceptual framework of the study will be discussed.

2.2.1. Defining Adolescence
Human beings go through many developmental stages as they grow from birth until old age. As previously defined in chapter one, adolescence, which is the focus of this study, is defined as the transitory stage or junction between childhood and adulthood. Many authors (Jaffe, 1998; Jansen, et al., 2012; Leifer & Fleck, 2013) have indicated that the concept of adolescence comes from the Latin word *adolescere* which is a process where an individual grows up and matures. This life stage begins with the onset of puberty that typically starts between the ages of 11–13 years but may vary between individuals (Papalia, et al., 2006; Jansen et al., 2012; Leifer & Fleck, 2013), and ends when an individual enters adulthood between the ages of 17 and 21 years with the adoption of roles such as marriage (Jansen et al., 2012; Leifer & Fleck, 2013). In addition, this stage is characterised by multiple physical, cognitive, and psychosocial changes (Papalia et al., 2006; Jansen et al., 2012; Leifer & Fleck, 2013). Talwar, Sharma, and Kapur (2009) add that the multiple changes may differ significantly in onset, duration, and tempo between and within individuals and populations.

Some authors (Jaffe, 1998; Beck, 2005; Jansen et al., 2012) have divided the adolescence stage into three sub-stages. According to Beck (2005), the first sub-stage is early adolescence (11–14 years) which is characterised by a change from childhood to adulthood and is related with the onset of puberty. He also indicates that the second sub-stage is middle adolescence (15–16 years) and is characterised by a change from early to late adolescence as well as psychological, physical and social changes (Beck, 2005). Furthermore, Beck (2005) highlights that the third sub-stage are late adolescence (17–21 years); this stage is characterised by a preparation into adulthood and is marked by a readiness for adulthood and more intensified heterosexual relationships. In addition, Jaffe (1998) divides the sub-stages of adolescence by placing emphasis on school transitions: early adolescence corresponds with the middle school years (11–13 years), middle adolescence corresponds with high school years (14–17 years), and late adolescence corresponds with the college years (18–early 20s).
The stage of adolescence is characterised by multiple changes and challenges; what follows is a discussion on the physical changes.

### 2.2.2. Physical Changes

The most recognised signs of adolescence stage are physical developmental changes. When children enter the stage of adolescence, most adults would exclaim: “You look like a grown-up.” Such exclamations have stimulated many researchers to focus on the physical developmental changes that occur in adolescence. One of the most prominent physical developmental is puberty (Bukatko, 2008).

#### 2.2.2.1. Puberty

As mentioned above, adolescence is marked by the onset of puberty. Numerous authors (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen et al., 2012) have discussed puberty and defined it as a period that involves biological processes where an individual’s body transitions from reproductive immaturity to maturity, hence the ability to reproduce.

Puberty is firstly recognised by an adolescent’s growth spurt characterised by a rapid increase in physical growth – the height and weight of an adolescent increase at double the rate of the childhood stage (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen, et al., 2012). Jansen et al, (2012) further mention that the adolescent growth-spurt onset varies between girls and boys; in girls, it starts approximately between the ages of 10 and 11 years, and in boys between the ages of 12 and 13 years.

In addition, puberty is characterised by primary and secondary sexual changes. The primary sexual characteristic changes are linked to reproductive organs. The reproductive organs include the ovaries, uterus, and vagina for girls; and the penis, scrotum and testes for boys. In puberty, the primary sexual characteristics mature. This ultimately means that the individual has the ability to reproduce: girls experience menstrual periods and boys experience ejaculation or start to produce sperm. As for the secondary sexual characteristics, they occur on the exterior of the body and are indirectly related to reproduction. Boys experience an increase in pubic, facial, and body hair, an enlargement and darkening in the colour of the scrotum, an increase in penis size, and a deepening and instability of the voice due to a lengthening and thickening the vocal cord. Girls experience the appearance pubic and body hair, an enlargement of the breasts, and the deposition of fat in hips and thighs (Jaffe, 1998; Papalia et al, 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen et al., 2012).

All of the mentioned changes experienced during puberty are influenced by hormonal changes (Jaffe, 1998; Papalia et al, 2006; Bukatko, 2008; Jansen et al., 2012). In boys, a hormone, gonadotropin-releasing hormone (GnRH), is secreted from the hypothalamus of the brain. This hormone is responsible for stimulating the anterior pituitary gland to secrete gonadotropins, the follicle-stimulating hormone (FSH) and the luteinizing hormone (LH). The LH produces testosterone, which further produces sperm (Jaffe, 1998; Papalia et al, 2006; Jansen et al., 2012). In girls, the production of oestrogen and progesterone by ovaries regulates the menstrual cycle; these hormones also stimulate the development of secondary sexual characteristics (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008).

In a nutshell, puberty includes physiological changes that are complex and unique and adolescents may experience a variety of reactions and feelings towards such changes (Hajikhani Golchin, Hamzehgardeshin, Fakhri, & Hamzehgardeshin, 2012). In a study conducted in Sari of Iran by Hajikhani Golchin, et al, (2012), the researchers found that there was a distinct difference in
perceptions of experience from girls who had an early onset of puberty and those who had a late onset of puberty. The study found that girls who had an early onset of puberty perceived puberty as an unpleasant process, that they associated with feelings of hatred, fear, shame, surprise, and a sense of sickness. However, the girls who reached puberty late experienced feelings of relief from their worries. In addition, Hajikhani Golchin et al. (2012) found that girls in adolescence generally viewed bodily changes as a source of confusion and pressure, and they associated this stage with feelings of sorrow, impatience, shyness, nervousness, shame and sensitivity.

### 2.2.2.2. Brain Development

During the adolescence stage, the brain experiences two major changes. The first major change, which occurs in the cerebral cortex, is a decrease in the weaker synaptic connections through the process of pruning. The second one is an increase in myelination and a reorganization of synapses in the frontal and prefrontal cortex. Consequently, this impacts the functioning of the brain and the adolescent’s behaviour (Steinberg, 2005; Bukatko, 2008; Luna, 2009; Jansen et al., 2012).

There are two domains that mature within the functioning of the brain. The first domain is a modification of the executive control and the achievement of a more conscious, self-directed and self-regulatory minds (Steinburg, 2005; Kuhn, 2006; Luna 2009). The second domain is the maturity of executive functioning (EF) processes, which includes response planning, improved processing speed, cognitive flexibility, and rule-guided behaviour (Kuhn, 2006; Luna, 2009). This results in improvements in memory, language, processing speed, attention and concentration (Kail & Ferrer, 2007). Furthermore, Zarrett and Eccles (2006) mention that the development of the brain may enable the adolescent to acquire some developmental tasks (to be explained later), as well as an acute ability to deal with challenges, form an identity and to develop their sense of morality. Papallia et al. (2006) mention that although the prefrontal cortex (responsible for planning and decision-making) develops in adolescence, it is not yet fully mature compared to the amygdala (responsible for emotions). Consequently, adolescents are more prone to risky behaviours and psychological disorders, as well as an inability to control strong emotional impulses.

In addition, the brain changes in adolescence stage will impact on the cognitive function. According to Piaget (cited in Bukatko, 2008) theorises that cognitive development involves reorganisation at different life stages of development. The highest level of cognitive development, referred to as formal operational thinking, is in adolescence (Bukatko, 2008; Leifer & Fleck, 2013). Formal operators have the ability to think logically about hypothetical processes and scenarios that may occur in reality (Shaffer & Kipp, 2010). Furthermore, Piaget reports that hypothetically thinking adolescents have the ability to plan for the future and predict the possible consequences of present actions (Van Dyke, 2012). Thus, adolescents have the ability to reason abstractly and hypothetically, understand symbols, and are future-orientated (Bukatko, 2008; Leifer & Fleck, 2013). Piaget also reports that formal operators have the skill of deductive and inductive reasoning. Deductive reasoning as the ability to reason from general to specific, while inductive reasoning is the ability to reason from specific to general (Bukatko, 2008; Shaffer & Kipp, 2010; Leifer & Fleck, 2013). Thus, formal operational thinkers have the ability to reason in an organised way to create ideas and hypothetical concepts, test the hypotheses, eliminate falsities and conclude (Papalia et al., 2012; Shaffer & Kipp, 2010). He called this process the hypothetico-deductive reasoning. The process is also called scientific thinking. However, formal operational thinking may not be reached by all adolescents, as others may operate as concrete operational thinkers in their adolescence stage (Leifer & Fleck, 2013).
Thus, individuals are in the adolescence stage experience multiple physical changes and challenges which might impact their psychosocial changes (Beck, 2005). These psychosocial changes are discussed next.

2.2.3 Psychosocial Challenges

According to Levine, Carey and Croker (cited in Laughton, Cornell, Boivin, & Van Rie, 2013), adolescents experience challenges in developing an identity and independence, as well as considering the future. This can be maintained through social interactions, including family relationships and peer relationships (Zarrett & Eccles, 2006; Laughton et al., 2013). According to the social ecological framework (cited in Mburu, Ram, Oxenham, Haamujompa, Lorpenda, & Ferguson, 2014), it is believed that adolescents’ development is impacted by their circumstances, which depend on the following factors:

2.2.3.1 Family Relationships

According to the family systems model (Jaffe, 1998), change in one of the family members will impact on the whole family system. Individuals who go through adolescence experience major changes in their lives that will impact on the whole family. This is evident in the adolescents developing their own identity, having an increased sense of independence and autonomy. Consequently, the family must create a space that accommodates the changes experienced by the adolescents, especially changes in the parent-adolescent relationship (Jaffe, 1998). In addition, Zarrett and Eccles (2006) highlight that, on one hand, a family functions as a primary support system for adolescents and a safe context for adolescents to successfully develop, while on the other hand, a lack of support from family may create a high risk of failure in the adolescent. Over and above this, a study conducted in South Africa by Brook et al., (cited in Fatusi & Hindin, 2010) found that a young girl who experiences poverty, low employment levels, and lack of social support may end up being involved in sex work to sustain herself.

Similarly, a study conducted in the USA by Elkington, Bauermeister and Zimmerman (2011) found that adolescents who are raised in families characterised by conflict, substance abuse or abuse by parents, and negligent and unsupportive family relationships may be at a high risk of developing risky behaviours, including substance abuse and unsafe sexual behaviours; while, adolescents who are raised by families characterised by close and supportive family relationships and parental involvement may be at a lower risk of developing risky behaviours. Furthermore, a study conducted by Boislard and Poulin (2011) found that adolescents raised in families with long-distance relationships and without parental supervision are more likely to spend more time outside their families, develop multiple sexual partners and utilize their peers as social agents.

2.2.3.2 Parent-Adolescent Relationship

During adolescence, there is a decline in the relational closeness in the parent-adolescent bond due to the decrease in time spent together. Early adolescents spend time being alone – in their rooms, using phones, watching television, or with their peers (Cobb, 2010; Jansen et al., 2012). Thus, shared activities and physical affection in parent-adolescent relationships decrease and there is an increased need of privacy from adolescents (Scharf & Mayseless, 2007). In addition, Cobb (2010) reports that adolescents start to keep secrets from their parents, especially with issues involving sexual orientation. In support of this, Hajikhani Gochin et al., (2012) mention that adolescents felt uncomfortable discussing sexual orientation at home and viewed their parents as lacking knowledge about sexual issues. Similarly, a study conducted in Canada by Boislard and Poullin (2011) found that adolescents who are able to talk to their parents about sexual intercourse are likely to delay in engaging in sexual
activities. This indicates a high communication quality in the parent-adolescent relationship. However, adolescents whose parents are less involved in their lives don’t confide to the parents about sexual intercourse, and they are likely to engage in sexual activity earlier.

Furthermore, Jaffe (1998) mentions that adolescents spend more time with their mothers than with their fathers. This is due to the observation that adolescents experience empathy, openness, acceptance, as well as attention in their relationships with their mothers. While in relationships with their fathers, adolescents experience less acceptance, more demands and less interest and attention (Jaffe, 1998; Jansen et al., 2012).

According to Cobb (2010), the perceptions of adolescents towards their parents change. They perceive their parents as less supportive and opposing. Similarly, Bukatko (2008) mentions that the adolescents’ change in perception towards their parents was as a result of their ability to view people as having both strengths and weaknesses and an ability to think in an abstract manner. During the adolescence stage, the parent-adolescent relationship sees an increase in conflict and communication discord (Jansen, et al., 2012; Bukatko, 2008; Hajikhani Golchin et al, 2012; Scharf & Mayseless, 2007). The conflict becomes intense in early adolescence and gradually decreases towards the middle to late adolescence phases (Zarrett & Eccles, 2006; Bukatko, 2008; Jansen et al., 2012; Ogwo, 2013). This is as a result of early adolescents asserting their individuality, practising their independence and forming their own identity (Zarrett & Eccles, 2006; Seiffge-Keransen, Kiuru & Nurmi, 2009; Ogwo, 2013) by challenging their parents’ authority (Zarrett & Eccles, 2006; Cobb, 2010), and renegotiating and rebelling against rules and restrictions of parents (Zarrett & Eccles, 2006; Ogwo, 2013). Parents also find it difficult to adjust to their children’s early adolescence; however, by the middle and late adolescence, the parents have adjusted to an adolescent child and the relationship has returned to normality (Cobb, 2010), because the adolescents have now acquired emotional maturity, reduced egocentrism, and they acknowledge their parents (Ogwo, 2013).

Moreover, Hajikhani Golchin et al., (2012) point out that the conflict may result from the following: parents having difficulty in recognising adolescents’ concerns; adolescents attempting to establish independence; adolescents lacking trust in the family; adolescents disagreeing with their parents’ views; adolescents experiencing confusion about their family roles; and parents attempting to control adolescents’ personal choices such as clothes, friends and subjects to study. However, Scharf and Mayseless (2007) note that the conflicts in parent-adolescent relationships may create a platform for adolescents to improve their negotiation skills, solve interpersonal problems, acquire individualism, and be responsible. Scharf and Mayseless (2007) further note that through conflict in parent-adolescent relationships, adolescents attempt to acquire autonomy and parents are strive to detach and accept the independence of their adolescents. Conversely, a study conducted in Spain by Orejudo, Puyuelo, Fernandez-Turrado and Ramos (2012) found a correlation between adolescent-parent relationships and optimism, in that adolescents who are continuously involved in conflict with their parents may develop a sense of pessimism that may result in less support, preference of unhealthy attachment styles, or a focus on relationships that are more disciplinary and authoritative in style.

The changes mentioned above about the parent-adolescent relationship depend on the kind of attachment formed in that relationship. To emphasise this, Bukatko (2008) highlights that secure attachment creates more closeness and connection in parent-adolescent relationships. Similarly, Jansen et al., (2012) note that secure attachment allows adolescents to have confidence in creating and exploring new relationships outside the family. In addition, Dykas and Cassidy (2007) mention that adolescents who have secure attachment have the ability to be more open in processing social
information than adolescents with insecure attachment. Furthermore, Pace and Zappulla (2011) mention that insecure attachment in adolescents may result in externalised problems such as oppositional defiance and substance abuse. Therefore, parents still remain a social and emotional support for their adolescents, and they influence the decisions made by their adolescents (Bukatko, 2008; Jaffe, 1998).

To this end, Scharf and Mayseless (2007) mention that adolescents still have the need for close and warmth parent-adolescent relationships, as well as the need for confirmation and guidance when attempting to solve problems. This is further supported by a study conducted in Germany by Seiffge-Kerkenke, et al. (2009), which found that adolescents are highly stressed by and concerned with the conflict in the parent-adolescent relationships. Similarly, a study conducted in the United Kingdom by Shelton and Van den Bree (2010) found that the quality of the parent-adolescent relationship correlated with the use of cigarette and alcohol, concluding that this was due to emotional distance and a lack of support in the parent-adolescent relationships. The adolescents within such relationship structures are at a high risk of using drugs and alcohol as a coping mechanism. Furthermore, Zarrett & Eccles (2006) mention that a lack of support and continuous unresolved conflicts in parent-adolescent relationships may increase the risk of adolescents engaging in drug and alcohol abuse, school drop-outs, violence, sexual intercourse and gang-related behaviours.

In addition, the Centre for Disease Control and Prevention (Thornberry, Matsuda, Greenman, Augustyn, Henry, & Ireland, 2014) defines maltreatment as any behaviour of omission or commission by a parent or a caregiver that has an end product of harm, or potential to harm, which threatens the child or adolescent. This behaviour may be physical abuse, sexual abuse, psychological abuse, and/or neglect. Yates and Weckerle (2009) found that maltreatment may impact on the adolescent’s emotional well-being; thus, eliciting a depressive response, withdrawal, disengagement, anxiety and decreased self-efficacy in adolescents. Similarly, a study conducted by Gren-Landell, Aho, Andersson and Svedin (2011) in Sweden found that adolescents who experienced victimisation from their parents and the community and maltreatment from parents may develop an enormous fear of negative feedback in social interactions and evaluations of performance that may escalate to behaviours of avoidance and impairment, called social anxiety disorder. The relationship between victimisation, maltreatment and social anxiety disorder is further explained by Gren-Landell et al., (2009), who state that when adolescents experience victimisation and maltreatment, they develop symptoms of a sense of helplessness and anxiety towards stressful events. They, adolescents, believe that they are different and are being perceived as less attractive by others; and they view the world as unsafe. These symptoms may lead to the development or maintenance of a social anxiety disorder. In addition, a study by Melander, Hartshorn and Whitbeck (2013) revealed that adolescents raised in families where bullying exists, developed feelings of anger, had poor relationships with their parents, and had a high risk of transferring the bullying behaviour to the school environment where they end up bullying their peers.

### 2.2.3.3. Peer Relationships

As mentioned earlier, adolescents spend less time with their parents than they do being outside. In the outside context, peers serve as the main focus for socialisation. Therefore, when adolescents are faced with challenges of increasing autonomy and independence, their peers provide emotional and social support, and they share social skills. Thus, peers reward each other, accept each other and create popularity and status (Cobb, 2010). Similarly, adolescents establish friendships and groups for the purpose of emotional support and exploration of values, as well as to fulfil their need for the formation of identity and belonging, building self-esteem and access to information (Jansen et al.,...
2012; Zarrett & Eccles, 2006). In addition, groups shape and influence the behaviour of adolescents (Jansen et al., 2012). However, Bukatko reported the group influence depends on how the adolescent identifies with and values the group. This is further explained by Elkington et al., (2011), who conducted a study in the USA that found that group norms are very important. For instance, peer groups that support activities such as drug abuse and unprotected sexual intercourse may lead to the adolescents belonging to those groups and developing such risky behaviours. On the other hand, peer groups with norms that include supportive relationships, pro-social behaviours, condom use and safe sex may lead to its member adolescents developing similar behaviours (Elkington et al., 2011).

Furthermore, Boislard and Poullin (2011) found that peer groups which are made up of mixed-gender members are more likely to have adolescents develop sexual partners within the group. As the adolescents grow older, their interest in peer groups decrease and they spend more time in romantic relationships and with close friends (Bukatko, 2008; Jansen et al., 2012); this contributes to the development of a sense of competence (Zarrett & Eccles, 2006). Furthermore, Canvanagh (2011) conducted a study and found that adolescents who experience early onset of puberty may perceive themselves as sexual and romantic actors; this may determine the types of relationships they are involved in during adolescence and can have long-term consequences. A study conducted by Phillips and Malcolm (2010) found that adolescents may experience violence in their peer-sex interactions, which may result in depression, alcohol abuse, anxiety, suicidal behaviours, sexually transmitted diseases, unwanted pregnancies and sexual dysfunction. The study also found that early exposure to violent sex-peer relationships may impact on the future romantic adult relationships.

In addition, Parker, Rubin, Erath, Wojslawowicz and Buskirk (2006) highlight that early adolescents form peer groups that require social skills in order to be handled effectively. Flanagan, Erath, and Bierma (2008) found a high correlation between social anxiety, peer nominations and victimisation as individuals with high levels of maladjustment behaviour (for example, ineffective social skills, low self-esteem and social withdrawal) may have higher levels of social anxiety. This is further supported by Grills and Ollendick (2002), who mention that adolescents with ineffective social skills and maladjustment social behaviours are victimised, harassed and rejected by other peers. This may impact on the mental functioning of those adolescents with ineffective social skills in that they may have negative self-perceptions that damage their sense of self and their social world. This may in turn create social anxiety and a continuation of maladaptive appraisals.

Similarly, Orejude et al., (2011) found that positive relationships with peers may create a sense of optimism, while negative relationships may create a sense of pessimism. This is further supported by Jonkman, Trautwein and Ludtke (2009), who found that adolescents who effectively adjust in peer relationships are likely to experience peer acceptance and dominance, which may positively affect both their social self-esteem and academic self-esteem. However, Savin-Williams and Berndt (cited in Zarrett & Eccles, 2006) report that in early adolescence, individuals who experience peer acceptance spend more time engaging in peer activities, may be unable to handle peer pressure, which negatively impacts on their academic performance and creates behavioural problems.

Furthermore, during adolescence, individuals start to develop sexual thoughts and feelings and experiment with love and sexual intercourse with their peers (Giannotta, Ciaranon, & Spruijt-Metz, 2009; Maccoby, cited in Boislard & Poullin, 2011) resulting in positive (Giannotta et al., 2009) and negative (Giannotta et al., 2009; Boislard and Poullin, 2011) consequences. In terms of positive consequences, adolescents start acquiring skills of creating and maintaining intimate, romantic and sexual relationships, which is one of the developmental tasks of adulthood (Giannotta et al., 2009).
Whereas in terms of the negative consequences, especially in early and middle adolescence, adolescents are still cognitively and emotionally developing and lack inadequate abilities to engage in romantic relationships. This may impact negatively on their psychological functioning, leading to teenage pregnancy and sexually transmitted infections including HIV (Giannotta et al., 2009; Boislard and Poullin, 2011). Furthermore, Giannotta et al., (2009) conducted a study in Italy, in which they found that adolescent behaviours are motivated by variables other than love. Those variables are imitation of peers, called social meaning, including peer pressure (for example, having sex because other teenagers have or had sex, and/or to prove that they can also have sex), and being involved in sexual intercourse for coping with needs, called personal meaning.

Pellegrini (cited in Pepler, Jiang, Craig & Connolly, 2008) describes bullying as an aggressive behaviour that is used as power to obtain dominance, status and control over others within the group. Furthermore, Pepler et al. (2008) mentions that adolescents who are continuously exposed to bullying become trapped in being victimised and become increasingly helpless. On the other hand, the adolescents who bully their peers have learned the behaviour from their social context, especially from families in which the adolescents experience physical abuse (direct or indirect), lack of close relationships, and a lack of supervision in adolescence. This is further supported by Siyahhan, Aricak and Cayirdag-Acar (2012), who found that girls are likely to experience verbal bullying, whereas boys are likely to experience both verbal and physical bullying. Boys who experience both verbal and physical bullying may develop symptoms of depression, a sense of hopelessness, and suicidal thoughts. Furthermore, the study found that parents and teachers are more likely to intervene in physical bullying rather than verbal bullying.

2.2.3.4. School Context and scholastic achievements

Libbey (cited in Melaughlin & Clarke, 2010) highlights that the school context is very important in the adolescence stage. The school context creates a space where adolescents are able to develop social and cognitive functioning, which enables them to have interpersonal relationships in order to acquire social identities and a sense of belonging (Wentzel, cited in Jonkmann et al., 2009) According to Lester, Waters & Cross (2013), during the adolescence stage, the individuals transit from primary to secondary school. The transition from primary to secondary school is supported by Piaget theory of cognitive development from different life stages. As previously mentined, according to Piaget (cited in Bukatko, 2008) theorises that cognitive development involves reorganisation at different life stages of development. He also focuses on the cognitive milestones of development and describes the following four stages of development, in relation to learning to understand and relate logically to the world (Leifer & Fleck, 2013):

<table>
<thead>
<tr>
<th>1. Sensorimotor intelligence</th>
<th>&gt;&gt;</th>
<th>Birth to two years</th>
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</thead>
<tbody>
<tr>
<td>2. Preoperational thought</td>
<td>&gt;&gt;</td>
<td>Two to seven years</td>
</tr>
<tr>
<td>3. Concrete operational thinking</td>
<td>&gt;&gt;</td>
<td>Seven to eleven years</td>
</tr>
<tr>
<td>4. Formal operational thinking</td>
<td>&gt;&gt;</td>
<td>Adolescence</td>
</tr>
</tbody>
</table>

Thus, when an individual enters adolescence stage, he or she shifts from concrete thinking to formal operational thinking (Leifer & Fleck, 2013); the individual will also shift from primary school to secondary school (Lester, et al., 2013). The shift of the school context is associated with adolescents experiencing a new social environment, where, while primary school is experienced as small intact classes with close relationships and one main teacher, secondary school is experienced as attending
many classrooms with different teachers, and classmates changing throughout the day. This may lead to adolescents experiencing a lesser sense of connectedness, which may be associated with depression and anxiety (Lester et al., 2013), poor school performance, school drop-out, risk of early sexual initiation and sexual activities (Fatusi & Hindin, 2010).

In addition the adolescents’ ability to achieve in the school context may lead to a sense of accomplishment and a high self-esteem (Melaughlin & Clarke, 2010). In order to achieve in the school context, adolescents need high self-esteem and effective coping mechanisms to manage and learn in school (Zarrett & Eccles, 2006). Furthermore, Hajikhani Golchin et al. (2012) found that during adolescence, there is a drop in school performance with adolescents reporting feeling discomfort when compared to their peers. The drop in school performance is twofold. The first reason is explained by Simmons and Blyth (cited in Zarrett & Eccles, 2006), who mention that adolescents may be unable to adjust or manage the developmental changes of the adolescence stage. The other reason is explained using the person-environment fit theory (cited in Zarrett & Eccles, 2006), which states that when the adolescent’s changing needs are not met by the school environment, their academic motivation, interest and performance may decline.

Similarly, Barclay and Doll (cited in Melaughlin & Clarke, 2010) mention that failure to adjust to the school context by having effective peer and teacher relationships may impact on the mental functioning of the adolescents, which can be detected through symptoms of depression and anxiety, engaging in disruptive social behaviours and using of drugs as coping mechanisms, as well as dropping out of secondary school. Melaughlin and Clarke (2010) add that adolescents may experience a sense of rejection that may impact on the development of their personal identity. Furthermore, adolescents who drop out of school may not have the platform to explore and experiment what others (who continue with school) are experiencing in the school context (Zarrett & Eccles, 2006). This includes information about health-related matters and certain skills that may contribute to their development (Fatusi & Hindin, 2010), that may help them establish and develop societal norms (Kabiru & Orpinas, 2009).

On the contrary, the school context may create an opportunity for adolescents to explore and practice risky behaviour without the supervision of their parents and caregivers; these risky behaviours include sexual experimentation, substance use, bullying and violence (Fatusi & Hindin, 2010; Kabiru & Orpinas, 2009). In addition, Harel-Fisch, Walsh, Fogel-Grinvald, Amita, Pickett, Molcho, de Matos, Craig, Members of the HBSCA violence & injury prevention focus group (2011) report a correlation between negative experiences in adolescent-teacher relationships and the development of bullying behaviours. This conclusion resulted from the findings that adolescents, who felt ill-treated by and received unfair treatment from their teachers, while also experiencing negative academic achievement, may in turn bully other adolescents either as a way of relieving their frustrations and hurt or as a way of re-establishing a sense of dominance. Therefore, the more the adolescents experienced a sense of belonging, accomplishment, satisfaction, and safety at school, the less is their risk of developing bullying behaviours. Furthermore, a study conducted in the Western Cape of South Africa by Phillips and Malcolm (2010) revealed that when adolescents experience bullying and violence in the school context, the adolescents miss school and feel unsafe while at school.

2.2.3.5. Psychological challenges
Adolescence is a period associated with numerous and rapid physical, cognitive and social changes. Jain, Kumar and Khanna (2013) found that adolescents lack correct information related to the multiple changes associated with adolescence; although, they are aware of the changes. These changes have an
impact on the mental functioning of adolescents (Pace & Zappulla, 2011; Jain et al., 2013). For example, Olatundun, Osiki, Abd Ajibola (2010) reported that during adolescence, individuals start to act and desire to be treated like adults, including beginning to engage in smoking and drinking, girls wear make-up, both boys and girls shave their body hair, and start dating.

Campas and Wagner (cited in Lanteigne, Flynn, Eastabrook & Hollenstein, 2012) mention that individuals who are in the adolescence stage experience more social stress as compared to other individuals who are in other developmental stages or age groups. This is explained by Eric Erikson (1968), identity versus role confusion, which corresponds with the adolescence stage, will be discussed in detail. According to Erikson (1968), identity is defined as an individual’s awareness and discovery of himself or herself as an independent person with a definite role in society. He further mentions that adolescents have the task of achieving a feeling of identity. Furthermore, the successful resolution of the identity crisis will promote adolescents’ sense of identity, and decrease role confusion (Louw et al., 1998; Papalia et al., 2012; Leifer & Fleck, 2013). The hypothetical solution to the identity crisis lies in the synthesis of reliability, where the individual establishes self-confidence (Louw et al., 1998; Papalia et al., 2012; Leifer & Fleck, 2013). This means that adolescents must be certain of their identity and also be aware and accept that there are numerous identity choices which they could have chosen (Louw et al., 1998). Failure to resolve this crisis may promote adolescents with identity confusion, a situation in which adolescents may experience a mixed personal identity and become confused about ‘who’ they are, leading to low self-esteem (Jaffe, 1998; Jansen et al., 2012).

This is further supported by Kessler, Chiuwalter and Demler (cited in Gilbert, 2012), who mention that adolescence is a period when most psychopathology such as anxiety, depression, bipolar disorder, eating disorder, as well as alcohol and substance abuse develops. Prasla (2012), together with Vogel (2012), report that numerous adolescents experience depression and anxiety disorder. Prasla (2012) further elaborates on how depression and anxiety may have resulted from changes in adolescence. Regarding physical changes, Prasla (2012) mentions that the adolescents are faced with a task of adjusting to the physical changes, and a failure to adjust may lead to fear and isolation, perpetuating depression and anxiety. In terms of cognitive changes, Prasla (2012) highlights that adolescents acquire the ability to think abstractly and scientifically. This may lead to situations of intense argument in a social context that may in turn lead to emotional frustration, isolation and depression.

Parents’ failure to acknowledge and accommodate the changes in their adolescents may lead to a significant breakdown in parent-adolescent relationships, which may in turn impact the mental functioning of the adolescents (Prasla, 2012). In addition, Hubib and Labruna (2011) report that most of adolescents are exposed to dangerous situations when they attempt to perform developmental tasks, such as driving cars, being in romantic relationships and substance use or abuse, that are more typical of adults. Stevens, Kiehl, Pearlson and Calhoun (cited in Hubib & Labruna, 2011) explain that this may be as a result of the neurobiological development of adolescents, since adolescents are not fully capable of controlling their impulses, as opposed to adults. This means that although adolescents are aware of the risks of many situations, they usually get involved in situations that have stressful consequences and the potential to harm them. This may lead to the development of post-traumatic stress disorder (PTSD) (Hubib & Labruna, 2011). Building on the development of psychopathology, Gilbert (2012) reports that the onset of psychopathology may result in emotional dysregulation, which refers to an inability to adapt and modulate responses in order to reach certain goals; an inability to use coping strategies, or an inability to make effective decisions, or solve problems, when faced with situations that may evoke enormous emotions.
Similarly, Alberga, Sigal, Goldfield, Homme and Kenny (2013) found that numerous adolescents use food as a coping mechanism for stress; this may lead to emotional eating and being overweight. The study also found that stress may be caused by a low self-esteem, poor social skills, discrimination, or parental separation and divorce. Furthermore, the study found that stress impacts negatively on the immune system (Alberga et al., 2013).

The study conducted by Natsuaki, Klimes-Dougan, Ge, Shiltcliff, Hastings and Zahn-Waxler (2009) found a significant relationship between the early onset of puberty and symptoms of internalizing problems like depression and anxiety. The study further highlights that the adolescent girls who experience early onset of puberty are more likely to start a relationship with deviant peers and have older sexual partners. This may impact negatively on the parents, who may not acknowledge the relationship and may add to the adolescent internalizing problems. In contrast, Lindfors, Eloaino, Wickman, Vuorinen, Sinkkonen, Dunkel, Raappana, (2007) found a link between the late onset of puberty and the symptoms of internalising problems such as depression and anxiety. The study found that adolescent boys with delayed puberty were psychologically immature and developed inferior egos. Lindfors et al. (2007) further explains this by giving three reasons. The first reason stemming from the social context is where society treats adolescent boys with delayed puberty by looking at their physical appearances instead of their chronological age. This impacts on the psychological development of the boys. The second explanation pertains to the cognitive development, stating that during the puberty stage, there is reorganisation of the brain that is linked to psychological maturity. The third explanation relates to perceptions on sexuality, in that boys with delayed puberty experienced negative feelings towards their sexuality as opposed to boys with average puberty maturity (Lindfors et al., 2007).

Furthermore, a study conducted by Pace and Zappulla (2011) found that attachment may serve as a protective factor against internalising problems. On one hand, adolescents with secure attachment seem to be protected from developing internalised problems and may be able to adjust to the developmental tasks; while adolescents with insecure attachment are likely to develop internalised problems and may be unable to adjust to the developmental tasks. Thus, adolescents with secure attachment to their parents are less likely to develop depression, anxiety and aggressive behaviours, and also less likely to use banned substances and alcohol as coping mechanisms (Pace & Zappulla, 2011). Similarly, Vogel (2012) conducted a study in the Western Cape of South Africa and found that adolescents who were raised in families with low levels of parental care, high family conflicts, maltreatment, poverty, or chronic illnesses in the family are likely to develop depression and, if left untreated, this may negatively impact on the development of the adolescents.

Therefore, the adolescence stage is characterised by multiple changes and challenges, including physical and psychosocial changes and challenges. In order for adolescents to move through those multiple changes and challenges, they need to acquire developmental tasks, which will be discussed next.

### 2.2.4. Developmental Tasks

According to Louw, et al. (1998), society expects certain characteristics and skills (called developmental tasks) to be reached by an individual at each developmental stage. In addition, Cobb (2010) mention that adolescents experience numerous physical and psychosocial changes that challenge them to perform new developmental tasks. As mentioned previously, Levine et al. (cited in
Laughton, et al., 2013) have mentioned that adolescents experience challenges in developing identity, increasing independence, and considering the future.

This is further supported by Leifer and Fleck (2013), who highlight that each of the three sub-stages of adolescence is characterised by its own challenges.

2.2.4.1 Early Adolescence
According to Leifer and Fleck (2013), in the early adolescence phase, adolescents are faced with numerous challenges: they become conscious of their body image and attempt to adjust to pubertal changes; they develop a sense of denial about reality and the self and have low self-esteem; their behaviour is motivated by rewards; they develop best friends, and engage in hero-worship and have adult crushes; they develop ambivalence towards their family and strive towards independence; they have concrete thinking and focus on the here and now; their main goal is to socialise, and their goals may be impractical (Leifer & Fleck, 2013).

2.2.4.2 Middle Adolescence
Leifer and Fleck (2013) note that in the middle adolescence phase, adolescents are faced with the following challenges: their physical growth changes more in height; they explore various images and appearances; they become impulsive and experience identity confusion; their behaviour is motivated by conformity; they are interested in sexual experimentation; they start dating, are concerned with satisfying significant peers, and they develop a heterosexual peer group; in their family context, they struggle for autonomy and acceptance, and they may rebel against or withdraw from the family and demand privacy; they start to develop abstract thinking, and they experience daydreams and fantasies; their goal is to identify their skills and interests and become a super-achiever, or they drop out of school; they are more interested in experimenting with sex or drugs (Leifer & Fleck, 2013).

2.2.4.3 Late Adolescence
Leifer and Fleck (2013) note that in the late adolescence phase, adolescents are also faced with many challenges: physical growth decreases; they start to accept their body images and their personality develops; they develop a positive concept of the self and become empathetic independent thinkers; they develop responsibility for their behaviour; they develop their own sexual identity and caring relationships; they care and value relationships, and begin to select partners; in their family context, they reach independence and re-establish family relationships; they identify career goals and enter work or tertiary institutions; they make decisions based on their lifestyle choices (Leifer & Fleck, 2013).

In addition, the other developmental task that must be reached is the vocational development. According to Savickas (2002), occupational careers create a space where individuals become involved and meaningfully contribute to the society. These careers lead to a continuous process of validating and confirming an individual’s self-concept or the individual’s picture of him or herself. The life-stage career-development theory (cited in Usinger & Smith, 2010) highlights that career develops from the process where individuals decide and express their self-concept. This process includes social relationships and negotiation of meaning. Thus, career development is derived when the individual constructs a meaning of his or her life experience through social interaction. According to the construction theory (cited in Usinger & Smith, 2010), this process of career development is divided into three stages, namely, life themes, vocational personality, and career adaptation. With regard to the first stage – life themes – the construction theory notes that individuals formulate their ideals of the type of occupations in which they would like to be involved. Vocational personality involves individual’s career-related abilities, needs, values, and interests – the individual explores his/her
abilities, needs, values and interests through exploring his/her ideal occupation. Career adaptability involves a process where individuals validate their self-concept by analysing behaviours and competencies that are required in different occupations and then aligning themselves to those occupations that match the self-concept (Usinger & Smith, 2010).

Adding to the construction theory, Super and Savickas (Ferreira, Santos, Fonsea & Haase, 2007) mention that career development does not occur in a vacuum; it occurs in a social context in which the individual exists, through the process of feedback loops. Super and Savickas (cited in Ferreira, et al., 2007) also mention that individuals may develop a premature career when they drop out of school. On the other hand, Usinger and Smith (2010) found that adolescents who are self-absorbed, detached, angry, or overwhelmed appeared to have low self-esteem towards their internal sense of self, thus impacting on their career development. This is because these adolescents consciously focusing on themselves in the present situation rather than their future selves. The study also found that adolescents who are self-absorbed and angry were pre-occupied with conflicting beliefs; they have beliefs about how others perceive them in relation to beliefs about their moral self, which is a reflection of the ideal self-concept. These conflicting beliefs may result in the adolescent becoming fixated or stuck within their internal conflict. Furthermore, the study found that adolescents who are detached and/or overwhelmed may be withdrawn from the societal expectations, due to either being overwhelmed by personal circumstances or being deliberately withdrawn or disengaged (Usinger & Smith, 2010).

Furthermore, Havighurt (cited in Jaffe, 1998) note that an individual who successfully reaches the developmental tasks in adolescence may develop a sense of accomplishment and successfully move on to the next stage; failure to reach the developmental tasks may result in feelings of unhappiness, rejection by society, and difficulty to move to next developmental stages.

From the above, adolescents experience numerous developmental changes and tasks that needs to be dealt with effectively in order to move to adulthood. The conceptual framework of the study will be discussed in the next section.

2.2.5. Conceptual framework
The biopsychosocial model is used as a conceptual framework to conceptualise adolescents and their challenges. This will be further discussed below.

2.2.5.1. Biopsychosocial model
Over the past few decades, the field of psychology has evolved from focusing on the individual to understanding the importance of additional contributing factors to mental health. This paradigm shift includes acknowledging the importance of health psychology, as a subspecialty of psychology, which is aimed at promoting and maintaining health, and preventing and treating illnesses (Gurung, 2010). Health psychologists incorporate a biopsychosocial approach with a specific focus on the importance of a biological constituent of health.

The biopsychosocial approach was originated by George Engel (1977). According to Engel (1977), individuals are biological, psychological, and social beings who behave in a specific ways that can either promote or damage their health. Thus, the biopsychosocial model regards the health of a person as a totality – the health of an individual is the end result of variables including biological characteristics, behavioural factors, and social factors (Marks, et al, 2006). Health is impacted by the thoughts, beliefs, and behaviour of a person, and the way these interacts with physical systems. Furthermore, this interaction is impacted by the social context. Thus, in order to create changes in the
health, it is important to understand the interactions between biological, psychological and social factors. This is called biopsychosocial model (Marks et al., 2006; Albelheim, 2011). From the above, it is evident that the stage of adolescence is a period where individuals are faced with numerous developmental changes and tasks including physical, psychological and social changes and tasks. Furthermore, in this study, the focus will be on adolescents who were vertically infected with HIV and this biopsychosocial model can be used to conceptualise how HIV impacts on these adolescents. This will be further discussed in chapter 2 section 2.3.

2.2.6. Conclusion
The literature reviewed in this chapter highlights that adolescents experience physical, cognitive and psychosocial changes and challenges. These changes may differ in the onset, duration, and tempo between and within individuals. Such differences may also impact on the psychological development of the individual. In addition, with these changes, individuals need to acquire numerous developmental tasks to transit effectively to adulthood. Failure to complete those developmental tasks may result feelings of unhappiness, rejection by society, and difficulty to move to next developmental stages. However, when an individual successfully completes these developmental tasks, they develop a sense of accomplishment.

This section presented a general framework on the adolescence stage as covered by the literature. The next part reviews literature on adolescents living with perinatal HIV/AIDS which is the main focus of this study.

2.3. ADOLESCENTS WHO WERE VERTICALLY INFECTED WITH HIV

2.3.1. Introduction
In the previous section, the stage of adolescence was discussed. Over thirty years have passed since the first discovery of HIV/AIDS (Evian, 2011). Numerous studies have been conducted as an attempt to understand the concept of HIV. Thus, in this section, a brief overview of HIV and how it is transmitted will be highlighted. This section further discusses how HIV affects adolescents from a physical, psychological and social perspective. Furthermore, adolescents’ perceptions of perinatal HIV as a chronic illness will be discussed. Finally, various types of treatment that are available for adolescents will be discussed.

2.3.2. The origins of HIV/AIDS
In June 1981 in Los Angeles, in the United States, a rare kind of pneumonia, known as Pneumonia Carinii, was detected in homosexual men. Blood testing and testing of other samples began that year which resulted in many studies that led to the discovery of acquired immunodeficiency syndrome (AIDS) a year later (Rohlede, et al., 2009; Wexler, 2013). AIDS was initially hypothesised to affect only homosexual men; however, as time progressed, the hypothesis was changed due to the diagnosis of AIDS in immigrants in the USA. The disease was later diagnosed in heterosexual people in Africa (Van Dyke, 2012). In South Africa, the first cases of AIDS were diagnosed in 1983 (Rohlede, at al., 2009; Wexler, 2013) in two homosexual men (Van Dyke, 2012). Subsequent to these and other reported cases, the human immunodeficiency virus (HIV) was identified as the causal agent for AIDS in 1986. Since then, HIV/AIDS has spiralled into the biggest epidemic in history (Rohlede et al., 2009; Wexler, 2013). This epidemic affects everyone across age, race, sex, socio-economic status and geographical location (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios, ..., 2014). In 1996, new HIV infections spiralled to an estimated 3.5 million worldwide (Van Dyke, 2012).
The most highly affected region in the world is sub-Saharan Africa (Swanepoel & Louw, 2010; Van Dyke, 2012; Shisana et al., 2014), with South Africa having 5.7 million people infected with HIV/AIDS and recording 71% of new HIV infections in 2009 alone (Van Dyke, 2012). According to Shisana et al. (2014), between 2008 and 2012, South Africa experienced an increase of 1.2 million people living with HIV, increasing from 10.6% of the population (5.2 million people) in 2008 to 12.2% (6.4 million people) in 2012.

The diagnosis of HIV/AIDS evoked numerous responses worldwide. Initially, people responded to the HIV/AIDS epidemic with denialism, blame shifting and moralisation (Van Dyke, 2012). HIV/AIDS was initially labelled as a disease of the ‘gay’ population; this population was blamed for the infections, but the belief disappeared with time. Later, many people were infected through blood transfusion products. This led to a new perception about AIDS, as people infected with AIDS were then grouped into two categories: the ‘innocent victims’ and the ‘promiscuous guilty’ who spread the disease. In South Africa, the responses towards AIDS were similar to those around the world (Van Dyke, 2012).

2.3.3. The nature of HIV/AIDS

According to Van Dyke (2012) and Evian (2011), the human body consists of the immune system that functions as a protective agent that defends the body against either new pathogens or future attacks by existing pathogens. When the body is infected by pathogens, this indicates that the immune system is either unable to fight against or adapt when challenged by pathogens (Van Dyke, 2012; Evian, 2011). With regard to HIV, the virus invades the human body and gradually causing a decline in the immune cells, especially the CD4+ T cells (Evian, 2011; Van Dyke, 2012; Wexler, 2013) which are responsible for regulating and controlling the immune system (Evian, 2011). Eventually, the immune system becomes ineffective (Evian, 2011; Van Dyke, 2012; Wexler, 2013). HIV directly fights the important defensive immune cells, called the CD4+T cells. This gradual decline in the number of CD4+ T cells results in the protective immune system’s inability to effectively fight against HIV and other pathogens (Evian, 2011; Van Dyke, 2012; Wexler, 2013). Therefore, the ineffectiveness of the body’s immune system creates an opportunity for other infections and viruses to invade the body (Evian, 2011; Wexler, 2013). In a nutshell, HIV is a retrovirus that damages specific white blood cells.

According to Wexler (2013), AIDS is the last stage of an infection that arises from HIV. AIDS is viewed as a collection of diseases in the human body that result from the body’s weak immune system. Therefore, AIDS is defined as a specific group of diseases that indicate the severity of immunosuppression related to infection with HIV (Wexler, 2013).

2.3.4. The transmission of HIV

According to Wexler (2013) and Van Dyke (2012), HIV can be transmitted from one person to another via:

- Oral, anal, or vaginal sex – sexual intercourse – specifically unprotected sex
- Mother-to-child transmission at birth and through breastfeeding
- Blood contact, e.g., sharing needles during drug injection, transplantation of HIV-infected body organs, or transfusion of infected bodily fluids.
Shisana et al. (2014) also reported that the most prominent modes of transmission that increases vulnerability to HIV/AIDS infection are sexual intercourse and maternal transmission to a baby. However, maternal transmission decreased from 3.5% in 2010 to 2.7% in 2011 (Shisana et al., 2014). Thus, the most recognised mode of transmission is sexual intercourse, followed by mother-to-child-transmission.

2.3.5. Diagnosis and symptoms of HIV

HIV/AIDS can only be diagnosed by qualified health professionals through diagnostic laboratory tests that use blood as a specimen. HIV infection takes place through different stages. The first stage is the primary infection, which is the establishment of the infection; thereafter followed by a typically prolonged asymptomatic (symptom free) period – a stage with no appearance of physical symptoms and deterioration of the patient’s health. Subsequent is the symptomatic period; during this stage physical symptoms appear and the patient’s health condition deteriorates. The symptoms that develop are the following: weight loss, profound unexplained fatigue, nausea, fever, night sweating, swollen lymph glands, a heavy persistent dry cough, easy bruising or unexplained bleeding, watery diarrhoea, loss of memory, balance problems, mood changes, blurring or loss of vision, and oral lesions such as thrush. In terms of its structure and genetic makeup, the infection presents itself in the same manner in affected people. However, people react differently to the virus. Death results from opportunistic infections that arise because of the impaired immune system, not HIV (Wexler, 2013).

For the purpose of this study, the focus shifts to the adolescents who were perinatally infected with HIV/AIDS.

2.3.6. Adolescents living with vertical HIV/AIDS

2.3.6.1 History of Adolescence Living With Vertically HIV/AIDS

The first cases of paediatric HIV/AIDS were reported in in the USA in 1982 (Swanepoel & Louw, 2010). Before 1997, there was insufficient information in South Africa on paediatric HIV/AIDS, until the case of Nkosi Johnson emerged. However, cases of pregnant women who were infected with HIV had already been recorded since 1990, suggesting that there were a significant number of children who could have been born with HIV since the early 1980s (Rohlede et al., 2009). According to Van Dyke (2012), and Swanepoel and Louw (2010), the most common mode of HIV infection in children is mother-to-child transmission (MTCT), also known as maternal transmission or vertical transmission. About 90–95% of children are infected through maternal transmission, and approximately about 590 000 children are infected through MTCT every year. However, with the use of anti-retroviral (ARV) treatment drugs, cases of MTCT have reduced from 3.5% in 2010 to 2.7% in 2011 (Swanepoel & Louw, 2010; Van Dyke, 2012; Pillay, Dinh, Goga et al., cited in Shisana et al., 2014). In addition, with the improvement of ARV medication, there has been a decrease in mortality rates and HIV has transformed from an acute terminal illness into a chronic disease (Midtbo, 2012; Rohlede et al., 2009; Swanepoel & Louw, 2012; Foster & Lyall, 2005).

The majority HIV-infected children and adolescents live in South Africa (Swanepoel & Louw, 2010; Meyer, 2013), with 90% of perinatally HIV-positive children and adolescents of the world residing in sub-Saharan Africa (Van Dyke, 2012). Shisana et al. (2014) add that South Africa has 45.1% of children (aged 0 to 14 years old) living with HIV/AIDS. HIV-positive adolescents’ health is becoming a critical subject, as antiretroviral (ARV) medications have significantly increased the chances of HIV-positive children growing into adolescence and adulthood.
According to Karim and Karim (2010), in the context of a child who has had vertical transmission of HIV, HIV has a direct and indirect impact on both maternal and child survival. In an indirect impact to the child, HIV-positive mothers are at an increased risk of dying compared with HIV-negative mothers which this places their infants at an increased risk of being orphans. Thus, HIV impacts family system of the child. On the other hand, in a direct impact to the child, HIV impacts on the physical well-being of the child. For instance, 60% of HIV-positive infants manifest some symptoms of disease such as growth failures and developmental delays; respiratory system diseases; tuberculosis; neurological system diseases; cardiovascular system diseases; and renal diseases (Karim & Karim, 2010). Thus, the medical problems place the infants at an increased risk of being dead.

However, with the improvement of antiretroviral (ARV) medication, there has been a decrease in the mortality rates and HIV has transformed from an acute terminal illness into a chronic disease (Foster & Lyall, 2005; Rohlede et al., 2009; Swanepoel & Louw, 2011). This means that people who are living with HIV/AIDS are faced with the challenge of living with a chronic illness that has a significant impact on the quality of life. The life expectancy of children living with perinatal HIV/AIDS has increased, and they are expected to live beyond the childhood phase. However, they face challenges of growing up with a chronic health condition (Midtbo, 2012; Rohlede et al., 2009; Foster & Lyall, 2005). These children may, therefore, experience developmental and behavioural challenges (Sherr, Crome, Castaneda, Bradshaw & Romero, 2014). Etang (2011) also shows that the adolescent stage, on its own, is a period where individuals are faced with numerous challenges and changes, and having to cope with the chronic illness of HIV/AIDS can have a huge effect on the young person’s life. Thus, adolescents living with HIV are exposed to experiences, thoughts, and challenges that may result in physical, psychological and social difficulties. Hence, from biopsychosocial model perspective, adolescents who are vertically transmitted with HIV are negatively impacted by HIV and this result in physical and psychosocial challenges. These challenges will be discussed in the following section.

### 2.3.6.2. Challenges of perinatal HIV infected adolescents

As mentioned above, adolescents who were vertically transmitted with HIV are negatively impacted by HIV as this leads to physical and psychosocial challenges (Etang, 2011).

#### 2.3.6.2.1. Physical Challenges

Children who were vertically infected with HIV are genetically predisposed to HIV risk factors from birth and are prone to develop symptoms related to the virus from an early age (Gurung, 2010). According to Rohlede et al. (2009), many children who are HIV positive are chronically ill; they have multiple hospital admissions and are at a high risk of being diagnosed with a range of neurological, cognitive, and other illnesses. These predisposing factors are not limited to physical wellbeing and developmental delays (Karim & Karim, 2010; Rohlede et al., 2009). As stated earlier, the adolescence stage is characterised by physical development, especially the onset of puberty and brain functioning (Bukatko, 2008). The physical development such as puberty and brain functioning of adolescents with perinatal HIV/AIDS is negatively impacted by HIV/AIDS. This may result in difficulties in physical wellbeing and in developmental delays.

- **Puberty**

  As mentioned in the preceding part of this chapter, adolescence is marked by the onset of puberty defined as a period that involves biological processes of an individual’s body to transit from
reproductive immaturity to reproductive maturity – a person’s ability to reproduce develops (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen et al., 2012). Adolescents living with perinatal HIV/AIDS may experience difficulties in their physical wellbeing and developmental delays, which result from how HIV impacts on the human body (Rohlede et al., 2009; Swanepoel & Louw, 2010). According to Gillard, Witt and Watts (2011), HIV positive children and adolescents may experience physical symptoms that include prolonged fever, diarrhoea, fatigue, pneumonia, and mouth and skin disorders. This is because HIV attacks and weakens the immune system, resulting in HIV-positive children and adolescents becoming more vulnerable to opportunistic infections and diseases (Gillard, et al., 2011).

Similarly, Ferrand, Lowe, Whande, Munaiwa, Langhaug, Cowan, Mugurung, ..., (2010) found that HIV-positive adolescents are more likely to be hospitalised and experience a delayed onset of puberty. Sherr et al. (2014) also shows that children and adolescents who are living with perinatal HIV/AIDS may experience prematurity and developmental delays that may perpetuate feelings of fear. This is further supported by a study conducted by Hajikhani Golchin, et al. (2012) which found that girls who had late onset of puberty experienced feelings of worry and concern. Such feelings may impact on their body image.

According to Cash (cited in Pinquart, 2013), body image is made up of one’s perception and attitude towards one’s body, such as body satisfaction. A positive body image is very important in the adolescence stage, because this stage characterises a period of rapid physical change, during which adolescents undergo a process of formulating and defining their ideal body image. Any disfiguring of the body due to a chronic illness can impact the process of defining an adolescent’s body image. It is worth noting that body image dissatisfaction can lead to poor health habits, a low self-esteem and depression, especially in adolescent females. Youth expressed a fear of developing physical changes related to HIV infection, and how those physical changes could rely on what they heard about HIV and the possible physical changes that would result from the infection (Pinquart, 2013). Thinking about these changes appeared to fuel their fear (Martinez, Lemons & Hosek, 2012). Furthermore, Donald, Walker, Riordan, Governder and Wilmshurst (2012) report that children and adolescents with perinatal HIV/AIDS may suffer from stroke and epilepsy hydrocephalus, which may impact on their physical appearance.

• **Brain Functioning**

In the previous part, adolescence was defined as the period when the brain undergoes numerous changes (Steinberg, 2005; Bukatko, 2008; Luna, 2009; Jansen et al., 2012). The changes that occur in the adolescent stage may be affected by perinatal HIV/AIDS in adolescents living with the disease. Armstrong (cited in Sherr et al., 2014) notes that HIV can enter the blood-brain barrier and invade the central nervous system, thereby destroying neural tissues in the central nervous system eventually causing dysfunctionality of all modalities secondary to HIV/AIDS (Rohlede et al., 2009; Swanepoel & Louw, 2010). In South Africa, HIV infection occurs simultaneously with multiple environmental stressors, including poverty, and other forms of deprivation (Rohlede et al., 2009; Gillard et al., 2011). These increase the children’s chances of being exposed to malnutrition compared to children who are born HIV negative (Magadi, 2011). These risk factors continue from childhood to adolescence. In such conditions, the negative neurological effects of HIV on the children’s development are likely to be enhanced.

Furthermore, Sherr et al. (2014) found that the prolonged use of ARV therapy may impact negatively on the children’s cognitive performance and may cause delays in development. The delays
progressively continue throughout the development of childhood into adolescence and adulthood (Gillard et al., 2011). Thus, the brain function of adolescents living with HIV/AIDS might be negatively impacted by the mechanism of HIV/AIDS in the brain, together with the environmental stressors and side effects of ARV therapy. Consequently, adolescents and children living with perinatal HIV/AIDS may experience impairment in their mental, motor, and emotional development.

Similarly, according to Laughton et al. (2013), Swanepoel and Louw (2010) and Donald et al., (2012), HIV impacts the neuro-development of children and adolescents, thus resulting in neuropathology (Laughton et al., 2013), HIV encephalopathy (any type of brain disorder) (Swanepoel & Louw, 2010; Donald et al., 2012), micro-encephalopathy (small brain) and possible atrophy (Swanepoel & Louw, 2010). Neuropathology caused by HIV greatly occurs in the basal ganglia and cerebral white matter. There is also occurrence of neural loss in the prefrontal cortical regions, which may result in difficulty with complex mental processing (Martin, Wolters, Toledo-Tamula, Zeichner, Hazra & Civitello, 2006). These are the regions where, during the adolescent period, myelination and remodelling of synaptic connections occurs (Tau & Peterson, 2010).

Studies have been conducted to explore the impact of HIV on important neurocognitive domains. Thus, developing cognitive challenges in children refers to their inability to gain cognitive skills (Sherr et al., 2014). HIV-positive children and adolescents perform significantly poorer in executive functioning (EF) tasks, especially in processing speed memory including the attention span (Ruel, Boivin, Boal, Bangirana, Charlebois, Havlir, …, 2012). The following authors also concur with the aforementioned Donald et al., (2012), Smith, Chernoff, Williams, Malee, Siros and Kammerer, et al., (2012), Smith et al., (2012), Hoare, Fouche, Spottiswoode, Donald, Philipps, Bezuidenhout, …, (2012), Allison, Wolters and Brouwer (2009), and Ruel et al., (2012).

Other studies have found that HIV-positive children and adolescents score lower in visual-spatial processing, which is important for adolescents as it affects reading, writing, and learning (Blanchette, Smith, King, Fernandes-Penney, & Read, 2002). HIV-positive children and adolescents have been found to be slower and less accurate in pattern recognition (Koekkoek, Sonneville, Wolfs, Licht & Geelen, 2008), and to have lower scores in sequential processing, simultaneous processing, planning, reasoning (Ruel et al., 2012) and visual memory (Hoere et al., 2012).

Swanepoel and Louw (2010) also found that children and adolescents living with HIV/AIDS are likely to experience difficulties in balance, which may have resulted from the HIV virus damaging their vestibular structures. Sherr (2005), who reviewed 27 studies on the impact of HIV on the development of young children, found that HIV-positive children and adolescents are more prone to negative effects on growth as well as motor and mental development, language acquisition, adjustment, and behaviour and school performance. Similarly, Swanepoel and Louw (2010) report that children living with perinatal HIV/AIDS are at a high risk of developing communication and hearing disorders, as well as experiencing difficulties in swallowing and feeding.

According to Piaget, the highest level of cognitive development is in adolescence, which is referred to as formal operational thinking. This is an ability to reason in an organised way creating ideas and hypothetical concepts, testing the hypotheses, eliminating false hypotheses, and drawing conclusions (Papalia et al, 2012; Shaffer & Kipp, 2010). Armstrong (cited in Sherr et al., 2014) found that HIV can enter the blood-brain barrier and invade the central nervous system, thereby destroying the neural tissues in the central nerves system and consequently causing dysfunctionality in all modalities secondary to HIV/AIDS (Rohlede et al., 2009; Swanepoel & Louw, 2010). This might impact on the
development of formal operational thinking in the adolescent stage. Overall, children and adolescents living with perinatal HIV/AIDS are at a high risk of developing cognitive, behavioural and motor deficits. This increases their chances of poor academic achievement (Sherr, Mueller & Varral, 2009).

2.3.6.2.2. Psychosocial Challenges
According to the social ecological framework (cited in Mburu, et al. 2014), it is believed that adolescents’ development is impacted by the context in which they exist. Adolescents living with perinatal HIV/AIDS infection may experience psychological and social changes that might be negatively impacted by HIV/AIDS. In this study, stigma and disclosure will be briefly discussed before social and psychological challenges.

In South Africa (SA) people respond with great denial to HIV/AIDS. This continues to create a huge challenge in dealing with the epidemic (Rohlede et al., 2009), and it impacts negatively on the social functioning of people living with HIV. These responses give rise to stigma and disclosure of HIV status. In this study, stigma will be discussed first, and disclosure later.

- **Stigma**
Stigma is a prominent concern as youth navigate relationships. The perception of stigma leads to depression, fear, isolation, and hesitance to disclose the HIV status to others (Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). Stigma is a defined social process as the illness is viewed to be preventable or controllable and indicative of ‘immoral’ behaviours. Some people are blamed and perceived to be responsible for their own infection, which may result in active discrimination and social devaluation (Rohlede, et al., 2009). HIV stigma is, therefore, defined as discrimination pointed at people apparent to have HIV/AIDS, and the individuals, groups, and communities with which they belong to (Herek, 1999).

In society, those who are HIV positive are perceived as interrupting social order. This means that they provoke responses of stigmatisation, thereby putting more social burden on those who are presently dealing with the physical effects of HIV infection (Edgar, Noar & Freimuth, 2012). The sources of HIV stigma are as follows:

*Association with deviant groups*
The discovery of HIV illness was discovered in the 1980s. It was perceived to belong to certain social groups, such as gay men, intravenous drug users and Americans of African and Latino descent. Most of these social groups are usually associated with sexual promiscuity and intravenous drug use, and they are mostly perceived as conduits of HIV transmission. The perception that the disease belongs to deviant groups may be used as a psychological coping strategy for dealing with HIV. Thus, society may blame social groups to which one does not belong to as a means to decrease the level of anxiety associated with the danger of contamination. This, however, can eventually prove to be self-defeating and society may decrease the use of protective strategies when engaging in sexual behaviours, thus placing them at risk for HIV infection (Edgar, et al., 2012; Van Dyke, 2012).

*Responsibility for infection*
The society views the transmission of HIV to be driven by behaviours that are believed to be solely one’s own responsibility. Infected people are judged and blamed for being infected and the public may say ‘they deserve it.’ (Edgar, et al., 2012; Van Dyke, 2012)

Religion and mortality
The modes of transmission of HIV are viewed as ‘immoral’. These views are influenced by religious institutions. Some churches, directly or indirectly, increase HIV stigmatisation and discriminate against those living with the virus. Religious influences also reason that people even perceive HIV positive as a punishment for sin (Edgar, et al., 2012; Van Dyke, 2012; Lowenthal, Jibril, Sechele, Mathuba, Tshume & Anabwani, 2014).

Contagion
Stigmatising behaviours are associated with misunderstanding the modes of HIV transmission. People express feelings of fear of contagion towards HIV. This fear of contagion is a motivation of how the society reacts negatively towards people living with HIV. Despite considerable efforts to educate the public about how HIV can be transmitted, illogical and wholly incorrect common beliefs, such as the belief that HIV could be transmitted by coming in contact with objects previously touched by people living with HIV/AIDS (PLWHA) are perpetuated (Edgar, et al., 2012; Castle, 2004). Thus, the fear of contagion perpetuates HIV stigma.

Association with death
Despite the effectiveness of the ARV treatment in increasing the lifespan of HIV-positive people and changing HIV from a terminal disease to a chronic illness, the general public still perceives HIV as a terminal disease. This results from a misperception of associating HIV with death, which provokes fear and a sense of hopelessness in the society (Edgar, et al., 2012).

A study conducted by Archibald (2010) on Afro-Carribean people in the United States was aimed at exploring attitudes towards HIV/AIDS among churchgoing people. The study found that people expressed anger at HIV/AIDS discrimination and discrimination based on fear. Thus, discriminatory attitudes towards PLWHA engendered anger. Teenagers who had family members with HIV expressed disappointment in church members’ behaviours; one described her frustration with discriminatory labelling. Family members experienced discrimination from members of the church community due to fear of transmission, and children were not allowed to play together even after services. The adolescents were warned against ‘hanging’ or associating with PLWHA. A group of members preferred their daughters not to have close friendships with someone with HIV/AIDS. These mothers did not think that they were being discriminatory, but they were concerned for the welfare of their children (Archibald, 2010). Clearly, HIV stigma is a huge challenge that adolescents who were perinatally infected with HIV are faced with as it affects many social situations that these adolescents encounter, including the disclosure of HIV status, family context, school context and society. The HIV stigma also affects the psychological and physical functioning of the adolescents (Edgar, et al., 2012).

- Disclosure
The disclosure of HIV status is a process where there is communication about an individual’s HIV status, which is a potentially life-threatening, stigmatised and transmissible virus (Wiener, Zobel, Battles & Ryder, 2007). Thus, disclosure is defined as being told about one’s own HIV status, or disclosing one’s HIV status to others (Midtbo, 2012). A study conducted in Odi Hospital, Pretoria, by
Mahloko and Madiba (2012) found that children who have perinatally transmitted HIV/AIDS and are receiving ARV treatment grow into the adolescence stage, and this has given rise to a challenge of parents disclosing to adolescents about their HIV status.

**Disclosure to adolescents about their HIV status**

The main caregiver is found to have an influence on disclosure to young people with perinatally acquired HIV (Michaud, Suris, Thomas, Kahlert, Rubin, Cheseaux, the Swiss mother & child HIV cohort study (MoCHiV), 2009). However, caregivers who reported disclosing their children’s HIV status to a close adult family member found it is easier compared to disclosing to their infected children. This is because caregivers expressed feelings of helplessness and guilt about their role in the child’s infection through vertical transmission and fear of discrimination (Rohlede, et al., 2009; Madiba, 2012; Kyaddondo, Wanyenza, Kinsman & Hardon, 2013). Thus, for the majority (61%) of children disclosure was done by people other than their biological caregivers (Madiba, 2012; Mahloko & Madiba, 2012). However, Lowenthal et al. (2014) report that healthcare workers perceive disclosure to be the responsibility of the family.

A study conducted by Vaz, Eng, Mamas, Tshikandu, and Behets (2010) found that, in the moment of disclosure of HIV status to adolescents who were vertically infected with HIV, there were significant differences and similarities about information received by adolescents who were disclosed in medical setting as opposed to adolescents who were disclosed in family context. The similarity was that, in both contexts, medication mostly featured in the disclosure conversation or as advice on staying on healthy. The differences in the medical context were the manner in which the healthcare providers explained the mechanism of HIV and the importance of adherence to treatment; whereas in the family context, the caregiver discussed avoiding contaminating others through sharing sharp objects. Thus, in family context, the caregivers provided limited or no information about the mechanism of HIV. Furthermore, in both in context, the healthcare providers and caregivers focus more on providing information rather on the adolescents themselves (Vaz, et al., 2010).

A large number of these children have for a great part of their lives been unaware of their diagnosis, as their caregivers have kept it a secret (Kyaddondo et al., 2013; Midtbo, 2012). Vorster (2011) showed that the context defines and impacts the behaviour of an individual. The majority of the children only heard about their HIV status around the ages of 7 to 13 years (Midtbo, 2012) or during the adolescent stage (Kyaddondo et al., 2013). The moment of disclosure is experienced as dramatic and deracinating, with the physical and emotional response of ‘shock’ to a positive result and anger, depression, and other reactions (Rohlede et al., 2009; Martinez, et al., 2012; Van Dyke, 2012). These other reactions may be denial, anxiety, low self-esteem, sadness, hopelessness, guilt, feelings of loss (Van Dyke, 2012).

The adolescents found it important to be aware of their status for several reasons, including knowing why they had to keep on taking medications and going to hospital for follow-up visits. It is important for the adolescents to take care of themselves (Midtbo, 2012; Van Dyke, 2012), and to avoid high-risk sexual behaviours (Van Dyke, 2012). In contrast, a study conducted by Mutwa, Van Nuil, Assimwe-Keteera, Kestelyn, Vyankandandere, Pool, Ruhirimbura, ..., (2013) found that adolescents who were made aware their perinatal HIV infection expressed confusion or anger towards their parents. This anger, in some cases, also led to the adolescents being less obedient. This is sometimes in an attempt to punish their parents while, at other times, it is an attempt to come to terms with their status.

During normal adolescent development, youth develop future goals and work towards achieving them. Receiving HIV diagnosis initially interfered with their goals and expectations because having
HIV made them to question whether they would have any future. Youth concerns centre on reproductive health; for some of this youth, having children and building a family is an important milestone on their way to becoming adults. Thus, receiving an HIV diagnosis raises concerns about their reproductive health, including parenting, childbearing and childrearing (Martinez, et al., 2012).

Disclosure to family, friends, and society
According to Van Dyke (2012), each child has a right to confidentiality about his or her HIV status. Disclosure of HIV status to a child can only occur with the consent of the child who is 12 years old, and/or who has the intellectual ability to understand the consequences of disclosure. Disclosing one’s status automatically reveals the mother’s status and young people will often avoid family conflict and distress by keeping it a secret (Dorrel, Earle, Katz & Reveley, 2008). Studies that examined the disclosure of HIV status to adolescents with perinatally acquired HIV found that these young people experience a dilemma between a desire to let people know and their parent’s views, which sometimes results in feelings of isolation and loneliness (Dorrel et al., 2008).

A study conducted by Hoogwood, Campbell and Butler (2012) in the UK found that there are a number of factors that contribute to adolescents not disclosing their HIV status. Reasons being the myths and assumptions that occur in society, disclosure evoked a huge dilemma for young people and brought strong emotions of being fearful for the consequences. They did not want to be separated from peers and/or be rejected and isolated. This is particularly significant as peer relationships are one of the developmental tasks that are important in adolescence and contribute to increasing independence, influencing identity and providing social support. Although young people experience fears and dilemmas around HIV disclosure, they do not want to be associated with an identity linked to illness, contagion and death. In some ways, this desire motivates the young people not to disclose their HIV status as they choose to have a different image or identity where HIV does not belong. Adolescents have other priority developmental tasks, such as making friends, claiming independence and developing their sexuality, and they do not want to consider HIV (Hoogwood, et al., 2012).

This is further supported by a study conducted by Vann Staa, Jedeloo, Latour and Trappenburg (2008), which found that young people use a strategy of normalising a chronic illness as a way of forming identity so that they are able to accept that a chronic illness was present but prevent it from dominating their lives. Pettitt, Greifinger, Phelps, Bowsky (2013) also found that HIV/AIDS diagnosis has a great impact on developing sexual relationships with adolescents who have perinatal HIV/AIDS; they stand the risk of transmitting the disease to their partners, experience stigma and trust issues related to disclosing to their partners, boys experience peer pressure to have multiple partners, and the delay of the onset of puberty. These challenges are exacerbated in that some of these adolescents are orphans and have no family support to discuss these issues with; the only place they might seek support from is clinical care, especially the healthcare workers. However, the healthcare workers do not perceive adolescents who were perinatally HIV/AIDS infected as sexual beings, and do not focus on whether these adolescents have sex or not (Pettitt et al., 2013).

Furthermore, a study conducted by Martinez, et al. (2012) found that young people disclose their HIV status to family members and friends with the intentions of finding support. However, they are fearful of negative reactions that this disclosure may elicit. Very few had disclosed their HIV status to members of the wider community, including teachers and day-care providers (Rohlede et al., 2009).

Young people reported witnessing teachers and pupils discussing HIV without sensitivity or with limited understanding, which made the possibility of disclosure within a school context a difficult
prospect (Michaud, et al., 2009). However, with peers forming a central part of adolescence, research (Sherman, Bonanno, Wiener & Battles, 2000) found that some young people were disclosing to friends and this seemed to be beneficial in increasing self-competence in peer relationship and a possible link with the slowing of disease progression.

Thus, HIV stigma and disclosure of HIV status may impact on the social and psychological functioning of the adolescents living with perinatal HIV/AIDS. In this study, social challenges and psychological functioning will be discussed.

- **Social Challenges**

Environmental and social factors shared by many youth with HIV include single-parent homes, poverty, drug abuse, community violence, and loss of loved ones (Kang, Mellins, YiuKee Ng, Robinson & Abrams, 2008).

**Challenges within family context**

In the previous part, it was highlighted that a family functions as a primary support system for adolescents and a safe context for adolescents to successfully develop; however, a family with a lack of support may create a high risk for failure in adolescence (Zarrett & Eccles, 2006). Thus, stigma from the society may negatively affect HIV-positive mothers and their children, resulting in difficulty for them to create and maintain meaningful relationships outside the family context. This may result in many HIV-positive mothers and their children experiencing feelings of loneliness, being rejected and friendlessness, and being discriminated against and judged by community members (Rohlede et al., 2009; Van Dyke, 2012).

According to Rohlede et al. (2009), the biological effects of vertical HIV infection are often experienced simultaneously upon parental death or separation, parental illness and/or parental anxiety and preoccupation. The mother’s health, mental health, and support system may be negatively impacted by HIV diagnosis and may affect parenting on an on-going basis. This may impact on their psychological functioning, as they may have depression and lower levels of parental confidence (Rohlede et al., 2009).

A study conducted by Kidman, Hanley, Subramanian, Foster and Heymann (2010) found that children living with sick parents have deteriorating health, as they also suffer from an acute illness/injury and have to report chronic illnesses besides HIV infection. These children may receive sub-optimal care because the parental illness or HIV/AIDS reduces the amount of time the parents are able to spend on caregiving responsibilities for their children.

Several patients reported that the specifics of their condition were not greatly discussed with parents, and some of them had actually resorted to the internet for information. Most of the adolescents living with an infected mother expressed how difficult it was to raise this topic with her, given the guilt, torn loyalties and emotional dilemmas it evoked (Michaud, Suns, Thomas, Gnebm & Cheseax, & Swiss HIV Mother+Child Cohort Study (MoCHiV), 2010). Pettitt et al. (2013) added that adolescents living with perinatal HIV/AIDS infection may have feelings of anger and blame, both at themselves and their parents, which might impact on the quality of parent-child relationships.
Parental death is exceptionally difficult for a child at any developmental age. More than 95% of children who lose one or both parents to AIDS live with members of their extended family, including grandparents (Rohlede et al., 2009). Meyer (2013) shows that millions of children have been orphaned or made vulnerable by HIV/AIDS. Shisana et al. (2014) also report that approximately 16.9% of children have been orphaned by AIDS (maternal at 4.4%, paternal at 9.3%, and both at 3.2%).

Parental death has a negative impact on the child’s future and behaviour. It is estimated that 55% of all orphans in the world are children aged 12 to 17 years old (adolescents). This is important to know since adolescents need parental guidance through this developmental stage and at an age where they take part in activities that make them ready to be adults. There are several emergent challenges that adolescents orphaned by AIDS face in transitioning into adulthood. Their journey into adulthood without parental guidance results in them learning from their own mistakes and that of their peers without prior preparation of what to expect (Thupayagale-Tshweneagae, Mgutshini & Moleki, 2012).

The loss of a parent may also impact on the education of the adolescents experience of a normal childhood (Rohlede, et al., 2009; Van Dyke, 2012; Meyer, 2013) as they may be forced to drop out of school due to role changes at home, such as looking after their siblings, caring for an ill parent (Rohlede et al., 2009; Van Dyke, 2012; Meyer, 2013), and taking on the role of heading their households (Geifinger & Dick, 2011). This may in turn create limited, or a lack of, educational skills, resulting in them being exposed to a higher risk of unemployment or low-income employment. Those who relocated to their relatives’ homes are faced with the challenge of adjusting to the new context, as well as dealing with grief; they may also experience rejection from those relatives as they may be viewed as a threat to already limited resources (Rohlede et al., 2009; Meyer, 2013). Thus, the economic and social effects of HIV/AIDS on children includes malnutrition, poverty, neglect, migration, and homelessness (Foster, 2006; Van Dyke, 2012).

Other effects of HIV/AIDS are the collapse of family structures as safe havens for nurturing and guiding children as they develop their personal identities (Loubser & Müller, 2011). People are born into families and they understand themselves and their world from the perspective of their experiences in families (Barolsky, 2003). Therefore, the loss of a caregiver leaves a child confused, especially because the caregiver is often the only stable source of support in the family (Loubser & Müller, 2011).

The participants in the study conducted by Loubser and Müller (2011) stated that they did not only suffer physical loss, but also emotional and psychological distress as they had no one to support, love and guide them into adulthood. It is clear that the loss caused by the HIV/AIDS pandemic is not one-dimensional – it does not only leave orphans; it also causes loss of income, which makes one to lose one’s sense of security. The absence of a loving and caring adult in the house, especially for an early adolescent, means that a child does not develop a stable identity. This causes children to lose a sense of direction and purpose, without prioritising education and developing meaningful, stable relationships. It is clear that children suffer multiple losses owing to HIV/AIDS (Loubser & Müller, 201). Van Dyke (2012) also shows that children who were perinatally HIV infected experience pain from death of their parents from HIV/AIDS as exposure to such a traumatic experience may create fear and uncertainty about their future and anticipation of their own death.

Foster (2006) indicated that these children might also suffer psychological consequences, such as depression, guilt, and fear, which are associated with mental health in the long run. Furthermore, Van
Dyke (2012) found that the loss of someone to whom an individual is attached may create bereavement. Bowlby (cited in Van Dyke, 2012) further mentions that individuals normally form attachments with significant others for the purpose of satisfying their own needs of security and safety. The loss of someone to whom an individual is attached may cause the individual to experience grief, which is a natural reaction to that loss. Individuals who experience grief in the adolescence stage may have the cognitive ability to deal with the loss; however, they may be unable to express their emotions of grief, pain, fear, helplessness, and guilt. This may negatively impact on their daily functioning, by having a negative impact on their school work, creating a sense of withdrawal and tiredness, and having difficulties in concentration. In addition, when there is a death from HIV, it is often difficult for families (and young people) to be open about the cause of death due to fear of discrimination and stigma. When a family member dies from HIV, young people speak about having to lie about the cause of death, and they find it equally hard to share their grief with anyone, because they could not tell the truth (Dorrel, et al., 2008; Van Dyke, 2012).

A study conducted by Van Vilsteren, Haffejee, Patel and Bowman (2011) found that adolescents who are living in a residential care facility may experience numerous challenges. These authors found that adolescents had ambivalent feelings towards living in a residential care facility. Although the facility provided them with many materials and cared for them, they viewed the residential care facility as a very restrictive and regulated environment that limited their freedom to explore things. This study also found that adolescents experienced feelings of discomfort with how people reacted to them relative to their living in the residential care facility; many people might reacted by expressing feelings of pity towards them or discriminated against them. This resulted in the adolescents distancing themselves from the facility or lying to people telling them that the facility was the parents’ workplace. This study also found that the facility was funded by donors, and those donors visited and accessed the facilities, which caused the adolescents to feel pressurised in being congruent towards the donors. This further perpetuated the development of a sense of not feeling at home and comfortable in the facility. Finally, the study found that adolescents may develop a low self-esteem, passivity and aggression, and may use various defence mechanisms to protect themselves (Van Vilsteren, et al., 2011).

Challenges within peer context

As mentioned previously, peer relationships are important in the adolescence stage, because they provide emotional and social support to adolescents when faced with challenges of developing autonomy and independence (Cobb, 2010). Similarly, Jansen et al. (2012), together with Zarrett and Eccles (2006), report that adolescents establish friendships and groups for the purpose of emotional support and exploration of values, and also to fulfil their need for the formation of identity and sense of belonging, developing self-esteem, and sharing information. For adolescents living with perinatal HIV/AIDS, developing peer relationships may be challenging.

A study by Thupayagale-Tshweneagae, et al., (2012) found that orphaned adolescents have difficulties in interpersonal relationships, that is, building meaningful relationships with others seemed difficult and at times, impossible for them. This was as a result of many adolescents living with perinatal HIV/AIDS playing the role of young carers. Bauman, Foster, Silver, Berman, Gamble, and Muchaneta (2006) define young carers as children and adolescents who take on ‘substantial and significant tasks’ with responsibilities that would normally be associated with an adult when someone, particularly a member of the household, becomes unwell. This may result in loss of time to start peer friendships (Bauman et al, 2006). On the other hand, adolescents living with perinatal HIV/AIDS may experience stigma which might negatively impact on the development of peer relationships (Edgar, et
al., 2012). A study conducted in Kenya by Skovdal and Ogutu (2012) found that children affected by HIV may experience stigmatisation and bullying in their peer groups at school. Their peer relationships may also be affected by limited time and space for socialising with peers. Furthermore, adolescents living with perinatal HIV/AIDS grow in contexts where poverty exists; because these children usually do not bring any lunch to school, this seems to affect them in terms of social isolation and feeling different from other students (Cluver, Operario, Lane & Kganekge, 2011).

In addition, as the adolescents grow older, their interest in groups decreases as they spend more time on romantic relationships and close friendships which contributes to their development of a sense of competence (Zarrett & Eccles, 2006; Bukatko, 2008; Jansen et al., 2012). A study conducted in Zimbabwe investigating challenges faced by adolescents with perinatal HIV/AIDS found that adolescent girls lacked interpersonal skills that are necessary to form romantic relationships (Chinyezi, 2010).

**Challenges of poverty**

Children and adolescents who are infected and affected by HIV mostly grow up in poverty-stricken households (Rohlede et al., 2009). Ssewamal, Han, and Neilands (2009) reported that the death of parent may cause poverty in the family, as prolonged parental illness and subsequent death creates a financial strain on the family. Poverty negatively impacts on parenting causing parental stress, exhaustion, distraction, and frequent absences due to poorly paid, labour-intensive, and menial work (Rohlede et al., 2009).

Poverty and lack of resources may disappoint children in need, causing them to drop out of school (Rohlede et al., 2009; Skovdal & Ogutu, 2012). An impoverished child may be pushed into relationships with an adult, who is generally referred to as ‘sugar daddy’ or ‘sugar mommy’, for financial support. This increases the risk of infection as these partners are not only older, but they tend to be in multiple sexual relationships. In such situations, young people are dependent on the ‘sugar daddy’ or sugar mommy’ and are powerless to negotiate safe sex (Rohlede et al., 2009). A study conducted by Cluver and Orkin (2009) found that children and adolescents who are living with HIV/AIDS and experience poverty are at a high risk of developing internalising disorders. Similarly, a study conducted in South Africa by Cluver, Boyes, Orkin and Sherr (2013) found that there is a significant relationship between household poverty, which exists when a parent suffers from HIV/AIDS, and a child’s mental health and educational challenges.

Due to many children experiencing poverty due to loss of their caregivers, the foster child grant was introduced with the aim of protecting the child financially (Hall & Proudlock, 2011). The child grant is reaching nearly 11 million children in South Africa.

**Challenges in school context and scholastic achievements**

According to Libbey (cited in Melaughlin & Clarke, 2010), the school context is very important in the adolescent stage, in that the school is a space where adolescents are able to develop social and cognitive functioning. Similarly, a study conducted by Mburu et al. (2014) in Zambia found that the school context plays a crucial role in giving meaning to the experiences of adolescents living with perinatal HIV/AIDS infection. Schools also provide a space where adolescents living with perinatal HIV/AIDS may connect and form attachment with their peers. However, adolescents living with perinatal HIV/AIDS may drop out of school or repeat grades due to discrimination and frequent hospital appointments (Mburu et al., 2014). In addition, Bauman et al. (2006) highlights that parental illness could have a huge impact on the education of adolescents, since adolescents may assume the
role of young carers. These young people experience disadvantages in their access to education (Bauman et al, 2006; Van Dyke, 2012).

This was further supported by Gray, Van Niekerk, Struthers, Violari, Martinson, McIntyre and Naidu (2006) who conducted a study in South Africa that examined the impact of any sickness in the household on children. Children in sickness-affected households were found to be less likely to have school fees paid, more likely to be absent from school and be unsupervised while doing homework (Gray, et al., 2006). Similarly, a study conducted by Ismayilova, Ssewamala, Mooers, Nabunya, and Sheshadri, (2012) highlights that young people miss school or drop out of school due to several reasons. Firstly, the adolescents felt a strong sense of moral obligation to prioritise care of the unwell person; they had to accompany adults for emergency admissions to hospital, attend hospital and clinic appointments in order to fetch medication or stand in the queue for the sick person, provide care at home, including washing, medical care, intimate care (such as bathing the sick person) and sibling care (Cluver et al., 2011; Bauman et al., 2006). Secondly, the study found that young people attended school hungry as they constantly had no food for meals at home and a lunch at school. Thirdly, the study found that adolescents reported experiencing disruption and difficulties in their concentration (Cluver et al., 2011).

On the other hand, as previously mentioned, According to Piaget, the highest level of cognitive development is in adolescence, which is referred to as formal operational thinking. HIV might impact on the development of formal operational thinking in the adolescent stage (Sherr et al., 2014). This might impact on the scholastic achievements.

- **Psychological Challenges**

According to Cobb (2010), adolescence is a stage where numerous physical and psychosocial changes occur and requires adolescents to acquire new developmental tasks. As mentioned earlier, Levine et al. (cited in Laughton et al., 2013) have shown that adolescents experience challenges in developing an identity, increasing their independence, and considering the future.

According to Erikson (1968), identity is defined as an individual’s awareness and discovery of himself as an independent person with a definite role in society. He further explained that identity is made up of three components, including one’s identity (Who am I?), social identity (Which group do I belong to?) and the individual’s goals and values (What do I wish to achieve?). Furthermore, Barolsky (2003, p14) reported that “people are born into families and it is in families that they make sense of themselves and the world around them”. In the context of adolescents living with HIV/AIDS, the following may happen: important caregivers fall ill, parents die, children are orphaned, the family structure is placed under an immense pressure, and its ability to operate as a place of open socialising, economic support, nurturing and care is compromised (Van Dyke, 2012; Meyer, 2013). This results in a breakdown of the family structure and children relocating.

Consequently, the child experiences a loss of siblings, peer friendships, contact with extended family and cultural and family identity, together with a loss of a normal childhood context for the development of healthy self-esteem. This may perpetuate the development of feelings of loss of belonging, autonomy and control of one’s destiny, which then results in confusion. This may perpetuate the development of emotional trauma, which may result in an identity crisis and developmental delays (Van Dyke, 2012). In instances where the social environment generates negative feedback or the adolescent experiences rejection, the adolescent experiences role diffusion
and identity confusion (Brown & Pedder, 1991). Adolescents who are HIV positive are at risk of being rejected by their peers, community and the social environment. Erickson (cited in Louw, et al, 1998) suggested that this type of negative feedback loop may have a significant impact on this developmental stage.

From the above, it is evident that adolescents who are vertically infected with HIV can develop identity crisis. This is further supported by a study conducted by Anastasopoulos, Soumaki, and Anagnostopoulos (2010) found that adolescents who were perinatally infected with HIV are unable to develop their identity, because they are unable to detach from family and attach to peers (Anastasopoulos, et al., 2010).

According to Van Dyke (2012), HIV/AIDS may evoke highly emotional responses within individuals who are infected with and/or affected by the disease. He further shows that people living with HIV/AIDS experience tremendous fear, including fear of isolation, stigmatisation, and rejection (Van Dyke, 2012). A study conducted in Zambia by Mburu, et al., (2014) found that adolescents living with perinatal HIV/AIDS need a positive self-concept and strong locus of control and resilience in order to effectively deal with challenges caused by the HIV/AIDS epidemic.

A study conducted by Thupayagale-Tshweneagae, et al., (2012) had already found that powerlessness, poor communication and difficulties in interpersonal relationships were among the challenges mentioned by orphaned adolescents. In terms of powerlessness, the orphaned adolescents felt anxious about what the future held for them. The anxiety was mostly around the fear of getting pregnant, an inability to get a job, and failure to complete their studies. Participants found the transition to adulthood challenging because they were not sure what to do and what not to do. They also had difficulties in making decisions regarding their life choice. Thus, the transition into adulthood was an unfamiliar territory for the participants as they generally expressed a lack of knowledge about common things such as where and how to get social grants and bursaries for their education, family planning and, for some, even food rations. Warner, Malhotra and McGonagle (2012) report that a lack of assertion for adolescent girls was closely intertwined with the exclusion from essential services such as education and health. Being orphaned by a disease associated with stigma, especially AIDS, and discrimination also contributes to poor communication skills by orphaned adolescent girls (Thupayagale-Tshweneagae, et al., 2012).

The study by Thupayagale-Tshweneagae, et al., (2012) also found that orphaned adolescents have difficulties in interpersonal relationships; they find it difficult, or at times impossible, to build meaningful interpersonal relationships. The feeling of not being able to connect with others meaningfully was real for most participants. Failure to build these relationships related to their interactions with peers who manipulated them, relatives who were not empathetic towards them, or one-sided romantic relationships where their partners demanded and the participants felt obligated. The difficulty in building interpersonal relationships is a very crucial challenge because adolescence is a time of personal change and transition in which the adolescent is faced with establishing social relationships that differ from those established during childhood. Furthermore, adolescents require that individuals develop the ability to solve social problems independently. For the most part, the nature of problems in adolescence involves interpersonal relationships which require that individuals develop and effectively utilise social skills. The fact that many of the interpersonal relationship problems differ from those of childhood and are essentially being encountered for the first time often results in their resolution involving a measure of some personal difficulty (Thupayagale-Tshweneagae, et al, 2012)
Hinshaw (2005) highlights that adolescence is a period characterised by a number of developmental tasks; to deal with the demands that confront them, adolescents draw on their coping resources, which included their problem-solving competencies and skills. Adolescents are unable to deal adaptively with stress, or they have poor problem-solving abilities (Hinshaw, 2005). According to Pettit, et al., (2013), many adolescents living with HIV/AIDS suffer from self-blame and self-stigma and view themselves as lacking opportunities in their communities as compared to their uninfected peers. They also live in denial about their HIV status, and those who have accepted their status have a sense of hopelessness about their future.

Betancourt, Meyers-Onki, Stulac, Barrera, Mushash, Beardslee, Mushash, and Beardslee, (2011) note that extreme poverty, poor access to services, and family conflict, put children and families affected by HIV/AIDS at an increased risk of mental health problems. Many studies have identified common mental health problems in people living with HIV/AIDS, and listed them as depression (feeling depressed, lonely, and isolated from family and friends) (Cluver et al., 2013; Hinshaw, 2005; Lyon & D’Angelo, 2006; Miah, 2004), anxiety and stress (Cluver et al., 2013; Hinshaw, 2005), being suicidal (Cluver et al., 2013), post-traumatic stress disorder (Cluver et al., 2013), attention deficit hyperactivity disorder (Hazra, Siberry & Mofenson, 2010; Swanepoel & Louw, 2012; Donald et al., 2012; Mellins & Malee, 2013), mental retardation and cerebral palsy (Swanepoel & Louw, 2012), conduct disorder and oppositional-defiant disorder (Donald, et al., 2012).

Studies on parental bereavement and illness more have generally shown understandable negative effects on children’s well-being, which are connected to grief, loss of attachment figure, and uncertainty ((Dowdney, 2008; Forrest, Plumb, Ziebland & Stein, 2006). Child abuse (severe physical, emotional and sexual abuse) was also experienced by adolescents with perinatal HIV infection as well as conflict and violence in the household (Cluver et al., 2013).

- Adolescent’s perceptions about their chronic illness

Younger adolescents consider their condition as fate. They seem to live with the disease without reflecting on its meaning to them or on how they acquired it. This absence of in-depth reflection may be attributed to the pattern of concrete thinking that is characteristic of early adolescence. Older adolescents keep comparing themselves with adolescents with no physical illness or developmental disabilities (Van Dyke, 2012). According to Swanepoel and Louw (2010), individuals with communication and hearing impairments and traumatic brain injury may have low self-esteem and loss of control in their social relationships. This may have resulted from an inability to negotiate within their relationships, which perpetuates feelings of inadequacy. Furthermore, Swanepoel and Louw (2010) highlight that the relationship between hearing impairment and possible HIV infection, after they had found individuals who had hearing impairment secondary to HIV/AIDS, might become socially isolating, creating feelings of discrimination and rejection, and experiencing feelings of inadequacy in romantic, peer and family relationships, which may in turn lead to the development of depression, fears, and lack of psychosocial support.

A study conducted in Rwanda and Uganda (cited in Swnepoel & Louw, 2010) found that adolescents with different disabilities may experience difficulties at school, due to inappropriate teaching techniques and access to information. In addition, the study also revealed that those adolescents might experience difficulties in accessing health services due to many health workers being unskilled in treating adolescents with disabilities.
A study conducted by Kerr, Nixon and Angalakuditi (2011) in the United Kingdom found that epilepsy has negatively impacted on children and adults who are diagnosed with HIV/AIDS. Firstly, epilepsy had negatively impacted on their emotions, thus developing feelings of anger, annoyance or frustration, sadness, bad mood, or depression, embarrassment, worry/anxiety, fear of loneline, and, eventually, seizures. People with epilepsy also reported feelings of being different from other people around them. This may be due to their perception or actual experience of being labelled as different. Second, the study found that children and adolescents diagnosed with epilepsy may experience loss of independence and autonomy. Third, the study also found that people diagnosed with epilepsy may experience loss of control over their body and disruption of goals and plans. Fourth, the study further found that people diagnosed with epilepsy may have a low self-esteem which may have resulted from stigma and being treated differently. Fifth, it was also found that adolescents diagnosed with epilepsy may experience difficulties such as rejection in attempting to develop romantic relationships, friendship and social networks. They also felt annoyed by excessive concern and protectiveness from their parents and experienced stigma and bullying. This may further result in loneliness and social isolation. This was further supported by Wadman, Durkin and Conti-Ramsden (2011), who found that adolescents with specific language impairment are at a high risk of experiencing a high level of social stress compared to adolescents with no language impairment.

Chronic, physical illnesses and disabilities may negatively impact on the body image of adolescents. This is supported by the study conducted by Pinquart (2013) in Germany, which found that children and adolescents with chronic illnesses of obesity, cancer, diabetes, and visual impairment may be more dissatisfied with their body image compared to peers with no chronic and physical illness.

A study conducted by Hanna and Decker (2010) found that adolescents with Type1 diabetes acquired the task of self-responsibility through self-care. This self-care takes place through ownership of one’s diabetic care and consists of both behavioural and decision-making autonomy. However, self-care may be challenged, especially were parents are overprotective towards adolescents diagnosed with diabetes and may limit autonomy.

According to Boekaerts and Roder (cited in Kraaij & Garnefskei, 2012), people who are diagnosed with chronic illnesses and are in the adolescent stage may experience numerous difficulties related to their conditions, such as dependence upon their families, isolation from peers and numerous physical limitations. Thus, a chronic medical condition may be perceived as a stressor during the developmental period. A study conducted by Kraaij and Garnefski (2012) found that chronic medical conditions, such as diabetes, rheumatism, asthma and epilepsy, have a significant relationship with depressive symptoms, which may have been caused by the use of cognitive coping mechanisms such as self-blame, ramification and catastrophising and denial.

Similarly, a study conducted by Garnefski, Koopman, Kraaij and Cate (2009) found that adolescents diagnosed with juvenile idiopathic arthritis may develop internalising problems such as depression and anxiety, which may negatively impact on their quality of life. This study also found that the cause of internalising problems may have originated from maladjustments to daily functioning by using cognitive emotional regulation strategies of catastrophising and rumination. According to Garnefski et al. (2009), rumination is defined as a preoccupation of thoughts and feelings with being diagnosed with a chronic disease, and catastrophising is defined as an excessive focus on the terror of being diagnosed with a chronic disease. Another study conducted by Forgeron, McGrath, Stevens, Evans,
Dick, Finley, Carlson, (2011) found that adolescents with chronic pain are at a high risk of developing a depressive mood, low self-esteem, and becoming isolated.

Pereira and Valente (2013) found a significant relationship between adolescents with epilepsy and psychiatric disorders. A study conducted by Hillge, Beale and McMaster (2011) concluded that adolescents diagnosed with Type 1 diabetes perceived their illness as an intrusion, interruption, and immersion. Those adolescents reported that diabetes had interfered with their life goals and desires, which narrowed their choices and created a loss of self-control. Thus, they became more immersed in their disease and risked developing depression; they developed a sense of helplessness and hopelessness towards their future, and they also experienced feelings of grief and loss associated with loss of ability and creditability.

Similarly, the study found that diabetes had negatively impacted on the adolescents’ social relationships, making them socially isolated and emotionally stressed adolescents with diabetes, lacking support and receiving conditional approval that created a risk of developing false self-behaviour. Health professionals may discomfort adolescents when achieving and sustaining appropriate diabetes management; this may lead to discouragement, anxiety, depression and suicidal ideation. On the other hand, adolescents were experiencing a decline in physical health which led to feelings of concern and worry about being rejected as a marriage partner. This is important in the adolescent stage; at this stage, approval and the task of moving away from parental authority and developing one’s own identity may be important (Hillge, et al., 2011).

According to social psychology (cited in Zambo, 2010), social identity refers to how we view and understand ourselves in relation to others – having a sense of who we are and where we belong in the world. This is also influenced by how others perceive us. In addition, adolescents with disabilities may not obtain group status due to their peers perceiving them as being different thus developing a social identity of being ‘different.’ Furthermore, adolescents with disabilities may be viewed as outsiders and may be rejected by their peers when forming groups.

From the above, it has been shown that, punctuating from the biopsychosocial approach, adolescents with perinatal HIV infection experience multiple challenges in physical, psychological, and social functioning. This has indicated the importance of treatment in order for them to cope with these challenges.

### 2.3.6.3. HIV Treatment for adolescents

The biopsychosocial model was originated by George Engel (1977) as a critique to the medical profession to re-examine the biomedical approach to medical education and care. According to Albelheim (2011), the biopsychosocial model requires practitioners to change their perspective of using interventions at one level of a system which might be ineffective. Thus, the practitioners should work hand-in-hand and simultaneously at multi-levels, such as at biological, cognitive, behavioural and/or emotional levels in treatment planning and understanding of health and illness (Marks et al., 2006; Albelheim, 2011).

This is further supported by Van Dyke (2012) who notes that individuals living with HIV/AIDS experience numerous challenges ranging from physical, social and psychological challenges. Therefore, these individuals need a palliative treatment. He further defines palliative treatment as care that consists of a range of therapies, also called a multidisciplinary team, with the purpose of focusing on the physical, social and psychological needs of people living with HIV/AIDS. This type of
treatment is aimed motivating living a high-quality life, and it rebuilds hope and basic skills to deal with daily functions.

2.3.6.3.1. Biomedical or Physical Treatment

According to Shisana et al. (2014), in South Africa, the number of people taking ARV treatment increased from 16.6% in 2008 to 31.2% in 2012. South Africa has the largest ART programme in the world (Shisana et al., 2014). Furthermore, an increase in ARV treatment was noticed in children living with perinatal HIV/AIDS. Van Dyke (2012) reports that early testing, diagnosis and initiations of treatment were critical for caregivers and children, and that the complexity of ARV treatment was less of a barrier to treatment than issues of disclosure and support. Antiretroviral therapy rapidly improves a child’s condition and parents accepted treatment very positively. Fewer persistent side effects were observed among these children. Parents did not struggle to encourage their children to take medication, and most said that they had made it a way of life (Van Dyke, 2012). On the other hand, Pettitt, et al. (2013) report that adolescents living with perinatal HIV/AIDS and on ARV treatment may experience side effects with regard to metabolism, growth and development.

A study conducted by Thurston, Bogart, Wachman, Closson, Skeer and Mimiaga (2013) was aimed at addressing adherence issues among perinatally HIV infected adolescents and gay individuals. The study found a pattern with perinatally infected adolescents and young adults who are often fatigued by the complexity of their medication regimes and the chronicity of managing HIV their entire lives. The pattern was that the participants benefited greatly from the adherence skills they learned in the study; however, those gains were not maintained after the study had ended. The effects of neonatal HIV infection, HIV crossing the blood-brain barrier, and long-term usage of antiretrovirals may lead to deficits in neuropsychological functioning, or stunted cognitive development. These effects, coupled with the impact of living with a chronic illness from a young age, might play a negative role in cognitive maturity, resulting in poor planning, problem-solving deficits and increased dependency on caregivers for support among perinatally infected youth (Thurston, et al., 2013).

Thus, perinatally infected youth may require consistent and frequent check-ins with a provider to ensure that they are staying adherent to their medication regimen. The importance of mood monitoring was also highlighted, as one of the participants was struggling with depression and anxiety symptoms during the follow-up sessions, which had a huge impact on her adherence. The role of disclosure in promoting adherence is also illustrated. Some participants lacked disclosure, which prevented them from taking medications at certain settings and got in the way of adherence. Whereas others with full disclosure and a sense of agency related to disclosure (by encouraging others to disclose) and promoted continued adherence to the regimen (Thurston, et al., 2013).

A study conducted by Michaud, et al. (2010) was aimed at describing the adolescents’ perceptions of their illness, their therapeutic adherence and their participation in decisions regarding their treatment, with the idea that a better understanding by health professionals of these perceptions would assist the health professionals in improving the outcomes, both in terms of the adolescents’ coping capacities and how to improve adherence to treatment in Switzerland. The results suggested that adherence was linked to the kind of relationship established with the healthcare provider. Some subjects vividly described how they were able to find new adherence strategies when openly discussing with their physicians how to improve the situation. Although, the progressive assumption of responsibility for taking one’s medication purely belongs to a process of increasing autonomy during late adolescence, the drop in adherence observed in some older adolescents may suggest that they have not developed properly (Michaud et al., 2010).
A study conducted by Mattes (2014) in Tanzania found that many institutions that offer ARV treatment were understaffed with healthcare professionals, despite dozens of people receiving treatment at these institutions. This may negatively impact on the quality of services provided to the patients, resulting in neglect of physical examination and a lack of communication between healthcare workers and patients. A lack of communication between healthcare workers and patients may result in children and adolescents experiencing inconsistent practices and receiving insufficient information about their treatment and illness, which may further evoke confusion (Mattes, 2014).

On the other hand, a study conducted in Zambia by Mburu et al. (2014) found that many HIV clinics have healthcare workers who are inadequately trained to treat patients in the adolescent stage. This may prevent adolescents from accessing health services thus impacting on adherence to ARV treatment. Similarly, Pettitt et al. (2013) further notes that clinical services for HIV/AIDS in Southern Africa are not adolescent-friendly and healthcare workers lack skills to treat adolescents, as adolescents feel uncomfortable to receive treatment in either a paediatric clinic or an adult clinic. Furthermore, Pettitt et al. (2013) mentions that many clinical care units lack the ability to ensure a smooth transition of adolescents living with perinatal HIV/AIDS from a paediatric clinic to the adult clinic. Consequently, some adolescents may go back to the paediatric clinic or stop engaging in treatment.

Similarly, Van Dyke (2012) reports that adherence to ARV treatment was negatively impacted on by treatment fatigue, depression, relationship between patient and healthcare workers and side effects. Furthermore, other reasons for poor adherence to treatment include practical problems such as difficulties with transport to clinic, not having enough food for each ARV food requirement, lack of visiting and transport fees (Van Dyke, 2012; Pettitt et al., 2013), forgetfulness, bad planning and running out of ARVs, no social support, and stigma causing secrecy, fear and hiding of pills (Van Dyke, 2012). In addition, Piaget (cited in Van Dyke, 2012) mentions that adolescents are egocentric, and Van Dyke (2012) adds that the egocentrism of adolescents may negatively impact on their adherence to ARV treatment, as adolescents may refuse to take and/or drink medication at school because others will become aware. This leads to adolescents becoming limited in engaging in certain activities (Van Dyke, 2012). Thus, social support (such as family and peer groups) can be very important for adolescents to adhere to their medication (Mburu et al., 2014).

2.3.6.3.2. Psychosocial Treatment
Adolescence is a complex developmental process that includes the progressive adoption of autonomy and identity. Adolescents, like with other individuals, suffering from chronic conditions, and HIV-positive adolescents undergoing highly active ARV treatment face a number of challenges related to their developmental tasks. On one hand, HIV-positive adolescents have to develop their identity, a sense of a stable personality and continuity paired with some belief in the meaning of their life and their role in the community. HIV-positive adolescents have to integrate the fact they have to take medication and they have to accept life in a context of uncertainty about whether they will survive, and for how long. Thus, beyond providing the medication and follow-up for the HIV treatment, health professionals caring for these young people must assist them in developing their autonomy as well as a stable identity by discussing the impact of the disease and its treatment on their everyday lives (Michaud et al., 2010). Fair et al. (2012) report that psychosocial support groups impacted positively on the lives of adolescents living with perinatal HIV/AIDS, including creating and giving support to those adolescents, improving behaviour at home and school, as well as motivating sharing and peer support.
- **Group therapy and support groups**

Yaloom (1995) identified aspects of group therapy that contributed to group effectiveness, including a sense of universality, installation of hope, cohesiveness, and self-understanding. These therapeutic factors are important components of human growth and change. A study by Solorzano and Glassgold (2010) examined a psycho-educational and support group for young gay and bisexual HIV-infected men, and its findings supported Yaloom’s theory on the benefits of group therapy. The participants found therapeutic value in the group through the experience of group cohesion, universality, and focus on hope. This was effective in providing support to an often isolated population of emerging adults living with a highly stigmatised illness. A study conducted by Fair, et al. (2012), aimed at evaluating the Teens Out Loud group of adolescents living with HIV infection in the United States, found that group members identified the following four benefits associated with participating in the group: increased confidence, better communication skills, increased support, and a desire to share their experiences with others.

Midtbo (2012) reports that the Teen Club (support group) and other services including counselling and medical treatment were found to be important resources for the adolescents in different ways. The themes discussed in the Teen Club were HIV treatment, reproductive health, and how to deal with different challenges related to HIV, such as stigma and discrimination. The adolescents viewed the Teen Club as a place where they could be open to one another, share problems and find support. The Teen Club seemed to make the adolescents confident and believe in themselves; they felt safe and secure. Adolescents reported that some hospital staff members are supportive while some were sources of frustration that did not treat them well by being impatient with the adolescents, especially when receiving their medication. The adolescents reported that it was difficult to develop a trusting relationship with the doctors when they often had to see different doctors for each check-up. They developed friendships in the Teen Club. Acceptance, and being accepted and understood, were evident (Midtbo, 2012). Van Dyke (2012) shows that an effective peer support group creates a platform where control shifts from experts to the group members, allowing debates and discussions among group members, developing new group norms of behaviour, and changing education to be less threatening and available to group members.

- **Summer Camps**

Camps are designed to foster positive relationships and competence-building opportunities. They offer support and opportunities for youth to initiate and engage in behaviour that aids in the transition to adulthood (Van Dyke, 2012).

Although, camps aim to provide support and opportunities for positive youth development to all campers, occasional negative issues arise (Van Dyke, 2012). Friendship difficulties can be experienced in the camp as well as in other youth settings (Blachman & Hinshaw, 2002). However, research on the outcomes of camp participation consistently demonstrated that a camp has positive implications for identity development, social skills, physical and thinking skills, and positive values and spirituality (Bialeski, Henderson & James, 2007).

A study conducted by Gillard, et al., (2011) found that when campers felt connected to a positive accepting community that cared for them, a space was created in which campers became more open to trying out new ideas, activities and attitudes. In addition, campers saw the camp as a place to enjoy themselves, to participate in activities that they normally would be unable to do at home because of a
lack of availability or accessibility (especially for those with mobility impairments). Campers reported feeling relieved from the stress of having to hide their status at home and feeling isolated; this was their escape from stress. Participants reported that while at camp, youth increased their positive attitude, skills, and knowledge in several categories. These categories included anger and conflict management, disclosure, skills learning, education and medication adherence. There was also a personal change to campers’ self-concept and self-efficacy which was influenced by participation (Gillard et al., 2011).

Florindo (2007) highlights that friendship quality is also crucial to the psychological health of youth with chronic illnesses because it affects their physical well-being. Developing connections within supportive social networks can guard against the increased chances of depression, anxiety and other psychopathological disorders. The role of leisure in the lives of people living with HIV/AIDS has been found to be important for coping with the negative effects of diagnosis, and increasing health and quality of life (Florindo, 2007).

The aforementioned studies showed that it is clear that adolescents with perinatal HIV infection benefit a lot from the psychosocial interventions. This is further supported by a study conducted by Fawzi, et al. (2012) in Uganda that found that although participants indicated psychological symptoms at the beginning of the study, this decreased with follow-ups. The psychological symptoms were headaches and stomach aches, and depressive symptoms reflecting social withdrawal among the youth, isolation, and feelings worthlessness, increased confidence, improvement in the social support and quality of life of HIV-affected youth. All these identified symptoms decreased at follow-up sessions. The participants also indicated a greater ability to cope with adversity and plans for the future; they showed great confidence in coping with the stigma attached to HIV in their communities, and an increased capacity to communicate with one another, and a stronger sense of family cohesion (Fawzi, et al., 2012).

- **Psychosocial Treatment in South Africa**

According to Rogers (cited in Vorster, 2011), human beings are trustworthy, goal-directed, resourceful, capable of self-understanding and self-directed. This occurs if conditions fostering interpersonal growth are present. In many cases, this is not true for South African adolescents in previously disadvantaged communities. At this developmental stage, the importance of psychological interventions is fundamental to personal and interpersonal growth. This may be achieved through empathy (being understood from the individual’s frame of reference), unconditional acceptance (accepted by others without conditions and judgements) and congruence (openly expressing feelings, thoughts, reactions, and attitudes, without distorting ones inner experiences). Vorster (2011) illustrates that empathy, unconditional acceptance and congruence enable the individual to experience self-actualisation and once this is achieved, the individual is capable to fully accept themselves and others.

There are currently a large number of young PLWHA, both globally and nationally, who have increased levels of psychological distress (Pettifor, MacPhail, Rees & Coates, 2008; Murphy, Moscick, Vermund & Muenzi, 2000) and are in need of mental health services in order to live meaningful and productive lives beyond their diagnosis (Kelly, Freeman, Nkomo & Ntlabathi, 2007; Patel, Flisher, Hetrick & McGorry, 2007). However, worldwide interventions targeted young PLWHA focus mainly on health promotion and voluntary counselling and testing (VCT), and less attention is being paid to the mental health of young PLWHA post-diagnosis (Pettifor et al., 2008; Patel et al., 2007). In sub-Saharan Africa, mental health interventions are even fewer (Pettifor et al.,
A review of programmes available to young PLWHA in South Africa found that there are mainly two types of programmes: communication intervention programmes (Abdool, Karim, Meyer-Weitz & Harrison, 2009; Shisana et al., 2009) and VCT programmes (Pettifor et al., 2008). The difference being that the former is prevention driven, and latter is confined to pre-test and post-test counselling rather than providing on-going support. In other words, neither caters for the mental health needs of young PLWHA after diagnosis (Pettifor et al., 2008; Patel et al., 2007).

**Communication Intervention Programme**

There are a number of communication intervention programmes (for example, Khomanani’s Coming Together, Love Life, Soul City, etc.) that have targeted young people in South Africa. Research has highlighted that such programmes focus mainly on health promotion and the prevention of HIV.

**VCT model**

Studies in South Africa have revealed frequent inadequate standards of counselling (Olley, Seedat & Stein, 2004; Van Dyke & Van Dyke, 2003). There has been an increase in the number of people receiving VCT, with 13.4 million people reported to have been tested in 2011 (Shisana, 2014). For example, a study conducted by Olley et al. (2004) in Cape Town found that 64% of people tested for HIV received post-test counselling. This highlights that not all patients who go for an HIV test receive post-test counselling and information about safe sexual practices, regardless of the test results. Similarly, Kelly (2001) reports very poor standards of counselling services offered to PLWHA in the Eastern Cape, where it was reported that a counsellor was reading off a pamphlet, and talking on the telephone during a session. Similar findings were reported by Russell and Scheider (2000) and Van Dyke and Van Dyke (2003). Pettifor, et al. (2008) reports that the current VCT services are not youth-friendly and are considered inappropriate for the youth’s needs.

In summary, although the need for counselling immediately after a positive diagnosis and during the early stages of infection has been indicated, research findings suggest a contradictory picture of current counselling practices in South Africa. The needs of young PLWHA are not being met by the current health system and their testing experiences have not always corresponded with the VCT model.

A study conducted by Etang (2011) reports that participants felt that living with the knowledge of one’s positive HIV status without follow-up care and support could lead to depression, despair and death. Pettifor et al. (2008) found that the role of on-going counselling was viewed by young people as crucial to the adjustment and management of a positive diagnosis so as to prevent associated stress and psychological distress. However, on-going counselling is currently not part of the VCT model in South Africa.

Pettifor et al. (2008) found that young people had identified gaps in services by making requests for services such as on-going counselling, which currently does not form part of the services offered to them. Thus, counsellors need to pay attention to the unique needs of young PLWHA in South Africa. Similarly, Van Dyke (2012), together with Mattes (2014), highlight that many children in Southern Africa do not receive any psychosocial treatment.

### 2.4 CONCLUSION

From the consulted body of knowledge, it is evident that adolescence, on its own, is a period where individuals are faced with numerous challenges, and having to cope with a chronic illness such as
HIV/AIDS can have a huge impact on the adolescents’ well-being. Furthermore, it is evident that punctuating from a biopsychosocial approach, adolescents who were vertically infected with HIV are negatively affected by HIV, which leads to physical and psychosocial challenges. It is also evident that adolescents who were vertically infected with HIV need tailor-made multidisciplinary treatment in hospitals and clinics. There is lack of such tailor-made treatments for adolescents in South Africa.

In order to develop this kind of treatment in South Africa, the healthcare professional teams should have an understanding of the experiences and thought of adolescents who were vertically infected with HIV. There seems, however, to be a paucity in research pertaining to the experiences and thoughts of adolescents who were vertically infected with HIV in South Africa. Hence, this study was conducted. The research methodology and design of the current study will be discussed in the next chapter.
CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION
This chapter will provide information on how the study was conducted. It will provide an explanation on the research design implemented, the research setting, research population and data collection techniques applied. Furthermore, it will explain data management and analysis, and lastly provide a detailed explanation on the ethical considerations.

3.2 RESEARCH DESIGN
According to Cresswell, Eberöhn, Eloff, Ferreira, Ivankova, Jansen, …, (2011), a research design is referred to as a framework which involves steps starting from the underlying philosophical assumption to the selection of participants, the data collection methods and the data analysis to be done. Bertram and Christiansen (2014) showed that the aim of a research design is to create a framework to reach a bridge between research questions and the execution of the research. Denscombe (2010) illustrates that the choice of a research design must go hand-in-hand with the research question. Babbie (2010) shows that there are three most common research designs, namely descriptive, explanatory, and exploratory where:

3.2.1. Descriptive research design
Descriptive research has the purpose of describing situations and events in that the researcher observes and then describes what was observed – the aim is description (Babbie, 2010). Punch (2014) adds that descriptive research aims to describe what happened, or describe how it unfolded, or describe what something or someone looks like.

3.2.2. Explanatory research design
Explanatory research explains and attempts to answer the question of why (Ritchie, Lewis, Nicholls, & Ormston, 2014).

3.2.3. Exploratory research design
Exploratory research explores a topic by starting with familiarising the researcher with that topic. Exploratory research has three major aims, that is; to have a better understanding; to test the possibility of undertaking a more extensive study; and to create procedures which can be used in any subsequent study (Babbie, 2010). Terre Blanche, Durreim and Painter (2006) found that exploratory research uses open, flexible, and an inductive approach as they attempt to uncover new insights into the phenomenon.

The design for this study was based on an exploratory qualitative approach which was carried out through a face-to-face interview based on an interview guide. Conversations from the interview were also recorded using a tape recorder and transcribed. This approach was selected with the aim of exploring and documenting the subjective lived experiences of adolescents who were infected with HIV through vertical transmission at birth and are receiving treatment at Dr George Mukhari
Academic Hospital. The research design has been employed to meet the following objectives which also make up research questions that need to be answered:

- To gain insight into the experiences and challenges of adolescents who are vertically transmitted with HIV;
- To explore the current support systems of adolescents who are vertically transmitted with HIV; and
- To stimulate future research and generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

The aims and objectives of the research were achieved by engaging an exploratory research design rather than a descriptive and explanatory research design. Hence, this study is an exploratory research, in that the study attempts to understand, explore, stimulate future research and create debate around the importance of psychological interventions.

3.3. QUANTITATIVE AND QUALITATIVE RESEARCH METHODS

Many research methods exist in order to create a framework for guiding the researcher in conducting the research. The researcher chooses the best research methodology that will fulfil the purpose of that study. According to Punch (2014), there are two types of research methods namely quantitative and qualitative research methods. In order to highlight these research methods, the researcher has looked at the characteristics of both, and the criticisms against these research methods.

3.3.1. Quantitative research methods

According to Cresswell, et al. (2011), a quantitative research method is defined as a process which utilises numerical data through systematic and objective ways, and is collected from a small portion of the population (sample) to generalise the results to the population that has been studied. Similarly, Hurley, Denegar, and Hertel (2011) highlight that quantitative research creates a framework of scientific method in that the researcher manipulates the context by objectively and systematically collecting data and utilising statistical analysis to test hypotheses. Punch (2014) summarises both definitions by stating that in testing the hypothesis, the researcher examines the relationship between the variables which can be measured, typically on instrument, so that numerical data can be analysed using statistical procedures.

Furthermore, Punch (2014) highlights that the aim of quantitative research is to determine the relationship between the independent and the dependent variables. Bertram and Christiansen (2014) note that the independent variable is the cause variable, whereas the dependent variable is the result or outcome of another variable. Therefore, independent variables cause the dependent variable to change (Punch, 2014; Bertram & Christiansen, 2014; Richards & Morse, 2007).

In order to reach the aim, the researcher utilised a post-positivist approach that entailed that the researcher works under the framework of a cause-and-effect thinking, reduction to specific variables, hypotheses and questions, and utilises instruments and observations to test the theory (Punch, 2014).

In a nutshell, a quantitative research method is best in finding probabilistic relationships among variables in a large population, and conceptualises reality in terms of variables.

Quantitative research has its limitations, in that:

- The researcher has little or no contact with people or field settings (Punch, 2014).
• Statistical correlations may be based on variables that are arbitrarily defined by the researchers themselves (Punch, 2014; Grey, 2009).
• The variables are measured without including context (Punch, 2014; Grey, 2009).
• The methods used do not allow for participant individual differences or opinions to be highlighted (Punch, 2014).

3.3.2 Qualitative research methods
According to Punch (2014), qualitative research is a method which studies the subjective meanings of individuals’ experiences and behaviours within their social context. Silverman (2011) illustrates that the aim of qualitative research is to study and recognise how people perceive their social problems and situations. Frost (2013) indicates that the researcher places the texts of participants into context with the aim of exploring and understanding the participants within their context. This is further supported by Vorster (2011) who found that behaviour does not exist within a vacuum; behaviour occurs within a specific context and the context defines and impacts on the behaviour. Thus, the context is very important.

Bertram and Christiansen (2014) show that qualitative research punctuates from an interpretive, naturalistic approach where the researcher studies participants in their natural context. The aim of qualitative research is to explore and understand a phenomenon from the participants’ frame of reference (Bertram & Christiansen, 2014). Terre Blanche et al. (2006) coined the concepts ontology and epistemology meaning that qualitative research attempts to consider the participants’ frame of reference as it is part of their reality (ontology), and attempting to understand the participants’ subjectivity by interacting with them and carefully considering what they say with the aim of creating a space of permitting participants to answer questions posed by the researcher with in-depth answers. This may provide important information to close gaps which might have been missed by other studies (Terre Blanche et al., 2006).

In summary, Punch (2014) has shown that qualitative research is the finest approach in getting an insider’s perspective to study the lived experiences of people, including people’s meanings and purposes.

Qualitative research has its limitations, in that:
• It is sometimes viewed as less valid and reliable when compared to quantitative research (Punch, 2014; Terre Blanche, et al., 2006).
• The results are often non-generalizable and specific to the event or individuals studied (Punch, 2014; Richards & Morse, 2007; Terre Blanche, et al., 2006).

In this study, a qualitative research method was utilized in order to meet the aim and objectives of the study.

3.3.3. The rationale for choosing qualitative research method
In this study, qualitative research was chosen as method of choice to investigate this phenomenon rather than a quantitative approach. Also, qualitative research is best suited in discovering an insider’s perspective in the study of the lived experiences of people, including people’s meanings and purposes.
Contrarily, quantitative research is best in finding probabilistic relationships among variables in a large population, and conceptualises reality in terms of variables (Punch, 2014).

The main aim quantitative research is to test hypotheses and statistical generalisations whereas qualitative research aims to understand the nature of the research problem rather than the quantity of observed characteristics (Baškarada, 2014). Qualitative research is important to understand an individual’s attitude and beliefs, motives and demands, or obstacles that hinder the understanding of the contextual experience of the individual. If reduced to a number alone (such as 5%) the findings would lose their context. Furthermore, qualitative research focuses on the study of issues in depth and in detail, and tends to centre on how people make meaning out of their experiences (Stuckey, 2013).

The main aim of qualitative research is in line with the aim of this study. Qualitative research has enabled the researcher to create a space where the adolescents who were perinatally infected with HIV have provided the researcher with richer responses which aided the researcher in understanding the adolescents’ frame of reference, within the adolescents’ context; and recognise how adolescents who are living with perinatal HIV infection perceive and understand their social problems and situation. Furthermore, qualitative research gave voice to the participants in the study and it allowed the participants to show their experiences of living with HIV. This has opened eyes to new aspects of the experiences of the participants.

The next sections will discuss the research design and research method of the current study.

3.4. STUDY SETTING

According to Bazeley (2013) the context is vital in qualitative research and cannot be ignored as it influence the place of behaviour. Vorster (2011) shows that the context defines and impacts the behaviour of an individual. Neuman (2009) found that the meaning of a social action or statement depends on the context in which it appears and when a researcher removes an event, social action, answer to a question, or conversation from the social context in which it appears, the social meaning and significance are distorted. Thus, Bazeley (2013) notes that in qualitative research a thorough explanation of research context very crucial.

In this study, the initial proposed setting was Tshepang Clinic; however, the researcher was unable to find potential participants who met the criteria (to be discussed later). Consequently, the setting was the Paediatric Clinic at Dr George Mukhari Academic Hospital. According to the nurse-in-charge of the Paediatric Clinic, the potential participants are kept at this clinic instead of being transferred to the adult clinic because they have a history of poor adherence to treatment. The nurses and doctors aim to assist the potential participants to adhere to treatment before they are transferred to adult clinic.

The Paediatric Clinic caters for children from birth until they reach 14 years old, as well as the adolescents who were vertically transmitted with HIV and have difficulties with adherence. The clinic is divided into two sections: the general section which treats all diseases that affect children and another section for antiretroviral therapy (ART) focusing only on children who receive treatment for HIV. The patients attend the clinic once a month as outpatients for doctor’s appointments. The patients are only seen by doctors and nurses for receiving ARVs. Some patients have been on medication since a young age. The participants of this study were found in this setting. The in-depth interviews were conducted in a consultation room during official hours before the participants consult the doctors. This room was a private, comfortable and quiet setting with no disturbances.
3.5. RESEARCH SAMPLING AND POPULATION

Bertram and Christiansen (2014) define a population as a group of people or organisations that could be involved in research. Bertram and Christiansen (2014) also show that it would be impossible to study the whole population, so the researcher needs to choose a sample from the population. DePoy and Gitlin (2011) define a sample as a subset of the population; and/or the individuals or units from the population which has been identified for the research. This subset of the population is obtained through sampling (Depoy & Gitlin, 2011). According to Hurley, et al. (2011) sampling is referred as the process of selecting of research participants from the population. There are two types of sampling methods, namely; probability and non-probability sampling (Babbie, 2010). Non-probability sampling involves selecting subjects from any kind of sampling which is not based on the statistical principle of randomness; whereas probability sampling uses random selection where each element in the sampling frame has an equal and independent chance of being selected for the sample (DePoy & Gitlin, 2011).

The various types of non-probability sampling are discussed below:

3.5.1 Convenience sampling

DePoy and Gitlin (2011) define convenience sampling as a process where the researcher involves any available subjects or elements as they enter the study until the desired sample size are reached. Hence, it is referred to as accidental sampling. For example, the researcher may stop people at the corner of the street. This type of sampling is important when the population is not known (David & Sutton, 2010). On the other hand, Babbie (2010) adds that this type of sampling does not allow any control over the representativeness of the sample and the researcher must be cautious about generalising from the data. The disadvantage of using this sampling method is that it is not generalizable to the population, thus creating problems in analysis beyond simply describing the sample (David & Sutton, 2010).

3.5.2 Snowball sampling

According to DePoy and Gitlin (2011), snowball sampling is referred as a process that includes requesting subjects to provide access to others who may meet the study criteria. This sampling is mostly utilised when the researcher does not have direct access to the population (DePoy & Gitlin, 2011). Babbie (2010) reports that in this type of sampling, the researcher initially conducts research on a few individuals of the target population that he/she can find and then requests those few participants to provide the details required to find other individuals of the population whom they happen to know. In addition, David and Sutton (2010) report that the disadvantage of this type of sampling is that it will lead to sample bias because the sample will only reflect the participants who are preferred by those who have selected them.

3.5.3. Quota sampling

Babbie (2010) highlights that quota sampling involves a process where the researcher starts with a table or matrix describing the features of the target population and is aware of the proportion of each feature. The researcher then collects data from individuals having all the characteristics of a given proportion and the overall data should include a reasonable representation of the population (Babbie, 2010). The proportion of each feature is predefined categories, and these categories are also referred to as quotas. The quotas are chosen to accurately represent the population’s profile (David & Sutton, 2010). Furthermore, David and Sutton (2010) highlight that the disadvantage of this type of sampling include choosing a certain type of sample with preferred characteristics of the quotas and excluding other population characteristics, such as, ethnicity, might limit the information for the full population characteristics.
3.5.4. Purposive sampling

Babbie (2010) refers purposive sampling as the process of selecting an appropriate sample on the basis of knowing population and the purpose of the study. It also uses the judgement of an expert in selecting cases (David & Sutton, 2010). Bertram and Christiansen (2014) report that this type of sampling is effective if the researcher does not intend to generalise the research results beyond the grouped sample.

The proposed study aims to explore and document the experiences of HIV positive adolescents, aged between 15 and 18 years. The study population includes all adolescents who were vertically transmitted with HIV. The sample frame was chosen from individuals attending the outpatient clinic at Dr George Mukhari Academic Hospital in Ga-Rankuwa, Gauteng Province. The sample was selected through non-probability sampling. The main concern is not on the size of the sample; in qualitative research, the researcher typically collects data until saturation is reached (Punch, 2014). Therefore, small portion/sample of the population was 11 participants or until theoretical saturation is reached – the point in data collection where new data can no longer brings additional insights to the research questions.

Convenience sampling was inappropriate for the study since the sample is known. Also, because the researcher had direct contact with the population, snowball sampling was inappropriate. Since no preference towards gender, race, or ethnicity was given and the participants gave consent to participate in the study, quotas sampling was also inappropriate. The researcher has selected the sample through purposive sampling from the Paediatric Clinic. Purposive selection has enabled the collection of the most relevant data, thus allowing the researcher to use certain criteria to select participants (Baškarada, 2014).

The researcher has highlighted inclusion criteria and exclusion criteria for participants. Baškarada (2014) mentioned that a criterion for selection of participants is utilized to strengthen accuracy and evidence. Inclusion criteria and exclusion criteria will be discussed next.

**Inclusion criteria:**

- Participants who are adolescents (between ages of 15-18 years)
- Participants who are vertically transmitted with HIV.
- Participants who are minor, consent to participate in the study will be requested from their parents/guardians
- Only participants who are on treatment at Dr George Mukhari Academic Hospital will be included

**Exclusion criteria:**

- Individuals who are vertically transmitted with HIV but are in a different developmental stage other than adolescents between ages of 15-18 years
- Individuals who are not vertically transmitted with HIV, however are infected with HIV from other modes of transmission (discussed in chapter 2)
- Individuals who are minor and whose parents decline to give consent for participating.
After the sampling process, it will be followed by data collection.

3.6. DATA COLLECTION

According to Bertram and Christiansen (2014) data is defined as information or evidence that the researcher gathers with the aim of finding answers to the research questions. Data can be collected through many forms, namely: from documents, observation, individual interviews, and focus groups.

3.6.1. Documents

Documents can be used to gather data in instances where the researcher utilises written communications that may give insight on the concept that is investigated. Written communication includes published and unpublished documents, company reports, memoranda, agendas, administrative documents, letters, emails, faxes, newspaper articles, or any document that focuses on the study subject (Cresswell, et al., 2011).

3.6.2. Observations

Observation is a strategy that involves recording the behavioural patterns of participants without necessarily asking questions or communicating with them. Observation is done daily where the researcher relies on his/her senses (seeing, hearing, touching, smelling, and tasting) (Cresswell et al., 2011). The advantage of observation, as a data collection method, is that it allows the researcher to gain insight into the situation. On the other hand, observation is selective and as a result, the researcher may choose, select and focus on interactions that are based on his/her frame of reference for interpretation. Therefore, observations are disadvantageous because the researcher may perceive only what he/she expects to see. Furthermore, the presence of the researcher might impact on the situation and observation may be disturbing to the participants (Bertram & Christiansen, 2014).

3.6.3. Focus group

The focus group strategy is a group intervention where the researcher uses semi-structured and structured questions with a specific topic addressed to participants within the group; debate and conflict in the discussions within the group is allowed and group dynamics are also included as part of data gathering (Cresswell et al., 2011).

In addition, David and Sutton (2010) highlight that although the advantage of the focus group is to allow the participants to have more control over the direction of the discussion, the researcher is ethically unable to guarantee confidentiality and the participants may not feel totally secure to discuss issues that might be sensitive in nature within the group. As a result, this may adversely impact the depth validity of the data obtained. Furthermore, David and Sutton (2010) also highlight that the focus group allows members of the group to stimulate others within the group. Consequently, dominant members within the group may control the discussion, resulting in limited participation from group members or similar expressed views. Another issue is that the members of the group might attempt to please the researcher or facilitator (David & Sutton, 2010).

3.6.4. Individual interviews

An interview is an interaction between an interviewer and a participant where the interviewer asks the participant questions to gather data and to understand the ideas, beliefs, perceptions and behaviours of the participant. A qualitative interview aims to understand the participant’s frame of reference to facilitate understanding of the participant’s reality and social functioning (Cresswell, et al., 2011). The
advantages of interviews is that the researcher is present when conducting interviews and can ask more questions, and seek clarity for more information. This method of data collection is important when obtaining in-depth information from a small portion of people. The disadvantage of this method is that the researcher may influence the type of information obtained from the participants (Bertram & Christiansen, 2014).

Furthermore, Bertram and Christiansen (2014) note that individual interviews can be divided into structured semi-structured and unstructured interviews. In structured interviews, the researcher uses questions that require closed responses (for example, yes or no, or one-word answers). Furthermore, David and Sutton (2010) mention that structured interviews are good in keeping reliability and repeatability, as well as allowing greater scope of quantification. The semi-structured nature of the interview allows the researcher to keep the interview on track and guide the participant through various themes. Following the unstructured interview strategy, the respondent speaks openly and freely about the topic with no directions from the researcher (Bertram & Christiansen, 2014). Furthermore, David and Sutton (2010) stress that the semi-structured and unstructured interviews allow more depth and personal details; however, they create difficulties in numerical comparisons.

In this study, the data was collected from adolescents who were vertically transmitted with HIV and receive treatment at Dr George Mukhari Academic Hospital. The researcher did not use documents as a method for collecting data because there is insufficient past documents that focus specifically on the adolescents who were vertically transmitted with HIV and are presently receiving treatment at Dr George Mukhari Academic Hospital. Furthermore, the researcher did not choose observation for data collection to avoid punctuating from his/her frame of reference for interpretation, choosing what to expect and influencing the interactions of the adolescents. In addition, the focus group method of data collection was not selected because HIV is a sensitive topic and the participants may feel uncomfortable speaking about their sensitive issues thus impacting the quality and depth of the information. In addition, the researcher has not chosen structured and semi-structured interviews because this might impact on the depth of data.

As a result, the researcher has chosen the flexibility of unstructured, in-depth interviews with each participant using an interview guide with open-ended questions as a means of data collection. The nature of unstructured open-ended interview questions allowed the researcher to keep the interview on track and to guide the participant through various themes outlined in the interview schedule (Appendix C). The interviews have broadened the researcher’s frame of reference into a social phenomenon rather than assuming that the information obtained was representative of a larger population.

Furthermore, the interviews were used on a small number of participants as a way of understanding the complexity of the participants’ behaviour, rather than imposing prior categorisation which may limit the field of investigation (Punch, 2014). The aim of the open-ended interview is to elicit the participant’s story. This is achieved through the utilisation of probes or open-ended questions, which are designed to elicit information, or to clarify themes (Bertram & Christiansen, 2014). The questions used in the interview are designed and based on the aims and objectives of the study.

Notwithstanding, how the researcher conducts the individual interviews is of paramount importance. In the next section, the procedure of conducting the research will be discussed.
3.7. PROCEDURE

The permission for conducting the research was granted through three research committees. The first research committee is the Dr George Mukhari Academic Hospital Research Committee which approved the research protocol to be feasible, thus permitting the study to be conducted at Dr George Mukhari Academic Hospital, on condition of the study being approved by the School Research Ethics Committee (SREC) and Medunsa Research Ethics Committee (MREC), respectively. Both research committees granted permission for the research to be conducted (See Appendix D and E).

Outpatients who meet the criteria for participating in the research have their appointments set every Tuesday in the Paediatric Clinic. The nurse-in-charge of the Paediatric Clinic reported that this clinic keeps adolescents who are on ARV treatment because they are or have defaulted on their treatment and the nurses and doctors are attempting to assist the adolescents to adhere to their medication before sending them to local clinics.

During data collection, the researcher was introduced to patients by the nurse-in-charge of the clinic in the morning before the doctor starts with patients. Then the researcher explained the research and criteria for participating in the research to the patients. Once the patients and their parents verbally agree to participate in the study, they were given a package including an information pamphlet (Appendix A), and the consent form (Appendix B). Each patient, together with their parents or guardians, was given a chance to read through the information pamphlet and consent form and to ask questions for clarity. For those participants who are ethically eligible to consent, the researcher obtained their permission by accepting their signed consent forms before participating in the research. For those patients who are considered minor, the researcher obtained the permission from the participant and their parents/guardians by accepting their signed consent forms.

The researcher has emphasised and guaranteed the issue of confidentiality, anonymity, privacy, and confidentiality of the data. Only then can the researcher start individual interviews in a consultation room where privacy and confidentiality are ensured. Initially, the researcher has established rapport by speaking with the patient about topics that the participant is comfortable with and creating a space where the participant will feel at ease. The duration of the interview was approximately 60 to 90 minutes. The interviews were tape-recorded with consent from the participants. Once the interviews are completed, each interview was transcribed and validated by reading through each transcript thoroughly whilst listening to the recorded interview to ensure that no errors have occurred. After transcription and validation, the next step will be data analysis which is discussed in the next section.

3.8. DATA ANALYSIS

Bertram and Christiansen (2014) define data analysis as the process of separation of a whole into its parts. David and Sutton (2010) also illustrate that qualitative data analysis is defined as being able to extract meaning from the content. The process of data analysis is to create and identify meaningful themes, ideas, and beliefs. In addition, Cresswell (2009) also reports that data analysis inductively builds from particulars to general themes while the researcher interprets the meaning of the data. Thus, the aim of data analysis is an attempt to understand how the participants view the specific phenomenon; this is obtained by analysing their thoughts, attitudes, understandings, knowledge, values, feelings and experiences (Cresswell, 2009).
There are numerous types of data analysis methods: narrative, grounded theory, discourse, conversation, interpretative phenomenological analysis and content analysis (Punch, 2014). The researcher has chosen content analysis for analysing the data collected for this study.

Ritchie et al. (2014) report that content analysis is the process of analysing both the content and context of documents, with the researcher identifying themes, and focusing on the way the themes are treated or presented and the frequency of their occurrence. In addition, Bazeley (2013) reports that content analysis is a systemic approach of analysis that identifies and summarises message content. Content analysis is usually used in analysing books, brochures, written documents, transcripts, news reports, and visual media; as well as analysing open-ended questions from surveys, interviews or focus groups. It is a process of looking at data from different angles with a view of identifying keys in the text that will help us understand and interpret the raw data (Bazeley, 2013).

Content analysis is beneficial in such a study because it (Writing@CSU Writing Guide, 2014):
- looks directly at communication via texts or transcripts, and hence gets at the central aspect of social interaction;
- allows a closeness to text which can alternate between specific categories and relationships;
- is an unobtrusive means of analysing interactions; and
- Provides insight into complex models of human thought and language use.

Content analysis is disadvantageous in its use because:
- it is subject to increased error;
- it is inherently reductive, particularly when dealing with complex texts as it tends to often consist of simple word counts; and
- it can be extremely time consuming

Content analysis was found to be appropriate to refine and group words into fewer related categories which can then provide meaning (Elo & Kynga, 2008; Punch, 2014). This process has also allowed the researcher to extract words, concepts, categories or themes from the data that support the interpretation of the data.

The researcher has applied the data analysis process as proposed by Taylor-Powell and Renner (2003) and Bazeley (2013) as follows:

**Step 1: Get to know the data**
The researcher has learnt and understood the data through listening to the voice recordings several times and transcribing the voice recordings. Then, the researcher wrote down the clinical impressions which were useful in compiling a matrix to categorise the interview data captured from the participants as guided by the interview guide.

**Step 2: Categorise information**
Information was categorised by bringing meaning to the words which involved re-reading the text and identifying consistent categories. The researcher assigned abbreviated codes and placed them next to the ideas found. This helped to organise the data into categories. The researcher was clear about what
was included and excluded in the category by using the matrix for ease of creating meaning into statements expressed by the participants.

**Step 3: Identify patterns and connections within and between categories**

The researcher organised the data into category patterns and/or connections (relationships) with specific themes identified, both within and between the categories.

**Within category description:** the researcher captured the similarities and differences of the participants’ responses within a category. The researcher identified key ideas, similarities and differences being expressed within the category.

**Larger categories:** the researcher created larger or super categories that combined several categories starting from more specific categories to larger or general ideas and concepts. The individual parts/themes were linked and related to broader themes across different categories.

**Relationships:** the researcher explored categories which occur consistently across the data. The researcher explored the connections within the experiences and challenges of HIV-positive adolescents, who are currently undergoing treatment, reviewed the cause and effect (action-reaction) relationship, and created a sort of sequence for the purposes of analysis. These connections were useful to explain the experiences and challenges faced by the HIV-positive adolescents who are currently undergoing treatment efficiently.

**Step 4: Interpretation-bringing it all together**

The researcher applied categories and connections to explain the findings. This was achieved by attaching meaning and significance to the analysis. The findings are described in Chapter 4 and 5 of this research report.

The participants’ gender was maintained as either male or female, and they were further identified according to codes. For the female participant the letter F will precede the code and the letter M will be used to refer to the male participant in the coding. Also where the interview question required either a “yes” or “no” answer, this was also categorized and quantified in order to create data categories for ease of explaining the findings.

**3.9. TRUSTWORTHINESS**

According to Holloway and Wheeler (2010), trustworthiness in qualitative research is referred to as procedural accuracy and adequacy of the study. Trustworthiness in qualitative research has four concepts, namely: credibility of the interpretations of the data; transferability of the results of the study beyond the bounds of the project; dependability of the quality of the study; conformability of study whereby the research results meet the aims and objectives illustrating that the researcher did not manipulate the results (Holloway & Wheeler, 2010).

In this study, trustworthiness was ensured through the development of a research audit trail. Bazeley (2013) suggests that a study’s trustworthiness may be established if a reader is able to audit the events, influences and actions of the researcher, while Akkerman, Admiral, Brekelmans and Oost (cited in Carcary, 2009) suggest that audit trails represent a means of ensuring quality in qualitative studies. During the implementation of a research audit trail, an auditor or second party becomes familiar with the qualitative study, its methodology, findings and conclusions. This process allows for
an objective audit of the researcher’s decisions, methodological approach and analytical processes. Furthermore, this ensures that the researcher has completed the study, thus confirming the research findings. In order to develop a detailed audit trail, the researcher has maintained a record of all research activities, develop notes, and document all data collection and analysis procedures throughout the study. This allowed the researcher to follow each stage of the research process and trace through the researcher’s logic. In addition, it provided other researchers the opportunity to determine whether the research findings may be reliable or require further inquiry (Carcary, 2009). The researcher has utilized up to three independent researchers during the research audit trail.

3.10. BIAS

According to DePoy and Gitlin (2010), bias is defined as the chance of having an unintended or unavoidable effect on study outcomes. The researcher was cognisant of the following sources of bias: firstly, assumption (conceptual) bias which is an error arising from the faulty logic of the investigator that can lead to faulty conceptualisation of the research problem, faulty interpretations and conclusions. This can be minimized by using three independent researchers to verify the primary researcher’s conceptualisation of the research problem, interpretations and conclusions. Secondly, the biases may occur from the anxiety generated in the participants being tested. This may lead to participants giving responses that are not their true responses. Thirdly, interviewer bias may occur based on particular values that have the potential to lead to a social desirability response, or by asking leading questions (DePoy & Gitlin, 2010). These types of bias was minimised by using Person Centred Interviewing (PCI) when conducting the interviews.

In PCI, the interviewer adopts four principles which are non-directive, empathy, unconditionally accepting and congruency. The four principles were originated from Person Centred Therapy (PCT) by Carl Rogers in the 1940s (Vorster, 2011). This method of interviewing provides the interviewee with an optimal psychological ‘climate’ in which he/she could feel understood, accepted and respected. This method mobilised the interviewees to set out his or her experiences without being restricted in any significant manner (Vorster, 2003).

3.11. ETHICAL CONSIDERTIONS

According to Denscombe (2010), ethics is defined as an organisation of moral principles by which individuals can judge their actions as right or wrong. Thus, Bertram and Christiansen (2014) highlight that ethics are crucial in research, especially with research that studies humans and animals. Furthermore, Denscombe (2010) reports that social researchers are expected to conduct their research in an ethical manner, meaning that researchers need to introduce a moral perspective to the way they design and conduct their investigations. There are several ethical codes which need to be considered:

3.11.1 Ethical approval

According to Denscombe (2010), researchers need to gain formal approval from a research ethics committee before they embark on research. The relevant committees are those that screen proposed pieces of research to check that they meet ethical principles for research (Denscombe, 2010). Furthermore, DePoy and Gitlin (2011) note that there are very strict protocols that require anyone planning to conduct research to submit a proposal to a research ethics committee for approval. Universities normally make use of ethics committees to ensure that research conducted under their auspices conforms to the relevant principles (Denscombe, 2010). In this study, the research proposal was submitted to three committees: the hospital research committee at Dr George Mukhari Academic
Hospital, SREC and MREC (Appendix D and E, respectively) prior to the commencement of the research.

3.11.2 Autonomy
According to Bertram and Christiansen (2014), research must be conducted in such a way that respects the autonomy of all participants. Similarly, DePoy and Gitlin (2011) add that participants should be treated as autonomous individuals who are capable of personal choice and self-determination. This implies that the researcher must obtain the permission of every individual participating in the research; every person must participate voluntarily in the study, and they must have the freedom to withdraw at any time (Bertram & Christiansen, 2014; Punch, 2014). Autonomy leads to another ethical consideration of informed consent. In this study, participants were informed that their participation in the proposed research study is voluntary and they may, at any time, withdraw from the research study should they want to.

3.11.3. Informed Consent
Before the participants give permission, the researcher must clearly explain what the research study entails and is expected from the participants, so that the participants can make an informed choice to participate voluntarily in the research (Bertram & Christiansen, 2014; David & Sutton, 2010). Thus, it is important that the participants give voluntary consent. This means that the person involved should have legal capacity to give consent; each participant should be so situated as to be able to exercise free power of choice without the intervention of any element of force, fraud, deceit, duress, over-reaching or any other ulterior form of constraint or coercion. Each participant should have sufficient knowledge and comprehension of elements of the subject matter involved as to enable him/her to form an understanding and take an enlightened decision (Denscombe, 2010). In this study, the researcher explained the research and criteria for participation in the research to the patients. Once the patient and parent/guardian verbally agree to participate in the study, they were given a package including an information pamphlet (see Appendix A), and the consent form (see Appendix B). Each patient together with their parent/guardian was given a chance to read through the information pamphlet and consent form and ask questions for clarity where applicable.

Special populations, such as children, mentally retarded individuals and prisoners, require particular care with regard to obtaining consent. Researchers need to get the consent of a legal guardian when working with the special populations (David & Sutton, 2010; Bertram & Christiansen, 2014). In this study, the researcher was cognisant of the fact that all participants of the proposed research study are adolescents; the researcher obtained informed consent from the parents or the legal guardian, and from the participants if they met the legal age for consent.

Furthermore, Bertram and Christiansen (2014) note that for the researcher to have informed consent from the participant, the potential participant needs to be provided with written information to understand what the research is about and what type of commitment is called for. In this study, the informed consent forms (see Appendix B) were given to the participants and their parents for obtaining written informed consent. The informed consent form has outlined information about the study so that the participants have full knowledge of the study and their participation roles.

3.11.4. Non-malfeasance
According to Punch (2014), the meaning of non-malfeasance is to do no harm. The researcher should do no harm to the research participants or to any other person. Researchers need to consider whether their study will do any physical, emotional, social or any other harm to any person. Furthermore, Bertram and Christiansen (2014) highlight that sometimes participants could be negatively affected if their personal information is made public. Therefore, participants need to know how the information will be made public. This generally means that all participants need to be assured of the confidentiality of the information supplied by them. This means that researchers need to be careful in protecting the identities of the groups and individuals when they publish the results of their study (Bertram & Christiansen, 2014; Punch, 2014). For instance, the researcher should avoid publishing reports of the research which allow individuals or organisations to be identified either by name or by role (Denscombe, 2010). To protect such identities, researchers tend to use pseudonyms for people and organisations. However, it is not enough that names are changed, it may also be necessary to change the descriptions of the participants or schools (Bertram & Christiansen, 2014). In this study, participants were informed that the research findings of the proposed research study might be published; however, the participants’ names and identifying information will not be mentioned. The researcher made use of pseudonyms to protect the identity of the participants.

However, Hennink, Hutter, and Bailey (2011) indicate that the researcher might be faced with a challenge of dealing with emotions. The research may focus on a sensitive topic, such as rape, HIV/AIDS or human trafficking. For qualitative research on clearly sensitive issues that may cause emotional stress to participants, it is good practice to have a counsellor involved in the study to which participants can be referred if needed (Hennink, et al., 2011). In this study, the focus of the study was on HIV/AIDS, which is a sensitive topic and may elicit distress from the participants. Those participants who might be left with an unfinished emotional impact from the interviews will be referred to the clinical psychologist at Dr George Mukhari Academic Hospital. In this study, one participant was left with an unfinished emotional impact from the interviews and was referred to the clinical psychologist at Dr George Mukhari Hospital.

3.11.5 Beneficence
According to Bertram and Christiansen (2014), the research should be of benefit, either directly to the research participants, or more broadly to other researchers and to society at large. Beneficence means the study must be beneficial. In addition, Hennink, et al., (2011) note that the researcher should bear in mind whether the research will contribute to theoretical knowledge, or whether conducting research will respond to a problem from the research community or for an organisation working with the study community. This will be reflected in the purpose of the research and its outcome (Hennink, et al., 2011). Other objectives of this study include to stimulate future research, and to generate debate around the importance of psychological interventions at tertiary hospitals in South Africa. This will be beneficial to future studies, and to stimulate intervention of psychological treatment at tertiary hospitals which will benefit the community.

3.11.6 No misrepresentation or deception
According to Denscombe (2010), social researchers are expected to be honest and open about who they are, what they are doing and not rely on misrepresentation or deception as a means of getting the necessary information. In this study, the researcher displayed a student card which has researcher’s full personal detail. Furthermore, the researcher was formally introduced to the population and gave a full context about the study before giving out the consent forms.
3.11.7 Security of the data
The researcher will ensure that records, data and information that relates to individuals are kept secure. Thus, the researcher has the responsibility to keep the information secure, and to ensure that the information is used for the purposes for which it is meant for (Descombe, 2010). In this study, all identifying data were kept confidential. In addition, the raw data was stored in a secure environment.

3.11.8 Confidentiality
As with any research, reasonable precautions should be taken to avoid the disclosure of personal identities and sensitive information to third parties. The participants should be reassured about confidentiality (Descombe, 2010). In this study, all interviews were conducted in a place that allows for privacy and confidentiality. In addition, confidentiality was ensured by using anonymity in the writing of Chapter four of the results and when publishing the results.

3.12. CONCLUSION
In the current Chapter, the research methodology was discussed. The rationale for using the qualitative approach was explained. The methodology and the procedures employed for data collection and analysis were discussed extensively. The process of data collection brought about the information and results that will be discussed in the next chapter.
CHAPTER 4
PRESENTATION OF RESULTS

4.1 INTRODUCTION
The aim of the study was to explore the experiences and challenges of adolescents who were vertically transmitted with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital in Ga-Rankuwa, Gauteng Province. The study was carried out using thorough face-to-face interviews based on the qualitative approach as detailed in Chapter three of this study. In this chapter, the results of the study will be presented. Firstly, the participants’ demographic information will be presented, followed by a presentation of their experiences and challenges. This will be done using main themes and subthemes as detailed in the sections below.

4.2 DEMOGRAPHY OF THE PARTICIPANTS
This section will look at the participants’ demography. Each of the eleven participants were interviewed using a face-to-face strategy. Because the study is qualitative in nature, frequencies were only used to indicate the participants’ representation. This section is intended to give the reader a broader context of the participants from which data was gathered. It presents the participants’ demographics which consist of the participants’ race, language, gender, grade, and age. The demographic information will also determine who participant stays with, when the participants learned of their HIV status and started taking treatment. For ease of reference, table 4.2.1 was used (see Appendix D attached).

4.2.1. First language
In terms of the language spoken, all the participants were seTswana speakers. This was no surprise since the hospital is situated in a seTswana-speaking community. The study was open to participants from all language groups. Although it was not the intention of the study to use seTswana speakers only, the participants each chose to be interviewed in seTswana despite being afforded the opportunity to speak any official language.

4.2.2. Race
The participants were all black. It was no surprise that the sample population was only black people because the hospital is situated and mainly serves a community that is predominantly black.

4.2.3. Geographic area
The hospital is situated in a peri-urban community; therefore, all the participants were from a peri-urban area. Ga-Rankuwa is situated north west of Pretoria approximately 30km from the central business district of Pretoria in the Gauteng Province. Although the study was conducted in a peri-urban area, participation was open to participants from any geographic location.

4.2.4. Gender
Of the 11 participants interviewed, six were female and five male. Only five boys and six girls agreed to be interviewed. The study did not intentionally set to utilize unequal number of participants between boys and girls. It remained equally open to participants who are males and females.

4.2.5. Age
The participants interviewed were between the ages 16 and 18 years. Of the 11 participants interviewed, five of the participants were 16-years old, four were 17-years old and only two participants were 18-years old.

4.2.6. Level of education
Of the 11 participants interviewed, five were in Grade 10 and three were in Grade 7. Only one participant attended a special with the remaining two in Grade 6 and Grade 12 respectively.

4.2.7. Participants stay with
The results indicate that four of the participants lived with their grandmother and other siblings while three stayed lived with their mother and other siblings. Only two participants lived with both parents and one stayed with his/her uncle and sister.

4.2.8. Age of being disclosed HIV status
The findings show that three participants knew of the HIV status within the last 5–8 years. Furthermore, One participant knew about his/her HIV status when he/she was 2, another participant was 4 years old, another participant was 10 years old when he knew his/her HIV status. In addition, one participant attested to discover his/her HIV status when he/she was 11 years old. It emerged from the interviews that only one participant found out about his HIV status during the year (2014).

4.2.9. Receiving ARVs treatment
All 11 participants receive ARVs treatment in Dr George Mukhari Academic Hospital.

4.2.10. Support group and youth camp
It emerged from the study results that seven participants did not attend youth camps or any form of support group either at Dr George Mukhari Academic Hospital or elsewhere. This meant that the remaining four study participants attended the support groups. Of those attending the support group and youth camp, one participant was attending the youth camp at Dr George Mukhari Academic Hospital but attended a support group outside of Dr George Mukhari Academic Hospital; three participants also attended support groups outside of Dr George Mukhari Academic Hospital.

4.3. EXPERIENCES AND CHALLENGES OF ADOLESCENTS WHO ARE VERTICALLY TRANSMITTED WITH HIV AND ARE TAKING TREATMENT
This section will present the yielded results. The presented themes and subthemes will follow the interview guide structure for ease of reference (see Appendix C). In presenting the main themes and subthemes, the participants’ verbatim responses will be used to clarify the meaning from the derived themes and subthemes. Furthermore, visual sketches will be presented to show a link between the main themes and subthemes.

4.3.1 Experience prior to HIV diagnosis
The participants expressed various experiences which included engaging in carefree behaviors, feelings of positive self-perception, losing loved ones, experiencing medical problems, taking HIV treatment, experiences from childhood stage (from birth until ten to eleven years old) including having multiple relocations during childhood, having difficult or unhappy childhoods and confusion. This is explained by theme and related subthemes as illustrated in Figure 4.3.1 below.
4.3.1. Engaging in carefree behaviours
A few (three) participants reported living a careless life and making reckless decisions prior to discovering they were HIV positive:

“Last year I had my own gang of boys. We used to go around anywhere, going to parties without invitation and we would get into those parties. The way we were so popular, people knew use and they knew that they are powerless towards use. Then in December last year we were arrested by police after being involved in a fight with other gang.” (Participant A)

4.3.1.2. Positive self-perception
Two participants reported that they perceived themselves in a positive light, being like other children and being able to play with their peers prior to receiving their HIV status. The positive self-perception emerged in the data of participants who started treatment at a young age:

“(Decreased pitch) Before I knew about my status, I viewed myself as a person like any other kid, even with my friends.” (Participant D)

4.3.1.3. Loss of loved
Nine participants reported losing their loved ones prior to receiving their HIV status. Their status had impacted their lives negatively, especially by creating instability at home:

“In 2001, my father just died instantly, he was in another country, he died there and he was deposited in South Africa without any explanation. I felt shocked and confused. They moved me to place R because financially my mother was unable to support me.” (Participant A).

4.3.1.4. Experiencing medical problems
Prior receiving their HIV diagnosis, eight participants reported having a lot of medical problems and always going in and out of hospital. Being sick a lot had negative implications on the participants’ lives. It prevented two participants from doing their academic work effectively with some experiencing reading and writing problems:

“At home, my grandmother was keeping an eye on me because I was always sick and it interfered with school. I then become left out and repeat Grade 3.” (Participant G)
“I was able to write but as I got sick I lost the ability to write. I also have difficulty in reading. I wish I can go back, be able to read and write. But I don’t have control.” (Participant H)

4.3.1.5. Taking HIV treatment
Three participants reported being on HIV treatment prior to discovering they were HIV positive and without them understanding the treatment were they put on and why they were put on the treatment.

“Before I knew about my status, I was taking medication but not know their purpose. My life was perfect” (Participant G)

Four participants mentioned that, as children, they did not understand the purpose of the medication they were taking, and as they entered the adolescence stage, they started asking questions of why they are taking medication. One of the participants said:

“I was very young and not aware that I’m taking medication. When I was 11 years I asked my mother why I was taking medication and she said I should ask the doctor in the clinic, she can’t tell me because something just happened and she doesn’t know why.” (Participant B)

4.3.1.6. Engaging in childlike behaviours
Being childlike, which involved being playful, was a life lived by two participants prior to receiving their HIV diagnosis:

“I was still a child, playing, behaving in a childish way; I didn’t know that this thing was in my life. Yah! Everything was flowing. Yes, fun (laughing) misbehaving (laughing) well, you know how the nature of a child who is a boy is like, misbehaving, being naughty, mischievous, fighting, making noise, missing periods in class.” (Participant D)

4.3.1.7. Lack of understanding
All participants reported that, prior to receiving treatment; they didn’t understand what was happening. Some reported that they were confused about attending appointments in hospital, and being hospitalized without knowing the reasons,

“I was confused, because I could not play with other children; I was in and out of hospital. And I didn’t understand why.” (Participant H)

4.3.1.8. Normal life
Two participants reported that their life was normal just like other children prior to receiving their HIV diagnosis:

“My life (3 seconds pause) ... it was fine (increasing pitch) (5 seconds pause), I was still a child, taking treatment, playing, behaving in a childish; I didn’t know that this thing was in my life. Yah! Everything was flowing”. (Participant D)

4.3.1.9. Childhood experiences of living with HIV
Three subthemes emerged from this category:

- **Happy childhood**

Two participants led a happy childhood life before they learnt of their status. One of the participants said:

“Before I knew, I was living a pleasant life ...” (Participant I)

- **Difficult childhood**
Nine participants agreed to having a difficult childhood. The participants’ biggest challenge was that they are always sick and hospitalised for quite some time. The participants mentioned that they did not enjoy their childhood: they couldn’t play with other children, attend school and felt left behind when compared to their classmates because they had to repeat the same grade only once their health improved. These participants were not outgoing because of the health challenges they faced. One of the participants has been attending a special school since losing the ability to read and write. Another challenge faced by the participants was a loss of loved ones which exacerbated participants’ health. One of the participants said:

“My childhood was difficult (high pitched tone). (Decreasing pitch) my mother struggled with me. We were sleeping in hospital, and always in the hospital. I was sick. My mother knows. I was sick and unable to walk (6 seconds pause), it was difficult. I didn’t enjoy my childhood. I was not playing with other children, not attending school.” (Participant E)

- **Multiple relocations**

Six participants said that their childhood was challenging because it involved a lot of relocations, which resulted in them losing friends and difficulties in making new ones. Relocation also added some challenges in that the participants felt confused and unable to concentrate at school resulting in school results literally dropping. One of the participants said:

“My childhood was disrupted because, I moved from one place to another most of the time, there was lot of relocation. And this was killing me big time and it affected me, well... I started staying here in place w, then by the time I started growing up my mother and I changed, relocated from different places, is like that situation of relocating was puzzling me. I felt confused, I didn’t know (high pitch with feelings of irritation) what was happening, not knowing why we were relocating”. (Participant B)

- **Confusion**

Nine participants reported that they were confused about their childhood. They reported that they didn’t understand the purpose of their treatment, the hospital appointments, multiple relocations, loss of their loved ones, and the reason behind being sick. One of the participants said:

“I didn’t understand and I didn’t take them seriously. Actually they told me the purpose of medication but I didn’t understand. In April 2010, I was in Grade 5, I started asking myself what is the purpose of the medication, why people are on medication. I didn’t understand.” (Participant C)

4.3.2 Context of discovering HIV diagnosis

The context in which participants discovered they were HIV positive differed. Six participants were told their status in a medical context by medical personnel, while two participants learned of their HIV diagnosis in a camp setup. Three participants were told of their HIV diagnosis in a family context through a family member. The participants further expressed various emotional responses which included shock and disbelief, sadness, shame, loneliness, anxiety, anger, and acceptance. Figure 4.3.2 below indicates the themes and resultant subthemes.
4.3.2.1. Medical context

Six participants were told by nurses in a medical setup that they were HIV positive. One of the participants who learnt of his HIV status from a family member enquired from his parents why they were taking the medications and was referred to medical personnel where this explained. After learning of his status, the participant was shocked and depressed, started misbehaving and stopped taking the medication. Until medical personnel encouraged the participant to adhere to the treatment, the participant attested to constantly thinking about being sick:

“(His pitch and tempo increased) it was during a counseling session, two years ago. Before I went for counseling, when I was at the clinic I asked the nurse (his pitch was high) is like it became a shock…. I started constantly thinking about it (decreasing tempo and pitch) is like, yah, is true I have the virus…. (He then looked down)” (Participant B)

Another participant reported that she attended VCT; counseling sessions followed after the participants discovered their HIV status:

“I was sick, my mother took me to hospital and they told my mother that I should go for blood testing, and she agreed. So we found out that day. I was told by nurse, she began by explaining to me what is HIV, and she then disclosed my status. So she said I should begin counseling, of which it didn’t benefit me, and then I began to take medication. They explain HIV and treatment and what to eat. But they don’t ask you how I view HIV and how I feel about me being infected. They only teach you what HIV is. And like at the beginning when they were explaining HIV I didn’t understand, I was still a child”. (Participant K)
Another participant shared that their status was disclosed after taking a blood test. After disclosure, the participant began taking treatment although the participant didn’t understand the treatment. The participant was irritated to learn about his/her sickness; when other children were playing on the street, the participant had to go take treatment which disturbed his interaction with other children. However, the participants’ feelings have since changed because the participant understands the purpose and reason of being on medication and has started taking the medication autonomously. Initially, the participant attested to feelings of hurt and sadness but once the participant received support and learned that people live long healthy lives if they take care of themselves, this changed. The participant is well-taken care off and feels well.

“They took blood for testing, and then they disclosed my HIV status after two weeks and I begin taking treatment. I didn’t understand, is now that I asked questions. I asked psychologist and social worker and they answered me. Is like I didn’t have a problem, what do I say, eish! But I was irritated, in that I’m sick. I was irritated, they said I had to take treatment. But now I know that at 18h00 I’m taking my medication. Back then they used to shout at me and argue with me, and arguing about medication. I didn’t understand. They always asked me if I know why I’m taking medication and I said yes. I said yes is for HIV. But I didn’t understand. But when I was growing up I begin to ask why I had to be on medication, then I begin to understand the reasons of being on medication. I felt hurt and sad, and they supported me. People live long if they are taking care for themselves, then I said ok. And I saw it for myself in that I’m taking care of myself and I’m ok”. (Participant C).

4.3.2.2. Camping context

Two participants reported discovering their status in a camping setup with other young people who were told in a group setting that they were HIV positive:

“It was a camp of adolescents who didn’t know about their status. They gathered us all and it was fun, it was fun, it was fun, but there were individual sessions. Well they disclosed to all of us in a group.” (Participant D)

Participants, who learnt of their HIV status at the hospital during counselling, still did not understand the meaning of being HIV positive until they attended youth camps where they began to understand HIV. The participants began to adjust and accept their diagnosis. However, the participants agreed that HIV is not discussed with their parents at home as they are not used to speaking about HIV. The participant also mentioned that they speak about other unrelated matters except HIV to avoid awkward relationships with the parent.

“When they were disclosing my status, well…. (3 seconds pause) (Increase in pitch and tempo)….I didn’t react, I just said Ok then kept quite (he started rubbing hands and tapping his right foot on the floor and he looked away from the researcher). ... (10 seconds pause)….and the nurse asked me if I’m ok and understand what they she was saying, I said I understand then I kept quiet. I didn’t understand what they were saying until in 2009, where I began to understand in youth camp. That’s when I started to adjust; I began to accept, in the camp from Dr George Mukhari Hospital in December. At home, with my mother, I never spoke about it; we are not used to speak about HIV at all.” (Participant A)

4.3.2.3. Family context

Three participants’ mentioned being told by their family members about their HIV status. Two participants were told by their grandmothers and one participant was told by his mother:
“I was told by my grandmother. This was heavy on me. She told me that I have HIV and I have to take medication. I don’t even understand what HIV is.” (Participant H)

“My mother disclosed to me, even the doctors asked her if she disclosed to me. She said yes she told me. She told me I’m infected with HIV. I asked her how and she didn’t explain how I was infected. She never explained to me how I was infected. She disclosed my status when I was at home. We were from the hospital, she started telling that I’m infected with HIV, and she said I had to take treatment. She said I must not tell anyone (she started crying loudly).” (Participant E)

4.3.2.4. Emotional responses to receiving HIV diagnosis

The participants further expressed various emotional responses which included shock and disbelief, sadness, shame, loneliness, anxiety, anger, and acceptance. This will be explained below.

- **Shock and disbelief**

Being shocked and in disbelief was an initial response expressed by three participants in the study after learning of their HIV diagnosis:

“I didn’t react, I just said Ok then kept quite (he started rubbing hands and tapping his right foot on the floor and he looked away from the researcher). ...(10 seconds pause)....and the nurse asked me if I’m ok and understand what she was saying, I said I understand then I kept quiet.” (Participant A)

“Well, I didn’t know (10 seconds pause), I was asking myself questions. What (2 seconds pause)? I didn’t have sex with anyone (3 seconds pause), how can it be (increasing pitch and tempo)? How can it be? Because, how did I get HIV from other people (5 seconds pause), like through sexual intercourse. Then they explained to me and I started to realize that I’m sick.” (Participant D)

- **Sadness**

When two participants found out about their HIV diagnosis, it was a very painful experience filled with a lot of sadness:

“All of us (people in the camp setting) there was no one who would say he or she is happy. When I went out I wanted to be alone, I felt hurt and I wanted to cry. I’m a type of person that if I’m told something I understand it, but deep inside is killing me and it is difficult to heal (5 seconds pause). Eee... when they finished disclosing our status, I wanted to keep quiet, I didn’t want to eat.” (Participant D)

- **Shame**

Feelings of shame were expressed by two participants in the study:

“I’m ashamed. I feel like my life has already ended; others they are living. Like I’m sick, without medication I will die. However, others don’t take medication, they are ok. I wish I become healed and stop taking medication. The disease and medication already took my life.” (Participant I)

- **Loneliness**

Participant B expressed feelings of loneliness.
“I felt so alone like no one could understand my feelings and how it feels like to be told you are HIV positive”.

- **Anxiety**

Three participants expressed feelings of anxiety. The participants were anxious about living with HIV and feared that other people could see that they were HIV positive:

“I don’t know. I don’t have confidence of speaking in front of people. I think they will see that I have HIV. I know that they won’t see me, but is the feeling that I have. You know since I knew that I have HIV I live with fear, fear of being exposed and fear of living with HIV. Some days this fear grows inside me. It is difficult.” (Participant G)

- **Anger**

A majority of the participants (six) expressed feelings of anger for being diagnosed with HIV:

“I’m very angry, why me, why can’t I be like other children. I hate it very much (she started crying). (After 15 minutes) I won’t change it” (Participant F).

Feelings of anger led to a Participant B being rebellious, acting out and engaging in deviant behaviors:

“Yah, so I begin to stop taking my medication and started to misbehave. Yes, when I stopped taking medication. Like I started misunderstanding my mother and elderly people, and disobeying. I refused to wash dishes at home. Mostly, I spend time alone in my room and constantly being in an argument with my mother and elderly people.” (Participant B)

- **Acceptance**

Three participants reported having accepted their HIV diagnosis and making peace with it. Participant A suggested that

“I began to understand in the youth camp. That’s when I started to adjust; I began to accept, at the camp from Dr George Mukhari Hospital.”

4.3.3 Experience of taking HIV treatment

Three participants started taking treatment when they were 7, 9 and 11 years old respectively while others started taking treatment when they were 2, 10, 12 and 14 years old, respectively. Only one participant could not remember when treatment was started.

The participants confessed that taking the HIV treatment was a difficult experience initially, with some participants only starting to accept that they will need to take treatment for the rest of their lives. The participants’ experiences involved some participants keeping it secret that they were on treatment for HIV. Other participants expressed taking treatment as being a barrier because it prevented them from engaging in certain activities. Some participants expressed a lack of understanding the purpose of being on treatment on a daily basis for HIV. Lastly, a few participants demonstrated an understanding the purpose of taking treatment for HIV on a daily basis.
Figure 4.3.3 illustrates the participants’ response to their experience of taking HIV treatment.

**Figure 4.3.3 Experience of taking HIV treatment**

### 4.3.3.1. Secrecy

Although other participants did not have any problems in taking their medication, there are those who cannot take their medication in front of friends when playing or visiting relatives because they do not want people to notice that they are on medication. The most common reason expressed by participants not wanting friends or relatives knowing about their status is fear of judgement. Three participants disclosed to family members only that they were on medication for HIV:

> “Every day I eat then take medication. I take them in the morning and afternoon. When I visit, unless I have them, I cover them with a toilet paper; no one knows that I’m taking medication, except my sister and grandmother. And most of the time I visit my extended family members.” (Participant G)

### 4.3.3.2. Constraint

One participant highlighted that taking treatment for HIV was a constraint that limited him from engaging in activities that he would have loved to freely engage in:

> “jo! (Inhaled deeply)... (10 seconds pause). (He laughed) well, honestly speaking taking medication on a daily basis is challenging because I take medication at 20h00, so (9 seconds pause). And there was once a talent show in Hammanskraal. Yah! They were taking position 1, 2, and 3. So I couldn’t go because of medication. People told me to go to the talent show; my songs really rock and I will win, plus I have what it takes. So I wanted to go but because of medication I couldn’t go.” (Participant D)

### 4.3.3.3. Lack of understanding

Three participants demonstrated a lack of understanding the reasons they were taking treatment for HIV on a daily basis at a certain time. Participants indicated feelings of irritation and dislike at taking the treatment.

> “They asked me if I know why I’m taking medication, I said yes. But every time when I was taking medication I asked myself why do I have to take medication. Actually they told me the
purpose of medication but I didn’t understand. I started asking myself what is the purpose of the medication, why people are on medication. I didn’t understand.” (Participant C)

Receiving explanations from psychologists and social workers assisted participant C in developing an understanding of the reasons why she needed to take her treatment.

“I asked psychologist and social worker and they answered me. Yah! Is like I didn’t have a problem, is like, what do I say. The social worker and psychologist answered me and they told me to take medication, for the rest of my life and I won’t be healed and if I take well medication then I my disease will be manageable. But I asked myself why me.” (Participant C)

4.3.3.4. Acceptance

Four participants mentioned that they have been taking medication since a young age so they are used to and therefore have no problem in taking the medication. Other participants shared that taking medication on a daily basis is part of their lives and they have to do it. They mentioned that they will die if they do not follow the treatment. They reported accepting that they will be taking treatment for HIV for the rest of their lives. Participant I indicated incorporating the medication in her life:

“What can I say, is my life, I don’t have choice. If I don’t take the medication I will be dead. It’s my life now for me to take medication.”

4.3.3.5. Side effects

The participants mentioned feeling dizzy after taking the medication. However, since they take the medication in the evening, these side effects do not interfere with their daily activities anymore. One of the participants said:

“Some days, after taking medication I feel dizzy, however, because I take my medication at night, the dizziness does not interfere with my daily activities.” (Participant A)

4.3.3.6. Irritated

One of the participant mentioned that taking medication on a daily basis makes the participant feel irritated and angry:

“Is like I was irritated by my medication, at 18h00, on a daily basis I had to take medication.” (Participant C)

4.3.4 Challenges of living with HIV

The challenges of living with HIV consisted of difficulties with disclosing HIV diagnosis to others, adhering to the treatment, and attending to monthly appointments; financial constraints; dealing with previous traumas and conflicts with family members; and difficulties accepting one’s HIV diagnosis, relationships and coping mechanisms.
4.3.4.1. Disclosure
Participants had disclosure difficulties. Seven participants mentioned that they did not disclose their status while four participants disclosed their status.

Difficulties expressed by participants are as follows: fear withheld participants from disclosing their HIV status to other people despite those that already knew about their diagnosis. Fear was divided into:

- Participants expressed fear of being rejected by both family members and friends:
"I’m afraid of being rejected. I have a family member who likes to say bad things about people who are living with HIV infection and he doesn’t know that I’m also infected then I would tell him those people who are living with HIV will not like what you are saying about them. So I’m afraid if I disclose my status to them they will reject me." (Participant B)

- one participant’s fear of disclosure involved a fear of being laughed at:
  
  “eish…. Is like I don’t ….ha…ha… disclose, like, they will make jokes about me about me, so I don’t want them to make jokes about me. I hate to be centre of attraction. Like even at school, if they know about my status, whenever they see me they will be laughing behind my back, I won’t disclose.” (Participant K)

- Two participants expressed fear of being disrespected if they disclosed their HIV status.
  
  “People will view me as inferior. So if I disclose to them they will disrespect me.” (Participant J)

Two participants expressed attempting to express their HIV status to their friends but were betrayed by friends. As a result, the participants’ could not trust other people revealing their HIV diagnosis.

“I think if I disclose, they will be angry at me and spread my status to everyone. My friend once did that (increased pitch) and she told everyone. At school, the classmates asked me if I have HIV, I answered by saying yes. I asked them who told you, they said from my friend. They started laughing at me, they distanced themselves away from me. I started to not want to go to school. (She started crying). That is why I changed school, but the problem was the transport money and I had to relocate.” (Participant I)

- Six participants reported a fear of judgment by others if they disclosed their HIV diagnosis:
  
  “I won’t tell them (friends) the truth, they will reject me. I heard their comments about people who are living with HIV, so I won’t tell them. I realize why my mother doesn’t have close friends, she is alone. I not have friends, and then now my mother is my close friend. I tell her everything except about boyfriends.” (Participant C)

- One participant reported a fear of gossip about her status if she disclosed to others:
  
  “Like (increasing pitch) people who are my street mates like to gossip. They can’t keep a secret. They will gossip about me, when they finish, then they will tell others outside our street. So people will be afraid of me and not want to associate with me. They will reject me. And my grandmother told me not to disclose.” (Participant G)

The fears about disclosure and the experiences of the participants mentioned above has led them choosing not to disclose their HIV diagnosis to others:

“no, no (he laughed) is a secret which I will never trust to talk about, I will never do. I don’t trust anyone and I will never do that (disclosing HIV status to others); is not like I am ashamed; is not the right thing and the right time.” (Participant D)

4.3.4.2. Adhering to treatment

Three participants admitted that they were unable to take treatment in the presence of others. Only one participant highlighted a fear of judgement by other people while taking treatment for HIV. Two participants reported being tired of taking HIV treatment.
“mmmmmm...like taking medication, like when I visit somewhere, they will ask me questions about my medication, what’s happening.... Then I have to come with excuses, so now I don’t visit anymore, I’m always at home.” (Participant A)

“Is the issue of treatment (high pitched), I become tired of them. I feel like is being long since I started taking medication. I feel like they are not effective, like when I take them, like is in it that I’m supposed to take them for my whole life. I want to take them, but I’m getting tired because I feel like, I want to stop them for two years and see what will happen. Is how I wish.” (Participant F)

4.3.4.3. Attending monthly appointments
Attending monthly appointments was a challenge for two participants as it affected their academic performance.

“For me to go to monthly appointments really disturb my school work, when I’m not there they are writing tests.” (Participant J)

4.3.4.4. Financial constraints
Not having enough money at home led to three participants being unable to buy the necessary food needed for them to take treatment as well as not having money to attend to their appointments at the clinics:

“I had difficulty in taking medication because of being unable to eat healthy food to accommodate treatment.” (Participant J)

“Sometimes when I’m from hospital and I ask my grandmother transport money for the next appointment and she does not have it, I even skip an appointment because of not having money because my grandmother is the only one who works.” (Participant G)

“Financially, at home, we suffer because my aunt and uncle don’t have a stable job, so this affects my medication in that I struggle to have money for every appointment; I have to borrow the money for every appointment because I have to travel to the clinic.” (Participant D)

4.3.4.5. Trauma
One participant was raped by a neighbor during her childhood years and is still preoccupied with the traumatic experience. She is also dealing with being HIV positive as well as the rape:

“He raped me. I cried and cried and cried. He then left me. This thing never sits well with me, I always think about it.” (Participant E)

4.3.4.6. Family conflicts
Three participants expressed having conflicted relationship with the family members they are living with. One participant highlighted conflicts involved parents arguing with each other and with children. Lastly, one participant highlighted being beaten up at home without reason and understanding why:

“At home, if someone is angry he wants others to be angry as well. Like my stepfather is a person who when I visit my biological father he becomes angry, he doesn’t want. So when he fights with my mother, he becomes angry when I’m with my mother; when he fights with me, he becomes angry when I’m with my mother, without any reason. He includes me when he
fights with my mother. When he fights with me he includes my mother. My stepfather and I
don’t speak to each other when I’m left with him.” (Participant C)

“At home, sometimes they beat me and they beat me too much. I don’t know why and they
physically hurt me.” (Participant H)

4.3.4.7. Difficulty accepting HIV diagnosis
Participant A experienced difficulty accepting his HIV diagnosis. As a result, Participant A seems to
be fixated on the anger of being HIV positive which prevents him from accepting his diagnosis:
“well… I haven’t accepted the condition. I wish one day when I wake-up I’m HIV negative. I
have anger towards this and not this only, at everything. And sometimes I break in such a
way that I lock the house and control that gets in-and-out of the house.” (Participant A)

Some days, participants feel like they have accepted their status while on other days, the fear grows
inside them which make the situation difficult.

4.3.4.8. Relationship with medical personnel
One participant reported that sometimes he don’t have enough transport money to attend
appointments. The participant then skips the appointment resulting in the medical personnel
reprimanding him without enquiring about the reason behind him absconding. This cycle has created
distance between the participant and medical personnel since he cannot confide in the medical
personnel regarding his personal issues.

“I even skip an appointment because of not having money because my grandmother is the
only one who works. And if you have skipped an appointment, the nurses and doctors will
shout at you without asking the reason. So I’m not used to the nurses and I can’t tell them my
personal issues.” (Participant G)

Furthermore, more than half (nine) of the participants highlighted having negative experiences with
the nurses they interact with when collecting their treatment at the clinics and hospital. Nurses lack of
empathy; they are impatient, judgmental and inconsistent in supporting the participants. This was
expressed as:
“In the clinic, I don’t receive any support. They are very bad! (3 seconds pause). Is like they
are impatient, if you miss an appointment, joh! They will shout at you. Each appointment you
are helped by different nurse and there is no relationship between me and the nurses. They
ask you questions just to analyse without caring about you. Well, I don’t understand. They
are irritating me.” (Participant)

4.3.4.9. Social life
The challenges illustrated in figure 4.3.4 above lead to relationships problems. These were expressed
in terms of participants’ social life based on friendship, peer relationship and intimate relationships.
Various responses, ranging from positive to negative responses, as well as mix responses, were
reported by the participants.

- Positive responses
Six participants mentioned that they lead a normal social life. They are liked by people and they enjoy
peoples’ company since they view themselves similar to others.
“Is like I’m similar to others. I enjoy, I’m free, I don’t have problems, I’m always happy, I’m open. I live with people, we are happy, and we speak, we enjoy, they eat food, I eat food. We are not different, we are the same. I’m ok and I’m always happy.” (Participant C)

As adolescents, they portray different kind of social life. For instance, one of the participants was involved in gang but eventually stopped due to a police order while another was misbehaving and being naughty:

“Last year I had my own gang of boys. The way we were so popular, people knew us and they knew that they are powerless towards us. Yah! Then in December last year we were arrested by police after being involved in a fight with other gang, then they gave us two options, either to stop the gang or to be arrested. So the police knew that I was the gang leader, and I decided to stop the gang.” (Participant A)

“Well, I live free like anyone. I’m naughty, and I misbehave. I mean being naughty like they discipline and I continue misbehaving, they discipline and I continue misbehaving (he laughed). I even enjoy doing it.” (Participant D)

On the other hand, three participants enjoy playing soccer with friends but try by all means to only talk about soccer and school; they do not talk about personal issues.

“I’m playing soccer, so every day I go to practice and I have created friendship with other soccer teammates. But we only speak about soccer and school, not about personal issues.” (Participant I)

Other participants attested to being free because of the level of openness they have when engaging with friends either through cell phone or texting; they also enjoy music. Involvement with friends and attending various activities helped participants lead a normal social life and they attested to having fun.

“I like to communicate with people through cellular phone and whatapp. Yah, also one of my friends, who is very supportive and knows about my status, has a music band and they want to shoot a music video, so they want me to join them.” (Participant B)

One participant also mentioned receiving encouragement from outstanding school performance and being involved in most of the social activities at school. However, the participant is being affected by negative peer pressure; some participants are still trying to find their talents and what they are good at:

“I also cope with school work. Most of learners and teachers approach me because of my achievements. In every sport I’m there, drama I’m there, chess I’m there, music I’m there (he laughed). So far I’m exploring things. I want to broaden my frame of reference. When I first entered this school, I realised that if you are a good boy, you are left behind. So I changed to become a bad guy. When they escape class, I also escape.” (Participant D)

• Negative response:

One of the participants also mentioned that despite having a good social life, the problem is his parents still use corporal punishment and they sometimes physically hurt him.

“at home, sometimes they beat me and they beat me too much. I don’t know why and they physically hurt me.” (Participant H)
Participants reported it being difficult to develop friendships with people who appear to be trustworthy. As a result, two participants reported not having any friends at all.

“At home, they don’t want me to go outside to play on streets. So I’m always at home playing with cars, I don’t have friends. My grandmother said if I go outside they will know that I have HIV.” (Participant H)

“I’m always at home and spending time with my family. I don’t have friends. If I have friends, they will tell others about my status; I don’t want people to know. So if a girl or my classmates want to visit me at home, I always say I’m busy with schoolwork. If they know they won’t want to socialise with me at school.” (Participant K)

Two participants mentioned having a few friends. However, their conversations are superficial and they do not disclose their HIV status to them.

“I have created friendship with other soccer teammates. But we only speak about soccer and school, not about personal issues. My relationship with my friends is more on superficial level.” (Participant I)

Six participants declared that they have a lot of friends; however, they do not disclose their HIV status to them as well.

“is ok, I have friends and a crew, but they don’t know about my status; even though I feel different from them.” (Participant F)

Four participants indicated a withdrawal from their social life because they are always at home to the extent that if people visit, they can just leave them unattended and always play with dolls:

“I have three friends (they are younger than Participant E) we like to play. I always play with dolls at home”. (Participant E)

One of the participant said she does not understand why she is suffering while other children are not, especially with regard to taking medication and HIV is a chronic disease:

“I view myself being different from others because know I’m HIV positive and others are not, why me, why me, why me..... (She cried out loud for 10 minutes)” (Participant F).

Although four participants are fully withdrawn and want to stay alone, there are those participants who just do not want to be with friends but would rather spend time at home with their family. These participants prefer to talk to their family and prefer this type of socialising because they take their medication at the right time and not forget or default on taking medication. One of the participants said:

“If people visit me, I just leave them and go to my room and lock. I like to be alone. I sleep, and wake up, and go to the kitchen, and come back to my room, and sleep. I have three friends we like to play. I always play with dolls at home”. (Participant G).

Three participants mentioned that they have disclosed to their friends and they got mix responses, with some friends accepting them and others rejecting them. One participant said:

“I have two friends, and I disclosed my HIV status to them. The other one likes to be bossy and he likes to call me ‘a thing of AIDS’ and the other one is very supportive and caring.” (Participant B)

- Relationship with peer
When the participants were asked to describe their relationships with their peers, nine participants attested to having good relationship with their peer while one of the participant mention that the challenge is that her boyfriend doesn’t want her to spend time with her friends:

“Like my boyfriend (boyfriend F) is always angry when I’m with other people. My boyfriend and I are friends. He doesn’t want me to be with other people.” (Participant C)

Another participant said:

“Well.... with my peers we get along, we never fight and argue.... we get well together, we get well with everything. At the moment, I told myself I will never argue when someone has another opinion opposite mine, and then I just accept the other person’s point.” (Participant A)

Five participants mentioned that they belong to certain crews which they associate with but they didn’t disclose their HIV status to these crews. One participant said:

“Is ok, I have friends and a crew, but they don’t know about my status; even though I feel different from them.” (Participant F)

Others will never disclose their status because they feel it will change the way their friends perceive them.

“So at school they will treat me like a princess, like F do what this, F do you want this. They won’t treat me as being normal, like I’m different from them.” (Participant F)

Another participant mentioned that

“Is like even to my friends, there is no one that I trust with this thing. I think if I disclose my status to my best friend, the relationship will change completely, he will reject me”. (Participant A)

Others said they only play well with their peers at school but when they go home their parents do not allow them to play with others.

“I play with my peers at school. At home, they don’t want me to go outside to play on streets. So I’m always at home playing with cars, I don’t have friends.” (Participant H)

- **Intimate relationship**

Four participants had a boyfriend/girlfriend while five participants did not have any boyfriend/girlfriend. Furthermore, although two participants said they currently do not have a boyfriend/girlfriend, their family members forced them to end the relationship and prohibited her in being involved in intimate relationships.

“No, but I once had a boyfriend. But my uncle threatened him to break-up with me, so he did. So I asked my uncle why he threatened him, he didn’t answer me (high pitched). I said ok, I will ask nurse why I’m not allowed to have a boyfriend, I mean I’m not stupid, I won’t sleep with him..... I was denied an opportunity to explore things.” (Participant I)

Of the four participants who had a boyfriend/girlfriend, only one disclosed their status while the others never disclosed their status.

“Yes, my relationship with her is flowing well, we are open, help each other, support each other, when she is low I pick her up and when I’m low she picks me up. She also has HIV.
We talk about how to take treatment and advice each other. She is important.” (Participant D)

“Yes, but I didn’t disclose my status to her and I always avoid to meet her, I always give an excuse.” (Participant B)

Of the two who used to have boyfriend/girlfriend, none had disclosed their status to their boyfriend/girlfriend:

“No, but I once had a girlfriend and we broke-up because she was cheating on me. So I walked away. She didn’t know my HIV status”. (Participant J)

Participants also mentioned that their relationships do not last long because of fights, break-ups and anger towards each other:

“I have problem with relationships, they don’t take long, we fight and break-up, and we become angry towards each other.” (Participant C)

One participant also mentioned that she tests her boyfriends to see if they will accept her with her HIV status prior disclosure:

“We are still in new love, I won’t tell him about my status. I will wait for a while, and then test him to see if he will accept me. If he does accept me, I will disclose my status.” (Participant C)

Other relationships ended due to infidelity, having difficulties with concentrating at school, and struggling to sustain relationships:

“Ah, I then broke-up with him because he was disturbing me with my school work, he would write love letters in class while the teacher is busy teaching us, and I was unable to concentrate, always thinking about him. So my marks in class dropped.” (Participant F)

4.3.4.10. Coping mechanism

The coping mechanisms that emerged from the data include avoidance, hopeful, denial, creating meaning and acceptance. These mechanisms will be further discussed.

• **Avoidance**

Two participants avoided forming close relationships and isolated themselves by staying at home and limited interaction with peers in order to cope with the anxiety of other people discovering they are HIV status.

“I play with my peers at school. At home, they don’t want me to go outside to play on streets. So I’m always at home playing with cars, I don’t have friends. My grandmother said if I go outside they will know that I have HIV.” (Participant H)

• **Hopeful**

Being hopeful that one day they will be healed from living with HIV and be free from HIV was a coping mechanism adopted by two participants who faced the challenges of living with HIV:

“Well I don’t believe that I won’t be healed. I believe that I will be healed in the future, and the doctor will stop me from taking treatment either if my CD4 count has increased or if I’m
ok physically. They say the doctors can stop you for about three years. I know that is a chronic disease but I believe that I will be healed.” (Participant C)

- **Denial**
  Two participants confided that that pretend to agree with the negative comments made towards HIV-positive people to avoid being discovered as being infected as well:
  
  “At the moment, at the moment, I told myself I will never argue with someone who has another opinion opposite mine, and then I just accept the other person’s point. Yah, because if I don’t accept it there will be another issue.” (Participant A)

- **Creating meaning and acceptance**
  Two participants realized that by creating meaning from living with HIV helped them with accepting their HIV status.
  
  “I picture myself as the chosen one, so I’m living the life in another world, where others cannot experience what I’m experiencing. Is like a treasure hunt.” (Participant D)

4.3.5. Experience of living with HIV

The participants shared different experiences to living with HIV. Such experiences included participants psycho-educating others about HIV, developing confidence in themselves; having and sharing family responsibilities; engaging in sports; losing loved ones to HIV; experiencing medical problems; developing friendships and being in romantic relationships. These experiences as illustrate by Figure 4.3.5 are described in detail below:

![Experiences of living with HIV](image)

**Figure 4.3.5: Experiences of living with HIV**

4.3.5.1. Psycho education

One participant reported psycho-educating people who are HIV positive about the importance of adhering to treatment:
“Like even when I’m at support group, someone complains about taking medication, it hurt me. We once went to the wards in Dr George Mukhari Hospital, we saw patients whom we are at the same status, is a shame, and is a pity. Like I told them that guys if we don’t take our medication we will be like this, is not that they were crazy, they were not crazy, they are normal like us, don’t cheat on our medication, and drink your medication (She is demonstrating using her hands). You just close your eyes and swallow it and drink water.” (Participant C)

4.3.5.2. Increased self-confidence
One participant did not discriminate or judge herself for taking treatment for HIV. The participant reported feeling and acting normal like other children and having a positive self-esteem:

“But for me the problem is I take treatment and they are not taking medication and we are similar. When I’m at the street I’m normal, I’m similar to any person, and I even forget that I’m on medication……I have sense of hope.” (Participant C)

4.3.5.3. Sense of responsibility
One participant reported having the responsibility of taking care of her grandmother and having less of a social life outside the house:

“I’m always at home taking care of my grandmother, at home I stay with my grandmother and uncle. And if I leave my grandmother I will hurt her… I feel responsible. I love her, but she is not sick. So I’m the one who takes care of her. If I visit, I feel like I’m hurting her. I love her; I don’t want to leave her alone.” (Participant I)

4.3.5.4. Engaging in sports and arts
One participant expressed a love of playing soccer while another enjoys spending time in studio recording music.

“We play soccer, we always attend practice. Yah, that’s it”. (Participant I)

“Most of the time I’m always at the studio so when I go home we always fight about being late, we are always fighting (he laughed). Well, they don’t trust me.” (Participant D)

4.3.5.5. Loss of loved ones
Six participants expressed losing loved ones who died from AIDS. The participants expressed losing their grandparents, aunts, uncles, friends, nephews, step parents and mothers to AIDS:

“Well it was a challenge that I had to concur because of three people who I was close to passed on – my mother, father, and my younger brother – so that makes me feel lonely.” (Participant D)

“Is my friend, she died in June this year.” (Participant I)

“her death was a shock because I thought she will live. She also died because of HIV. And after the death I was told I’m HIV, so I begin to be afraid. On top of it my mother died because she was also HIV positive.” (Participant J)

4.3.5.6. Medical problems
After receiving her HIV diagnosis, one participant reported being sick and being in and out of the hospital a lot which affected her ability to enjoy her childhood:
“My life was ok. But I was a person who was always sick. They knew why I was sick and I didn’t know. I was always weak, and not being similar to other children.” (Participant K)

4.3.6. Knowledge of HIV

Figure 4.3.6. below illustrates how the participants assessed their knowledge of HIV:

![Knowledge of HIV AIDS diagram]

Figure 4.3.6: Knowledge of HIV AIDS

4.3.6.1. Adequate information on HIV

Four participants demonstrated understanding and having information about HIV:

“HIV, the way I understand HIV is a disease, does not heal, immune system drops, does not heal, is similar to heart disease does not heal. If you treat it sharp then you will also be sharp. Is a chronic illness.” (Participant C)

“I know that you can contract it from having unprotected sexual intercourse, and also when you touch the blood of a person who is infected. Yah! As well as sharing injections. And you have to take medication every day, so if they check you and they don’t see it; they can stop you from taking medication.” (Participant B)

All participants who have adequate knowledge of the disease attend support group.

4.3.6.2. Limited information of HIV

Five participants demonstrated having limited information regarding HIV:

“HIV is the disease that is a chronic in its nature, so you have to take medication so that you are well and healed.” (Participant J)

One participant reported that at home they don’t want to answer her question relating to HIV:

“I heard that is a virus, but I don’t know what kind of virus. And at home, when I ask them questions related to HIV they don’t answer me... And the fact that HIV is a chronic illness, it really hurts me. It’s very heavy on me, I mean to take medication for the rest of my life, no, it is heavy.” (Participant I)
“I only know that I have to take medication, and I don’t know about other things. I always ask them when I will be healed. They only say I must take medication and I will be well. So I know I will be healed.” (Participant E)

One participant who has limited information on HIV found the information from the internet:
“I went to the internet and searched about HIV, trying to understand it.” (Participant K)

4.3.6.3. Lack of information on HIV
Two participants reported a lack of information regarding HIV:
“I don’t understand HIV.” (Participant H)

4.3.7 Coping resources
The participants’ coping resources including receiving support from family members, support groups, and receiving a social grant.

Figure 4.3.7: Coping resources

4.3.7.1 Family
All ten participants received support from their family members who were taking care of them:
“Yes, is my grandmother and sister, they always support me.” (Participant G)

Another participant reported that:
“My parents are the one who support me. So I always talk to my parents, especially my mother about HIV. So I’m afraid of my father. My father and I communicate only through phone and not in person – we don’t. I have two siblings, they don’t know about my status, so I’m not ‘that’ close to them.” (Participant K)

4.3.7.2. Other HIV patients known to participants
Although seven participants do not know anyone else who is HIV positive, four participants mentioned that know someone else who is HIV positive:

One of the participants, who knows someone who is HIV positive, said:

“Yes, I know few, some of them I’m familiar with them and there was an incident where I was at check-up for ARVs in the clinic, this guy who attends same school with me was also at check-up for ARVs, both of us were shocked to see each other and never spoke to each other till today.” (Participant B)

Participant C mentioned:

“We are many. My relationship with them is normal, everyone is open, we advise each other about everything, we view each other as friends, and others are dating each other, eish (she smiles). But I like to give them advice.” (Participant C)

Another participant also added:

“So most of the guys we are like a crew, we attended camp. We are too close like friends. We do everything together; we don’t have secrets between us. Yah, we don’t have secrets.” (Participant D)

The participants are of the view that knowing other HIV-positive patients brings a sense of relief because they are not alone, feel encouraged to take their medication and have someone they can confide in who is on the same level.

4.3.7.3. Support Groups

Because Dr George Mukhari Academic Hospital does not cater for a youth support system, some participants attend support groups outside of the hospital. Attending support groups with other young people born with HIV enabled the participants disclose the challenges they experienced of living with HIV to others. One participant mentioned that:

“In the support group, I can talk about whatever I want and we don’t keep secrets. I also created a friendship with this girl in that support group. And even if we are not in the support group we call each other, meet and talk about us and HIV.” (Participant B)

4.3.7.4. Social Grant

Receiving a social grant assisted one participant who was struggling financially to buy the food needed in order to take medication for HIV. This support grant allowed him to buy healthy food and to gain access to medication by paying for transport.

“I had difficulty in taking medication because of being unable to eat healthy food to accommodate treatment. Now I have money from social grants and it helps me to eat healthy food so that I can take medication.” (Participant J)

4.4. CONCLUSION

Presenting the results by way of themes and subthemes illustrates that being an adolescent living with HIV is a complex phenomenon with multiple challenges that have to be navigated in order to live healthy while on treatment. In the following section the yielded results will be integrated with the reviewed literature.
CHAPTER 5
INTEGRATION AND DISCUSSION OF RESULTS

5.1. INTRODUCTION
The study was aimed at exploring the experiences and challenges of adolescents who were vertically infected with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital in Ga-Rankuwa, Gauteng Province. The main objectives of the study were to gain insight into the experiences and challenges of adolescents who were vertically infected with HIV; to explore the current support systems of adolescents who were vertically infected with HIV; to stimulate future research; as well as to generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

According to the body of literature, adolescence, on its own, is a period where individuals are faced with numerous challenges. Simultaneously, having to cope with their chronic illness of HIV/AIDS can have a huge impact on the adolescents’ well-being (Etang, 2011). Furthermore, the biopsychosocial model views individuals as biological, psychological and social beings who behave in a specific way that can either promote or adversely impact their health. Thus, the health of an individual is the end result of variables including biological characteristics, behavioural factors, and social factors (Marks, et al, 2006).

The previous chapter presented the study’s results which were organised into main themes and subthemes that emerged from the data. In the current chapter, the results will be integrated with the reviewed literature following the format outlined in the previous chapter (following master themes and subthemes). This is followed by presentation of the limitations and recommendations.

5.2. INTEGRATION

5.2.1. Experience prior HIV diagnosis
When investigating the participants’ childhood, the results showed that there were some variations in the childhood experiences. More than half (nine) participants attested to having a difficult childhood while few (two) attested to having a positive self-perception and happy childhood. These variations will be further explored in an attempt to investigate how the background of the participants may contribute to the contradictions found in the study results. Armstrong (cited in Sherr et al., 2014) notes that HIV can enter the blood-brain barrier and affect the central nervous system thereby destroying neural tissues in the central nervous system. This eventually causes dysfunctionality of all modalities secondary to HIV/AIDS (Rohlede et al., 2009; Swanepoel & Louw, 2010). Other studies have found that HIV-positive children and adolescents score lower on the visual-spatial processing, which is important for adolescents as it affects reading, writing, and learning (Blanchette, et al., 2002).

Those participants who attested to having a happy childhood and a positive self-perception started treatment at a young age. They perceived themselves in a positive manner, being like other children and being able to play. According to Wexler (2013), the average time from the initial HIV infection to the development of AIDS has decreased since the introduction of antiretroviral (ARV) therapy, which has increased the life expectancy of patients with AIDS. This is due to the mechanism of ARV therapy, which stops the virus from replicating thus decreasing the viral load resulting in the immune system starting to repair itself (Wexler, 2013).
The above findings show that there is a difference between the participants who received HIV treatment using a biomedical approach and participants who didn’t receive their HIV treatment. It is evident that early testing, diagnosis, and initiation of treatment have a positive impact on the lives of adolescents who were perinatally infected.

In addition to reporting experiences prior HIV diagnoses, numerous participants reported that they lost their loved ones through death.

Some of the participants who experienced a difficult childhood reported that they experienced medical problems, which impacted negatively on their childhood. This prevented them from doing their academic work effectively, with some participants experiencing reading and writing problems as well as being unable to walk. A difficult childhood emerged from participants who started treatment during their adolescence stage. According to Karim and Karim (2010), HIV impacts on the physical well-being of a child with 60% of HIV-positive infants manifesting some symptoms of disease. This includes, but is not limited to, growth failures and developmental delays; respiratory system diseases such as tuberculosis; neurological system diseases; cardiovascular system diseases; and renal diseases. In addition, according to Piaget (Leifer & Fleck, 2013), adolescents develop formal operational thinking; this might be impacted by HIV. Hence, adolescents who are vertically infected with HIV might not reach formal operational thinking.

A majority of participants had reported that they didn’t understand the purpose of their treatment, the hospital appointments, multiple relocations, the loss of their loved ones, and the reason of being sick. This entire process confused them. This is in line with Van Dyke (2012) showing that the breakdown of the family structure and multiple relocations for children and adolescents may perpetuate the development of feelings of loss of belonging, autonomy and control of one’s destiny which then results in confusion. Consequently, this may perpetuate the development of emotional trauma, which may result in identity crises and developmental delays (Van Dyke, 2012).

What is noteworthy is that a lack of understanding the research result may be due to two reasons. The first reason, which can be explained using Piaget’s theory of cognitive development (cited in Louw, et al., 1998), illustrates that children and younger adolescents consider their condition as akin to their fate. They seem to live with the disease without reflecting on its meaning as it relates to them or on how they acquired it. This absence of in-depth reflection may be attributed to the pattern of concrete thinking that is characteristic of childhood and early adolescence (Van Dyke, 2012). The second reason can be explained using the research results from a study conducted by Midtbo (2012) and Kyaddondo et al. (2013) which found that a large number of these children have, for a great part of their lives, been unaware of their diagnosis as their caregivers have kept it a secret (Midtbo, 2012; Kyaddondo et al., 2013).

In summation, using the biopsychosocial model shows adolescents who were vertically transmitted with HIV, prior HIV diagnoses, are impacted by HIV from multiple levels. The multiple levels are biological, social and psychological factors (Marks, et al, 2006). The biological factors are experiencing medical problems while the social factors include a loss of loved ones, and multiple relocations. The psychological factors are confusion, lack of understanding and engaging in carefree behaviours. It is important to understand the interactions between biological, psychological and social factors (Marks et al., 2006; Albelheim, 2011). In this study, HIV impacts on both the biological factors (resulting in experiencing medical problems and difficulty to develop formal
operational thinking) and social factors (resulting in loss of loved ones and multiple relocations). The biological factors and social factors perpetuate and impacts on the psychological factors (resulting in confusion and lack of understanding). In addition, those participants who received treatment earlier have decreased the biological factors which in turn impact their psychological factors (positive self-perception).

5.2.2. Context of disclosure HIV diagnosis

From various studies, it is evident that HIV disclosure can be challenging and important aspect. The research results indicated that participants disclosed in various contexts. Eight participants were disclosed by healthcare providers and three participants were told at home. At home, two participants were told by grandmothers and one participant was told by his mother. With those who received disclosure from healthcare providers, two participants were in a camping context and six were in medical context. A study conducted at Odi Hospital, Pretoria by Mahloko and Madiba (2012) found that children who have perinatal HIV/AIDS and are receiving ARV treatment grow up and reach the adolescence stage. This has given rise to a challenge faced by parents who have to disclose to their adolescents about their HIV status. Caregivers, who reported disclosing the HIV status of their children to a close adult family member, found it is easier as compared to directly disclosing their children’s status of infected because of feelings of helplessness and guilt, and fears of discrimination about their role in the child’s infection through vertical transmission (Rohlede, et al., 2009; Madiba, 2012; Kyaddondo, et al. 2013). For the majority of children, disclosure was done by people other rather than their biological caregivers. A majority (61%) of the participants were informed of the diagnosis by people other than their biological mothers (Madiba, 2012; Mahloko & Madiba, 2012).

When investigating the disclosure in the medical context, participants attested that the healthcare providers focused on giving information about HIV and the participant didn’t understand what they were saying. Furthermore, the participants indicated that although they attended VCT, they didn’t benefit from it as the focus was on explaining mechanism of HIV instead of focusing on how the participants felt about their HIV status or how they perceived HIV. A study conducted by Vaz, et al. (2010) corroborates these findings that in the medical context, the healthcare providers focused on explaining the mechanism of HIV and the importance of adherence to treatment rather than focusing on the participant’s themselves. Furthermore, studies in South Africa have revealed in the VCT model, there are frequent inadequate standards of counselling (Olley, et al., 2004). Similar findings were reported by Russell and Scheider (2000), and Van Dyke and Van Dyke (2003). In addition, Pettifor, et al. (2008) report that current VCT services are not youth-friendly and are considered inappropriate for the youth’s needs.

Within the family context, the participants’ experiences about the disclosure are similar to the findings presented by Vaz, et al., (2010) which show that the caregiver puts more emphasis on adhering to medication. Thus, within this context, the caregivers provide limited or no information about the mechanism of HIV. Furthermore, caregivers focus more on providing information instead of the adolescent’s themselves (Vaz, et al., 2010). In addition to reporting the participants’ experiences about disclosure in a family context, some participants attested to not discussing topics related to HIV with their caregivers. The study conducted by Michaud, et al. (2010) revealed that several patients reported that the specifics of their condition were barely discussed with parents, and some of the participants actually resorting to the internet for information. Most of the adolescents living with an infected mother expressed how difficult it was to raise this topic with her, given the guilt, torn loyalties and emotional dilemmas it evoked (Michaud, et al., 2010).
When looking closely at the **camping context**, participants reported that because they were disclosed in a camp context, they began to understand HIV, adjust and accept their status. According to Van Dyke (2012), camps are designed to foster positive relationships and competence-building opportunities, and offer support and opportunities for youth to initiate and engage in behaviour that aids in the transition to adulthood (Van Dyke, 2012). Similarly, a study conducted by Bialeski, et al. (2007) focusing on the outcomes of camp participation consistently demonstrated that a camp has positive implications for identity development, social skills, physical and thinking skills, and positive values and spirituality.

Participants expressed various emotional responses to the disclosure of their HIV status. This is in line with other studies that indicate that the participants’ moment of having their HIV status disclosed is mostly experienced as dramatic and deracinating, with the physical and emotional ‘shock’ of a positive result, anger, depressive, other reactions to being informed of their HIV status (Rohlede et al., 2009; Martinez, et al., 2012; Van Dyke, 2012).

Van Dyke (2012) highlights that the adolescents who were perinatally infected with HIV had various reactions such as denial, anxiety, low self-esteem, sadness, hopelessness, guilt, and feelings of loss. Similarly, a study conducted by Mutwa, et al, (2013) found that adolescents who were made aware their perinatal HIV infection, expressed confusion or anger towards their parents. This anger, in some cases, also led to the adolescents being less obedient sometimes in an attempt to punish their parents, while at other times as an attempt to come to terms with, or due to confusion about, why this happened to them and not their siblings.

The emotional reactions that are in line with the abovementioned studies include **shock and disbelief, sadness, shame, loneliness, anxiety, and anger**. On the other hand, the emotional reaction that is in contrast to abovementioned studies include **acceptance**. This is because of a context where disclosure of HIV has occurred. The emotional reactions that are in line with abovementioned studies occurred in the medical and family context while the emotional reaction that is in contrast to abovementioned studies occurred in the context of camps. Therefore, this current study adds to our knowledge that HIV disclosure in a family and medical context leaves adolescents with unresolved emotions towards their HIV diagnosis while HIV disclosure in the camp context enables the adolescents to accept their HIV diagnosis.

In nutshell, HIV disclosure to adolescents who were vertically infected with HIV creates an enormous emotional experience. The current VCT and medical context, as well as family context, services are ineffective, unfriendly to youth in disclosing HIV diagnosis; while the camp context is effective in disclosing HIV status.

### 5.2.3. Experience of taking HIV treatment

There are numerous studies that focus on adherence to ARV treatment. In this study, the researcher explored the experiences of HIV treatment and found various responses. Few participants mentioned that they have been taking medication since a young age and prior to HIV diagnosis so they are used to the treatment and therefore have no problem in taking medication and have accepted taking medication. Van Dyke (2012) highlights that early testing, diagnosis and initiations of treatment were critical for caregivers and children, and that the complexity of ARV treatment was less of a barrier to treatment.
Those participants who started treatment after HIV diagnosis reported different responses. More than half of the participants attested that they take their medication in secrecy because they cannot take their medication in front of friends or relatives if they are visiting or when playing. The secrecy is motivated by participants don’t want people to notice that they are on medication as it will reveal their HIV status. Thurston, et al. (2013) found that the role of disclosure is important in promoting adherence – some participants who experienced lack of disclosure were prevented them from taking medications at certain settings which stood in the way of adherence.

Some participants attested that taking treatment caused constraint in their social life because it limited them from engaging in activities that they would have loved to engage in freely. Piaget (cited in Van Dyke, 2012) mentions that adolescents have egocentrism, while Van Dyke (2012) adds that the egocentrism of adolescents may negatively impact on adherence to ARV treatment as adolescents may refuse to take medication at school because others will gain awareness of their illness. This leads to limited engagement in certain activities by adolescents (Van Dyke, 2012).

Other participants mentioned that taking medication on a daily basis makes the participant feel irritated and angry which has affected adherence to treatment. A study conducted by Thurston, et al. (2013) found that it is important to monitor the mood of those taking medication. One of the participants was struggling with depression and anxiety symptoms during the follow-up sessions, which had a huge impact on her adherence.

The findings also demonstrated that some participants demonstrated a lack of understanding on the importance of adhering to ARVs treatment. Mattes (2014) shows that many institutions that offer ARV treatment are understaffed by healthcare professionals, with dozens of people receiving treatment at the same time from those institutions. This may negatively impact on the quality of services provided to the patients, therefore neglecting physical examination and resulting in a lack of communication between healthcare workers and patients. The lack of communication between healthcare workers and patients may result in children and adolescents experiencing inconsistent practices and receiving insufficient information about their treatment and illness which may further evoke confusion (Mattes, 2014).

In addition, the results indicated that psychosocial interventions are important. One participant attested that she initially lacked understanding about HIV treatment; she then received explanations from psychologists and social workers to aid her to develop an understanding of the importance of adhering to treatment. According to Albelheim (2011) and Mark, et al (2006), the biopsychosocial model requires practitioners to change their perspective about using interventions at one level of a system which might be ineffective. Thus, the practitioners should work hand-in-hand and simultaneously at multi-levels, such as at biological, cognitive, behavioural and/or emotional levels in treatment planning and understanding of health and illness (Albelheim, 2011; Marks et al., 2006).

Therefore, early testing, diagnosis and initiation of treatment in adolescents who were vertically infected with HIV promotes adherence to treatment. Furthermore, adherence to treatment is impacted by social variables and psychological factors as well as medical personnel. The psychological factors are the perceptions (egocentrism leads to constraint) and mood (irritated); and the social factors (the adolescents experienced inconsistency and insufficient information from medical personnel which leads to lack of understanding) relate to secrecy (stigma and difficulties in disclosure leads to secrecy). Thus, palliative treatment is indicated in order to effectively provide services to adolescents.
5.2.4. Experiences of living with HIV

From the subtheme of prior HIV disclosure, it was evident that participants experienced difficulties in their childhood. The researcher then explored the experiences of participants in their adolescence stage and some subthemes were repeatedly expressed by the participants including **medical problems** and **loss of loved ones**. Other subthemes were also added.

Some participants reported having the **responsibility** of taking care of their grandmothers and having less of a social life outside the house. The study by Thupayagale-Tshweneagae, et al., (2012) also found that orphaned adolescents have difficulties in interpersonal relationships – building meaningful relationships with others seems difficult and at times impossible for them. This is as a result of many adolescents living with perinatal HIV/AIDS being in the role of young carers. Bauman et al. (2006) defines young carers as children and adolescents who take on ‘substantial and significant tasks’ with responsibilities that would normally be associated with an adult when someone, particularly a member of the household, becomes unwell. This may result in loss of time to start peer friendships (Bauman et al, 2006).

Regarding the importance of adhering to treatment in the support group, other participants reported **psycho educating** people who are HIV positive. According to Van Dyke (2012), camps are designed to foster positive relationships, competence-building opportunities, and offer support and opportunities for youth to initiate and engage in behaviour that aids in the transition to adulthood. Similarly, Fair, et al. (2012) found that group members identified the following four benefits associated with participating in the group: increased confidence, better communication skills, increased support, and a desire to share their experiences with others. In addition, the findings suggests that those participants attending support groups did not discriminate or judge themselves for taking treatment for HIV and they experienced **increased self-confidence**. Midtbo (2012) shows that Teen Club (a support group) seemed to make the adolescents confident and believe in themselves; they felt safe and secure.

In conclusion, from a biopsychosocial model, HIV impacts on multiple levels in the experiences of adolescents who were vertically transmitted with HIV. The multiple levels include social factors (loss of loved ones and sense of responsibility) and biological factors (medical problems). Adolescents who were perinatally infected with HIV are at a high risk of experiencing delays in their developmental tasks due to these biological and social factors. The biological factors include medical problems and difficulties in physical well-being; and the social factors include the experience of grief, and having limited time to form peer relationships, which is one of the developmental tasks. Anastasopoulos, et al. (2010) highlight that adolescents who were perinatally infected with HIV are unable to develop their identity, because they are unable to detach from family and attach to peers (Anastasopoulos, et al., 2010).

5.2.5. Knowledge about HIV

As presented in the results chapter of this study, there were some variations in the knowledge about HIV. The variations occurred between participants who are attending support groups and participants who are not attending support groups. The participants who attend the support group demonstrated **adequate information on HIV**, understanding and having information about HIV. All participants who have adequate knowledge of the disease attend support groups. Van Dyke (2012) shows that an effective peer support group creates a platform where control shifts from experts to the group members, allowing debates and discussions among group members, developing new group norms of behaviour, and changing education to be less threatening and available to group members.
Those participants not attending support group have demonstrated **limited information and lack of information** about the disease. Thus, in a family context, the caregivers explain limited information or provide no information about the mechanism of HIV (Vaz, et al., 2010) and the lack of communication between healthcare workers and patients may result in children and adolescents experiencing inconsistent practices and receiving insufficient information about their treatment and illness, which may further evoke confusion (Mattes, 2014).

Therefore, the findings demonstrate the importance and the effectiveness of support groups as well as the ineffectiveness of family context and medical context.

### 5.2.6. Challenges of living with HIV

Punctuating from the above discussed main themes, it is evident that adolescents experienced numerous emotions towards the discovery of their HIV status. In this main theme, the findings suggest that adolescents who were vertically infected with HIV are faced with numerous challenges. In the section that follows these challenges will be discussed.

The results suggest that more than half of the participants expressed **difficulty in accepting their HIV diagnosis**. Some participants seem to be fixated on the anger of being HIV positive which prevented them from accepting their diagnosis. The above findings seem to be supported by Mutwa, et al, (2013) who indicate that once adolescents were made aware their perinatal HIV infection, they expressed confusion or anger towards their parents. Furthermore, the study conducted by Usinger and Marilyn (2010) found that adolescents who are self-absorbed, detached, angry, or overwhelmed were pre-occupied with conflicting beliefs on how others perceive them versus beliefs about their moral self which is the reflection of the ideal self-concept. The conflicting beliefs may result in the adolescent becoming fixated or stuck with an internal conflict.

In addition to reporting difficulties in accepting HIV diagnosis, other participants reported that this was due to stigma which they experienced from their social relationships. According to Rohlede, et al. (2009), stigma is a social process defined since the illness is viewed to be preventable or controllable, or indicative of ‘immoral’ behaviours. Some people are blamed and perceived to be responsible for their own infection, resulting in active discrimination and social devaluation (Rohlede, et al., 2009). HIV stigma is perceived as discrimination pointed at people apparent to have HIV/AIDS, and the individuals, groups, and communities with which they belong to (Herek, 1999).

As shown in the previous sections, it is evident that the concept of disclosure is an enormous challenge. This concept also emerged in this main theme: numerous participants reported having a challenge in **disclosure** which was due to fear. The participants mentioned that fear restrained the participants from disclosing their HIV diagnosis to other people apart from those that already knew about their diagnosis. Some participants expressed that they feared being rejected, laughed at, judged, and gossiped about. Hence, this fear led to participants choosing to not disclose their HIV diagnosis.

The above results seem to be in line with previous studies that indicated that when young people disclose their HIV status, they do so with the intention of finding support. However, they are fearful of negative reactions that this disclosure may elicit (Martinez, et al., 2012; Hoogwood, et al., 2012). According to Van Staa, et al. (2008), young people utilise a strategy of normalising a chronic illness as a way of forming identity so that they are able to accept that a chronic illness was present but prevent it from dominating their lives by not disclosing their status.
The findings indicate that some participants have formed peer relationships and belong to certain crews that they associate with. However, they didn’t disclose their HIV status. Parker, et al. (2006) highlight that early adolescents form peer groups which require social skills in order to handle them effectively. Similarly, adolescents establish friendships and groups (Cobb, 2010) for the purpose of emotional support and exploration of values as well as to fulfil their need for formation of identity, belonging, building self-esteem and access to information (Jansen et al., 2012; Zarrett & Eccles, 2006; Hoogwood, et al. 2012). Although young people experience fears and dilemmas around HIV disclosure, they do not want to be associated with an identity linked to illness, contagion and death. In some ways, this desire motivates the young people not to disclose their HIV status as they choose to have a different image or identity where HIV does not belong. (Hoogwood, et al., 2012).

Other participants (two) showed a preference for playing soccer with friends but try by all means to only talk about soccer and school and not about personal issues. They also attested that attending to various activities with friends helped participants lead a normal social life, which they attested to being fun. This is supported by the study conducted by Florindo (2007) that indicates that the role of leisure in the lives of people living with HIV/AIDS has been important for coping with the negative effects of diagnosis, and increasing health and quality of life (Florindo, 2007).

Some participants reported that with their peers they get along, they never fight and argue, and they decided to avoid arguments and accept other people’s point. Thupayagale-Tshweneagae, et al. (2012) found that for the most part, the nature of problems in adolescence involves interpersonal relationships which require that individuals develop and effectively utilise social skills. However, orphaned adolescents have difficulties in interpersonal relationships and this has resulted from experiencing manipulations from their peers (Thupayagale-Tshweneagae, et al. 2012).

In addition to reporting peer relationships, other participants said they only relate well with their peers at school because their parents do not allow them to play with other children at home. Leifer and Fleck (2013) note that one of the developmental tasks, in late adolescence phase, is to care and value relationships and begin to select partners. However, in the context of HIV, Archibald (2010) found that family members, who are from families were one or more individuals are HIV infected, experienced discrimination from members of the church community due to fear of transmission, and children were not allowed to play together even after services. The adolescents expressed being warned not to hang with people living with HIV/AIDS (PLWHA). A group of members preferred their daughters not to have close friendships with someone with HIV/AIDS (Archibald, 2010). It is interesting to note that HIV stigma is a huge challenge that adolescents who are perinatally infected with HIV are faced with, and it creates many social difficulties that these adolescents encounter. Similarly, a study conducted by Kerr, et al. (2011) found that parents were being excessively protective towards their children. Thus, adolescents who were vertically infected with HIV do not experience psychosocial moratorium.

Some participants reported being socially withdrawn from their peers. Edgar, et al. (2012) found that adolescents living with perinatal HIV/AIDS experience difficulties when developing relationships. Similarly, Usinger and Marilyn (2010) found that adolescents who are detached and/or overwhelmed may be withdrawn from societal expectations because they are being overwhelmed by personal circumstances or being deliberately withdrawn or disengaged. On the other hand, Dorrel, et al. (2009) found that these young people experience a dilemma between a desire to let people know their status and their parents’ views which sometimes results in feelings of isolation and loneliness.
Other participants attested to viewing themselves as being different from their peers. They reported that they do not understand why they are the ones suffering while other children are not. According to Piaget (cited in Van Dyke, 2012) older adolescents keep comparing themselves with adolescents with no physical illness or developmental disabilities. Similarly, within the field of social psychology (cited in Zambo, 2010), social identity refers to how we view and understand ourselves in relation to others – having a sense of who we are and where we belong in the world. This is also influenced by how others perceive us. Furthermore, a study conducted by Kerr, et al. (2011) found that people with epilepsy also reported feelings of being different from others around them; this may be due to their perception or actual experienced of being labelled as different.

The findings above imply that adolescents who were vertically infected with HIV experience difficulties in forming peer relationships and this might impact on the development of their identity (Erikson, 1968), which might result in identity crisis.

As presented in the results chapter of this study, there were some variations in the investigation of formation of intimate relationship. Few participants reported that they are involved in romantic relationship while majority of participants reported that they are not involved in a romantic relationship. Leifer and Fleck (2013) mentioned that the developmental tasks in late adolescents is to develop their own sexual identity and caring relationships; they care and value relationships and begin to select partners. In the following discussion, these variations are explored in an attempt to investigate how the background of the individuals may contribute to the differences.

The background of the participants indicated that those participants involved in romantic relationships were attending support groups while those not in a romantic relationship were not attending support groups. Those participants who reported not having any intimate and/or romantic relationships expressed various reasons. Some reported that their caregivers did not allow them to have any romantic partners. Based on the family systems model (Jaffe, 1998), change in one of the family members will impact on the whole family system. Individuals who go through adolescence experience major changes in their lives which will impact on the whole family. This is evident through the adolescents developing their own identity, increased independence and autonomy. Consequently, the family must create a space to accommodate the changes experienced by the adolescents, especially changes in the parent-adolescent relationship (Jaffe, 1998). Hajikhani Golchin et al., (2012) point out that the conflict may result in strained parent-adolescent relationship. Parents have difficulty in recognising adolescents’ concerns; adolescents attempting to establish independence; adolescents lacking trust in the family; and parents attempting to control adolescents’ personal choices such as clothes, friends and subjects to study in school.

Others participants attested experiencing difficulties in sustaining their romantic relationships. Chinyezi (2010) found that adolescent girls who were perinatally infected with HIV lacked interpersonal skills that are necessary to form romantic relationships (Chinyezi, 2010).

Some participants also mentioned that they have difficulties in trusting their partners and this was due to past experiences were the participants disclosed their HIV status and their partners broke-up with them. Adolescents who are HIV positive are at risk of being rejected by their peers, community and the social environment (Brown & Pedder, 1991). Erikson (1968) suggests that this type of negative feedback loop may have a significant impact on this developmental stage because the adolescents may experience role diffusion. Furthermore, Pettitt, et al. (2013) also found that HIV/AIDS diagnosis has a
great impact on developing sexual relationships with adolescents who have perinatal HIV/AIDS; they stand the risk of transmitting the disease to their partners, experience stigma and trust issues related to disclosing to their partners (Pettitt et al., 2013).

The above findings on intimacy indicate that adolescents who do not attend support groups experience numerous challenges which prevent them from developing romantic relationship. However, those individuals who attend support groups are able to form romantic relationships. Hence, the support group has positively impacted on adolescents who are living with perinatal HIV, in that it has equipped those adolescents to deal effectively with their challenges and enabled them to form romantic relationships. These findings is consistent with previous research that suggests that adolescents viewed Teen Club (a support group) as a place where they could be open to one another, share problems and find support (Midtbo, 2012).

In addition to reporting various challenges, some participants attested that they experienced abuse from their caregivers. Caregivers are still using corporal punishment and they sometimes physically hurt the participants. On the other hand, other participants experienced trauma from being raped. Leifer and Fleck (2013) note that in the late adolescence phase, adolescents are faced with the developmental task of reaching independence and re-establishing family relationships in their family context. However, the study conducted by Gren-Landell, et al. (2011) found that adolescents who experienced maltreatment from parents and the community may develop an enormous fear of negative feedback in social interactions and evaluations of performance that may escalate to behaviours of avoidance and impairment, called social anxiety disorder. Similarly, the Centre for Disease Control and Prevention (Thornberry, et al., 2014) defines maltreatment as any behaviour of omission or commission by a parent or a caregiver that has an end product of harm, or potential to harm, which threatens the child or adolescent. In addition, the study conducted by Cluver et al., (2013) found that child abuse was also experienced by adolescents with perinatal HIV infection, who were exposed to severe physical, emotional and sexual abuse, as well as conflict and violence in the household.

The results further demonstrate that some participants are involved in conflict with their parents. According to Cobb (2010), the perceptions of adolescents towards their parents change. They perceive their parents as less supportive and opposing them. Similarly, Bukatko (2008) mentioned that the change in perception towards their parents resulted from the adolescents’ ability to view people with both strengths and weaknesses and to think in an abstract manner. Other participants expressed feelings of anger towards their parents which lead to participants being rebellious, acting-out and engaging in deviant behaviours. These findings are consistent with a study conducted by Mutwa, et al, (2013) that shows that adolescents that were made aware of their perinatal HIV infection, expressed confusion or anger towards their parents. This anger, in some cases, also led to the adolescents being less obedient sometimes in an attempt to punish their parents, and other times trying to come to terms with the diagnosis, or due to confusion about their status, why this happened to them and not their siblings.

The findings indicated that some participants experienced financial constraints including having insufficient money at home that led to three participants being unable to buy the necessary food needed for them to take treatment for HIV as well as not having money to attend to their appointments at the clinics. According to Rohlede et al. (2009), children and adolescents who are infected and affected by HIV mostly grow up in poverty-stricken households. Similarly, Ssewamal, et al. (2009) reported that the death of parent may cause poverty in the family, as a prolonged parental illness and subsequent death creates a financial strain in the family resulting in poverty.
All participants identified ineffectiveness from nurses including experiencing a lack of empathy, and being impatient, judgmental and inconsistent in supporting the patients. This created distance between the participants and medical personnel. This is support by Pettitt et al. (2013) finding that suggest that clinical services for HIV/AIDS in Southern Africa are not adolescent-friendly and healthcare workers lack skills to treat adolescents, as adolescents feel uncomfortable to receive treatment in either a paediatric clinic or an adult clinic.

Other challenges which were identified in this study showed that four participants were in middle-school years (aged 16 to 17 years), and seven participants in high school years (aged 16 to 18 years). This is contrary to Jaffe’s (1998) division of sub-stages of adolescence: early adolescence corresponds with middle-school years (11–13 years), middle adolescence corresponds with high-school years (14–17), and late adolescence corresponds with college years (18 to early 20s). The study participants’ age results do not correspond with the ages of adolescents as indicated by Jaffe (1998). This is primarily due to adolescents in this study being vertically infected with HIV whereas the adolescents in Jaffe’s study (1998) were not vertically transmitted with HIV. Therefore, participants in this study were delayed in starting their schooling years. In addition, according to Piaget (Leifer & Fleck, 2013), adolescents develop formal operational thinking and shift from primary to secondary; adolescents who are prenatally infected with HIV may not reach formal operational thinking and may operate as concrete operational thinkers in their adolescence stage (Sherr et al., 2014) and this might impact on the adolescents to shift from primary to secondary school. This study’s finding is supported by Ismayilova, et al (2012) who highlights those children and adolescents who were vertically infected with HIV are at a high risk to miss school or drop out of school. Similarly, the study conducted by Cluver et al, (2011) found that adolescents who were vertically transmitted with HIV reported experiencing disruption and difficulties in their concentration which affected their performance at school.

Some participants reported that attending monthly appointments was a challenge as it affected their academic performance. Mburu et al. (2014) found that adolescents living with perinatal HIV/AIDS may drop out of school or repeat grades due to discrimination and frequent hospital appointments (Mburu et al., 2014).

From the above, it is evident that adolescents who were vertically infected with HIV faced various challenges and this motivated the researcher to explore the coping mechanisms which are used by these adolescents. Hinshaw (2005) highlights that adolescence is a period characterised by a number of developmental tasks. To deal with the demands that confront them, adolescents draw on their coping resources, which include their problem-solving competencies and skills.

The research results indicate that participants used denial, avoidance, and hopefulness as their coping mechanisms. According to Pettit, et al., (2013), many adolescents living with HIV/AIDS suffer from self-blame and self-stigma, view themselves as lacking opportunities in their communities when compared to their uninfected peers and also live in denial about their HIV status. However, results from the study conducted by Pettitt, et al., (2013) are in contrast with the results of this study: Pettitt, et al., (2013) found that those participants who have accepted their status showed a sense of hopelessness about their future while in this study those who have accepted their status are creating meaning from living with HIV and this has helped them with accepting their HIV status. The contrast between the two studies may be a function of the context in which the study was conducted. The participants who expressed acceptance in the study conducted by Pettitt, et al., (2013) did not
attend support groups and youth camps while the participants in this study attended support group and youth camps.

Thus, from the above, adolescents who were perinatally infected with HIV are faced with challenges from multiple levels including social, biological and psychological factors. In addition, those adolescents who attend support groups are using coping mechanisms of creating meaning and acceptance while those not attending support groups utilise coping mechanism of denial, avoidance, and hopefulness to being healed. Thus, adolescents who are not attending support group are missing the opportunities of benefiting from support groups.

5.2.7. Coping resources
From the above, it is evident that having to cope with HIV can be quite challenging for adolescents who were vertically infected with HIV and support is vital in helping adolescents living perinatal HIV in coping with these challenges. The researcher explored the available coping resources. The findings indicated that some participants made use of family as a coping resource. Meyer (2013) showed that millions of adolescents who were vertically infected with HIV have been orphaned or made vulnerable by HIV/AIDS. This leads to those adolescents who were vertically infected with HIV being relocated to their relatives’ homes (Rohlede et al., 2009; Meyer, 2013). Similarly, the adolescents who were vertically infected with HIV experienced loss in their family context which results in instability and further impacted on the family’s ability to support the adolescents who were vertically transmitted with HIV (Van Dyke, 2012).

Some participants reported receiving social grants for assisting them in buying healthy food and access to medication through transport. Van Dyke (2011) highlights that a loss of caregivers may result in those adolescents experiencing poverty. According to Hall and Proudlock (2011), the foster child grant was introduced with the aim of protecting the child financially.

The findings indicated that few participants were attending support groups outside Dr George Mukhari Academic Hospital, because the hospital does not have any support system for youth. Attending support groups with other young people who were vertically infected with HIV enabled some participants to discuss the challenges they experienced with living with HIV. This is in line with the study conducted by Midtbo (2012) that shows that adolescents viewed the Teen Club (a support group) as a place where they could be open to one another, share problems and find support. Similarly, Van Dyke (2012), together with Mattes (2014), highlight that many children in Southern Africa do not receive any psychosocial treatment.

From the above, punctuating from the biopsychosocial model, it is evident that adolescents who were vertically transmitted with HIV are in need of psychosocial treatment (Marks et al., 2006; Albelheim, 2011). This type of treatment aims at motivating for a high-quality life, and it rebuilds hope and basic skills to deal with daily functions (Van Dyke, 2012).

5.3. CONCLUSION
In this chapter the experiences, thoughts and challenges of adolescents who were vertically infected with HIV were discussed. The research results clearly indicate that individuals going through the adolescence stage as well as living with perinatal HIV infection are faced with an emotional and stressful situation. Furthermore, for adolescents living with perinatal HIV, HIV impacts on their social, psychological and biological factors. This leads to physical and psychosocial challenges.
addition, it is evident that physical and psychosocial challenges occur in three levels namely: prior, during and after HIV disclosure.

The findings demonstrate that adolescents who were vertically infected with HIV are in need of psychosocial treatment. The biopsychosocial treatment should be offered prior, during and after HIV disclosure. The study indicated that the majority of participants do not attend support groups; and for those who attend support groups, the support group is not offered at Dr George Mukhari Academic Hospital. According to Van Dyke (2012), and Mattes (2014), many children in Southern Africa do not receive any psychosocial treatment and there is lack and/or few such treatments tailor-made for adolescents. The findings indicated that those participants who attended the support group experienced less or no difficulties as compared to adolescents not attending the support group. This is supported by Albelheim (2011) who reported that the biopsychosocial model requires practitioners to change their perspective of using interventions at one level of a system which might be ineffective. Furthermore, it was evident that adolescents who are living with perinatal HIV infection experience unresolved emotions and are at an increased risk of developing psychological difficulties. Thus, the services of psychologist may be beneficial in addressing these psychological and emotional barriers.

In addition, the findings demonstrated that the biomedical approach is ineffective and unfriendly to adolescents who were living with perinatal HIV infection. This is consistent with Engel’s suggestion (1977) that states that from a biopsychosocial model, the medical profession is criticized and should re-examine education and care. Furthermore, the findings illustrated that early testing, diagnosis and initiation of treatment is effective; those participants who tested, diagnosed and initiated treatment later had medical difficulties and accepting treatment as compared to those participants who tested, diagnosed and initiated treatment earlier.

5.4. STRENGTHS OF THE STUDY

- The study aimed at exploring the experiences, thoughts and challenges of adolescents who were vertically infected with HIV. It is during the process of exploring their experiences that the richness and quality of data was derived from the in-depth interviews.

- While exploring the experiences and challenges of adolescents who were vertically infected with HIV, the differences were found between the individuals attending support groups and those not attending support groups. Furthermore, the research reflected on how psychosocial treatment positively impacted on the lives of adolescents who were vertically infected with HIV.

- When exploring the participants’ challenges, the findings indicated how the biomedical approach is ineffective and not youth friendly. The research provided information that will lead to further research and the ability to improve healthcare services as well as the mental health of adolescents who were vertically infected with HIV.
5.5. LIMITATIONS
Despite the strengths of this study, as seen in section 5.4., the following limitations were also noted:

- The final sample used in the current study did not show great variability; there wasn’t an equal distribution within the different races, only black Setswana-speaking adolescents were interviewed, all the participants hailed from the same peri-urban area. The sample size was small, with participants from same clinic served one hospital. Therefore, the results may not be generalizable to the larger population. Therefore, the findings cannot account for the experiences of other adolescents who were vertically transmitted with HIV, of different races, or coming from urban and rural places, as such findings may differ from the findings of this study.

- The sensitive nature of the interview questions and meeting the participants’ one-at-a-time may have impacted on the rapport and may have led to some adolescents not reporting their experiences thoroughly.

5.6 RECOMMENDATIONS
After gaining insight into the experiences and challenges of HIV-positive adolescents, the following recommendations are made:

- From the results and literature, it is evident that individuals who are living with HIV/AIDS experience numerous challenges ranging from physical, social and psychological challenges; therefore, these individuals need a palliative treatment (also called multidisciplinary team) prior, during and after HIV disclosure.

- This study also recommends the full assessment of Biomedical or Physical Treatment to adolescents who are perinatal HIV infected. This encourages early testing, diagnosis and initiations of treatment. This will ensure and address the adherence issue. This study also recommends holding workshops and training medical professionals working with HIV-positive adolescent to address negative experiences by adolescents when interacting with nurses collecting their treatment at the clinics and hospital.

- The study also recommends psychosocial treatment and support groups: HIV-positive adolescents have to develop effective skills to deal with psychosocial challenges.

The following are suggested research studies that can be explored further:
• It is recommended that future research efforts in this area should include participants from different hospitals, from wider geographic areas, and from different racial groups in order to broaden the understanding of the phenomenon.

• The time frame for the study should be expanded and increasing the number of participants is recommended in order to strengthen the findings of this study.

REFERENCES


You are requested to participate in a research study which has a research topic of: An investigation into the experiences and challenges of adolescents who were vertically infected with HIV at birth and currently receiving treatment at Dr George Mukhari Academic Hospital, Garankuwa Gauteng Province.

The aim of the study is: The aim of the study is to explore the experiences and challenges of HIV positive adolescents who are currently undergoing treatment at Dr George Mukhari Academic hospital, Garankuwa Gauteng Province.

The objectives of the study are:
To gain insight into the experiences, challenges of HIV positive adolescents.

Furthermore, the researcher’s objective includes exploring the current support systems of HIV positive adolescents.

The proposed research, viewed as a pilot study, aims to stimulate future research and generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

The participation of the research study is voluntary and if the participants are willing to participate in this study they will be required to ask their parents or legal guardian for agreement to allow their child to participate, and then the participant together with their parent or legal guardian should fill in their written consent by completing the informed consent form. After the filling-in the informed consent form, the participants will be interviewed by the researcher and the interview will be recorded.

The participation to this study will not cause any harm or be detrimental to the participants. The participants will be assured that they will be anonymity (not providing their names) throughout the whole research study and even when publishing the research results. The will be no reward (being paid or given gifts) to the participants.

After reading the above invitation and having concluded to participate in this study, you should complete the consent form.
Statement concerning participation in a Research Project

Name of the Study: An investigation into the experiences and challenges of adolescents who were vertically infected with HIV at birth and currently receiving treatment at Dr George Mukhari Academic Hospital.

I have read the information on the aims and objectives of the study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this study has been approved by the Medunsa Campus Research and Ethics (MCREC), University of Limpopo (Medunsa Campus)/Dr George Mukhari Hospital. I am aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participation in this study.

.........................................................................................   .........................
Name of patient/volunteer                      signature of patient or guardian

.........................................................................................   .........................
Place                          Date                          Witness

Statement by the researcher
I provide verbal and/or written information regarding this study. I agree to answer any future questions concerning the study as best as I am able. I will adhere to the approved protocol.

.........................................................................................   .........................
Name of Researcher                      Signature                      Place                          Date
APPENDIX C
INTERVIEW SCHEDULE
1. Before you found out you were HIV positive, describe how your life was like for you?
2. When and how did you find out about your HIV status
3. What can you tell me about your childhood
4. Do you remember when you first started taking your HIV treatment?
5. Are you currently receiving treatment for your HIV?
6. How do you experience taking medication on a daily basis?
7. Do you know of anyone else who is HIV positive
8. Have you disclosed your HIV status to anyone?
9. What would be some of reasons why you would not disclose your HIV status
10. How would you describe your social life?
11. Do you have a girlfriend/boyfriend?
12. Do they know about your HIV status?
13. How would people react if they knew about your HIV status
14. How would you explain to people how you contracted HIV
15. What are some the daily challenges you face
16. Please describe your peer relationships
17. Do you currently have any support systems?
18. What is your understanding of HIV?
APPENDIX D
(MREC APPROVAL)
To: Mrs. Veronica Khuto  
Department of Clinical Psychology  
P.O. Box 110  
University of Limpopo  
MEDUNSA  
0204

Date: 15 October 2013

PERMISSION TO CONDUCT RESEARCH

The Dr. George Mukhari Hospital hereby grants you permission to conduct research on "An investigation into the experience and challenges of adolescents who are vertically infected with HIV and on treatment at Dr. George Mukhari Academic Hospital."

This permission is granted subject to the following conditions:

☐ That you obtain Ethical Clearance from the Human Research Ethics Committee of the relevant University.

☐ That the Hospital incurs no cost in the course of your research.

☐ That access to the staff and patients at the Dr. George Mukhari Hospital will not interrupt the daily provision of services.

☐ That prior to conducting the research you will liaise with the supervisors of the relevant sections to introduce yourself (with this letter) and to make arrangements with them in a manner that is convenient to the sections.

Yours sincerely,

[Signature]

DR. P. SHEMBE
DIRECTOR: CLINICAL SERVICES
UNIVERSITY OF LIMPOPO
Medunsa Campus

MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 09/2013
PROJECT NUMBER: MREC/M/293/2013: PG
PROJECT:

Title: An investigation into the experiences and challenges of adolescents who are vertically infected with HIV and on treatment at Dr George Mukhari Academic Hospital

Researcher: Mrs V Khuto
Supervisor: Ms K Thobejane
Hospital Superintendent: Dr MC Holm
Department: Psychiatry, Clinical Psychology & Psychology
School: Medicine
Degree: MSc Clinical Psychology

DECISION OF THE COMMITTEE:
MREC approved the project.

DATE: 07 November 2013

PROF GA OGUNBANJO
CHAIRPERSON-MREC

The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an International Organisation (ORG20064319), as an Institutional Review Board (IRB00005122), and functions under a Federal Wide Assurance (FWA00009419)

Expiry date: 11 October 2016

Note:
(i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
(ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.
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DECLARATION

I, ______________________________________, with student number: 200603342 declare that the submitted work on ______________________ is my own work and that I have not used any other source than the permitted reference sources or materials nor engaged in any plagiarism. All references duly acknowledged by means of complete references. I further declare that the work has not been submitted for the purpose of academic examination, either in its original or similar form, anywhere else.

Signed: ______________________

Date: ______________________
DEDICATION

This dissertation is dedicated to my late great grandmother, Mrs Elizabeth Raesetja Mashabela, and my late brother, Solomon Maboyane Malatji. I dedicate this research to those adolescents who were vertically transmitted with HIV, especially those who participated in this study. Although it might be difficult living with a chronic illness, HIV/AIDS, I hope that psychologists might assist you in installing hope and impacting your lives positively.
ACKNOWLEDGMENTS

The journey of studying towards master’s degree was challenging both academically and personally. Although it was challenging, I’m grateful to the experience this journey has afforded me as it was also fruitful.

I’m grateful to being given every form of assistance during this journey. The assistance has motivated and helped me go through the process of completing this degree. Based on this, I’m expressing my deepest gratitude and appreciation towards everyone who assisted me.

Firstly, I would like to thank the Almighty God of S.T. Engenas for His grace, mercy and protection throughout this degree, as well as spiritual support from the congregation.

It was one of my goals to fulfill my late great grandmother’s, Elizabeth Raesetja Mashabela, wish. Her wish was to move-out of poverty with our family by being educated. Hence, I thank my great grandmother for her words of wisdom.

As I was on the journey of completing my master’s degree, I experienced a tremendous loss with the passing of loving late brother Solomon Maboyane Malatji. I am grateful to have shared my life and my studies with him. He encouraged and supported me. I will always cherish, love, and remember you ‘Nko’ ‘Kwashu!’

I’m grateful for the support my loving husband, Oupa Morwakoma Khuto, ‘Waka’, gave. I really appreciate your compassion, empathy, unconditional regard, and warmth: you are my pillar.

I wish to extend my deepest gratitude to my three loving sons Phaahla, Malope, and Hlabirwa. Every time when I was overwhelmed, you always comforted me and uplifted my spirit and you gave me a sense of hope. Furthermore, I give thanks to my mother-in-law, Maria Ramatsimela Matabane, for taking care of my sons when I was busy with my studies.

I do sincerely thank my family for the support and encouragement; my parents, Motsuadi and Motlalekgomo, and my brothers Enock and Julius. Without your effort, love and support, I
would not be where I am. A special acknowledgment to my mother, Motsuadi Malatji, who even left her home and lived with me at Medunsa City while I was completing this research. I love you mom, ‘Motsuadi A Mphela A Ngweka A Moraswi!’

My supervisor, Ms Kgadi Thobejane, for continuous professional guidance and support: I thank you! In addition, I would like to thank Malete for her assistance and support through this journey of research.

I would like to thank my colleagues, Steven Mangena, Brian Pieterson, Handrina Radebe and Phindile Sibisi for the support and sharing our experiences of becoming clinicians. I would also like to give thanks to my friends, Dineo Mashego, Maletjima Modise and Tsiri Theo, for their encouragement and support.
ABSTRACT

This study aims to explore the experiences and challenges of adolescents who were vertically infected with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital. A qualitative research methodology was used, using semi-structured interviews to collect data. Eleven participants were purposively sampled. Content analysis was used to make meaning and extract themes from the participants’ experiences.

The results indicate that participants are exposed to experiences and challenges that may result in physical and psychosocial difficulties prior, during and after HIV disclosure. Furthermore, numerous participants are not receiving any psychosocial support putting them at risk of social isolation, stigmatisation and self-doubt, as well as difficulties in developing identity and unable to reach formal operational thinking. Based on the current study results, the stage of adolescence is a period where individuals are faced with numerous developmental challenges; yet having to cope with HIV/AIDS while going through this developmental crisis of adolescence can have a huge impact on the adolescent’s well-being. Furthermore, adolescents who were vertically infected with HIV are negatively affected by HIV as this leads to physical and psychosocial challenges. In addition, these adolescents need tailor-made multidisciplinary treatment in hospitals and clinics. In South Africa there is lack of and/or limitation of such treatments tailor-made for adolescents. Despite the light shed by the experiences of vertically HIV-infected adolescents, the results of this study cannot be generalised to a larger population. Therefore, a study with larger sample is recommended.

Keywords: Adolescence, Vertically infected, HIV, Challenges, Psychological, Social difficulties.
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According to Karim and Karim (2010), the human immunodeficiency virus (HIV) affects the human immune system. In South Africa, HIV was first discovered in 1983 (Wexler, 2013). Since then, the disease has spread rapidly resulting in a pandemic that has impacted every country in the world, affecting young, old, rich, poor, educated, uneducated, female, and male. Approximately 90% of all HIV-infected children live in Sub-Saharan Africa (Karim & Karim, 2010).

Wittenberg (2009) indicates that HIV infection in children occurs through Mother-to-Child-Transmission (MTCT) as vertical transmission (infection during birth) or after birth through breastfeeding and accounts for a large majority (more than 95%) of HIV infections in children. Other forms of transmission include sexual abuse of children by HIV-infected individuals and blood transfusions (Wittenberg, 2009).

In instances of vertical transmission of HIV, HIV has a direct and indirect impact on both mother and the child’s survival. In an indirect impact to the child, HIV-positive mothers are at an increased risk of death compared with HIV-negative mothers which places their infants at an increased risk of being orphans. Therefore, loss of a caregiver leaves a child confused, especially because the caregiver is often the only stable source of support in the family (Loubser & Müller, 2011).

On the other hand, HIV directly impacts on the physical well-being of the child. A study by Karim and Karim (2010) shows that 60% of HIV-positive infants manifest some symptoms of disease such as growth failure and developmental delay; respiratory system diseases like tuberculosis; neurological system diseases; cardiovascular system diseases; and renal disease. Thus, the medical problems place the infants at an increased risk of being dead. However, with the improvement of antiretroviral (ARV) medication, there has been a decrease in the mortality rates and HIV has transformed from an acute terminal illness into a chronic disease (Foster & Lyall, 2005; Rohlede, Swartz, & Kalichman, 2009; Swanepoel & Louw, 2011). The health of HIV positive adolescents is becoming a critical subject as ARV medications
have significantly increased the chances of HIV-positive children to grow into adolescence and adulthood (Rohlede et al., 2009; Swanepoel & Louw, 2011).

The researcher has conducted a qualitative research study exploring and documenting the subjective lived experiences of adolescents receiving treatment at Dr George Mukhari Academic Hospital in Garankuwa, Gauteng Province. These adolescents were infected with HIV through vertical transmission. The qualitative research methodology of this study is comprehensively explained in chapter three of this research report. The research articulates a contextualised understanding of the experiences and challenges of adolescents infected with the human immunodeficiency virus (HIV). Furthermore, the research aims to explore the experiences and challenges of adolescents living with HIV, thus understanding how psychology as a discipline can better incorporate considerations of psychological treatment and preventative measures. The current chapter (chapter One) then introduces the reader to this study through discussing background to the research problem relating to adolescents who were perinatally infected with HIV, the problem statement, as well as giving an overview of the chapters contained in this study.

1.1 BACKGROUND OF THE RESEARCH PROBLEM

Adolescents living with HIV are exposed to experiences, thoughts, and challenges which may result in physical, psychological and social difficulties. A study conducted by Tanney, Naar-king, and MacDonnel (2011) found that adolescents diagnosed with HIV and being exposed to stigmatisation are prone to develop depression.

This is further supported by research conducted by Gadow, Chernoff, Williams, Brouwers, Morse, Heston, Hodge, …, (2010) who found that HIV-positive adolescents experience limited social support, loss of family members as a result of HIV/AIDS, and are at a risk of developing behavioural and emotional disturbance. The experience of traumatic events and HIV-related stigmatisation has a direct contributory effect on depression among children affected with HIV/AIDS. Literature suggests that trusting relationships together with future orientation and perceived social support mediates positive outcomes of traumatic events and HIV-related stigmatisation (Wang, Li, Barnett, Zhao, Zhao & Stanton, 2012).

Fair, Connor, Albright, Wise, and Jones (2012) highlight the importance of supportive group (such as Youth Camps and Youth Support group) in the treatment of HIV-positive
individuals. Furthermore, this type of intervention has a positive impact on individual growth and decrease isolation in adolescents living with HIV. In addition, Fawzi, Eustache, Oswald, Louis, Surkan, Scanlan, Hook, …, (2012) found that psychosocial support groups reduced the psychological symptoms, psychosocial difficulties, isolation and HIV-related stigma on HIV-positive adolescents. Furthermore, these types of intervention have shown positive changes in the adolescents support networks.

The aim of this study is to explore and document the subjective lived experiences of adolescents who were infected with HIV through vertical transmission and are now receiving treatment at Dr George Mukhari Academic Hospital.

1.2. PROBLEM STATEMENT

Over the past few decades, the field of psychology has evolved from focusing on the individual to understanding the importance of additional contributing factors to mental health. This paradigm shift includes acknowledging the importance of health psychology as a subspecialty of psychology which is aimed at promoting and maintaining health, while also preventing and treating illnesses (Gurung, 2010). Health psychologists incorporate a biopsychosocial approach with a specific focus on the importance of a biological constituent of health. Furthermore, this approach acknowledges the psychology of health, which is understood through exploring thoughts, feelings and behaviours, as well as the influence of society and culture on health. In addition, this approach can be used in promoting the health of individuals who are HIV infected (Gurung, 2010). For this study, the focus is on the individuals who are in adolescence stage and are vertically infected with HIV.

Adolescence is a developmental stage from the age of 12 years characterised by the transition from childhood to adulthood, the adolescent begins a process of establishing his/her identity as an individual with a sense of belonging to a certain group of individuals (Nolen-Hoeksema, Fredrickson, Loftus & Wagenaar, 2009). An HIV positive adolescent may be at an increased risk of experiencing anxiety, hopelessness, helplessness, shame and suicidal ideation (Gurung, 2010). These experiences may be linked to disclosure and nondisclosure of their HIV status. Chaudoir, Fisher and Simoni (2011) highlight the potential risks of disclosing ones HIV status. This may increase the risk of stigmatisation, social isolation, physical harm and social discrimination. Thus, the health of an individual is the end results of variables
including biological characteristics, behavioural factors, and social factors (Marks, Murray, Evans, Willig, Wooddall, & Sykes, 2006).

A biopsychosocial approach to disease control, more specifically HIV, can be effective in managing and treating adolescents who were infected with HIV through vertical transmission. This approach suggests multiple interventions with specific focus placed on the biological, psychological and social factors contributing to disease management (Mark, et al., 2006). The researcher has identified limitations to the treatment which is tailor made for HIV-positive adolescents at Dr George Mukhari Academic Hospital. The researcher has identified a need for psychological intervention and management of HIV-positive individuals at this facility. Thus, the study aims to understand and explore the experiences and challenges of HIV-positive adolescents. The researcher aims to use this knowledge to improve and promote the importance of psychological interventions when treating and managing HIV-positive adolescents.

1.3. RATIONALE OF THE STUDY

The study results will inform healthcare providers about the experiences, challenges of HIV-positive adolescents and provide information on the current systems of HIV-positive adolescents at Dr George Mukhari Academic Hospital. Furthermore, the study results will generate debate around the importance of psychological interventions at tertiary hospitals in South Africa. The findings will also assist the healthcare providers with information to improve mental health of adolescents who are vertically infected with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital.

1.4. AIM AND OBJECTIVES

1.4.1. AIM OF THE STUDY

The aim of the study is to explore the experiences and challenges of adolescents who were infected with HIV through vertically transmission and are currently undergoing treatment at Dr George Mukhari Academic Hospital in Garankuwa, Gauteng Province.

1.4.2. OBJECTIVES OF THE STUDY

The research objectives are:

- To gain insight into the experiences and challenges faced by adolescents who were infected with HIV through vertical transmission.
• To explore the current coping resources given to adolescents who were infected with HIV through vertical transmission.

• To stimulate future research and generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

1.5. OVERVIEW OF METHODOLOGY
The methodological approach to an exploratory research design will be used to address the research question. The research seeks to explore and document the subjective lived experiences of adolescents who were infected with HIV through vertical transmission and are receiving treatment at Dr George Mukhari Academic Hospital. This was reached through adopting qualitative research method. This research method allows for a well-organized analysis of personal meaning, attached to the context of an individual’s social environment (Polgar & Thomas, 2008). Personal meaning is understood within the context of an individual’s subjective observation and the meanings attached to these experiences, actions and social environments (Punch, 2014).

The researcher used purposive sampling. This subtype of non-probability sampling is a technique in which the research participants are selected based on the researcher’s clinical judgement. This is based on the characteristics identified within the sample population (Polonsky & Waller, 2011; Punch, 2014). The sample frame was generated through the distribution of an information hand-out (Appendix C) requesting the nurse-in-charge of the Paediatric Clinic to identify, approach and refer possible candidates who meet to the inclusion criteria of the study. A mental healthcare practitioner informed possible research candidates about the role and aims of the research, allowing participants to agree to participation in the proposed research by completing and signing the consent form (Appendix A).

The study aims to explore and document the experiences of HIV-positive adolescents, aged between 15 and 18 years. The sample frame was taken from individuals attending the outpatient Paediatric clinic at Dr George Academic Mukhari Hospital. The sample size consists of 11 participants. As part of the inclusion criteria, only participants who have been
infected with HIV through vertical transmission at birth were considered for the research. Participants and their parents who are unwilling or unable to provide written assent/consent were excluded in the study. No preference towards gender, race, and/or ethnicity was given. The participants must be willing to participate in the study. All interviews were conducted in English and/or Setswana which are the dominating languages used in Dr George Mukhari Academic hospital.

1.6 DEFINITION OF KEY CONCEPTS

1.6.1. Adolescence
Adolescence is the developmental stage between childhood and adulthood (Louw, Ede, & Louw, 1998). This life stage begins at ages between 11 and 13 years; the stage may vary between individuals (Papalia, Olds & Feldman, 2006; Jansen, Moeletsa, Neves, Soudien, Stroud, Swart, & Wild, 2012; Leifer & Fleck, 2013), and ends at the ages of 17 to 21 years (Jansen et al. 2012; Leifer & Fleck, 2013).

1.6.2. HIV
Human Immunodeficiency Virus (HIV) is a retrovirus that destroys the CD4 (which is a type of white blood cell that fights infection) of the immune system, leaving the body vulnerable to life-threatening infections (Evian, 2011; Van Dyke, 2012; Wexler, 2013).

1.6.3. HIV-positive
A person is HIV positive when the HIV antibodies are detected in his or her blood indicating that the person is infected with the virus (Evian, 2011; Van Dyke, 2012; Wexler, 2013).

1.6.4. AIDS
Acquired Immune Deficiency Syndrome (AIDS) is a group of different diseases resulting from a breakdown in the body’s immune system. This is not just one disease but it presents itself as a number of diseases that come about as the immune system fails. Hence, it is regarded as a syndrome (Evian, 2011; Van Dyke, 2012; Wexler, 2013).

1.6.5. Perinatally infection of HIV
Perinatally infection of HIV is the contraction of HIV from Mother-To-Child-Transmission at birth and through breastfeeding (Evian, 2011; Van Dyke, 2012; Wexler, 2013). Perinatal
infection is also referred as vertical infection, therefore in this study the two words will be used interchangeably.

1.7. CHAPTER OVERVIEW
This section provides the reader with a brief outline of the chapters that follow and what they cover:

- Chapter one provided an introduction to the study and aimed at orientating the reader to the study.

- Chapter two presents a review of the relevant literature on the study topic. It is divided into two parts: part one focuses on adolescence and its theories, and part two focuses on adolescents who are vertically transmitted with HIV.

- Chapter three outlines the research methodology. The researcher discusses the design and method used in the study.

- In Chapter four the research results will be presented by using main themes and subthemes.

- Chapter five will detail a discussion of the results will be integrated with literature review of chapter 2, and provide a conclusion and recommendations drawn from the study’s findings.
CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION
The aim of the study is to explore the experiences and challenges of adolescents who were vertically infected with HIV. This literature review chapter is divided into two parts. The first part, section 2.2, focuses on how adolescence is defined based on the literature. The discussion also looks at the physical changes associated with adolescence and challenges associated with this stage. Furthermore, and a theoretical perspective on adolescents and the developmental tasks faced by adolescents are discussed. The second part, section 2.3, of the literature review will take a closer look at the experiences of adolescents who were vertically infected with HIV.

2.2. THE CONCEPT OF ADOLESCENCE
This part focuses on how adolescence is defined based on the literature. The stage of adolescence, physical changes associated with adolescence and the psychosocial changes of adolescence are discussed in this section. Likewise, the developmental tasks acquired by adolescents while moving through multiple changes and challenges are also discussed in this section. Lastly, conceptual framework of the study will be discussed.

2.2.1. Defining Adolescence
Human beings go through many developmental stages as they grow from birth until old age. As previously defined in chapter one, adolescence, which is the focus of this study, is defined as the transitory stage or junction between childhood and adulthood. Many authors (Jaffe, 1998; Jansen, et al., 2012; Leifer & Fleck, 2013) have indicated that the concept of adolescence comes from the Latin word *adolesere* which is a process where an individual grows up and matures. This life stage begins with the onset of puberty that typically starts between the ages of 11–13 years but may vary between individuals (Papalia, et al., 2006; Jansen et al., 2012; Leifer & Fleck, 2013), and ends when an individual enters adulthood between the ages of 17 and 21 years with the adoption of roles such as marriage (Jansen et al., 2012; Leifer & Fleck, 2013). In addition, this stage is characterised by multiple physical, cognitive, and psychosocial changes (Papalia et al., 2006; Jansen et al, 2012; Leifer & Fleck,
2013). Talwar, Sharma, and Kapur (2009) add that the multiple changes may differ significantly in onset, duration, and tempo between and within individuals and populations. Some authors (Jaffe, 1998; Beck, 2005; Jansen et al., 2012) have divided the adolescence stage into three sub-stages. According to Beck (2005), the first sub-stage is early adolescence (11–14 years) which is characterised by a change from childhood to adulthood and is related with the onset of puberty. He also indicates that the second sub-stage is middle adolescence (15–16 years) and is characterised by a change from early to late adolescence as well as psychological, physical and social changes (Beck, 2005). Furthermore, Beck (2005) highlights that the third sub-stage are late adolescence (17–21 years); this stage is characterised by a preparation into adulthood and is marked by a readiness for adulthood and more intensified heterosexual relationships. In addition, Jaffe (1998) divides the sub-stages of adolescence by placing emphasis on school transitions: early adolescence corresponds with the middle school years (11–13 years), middle adolescence corresponds with high school years (14–17 years), and late adolescence corresponds with the college years (18–early 20s).

The stage of adolescence is characterised by multiple changes and challenges; what follows is a discussion on the physical changes.

2.2.2. Physical Changes
The most recognised signs of adolescence stage are physical developmental changes. When children enter the stage of adolescence, most adults would exclaim: “You look like a grown-up.” Such exclamations have stimulated many researchers to focus on the physical developmental changes that occur in adolescence. One of the most prominent physical developmental is puberty (Bukatko, 2008).

2.2.2.1. Puberty
As mentioned above, adolescence is marked by the onset of puberty. Numerous authors (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen et al., 2012) have discussed puberty and defined it as a period that involves biological processes where an individual’s body transitions from reproductive immaturity to maturity, hence the ability to reproduce.
Puberty is firstly recognised by an adolescent’s growth spurt characterised by a rapid increase in physical growth – the height and weight of an adolescent increase at double the rate of the childhood stage (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen, et al., 2012). Jansen et al, (2012) further mention that the adolescent growth-spurt onset varies between girls and boys; in girls, it starts approximately between the ages of 10 and 11 years, and in boys between the ages of 12 and 13 years.

In addition, puberty is characterised by primary and secondary sexual changes. The primary sexual characteristic changes are linked to reproductive organs. The reproductive organs include the ovaries, uterus, and vagina for girls; and the penis, scrotum and testes for boys. In puberty, the primary sexual characteristics mature. This ultimately means that the individual has the ability to reproduce: girls experience menstrual periods and boys experience ejaculation or start to produce sperm. As for the secondary sexual characteristics, they occur on the exterior of the body and are indirectly related to reproduction. Boys experience an increase in pubic, facial, and body hair, an enlargement and darkening in the colour of the scrotum, an increase in penis size, and a deepening and instability of the voice due to a lengthening and thickening the vocal cord. Girls experience the appearance pubic and body hair, an enlargement of the breasts, and the deposition of fat in hips and thighs (Jaffe, 1998; Papalia et al, 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen et al., 2012).

All of the mentioned changes experienced during puberty are influenced by hormonal changes (Jaffe, 1998; Papalia et al, 2006; Bukatko, 2008; Jansen et al., 2012). In boys, a hormone, gonadotropin-releasing hormone (GnRH), is secreted from the hypothalamus of the brain. This hormone is responsible for stimulating the anterior pituitary gland to secrete gonadotropins, the follicle-stimulating hormone (FSH) and the luteinizing hormone (LH). The LH produces testosterone, which further produces sperm (Jaffe, 1998; Papalia et al, 2006; Jansen et al., 2012). In girls, the production of oestrogen and progesterone by ovaries regulates the menstrual cycle; these hormones also stimulate the development of secondary sexual characteristics (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008).

In a nutshell, puberty includes physiological changes that are complex and unique and adolescents may experience a variety of reactions and feelings towards such changes (Hajikhani Golchin, Hamzehgardeshin, Fakhri, & Hamzehgardeshin, 2012). In a study conducted in Sari of Iran by Hajikhani Golchin, et al, (2012), the researchers found that there
was a distinct difference in perceptions of experience from girls who had an early onset of puberty and those who had a late onset of puberty. The study found that girls who had an early onset of puberty perceived puberty as an unpleasant process, that they associated with feelings of hatred, fear, shame, surprise, and a sense of sickness. However, the girls who reached puberty late experienced feelings of relief from their worries. In addition, Hajikhani Golchin et al, (2012) found that girls in adolescence generally viewed bodily changes as a source of confusion and pressure, and they associated this stage with feelings of sorrow, impatience, shyness, nervousness, shame and sensitivity.

2.2.2.2. Brain Development

During the adolescence stage, the brain experiences two major changes. The first major change, which occurs in the cerebral cortex, is a decrease in the weaker synaptic connections through the process of pruning. The second one is an increase in myelination and a reorganization of synapses in the frontal and prefrontal cortex. Consequently, this impacts the functioning of the brain and the adolescent’s behaviour (Steinberg, 2005; Bukatko, 2008; Luna, 2009; Jansen et al., 2012).

There are two domains that mature within the functioning of the brain. The first domain is a modification of the executive control and the achievement of a more conscious, self-directed and self-regulatory minds (Steinburg, 2005; Kuhn, 2006; Luna 2009). The second domain is the maturity of executive functioning (EF) processes, which includes response planning, improved processing speed, cognitive flexibility, and rule-guided behaviour (Kuhn, 2006; Luna, 2009). This results in improvements in memory, language, processing speed, attention and concentration (Kail & Ferrer, 2007). Furthermore, Zarrett and Eccles (2006) mention that the development of the brain may enable the adolescent to acquire some developmental tasks (to be explained later), as well as an acute ability to deal with challenges, form an identity and to develop their sense of morality. Papallia et al. (2006) mention that although the prefrontal cortex (responsible for planning and decision-making) develops in adolescence, it is not yet fully mature compared to the amygdala (responsible for emotions). Consequently, adolescents are more prone to risky behaviours and psychological disorders, as well as an inability to control strong emotional impulses.

In addition, the brain changes in adolescence stage will impact on the cognitive function. According to Piaget (cited in Bukatko, 2008) theorises that cognitive development involves
reorganisation at different life stages of development. The highest level of cognitive
development, referred to as formal operational thinking, is in adolescence (Bukatko, 2008;
Leifer & Fleck, 2013). Formal operators have the ability to think logically about hypothetical
processes and scenarios that may occur in reality (Shaffer & Kipp, 2010). Furthermore,
Piaget reports that hypothetically thinking adolescents have the ability to plan for the future
and predict the possible consequences of present actions (Van Dyke, 2012). Thus, adolescents
have the ability to reason abstractly and hypothetically, understand symbols, and are future-orientated (Bukatko, 2008; Leifer & Fleck, 2013). Piaget also reports that formal operators have the skill of deductive and inductive reasoning. Deductive reasoning as the
ability to reason from general to specific, while inductive reasoning is the ability to reason
from specific to general (Bukatko, 2008; Shaffer & Kipp, 2010; Leifer & Fleck, 2013). Thus,
formal operational thinkers have the ability to reason in an organised way to create ideas and
hypothetical concepts, test the hypotheses, eliminate falsities and conclude (Papalia et al.,
2012; Shaffer & Kipp, 2010). He called this process the hypothetico-deductive reasoning.
The process is also called scientific thinking. However, formal operational thinking may not
be reached by all adolescents, as others may operate as concrete operational thinkers in their
adolescence stage (Leifer & Fleck, 2013).

Thus, individuals are in the adolescence stage experience multiple physical changes and
challenges which might impact their psychosocial changes (Beck, 2005). These psychosocial
changes are discussed next.

2.2.3 Psychosocial Challenges
According to Levine, Carey and Croker (cited in Laughton, Cornell, Boivin, & Van Rie,
2013), adolescents experience challenges in developing an identity and independence, as well
as considering the future. This can be maintained through social interactions, including
family relationships and peer relationships (Zarrett & Eccles, 2006; Laughton et al., 2013).
According to the social ecological framework (cited in Mburu, Ram, Oxenham,
Haamujompa, Lorpenta, & Ferguson, 2014), it is believed that adolescents’ development is
impacted by their circumstances, which depend on the following factors:

2.2.3.1 Family Relationships
According to the family systems model (Jaffe, 1998), change in one of the family members
will impact on the whole family system. Individuals who go through adolescence experience
major changes in their lives that will impact on the whole family. This is evident in the adolescents developing their own identity, having an increased sense of independence and autonomy. Consequently, the family must create a space that accommodates the changes experienced by the adolescents, especially changes in the parent-adolescent relationship (Jaffe, 1998). In addition, Zarrett and Eccles (2006) highlight that, on one hand, a family functions as a primary support system for adolescents and a safe context for adolescents to successfully develop, while on the other hand, a lack of support from family may create a high risk of failure in the adolescent. Over and above this, a study conducted in South Africa by Brook et al, (cited in Fatusi & Hindin, 2010) found that a young girl who experiences poverty, low employment levels, and lack of social support may end up being involved in sex work to sustain herself.

Similarly, a study conducted in the USA by Elkington, Bauermeister and Zimmerman (2011) found that, adolescents who are raised in families characterised by conflict, substance abuse or abuse by parents, and negligent and unsupportive family relationships may be at a high risk of developing risky behaviours, including substance abuse and unsafe sexual behaviours; while, adolescents who are raised by families characterised by close and supportive family relationships and parental involvement may be at a lower risk of developing risky behaviours. Furthermore, a study conducted by Boislard and Poulin (2011) found that adolescents raised in families with long-distance relationships and without parental supervision are more likely to spend more time outside their families, develop multiple sexual partners and utilize their peers as social agents.

### 2.2.3.2 Parent-Adolescent Relationship

During adolescence, there is a decline in the relational closeness in the parent-adolescent bond due to the decrease in time spent together. Early adolescents spend time being alone – in their rooms, using phones, watching television, or with their peers (Cobb, 2010; Jansen et al., 2012). Thus, shared activities and physical affection in parent-adolescent relationships decrease and there is an increased need of privacy from adolescents (Scharf & Mayseless, 2007). In addition, Cobb (2010) reports that adolescents start to keep secrets from their parents, especially with issues involving sexual orientation. In support of this, Hajikhani Gochin et al., (2012) mention that adolescents felt uncomfortable discussing sexual orientation at home and viewed their parents as lacking knowledge about sexual issues. Similarly, a study conducted in Canada by Boislard and Poullin (2011) found that adolescents
who are able to talk to their parents about sexual intercourse are likely to delay in engaging in sexual activities. This indicates a high communication quality in the parent-adolescent relationship. However, adolescents whose parents are less involved in their lives don’t confide to the parents about sexual intercourse, and they are likely to engage in sexual activity earlier.

Furthermore, Jaffe (1998) mentions that adolescents spend more time with their mothers than with their fathers. This is due to the observation that adolescents experience empathy, openness, acceptance, as well as attention in their relationships with their mothers. While in relationships with their fathers, adolescents experience less acceptance, more demands and less interest and attention (Jaffe, 1998; Jansen et al., 2012).

According to Cobb (2010), the perceptions of adolescents towards their parents change. They perceive their parents as less supportive and opposing. Similarly, Bukatko (2008) mentions that the adolescents’ change in perception towards their parents was as a result of their ability to view people as having both strengths and weaknesses and an ability to think in an abstract manner. During the adolescence stage, the parent-adolescent relationship sees an increase in conflict and communication discord (Jansen, et al., 2012; Bukatko, 2008; Hajikhani Golchin et al, 2012; Scharf & Mayseless, 2007). The conflict becomes intense in early adolescence and gradually decreases towards the middle to late adolescence phases (Zarrett & Eccles, 2006; Bukatko, 2008; Jansen et al., 2012; Ogwo, 2013). This is as a result of early adolescents asserting their individuality, practising their independence and forming their own identity (Zarrett & Eccles, 2006; Seiffge-Kernek, Kiuru & Nurmi, 2009; Ogwo, 2013) by challenging their parents’ authority (Zarrett & Eccles, 2006; Cobb, 2010), and renegotiating and rebelling against rules and restrictions of parents (Zarrett & Eccles, 2006; Ogwo, 2013). Parents also find it difficult to adjust to their children’s early adolescence; however, by the middle and late adolescence, the parents have adjusted to an adolescent child and the relationship has returned to normality (Cobb, 2010), because the adolescents have now acquired emotional maturity, reduced egocentrism, and they acknowledge their parents (Ogwo, 2013).

Moreover, Hajikhani Golchin et al., (2012) point out that the conflict may result from the following: parents having difficulty in recognising adolescents’ concerns; adolescents attempting to establish independence; adolescents lacking trust in the family; adolescents
disagreeing with their parents’ views; adolescents experiencing confusion about their family roles; and parents attempting to control adolescents’ personal choices such as clothes, friends and subjects to study. However, Scharf and Mayseless (2007) note that the conflicts in parent-adolescent relationships may create a platform for adolescents to improve their negotiation skills, solve interpersonal problems, acquire individualism, and be responsible. Scharf and Mayseless (2007) further note that through conflict in parent-adolescent relationships, adolescents attempt to acquire autonomy and parents are strive to detach and accept the independence of their adolescents. Conversely, a study conducted in Spain by Orejudo, Puyuelo, Fernandez-Turrado and Ramos (2012) found a correlation between adolescent-parent relationships and optimism, in that adolescents who are continuously involved in conflict with their parents may develop a sense of pessimism that may result in less support, preference of unhealthy attachment styles, or a focus on relationships that are more disciplinary and authoritative in style.

The changes mentioned above about the parent-adolescent relationship depend on the kind of attachment formed in that relationship. To emphasise this, Bukatko (2008) highlights that secure attachment creates more closeness and connection in parent-adolescent relationships. Similarly, Jansen et al., (2012) note that secure attachment allows adolescents to have confidence in creating and exploring new relationships outside the family. In addition, Dykas and Cassidy (2007) mention that adolescents who have secure attachment have the ability to be more open in processing social information than adolescents with insecure attachment. Furthermore, Pace and Zappulla (2011) mention that insecure attachment in adolescents may result in externalised problems such as oppositional defiance and substance abuse. Therefore, parents still remain a social and emotional support for their adolescents, and they influence the decisions made by their adolescents (Bukatko, 2008; Jaffe, 1998).

To this end, Scharf and Mayseless (2007) mention that adolescents still have the need for close and warmth parent-adolescent relationships, as well as the need for confirmation and guidance when attempting to solve problems. This is further supported by a study conducted in Germany by Seiffge-Kerena, et al. (2009), which found that adolescents are highly stressed by and concerned with the conflict in the parent-adolescent relationships. Similarly, a study conducted in the United Kingdom by Shelton and Van den Bree (2010) found that the quality of the parent-adolescent relationship correlated with the use of cigarette and alcohol, concluding that this was due to emotional distance and a lack of support in the parent-
adolescent relationships. The adolescents within such relationship structures are at a high risk of using drugs and alcohol as a coping mechanism. Furthermore, Zarrett & Eccles (2006) mention that a lack of support and continuous unresolved conflicts in parent-adolescent relationships may increase the risk of adolescents engaging in drug and alcohol abuse, school drop-outs, violence, sexual intercourse and gang-related behaviours.

In addition, the Centre for Disease Control and Prevention (Thornberry, Matsuda, Greenman, Augustyn, Henry, & Ireland, 2014) defines maltreatment as any behaviour of omission or commission by a parent or a caregiver that has an end product of harm, or potential to harm, which threatens the child or adolescent. This behaviour may be physical abuse, sexual abuse, psychological abuse, and/or neglect. Yates and Weckerle (2009) found that maltreatment may impact on the adolescent’s emotional well-being; thus, eliciting a depressive response, withdrawal, disengagement, anxiety and decreased self-efficacy in adolescents. Similarly, a study conducted by Gren-Landell, Aho, Andersson and Svedin (2011) in Sweden found that adolescents who experienced victimisation from their parents and the community and maltreatment from parents may develop an enormous fear of negative feedback in social interactions and evaluations of performance that may escalate to behaviours of avoidance and impairment, called social anxiety disorder. The relationship between victimisation, maltreatment and social anxiety disorder is further explained by Gren-Landell et al., (2009), who state that when adolescents experience victimisation and maltreatment, they develop symptoms of a sense of helplessness and anxiety towards stressful events. They, adolescents, believe that they are different and are being perceived as less attractive by others; and they view the world as unsafe. These symptoms may lead to the development or maintenance of a social anxiety disorder. In addition, a study by Melander, Hartshorn and Whitbeck (2013) revealed that adolescents raised in families where bullying exists, developed feelings of anger, had poor relationships with their parents, and had a high risk of transferring the bullying behaviour to the school environment where they end up bullying their peers.

2.2.3.3. Peer Relationships

As mentioned earlier, adolescents spend less time with their parents than they do being outside. In the outside context, peers serve as the main focus for socialisation. Therefore, when adolescents are faced with challenges of increasing autonomy and independence, their peers provide emotional and social support, and they share social skills. Thus, peers reward each other, accept each other and create popularity and status (Cobb, 2010). Similarly,
adolescents establish friendships and groups for the purpose of emotional support and exploration of values, as well as to fulfil their need for the formation of identity and belonging, building self-esteem and access to information (Jansen et al., 2012; Zarrett & Eccles, 2006). In addition, groups shape and influence the behaviour of adolescents (Jansen et al., 2012). However, Bukatko reported the group influence depends on how the adolescent identifies with and values the group. This is further explained by Elkington et al., (2011), who conducted a study in the USA that found that group norms are very important. For instance, peer groups that support activities such as drug abuse and unprotected sexual intercourse may lead to the adolescents belonging to those groups and developing such risky behaviours. On the other hand, peer groups with norms that include supportive relationships, pro-social behaviours, condom use and safe sex may lead to its member adolescents developing similar behaviours (Elkington et al., 2011).

Furthermore, Boislard and Poullin (2011) found that peer groups which are made up of mixed-gender members are more likely to have adolescents develop sexual partners within the group. As the adolescents grow older, their interest in peer groups decrease and they spend more time in romantic relationships and with close friends (Bukatko, 2008; Jansen et al., 2012); this contributes to the development of a sense of competence (Zarrett & Eccles, 2006). Furthermore, Canvanagh (2011) conducted a study and found that adolescents who experience early onset of puberty may perceive themselves as sexual and romantic actors; this may determine the types of relationships they are involved in during adolescence and can have long-term consequences. A study conducted by Phillips and Malcolm (2010) found that adolescents may experience violence in their peer-sex interactions, which may result in depression, alcohol abuse, anxiety, suicidal behaviours, sexually transmitted diseases, unwanted pregnancies and sexual dysfunction. The study also found that early exposure to violent sex-peer relationships may impact on the future romantic adult relationships.

In addition, Parker, Rubin, Erath, Wojslawowicz and Buskirk (2006) highlight that early adolescents form peer groups that require social skills in order to be handled effectively. Flanagan, Erath, and Bierma (2008) found a high correlation between social anxiety, peer nominations and victimisation as individuals with high levels of maladjustment behaviour (for example, ineffective social skills, low self-esteem and social withdrawal) may have higher levels of social anxiety. This is further supported by Grills and Ollendick (2002), who mention that adolescents with ineffective social skills and maladjustment social behaviours
are victimised, harassed and rejected by other peers. This may impact on the mental functioning of those adolescents with ineffective social skills in that they may have negative self-perceptions that damage their sense of self and their social world. This may in turn create social anxiety and a continuation of maladaptive appraisals.

Similarly, Orejude et al., (2011) found that positive relationships with peers may create a sense of optimism, while negative relationships may create a sense of pessimism. This is further supported by Jonkmann, Trautwein and Ludtke (2009), who found that adolescents who effectively adjust in peer relationships are likely to experience peer acceptance and dominance, which may positively affect both their social self-esteem and academic self-esteem. However, Savin-Williams and Berndt (cited in Zarrett & Eccles, 2006) report that in early adolescence, individuals who experience peer acceptance spend more time engaging in peer activities, may be unable to handle peer pressure, which negatively impacts on their academic performance and creates behavioural problems.

Furthermore, during adolescence, individuals start to develop sexual thoughts and feelings and experiment with love and sexual intercourse with their peers (Giannotta, Ciaranon, & Spruijt-Metz, 2009; Maccoby, cited in Boislard & Poullin, 2011) resulting in positive (Giannotta et al., 2009) and negative (Giannotta et al., 2009; Boislard and Poullin, 2011) consequences. In terms of positive consequences, adolescents start acquiring skills of creating and maintaining intimate, romantic and sexual relationships, which is one of the developmental tasks of adulthood (Giannotta et al., 2009). Whereas in terms of the negative consequences, especially in early and middle adolescence, adolescents are still cognitively and emotionally developing and lack inadequate abilities to engage in romantic relationships. This may impact negatively on their psychological functioning, leading to teenage pregnancy and sexually transmitted infections including HIV (Giannotta et al., 2009; Boislard and Poullin, 2011). Furthermore, Giannotta et al., (2009) conducted a study in Italy, in which they found that adolescent behaviours are motivated by variables other than love. Those variables are imitation of peers, called social meaning, including peer pressure (for example, having sex because other teenagers have or had sex, and/or to prove that they can also have sex), and being involved in sexual intercourse for coping with needs, called personal meaning.

Pellegrini (cited in Pepler, Jiang, Craig & Connolly, 2008) describes bullying as an aggressive behaviour that is used as power to obtain dominance, status and control over
others within the group. Furthermore, Pepler et al. (2008) mentions that adolescents who are continuously exposed to bullying become trapped in being victimised and become increasingly helpless. On the other hand, the adolescents who bully their peers have learned the behaviour from their social context, especially from families in which the adolescents experience physical abuse (direct or indirect), lack of close relationships, and a lack of supervision in adolescence. This is further supported by Siyahhan, Aricak and Cayirdag-Acar (2012), who found that girls are likely to experience verbal bullying, whereas boys are likely to experience both verbal and physical bullying. Boys who experience both verbal and physical bullying may develop symptoms of depression, a sense of hopelessness, and suicidal thoughts. Furthermore, the study found that parents and teachers are more likely to intervene in physical bullying rather than verbal bullying.

2.2.3.4. School Context and scholastic achievements

Libbey (cited in Melaughlin & Clarke, 2010) highlights that the school context is very important in the adolescence stage. The school context creates a space where adolescents are able to develop social and cognitive functioning, which enables them to have interpersonal relationships in order to acquire social identities and a sense of belonging (Wentzel, cited in Jonkmann et al., 2009) According to Lester, Waters & Cross (2013), during the adolescence stage, the individuals transit from primary to secondary school. The transition from primary to secondary school is supported by Piaget theory of cognitive development from different life stages. As previously mentioned, according to Piaget (cited in Bukatko, 2008) theorises that cognitive development involves reorganisation at different life stages of development. He also focuses on the cognitive milestones of development and describes the following four stages of development, in relation to learning to understand and relate logically to the world (Leifer & Fleck, 2013):

<table>
<thead>
<tr>
<th>Stages</th>
<th>Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sensorimotor intelligence</td>
<td>Birth to two years</td>
</tr>
<tr>
<td>2. Preoperational thought</td>
<td>Two to seven years</td>
</tr>
<tr>
<td>3. Concrete operational thinking</td>
<td>Seven to eleven years</td>
</tr>
<tr>
<td>4. Formal operational thinking</td>
<td>Adolescence</td>
</tr>
</tbody>
</table>

Thus, when an individual enters adolescence stage, he or she shifts from concrete thinking to formal operational thinking (Leifer & Fleck, 2013); the individual will also shift from
primary school to secondary school (Lester, et al., 2013). The shift of the school context is associated with adolescents experiencing a new social environment, where, while primary school is experienced as small intact classes with close relationships and one main teacher, secondary school is experienced as attending many classrooms with different teachers, and classmates changing throughout the day. This may lead to adolescents experiencing a lesser sense of connectedness, which may be associated with depression and anxiety (Lester et al., 2013), poor school performance, school drop-out, risk of early sexual initiation and sexual activities (Fatusi & Hindin, 2010).

In addition the adolescents’ ability to achieve in the school context may lead to a sense of accomplishment and a high self-esteem (Melaughlin & Clarke, 2010). In order to achieve in the school context, adolescents need high self-esteem and effective coping mechanisms to manage and learn in school (Zarrett & Eccles, 2006). Furthermore, Hajikhani Golchin et al. (2012) found that during adolescence, there is a drop in school performance with adolescents reporting feeling discomfort when compared to their peers. The drop in school performance is twofold. The first reason is explained by Simmons and Blyth (cited in Zarrett & Eccles, 2006), who mention that adolescents may be unable to adjust or manage the developmental changes of the adolescence stage. The other reason is explained using the person-environment fit theory (cited in Zarrett & Eccles, 2006), which states that when the adolescent’s changing needs are not met by the school environment, their academic motivation, interest and performance may decline.

Similarly, Barclay and Doll (cited in Melaughlin & Clarke, 2010) mention that failure to adjust to the school context by having effective peer and teacher relationships may impact on the mental functioning of the adolescents, which can be detected through symptoms of depression and anxiety, engaging in disruptive social behaviours and using of drugs as coping mechanisms, as well as dropping out of secondary school. Melaughlin and Clarke (2010) add that adolescents may experience a sense of rejection that may impact on the development of their personal identity. Furthermore, adolescents who drop out of school may not have the platform to explore and experiment what others (who continue with school) are experiencing in the school context (Zarrett & Eccles, 2006). This includes information about health-related matters and certain skills that may contribute to their development (Fatusi & Hindin, 2010), that may help them establish and develop societal norms (Kabiru & Orpinas, 2009).
On the contrary, the school context may create an opportunity for adolescents to explore and practice risky behaviour without the supervision of their parents and caregivers; these risky behaviours include sexual experimentation, substance use, bullying and violence (Fatusi & Hindin, 2010; Kabiru & Orpinas, 2009). In addition, Harel-Fisch, Walsh, Fogel-Grinvald, Amita, Pickett, Molcho, de Matos, Craig, Members of the HBSCA violence & injury prevention focus group (2011) report a correlation between negative experiences in adolescent-teacher relationships and the development of bullying behaviours. This conclusion resulted from the findings that adolescents, who felt ill-treated by and received unfair treatment from their teachers, while also experiencing negative academic achievement, may in turn bully other adolescents either as a way of relieving their frustrations and hurt or as a way of re-establishing a sense of dominance. Therefore, the more the adolescents experienced a sense of belonging, accomplishment, satisfaction, and safety at school, the less is their risk of developing bullying behaviours. Furthermore, a study conducted in the Western Cape of South Africa by Phillips and Malcolm (2010) revealed that when adolescents experience bullying and violence in the school context, the adolescents miss school and feel unsafe while at school.

2.2.3.5. Psychological challenges
Adolescence is a period associated with numerous and rapid physical, cognitive and social changes. Jain, Kumar and Khanna (2013) found that adolescents lack correct information related to the multiple changes associated with adolescence; although, they are aware of the changes. These changes have an impact on the mental functioning of adolescents (Pace & Zappulla, 2011; Jain et al., 2013). For example, Olatundun, Osiki, abd Ajibola (2010) reported that during adolescence, individuals start to act and desire to be treated like adults, including beginning to engage in smoking and drinking, girls wear make-up, both boys and girls shave their body hair, and start dating.

Campas and Wagner (cited in Lanteigne, Flynn, Eastabrook & Hollenstein, 2012) mention that individuals who are in the adolescence stage experience more social stress as compared to other individuals who are in other developmental stages or age groups. This is explained by Eric Erikson (1968), identity versus role confusion, which corresponds with the adolescence stage, will be discussed in detail. According to Erikson (1968), identity is defined as an individual’s awareness and discovery of himself or herself as an independent person with a definite role in society. He further mentions that adolescents have the task of
achieving a feeling of identity. Furthermore, the successful resolution of the identity crisis will promote adolescents’ sense of identity, and decrease role confusion (Louw et al., 1998; Papalia et al., 2012; Leifer & Fleck, 2013). The hypothetical solution to the identity crisis lies in the synthesis of reliability, where the individual establishes self-confidence (Louw et al., 1998; Papalia et al., 2012; Leifer & Fleck, 2013). This means that adolescents must be certain of their identity and also be aware and accept that there are numerous identity choices which they could have chosen (Louw et al., 1998). Failure to resolve this crisis may promote adolescents with identity confusion, a situation in which adolescents may experience a mixed personal identity and become confused about ‘who’ they are, leading to low self-esteem (Jaffe, 1998; Jansen et al., 2012).

This is further supported by Kessler, Chiuwalter and Demler (cited in Gilbert, 2012), who mention that adolescence is a period when most psychopathology such as anxiety, depression, bipolar disorder, eating disorder, as well as alcohol and substance abuse develops. Prasla (2012), together with Vogel (2012), report that numerous adolescents experience depression and anxiety disorder. Prasla (2012) further elaborates on how depression and anxiety may have resulted from changes in adolescence. Regarding physical changes, Prasla (2012) mentions that the adolescents are faced with a task of adjusting to the physical changes, and a failure to adjust may lead to fear and isolation, perpetuating depression and anxiety. In terms of cognitive changes, Prasla (2012) highlights that adolescents acquire the ability to think abstractly and scientifically. This may lead to situations of intense argument in a social context that may in turn lead to emotional frustration, isolation and depression.

Parents’ failure to acknowledge and accommodate the changes in their adolescents may lead to a significant breakdown in parent-adolescent relationships, which may in turn impact on the mental functioning of the adolescents (Prasla, 2012). In addition, Hubib and Labruna (2011) report that most of adolescents are exposed to dangerous situations when they attempt to perform developmental tasks, such as driving cars, being in romantic relationships and substance use or abuse, that are more typical of adults. Stevens, Kiehl, Pearlson and Calhoun (cited in Hubib & Labruna, 2011) explain that this may be as a result of the neurobiological development of adolescents, since adolescents are not fully capable of controlling their impulses, as opposed to adults. This means that although adolescents are aware of the risks of many situations, they usually get involved in situations that have stressful consequences and the potential to harm them. This may lead to the development of post-traumatic stress
disorder (PTSD) (Hubib & Labruna, 2011). Building on the development of psychopathology, Gilbert (2012) reports that the onset of psychopathology may result in emotional dysregulation, which refers to an inability to adapt and modulate responses in order to reach certain goals; an inability to use coping strategies, or an inability to make effective decisions, or solve problems, when faced with situations that may evoke enormous emotions.

Similarly, Alberga, Sigal, Goldfield, Homme and Kenny (2013) found that numerous adolescents use food as a coping mechanism for stress; this may lead to emotional eating and being overweight. The study also found that stress may be caused by a low self-esteem, poor social skills, discrimination, or parental separation and divorce. Furthermore, the study found that stress impacts negatively on the immune system (Alberga et al., 2013).

The study conducted by Natsuaki, Klimes-Dougan, Ge, Shirtcliff, Hastings and Zahn-Waxler (2009) found a significant relationship between the early onset of puberty and symptoms of internalizing problems like depression and anxiety. The study further highlights that the adolescent girls who experience early onset of puberty are more likely to start a relationship with deviant peers and have older sexual partners. This may impact negatively on the parents, who may not acknowledge the relationship and may add to the adolescent internalizing problems. In contrast, Lindfors, Elovaino, Wickman, Vuorinen, Sinkkonen, Dunkel, Raappana, (2007) found a link between the late onset of puberty and the symptoms of internalising problems such as depression and anxiety. The study found that adolescent boys with delayed puberty were psychologically immature and developed inferior egos. Lindfors et al. (2007) further explains this by giving three reasons. The first reason stemming from the social context is where society treats adolescent boys with delayed puberty by looking at their physical appearances instead of their chronological age. This impacts on the psychological development of the boys. The second explanation pertains to the cognitive development, stating that during the puberty stage, there is reorganisation of the brain that is linked to psychological maturity. The third explanation relates to perceptions on sexuality, in that boys with delayed puberty experienced negative feelings towards their sexuality as opposed to boys with average puberty maturity (Lindfors et al., 2007).

Furthermore, a study conducted by Pace and Zappulla (2011) found that attachment may serve as a protective factor against internalising problems. On one hand, adolescents with secure attachment seem to be protected from developing internalised problems and may be
able to adjust to the developmental tasks; while adolescents with insecure attachment are likely to develop internalised problems and may be unable to adjust to the developmental tasks. Thus, adolescents with secure attachment to their parents are less likely to develop depression, anxiety and aggressive behaviours, and also less likely to use banned substances and alcohol as coping mechanisms (Pace & Zappulla, 2011). Similarly, Vogel (2012) conducted a study in the Western Cape of South Africa and found that adolescents who were raised in families with low levels of parental care, high family conflicts, maltreatment, poverty, or chronic illnesses in the family are likely to develop depression and, if left untreated, this may negatively impact on the development of the adolescents.

Therefore, the adolescence stage is characterised by multiple changes and challenges, including physical and psychosocial changes and challenges. In order for adolescents to move through those multiple changes and challenges, they need to acquire developmental tasks, which will be discussed next.

### 2.2.4. Developmental Tasks

According to Louw, et al. (1998), society expects certain characteristics and skills (called developmental tasks) to be reached by an individual at each developmental stage. In addition, Cobb (2010) mentions that adolescents experience numerous physical and psychosocial changes that challenge them to perform new developmental tasks. As mentioned previously, Levine et al. (cited in Laughton, et al., 2013) have mentioned that adolescents experience challenges in developing identity, increasing independence, and considering the future.

This is further supported by Leifer and Fleck (2013), who highlight that each of the three sub-stages of adolescence is characterised by its own challenges.

#### 2.2.4.1 Early Adolescence

According to Leifer and Fleck (2013), in the early adolescence phase, adolescents are faced with numerous challenges: they become conscious of their body image and attempt to adjust to pubertal changes; they develop a sense of denial about reality and the self and have low self-esteem; their behaviour is motivated by rewards; they develop best friends, and engage in hero-worship and have adult crushes; they develop ambivalence towards their family and strive towards independence; they have concrete thinking and focus on the here and now; their main goal is to socialise, and their goals may be impractical (Leifer & Fleck, 2013).
2.2.4.2 Middle Adolescence
Leifer and Fleck (2013) note that in the middle adolescence phase, adolescents are faced with the following challenges: their physical growth changes more in height; they explore various images and appearances; they become impulsive and experience identity confusion; their behaviour is motivated by conformity; they are interested in sexual experimentation; they start dating, are concerned with satisfying significant peers, and they develop a heterosexual peer group; in their family context, they struggle for autonomy and acceptance, and they may rebel against or withdraw from the family and demand privacy; they start to develop abstract thinking, and they experience daydreams and fantasies; their goal is to identify their skills and interests and become a super-achiever, or they drop out of school; they are more interested in experimenting with sex or drugs (Leifer & Fleck, 2013).

2.2.4.3 Late Adolescence
Leifer and Fleck (2013) note that in the late adolescence phase, adolescents are also faced with many challenges: physical growth decreases; they start to accept their body images and their personality develops; they develop a positive concept of the self and become empathetic independent thinkers; they develop responsibility for their behaviour; they develop their own sexual identity and caring relationships; they care and value relationships, and begin to select partners; in their family context, they reach independence and re-establish family relationships; they identify career goals and enter work or tertiary institutions; they make decisions based on their lifestyle choices (Leifer & Fleck, 2013).

In addition, the other developmental task that must be reached is the vocational development. According to Savickas (2002), occupational careers create a space where individuals become involved and meaningfully contribute to the society. These careers lead to a continuous process of validating and confirming an individual’s self-concept or the individual’s picture of him or herself. The life-stage career-development theory (cited in Usinger & Smith, 2010) highlights that career develops from the process where individuals decide and express their self-concept. This process includes social relationships and negotiation of meaning. Thus, career development is derived when the individual constructs a meaning of his or her life experience through social interaction. According to the construction theory (cited in Usinger & Smith, 2010), this process of career development is divided into three stages, namely, life themes, vocational personality, and career adaptation. With regard to the first stage – life themes – the construction theory notes that individuals formulate their ideals of the type of
occupations in which they would like to be involved. Vocational personality involves individual’s career-related abilities, needs, values, and interests – the individual explores his/her abilities, needs, values and interests through exploring his/her ideal occupation. Career adaptability involves a process where individuals validate their self-concept by analysing behaviours and competencies that are required in different occupations and then aligning themselves to those occupations that match the self-concept (Usinger & Smith, 2010).

Adding to the construction theory, Super and Savickas (Ferreira, Santos, Fonsea & Haase, 2007) mention that career development does not occur in a vacuum; it occurs in a social context in which the individual exists, through the process of feedback loops. Super and Savickas (cited in Ferreira, et al., 2007) also mention that individuals may develop a premature career when they drop out of school. On the other hand, Usinger and Smith (2010) found that adolescents who are self-absorbed, detached, angry, or overwhelmed appeared to have low self-esteem towards their internal sense of self, thus impacting on their career development. This is because these adolescents consciously focusing on themselves in the present situation rather than their future selves. The study also found that adolescents who are self-absorbed and angry were pre-occupied with conflicting beliefs; they have beliefs about how others perceive them in relation to beliefs about their moral self, which is a reflection of the ideal self-concept. These conflicting beliefs may result in the adolescent becoming fixated or stuck within their internal conflict. Furthermore, the study found that adolescents who are detached and/or overwhelmed may be withdrawn from the societal expectations, due to either being overwhelmed by personal circumstances or being deliberately withdrawn or disengaged (Usinger & Smith, 2010).

Furthermore, Havighurt (cited in Jaffe, 1998) note that an individual who successfully reaches the developmental tasks in adolescence may develop a sense of accomplishment and successfully move on to the next stage; failure to reach the developmental tasks may result in feelings of unhappiness, rejection by society, and difficulty to move to next developmental stages.

From the above, adolescents experience numerous developmental changes and tasks that needs to be dealt with effectively in order to move to adulthood. The conceptual framework of the study will be discussed in the next section.
2.2.5. Conceptual framework

The biopsychosocial model is used as a conceptual framework to conceptualise adolescents and their challenges. This will be further discussed below.

2.2.5.1. Biopsychosocial model

Over the past few decades, the field of psychology has evolved from focusing on the individual to understanding the importance of additional contributing factors to mental health. This paradigm shift includes acknowledging the importance of health psychology, as a subspecialty of psychology, which is aimed at promoting and maintaining health, and preventing and treating illnesses (Gurung, 2010). Health psychologists incorporate a biopsychosocial approach with a specific focus on the importance of a biological constituent of health.

The biopsychosocial approach was originated by George Engel (1977). According to Engel (1977), individuals are biological, psychological, and social beings who behave in a specific ways that can either promote or damage their health. Thus, the biopsychosocial model regards the health of a person as a totality – the health of an individual is the end result of variables including biological characteristics, behavioural factors, and social factors (Marks, et al, 2006). Health is impacted by the thoughts, beliefs, and behaviour of a person, and the way these interacts with physical systems. Furthermore, this interaction is impacted by the social context. Thus, in order to create changes in the health, it is important to understand the interactions between biological, psychological and social factors. This is called biopsychosocial model (Marks et al., 2006; Albelheim, 2011). From the above, it is evident that the stage of adolescence is a period where individuals are faced with numerous developmental changes and tasks including physical, psychological and social changes and tasks. Furthermore, in this study, the focus will be on adolescents who were vertically infected with HIV and this biopsychosocial model can be used to conceptualise how HIV impacts on these adolescents. This will be further discussed in chapter 2 section 2.3.

2.2.6. Conclusion

The literature reviewed in this chapter highlights that adolescents experience physical, cognitive and psychosocial changes and challenges. These changes may differ in the onset, duration, and tempo between and within individuals. Such differences may also impact on the psychological development of the individual. In addition, with these changes, individuals
need to acquire numerous developmental tasks to transit effectively to adulthood. Failure to complete those developmental tasks may result feelings of unhappiness, rejection by society, and difficulty to move to next developmental stages. However, when an individual successfully completes these developmental tasks, they develop a sense of accomplishment.

This section presented a general framework on the adolescence stage as covered by the literature. The next part reviews literature on adolescents living with perinatal HIV/AIDS which is the main focus of this study.

2.3. ADOLESCENTS WHO WERE VERTICALLY INFECTED WITH HIV

2.3.1. Introduction
In the previous section, the stage of adolescence was discussed. Over thirty years have passed since the first discovery of HIV/AIDS (Evian, 2011). Numerous studies have been conducted as an attempt to understand the concept of HIV. Thus, in this section, a brief overview of HIV and how it is transmitted will be highlighted. This section further discusses how HIV affects adolescents from a physical, psychological and social perspective. Furthermore, adolescents’ perceptions of perinatal HIV as a chronic illness will be discussed. Finally, various types of treatment that are available for adolescents will be discussed.

2.3.2. The origins of HIV/AIDS
In June 1981 in Los Angeles, in the United States, a rare kind of pneumonia, known as Pneumonia Carinii, was detected in homosexual men. Blood testing and testing of other samples began that year which resulted in many studies that led to the discovery of acquired immunodeficiency syndrome (AIDS) a year later (Rohlede, et al., 2009; Wexler, 2013). AIDS was initially hypothesised to affect only homosexual men; however, as time progressed, the hypothesis was changed due to the diagnosis of AIDS in immigrants in the USA. The disease was later diagnosed in heterosexual people in Africa (Van Dyke, 2012). In South Africa, the first cases of AIDS were diagnosed in 1983 (Rohlede, at al., 2009; Wexler, 2013) in two homosexual men (Van Dyke, 2012). Subsequent to these and other reported cases, the human immunodeficiency virus (HIV) was identified as the causal agent for AIDS in 1986. Since then, HIV/AIDS has spiralled into the biggest epidemic in history (Rohlede et al., 2009; Wexler, 2013). This epidemic affects everyone across age, race, sex, socio-economic status and geographical location (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu,
In 1996, new HIV infections spiralled to an estimated 3.5 million worldwide (Van Dyke, 2012).

The most highly affected region in the world is sub-Saharan Africa (Swanepoel & Louw, 2010; Van Dyke, 2012; Shisana et al., 2014), with South Africa having 5.7 million people infected with HIV/AIDS and recording 71% of new HIV infections in 2009 alone (Van Dyke, 2012). According to Shisana et al. (2014), between 2008 and 2012, South Africa experienced an increase of 1.2 million people living with HIV, increasing from 10.6% of the population (5.2 million people) in 2008 to 12.2% (6.4 million people) in 2012.

The diagnosis of HIV/AIDS evoked numerous responses worldwide. Initially, people responded to the HIV/AIDS epidemic with denialism, blame shifting and moralisation (Van Dyke, 2012). HIV/AIDS was initially labelled as a disease of the ‘gay’ population; this population was blamed for the infections, but the belief disappeared with time. Later, many people were infected through blood transfusion products. This led to a new perception about AIDS, as people infected with AIDS were then grouped into two categories: the ‘innocent victims’ and the ‘promiscuous guilty’ who spread the disease. In South Africa, the responses towards AIDS were similar to those around the world (Van Dyke, 2012).

2.3.3. The nature of HIV/AIDS

According to Van Dyke (2012) and Evian (2011), the human body consists of the immune system that functions as a protective agent that defends the body against either new pathogens or future attacks by existing pathogens. When the body is infected by pathogens, this indicates that the immune system is either unable to fight against or adapt when challenged by pathogens (Van Dyke, 2012; Evian, 2011). With regard to HIV, the virus invades the human body and gradually causing a decline in the immune cells, especially the CD4+ T cells (Evian, 2011; Van Dyke, 2012; Wexler, 2013) which are responsible for regulating and controlling the immune system (Evian, 2011). Eventually, the immune system becomes ineffective (Evian, 2011; Van Dyke, 2012; Wexler, 2013). HIV directly fights the important defensive immune cells, called the CD4+T cells. This gradual decline in the number of CD4+ T cells results in the protective immune system’s inability to effectively fight against HIV and other pathogens (Evian, 2011; Van Dyke, 2012; Wexler, 2013). Therefore, the ineffectiveness of the body’s immune system creates an opportunity for other infections and
viruses to invade the body (Evian, 2011; Wexler, 2013). In a nutshell, HIV is a retrovirus that damages specific white blood cells.

According to Wexler (2013), AIDS is the last stage of an infection that arises from HIV. AIDS is viewed as a collection of diseases in the human body that result from the body’s weak immune system. Therefore, AIDS is defined as a specific group of diseases that indicate the severity of immunosuppression related to infection with HIV (Wexler, 2013).

2.3.4. The transmission of HIV
According to Wexler (2013) and Van Dyke (2012), HIV can be transmitted from one person to another via:

- Oral, anal, or vaginal sex – sexual intercourse – specifically unprotected sex
- Mother-to-child transmission at birth and through breastfeeding
- Blood contact, e.g., sharing needles during drug injection, transplantation of HIV-infected body organs, or transfusion of infected bodily fluids.

Shisana et al. (2014) also reported that the most prominent modes of transmission that increases vulnerability to HIV/AIDS infection are sexual intercourse and maternal transmission to a baby. However, maternal transmission decreased from 3.5% in 2010 to 2.7% in 2011 (Shisana et al., 2014). Thus, the most recognised mode of transmission is sexual intercourse, followed by mother-to-child-transmission.

2.3.5. Diagnosis and symptoms of HIV
HIV/AIDS can only be diagnosed by qualified health professionals through diagnostic laboratory tests that use blood as a specimen. HIV infection takes place through different stages. The first stage is the primary infection, which is the establishment of the infection; thereafter followed by a typically prolonged asymptomatic (symptom free) period – a stage with no appearance of physical symptoms and deterioration of the patient’s health. Subsequent is the symptomatic period; during this stage physical symptoms appear and the patient’s health condition deteriorates. The symptoms that develop are the following: weight loss, profound unexplained fatigue, nausea, fever, night sweating, swollen lymph glands, a heavy persistent dry cough, easy bruising or unexplained bleeding, watery diarrhoea, loss of memory, balance problems, mood changes, blurring or loss of vision, and oral lesions such as
thrush. In terms of its structure and genetic makeup, the infection presents itself in the same manner in affected people. However, people react differently to the virus. Death results from opportunistic infections that arise because of the impaired immune system, not HIV (Wexler, 2013).

For the purpose of this study, the focus shifts to the adolescents who were perinatally infected with HIV/AIDS.

2.3.6. Adolescents living with vertical HIV/AIDS

2.3.6.1 History of Adolescence Living With Vertically HIV/AIDS

The first cases of paediatric HIV/AIDS were reported in the USA in 1982 (Swanepoel & Louw, 2010). Before 1997, there was insufficient information in South Africa on paediatric HIV/AIDS, until the case of Nkosi Johnson emerged. However, cases of pregnant women who were infected with HIV had already been recorded since 1990, suggesting that there were a significant number of children who could have been born with HIV since the early 1980s (Rohlede et al., 2009). According to Van Dyke (2012), and Swanepoel and Louw (2010), the most common mode of HIV infection in children is mother-to-child transmission (MTCT), also known as maternal transmission or vertical transmission. About 90–95% of children are infected through maternal transmission, and approximately about 590 000 children are infected through MTCT every year. However, with the use of anti-retroviral (ARV) treatment drugs, cases of MTCT have reduced from 3.5% in 2010 to 2.7% in 2011 (Swanepoel & Louw, 2010; Van Dyke, 2012; Pillay, Dinh, Goga et al., cited in Shisana et al., 2014). In addition, with the improvement of ARV medication, there has been a decrease in mortality rates and HIV has transformed from an acute terminal illness into a chronic disease (Midtbo, 2012; Rohlede et al., 2009; Swanepoel & Louw, 2012; Foster & Lyall, 2005).

The majority HIV-infected children and adolescents live in South Africa (Swanepoel & Louw, 2010; Meyer, 2013), with 90% of perinatally HIV-positive children and adolescents of the world residing in sub-Saharan Africa (Van Dyke, 2012). Shisana et al. (2014) add that South Africa has 45.1% of children (aged 0 to 14 years old) living with HIV/AIDS. HIV-positive adolescents’ health is becoming a critical subject, as antiretroviral (ARV) medications have significantly increased the chances of HIV-positive children growing into adolescence and adulthood.
According to Karim and Karim (2010), in the context of a child who has had vertical transmission of HIV, HIV has a direct and indirect impact on both maternal and child survival. In an indirect impact to the child, HIV-positive mothers are at an increased risk of dying compared with HIV-negative mothers which this places their infants at an increased risk of being orphans. Thus, HIV impacts family system of the child. On the other hand, in a direct impact to the child, HIV impacts on the physical well-being of the child. For instance, 60% of HIV-positive infants manifest some symptoms of disease such as growth failures and developmental delays; respiratory system diseases; tuberculosis; neurological system diseases; cardiovascular system diseases; and renal diseases (Karim & Karim, 2010). Thus, the medical problems place the infants at an increased risk of being dead.

However, with the improvement of antiretroviral (ARV) medication, there has been a decrease in the mortality rates and HIV has transformed from an acute terminal illness into a chronic disease (Foster & Lyall, 2005; Rohlede et al., 2009; Swanepoel & Louw, 2011). This means that people who are living with HIV/AIDS are faced with the challenge of living with a chronic illness that has a significant impact on the quality of life. The life expectancy of children living with perinatal HIV/AIDS has increased, and they are expected to live beyond the childhood phase. However, they face challenges of growing up with a chronic health condition (Midtbo, 2012; Rohlede et al., 2009; Foster & Lyall, 2005). These children may, therefore, experience developmental and behavioural challenges (Sherr, Crome, Castaneda, Bradshaw & Romero, 2014). Etang (2011) also shows that the adolescent stage, on its own, is a period where individuals are faced with numerous challenges and changes, and having to cope with the chronic illness of HIV/AIDS can have a huge effect on the young person’s life. Thus, adolescents living with HIV are exposed to experiences, thoughts, and challenges that may result in physical, psychological and social difficulties. Hence, from biopsychosocial model perspective, adolescents who are vertically transmitted with HIV are negatively impacted by HIV and this result in physical and psychosocial challenges. These challenges will be discussed in the following section.

2.3.6.2. Challenges of perinatal HIV infected adolescents

As mentioned above, adolescents who were vertically transmitted with HIV are negatively impacted by HIV as this leads to physical and psychosocial challenges (Etang, 2011).
2.3.6.2.1. Physical Challenges

Children who were vertically infected with HIV are genetically predisposed to HIV risk factors from birth and are prone to develop symptoms related to the virus from an early age (Gurung, 2010). According to Rohlede et al. (2009), many children who are HIV positive are chronically ill; they have multiple hospital admissions and are at a high risk of being diagnosed with a range of neurological, cognitive, and other illnesses. These predisposing factors are not limited to physical wellbeing and developmental delays (Karim & Karim, 2010; Rohlede et al., 2009). As stated earlier, the adolescence stage is characterised by physical development, especially the onset of puberty and brain functioning (Bukatko, 2008). The physical development such as puberty and brain functioning of adolescents with perinatal HIV/AIDS is negatively impacted by HIV/AIDS. This may result in difficulties in physical wellbeing and in developmental delays.

- **Puberty**

As mentioned in the preceding part of this chapter, adolescence is marked by the onset of puberty defined as a period that involves biological processes of an individual’s body to transit from reproductive immaturity to reproductive maturity – a person’s ability to reproduce develops (Jaffe, 1998; Papalia et al., 2006; Bukatko, 2008; Shaffer & Kipp, 2010; Jansen et al., 2012). Adolescents living with perinatal HIV/AIDS may experience difficulties in their physical wellbeing and developmental delays, which result from how HIV impacts on the human body (Rohlede et al., 2009; Swanepoel & Louw, 2010). According to Gillard, Witt and Watts (2011), HIV positive children and adolescents may experience physical symptoms that include prolonged fever, diarrhoea, fatigue, pneumonia, and mouth and skin disorders. This is because HIV attacks and weakens the immune system, resulting in HIV-positive children and adolescents becoming more vulnerable to opportunistic infections and diseases (Gillard, et al., 2011).

Similarly, Ferrand, Lowe, Whande, Munaiwa, Langhaug, Cowan, Mugurung, …, (2010) found that HIV-positive adolescents are more likely to be hospitalised and experience a delayed onset of puberty. Sherr et al. (2014) also shows that children and adolescents who are living with perinatal HIV/AIDS may experience prematurity and developmental delays that may perpetuate feelings of fear. This is further supported by a study conducted by Hajikhani Golchin, et al. (2012) which found that girls who had late onset of puberty experienced feelings of worry and concern. Such feelings may impact on their body image.
According to Cash (cited in Pinquart, 2013), body image is made up of one’s perception and attitude towards one’s body, such as body satisfaction. A positive body image is very important in the adolescence stage, because this stage characterises a period of rapid physical change, during which adolescents undergo a process of formulating and defining their ideal body image. Any disfiguring of the body due to a chronic illness can impact the process of defining an adolescent’s body image. It is worth noting that body image dissatisfaction can lead to poor health habits, a low self-esteem and depression, especially in adolescent females. Youth expressed a fear of developing physical changes related to HIV infection, and how those physical changes could rely on what they heard about HIV and the possible physical changes that would result from the infection (Pinquart, 2013). Thinking about these changes appeared to fuel their fear (Martinez, Lemons & Hosek, 2012). Furthermore, Donald, Walker, Riordan, Governder and Wilmshurst (2012) report that children and adolescents with perinatal HIV/AIDS may suffer from stroke and epilepsy hydrocephalus, which may impact on their physical appearance.

**Brain Functioning**

In the previous part, adolescence was defined as the period when the brain undergoes numerous changes (Steinberg, 2005; Bukatko, 2008; Luna, 2009; Jansen et al., 2012). The changes that occur in the adolescent stage may be affected by perinatal HIV/AIDS in adolescents living with the disease. Armstrong (cited in Sherr et al., 2014) notes that HIV can enter the blood-brain barrier and invade the central nervous system, thereby destroying neural tissues in the central nervous system eventually causing dysfunctionality of all modalities secondary to HIV/AIDS (Rohlede et al., 2009; Swanepoel & Louw, 2010). In South Africa, HIV infection occurs simultaneously with multiple environmental stressors, including poverty, and other forms of deprivation (Rohlede et al., 2009; Gillard et al., 2011). These increase the children’s chances of being exposed to malnutrition compared to children who are born HIV negative (Magadi, 2011). These risk factors continue from childhood to adolescence. In such conditions, the negative neurological effects of HIV on the children’s development are likely to be enhanced.

Furthermore, Sherr et al. (2014) found that the prolonged use of ARV therapy may impact negatively on the children’s cognitive performance and may cause delays in development. The delays progressively continue throughout the development of childhood into adolescence and adulthood (Gillard et al., 2011). Thus, the brain function of adolescents living with
HIV/AIDS might be negatively impacted by the mechanism of HIV/AIDS in the brain, together with the environmental stressors and side effects of ARV therapy. Consequently, adolescents and children living with perinatal HIV/AIDS may experience impairment in their mental, motor, and emotional development.

Similarly, according to Laughton et al. (2013), Swanepoel and Louw (2010) and Donald et al., (2012), HIV impacts the neuro-development of children and adolescents, thus resulting in neuropathology (Laughton et al., 2013), HIV encephalopathy (any type of brain disorder) (Swanepoel & Louw, 2010; Donald et al., 2012), micro-encephalopathy (small brain) and possible atrophy (Swanepoel & Louw, 2010). Neuropathology caused by HIV greatly occurs in the basal ganglia and cerebral white matter. There is also occurrence of neural loss in the prefrontal cortical regions, which may result in difficulty with complex mental processing (Martin, Wolters, Toledo-Tamula, Zeichner, Hazra & Civitello, 2006). These are the regions where, during the adolescent period, myelination and remodelling of synaptic connections occurs (Tau & Peterson, 2010).

Studies have been conducted to explore the impact of HIV on important neurocognitive domains. Thus, developing cognitive challenges in children refers to their inability to gain cognitive skills (Sherr et al., 2014). HIV-positive children and adolescents perform significantly poorer in executive functioning (EF) tasks, especially in processing speed memory including the attention span (Ruel, Boivin, Boal, Bangirana, Charlebois, Havlir, …, 2012). The following authors also concur with the aforementioned Donald et al., (2012), Smith, Chernoff, Williams, Malee, Sirois and Kammerer, et al., (2012), Smith et al., (2012), Hoare, Fouche, Spottiswoode, Donald, Philipps, Bezuidenhout, …, (2012), Allison, Wolters and Brouwer (2009), and Ruel et al., (2012).

Other studies have found that HIV-positive children and adolescents score lower in visual-spatial processing, which is important for adolescents as it affects reading, writing, and learning (Blanchette, Smith, King, Fernandes-Penney, & Read, 2002). HIV-positive children and adolescents have been found to be slower and less accurate in pattern recognition (Koekkoek, Sonnevile, Wolfs, Licht & Geelen, 2008), and to have lower scores in sequential processing, simultaneous processing, planning, reasoning (Ruel et al., 2012) and visual memory (Hoere et al., 2012).
Swanepoel and Louw (2010) also found that children and adolescents living with HIV/AIDS are likely to experience difficulties in balance, which may have resulted from the HIV virus damaging their vestibular structures. Sherr (2005), who reviewed 27 studies on the impact of HIV on the development of young children, found that HIV-positive children and adolescents are more prone to negative effects on growth as well as motor and mental development, language acquisition, adjustment, and behaviour and school performance. Similarly, Swanepoel and Louw (2010) report that children living with perinatal HIV/AIDS are at a high risk of developing communication and hearing disorders, as well as experiencing difficulties in swallowing and feeding.

According to Piaget, the highest level of cognitive development is in adolescence, which is referred to as formal operational thinking. This is an ability to reason in an organised way creating ideas and hypothetical concepts, testing the hypotheses, eliminating false hypotheses, and drawing conclusions (Papalia et al, 2012; Shaffer & Kipp, 2010). Armstrong (cited in Sherr et al., 2014) found that HIV can enter the blood-brain barrier and invade the central nervous system, thereby destroying the neural tissues in the central nerves system and consequently causing dysfunctionality in all modalities secondary to HIV/AIDS (Rohlede et al., 2009; Swanepoel & Louw, 2010). This might impact on the development of formal operational thinking in the adolescent stage. Overall, children and adolescents living with perinatal HIV/AIDS are at a high risk of developing cognitive, behavioural and motor deficits. This increases their chances of poor academic achievement (Sherr, Mueller & Varral, 2009).

2.3.6.2.2. Psychosocial Challenges

According to the social ecological framework (cited in Mburu, et al. 2014), it is believed that adolescents’ development is impacted by the context in which they exist. Adolescents living with perinatal HIV/AIDS infection may experience psychological and social changes that might be negatively impacted by HIV/AIDS. In this study, stigma and disclosure will be briefly discussed before social and psychological challenges.

In South Africa (SA) people respond with great denial to HIV/AIDS. This continues to create a huge challenge in dealing with the epidemic (Rohlede et al., 2009), and it impacts negatively on the social functioning of people living with HIV. These responses give rise to
stigma and disclosure of HIV status. In this study, stigma will be discussed first, and disclosure later.

- **Stigma**

  Stigma is a prominent concern as youth navigate relationships. The perception of stigma leads to depression, fear, isolation, and hesitance to disclose the HIV status to others (Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). Stigma is a defined social process as the illness is viewed to be preventable or controllable and indicative of ‘immoral’ behaviours. Some people are blamed and perceived to be responsible for their own infection, which may result in active discrimination and social devaluation (Rohlede, et al., 2009). HIV stigma is, therefore, defined as discrimination pointed at people apparent to have HIV/AIDS, and the individuals, groups, and communities with which they belong to (Herek, 1999).

  In society, those who are HIV positive are perceived as interrupting social order. This means that they provoke responses of stigmatisation, thereby putting more social burden on those who are presently dealing with the physical effects of HIV infection (Edgar, Noar & Freimuth, 2012). The sources of HIV stigma are as follows:

  **Association with deviant groups**

  The discovery of HIV illness was discovered in the 1980s. It was perceived to belong to certain social groups, such as gay men, intravenous drug users and Americans of African and Latino descent. Most of these social groups are usually associated with sexual promiscuity and intravenous drug use, and they are mostly perceived as conduits of HIV transmission. The perception that the disease belongs to deviant groups may be used as a psychological coping strategy for dealing with HIV. Thus, society may blame social groups to which one does not belong to as a means to decrease the level of anxiety associated with the danger of contamination. This, however, can eventually prove to be self-defeating and society may decrease the use of protective strategies when engaging in sexual behaviours, thus placing them at risk for HIV infection (Edgar, et al., 2012; Van Dyke, 2012).
Responsibility for infection
The society views the transmission of HIV to be driven by behaviours that are believed to be solely one’s own responsibility. Infected people are judged and blamed for being infected and the public may say ‘they deserve it.’ (Edgar, et al., 2012; Van Dyke, 2012)

Religion and mortality
The modes of transmission of HIV are viewed as ‘immoral’. These views are influenced by religious institutions. Some churches, directly or indirectly, increase HIV stigmatisation and discriminate against those living with the virus. Religious influences also reason that people even perceive HIV positive as a punishment for sin (Edgar, et al., 2012; Van Dyke, 2012; Lowenthal, Jibril, Sechele, Mathuba, Tshume & Anabwani, 2014).

Contagion
Stigmatising behaviours are associated with misunderstanding the modes of HIV transmission. People express feelings of fear of contagion towards HIV. This fear of contagion is a motivation of how the society reacts negatively towards people living with HIV. Despite considerable efforts to educate the public about how HIV can be transmitted, illogical and wholly incorrect common beliefs, such as the belief that HIV could be transmitted by coming in contact with objects previously touched by people living with HIV/AIDS (PLWHA) are perpetuated (Edgar, et al., 2012; Castle, 2004). Thus, the fear of contagion perpetuates HIV stigma.

Association with death
Despite the effectiveness of the ARV treatment in increasing the lifespan of HIV-positive people and changing HIV from a terminal disease to a chronic illness, the general public still perceives HIV as a terminal disease. This results from a misperception of associating HIV with death, which provokes fear and a sense of hopelessness in the society (Edgar, et al., 2012).

A study conducted by Archibald (2010) on Afro-Carribean people in the United States was aimed at exploring attitudes towards HIV/AIDS among churchgoing people. The study found that people expressed anger at HIV/AIDS discrimination and discrimination based on fear. Thus, discriminatory attitudes towards PLWHA engendered anger. Teenagers who had family members with HIV expressed disappointment in church members’ behaviours; one
described her frustration with discriminatory labelling. Family members experienced discrimination from members of the church community due to fear of transmission, and children were not allowed to play together even after services. The adolescents were warned against ‘hanging’ or associating with PLWHA. A group of members preferred their daughters not to have close friendships with someone with HIV/AIDS. These mothers did not think that they were being discriminatory, but they were concerned for the welfare of their children (Archibald, 2010). Clearly, HIV stigma is a huge challenge that adolescents who were perinatally infected with HIV are faced with as it affects many social situations that these adolescents encounter, including the disclosure of HIV status, family context, school context and society. The HIV stigma also affects the psychological and physical functioning of the adolescents (Edgar, et al., 2012).

- Disclosure

The disclosure of HIV status is a process where there is communication about an individual’s HIV status, which is a potentially life-threatening, stigmatised and transmissible virus (Wiener, Zobel, Battles & Ryder, 2007). Thus, disclosure is defined as being told about one’s own HIV status, or disclosing one’s HIV status to others (Midtbo, 2012). A study conducted in Odi Hospital, Pretoria, by Mahloko and Madiba (2012) found that children who have perinatally transmitted HIV/AIDS and are receiving ARV treatment grow into the adolescence stage, and this has given rise to a challenge of parents disclosing to adolescents about their HIV status.

**Disclosure to adolescents about their HIV status**

The main caregiver is found to have an influence on disclosure to young people with perinatally acquired HIV (Michaud, Suris, Thomas, Kahlert, Rubin, Chesearx, the Swiss mother & child HIV cohort study (MoCHiV), 2009). However, caregivers who reported disclosing their children’s HIV status to a close adult family member found it is easier compared to disclosing to their infected children. This is because caregivers expressed feelings of helplessness and guilt about their role in the child’s infection through vertical transmission and fear of discrimination (Rohlede, et al., 2009; Madiba, 2012; Kyaddondo, Wanyenza, Kinsman & Hardon, 2013). Thus, for the majority (61%) of children disclosure was done by people other than their biological caregivers (Madiba, 2012; Mahloko & Madiba, 2012). However, Lowenthal et al. (2014) report that healthcare workers perceive disclosure to be the responsibility of the family.
A study conducted by Vaz, Eng, Mamas, Tshikandu, and Behets (2010) found that, in the moment of disclosure of HIV status to adolescents who were vertically infected with HIV, there were significant differences and similarities about information received by adolescents who were disclosed in medical setting as opposed to adolescents who were disclosed in family context. The similarity was that, in both contexts, medication mostly featured in the disclosure conversation or as advice on staying on healthy. The differences in the medical context were the manner in which the healthcare providers explained the mechanism of HIV and the importance of adherence to treatment; whereas in the family context, the caregiver discussed avoiding contaminating others through sharing sharp objects. Thus, in family context, the caregivers provided limited or no information about the mechanism of HIV. Furthermore, in both in context, the healthcare providers and caregivers focus more on providing information rather on the adolescents themselves (Vaz, et al., 2010).

A large number of these children have for a great part of their lives been unaware of their diagnosis, as their caregivers have kept it a secret (Kyaddondo et al., 2013; Midtbo, 2012). Vorster (2011) showed that the context defines and impacts the behaviour of an individual. The majority of the children only heard about their HIV status around the ages of 7 to 13 years (Midtbo, 2012) or during the adolescent stage (Kyaddondo et al., 2013). The moment of disclosure is experienced as dramatic and deracinating, with the physical and emotional response of ‘shock’ to a positive result and anger, depression, and other reactions (Rohlede et al., 2009; Martinez, et al., 2012; Van Dyke, 2012). These other reactions may be denial, anxiety, low self-esteem, sadness, hopelessness, guilt, feelings of loss (Van Dyke, 2012).

The adolescents found it important to be aware of their status for several reasons, including knowing why they had to keep on taking medications and going to hospital for follow-up visits. It is important for the adolescents to take care of themselves (Midtbo, 2012; Van Dyke, 2012), and to avoid high-risk sexual behaviours (Van Dyke, 2012). In contrast, a study conducted by Mutwa, Van Nuil, Assimwe-Keteera, Kestelyn, Vyankandandere, Pool, Ruhirimbara, …, (2013) found that adolescents who were made aware their perinatal HIV infection expressed confusion or anger towards their parents. This anger, in some cases, also led to the adolescents being less obedient. This is sometimes in an attempt to punish their parents while, at other times, it is an attempt to come to terms with their status.
During normal adolescent development, youth develop future goals and work towards achieving them. Receiving HIV diagnosis initially interfered with their goals and expectations because having HIV made them to question whether they would have any future. Youth concerns centre on reproductive health; for some of this youth, having children and building a family is an important milestone on their way to becoming adults. Thus, receiving an HIV diagnosis raises concerns about their reproductive health, including parenting, childbirth and childrearing (Martinez, et al., 2012).

Disclosure to family, friends, and society

According to Van Dyke (2012), each child has a right to confidentiality about his or her HIV status. Disclosure of HIV status to a child can only occur with the consent of the child who is 12 years old, and/or who has the intellectual ability to understand the consequences of disclosure. Disclosing one’s status automatically reveals the mother’s status and young people will often avoid family conflict and distress by keeping it a secret (Dorrel, Earle, Katz & Reveley, 2008). Studies that examined the disclosure of HIV status to adolescents with perinatally acquired HIV found that these young people experience a dilemma between a desire to let people know and their parent’s views, which sometimes results in feelings of isolation and loneliness (Dorrel et al., 2008).

A study conducted by Hoogwood, Campbell and Buttler (2012) in the UK found that there are a number of factors that contribute to adolescents not disclosing their HIV status. Reasons being the myths and assumptions that occur in society, disclosure evoked a huge dilemma for young people and brought strong emotions of being fearful for the consequences. They did not want to be separated from peers and/or be rejected and isolated. This is particularly significant as peer relationships are one of the developmental tasks that are important in adolescence and contribute to increasing independence, influencing identity and providing social support. Although young people experience fears and dilemmas around HIV disclosure, they do not want to be associated with an identity linked to illness, contagion and death. In some ways, this desire motivates the young people not to disclose their HIV status as they choose to have a different image or identity where HIV does not belong. Adolescents have other priority developmental tasks, such as making friends, claiming independence and developing their sexuality, and they do not want to consider HIV (Hoogwood, et al., 2012).
This is further supported by a study conducted by Vann Staa, Jedeloo, Latour and Trappenburg (2008), which found that young people use a strategy of normalising a chronic illness as a way of forming identity so that they are able to accept that a chronic illness was present but prevent it from dominating their lives. Pettitt, Greifinger, Phelps, Bowsky (2013) also found that HIV/AIDS diagnosis has a great impact on developing sexual relationships with adolescents who have perinatal HIV/AIDS; they stand the risk of transmitting the disease to their partners, experience stigma and trust issues related to disclosing to their partners, boys experience peer pressure to have multiple partners, and the delay of the onset of puberty. These challenges are exacerbated in that some of these adolescents are orphans and have no family support to discuss these issues with; the only place they might seek support from is clinical care, especially the healthcare workers. However, the healthcare workers do not perceive adolescents who were perinatally HIV/AIDS infected as sexual beings, and do not focus on whether these adolescents have sex or not (Pettitt et al., 2013).

Furthermore, a study conducted by Martinez, et al. (2012) found that young people disclose their HIV status to family members and friends with the intentions of finding support. However, they are fearful of negative reactions that this disclosure may elicit. Very few had disclosed their HIV status to members of the wider community, including teachers and day-care providers (Rohlede et al., 2009).

Young people reported witnessing teachers and pupils discussing HIV without sensitivity or with limited understanding, which made the possibility of disclosure within a school context a difficult prospect (Michaud, et al., 2009). However, with peers forming a central part of adolescence, research (Sherman, Bonanno, Wiener & Battles, 2000) found that some young people were disclosing to friends and this seemed to be beneficial in increasing self-competence in peer relationship and a possible link with the slowing of disease progression.

Thus, HIV stigma and disclosure of HIV status may impact on the social and psychological functioning of the adolescents living with perinatal HIV/AIDS. In this study, social challenges and psychological functioning will be discussed.
• **Social Challenges**

Environmental and social factors shared by many youth with HIV include single-parent homes, poverty, drug abuse, community violence, and loss of loved ones (Kang, Mellins, YiuKee Ng, Robinson & Abrams, 2008).

**Challenges within family context**

In the previous part, it was highlighted that a family functions as a primary support system for adolescents and a safe context for adolescents to successfully develop; however, a family with a lack of support may create a high risk for failure in adolescence (Zarrett & Eccles, 2006). Thus, stigma from the society may negatively affect HIV-positive mothers and their children, resulting in difficulty for them to create and maintain meaningful relationships outside the family context. This may result in many HIV-positive mothers and their children experiencing feelings of loneliness, being rejected and friendlessness, and being discriminated against and judged by community members (Rohlede et al., 2009; Van Dyke, 2012).

According to Rohlede et al. (2009), the biological effects of vertical HIV infection are often experienced simultaneously upon parental death or separation, parental illness and/or parental anxiety and preoccupation. The mother’s health, mental health, and support system may be negatively impacted by HIV diagnosis and may affect parenting on an on-going basis. This may impact on their psychological functioning, as they may have depression and lower levels of parental confidence (Rohlede et al., 2009).

A study conducted by Kidman, Hanley, Subramanian, Foster and Heymann (2010) found that children living with sick parents have deteriorating health, as they also suffer from an acute illness/injury and have to report chronic illnesses besides HIV infection. These children may receive sub-optimal care because the parental illness or HIV/AIDS reduces the amount of time the parents are able to spend on caregiving responsibilities for their children.

Several patients reported that the specifics of their condition were not greatly discussed with parents, and some of them had actually resorted to the internet for information. Most of the adolescents living with an infected mother expressed how difficult it was to raise this topic with her, given the guilt, torn loyalties and emotional dilemmas it evoked (Michaud, Suns, Thomas, Gnebm & Cheseax, & Swiss HIV Mother+Child Cohort Study (MoCHiV), 2010).
Pettitt et al. (2013) added that adolescents living with perinatal HIV/AIDS infection may have feelings of anger and blame, both at themselves and their parents, which might impact on the quality of parent-child relationships.

Parental death is exceptionally difficult for a child at any developmental age. More than 95% of children who lose one or both parents to AIDS live with members of their extended family, including grandparents (Rohlede et al., 2009). Meyer (2013) shows that millions of children have been orphaned or made vulnerable by HIV/AIDS. Shisana et al. (2014) also report that approximately 16.9% of children have been orphaned by AIDS (maternal at 4.4%, paternal at 9.3%, and both at 3.2%).

Parental death has a negative impact on the child’s future and behaviour. It is estimated that 55% of all orphans in the world are children aged 12 to 17 years old (adolescents). This is important to know since adolescents need parental guidance through this developmental stage and at an age where they take part in activities that make them ready to be adults. There are several emergent challenges that adolescents orphaned by AIDS face in transitioning into adulthood. Their journey into adulthood without parental guidance results in them learning from their own mistakes and that of their peers without prior preparation of what to expect (Thupayagale-Tshweneagae, Mgutshini & Moleki, 2012).

The loss of a parent may also impact on the education of the adolescents experience of a normal childhood (Rohlede, et al., 2009; Van Dyke, 2012; Meyer, 2013) as they may be forced to drop out of school due to role changes at home, such as looking after their siblings, caring for an ill parent (Rohlede et al., 2009; Van Dyke, 2012; Meyer, 2013), and taking on the role of heading their households (Geifinger & Dick, 2011). This may in turn create limited, or a lack of, educational skills, resulting in them being exposed to a higher risk of unemployment or low-income employment. Those who relocated to their relatives’ homes are faced with the challenge of adjusting to the new context, as well as dealing with grief; they may also experience rejection from those relatives as they may be viewed as a threat to already limited resources (Rohlede et al., 2009; Meyer, 2013). Thus, the economic and social effects of HIV/AIDS on children includes malnutrition, poverty, neglect, migration, and homelessness (Foster, 2006; Van Dyke, 2012).
Other effects of HIV/AIDS are the collapse of family structures as safe havens for nurturing and guiding children as they develop their personal identities (Loubser & Müller, 2011). People are born into families and they understand themselves and their world from the perspective of their experiences in families (Barolsky, 2003). Therefore, the loss of a caregiver leaves a child confused, especially because the caregiver is often the only stable source of support in the family (Loubser & Müller, 2011).

The participants in the study conducted by Loubser and Müller (2011) stated that they did not only suffer physical loss, but also emotional and psychological distress as they had no one to support, love and guide them into adulthood. It is clear that the loss caused by the HIV/AIDS pandemic is not one-dimensional – it does not only leave orphans; it also causes loss of income, which makes one to lose one’s sense of security. The absence of a loving and caring adult in the house, especially for an early adolescent, means that a child does not develop a stable identity. This causes children to lose a sense of direction and purpose, without prioritising education and developing meaningful, stable relationships. It is clear that children suffer multiple losses owing to HIV/AIDS (Loubser & Müller, 201). Van Dyke (2012) also shows that children who were perinatally HIV infected experience pain from death of their parents from HIV/AIDS as exposure to such a traumatic experience may create fear and uncertainty about their future and anticipation of their own death.

Foster (2006) indicated that these children might also suffer psychological consequences, such as depression, guilt, and fear, which are associated with mental health in the long run. Furthermore, Van Dyke (2012) found that the loss of someone to whom an individual is attached may create bereavement. Bowlby (cited in Van Dyke, 2012) further mentions that individuals normally form attachments with significant others for the purpose of satisfying their own needs of security and safety. The loss of someone to whom an individual is attached may cause the individual to experience grief, which is a natural reaction to that loss. Individuals who experience grief in the adolescence stage may have the cognitive ability to deal with the loss; however, they may be unable to express their emotions of grief, pain, fear, helplessness, and guilt. This may negatively impact on their daily functioning, by having a negative impact on their school work, creating a sense of withdrawal and tiredness, and having difficulties in concentration. In addition, when there is a death from HIV, it is often difficult for families (and young people) to be open about the cause of death due to fear of discrimination and stigma. When a family member dies from HIV, young people speak about
having to lie about the cause of death, and they find it equally hard to share their grief with anyone, because they could not tell the truth (Dorrel, et al., 2008; Van Dyke, 2012).

A study conducted by Van Vilsteren, Haffejee, Patel and Bowman (2011) found that adolescents who are living in a residential care facility may experience numerous challenges. These authors found that adolescents had ambivalent feelings towards living in a residential care facility. Although the facility provided them with many materials and cared for them, they viewed the residential care facility as a very restrictive and regulated environment that limited their freedom to explore things. This study also found that adolescents experienced feelings of discomfort with how people reacted to them relative to their living in the residential care facility; many people might reacted by expressing feelings of pity towards them or discriminated against them. This resulted in the adolescents distancing themselves from the facility or lying to people telling them that the facility was the parents’ workplace. This study also found that the facility was funded by donors, and those donors visited and accessed the facilities, which caused the adolescents to feel pressurised in being congruent towards the donors. This further perpetuated the development of a sense of not feeling at home and comfortable in the facility. Finally, the study found that adolescents may develop a low self-esteem, passivity and aggression, and may use various defence mechanisms to protect themselves (Van Vilsteren, et al., 2011).

Challenges within peer context
As mentioned previously, peer relationships are important in the adolescence stage, because they provide emotional and social support to adolescents when faced with challenges of developing autonomy and independence (Cobb, 2010). Similarly, Jansen et al. (2012), together with Zarrett and Eccles (2006), report that adolescents establish friendships and groups for the purpose of emotional support and exploration of values, and also to fulfil their need for the formation of identity and sense of belonging, developing self-esteem, and sharing information. For adolescents living with perinatal HIV/AIDS, developing peer relationships may be challenging.

A study by Thupayagale-Tshweneagae, et al., (2012) found that orphaned adolescents have difficulties in interpersonal relationships, that is, building meaningful relationships with others seemed difficult and at times, impossible for them. This was as a result of many adolescents living with perinatal HIV/AIDS playing the role of young carers. Bauman,
Foster, Silver, Berman, Gamble, and Muchaneta (2006) define young carers as children and adolescents who take on ‘substantial and significant tasks’ with responsibilities that would normally be associated with an adult when someone, particularly a member of the household, becomes unwell. This may result in loss of time to start peer friendships (Bauman et al, 2006). On the other hand, adolescents living with perinatal HIV/AIDS may experience stigma which might negatively impact on the development of peer relationships (Edgar, et al., 2012). A study conducted in Kenya by Skovdal and Ogutu (2012) found that children affected by HIV may experience stigmatisation and bullying in their peer groups at school. Their peer relationships may also be affected by limited time and space for socialising with peers. Furthermore, adolescents living with perinatal HIV/AIDS grow in contexts where poverty exists; because these children usually do not bring any lunch to school, this seems to affect them in terms of social isolation and feeling different from other students (Cluver, Operario, Lane & Kganekge, 2011).

In addition, as the adolescents grow older, their interest in groups decreases as they spend more time on romantic relationships and close friendships which contributes to their development of a sense of competence (Zarrett & Eccles, 2006; Bukatko, 2008; Jansen et al., 2012). A study conducted in Zimbabwe investigating challenges faced by adolescents with perinatal HIV/AIDS found that adolescent girls lacked interpersonal skills that are necessary to form romantic relationships (Chinyezi, 2010).

**Challenges of poverty**

Children and adolescents who are infected and affected by HIV mostly grow up in poverty-stricken households (Rohlede et al., 2009). Ssewamal, Han, and Neilands (2009) reported that the death of parent may cause poverty in the family, as prolonged parental illness and subsequent death creates a financial strain on the family. Poverty negatively impacts on parenting causing parental stress, exhaustion, distraction, and frequent absences due to poorly paid, labour-intensive, and menial work (Rohlede et al., 2009).

Poverty and lack of resources may disappoint children in need, causing them to drop out of school (Rohlede et al., 2009; Skovdal & Ogutu, 2012). An impoverished child may be pushed into relationships with an adult, who is generally referred to as ‘sugar daddy’ or ‘sugar mommy’, for financial support. This increases the risk of infection as these partners are not only older, but they tend to be in multiple sexual relationships. In such situations, young
people are dependent on the ‘sugar daddy’ or sugar mommy’ and are powerless to negotiate safe sex (Rohlede et al., 2009). A study conducted by Cluver and Orkin (2009) found that children and adolescents who are living with HIV/AIDS and experience poverty are at a high risk of developing internalising disorders. Similarly, a study conducted in South Africa by Cluver, Boyes, Orkin and Sherr (2013) found that there is a significant relationship between household poverty, which exists when a parent suffers from HIV/AIDS, and a child’s mental health and educational challenges.

Due to many children experiencing poverty due to loss of their caregivers, the foster child grant was introduced with the aim of protecting the child financially (Hall & Proudlock, 2011). The child grant is reaching nearly 11 million children in South Africa.

**Challenges in school context and scholastic achievements**

According to Libbey (cited in Melaughlin & Clarke, 2010), the school context is very important in the adolescent stage, in that the school is a space where adolescents are able to develop social and cognitive functioning. Similarly, a study conducted by Mburu et al. (2014) in Zambia found that the school context plays a crucial role in giving meaning to the experiences of adolescents living with perinatal HIV/AIDS infection. Schools also provide a space where adolescents living with perinatal HIV/AIDS may connect and form attachment with their peers. However, adolescents living with perinatal HIV/AIDS may drop out of school or repeat grades due to discrimination and frequent hospital appointments (Mburu et al., 2014). In addition, Bauman et al. (2006) highlights that parental illness could have a huge impact on the education of adolescents, since adolescents may assume the role of young carers. These young people experience disadvantages in their access to education (Bauman et al., 2006; Van Dyke, 2012).

This was further supported by Gray, Van Niekerk, Struthers, Violari, Martinson, McIntyre and Naidu (2006) who conducted a study in South Africa that examined the impact of any sickness in the household on children. Children in sickness-affected households were found to be less likely to have school fees paid, more likely to be absent from school and be unsupervised while doing homework (Gray, et al., 2006). Similarly, a study conducted by Ismayilova, Ssewamala, Mooers, Nabinya, and Sheshadri, (2012) highlights that young people miss school or drop out of school due to several reasons. Firstly, the adolescents felt a strong sense of moral obligation to prioritise care of the unwell person; they had to
accompany adults for emergency admissions to hospital, attend hospital and clinic appointments in order to fetch medication or stand in the queue for the sick person, provide care at home, including washing, medical care, intimate care (such as bathing the sick person) and sibling care (Cluver et al., 2011; Bauman et al., 2006). Secondly, the study found that young people attended school hungry as they constantly had no food for meals at home and a lunch at school. Thirdly, the study found that adolescents reported experiencing disruption and difficulties in their concentration (Cluver et al., 2011).

On the other hand, as previously mentioned, According to Piaget, the highest level of cognitive development is in adolescence, which is referred to as formal operational thinking. HIV might impact on the development of formal operational thinking in the adolescent stage (Sherr et al., 2014). This might impact on the scholastic achievements.

- **Psychological Challenges**

According to Cobb (2010), adolescence is a stage where numerous physical and psychosocial changes occur and requires adolescents to acquire new developmental tasks. As mentioned earlier, Levine et al. (cited in Laughton et al., 2013) have shown that adolescents experience challenges in developing an identity, increasing their independence, and considering the future.

According to Erikson (1968), identity is defined as an individual’s awareness and discovery of himself as an independent person with a definite role in society. He further explained that identity is made up of three components, including one’s identity (Who am I?), social identity (Which group do I belong to?) and the individual’s goals and values (What do I wish to achieve?). Furthermore, Barolsky (2003, p14) reported that “people are born into families and it is in families that they make sense of themselves and the world around them”. In the context of adolescents living with HIV/AIDS, the following may happen: important caregivers fall ill, parents die, children are orphaned, the family structure is placed under an immense pressure, and its ability to operate as a place of open socialising, economic support, nurturing and care is compromised (Van Dyke, 2012; Meyer, 2013). This results in a breakdown of the family structure and children relocating.

Consequently, the child experiences a loss of siblings, peer friendships, contact with extended family and cultural and family identity, together with a loss of a normal childhood context for
the development of healthy self-esteem. This may perpetuate the development of feelings of
loss of belonging, autonomy and control of one’s destiny, which then results in confusion.
This may perpetuate the development of emotional trauma, which may result in an identity
crisis and developmental delays (Van Dyke, 2012). In instances where the social environment
generates negative feedback or the adolescent experiences rejection, the adolescent
experiences role diffusion and identity confusion (Brown & Pedder, 1991). Adolescents who
are HIV positive are at risk of being rejected by their peers, community and the social
environment. Erickson (cited in Louw, et al, 1998) suggested that this type of negative
feedback loop may have a significant impact on this developmental stage.

From the above, it is evident that adolescents who are vertically infected with HIV can
develop identity crisis. This is further supported by a study conducted by Anastasopoulos,
Soumaki, and Anagnostopoulos (2010) found that adolescents who were perinatally infected
with HIV are unable to develop their identity, because they are unable to detach from family
and attach to peers (Anastasopoulos, et al., 2010).

According to Van Dyke (2012), HIV/AIDS may evoke highly emotional responses within
individuals who are infected with and/or affected by the disease. He further shows that people
living with HIV/AIDS experience tremendous fear, including fear of isolation, stigmatisation,
and rejection (Van Dyke, 2012). A study conducted in Zambia by Mburu, et al., (2014) found
that adolescents living with perinatal HIV/AIDS need a positive self-concept and strong locus
of control and resilience in order to effectively deal with challenges caused by the HIV/AIDS
epidemic.

A study conducted by Thupayagale-Tshweneagae, et al., (2012) had already found that
powerlessness, poor communication and difficulties in interpersonal relationships were
among the challenges mentioned by orphaned adolescents. In terms of powerlessness, the
orphaned adolescents felt anxious about what the future held for them. The anxiety was
mostly around the fear of getting pregnant, an inability to get a job, and failure to complete
their studies. Participants found the transition to adulthood challenging because they were not
sure what to do and what not to do. They also had difficulties in making decisions regarding
their life choice. Thus, the transition into adulthood was an unfamiliar territory for the
participants as they generally expressed a lack of knowledge about common things such as
where and how to get social grants and bursaries for their education, family planning and, for
some, even food rations. Warner, Malhotra and McGonagle (2012) report that a lack of assertion for adolescent girls was closely intertwined with the exclusion from essential services such as education and health. Being orphaned by a disease associated with stigma, especially AIDS, and discrimination also contributes to poor communication skills by orphaned adolescent girls (Thupayagale-Tshweneagae, et al., 2012).

The study by Thupayagale-Tshweneagae, et al., (2012) also found that orphaned adolescents have difficulties in interpersonal relationships; they find it difficult, or at times impossible, to build meaningful interpersonal relationships. The feeling of not being able to connect with others meaningfully was real for most participants. Failure to build these relationships related to their interactions with peers who manipulated them, relatives who were not empathetic towards them, or one-sided romantic relationships where their partners demanded and the participants felt obligated. The difficulty in building interpersonal relationships is a very crucial challenge because adolescence is a time of personal change and transition in which the adolescent is faced with establishing social relationships that differ from those established during childhood. Furthermore, adolescents require that individuals develop the ability to solve social problems independently. For the most part, the nature of problems in adolescence involves interpersonal relationships which require that individuals develop and effectively utilise social skills. The fact that many of the interpersonal relationship problems differ from those of childhood and are essentially being encountered for the first time often results in their resolution involving a measure of some personal difficulty (Thupayagale-Tshweneagae, et al, 2012)

Hinshaw (2005) highlights that adolescence is a period characterised by a number of developmental tasks; to deal with the demands that confront them, adolescents draw on their coping resources, which included their problem-solving competencies and skills. Adolescents are unable to deal adaptively with stress, or they have poor problem-solving abilities (Hinshaw, 2005). According to Pettit, et al., (2013), many adolescents living with HIV/AIDS suffer from self-blame and self-stigma and view themselves as lacking opportunities in their communities as compared to their uninfected peers. They also live in denial about their HIV status, and those who have accepted their status have a sense of hopelessness about their future.
Betancourt, Meyers-Onki, Stulac, Barrera, Mushash, Beardslee, Mushash, and Beardslee, (2011) note that extreme poverty, poor access to services, and family conflict, put children and families affected by HIV/AIDS at an increased risk of mental health problems. Many studies have identified common mental health problems in people living with HIV/AIDS, and listed them as depression (feeling depressed, lonely, and isolated from family and friends) (Cluver et al., 2013; Hinshaw, 2005; Lyon & D’Angelo, 2006; Miah, 2004), anxiety and stress (Cluver et al., 2013; Hinshaw, 2005), being suicidal (Cluver et al., 2013), post-traumatic stress disorder (Cluver et al., 2013), attention deficit hyperactivity disorder (Hazra, Siberry & Mofenson, 2010; Swanepoel & Louw, 2012; Donald et al., 2012; Mellins & Malee, 2013), mental retardation and cerebral palsy (Swanepoel & Louw, 2012), conduct disorder and oppositional-defiant disorder (Donald, et al., 2012).

Studies on parental bereavement and illness more have generally shown understandable negative effects on children’s well-being, which are connected to grief, loss of attachment figure, and uncertainty (Dowdney, 2008; Forrest, Plumb, Ziebland & Stein, 2006). Child abuse (severe physical, emotional and sexual abuse) was also experienced by adolescents with perinatal HIV infection as well as conflict and violence in the household (Cluver et al., 2013).

- **Adolescent’s perceptions about their chronic illness**

Younger adolescents consider their condition as fate. They seem to live with the disease without reflecting on its meaning to them or on how they acquired it. This absence of in-depth reflection may be attributed to the pattern of concrete thinking that is characteristic of early adolescence. Older adolescents keep comparing themselves with adolescents with no physical illness or developmental disabilities (Van Dyke, 2012). According to Swanepoel and Louw (2010), individuals with communication and hearing impairments and traumatic brain injury may have low self-esteem and loss of control in their social relationships. This may have resulted from an inability to negotiate within their relationships, which perpetuates feelings of inadequacy. Furthermore, Swanepoel and Louw (2010) highlight that the relationship between hearing impairment and possible HIV infection, after they had found individuals who had hearing impairment secondary to HIV/AIDS, might become socially isolating, creating feelings of discrimination and rejection, and experiencing feelings of inadequacy in romantic, peer and family relationships, which may in turn lead to the development of depression, fears, and lack of psychosocial support.
A study conducted in Rwanda and Uganda (cited in Swnepoel & Louw, 2010) found that adolescents with different disabilities may experience difficulties at school, due to inappropriate teaching techniques and access to information. In addition, the study also revealed that those adolescents might experience difficulties in accessing health services due to many health workers being unskilled in treating adolescents with disabilities.

A study conducted by Kerr, Nixon and Angalakuditi (2011) in the United Kingdom found that epilepsy has negatively impacted on children and adults who are diagnosed with HIV/AIDS. Firstly, epilepsy had negatively impacted on their emotions, thus developing feelings of anger, annoyance or frustration, sadness, bad mood, or depression, embarrassment, worry/anxiety, fear of loneliness, and, eventually, seizures. People with epilepsy also reported feelings of being different from other people around them. This may be due to their perception or actual experience of being labelled as different. Second, the study found that children and adolescents diagnosed with epilepsy may experience loss of independence and autonomy. Third, the study also found that people diagnosed with epilepsy may experience loss of control over their body and disruption of goals and plans. Fourth, the study further found that people diagnosed with epilepsy may have a low self-esteem which may have resulted from stigma and being treated differently. Fifth, it was also found that adolescents diagnosed with epilepsy may experience difficulties such as rejection in attempting to develop romantic relationships, friendship and social networks. They also felt annoyed by excessive concern and protectiveness from their parents and experienced stigma and bullying. This may further result in loneliness and social isolation. This was further supported by Wadman, Durkin and Conti-Ramsden (2011), who found that adolescents with specific language impairment are at a high risk of experiencing a high level of social stress compared to adolescents with no language impairment.

Chronic, physical illnesses and disabilities may negatively impact on the body image of adolescents. This is supported by the study conducted by Pinquart (2013) in Germany, which found that children and adolescents with chronic illnesses of obesity, cancer, diabetes, and visual impairment may be more dissatisfied with their body image compared to peers with no chronic and physical illness.
A study conducted by Hanna and Decker (2010) found that adolescents with Type 1 diabetes acquired the task of self-responsibility through self-care. This self-care takes place through ownership of one’s diabetic care and consists of both behavioural and decision-making autonomy. However, self-care may be challenged, especially were parents are overprotective towards adolescents diagnosed with diabetes and may limit autonomy.

According to Boekaerts and Roder (cited in Kraaij & Garnefskei, 2012), people who are diagnosed with chronic illnesses and are in the adolescent stage may experience numerous difficulties related to their conditions, such as dependence upon their families, isolation from peers and numerous physical limitations. Thus, a chronic medical condition may be perceived as a stressor during the developmental period. A study conducted by Kraaij and Garnefski (2012) found that chronic medical conditions, such as diabetes, rheumatism, asthma and epilepsy, have a significant relationship with depressive symptoms, which may have been caused by the use of cognitive coping mechanisms such as self-blame, ramification and catastrophising and denial.

Similarly, a study conducted by Garnefski, Koopman, Kraaij and Cate (2009) found that adolescents diagnosed with juvenile idiopathic arthritis may develop internalising problems such as depression and anxiety, which may negatively impact on their quality of life. This study also found that the cause of internalising problems may have originated from maladjustments to daily functioning by using cognitive emotional regulation strategies of catastrophising and rumination. According to Garnefski et al. (2009), rumination is defined as a preoccupation of thoughts and feelings with being diagnosed with a chronic disease, and catastrophising is defined as an excessive focus on the terror of being diagnosed with a chronic disease. Another study conducted by Forgeron, McGrath, Stevens, Evans, Dick, Finley, Carlson, (2011) found that adolescents with chronic pain are at a high risk of developing a depressive mood, low self-esteem, and becoming isolated.

Pereira and Valente (2013) found a significant relationship between adolescents with epilepsy and psychiatric disorders. A study conducted by Hillge, Beale and McMaster (2011) concluded that adolescents diagnosed with Type 1 diabetes perceived their illness as an intrusion, interruption, and immersion. Those adolescents reported that diabetes had interfered with their life goals and desires, which narrowed their choices and created a loss of self-control. Thus, they became more immersed in their disease and risked developing
depression; they developed a sense of helplessness and hopelessness towards their future, and they also experienced feelings of grief and loss associated with loss of ability and creditability.

Similarly, the study found that diabetes had negatively impacted on the adolescents’ social relationships, making them socially isolated and emotionally stressed adolescents with diabetes, lacking support and receiving conditional approval that created a risk of developing false self-behaviour. Health professionals may discomfort adolescents when achieving and sustaining appropriate diabetes management; this may lead to discouragement, anxiety, depression and suicidal ideation. On the other hand, adolescents were experiencing a decline in physical health which led to feelings of concern and worry about being rejected as a marriage partner. This is important in the adolescent stage; at this stage, approval and the task of moving away from parental authority and developing one’s own identity may be important (Hillge, et al., 2011).

According to social psychology (cited in Zambo, 2010), social identity refers to how we view and understand ourselves in relation to others – having a sense of who we are and where we belong in the world. This is also influenced by how others perceive us. In addition, adolescents with disabilities may not obtain group status due to their peers perceiving them as being different thus developing a social identity of being ‘different.’ Furthermore, adolescents with disabilities may be viewed as outsiders and may be rejected by their peers when forming groups.

From the above, it has been shown that, punctuating from the biopsychosocial approach, adolescents with perinatal HIV infection experience multiple challenges in physical, psychological, and social functioning. This has indicated the importance of treatment in order for them to cope with these challenges.

2.3.6.3. HIV Treatment for adolescents

The biopsychosocial model was originated by George Engel (1977) as a critique to the medical profession to re-examine the biomedical approach to medical education and care. According to Albelheim (2011), the biopsychosocial model requires practitioners to change their perspective of using interventions at one level of a system which might be ineffective. Thus, the practitioners should work hand-in-hand and simultaneously at multi-levels, such as
at biological, cognitive, behavioural and/or emotional levels in treatment planning and understanding of health and illness (Marks et al., 2006; Albelheim, 2011).

This is further supported by Van Dyke (2012) who notes that individuals living with HIV/AIDS experience numerous challenges ranging from physical, social and psychological challenges. Therefore, these individuals need a palliative treatment. He further defines palliative treatment as care that consists of a range of therapies, also called a multidisciplinary team, with the purpose of focusing on the physical, social and psychological needs of people living with HIV/AIDS. This type of treatment is aimed motivating living a high-quality life, and it rebuilds hope and basic skills to deal with daily functions.

### 2.3.6.3.1. Biomedical or Physical Treatment

According to Shisana et al. (2014), in South Africa, the number of people taking ARV treatment increased from 16.6 % in 2008 to 31.2% in 2012. South Africa has the largest ART programme in the world (Shisana et al., 2014). Furthermore, an increase in ARV treatment was noticed in children living with perinatal HIV/AIDS. Van Dyke (2012) reports that early testing, diagnosis and initiations of treatment were critical for caregivers and children, and that the complexity of ARV treatment was less of a barrier to treatment than issues of disclosure and support. Antiretroviral therapy rapidly improves a child’s condition and parents accepted treatment very positively. Fewer persistent side effects were observed among these children. Parents did not struggle to encourage their children to take medication, and most said that they had made it a way of life (Van Dyke, 2012). On the other hand, Pettitt, et al. (2013) report that adolescents living with perinatal HIV/AIDS and on ARV treatment may experience side effects with regard to metabolism, growth and development.

A study conducted by Thurston, Bogart, Wachman, Closson, Skeer and Mimiaga (2013) was aimed at addressing adherence issues among perinatally HIV infected adolescents and gay individuals. The study found a pattern with perinatally infected adolescents and young adults who are often fatigued by the complexity of their medication regimes and the chronicity of managing HIV their entire lives. The pattern was that the participants benefited greatly from the adherence skills they learned in the study; however, those gains were not maintained after the study had ended. The effects of neonatal HIV infection, HIV crossing the blood-brain barrier, and long-term usage of antiretrovirals may lead to deficits in neuropsychological functioning, or stunted cognitive development. These effects, coupled with the impact of
living with a chronic illness from a young age, might play a negative role in cognitive maturity, resulting in poor planning, problem-solving deficits and increased dependency on caregivers for support among perinatally infected youth (Thurston, et al., 2013).

Thus, perinatally infected youth may require consistent and frequent check-ins with a provider to ensure that they are staying adherent to their medication regimen. The importance of mood monitoring was also highlighted, as one of the participants was struggling with depression and anxiety symptoms during the follow-up sessions, which had a huge impact on her adherence. The role of disclosure in promoting adherence is also illustrated. Some participants lacked disclosure, which prevented them from taking medications at certain settings and got in the way of adherence. Whereas others with full disclosure and a sense of agency related to disclosure (by encouraging others to disclose) and promoted continued adherence to the regimen (Thurston, et al., 2013).

A study conducted by Michaud, et al. (2010) was aimed at describing the adolescents’ perceptions of their illness, their therapeutic adherence and their participation in decisions regarding their treatment, with the idea that a better understanding by health professionals of these perceptions would assist the health professionals in improving the outcomes, both in terms of the adolescents’ coping capacities and how to improve adherence to treatment in Switzerland. The results suggested that adherence was linked to the kind of relationship established with the healthcare provider. Some subjects vividly described how they were able to find new adherence strategies when openly discussing with their physicians how to improve the situation. Although, the progressive assumption of responsibility for taking one’s medication purely belongs to a process of increasing autonomy during late adolescence, the drop in adherence observed in some older adolescents may suggest that they have not developed properly (Michaud et al., 2010).

A study conducted by Mattes (2014) in Tanzania found that many institutions that offer ARV treatment were understaffed with healthcare professionals, despite dozens of people receiving treatment at these institutions. This may negatively impact on the quality of services provided to the patients, resulting in neglect of physical examination and a lack of communication between healthcare workers and patients. A lack of communication between healthcare workers and patients may result in children and adolescents experiencing inconsistent
practices and receiving insufficient information about their treatment and illness, which may further evoke confusion (Mattes, 2014).

On the other hand, a study conducted in Zambia by Mburu et al. (2014) found that many HIV clinics have healthcare workers who are inadequately trained to treat patients in the adolescent stage. This may prevent adolescents from accessing health services thus impacting on adherence to ARV treatment. Similarly, Pettitt et al. (2013) further notes that clinical services for HIV/AIDS in Southern Africa are not adolescent-friendly and healthcare workers lack skills to treat adolescents, as adolescents feel uncomfortable to receive treatment in either a paediatric clinic or an adult clinic. Furthermore, Pettitt et al. (2013) mentions that many clinical care units lack the ability to ensure a smooth transition of adolescents living with perinatal HIV/AIDS from a paediatric clinic to the adult clinic. Consequently, some adolescents may go back to the paediatric clinic or stop engaging in treatment.

Similarly, Van Dyke (2012) reports that adherence to ARV treatment was negatively impacted on by treatment fatigue, depression, relationship between patient and healthcare workers and side effects. Furthermore, other reasons for poor adherence to treatment include practical problems such as difficulties with transport to clinic, not having enough food for each ARV food requirement, lack of visiting and transport fees (Van Dyke, 2012; Pettitt et al., 2013), forgetfulness, bad planning and running out of ARVs, no social support, and stigma causing secrecy, fear and hiding of pills (Van Dyke, 2012). In addition, Piaget (cited in Van Dyke, 2012) mentions that adolescents are egocentric, and Van Dyke (2012) adds that the egocentrism of adolescents may negatively impact on their adherence to ARV treatment, as adolescents may refuse to take and/or drink medication at school because others will become aware. This leads to adolescents becoming limited in engaging in certain activities (Van Dyke, 2012). Thus, social support (such as family and peer groups) can be very important for adolescents to adhere to their medication (Mburu et al., 2014).

2.3.6.3.2. Psychosocial Treatment

Adolescence is a complex developmental process that includes the progressive adoption of autonomy and identity. Adolescents, like with other individuals, suffering from chronic conditions, and HIV-positive adolescents undergoing highly active ARV treatment face a number of challenges related to their developmental tasks. On one hand, HIV-positive adolescents have to develop their identity, a sense of a stable personality and continuity
paired with some belief in the meaning of their life and their role in the community. HIV-positive adolescents have to integrate the fact they have to take medication and they have to accept life in a context of uncertainty about whether they will survive, and for how long. Thus, beyond providing the medication and follow-up for the HIV treatment, health professionals caring for these young people must assist them in developing their autonomy as well as a stable identity by discussing the impact of the disease and its treatment on their everyday lives (Michaud et al., 2010). Fair et al. (2012) report that psychosocial support groups impacted positively on the lives of adolescents living with perinatal HIV/AIDS, including creating and giving support to those adolescents, improving behaviour at home and school, as well as motivating sharing and peer support.

- **Group therapy and support groups**

Yaloom (1995) identified aspects of group therapy that contributed to group effectiveness, including a sense of universality, installation of hope, cohesiveness, and self-understanding. These therapeutic factors are important components of human growth and change. A study by Solorzano and Glassgold (2010) examined a psycho-educational and support group for young gay and bisexual HIV-infected men, and its findings supported Yaloom’s theory on the benefits of group therapy. The participants found therapeutic value in the group through the experience of group cohesion, universality, and focus on hope. This was effective in providing support to an often isolated population of emerging adults living with a highly stigmatised illness. A study conducted by Fair, et al. (2012), aimed at evaluating the Teens Out Loud group of adolescents living with HIV infection in the United States, found that group members identified the following four benefits associated with participating in the group: increased confidence, better communication skills, increased support, and a desire to share their experiences with others.

Midtbo (2012) reports that the Teen Club (support group) and other services including counselling and medical treatment were found to be important resources for the adolescents in different ways. The themes discussed in the Teen Club were HIV treatment, reproductive health, and how to deal with different challenges related to HIV, such as stigma and discrimination. The adolescents viewed the Teen Club as a place where they could be open to one another, share problems and find support. The Teen Club seemed to make the adolescents confident and believe in themselves; they felt safe and secure. Adolescents reported that some hospital staff members are supportive while some were sources of frustration that did not
treat them well by being impatient with the adolescents, especially when receiving their medication. The adolescents reported that it was difficult to develop a trusting relationship with the doctors when they often had to see different doctors for each check-up. They developed friendships in the Teen Club. Acceptance, and being accepted and understood, were evident (Midtbo, 2012). Van Dyke (2012) shows that an effective peer support group creates a platform where control shifts from experts to the group members, allowing debates and discussions among group members, developing new group norms of behaviour, and changing education to be less threatening and available to group members.

- **Summer Camps**

Camps are designed to foster positive relationships and competence-building opportunities. They offer support and opportunities for youth to initiate and engage in behaviour that aids in the transition to adulthood (Van Dyke, 2012).

Although, camps aim to provide support and opportunities for positive youth development to all campers, occasional negative issues arise (Van Dyke, 2012). Friendship difficulties can be experienced in the camp as well as in other youth settings (Blachman & Hinshaw, 2002). However, research on the outcomes of camp participation consistently demonstrated that a camp has positive implications for identity development, social skills, physical and thinking skills, and positive values and spirituality (Bialeski, Henderson & James, 2007).

A study conducted by Gillard, et al., (2011) found that when campers felt connected to a positive accepting community that cared for them, a space was created in which campers became more open to trying out new ideas, activities and attitudes. In addition, campers saw the camp as a place to enjoy themselves, to participate in activities that they normally would be unable to do at home because of a lack of availability or accessibility (especially for those with mobility impairments). Campers reported feeling relieved from the stress of having to hide their status at home and feeling isolated; this was their escape from stress. Participants reported that while at camp, youth increased their positive attitude, skills, and knowledge in several categories. These categories included anger and conflict management, disclosure, skills learning, education and medication adherence. There was also a personal change to campers’ self-concept and self-efficacy which was influenced by participation (Gillard et al., 2011).
Florindo (2007) highlights that friendship quality is also crucial to the psychological health of youth with chronic illnesses because it affects their physical well-being. Developing connections within supportive social networks can guard against the increased chances of depression, anxiety and other psychopathological disorders. The role of leisure in the lives of people living with HIV/AIDS has been found to be important for coping with the negative effects of diagnosis, and increasing health and quality of life (Florindo, 2007).

The aforementioned studies showed that it is clear that adolescents with perinatal HIV infection benefit a lot from the psychosocial interventions. This is further supported by a study conducted by Fawzi, et al. (2012) in Uganda that found that although participants indicated psychological symptoms at the beginning of the study, this decreased with follow-ups. The psychological symptoms were headaches and stomach aches, and depressive symptoms reflecting social withdrawal among the youth, isolation, and feelings worthlessness, increased confidence, improvement in the social support and quality of life of HIV-affected youth. All these identified symptoms decreased at follow-up sessions. The participants also indicated a greater ability to cope with adversity and plans for the future; they showed great confidence in coping with the stigma attached to HIV in their communities, and an increased capacity to communicate with one another, and a stronger sense of family cohesion (Fawzi, et al., 2012).

- **Psychosocial Treatment in South Africa**

  According to Rogers (cited in Vorster, 2011), human beings are trustworthy, goal-directed, resourceful, capable of self-understanding and self-directed. This occurs if conditions fostering interpersonal growth are present. In many cases, this is not true for South African adolescents in previously disadvantaged communities. At this developmental stage, the importance of psychological interventions is fundamental to personal and interpersonal growth. This may be achieved through empathy (being understood from the individual’s frame of reference), unconditional acceptance (accepted by others without conditions and judgements) and congruence (openly expressing feelings, thoughts, reactions, and attitudes, without distorting one’s inner experiences). Vorster (2011) illustrates that empathy, unconditional acceptance and congruence enable the individual to experience self-actualisation and once this is achieved, the individual is capable to fully accept themselves and others.
There are currently a large number of young PLWHA, both globally and nationally, who have increased levels of psychological distress (Pettifor, MacPhail, Rees & Coates, 2008; Murphy, Moscick, Vermund & Muenzi, 2000) and are in need of mental health services in order to live meaningful and productive lives beyond their diagnosis (Kelly, Freeman, Nkomo & Ntlabathi, 2007; Patel, Flisher, Hetrick & McGorry, 2007). However, worldwide interventions targeted young PLWHA focus mainly on health promotion and voluntary counselling and testing (VCT), and less attention is being paid to the mental health of young PLWHA post-diagnosis (Pettifor et al., 2008; Patel et al., 2007). In sub-Saharan Africa, mental health interventions are even fewer (Pettifor et al., 2008; Patel et al., 2007). A review of programmes available to young PLWHA in South Africa found that there are mainly two types of programmes: communication intervention programmes (Abdool, Karim, Meyer-Weitz & Harrison, 2009; Shisana et al., 2009) and VCT programmes (Pettifor et al., 2008). The difference being that the former is prevention driven, and latter is confined to pre-test and post-test counselling rather than providing on-going support. In other words, neither caters for the mental health needs of young PLWHA after diagnosis (Pettifor et al., 2008; Patel et al., 2007).

Communication Intervention Programme

There are a number of communication intervention programmes (for example, Khomanani’s Coming Together, Love Life, Soul City, etc.) that have targeted young people in South Africa. Research has highlighted that such programmes focus mainly on health promotion and the prevention of HIV.

VCT model

Studies in South Africa have revealed frequent inadequate standards of counselling (Olley, Seedat & Stein, 2004; Van Dyke & Van Dyke, 2003). There has been an increase in the number of people receiving VCT, with 13.4 million people reported to have been tested in 2011 (Shisana, 2014). For example, a study conducted by Olley et al. (2004) in Cape Town found that 64% of people tested for HIV received post-test counselling. This highlights that not all patients who go for an HIV test receive post-test counselling and information about safe sexual practices, regardless of the test results. Similarly, Kelly (2001) reports very poor standards of counselling services offered to PLWHA in the Eastern Cape, where it was reported that a counsellor was reading off a pamphlet, and talking on the telephone during a session. Similar findings were reported by Russell and Scheider (2000) and Van Dyke and
Van Dyke (2003). Pettifor, et al. (2008) reports that the current VCT services are not youth-friendly and are considered inappropriate for the youth’s needs.

In summary, although the need for counselling immediately after a positive diagnosis and during the early stages of infection has been indicated, research findings suggest a contradictory picture of current counselling practices in South Africa. The needs of young PLWHA are not being met by the current health system and their testing experiences have not always corresponded with the VCT model.

A study conducted by Etang (2011) reports that participants felt that living with the knowledge of one’s positive HIV status without follow-up care and support could lead to depression, despair and death. Pettifor et al. (2008) found that the role of on-going counselling was viewed by young people as crucial to the adjustment and management of a positive diagnosis so as to prevent associated stress and psychological distress. However, on-going counselling is currently not part of the VCT model in South Africa.

Pettifor et al. (2008) found that young people had identified gaps in services by making requests for services such as on-going counselling, which currently does not form part of the services offered to them. Thus, counsellors need to pay attention to the unique needs of young PLWHA in South Africa. Similarly, Van Dyke (2012), together with Mattes (2014), highlight that many children in Southern Africa do not receive any psychosocial treatment.

**2.4 CONCLUSION**

From the consulted body of knowledge, it is evident that adolescence, on its own, is a period where individuals are faced with numerous challenges, and having to cope with a chronic illness such as HIV/AIDS can have a huge impact on the adolescents’ well-being. Furthermore, it is evident that punctuating from a biopsychosocial approach, adolescents who were vertically infected with HIV are negatively affected by HIV, which leads to physical and psychosocial challenges. It is also evident that adolescents who were vertically infected with HIV need tailor-made multidisciplinary treatment in hospitals and clinics. There is lack of such tailor-made treatments for adolescents in South Africa.

In order to develop this kind of treatment in South Africa, the healthcare professional teams should have an understanding of the experiences and thought of adolescents who were
vertically infected with HIV. There seems, however, to be a paucity in research pertaining to the experiences and thoughts of adolescents who were vertically infected with HIV in South Africa. Hence, this study was conducted. The research methodology and design of the current study will be discussed in the next chapter.
CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION
This chapter will provide information on how the study was conducted. It will provide an explanation on the research design implemented, the research setting, research population and data collection techniques applied. Furthermore, it will explain data management and analysis, and lastly provide a detailed explanation on the ethical considerations.

3.2 RESEARCH DESIGN
According to Cresswell, Eberöhn, Eloff, Ferreira, Ivankova, Jansen, …, (2011), a research design is referred to as a framework which involves steps starting from the underlying philosophical assumption to the selection of participants, the data collection methods and the data analysis to be done. Bertram and Christiansen (2014) showed that the aim of a research design is to create a framework to reach a bridge between research questions and the execution of the research. Denscombe (2010) illustrates that the choice of a research design must go hand-in-hand with the research question. Babbie (2010) shows that there are three most common research designs, namely descriptive, explanatory, and exploratory where:

3.2.1. Descriptive research design
Descriptive research has the purpose of describing situations and events in that the researcher observes and then describes what was observed – the aim is description (Babbie, 2010). Punch (2014) adds that descriptive research aims to describe what happened, or describe how it unfolded, or describe what something or someone looks like.

3.2.2. Explanatory research design
Explanatory research explains and attempts to answer the question of why (Ritchie, Lewis, Nicholls, & Ormston, 2014).

3.2.3. Exploratory research design
Exploratory research explores a topic by starting with familiarising the researcher with that topic. Exploratory research has three major aims, that is; to have a better understanding; to test the possibility of undertaking a more extensive study; and to create procedures which can
be used in any subsequent study (Babbie, 2010). Terre Blanche, Durreim and Painter (2006) found that exploratory research uses open, flexible, and an inductive approach as they attempt to uncover new insights into the phenomenon.

The design for this study was based on an exploratory qualitative approach which was carried out through a face-to-face interview based on an interview guide. Conversations from the interview were also recorded using a tape recorder and transcribed. This approach was selected with the aim of exploring and documenting the subjective lived experiences of adolescents who were infected with HIV through vertical transmission at birth and are receiving treatment at Dr George Mukhari Academic Hospital. The research design has been employed to meet the following objectives which also make up research questions that need to be answered:

- To gain insight into the experiences and challenges of adolescents who are vertically transmitted with HIV;
- To explore the current support systems of adolescents who are vertically transmitted with HIV; and
- To stimulate future research and generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

The aims and objectives of the research were achieved by engaging an exploratory research design rather than a descriptive and explanatory research design. Hence, this study is an exploratory research, in that the study attempts to understand, explore, stimulate future research and create debate around the importance of psychological interventions.

3.3. QUANTITATIVE AND QUALITATIVE RESEARCH METHODS

Many research methods exist in order to create a framework for guiding the researcher in conducting the research. The researcher chooses the best research methodology that will fulfil the purpose of that study. According to Punch (2014), there are two types of research methods namely quantitative and qualitative research methods. In order to highlight these research methods, the researcher has looked at the characteristics of both, and the criticisms against these research methods.
3.3.1. Quantitative research methods

According to Cresswell, et al. (2011), a quantitative research method is defined as a process which utilises numerical data through systematic and objective ways, and is collected from a small portion of the population (sample) to generalise the results to the population that has been studied. Similarly, Hurley, Denegar, and Hertel (2011) highlight that quantitative research creates a framework of scientific method in that the researcher manipulates the context by objectively and systematically collecting data and utilising statistical analysis to test hypotheses. Punch (2014) summarises both definitions by stating that in testing the hypothesis, the researcher examines the relationship between the variables which can be measured, typically on instrument, so that numerical data can be analysed using statistical procedures.

Furthermore, Punch (2014) highlights that the aim of quantitative research is to determine the relationship between the independent and the dependent variables. Bertram and Christiansen (2014) note that the independent variable is the cause variable, whereas the dependent variable is the result or outcome of another variable. Therefore, independent variables cause the dependent variable to change (Punch, 2014; Bertram & Christiansen, 2014; Richards & Morse, 2007).

In order to reach the aim, the researcher utilised a post-positivist approach that entailed that the researcher works under the framework of a cause-and-effect thinking, reduction to specific variables, hypotheses and questions, and utilises instruments and observations to test the theory (Punch, 2014).

In a nutshell, a quantitative research method is best in finding probabilistic relationships among variables in a large population, and conceptualises reality in terms of variables.

Quantitative research has its limitations, in that:

- The researcher has little or no contact with people or field settings (Punch, 2014).
- Statistical correlations may be based on variables that are arbitrarily defined by the researchers themselves (Punch, 2014; Grey, 2009).
- The variables are measured without including context (Punch, 2014; Grey, 2009).
The methods used do not allow for participant individual differences or opinions to be highlighted (Punch, 2014).

### 3.3.2 Qualitative research methods

According to Punch (2014), qualitative research is a method which studies the subjective meanings of individuals’ experiences and behaviours within their social context. Silverman (2011) illustrates that the aim of qualitative research is to study and recognise how people perceive their social problems and situations. Frost (2013) indicates that the researcher places the texts of participants into context with the aim of exploring and understanding the participants within their context. This is further supported by Vorster (2011) who found that behaviour does not exist within a vacuum; behaviour occurs within a specific context and the context defines and impacts on the behaviour. Thus, the context is very important.

Bertram and Christiansen (2014) show that qualitative research punctuates from an interpretive, naturalistic approach where the researcher studies participants in their natural context. The aim of qualitative research is to explore and understand a phenomenon from the participants’ frame of reference (Bertram & Christiansen, 2014). Terre Blanche et al. (2006) coined the concepts ontology and epistemology meaning that qualitative research attempts to consider the participants’ frame of reference as it is part of their reality (ontology), and attempting to understand the participants’ subjectivity by interacting with them and carefully considering what they say with the aim of creating a space of permitting participants to answer questions posed by the researcher with in-depth answers. This may provide important information to close gaps which might have been missed by other studies (Terre Blanche et al., 2006).

In summary, Punch (2014) has shown that qualitative research is the finest approach in getting an insider’s perspective to study the lived experiences of people, including people’s meanings and purposes.

Qualitative research has its limitations, in that:

- It is sometimes viewed as less valid and reliable when compared to quantitative research (Punch, 2014; Terre Blanche, et al., 2006).
• The results are often non-generalizable and specific to the event or individuals studied (Punch, 2014; Richards & Morse, 2007; Terre Blanche, et al., 2006).

In this study, a qualitative research method was utilized in order to meet the aim and objectives of the study.

3.3.3. The rationale for choosing qualitative research method

In this study, qualitative research was chosen as method of choice to investigate this phenomenon rather than a quantitative approach. Also, qualitative research is best suited in discovering an insider’s perspective in the study of the lived experiences of people, including people’s meanings and purposes. Contrarily, quantitative research is best in finding probabilistic relationships among variables in a large population, and conceptualises reality in terms of variables (Punch, 2014).

The main aim quantitative research is to test hypotheses and statistical generalisations whereas qualitative research aims to understand the nature of the research problem rather than the quantity of observed characteristics (Baškarada, 2014). Qualitative research is important to understand an individual’s attitude and beliefs, motives and demands, or obstacles that hinder the understanding of the contextual experience of the individual. If reduced to a number alone (such as 5%) the findings would lose their context. Furthermore, qualitative research focuses on the study of issues in depth and in detail, and tends to centre on how people make meaning out of their experiences (Stuckey, 2013).

The main aim of qualitative research is in line with the aim of this study. Qualitative research has enabled the researcher to create a space where the adolescents who were perinatally infected with HIV have provided the researcher with richer responses which aided the researcher in understanding the adolescents’ frame of reference, within the adolescents’ context; and recognise how adolescents who are living with perinatal HIV infection perceive and understand their social problems and situation. Furthermore, qualitative research gave voice to the participants in the study and it allowed the participants to show their experiences of living with HIV. This has opened eyes to new aspects of the experiences of the participants.

The next sections will discuss the research design and research method of the current study.
3.4. STUDY SETTING
According to Bazeley (2013) the context is vital in qualitative research and cannot be ignored as it influence the place of behaviour. Vorster (2011) shows that the context defines and impacts the behaviour of an individual. Neuman (2009) found that the meaning of a social action or statement depends on the context in which it appears and when a researcher removes an event, social action, answer to a question, or conversation from the social context in which it appears, the social meaning and significance are distorted. Thus, Bazeley (2013) notes that in qualitative research a thorough explanation of research context very crucial.

In this study, the initial proposed setting was Tshepang Clinic; however, the researcher was unable to find potential participants who met the criteria (to be discussed later). Consequently, the setting was the Paediatric Clinic at Dr George Mukhari Academic Hospital. According to the nurse-in-charge of the Paediatric Clinic, the potential participants are kept at this clinic instead of being transferred to the adult clinic because they have a history of poor adherence to treatment. The nurses and doctors aim to assist the potential participants to adhere to treatment before they are transferred to adult clinic.

The Paediatric Clinic caters for children from birth until they reach 14 years old, as well as the adolescents who were vertically transmitted with HIV and have difficulties with adherence. The clinic is divided into two sections: the general section which treats all diseases that affect children and another section for antiretroviral therapy (ART) focusing only on children who receive treatment for HIV. The patients attend the clinic once a month as outpatients for doctor’s appointments. The patients are only seen by doctors and nurses for receiving ARVs. Some patients have been on medication since a young age. The participants of this study were found in this setting. The in-depth interviews were conducted in a consultation room during official hours before the participants consult the doctors. This room was a private, comfortable and quiet setting with no disturbances.

3.5. RESEARCH SAMPLING AND POPULATION
Bertram and Christiansen (2014) define a population as a group of people or organisations that could be involved in research. Bertram and Christiansen (2014) also show that it would be impossible to study the whole population, so the researcher needs to choose a sample from the population. DePoy and Gitlin (2011) define a sample as a subset of the population; and/or the individuals or units from the population which has been identified for the research. This
subset of the population is obtained through sampling (Depoy & Gitlin, 2011). According to Hurley, et al. (2011) sampling is referred as the process of selecting of research participants from the population. There are two types of sampling methods, namely; probability and non-probability sampling (Babbie, 2010). Non-probability sampling involves selecting subjects from any kind of sampling which is not based on the statistical principle of randomness; whereas probability sampling uses random selection where each element in the sampling frame has an equal and independent chance of being selected for the sample (DePoy & Gitlin, 2011).

The various types of non-probability sampling are discussed below:

3.5.1 Convenience sampling
DePoy and Gitlin (2011) define convenience sampling as a process where the researcher involves any available subjects or elements as they enter the study until the desired sample size are reached. Hence, it is referred to as accidental sampling. For example, the researcher may stop people at the corner of the street. This type of sampling is important when the population is not known (David & Sutton, 2010). On the other hand, Babbie (2010) adds that this type of sampling does not allow any control over the representativeness of the sample and the researcher must be cautious about generalising from the data. The disadvantage of using this sampling method is that it is not generalizable to the population, thus creating problems in analysis beyond simply describing the sample (David & Sutton, 2010).

3.5.2 Snowball sampling
According to DePoy and Gitlin (2011), snowball sampling is referred as a process that includes requesting subjects to provide access to others who may meet the study criteria. This sampling is mostly utilised when the researcher does not have direct access to the population (DePoy & Gitlin, 2011). Babbie (2010) reports that in this type of sampling, the researcher initially conducts research on a few individuals of the target population that he/she can find and then requests those few participants to provide the details required to find other individuals of the population whom they happen to know. In addition, David and Sutton (2010) report that the disadvantage of this type of sampling is that it will lead to sample bias because the sample will only reflect the participants who are preferred by those who have selected them.
3.5.3. Quota sampling
Babbie (2010) highlights that quota sampling involves a process where the researcher starts with a table or matrix describing the features of the target population and is aware of the proportion of each feature. The researcher then collects data from individuals having all the characteristics of a given proportion and the overall data should include a reasonable representation of the population (Babbie, 2010). The proportion of each feature is predefined categories, and these categories are also referred to as quotas. The quotas are chosen to accurately represent the population’s profile (David & Sutton, 2010). Furthermore, David and Sutton (2010) highlight that the disadvantage of this type of sampling include choosing a certain type of sample with preferred characteristics of the quotas and excluding other population characteristics, such as, ethnicity, might limit the information for the full population characteristics.

3.5.4. Purposive sampling
Babbie (2010) refers purposive sampling as the process of selecting an appropriate sample on the basis of knowing population and the purpose of the study. It also uses the judgement of an expert in selecting cases (David & Sutton, 2010). Bertram and Christiansen (2014) report that this type of sampling is effective if the researcher does not intend to generalise the research results beyond the grouped sample.

The proposed study aims to explore and document the experiences of HIV positive adolescents, aged between 15 and 18 years. The study population includes all adolescents who were vertically transmitted with HIV. The sample frame was chosen from individuals attending the outpatient clinic at Dr George Mukhari Academic Hospital in Ga-Rankuwa, Gauteng Province. The sample was selected through non-probability sampling. The main concern is not on the size of the sample; in qualitative research, the researcher typically collects data until saturation is reached (Punch, 2014). Therefore, small portion/sample of the population was 11 participants or until theoretical saturation is reached – the point in data collection where new data can no longer brings additional insights to the research questions.

Convenience sampling was inappropriate for the study since the sample is known. Also, because the researcher had direct contact with the population, snowball sampling was inappropriate. Since no preference towards gender, race, or ethnicity was given and the participants gave consent to participate in the study, quotas sampling was also inappropriate.
The researcher has selected the sample through purposive sampling from the Paediatric Clinic. Purposive selection has enabled the collection of the most relevant data, thus allowing the researcher to use certain criteria to select participants (Baškarada, 2014).

The researcher has highlighted inclusion criteria and exclusion criteria for participants. Baškarada (2014) mentioned that a criterion for selection of participants is utilized to strengthen accuracy and evidence. Inclusion criteria and exclusion criteria will be discussed next.

**Inclusion criteria:**
The sample in this study will consist of:

- Participants who are adolescents (between ages of 15-18 years)
- Participants who are vertically transmitted with HIV.
- Participants who are minor, consent to participate in the study will be requested from their parents/guardians
- Only participants who are on treatment at Dr George Mukhari Academic Hospital will be included

**Exclusion criteria:**

- Individuals who are vertically transmitted with HIV but are in a different developmental stage other than adolescents between ages of 15-18 years
- Individuals who are not vertically transmitted with HIV, however are infected with HIV from other modes of transmission (discussed in chapter 2)
- Individuals who are minor and whose parents decline to give consent for participating.

After the sampling process, it will be followed by data collection.

**3.6. DATA COLLECTION**

According to Bertram and Christiansen (2014) data is defined as information or evidence that the researcher gathers with the aim of finding answers to the research questions. Data can be collected through many forms, namely: from documents, observation, individual interviews, and focus groups.
3.6.1. Documents
Documents can be used to gather data in instances where the researcher utilises written communications that may give insight on the concept that is investigated. Written communication includes published and unpublished documents, company reports, memoranda, agendas, administrative documents, letters, emails, faxes, newspaper articles, or any document that focuses on the study subject (Cresswell, et al., 2011).

3.6.2. Observations
Observation is a strategy that involves recording the behavioural patterns of participants without necessarily asking questions or communicating with them. Observation is done daily where the researcher relies on his/her senses (seeing, hearing, touching, smelling, and tasting) (Cresswell et al., 2011). The advantage of observation, as a data collection method, is that it allows the researcher to gain insight into the situation. On the other hand, observation is selective and as a result, the researcher may choose, select and focus on interactions that are based on his/her frame of reference for interpretation. Therefore, observations are disadvantageous because the researcher may perceive only what he/she expects to see. Furthermore, the presence of the researcher might impact on the situation and observation may be disturbing to the participants (Bertram & Christiansen, 2014).

3.6.3. Focus group
The focus group strategy is a group intervention where the researcher uses semi-structured and structured questions with a specific topic addressed to participants within the group; debate and conflict in the discussions within the group is allowed and group dynamics are also included as part of data gathering (Cresswell et al., 2011).

In addition, David and Sutton (2010) highlight that although the advantage of the focus group is to allow the participants to have more control over the direction of the discussion, the researcher is ethically unable to guarantee confidentiality and the participants may not feel totally secure to discuss issues that might be sensitive in nature within the group. As a result, this may adversely impact the depth validity of the data obtained. Furthermore, David and Sutton (2010) also highlight that the focus group allows members of the group to stimulate others within the group. Consequently, dominant members within the group may control the discussion, resulting in limited participation from group members or similar expressed views.
Another issue is that the members of the group might attempt to please the researcher or facilitator (David & Sutton, 2010).

3.6.4. Individual interviews

An interview is an interaction between an interviewer and a participant where the interviewer asks the participant questions to gather data and to understand the ideas, beliefs, perceptions and behaviours of the participant. A qualitative interview aims to understand the participant’s frame of reference to facilitate understanding of the participant’s reality and social functioning (Cresswell, et al., 2011). The advantages of interviews is that the researcher is present when conducting interviews and can ask more questions, and seek clarity for more information. This method of data collection is important when obtaining in-depth information from a small portion of people. The disadvantage of this method is that the researcher may influence the type of information obtained from the participants (Bertram & Christiansen, 2014).

Furthermore, Bertram and Christiansen (2014) note that individual interviews can be divided into structured semi-structured and unstructured interviews. In structured interviews, the researcher uses questions that require closed responses (for example, yes or no, or one-word answers). Furthermore, David and Sutton (2010) mention that structured interviews are good in keeping reliability and repeatability, as well as allowing greater scope of quantification. The semi-structured nature of the interview allows the researcher to keep the interview on track and guide the participant through various themes. Following the unstructured interview strategy, the respondent speaks openly and freely about the topic with no directions from the researcher (Bertram & Christiansen, 2014). Furthermore, David and Sutton (2010) stress that the semi-structured and unstructured interviews allow more depth and personal details; however, they create difficulties in numerical comparisons.

In this study, the data was collected from adolescents who were vertically transmitted with HIV and receive treatment at Dr George Mukhari Academic Hospital. The researcher did not use documents as a method for collecting data because there is insufficient past documents that focus specifically on the adolescents who were vertically transmitted with HIV and are presently receiving treatment at Dr George Mukhari Academic Hospital. Furthermore, the researcher did not choose observation for data collection to avoid punctuating from his/her frame of reference for interpretation, choosing what to expect and influencing the interactions
of the adolescents. In addition, the focus group method of data collection was not selected because HIV is a sensitive topic and the participants may feel uncomfortable speaking about their sensitive issues thus impacting the quality and depth of the information. In addition, the researcher has not chosen structured and semi-structured interviews because this might impact on the depth of data.

As a result, the researcher has chosen the flexibility of unstructured, in-depth interviews with each participant using an interview guide with open-ended questions as a means of data collection. The nature of unstructured open-ended interview questions allowed the researcher to keep the interview on track and to guide the participant through various themes outlined in the interview schedule (Appendix C). The interviews have broadened the researcher’s frame of reference into a social phenomenon rather than assuming that the information obtained was representative of a larger population.

Furthermore, the interviews were used on a small number of participants as a way of understanding the complexity of the participants’ behaviour, rather than imposing prior categorisation which may limit the field of investigation (Punch, 2014). The aim of the open-ended interview is to elicit the participant’s story. This is achieved through the utilisation of probes or open-ended questions, which are designed to elicit information, or to clarify themes (Bertram & Christiansen, 2014). The questions used in the interview are designed and based on the aims and objectives of the study.

Notwithstanding, how the researcher conducts the individual interviews is of paramount importance. In the next section, the procedure of conducting the research will be discussed.

3.7.PROCEDURE
The permission for conducting the research was granted through three research committees. The first research committee is the Dr George Mukhari Academic Hospital Research Committee which approved the research protocol to be feasible, thus permitting the study to be conducted at Dr George Mukhari Academic Hospital, on condition of the study being approved by the School Research Ethics Committee (SREC) and Medunsa Research Ethics Committee (MREC), respectively. Both research committees granted permission for the research to be conducted (See Appendix D and E).
Outpatients who meet the criteria for participating in the research have their appointments set every Tuesday in the Paediatric Clinic. The nurse-in-charge of the Paediatric Clinic reported that this clinic keeps adolescents who are on ARV treatment because they are or have defaulted on their treatment and the nurses and doctors are attempting to assist the adolescents to adhere to their medication before sending them to local clinics.

During data collection, the researcher was introduced to patients by the nurse-in-charge of the clinic in the morning before the doctor starts with patients. Then the researcher explained the research and criteria for participating in the research to the patients. Once the patients and their parents verbally agree to participate in the study, they were given a package including an information pamphlet (Appendix A), and the consent form (Appendix B). Each patient, together with their parents or guardians, was given a chance to read through the information pamphlet and consent form and to ask questions for clarity. For those participants who are ethically eligible to consent, the researcher obtained their permission by accepting their signed consent forms before participating in the research. For those patients who are considered minor, the researcher obtained the permission from the participant and their parents/guardians by accepting their signed consent forms.

The researcher has emphasised and guaranteed the issue of confidentiality, anonymity, privacy, and confidentiality of the data. Only then can the researcher start individual interviews in a consultation room where privacy and confidentiality are ensured. Initially, the researcher has established rapport by speaking with the patient about topics that the participant is comfortable with and creating a space where the participant will feel at ease. The duration of the interview was approximately 60 to 90 minutes. The interviews were tape-recorded with consent from the participants. Once the interviews are completed, each interview was transcribed and validated by reading through each transcript thoroughly whilst listening to the recorded interview to ensure that no errors have occurred. After transcription and validation, the next step will be data analysis which is discussed in the next section.

3.8 DATA ANALYSIS

Bertram and Christiansen (2014) define data analysis as the process of separation of a whole into its parts. David and Sutton (2010) also illustrate that qualitative data analysis is defined as being able to extract meaning from the content. The process of data analysis is to create and identify meaningful themes, ideas, and beliefs. In addition, Cresswell (2009) also reports
that data analysis inductively builds from particulars to general themes while the researcher interprets the meaning of the data. Thus, the aim of data analysis is an attempt to understand how the participants view the specific phenomenon; this is obtained by analysing their thoughts, attitudes, understandings, knowledge, values, feelings and experiences (Cresswell, 2009).

There are numerous types of data analysis methods: narrative, grounded theory, discourse, conversation, interpretative phenomenological analysis and content analysis (Punch, 2014). The researcher has chosen content analysis for analysing the data collected for this study.

Ritchie et al. (2014) report that content analysis is the process of analysing both the content and context of documents, with the researcher identifying themes, and focusing on the way the themes are treated or presented and the frequency of their occurrence. In addition, Bazeley (2013) reports that content analysis is a systemic approach of analysis that identifies and summarises message content. Content analysis is usually used in analysing books, brochures, written documents, transcripts, news reports, and visual media; as well as analysing open-ended questions from surveys, interviews or focus groups. It is a process of looking at data from different angles with a view of identifying keys in the text that will help us understand and interpret the raw data (Bazeley, 2013).

Content analysis is beneficial in such a study because it (Writing@CSU Writing Guide, 2014):

- looks directly at communication via texts or transcripts, and hence gets at the central aspect of social interaction;
- allows a closeness to text which can alternate between specific categories and relationships;
- is an unobtrusive means of analysing interactions; and
- Provides insight into complex models of human thought and language use.

Content analysis is disadvantageous in its use because:

- it is subject to increased error;
- it is inherently reductive, particularly when dealing with complex texts as it tends to often consist of simple word counts; and
Content analysis was found to be appropriate to refine and group words into fewer related categories which can then provide meaning (Elo & Kynga, 2008; Punch, 2014). This process has also allowed the researcher to extract words, concepts, categories or themes from the data that support the interpretation of the data.

The researcher has applied the data analysis process as proposed by Taylor-Powell and Renner (2003) and Bazeley (2013) as follows:

**Step 1: Get to know the data**
The researcher has learnt and understood the data through listening to the voice recordings several times and transcribing the voice recordings. Then, the researcher wrote down the clinical impressions which were useful in compiling a matrix to categorise the interview data captured from the participants as guided by the interview guide.

**Step 2: Categorise information**
Information was categorised by bringing meaning to the words which involved re-reading the text and identifying consistent categories. The researcher assigned abbreviated codes and placed them next to the ideas found. This helped to organise the data into categories. The researcher was clear about what was included and excluded in the category by using the matrix for ease of creating meaning into statements expressed by the participants.

**Step 3: Identify patterns and connections within and between categories**
The researcher organised the data into category patterns and/or connections (relationships) with specific themes identified, both within and between the categories.

**Within category description:** the researcher captured the similarities and differences of the participants’ responses within a category. The researcher identified key ideas, similarities and differences being expressed within the category.

**Larger categories:** the researcher created larger or super categories that combined several categories starting from more specific categories to larger or general ideas and concepts.
The individual parts/themes were linked and related to broader themes across different categories.

**Relationships:** the researcher explored categories which occur consistently across the data. The researcher explored the connections within the experiences and challenges of HIV-positive adolescents, who are currently undergoing treatment, reviewed the cause and effect (action-reaction) relationship, and created a sort of sequence for the purposes of analysis. These connections were useful to explain the experiences and challenges faced by the HIV-positive adolescents who are currently undergoing treatment efficiently.

**Step 4: Interpretation—bringing it all together**
The researcher applied categories and connections to explain the findings. This was achieved by attaching meaning and significance to the analysis. The findings are described in Chapter 4 and 5 of this research report.

The participants’ gender was maintained as either male or female, and they were further identified according to codes. For the female participant the letter F will precede the code and the letter M will be used to refer to the male participant in the coding. Also where the interview question required either a “yes” or “no” answer, this was also categorized and quantified in order to create data categories for ease of explaining the findings.

**3.9. TRUSTWORTHINESS**
According to Holloway and Wheeler (2010), trustworthiness in qualitative research is referred to as procedural accuracy and adequacy of the study. Trustworthiness in qualitative research has four concepts, namely: credibility of the interpretations of the data; transferability of the results of the study beyond the bounds of the project; dependability of the quality of the study; conformability of study whereby the research results meet the aims and objectives illustrating that the researcher did not manipulate the results (Holloway & Wheeler, 2010).

In this study, trustworthiness was ensured through the development of a research audit trail. Bazeley (2013) suggests that a study’s trustworthiness may be established if a reader is able to audit the events, influences and actions of the researcher, while Akkerman, Admiral, Brekelmans and Oost (cited in Carcary, 2009) suggest that audit trails represent a means of
ensuring quality in qualitative studies. During the implementation of a research audit trail, an auditor or second party becomes familiar with the qualitative study, its methodology, findings and conclusions. This process allows for an objective audit of the researcher’s decisions, methodological approach and analytical processes. Furthermore, this ensures that the researcher has completed the study, thus confirming the research findings. In order to develop a detailed audit trail, the researcher has maintained a record of all research activities, develop notes, and document all data collection and analysis procedures throughout the study. This allowed the researcher to follow each stage of the research process and trace through the researcher’s logic. In addition, it provided other researchers the opportunity to determine whether the research findings may be reliable or require further inquiry (Carcary, 2009). The researcher has utilized up to three independent researchers during the research audit trail.

3.10. BIAS

According to DePoy and Gitlin (2010), bias is defined as the chance of having an unintended or unavoidable effect on study outcomes. The researcher was cognisant of the following sources of bias: firstly, assumption (conceptual) bias which is an error arising from the faulty logic of the investigator that can lead to faulty conceptualisation of the research problem, faulty interpretations and conclusions. This can be minimized by using three independent researchers to verify the primary researcher’s conceptualisation of the research problem, interpretations and conclusions. Secondly, the biases may occur from the anxiety generated in the participants being tested. This may lead to participants giving responses that are not their true responses. Thirdly, interviewer bias may occur based on particular values that have the potential to lead to a social desirability response, or by asking leading questions (DePoy & Gitlin, 2010). These types of bias was minimised by using Person Centred Interviewing (PCI) when conducting the interviews.

In PCI, the interviewer adopts four principles which are non-directive, empathy, unconditionally accepting and congruency. The four principles were originated from Person Centred Therapy (PCT) by Carl Rogers in the 1940s (Vorster, 2011). This method of interviewing provides the interviewee with an optimal psychological ‘climate’ in which he/she could feel understood, accepted and respected. This method mobilised the interviewees to set out his or her experiences without being restricted in any significant manner (Vorster, 2003).
ETHICAL CONSIDERATIONS

According to Denscombe (2010), ethics is defined as an organisation of moral principles by which individuals can judge their actions as right or wrong. Thus, Bertram and Christiansen (2014) highlight that ethics are crucial in research, especially with research that studies humans and animals. Furthermore, Denscombe (2010) reports that social researchers are expected to conduct their research in an ethical manner, meaning that researchers need to introduce a moral perspective to the way they design and conduct their investigations. There are several ethical codes which need to be considered:

3.11.1 Ethical approval

According to Denscombe (2010), researchers need to gain formal approval from a research ethics committee before they embark on research. The relevant committees are those that screen proposed pieces of research to check that they meet ethical principles for research (Denscombe, 2010). Furthermore, DePoy and Gitlin (2011) note that there are very strict protocols that require anyone planning to conduct research to submit a proposal to a research ethics committee for approval. Universities normally make use of ethics committees to ensure that research conducted under their auspices conforms to the relevant principles (Denscombe, 2010). In this study, the research proposal was submitted to three committees: the hospital research committee at Dr George Mukhari Academic Hospital, SREC and MREC (Appendix D and E, respectively) prior to the commencement of the research.

3.11.2 Autonomy

According to Bertram and Christiansen (2014), research must be conducted in such a way that respects the autonomy of all participants. Similarly, DePoy and Gitlin (2011) add that participants should be treated as autonomous individuals who are capable of personal choice and self-determination. This implies that the researcher must obtain the permission of every individual participating in the research; every person must participate voluntarily in the study, and they must have the freedom to withdraw at any time (Bertram & Christiansen, 2014; Punch, 2014). Autonomy leads to another ethical consideration of informed consent. In this study, participants were informed that their participation in the proposed research study is voluntary and they may, at any time, withdraw from the research study should they want to.
3.11.3. Informed Consent

Before the participants give permission, the researcher must clearly explain what the research study entails and is expected from the participants, so that the participants can make an informed choice to participate voluntarily in the research (Bertram & Christiansen, 2014; David & Sutton, 2010). Thus, it is important that the participants give voluntary consent. This means that the person involved should have legal capacity to give consent; each participant should be so situated as to be able to exercise free power of choice without the intervention of any element of force, fraud, deceit, duress, over-reaching or any other ulterior form of constraint or coercion. Each participant should have sufficient knowledge and comprehension of elements of the subject matter involved as to enable him/her to form an understanding and take an enlightened decision (Denscombe, 2010). In this study, the researcher explained the research and criteria for participation in the research to the patients. Once the patient and parent/guardian verbally agree to participate in the study, they were given a package including an information pamphlet (see Appendix A), and the consent form (see Appendix B). Each patient together with their parent/guardian was given a chance to read through the information pamphlet and consent form and ask questions for clarity where applicable.

Special populations, such as children, mentally retarded individuals and prisoners, require particular care with regard to obtaining consent. Researchers need to get the consent of a legal guardian when working with the special populations (David & Sutton, 2010; Bertram & Christiansen, 2014). In this study, the researcher was cognisant of the fact that all participants of the proposed research study are adolescents; the researcher obtained informed consent from the parents or the legal guardian, and from the participants if they met the legal age for consent.

Furthermore, Bertram and Christiansen (2014) note that for the researcher to have informed consent from the participant, the potential participant needs to be provided with written information to understand what the research is about and what type of commitment is called for. In this study, the informed consent forms (see Appendix B) were given to the participants and their parents for obtaining written informed consent. The informed consent form has outlined information about the study so that the participants have full knowledge of the study and their participation roles.
3.11.4. Non-malfeasance

According to Punch (2014), the meaning of non-malfeasance is to do no harm. The researcher should do no harm to the research participants or to any other person. Researchers need to consider whether their study will do any physical, emotional, social or any other harm to any person. Furthermore, Bertram and Christiansen (2014) highlight that sometimes participants could be negatively affected if their personal information is made public. Therefore, participants need to know how the information will be made public. This generally means that all participants need to be assured of the confidentiality of the information supplied by them. This means that researchers need to be careful in protecting the identities of the groups and individuals when they publish the results of their study (Bertram & Christiansen, 2014; Punch, 2014). For instance, the researcher should avoid publishing reports of the research which allow individuals or organisations to be identified either by name or by role (Denscombe, 2010). To protect such identities, researchers tend to use pseudonyms for people and organisations. However, it is not enough that names are changed, it may also be necessary to change the descriptions of the participants or schools (Bertram & Christiansen, 2014). In this study, participants were informed that the research findings of the proposed research study might be published; however, the participants’ names and identifying information will not be mentioned. The researcher made use of pseudonyms to protect the identity of the participants.

However, Hennink, Hutter, and Bailey (2011) indicate that the researcher might be faced with a challenge of dealing with emotions. The research may focus on a sensitive topic, such as rape, HIV/AIDS or human trafficking. For qualitative research on clearly sensitive issues that may cause emotional stress to participants, it is good practice to have a counsellor involved in the study to which participants can be referred if needed (Hennink, et al., 2011). In this study, the focus of the study was on HIV/AIDS, which is a sensitive topic and may elicit distress from the participants. Those participants who might be left with an unfinished emotional impact from the interviews will be referred to the clinical psychologist at Dr George Mukhari Academic Hospital. In this study, one participant was left with an unfinished emotional impact from the interviews and was referred to the clinical psychologist at Dr George Mukhari Hospital.
3.11.5 Beneficence
According to Bertram and Christiansen (2014), the research should be of benefit, either directly to the research participants, or more broadly to other researchers and to society at large. Beneficence means the study must be beneficial. In addition, Hennink, et al., (2011) note that the researcher should bear in mind whether the research will contribute to theoretical knowledge, or whether conducting research will respond to a problem from the research community or for an organisation working with the study community. This will be reflected in the purpose of the research and its outcome (Hennink, et al., 2011). Other objectives of this study include to stimulate future research, and to generate debate around the importance of psychological interventions at tertiary hospitals in South Africa. This will be beneficial to future studies, and to stimulate intervention of psychological treatment at tertiary hospitals which will benefit the community.

3.11.6 No misrepresentation or deception
According to Denscombe (2010), social researchers are expected to be honest and open about who they are, what they are doing and not rely on misrepresentation or deception as a means of getting the necessary information. In this study, the researcher displayed a student card which has researcher's full personal detail. Furthermore, the researcher was formally introduced to the population and gave a full context about the study before giving out the consent forms.

3.11.7 Security of the data
The researcher will ensure that records, data and information that relates to individuals are kept secure. Thus, the researcher has the responsibility to keep the information secure, and to ensure that the information is used for the purposes for which it is meant for (Denscombe, 2010). In this study, all identifying data were kept confidential. In addition, the raw data was stored in a secure environment.

3.11.8 Confidentiality
As with any research, reasonable precautions should be taken to avoid the disclosure of personal identities and sensitive information to third parties. The participants should be reassured about confidentiality (Denscombe, 2010). In this study, all interviews were conducted in a place that allows for privacy and confidentiality. In addition, confidentiality
was ensured by using anonymity in the writing of Chapter four of the results and when publishing the results.

3.12. CONCLUSION
In the current Chapter, the research methodology was discussed. The rationale for using the qualitative approach was explained. The methodology and the procedures employed for data collection and analysis were discussed extensively. The process of data collection brought about the information and results that will be discussed in the next chapter.
CHAPTER 4
PRESENTATION OF RESULTS

4.1 INTRODUCTION
The aim of the study was to explore the experiences and challenges of adolescents who were vertically transmitted with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital in Ga-Rankuwa, Gauteng Province. The study was carried out using thorough face-to-face interviews based on the qualitative approach as detailed in Chapter three of this study. In this chapter, the results of the study will be presented. Firstly, the participants’ demographic information will be presented, followed by a presentation of their experiences and challenges. This will be done using main themes and subthemes as detailed in the sections below.

4.2 DEMOGRAPHY OF THE PARTICIPANTS
This section will look at the participants’ demography. Each of the eleven participants were interviewed using a face-to-face strategy. Because the study is qualitative in nature, frequencies were only used to indicate the participants’ representation. This section is intended to give the reader a broader context of the participants from which data was gathered. It presents the participants’ demographics which consist of the participants’ race, language, gender, grade, and age. The demographic information will also determine who participant stays with, when the participants learned of their HIV status and started taking treatment. For ease of reference, table 4.2.1 was used (see Appendix D attached).

4.2.1. First language
In terms of the language spoken, all the participants were seTswana speakers. This was no surprise since the hospital is situated in a seTswana-speaking community. The study was open to participants from all language groups. Although it was not the intention of the study to use seTswana speakers only, the participants each chose to be interviewed in seTswana despite being afforded the opportunity to speak any official language.
4.2.2. Race
The participants were all black. It was no surprise that the sample population was only black people because the hospital is situated and mainly serves a community that is predominantly black.

4.2.3. Geographic area
The hospital is situated in an peri-urban community; therefore, all the participants were from a peri-urban area. Ga-Rankuwa is situated north west of Pretoria approximately 30km from the central business district of Pretoria in the Gauteng Province. Although the study was conducted in a peri-urban area, participation was open to participants from any geographic location.

4.2.4. Gender
Of the 11 participants interviewed, six were female and five male. Only five boys and six girls agreed to be interviewed. The study did not intentionally set to utilize unequal number of participants between boys and girls. It remained equally open to participants who are males and females

4.2.5. Age
The participants interviewed were between the ages 16 and 18 years. Of the 11 participants interviewed, five of the participants were 16-years old, four were 17-years old and only two participants were 18-years old.

4.2.6. Level of education
Of the 11 participants interviewed, five were in Grade 10 and three were in Grade 7. Only one participant attended a special with the remaining two in Grade 6 and Grade 12 respectively.

4.2.7. Participants stay with
The results indicate that four of the participants lived with their grandmother and other siblings while three stays lived with their mother and other siblings. Only two participants lived with both parents and one stayed with his/her uncle and sister.
4.2.8. Age of being disclosed HIV status
The findings show that three participants knew of the HIV status within the last 5–8 years. Furthermore, one participant knew about his/her HIV status when he/she was 2, another participant was 4 years old, another participant was 10 years old when he knew his/her HIV status. In addition, one participant attested to discover his/her HIV status when he/she was 11 years old. It emerged from the interviews that only one participant found out about his HIV status during the year (2014).

4.2.9. Receiving ARVs treatment
All 11 participants receive ARVs treatment in Dr George Mukhari Academic Hospital.

4.2.10. Support group and youth camp
It emerged from the study results that seven participants did not attend youth camps or any form of support group either at Dr George Mukhari Academic Hospital or elsewhere. This meant that the remaining four study participants attended the support groups. Of those attending the support group and youth camp, one participant was attending the youth camp at Dr George Mukhari Academic Hospital but attended a support group outside of Dr George Mukhari Academic Hospital; three participants also attended support groups outside of Dr George Mukhari Academic Hospital.

4.3. EXPERIENCES AND CHALLENGES OF ADOLESCENTS WHO ARE VERTICALLY TRANSMITTED WITH HIV AND ARE TAKING TREATMENT
This section will present the yielded results. The presented themes and subthemes will follow the interview guide structure for ease of reference (see Appendix C). In presenting the main themes and subthemes, the participants’ verbatim responses will be used to clarify the meaning from the derived themes and subthemes. Furthermore, visual sketches will be presented to show a link between the main themes and subthemes.

4.3.1 Experience prior to HIV diagnosis
The participants expressed various experiences which included engaging in carefree behaviors, feelings of positive self-perception, losing loved ones, experiencing medical problems, taking HIV treatment, experiences from childhood stage (from birth until ten to eleven years old) including having multiple relocations during childhood, having difficult or
unhappy childhoods and confusion. This is explained by theme and related subthemes as illustrated in Figure 4.3.1 below.

Figure 4.3.1 Experience prior HIV diagnosis

4.3.1.1. Engaging in carefree behaviours
A few (three) participants reported living a careless life and making reckless decisions prior to discovering they were HIV positive:

“Last year I had my own gang of boys. We used to go around anywhere, going to parties without invitation and we would get into those parties. The way we were so popular, people knew us and they knew that they are powerless towards us. Then in December last year we were arrested by police after being involved in a fight with other gang.” (Participant A)

4.3.1.2. Positive self-perception
Two participants reported that they perceived themselves in a positive light, being like other children and being able to play with their peers prior to receiving their HIV status. The positive self-perception emerged in the data of participants who started treatment at a young age:

“(Decreased pitch) Before I knew about my status, I viewed myself as a person like any other kid, even with my friends.” (Participant D)
4.3.1.3. Loss of loved
Nine participants reported losing their loved ones prior to receiving their HIV status. Their status had impacted their lives negatively, especially by creating instability at home:

“In 2001, my father just died instantly, he was in another country, he died there and he was deposited in South Africa without any explanation. I felt shocked and confused. They moved me to place R because financially my mother was unable to support me.” (Participant A).

4.3.1.4. Experiencing medical problems
Prior receiving their HIV diagnosis, eight participants reported having a lot of medical problems and always going in and out of hospital. Being sick a lot had negative implications on the participants’ lives. It prevented two participants from doing their academic work effectively with some experiencing reading and writing problems:

“At home, my grandmother was keeping an eye on me because I was always sick and it interfered with school. I then become left out and repeat Grade 3.” (Participant G)

“I was able to write but as I got sick I lost the ability to write. I also have difficulty in reading. I wish I can go back, be able to read and write. But I don’t have control.” (Participant H)

4.3.1.5. Taking HIV treatment
Three participants reported being on HIV treatment prior to discovering they were HIV positive and without them understanding the treatment were they put on and why they were put on the treatment.

“Before I knew about my status, I was taking medication but not know their purpose. My life was perfect” (Participant G)

Four participants mentioned that, as children, they did not understand the purpose of the medication they were taking, and as they entered the adolescence stage, they started asking questions of why they are taking medication. One of the participants said:

“I was very young and not aware that I’m taking medication. When I was 11 years I asked my mother why I was taking medication and she said I should ask the doctor in the clinic, she can’t tell me because something just happened and she doesn’t know why.” (Participant B)
4.3.1.6. Engaging in childlike behaviours

Being childlike, which involved being playful, was a life lived by two participants prior to receiving their HIV diagnosis:

“I was still a child, playing, behaving in a childish way; I didn’t know that this thing was in my life. Yah! Everything was flowing. Yes, fun (laughing) misbehaving (laughing) well, you know how the nature of a child who is a boy is like, misbehaving, being naughty, mischievous, fighting, making noise, missing periods in class.” (Participant D)

4.3.1.7. Lack of understanding

All participants reported that, prior to receiving treatment; they didn’t understand what was happening. Some reported that they were confused about attending appointments in hospital, and being hospitalized without knowing the reasons,

“I was confused, because I could not play with other children; I was in and out of hospital. And I didn’t understand why.” (Participant H)

4.3.1.8. Normal life

Two participants reported that their life was normal just like other children prior to receiving their HIV diagnosis:

“My life (3 seconds pause) ... it was fine (increasing pitch) (5 seconds pause), I was still a child, taking treatment, playing, behaving in a childish; I didn’t know that this thing was in my life. Yah! Everything was flowing”. (Participant D)

4.3.1.9. Childhood experiences of living with HIV

Three subthemes emerged from this category:

- **Happy childhood**
  Two participants led a happy childhood life before they learnt of their status. One of the participants said:

  “Before I knew, I was living a pleasant life ...” (Participant I)

- **Difficult childhood**
  Nine participants agreed to having a difficult childhood. The participants’ biggest challenge was that they are always sick and hospitalised for quite some time. The participants
mentioned that they did not enjoy their childhood: they couldn’t play with other children, attend school and felt left behind when compared to their classmates because they had to repeat the same grade only once their health improved. These participants were not outgoing because of the health challenges they faced. One of the participants has been attending a special school since losing the ability to read and write. Another challenge faced by the participants was a loss of loved ones which exacerbated participants’ health. One of the participants said:

“My childhood was difficult (high pitched tone). (Decreasing pitch) my mother struggled with me. We were sleeping in hospital, and always in the hospital. I was sick. My mother knows. I was sick and unable to walk (6 seconds pause), it was difficult. I didn’t enjoy my childhood. I was not playing with other children, not attending school.” (Participant E)

- **Multiple relocations**

Six participants said that their childhood was challenging because it involved a lot of relocations, which resulted in them losing friends and difficulties in making new ones. Relocation also added some challenges in that the participants felt confused and unable to concentrate at school resulting in school results literally dropping. One of the participants said:

“My childhood was disrupted because, I moved from one place to another most of the time, there was lot of relocation. And this was killing me big time and it affected me, well... I started staying here in place w, then by the time I started growing up my mother and I changed, relocated from different places, is like that situation of relocating was puzzling me. I felt confused, I didn’t know (high pitch with feelings of irritation) what was happening, not knowing why we were relocating”. (Participant B)

- **Confusion**

Nine participants reported that they were confused about their childhood. They reported that they didn’t understand the purpose of their treatment, the hospital appointments, multiple relocations, loss of their loved ones, and the reason behind being sick. One of the participants said:
“I didn’t understand and I didn’t take them seriously. Actually they told me the purpose of medication but I didn’t understand. In April 2010, I was in Grade 5, I started asking myself what is the purpose of the medication, why people are on medication. I didn’t understand.” (Participant C)

4.3.2 Context of discovering HIV diagnosis

The context in which participants discovered they were HIV positive differed. Six participants were told their status in a medical context by medical personnel, while two participants learned of their HIV diagnosis in a camp setup. Three participants were told of their HIV diagnosis in a family context through a family member. The participants further expressed various emotional responses which included shock and disbelief, sadness, shame, loneliness, anxiety, anger, and acceptance. Figure 4.3.2 below indicates the themes and resultant subthemes.
4.3.2.1. Medical context

Six participants were told by nurses in a medical setup that they were HIV positive. One of the participants who learnt of his HIV status from a family member enquired from his parents why they were taking the medications and was referred to medical personnel where this explained. After learning of his status, the participant was shocked and depressed, started misbehaving and stopped taking the medication. Until medical personnel encouraged the participant to adhere to the treatment, the participant attested to constantly thinking about being sick:

“(His pitch and tempo increased) it was during a counseling session, two years ago. Before I went for counseling, when I was at the clinic I asked the nurse (his pitch was high) is like it became a shock.... I started constantly thinking about it (decreasing tempo and pitch) is like, yah, is true I have the virus.... (He then looked down)”

(Participant B)
Another participant reported that she attended VCT; counseling sessions followed after the participants discovered their HIV status:

“**I was sick, my mother took me to hospital and they told my mother that I should go for blood testing, and she agreed. So we found out that day. I was told by nurse, she began by explaining to me what is HIV, and she then disclosed my status. So she said I should begin counseling, of which it didn’t benefit me, and then I began to take medication. They explain HIV and treatment and what to eat. But they don’t ask you how I view HIV and how I feel about me being infected. They only teach you what HIV is. And like at the beginning when they were explaining HIV I didn’t understand, I was still a child**”. (Participant K)

Another participant shared that their status was disclosed after taking a blood test. After disclosure, the participant began taking treatment although the participant didn’t understand the treatment. The participant began to understand by asking the psychologist and social worker questions. The participant was irritated to learn about his/her sickness; when other children were playing on the street, the participant had to go take treatment which disturbed his interaction with other children. However, the participants’ feelings have since changed because the participant understands the purpose and reason of being on medication and has started taking the medication autonomously. Initially, the participant attested to feelings of hurt and sadness but once the participant received support and learned that people live long healthy lives if they take care of themselves, this changed. The participant is well-taken care off and feels well.

“**They took blood for testing, and then they disclosed my HIV status after two weeks and I begin taking treatment. I didn’t understand, is now that I asked questions. I asked psychologist and social worker and they answered me. Is like I didn’t have a problem, what do I say, eish! But I was irritated, in that I’m sick. I was irritated, they said I had to take treatment. But now I know that at 18h00 I’m taking my medication. Back then they used to shout at me and argue with me, and arguing about medication. I didn’t understand. They always asked me if I know why I’m taking medication and I said yes. I said yes is for HIV. But I didn’t understand. But when I was growing up I begin to ask why I had to be on medication, then I begin to understand the reasons of being on medication. I felt hurt and sad, and they supported me. People live long if they are taking care for themselves, then I said ok. And I saw it for myself in that I’m taking care of myself and I’m ok**”. (Participant C).
4.3.2.2. Camping context

Two participants reported discovering their status in a camping setup with other young people who were told in a group setting that they were HIV positive:

“It was a camp of adolescents who didn’t know about their status. They gathered us all and it was fun, it was fun, it was fun, but there were individual sessions. Well they disclosed to all of us in a group.” (Participant D)

Participants, who learnt of their HIV status at the hospital during counselling, still did not understand the meaning of being HIV positive until they attended youth camps where they began to understand HIV. The participants began to adjust and accept their diagnosis. However, the participants agreed that HIV is not discussed with their parents at home as they are not used to speaking about HIV. The participant also mentioned that they speak about other unrelated matters except HIV to avoid awkward relationships with the parent.

“When they were disclosing my status, well.... (3 seconds pause) (Increase in pitch and tempo)....I didn’t react, I just said Ok then kept quite (he started rubbing hands and tapping his right foot on the floor and he looked away from the researcher). ....(10 seconds pause)....and the nurse asked me if I’m ok and understand what they she was saying, I said I understand then I kept quiet. I didn’t understand what they were saying until in 2009, where I began to understand in youth camp. That’s when I started to adjust; I began to accept, in the camp from Dr George Mukhari Hospital in December. At home, with my mother, I never spoke about it; we are not used to speak about HIV at all.” (Participant A)

4.3.2.3. Family context

Three participants’ mentioned being told by their family members about their HIV status. Two participants were told by their grandmothers and one participant was told by his mother:

“I was told by my grandmother. This was heavy on me. She told me that I have HIV and I have to take medication. I don’t even understand what HIV is.” (Participant H)

“My mother disclosed to me, even the doctors asked her if she disclosed to me. She said yes she told me. She told me I’m infected with HIV. I asked her how and she didn’t explain how I was infected. She never explained to me how I was infected. She disclosed my status when I was at home. We were from the hospital, she started
telling that I’m infected with HIV, and she said I had to take treatment. She said I must not tell anyone (she started crying loudly).” (Participant E)

4.3.2.4. Emotional responses to receiving HIV diagnosis

The participants further expressed various emotional responses which included shock and disbelief, sadness, shame, loneliness, anxiety, anger, and acceptance. This will be explained below.

- **Shock and disbelief**

  Being shocked and in disbelief was an initial response expressed by three participants in the study after learning of their HIV diagnosis:

  “I didn’t react, I just said Ok then kept quite (he started rubbing hands and tapping his right foot on the floor and he looked away from the researcher). …(10 seconds pause)….and the nurse asked me if I’m ok and understand what they she was saying, I said I understand then I kept quiet.” (Participant A)

  “Well, I didn’t know (10 seconds pause), I was asking myself questions. What (2 seconds pause)? I didn’t have sex with anyone (3 seconds pause), how can it be (increasing pitch and tempo)? How can it be? Because, how did I get HIV from other people (5 seconds pause), like through sexual intercourse. Then they explained to me and I started to realize that I’m sick.” (Participant D)

- **Sadness**

  When two participants found out about their HIV diagnosis, it was a very painful experience filled with a lot of sadness:

  “All of us (people in the camp setting) there was no one who would say he or she is happy. When I went out I wanted to be alone, I felt hurt and I wanted to cry. I’m a type of person that if I’m told something I understand it, but deep inside is killing me and it is difficult to heal (5 seconds pause). Eeee… when they finished disclosing our status, I wanted to keep quiet, I didn’t want to eat.” (Participant D)

- **Shame**

  Feelings of shame were expressed by two participants in the study:
“I’m ashamed. I feel like my life has already ended; others they are living. Like I’m sick, without medication I will die. However, others don’t take medication, they are ok. I wish I become healed and stop taking medication. The disease and medication already took my life.” (Participant I)

- **Loneliness**
  Participant B expressed feelings of loneliness.
  “I felt so alone like no one could understand my feelings and how it feels like to be told you are HIV positive”.

- **Anxiety**
  Three participants expressed feelings of anxiety. The participants were anxious about living with HIV and feared that other people could see that they were HIV positive:
  “I don’t know. I don’t have confidence of speaking in front of people. I think they will see that I have HIV. I know that they won’t see me, but is the feeling that I have. You know since I knew that I have HIV I live with fear, fear of being exposed and fear of living with HIV. Some days this fear grows inside me. It is difficult.” (Participant G)

- **Anger**
  A majority of the participants (six) expressed feelings of anger for being diagnosed with HIV:
  “I’m very angry, why me, why can’t I be like other children. I hate it very much (she started crying). (After 15 minutes) I won’t change it” (Participant F).

Feelings of anger led to a Participant B being rebellious, acting out and engaging in deviant behaviors:

  “Yah, so I begin to stop taking my medication and started to misbehave. Yes, when I stopped taking medication. Like I started misunderstanding my mother and elderly people, and disobeying. I refused to wash dishes at home. Mostly, I spend time alone in my room and constantly being in an argument with my mother and elderly people.” (Participant B)
• **Acceptance**

Three participants reported having accepted their HIV diagnosis and making peace with it. Participant A suggested that

“I began to understand in the youth camp. That’s when I started to adjust; I began to accept, at the camp from Dr George Mukhari Hospital.”

4.3.3 Experience of taking HIV treatment

Three participants started taking treatment when they were 7, 9 and 11 years old respectively while others started taking treatment when they were 2, 10, 12 and 14 years old, respectively. Only one participant could not remember when treatment was started.

The participants confessed that taking the HIV treatment was a difficult experience initially, with some participants only starting to accept that they will need to take treatment for the rest of their lives. The participants’ experiences involved some participants keeping it secret that they were on treatment for HIV. Other participants expressed taking treatment as being a barrier because it prevented them from engaging in certain activities. Some participants expressed a lack of understanding the purpose of being on treatment on a daily basis for HIV. Lastly, a few participants demonstrated an understanding the purpose of taking treatment for HIV on a daily basis.

Figure 4.3.3 illustrates the participants’ response to their experience of taking HIV treatment.
Figure 4.3.3 Experience of taking HIV treatment

4.3.3.1. Secrecy
Although other participants did not have any problems in taking their medication, there are those who cannot take their medication in front of friends when playing or visiting relatives because they do not want people to notice that they are on medication. The most common reason expressed by participants not wanting friends or relatives knowing about their status is fear of judgement. Three participants disclosed to family members only that they were on medication for HIV:

“Every day I eat then take medication. I take them in the morning and afternoon. When I visit, unless I have them, I cover them with a toilet paper; no one knows that I’m taking medication, except my sister and grandmother. And most of the time I visit my extended family members.” (Participant G)

4.3.3.2. Constraint
One participant highlighted that taking treatment for HIV was a constraint that limited him from engaging in activities that he would have loved to freely engage in:

“jo! (Inhaled deeply)... (10 seconds pause). (He laughed) well, honestly speaking taking medication on a daily basis is challenging because I take medication at 20h00, so (9 seconds pause). And there was once a talent show in Hammanskraal. Yah! They were taking position 1, 2, and 3. So I couldn’t go because of medication. People told me to go to the talent show, my songs really rock and I will win, plus I have what it takes. So I wanted to go but because of medication I couldn’t go.” (Participant D)

4.3.3.3. Lack of understanding
Three participants demonstrated a lack of understanding the reasons they were taking treatment for HIV on a daily basis at a certain time. Participants indicated feelings of irritation and dislike at taking the treatment.

“They asked me if I know why I’m taking medication, I said yes. But every time when I was taking medication I asked myself why do I have to take medication. Actually they told me the purpose of medication but I didn’t understand. I started asking myself what is the purpose of the medication, why people are on medication. I didn’t understand.” (Participant C)
Receiving explanations from psychologists and social workers assisted participant C in developing an understanding of the reasons why she needed to take her treatment.

“I asked psychologist and social worker and they answered me. Yah! Is like I didn’t have a problem, is like, what do I say. The social worker and psychologist answered me and they told me to take medication, for the rest of my life and I won’t be healed and if I take well medication then I my disease will be manageable. But I asked myself why me.” (Participant C)

4.3.3.4. Acceptance

Four participants mentioned that they have been taking medication since a young age so they are used to and therefore have no problem in taking the medication. Other participants shared that taking medication on a daily basis is part of their lives and they have to do it. They mentioned that they will die if they do not follow the treatment. They reported accepting that they will be taking treatment for HIV for the rest of their lives. Participant I indicated incorporating the medication in her life:

“What can I say, is my life, I don't have choice. If I don't take the medication I will be dead. It's my life now for me to take medication.”

4.3.3.5. Side effects

The participants mentioned feeling dizzy after taking the medication. However, since they take the medication in the evening, these side effects do not interfere with their daily activities anymore. One of the participants said:

“Some days, after taking medication I feel dizzy, however, because I take my medication at night, the dizziness does not interfere with my daily activities.”

(Participant A)

4.3.3.6. Irritated

One of the participant mentioned that taking medication on a daily basis makes the participant feel irritated and angry:

“Is like I was irritated by my medication, at 18h00, on a daily basis I had to take medication.” (Participant C)
4.3.4 Challenges of living with HIV

The challenges of living with HIV consisted of difficulties with disclosing HIV diagnosis to others, adhering to the treatment, and attending to monthly appointments; financial constraints; dealing with previous traumas and conflicts with family members; and difficulties accepting one’s HIV diagnosis, relationships and coping mechanisms.

Figure 4.3.4 Challenges of living with HIV and coping mechanisms
4.3.4.1. Disclosure

Participants had disclosure difficulties. Seven participants mentioned that they did not disclose their status while four participants disclosed their status.

Difficulties expressed by participants are as follows: fear withheld participants from disclosing their HIV status to other people despite those that already knew about their diagnosis. Fear was divided into:

- Participants expressed fear of being rejected by both family members and friends:
  “I’m afraid of being rejected. I have a family member who likes to say bad things about people who are living with HIV infection and he doesn’t know that I’m also infected then I would tell him those people who are living with HIV will not like what you are saying about them. So I’m afraid if I disclose my status to them they will reject me.” (Participant B)

- One participant’s fear of disclosure involved a fear of being laughed at:
  “eish.... Is like I don’t ....ha...ha... disclose, like, they will make jokes about me about me, so I don’t want them to make jokes about me. I hate to be centre of attraction. Like even at school, if they know about my status, whenever they see me they will be laughing behind my back, I won’t disclose.” (Participant K)

- Two participants expressed fear of being disrespected if they disclosed their HIV status.
  “People will view me as inferior. So if I disclose to them they will disrespect me.” (Participant J)

Two participants expressed attempting to express their HIV status to their friends but were betrayed by friends. As a result, the participants’ could not trust other people revealing their HIV diagnosis.

“I think if I disclose, they will be angry at me and spread my status to everyone. My friend once did that (increased pitch) and she told everyone. At school, the classmates asked me if I have HIV, I answered by saying yes. I asked them who told you, they said from my friend. They started laughing at me, they distanced themselves away from me. I started to not want to go to school. (She started crying). That is why
I changed school, but the problem was the transport money and I had to relocate.”  
(Participant I)

- Six participants reported a fear of judgment by others if they disclosed their HIV diagnosis:
  “I won’t tell them (friends) the truth, they will reject me. I heard their comments about people who are living with HIV, so I won’t tell them. I realize why my mother doesn’t have close friends, she is alone. I not have friends, and then now my mother is my close friend. I tell her everything except about boyfriends.”  
(Participant C)

- One participant reported a fear of gossip about her status if she disclosed to others:
  “Like (increasing pitch) people who are my street mates like to gossip. They can’t keep a secret. They will gossip about me, when they finish, then they will tell others outside our street. So people will be afraid of me and not want to associate with me. They will reject me. And my grandmother told me not to disclose.”  
(Participant G)

The fears about disclosure and the experiences of the participants mentioned above has led them choosing not to disclose their HIV diagnosis to others:

  “no, no (he laughed) is a secret which I will never trust to talk about, I will never do. I don’t trust anyone and I will never do that (disclosing HIV status to others); is not like I am ashamed; is not the right thing and the right time.”  
(Participant D)

4.3.4.2. Adhering to treatment

Three participants admitted that they were unable to take treatment in the presence of others. Only one participant highlighted a fear of judgement by other people while taking treatment for HIV. Two participants reported being tired of taking HIV treatment.

  “mmmmmm...like taking medication, like when I visit somewhere, they will ask me questions about my medication, what’s happening.... Then I have to come with excuses, so now I don’t visit anymore, I’m always at home.”  
(Participant A)

  “Is the issue of treatment (high pitched), I become tired of them. I feel like is being long since I started taking medication. I feel like they are not effective, like when I take them, like is in it that I’m supposed to take them for my whole life. I want to take
them, but I’m getting tired because I feel like, I want to stop them for two years and see what will happen. Is how I wish.” (Participant F)

4.3.4.3. Attending monthly appointments
Attending monthly appointments was a challenge for two participants as it affected their academic performance.

“For me to go to monthly appointments really disturb my school work, when I’m not there they are writing tests.” (Participant J)

4.3.4.4. Financial constraints
Not having enough money at home led to three participants being unable to buy the necessary food needed for them to take treatment as well as not having money to attend to their appointments at the clinics:

“I had difficulty in taking medication because of being unable to eat healthy food to accommodate treatment.” (Participant J)

“Sometimes when I’m from hospital and I ask my grandmother transport money for the next appointment and she does not have it, I even skip an appointment because of not having money because my grandmother is the only one who works.” (Participant G)

“Financially, at home, we suffer because my aunt and uncle don’t have a stable job, so this affects my medication in that I struggle to have money for every appointment; I have to borrow the money for every appointment because I have to travel to the clinic.” (Participant D)

4.3.4.5. Trauma
One participant was raped by a neighbor during her childhood years and is still preoccupied with the traumatic experience. She is also dealing with being HIV positive as well as the rape:

“He raped me. I cried and cried and cried. He then left me. This thing never sits well with me, I always think about it.” (Participant E)
4.3.4.6. Family conflicts
Three participants expressed having conflicted relationship with the family members they are living with. One participant highlighted conflicts involved parents arguing with each other and with children. Lastly, one participant highlighted being beaten up at home without reason and understanding why:

“At home, if someone is angry he wants others to be angry as well. Like my stepfather is a person who when I visit my biological father he becomes angry, he doesn’t want. So when he fights with my mother, he becomes angry when I’m with my mother; when he fights with me, he becomes angry when I’m with my mother, without any reason. He includes me when he fights with my mother. When he fights with me he includes my mother. My stepfather and I don’t speak to each other when I’m left with him.” (Participant C)

“At home, sometimes they beat me and they beat me too much. I don’t know why and they physically hurt me.” (Participant H)

4.3.4.7. Difficulty accepting HIV diagnosis
Participant A experienced difficulty accepting his HIV diagnosis. As a result, Participant A seems to be fixated on the anger of being HIV positive which prevents him from accepting his diagnosis:

“well... I haven’t accepted the condition. I wish one day when I wake-up I’m HIV negative. I have anger towards this and not this only, at everything. And sometimes I break in such a way that I lock the house and control that gets in-and-out of the house.” (Participant A)

Some days, participants feel like they have accepted their status while on other days, the fear grows inside them which make the situation difficult.

4.3.4.8. Relationship with medical personnel
One participant reported that sometimes he don’t have enough transport money to attend appointments. The participant then skips the appointment resulting in the medical personnel reprimanding him without enquiring about the reason behind him absconding. This cycle has created distance between the participant and medical personnel since he cannot confide in the medical personnel regarding his personal issues.
“I even skip an appointment because of not having money because my grandmother is the only one who works. And if you have skipped an appointment, the nurses and doctors will shout at you without asking the reason. So I’m not used to the nurses and I can’t tell them my personal issues.” (Participant G)

Furthermore, more than half (nine) of the participants highlighted having negative experiences with the nurses they interact with when collecting their treatment at the clinics and hospital. Nurses lack of empathy; they are impatient, judgmental and inconsistent in supporting the participants. This was expressed as:

“In the clinic, I don’t receive any support. They are very bad! (3 seconds pause). Is like they are impatient, if you miss an appointment, joh! They will shout at you. Each appointment you are helped by different nurse and there is no relationship between me and the nurses. They ask you questions just to analyse without caring about you. Well, I don’t understand. They are irritating me.” (Participant)

4.3.4.9. Social life

The challenges illustrated in figure 4.3.4 above lead to relationships problems. These were expressed in terms of participants’ social life based on friendship, peer relationship and intimate relationships. Various responses, ranging from positive to negative responses, as well as mix responses, were reported by the participants.

- **Positive responses**

Six participants mentioned that they lead a normal social life. They are liked by people and they enjoy peoples’ company since they view themselves similar to others.

“Is like I’m similar to others. I enjoy, I’m free, I don’t have problems, I’m always happy, I’m open, I live with people, we are happy, and we speak, we enjoy, they eat food, I eat food. We are not different, we are the same. I’m ok and I’m always happy.” (Participant C)

As adolescents, they portray different kind of social life. For instance, one of the participants was involved in gang but eventually stopped due to a police order while another was misbehaving and being naughty:

“Last year I had my own gang of boys. The way we were so popular, people knew us and they knew that they are powerless towards us. Yah! Then in December last year
we were arrested by police after being involved in a fight with other gang, then they
gave us two options, either to stop the gang or to be arrested. So the police knew that
I was the gang leader, and I decided to stop the gang.” (Participant A)

“Well, I live free like anyone. I’m naughty, and I misbehave. I mean being naughty
like they discipline and I continue misbehaving, they discipline and I continue
misbehaving (he laughed). I even enjoy doing it.” (Participant D)

On the other hand, three participants enjoy playing soccer with friends but try by all means to
only talk about soccer and school; they do not talk about personal issues.

“I’m playing soccer, so every day I go to practice and I have created friendship with
other soccer teammates. But we only speak about soccer and school, not about
personal issues.” (Participant I)

Other participants attested to being free because of the level of openness they have when
engaging with friends either through cell phone or texting; they also enjoy music.
Involvement with friends and attending various activities helped participants lead a normal
social life and they attested to having fun.

“I like to communicate with people through cellular phone and whatsapp. Yah, also
one of my friends, who is very supportive and knows about my status, has a music
band and they want to shoot a music video, so they want me to join them.”
(Participant B)

One participant also mentioned receiving encouragement from outstanding school
performance and being involved in most of the social activities at school. However, the
participant is being affected by negative peer pressure; some participants are still trying to
find their talents and what they are good at:

“I also cope with school work. Most of learners and teachers approach me because
of my achievements. In every sport I’m there, drama I’m there, chess I’m there,
music I’m there (he laughed). So far I’m exploring things. I want to broaden my
frame of reference. When I first entered this school, I realised that if you are a good
boy, you are left behind. So I changed to become a bad guy. When they escape class,
I also escape.” (Participant D)
• **Negative response:**

One of the participants also mentioned that despite having a good social life, the problem is his parents still use corporal punishment and they sometimes physically hurt him.

“at home, sometimes they beat me and they beat me too much. I don’t know why and they physically hurt me.” (Participant H)

Participants reported it being difficult to develop friendships with people who appear to be trustworthy. As a result, two participants reported not having any friends at all.

“At home, they don’t want me to go outside to play on streets. So I’m always at home playing with cars, I don’t have friends. My grandmother said if I go outside they will know that I have HIV.” (Participant H)

“I’m always at home and spending time with my family. I don’t have friends. If I have friends, they will tell others about my status; I don’t want people to know. So if a girl or my classmates want to visit me at home, I always say I’m busy with schoolwork. If they know they won’t want to socialise with me at school.” (Participant K)

Two participants mentioned having a few friends. However, their conversations are superficial and they do not disclose their HIV status to them.

“I have created friendship with other soccer teammates. But we only speak about soccer and school, not about personal issues. My relationship with my friends is more on superficial level.” (Participant I)

Six participants declared that they have a lot of friends; however, they do not disclose their HIV status to them as well.

“is ok, I have friends and a crew, but they don’t know about my status; even though I feel different from them.” (Participant F)

Four participants indicated a withdrawal from their social life because they are always at home to the extent that if people visit, they can just leave them unattended and always play with dolls:

“I have three friends (they are younger than Participant E) we like to play. I always play with dolls at home”. (Participant E)
One of the participant said she does not understand why she is suffering while other children are not, especially with regard to taking medication and HIV is a chronic disease:

“I view myself being different from others because know I’m HIV positive and others are not, why me, why me, why me, why me..... (She cried out loud for 10 minutes)” (Participant F).

Although four participants are fully withdrawn and want to stay alone, there are those participants who just do not want to be with friends but would rather spend time at home with their family. These participants prefer to talk to their family and prefer this type of socialising because they take their medication at the right time and not forget or default on taking medication. One of the participants said:

“If people visit me, I just leave them and go to my room and lock. I like to be alone. I sleep, and wake up, and go to the kitchen, and come back to my room, and sleep. I have three friends we like to play. I always play with dolls at home”. (Participant G).

Three participants mentioned that they have disclosed to their friends and they got mix responses, with some friends accepting them and others rejecting them. One participant said:

“I have two friends, and I disclosed my HIV status to them. The other one likes to be bossy and he likes to call me ‘a thing of AIDS’ and the other one is very supportive and caring.” (Participant B)

- **Relationship with peer**

When the participants were asked to describe their relationships with their peers, nine participants attested to having good relationship with their peer while one of the participant mention that the challenge is that her boyfriend doesn’t want her to spend time with her friends:

“Like my boyfriend (boyfriend F) is always angry when I’m with other people. My boyfriend and I are friends. He doesn’t want me to be with other people.” (Participant C)

Another participant said:

“Well.... with my peers we get along, we never fight and argue.... we get well together, we get well with everything. At the moment, I told myself I will never argue
when someone has another opinion opposite mine, and then I just accept the other person’s point.” (Participant A)

Five participants mentioned that they belong to certain crews which they associate with but they didn’t disclose their HIV status to these crews. One participant said:

“Is ok, I have friends and a crew, but they don’t know about my status; even though I feel different from them.” (Participant F)

Others will never disclose their status because they feel it will change the way their friends perceive them.

“So at school they will treat me like a princess, like F do what this, F do you want this. They won’t treat me as being normal, like I’m different from them.” (Participant F)

Another participant mentioned that

“Is like even to my friends, there is no one that I trust with this thing. I think if I disclose my status to my best friend, the relationship will change completely, he will reject me”. (Participant A)

Others said they only play well with their peers at school but when they go home their parents do not allow them to play with others.

“I play with my peers at school. At home, they don’t want me to go outside to play on streets. So I’m always at home playing with cars, I don’t have friends.” (Participant H)

• Intimate relationship

Four participants had a boyfriend/girlfriend while five participants did not have any boyfriend/girlfriend. Furthermore, although two participants said they currently do not have a boyfriend/ girlfriend, their family members forced them to end the relationship and prohibited her in being involved in intimate relationships.

“No, but I once had a boyfriend. But my uncle threatened him to break-up with me, so he did. So I asked my uncle why he threatened him, he didn’t answer me (high pitched). I said ok, I will ask nurse why I’m not allowed to have a boyfriend, I mean
"I’m not stupid, I won’t sleep with him….. I was denied an opportunity to explore things.” (Participant I)

Of the four participants who had a boyfriend/girlfriend, only one disclosed their status while the others never disclosed their status.

“Yes, my relationship with her is flowing well, we are open, help each other, support each other, when she is low I pick her up and when I’m low she picks me up. She also has HIV. We talk about how to take treatment and advice each other. She is important.” (Participant D)

“Yes, but I didn’t disclose my status to her and I always avoid to meet her, I always give an excuse.” (Participant B)

Of the two who used to have boyfriend/girlfriend, none had disclosed their status to their boyfriend/girlfriend:

“No, but I once had a girlfriend and we broke-up because she was cheating on me. So I walked away. She didn’t know my HIV status”. (Participant J)

Participants also mentioned that their relationships do not last long because of fights, break-ups and anger towards each other:

“I have problem with relationships, they don’t take long, we fight and break-up, and we become angry towards each other.” (Participant C)

One participant also mentioned that she tests her boyfriends to see if they will accept her with her HIV status prior disclosure:

“We are still in new love, I won’t tell him about my status. I will wait for a while, and then test him to see if he will accept me. If he does accept me, I will disclose my status.” (Participant C)

Other relationships ended due to infidelity, having difficulties with concentrating at school, and struggling to sustain relationships:

“Ah, I then broke-up with him because he was disturbing me with my school work, he would write love letters in class while the teacher is busy teaching us, and I was
unable to concentrate, always thinking about him. So my marks in class dropped.”

(Participant F)

4.3.4.10. Coping mechanism

The coping mechanisms that emerged from the data include avoidance, hopeful, denial, creating meaning and acceptance. These mechanisms will be further discussed.

- **Avoidance**
  
  Two participants avoided forming close relationships and isolated themselves by staying at home and limited interaction with peers in order to cope with the anxiety of other people discovering they are HIV status.

  “I play with my peers at school. At home, they don’t want me to go outside to play on streets. So I’m always at home playing with cars, I don’t have friends. My grandmother said if I go outside they will know that I have HIV.” (Participant H)

- **Hopeful**
  
  Being hopeful that one day they will be healed from living with HIV and be free from HIV was a coping mechanism adopted by two participants who faced the challenges of living with HIV:

  “Well I don’t believe that I won’t be healed. I believe that I will be healed in the future, and the doctor will stop me from taking treatment either if my CD4 count has increased or if I’m ok physically. They say the doctors can stop you for about three years. I know that is a chronic disease but I believe that I will be healed.” (Participant C)

- **Denial**
  
  Two participants confided that that pretend to agree with the negative comments made towards HIV-positive people to avoid being discovered as being infected as well:

  “At the moment, at the moment, I told myself I will never argue with someone who has another opinion opposite mine, and then I just accept the other person’s point. Yah, because if I don’t accept it there will be another issue.” (Participant A)
Creating meaning and acceptance

Two participants realized that by creating meaning from living with HIV helped them with accepting their HIV status.

“I picture myself as the chosen one, so I’m living the life in another world, where others cannot experience what I’m experiencing. Is like a treasure hunt.” (Participant D)

4.3.5. Experience of living with HIV

The participants shared different experiences to living with HIV. Such experiences included participants psycho-educating others about HIV, developing confidence in themselves; having and sharing family responsibilities; engaging in sports; losing loved ones to HIV; experiencing medical problems; developing friendships and being in romantic relationships. These experiences as illustrate by Figure 4.3.5 are described in detail below:

Figure 4.3.5: Experiences of living with HIV

4.3.5.1. Psycho education

One participant reported psycho-educating people who are HIV positive about the importance of adhering to treatment:

“Like even when I’m at support group, someone complains about taking medication, it hurt me. We once went to the wards in Dr George Mukhari Hospital, we saw patients whom we are at the same status, is a shame, and is a pity. Like I told them..."
that guys if we don’t take our medication we will be like this, is not that they were crazy, they were not crazy, they are normal like us, don’t cheat on our medication, and drink your medication (She is demonstrating using her hands). You just close your eyes and swallow it and drink water.” (Participant C)

4.3.5.2. Increased self-confidence
One participant did not discriminate or judge herself for taking treatment for HIV. The participant reported feeling and acting normal like other children and having a positive self-esteem:

“But for me the problem is I take treatment and they are not taking medication and we are similar. When I’m at the street I’m normal, I’m similar to any person, and I even forget that I’m on medication……..I have sense of hope.” (Participant C)

4.3.5.3. Sense of responsibility
One participant reported having the responsibility of taking care of her grandmother and having less of a social life outside the house:

“I’m always at home taking care of my grandmother, at home I stay with my grandmother and uncle. And if I leave my grandmother I will hurt her... I feel responsible. I love her, but she is not sick. So I’m the one who takes care of her. If I visit, I feel like I’m hurting her. I love her; I don’t want to leave her alone.” (Participant I)

4.3.5.4. Engaging in sports and arts
One participant expressed a love of playing soccer while another enjoys spending time in studio recording music.

“We play soccer, we always attend practice. Yah, that’s it”. (Participant I)

“Most of the time I’m always at the studio so when I go home we always fight about being late, we are always fighting (he laughed). Well, they don’t trust me.” (Participant D)

4.3.5.5. Loss of loved ones
Six participants expressed losing loved ones who died from AIDS. The participants expressed losing their grandparents, aunts, uncles, friends, nephews, step parents and mothers to AIDS:
“Well it was a challenge that I had to concur because of three people who I was close to passed on – my mother, father, and my younger brother – so that makes me feel lonely.” (Participant D)

“Is my friend, she died in June this year.” (Participant I)

“her death was a shock because I thought she will live. She also died because of HIV. And after the death I was told I’m HIV, so I begin to be afraid. On top of it my mother died because she was also HIV positive.” (Participant J)

4.3.5.6. Medical problems
After receiving her HIV diagnosis, one participant reported being sick and being in and out of the hospital a lot which affected her ability to enjoy her childhood:

“My life was ok. But I was a person who was always sick. They knew why I was sick and I didn’t know. I was always weak, and not being similar to other children.” (Participant K)

4.3.6. Knowledge of HIV
Figure 4.3.6. below illustrates how the participants assessed their knowledge of HIV:

Figure 4.3.6: Knowledge of HIV AIDS
4.3.6.1. Adequate information on HIV

Four participants demonstrated understanding and having information about HIV:

“HIV, the way I understand HIV is a disease, does not heal, immune system drops, does not heal, is similar to heart disease does not heal. If you treat it sharp then you will also be sharp. Is a chronic illness.” (Participant C)

“I know that you can contract it from having unprotected sexual intercourse, and also when you touch the blood of a person who is infected. Yah! As well as sharing injections. And you have to take medication every day, so if they check you and they don’t see it; they can stop you from taking medication.” (Participant B)

All participants who have adequate knowledge of the disease attend support group.

4.3.6.2. Limited information of HIV

Five participants demonstrated having limited information regarding HIV:

“HIV is the disease that is a chronic in its nature, so you have to take medication so that you are well and healed.” (Participant J)

One participant reported that at home they don’t want to answer her question relating to HIV:

“I heard that is a virus, but I don’t know what kind of virus. And at home, when I ask them questions related to HIV they don’t answer me... And the fact that HIV is a chronic illness, it really hurts me. It’s very heavy on me, I mean to take medication for the rest of my life, no, it is heavy.” (Participant I)

“I only know that I have to take medication, and I don’t know about other things. I always ask them when I will be healed. They only say I must take medication and I will be well. So I know I will be healed.” (Participant E)

One participant who has limited information on HIV found the information from the internet:

“I went to the internet and searched about HIV, trying to understand it.” (Participant K)

4.3.6.3. Lack of information on HIV

Two participants reported a lack of information regarding HIV:

“I don’t understand HIV.” (Participant H)
4.3.7 Coping resources

The participants’ coping resources including receiving support from family members, support groups, and receiving a social grant.

![Coping resources diagram]

**Figure 4.3.7: Coping resources**

4.3.7.1 Family

All ten participants received support from their family members who were taking care of them:

“Yes, is my grandmother and sister, they always support me.” (Participant G)

Another participant reported that:

“My parents are the one who support me. So I always talk to my parents, especially my mother about HIV. So I’m afraid of my father. My father and I communicate only through phone and not in person – we don’t. I have two siblings, they don’t know about my status, so I’m not ‘that’ close to them.” (Participant K)

4.3.7.2 Other HIV patients known to participants

Although seven participants do not know anyone else who is HIV positive, four participants mentioned that know someone else who is HIV positive:
One of the participants, who knows someone who is HIV positive, said:

“Yes, I know few, some of them I’m familiar with them and there was an incident where I was at check-up for ARVs in the clinic, this guy who attends same school with me was also at check-up for ARVs, both of us were shocked to see each other and never spoke to each other till today.” (Participant B)

Participant C mentioned:

“We are many. My relationship with them is normal, everyone is open, we advise each other about everything, we view each other as friends, and others are dating each other, eish (she smiles). But I like to give them advice.” (Participant C)

Another participant also added:

“So most of the guys we are like a crew, we attended camp. We are too close like friends. We do everything together; we don’t have secrets between us. Yah, we don’t have secrets.” (Participant D)

The participants are of the view that knowing other HIV-positive patients brings a sense of relief because they are not alone, feel encouraged to take their medication and have someone they can confide in who is on the same level.

4.3.7.3. Support Groups

Because Dr George Mukhari Academic Hospital does not cater for a youth support system, some participants attend support groups outside of the hospital. Attending support groups with other young people born with HIV enabled the participants disclose the challenges they experienced of living with HIV to others. One participant mentioned that:

“In the support group, I can talk about whatever I want and we don’t keep secrets. I also created a friendship with this girl in that support group. And even if we are not in the support group we call each other, meet and talk about us and HIV.” (Participant B)
4.3.7.4. Social Grant

Receiving a social grant assisted one participant who was struggling financially to buy the food needed in order to take medication for HIV. This support grant allowed him to buy healthy food and to gain access to medication by paying for transport.

“I had difficulty in taking medication because of being unable to eat healthy food to accommodate treatment. Now I have money from social grants and it helps me to eat healthy food so that I can take medication.” (Participant J)

4.4. CONCLUSION

Presenting the results by way of themes and subthemes illustrates that being an adolescent living with HIV is a complex phenomenon with multiple challenges that have to be navigated in order to live healthy while on treatment. In the following section the yielded results will be integrated with the reviewed literature.
CHAPTER 5
INTEGRATION AND DISCUSSION OF RESULTS

5.1. INTRODUCTION
The study was aimed at exploring the experiences and challenges of adolescents who were vertically infected with HIV and are currently undergoing treatment at Dr George Mukhari Academic Hospital in Ga-Rankuwa, Gauteng Province. The main objectives of the study were to gain insight into the experiences and challenges of adolescents who were vertically infected with HIV; to explore the current support systems of adolescents who were vertically infected with HIV; to stimulate future research; as well as to generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

According to the body of literature, adolescence, on its own, is a period where individuals are faced with numerous challenges. Simultaneously, having to cope with their chronic illness of HIV/AIDS can have a huge impact on the adolescents’ well-being (Etang, 2011). Furthermore, the biopsychosocial model views individuals as biological, psychological and social beings who behave in a specific way that can either promote or adversely impact their health. Thus, the health of an individual is the end result of variables including biological characteristics, behavioural factors, and social factors (Marks, et al., 2006).

The previous chapter presented the study’s results which were organised into main themes and subthemes that emerged from the data. In the current chapter, the results will be integrated with the reviewed literature following the format outlined in the previous chapter (following master themes and subthemes). This is followed by presentation of the limitations and recommendations.

5.2. INTEGRATION

5.2.1. Experience prior HIV diagnosis
When investigating the participants’ childhood, the results showed that there were some variations in the childhood experiences. More than half (nine) participants attested to having a difficult childhood while few (two) attested to having a positive self-perception and happy childhood. These variations will be further explored in an attempt to investigate how
the background of the participants may contribute to the contradictions found in the study results. Armstrong (cited in Sherr et al., 2014) notes that HIV can enter the blood-brain barrier and affect the central nervous system thereby destroying neural tissues in the central nervous system. This eventually causes dysfunctionality of all modalities secondary to HIV/AIDS (Rohlede et al., 2009; Swanepoel & Louw, 2010). Other studies have found that HIV-positive children and adolescents score lower on the visual-spatial processing, which is important for adolescents as it affects reading, writing, and learning (Blanchette, et al., 2002).

Those participants who attested to having a happy childhood and a positive self-perception started treatment at a young age. They perceived themselves in a positive manner, being like other children and being able to play. According to Wexler (2013), the average time from the initial HIV infection to the development of AIDS has decreased since the introduction of antiretroviral (ARV) therapy, which has increased the life expectancy of patients with AIDS. This is due to the mechanism of ARV therapy, which stops the virus from replicating thus decreasing the viral load resulting in the immune system starting to repair itself (Wexler, 2013).

The above findings show that there is difference between the participants who received HIV treatment using a biomedical approach and participants who didn’t receive their HIV treatment. It is evident that early testing, diagnosis, and initiation of treatment have a positive impact on the lives of adolescents who were perinatally infected.

In addition to reporting experiences prior HIV diagnoses, numerous participants reported that they lost their loved ones through death.

Some of the participants who experienced a difficult childhood reported that they experienced medical problems, which impacted negatively on their childhood. This prevented them from doing their academic work effectively, with some participants experiencing reading and writing problems as well as being unable to walk. A difficult childhood emerged from participants who started treatment during their adolescence stage. According to Karim and Karim (2010), HIV impacts on the physical well-being of a child with 60% of HIV-positive infants manifesting some symptoms of disease. This includes, but is not limited to, growth failures and developmental delays; respiratory system diseases such as tuberculosis; neurological system diseases; cardiovascular system diseases; and renal
diseases. In addition, according to Piaget (Leifer & Fleck, 2013), adolescents develop formal operational thinking; this might be impacted by HIV. Hence, adolescents who are vertically infected with HIV might not reach formal operational thinking.

A majority of participants had reported that they didn’t understand the purpose of their treatment, the hospital appointments, multiple relocations, the loss of their loved ones, and the reason of being sick. This entire process confused them. This is in line with Van Dyke (2012) showing that the breakdown of the family structure and multiple relocations for children and adolescents may perpetuate the development of feelings of loss of belonging, autonomy and control of one’s destiny which then results in confusion. Consequently, this may perpetuate the development of emotional trauma, which may result in identity crises and developmental delays (Van Dyke, 2012).

What is noteworthy is that a lack of understanding the research result may be due to two reasons. The first reason, which can be explained using Piaget’s theory of cognitive development (cited in Louw, et al., 1998), illustrates that children and younger adolescents consider their condition as akin to their fate. They seem to live with the disease without reflecting on its meaning as it relates to them or on how they acquired it. This absence of in-depth reflection may be attributed to the pattern of concrete thinking that is characteristic of childhood and early adolescence (Van Dyke, 2012). The second reason can be explained using the research results from a study conducted by Midtbo (2012) and Kyaddondo et al. (2013) which found that a large number of these children have, for a great part of their lives, been unaware of their diagnosis as their caregivers have kept it a secret (Midtbo, 2012; Kyaddondo et al., 2013).

In summation, using the biopsychosocial model shows adolescents who were vertically transmitted with HIV, prior HIV diagnoses, are impacted by HIV from multiple levels. The multiple levels are biological, social and psychological factors (Marks, et al, 2006). The biological factors are experiencing medical problems while the social factors include a loss of loved ones, and multiple relocations. The psychological factors are confusion, lack of understanding and engaging in carefree behaviours. It is important to understand the interactions between biological, psychological and social factors (Marks et al., 2006; Albelheim, 2011). In this study, HIV impacts on both the biological factors (resulting in experiencing medical problems and difficulty to develop formal operational thinking) and
social factors (resulting in loss of loved ones and multiple relocations). The biological factors and social factors perpetuate and impacts on the psychological factors (resulting in confusion and lack of understanding). In addition, those participants who received treatment earlier have decreased the biological factors which in turn impact their psychological factors (positive self-perception).

5.2.2. Context of disclosure HIV diagnosis

From various studies, it is evident that HIV disclosure can be challenging and important aspect. The research results indicated that participants disclosed in various contexts. Eight participants were disclosed by healthcare providers and three participants were told at home. At home, two participants were told by grandmothers and one participant was told by his mother. With those who received disclosure from healthcare providers, two participants were in a camping context and six were in medical context. A study conducted at Odi Hospital, Pretoria by Mahloko and Madiba (2012) found that children who have perinatal HIV/AIDS and are receiving ARV treatment grow up and reach the adolescence stage. This has given rise to a challenge faced by parents who have to disclose to their adolescents about their HIV status. Caregivers, who reported disclosing the HIV status of their children to a close adult family member, found it is easier as compared to directly disclosing their children’s status of infected because of feelings of helplessness and guilt, and fears of discrimination about their role in the child’s infection through vertical transmission (Rohlede, et al., 2009; Madiba, 2012; Kyaddondo, et al. 2013). For the majority of children, disclosure was done by people other than their biological caregivers. A majority (61%) of the participants were informed of the diagnosis by people other than their biological mothers (Madiba, 2012; Mahloko & Madiba, 2012).

When investigating the disclosure in the medical context, participants attested that the healthcare providers focused on giving information about HIV and the participant didn’t understand what they were saying. Furthermore, the participants indicated that although they attended VCT, they didn’t benefit from it as the focus was on explaining mechanism of HIV instead of focusing on how the participants felt about their HIV status or how they perceived HIV. A study conducted by Vaz, et al. (2010) corroborates these findings that in the medical context, the healthcare providers focused on explaining the mechanism of HIV and the importance of adherence to treatment rather than focusing on the participant’s themselves. Furthermore, studies in South Africa have revealed in the VCT model, there are frequent
inadequate standards of counselling (Olley, et al., 2004). Similar findings were reported by Russell and Scheider (2000), and Van Dyke and Van Dyke (2003). In addition, Pettifor, et al. (2008) report that current VCT services are not youth-friendly and are considered inappropriate for the youth’s needs.

Within the **family context**, the participants’ experiences about the disclosure are similar to the findings presented by Vaz, et al., (2010) which show that the caregiver puts more emphasis on adhering to medication. Thus, within this context, the caregivers provide limited or no information about the mechanism of HIV. Furthermore, caregivers focus more on providing information instead of the adolescent’s themselves (Vaz, et al., 2010). In addition to reporting the participants’ experiences about disclosure in a family context, some participants attested to not discussing topics related to HIV with their caregivers. The study conducted by Michaud, et al. (2010) revealed that several patients reported that the specifics of their condition were barely discussed with parents, and some of the participants actually resorting to the internet for information. Most of the adolescents living with an infected mother expressed how difficult it was to raise this topic with her, given the guilt, torn loyalties and emotional dilemmas it evoked (Michaud, et al., 2010).

When looking closely at the **camping context**, participants reported that because they were disclosed in a camp context, they began to understand HIV, adjust and accept their status. According to Van Dyke (2012), camps are designed to foster positive relationships and competence-building opportunities, and offer support and opportunities for youth to initiate and engage in behaviour that aids in the transition to adulthood (Van Dyke, 2012). Similarly, a study conducted by Bialeski, et al. (2007) focusing on the outcomes of camp participation consistently demonstrated that a camp has positive implications for identity development, social skills, physical and thinking skills, and positive values and spirituality.

Participants expressed various emotional responses to the disclosure of their HIV status. This is in line with other studies that indicate that the participants’ moment of having their HIV status disclosed is mostly experienced as dramatic and deracinating, with the physical and emotional ‘shock’ of a positive result, anger, depressive, other reactions to being informed of their HIV status (Rohlede et al., 2009; Martinez, et al., 2012; Van Dyke, 2012).
Van Dyke (2012) highlights that the adolescents who were perinatally infected with HIV had various reactions such as denial, anxiety, low self-esteem, sadness, hopelessness, guilt, and feelings of loss. Similarly, a study conducted by Mutwa, et al, (2013) found that adolescents who were made aware their perinatal HIV infection, expressed confusion or anger towards their parents. This anger, in some cases, also led to the adolescents being less obedient sometimes in an attempt to punish their parents, while at other times as an attempt to come to terms with, or due to confusion about, why this happened to them and not their siblings.

The emotional reactions that are in line with the abovementioned studies include shock and disbelief, sadness, shame, loneliness, anxiety, and anger. On the other hand, the emotional reaction that is in contrast to abovementioned studies include acceptance. This is because of a context where disclosure of HIV has occurred. The emotional reactions that are in line with abovementioned studies occurred in the medical and family context while the emotional reaction that is in contrast to abovementioned studies occurred in the context of camps. Therefore, this current study adds to our knowledge that HIV disclosure in a family and medical context leaves adolescents with unresolved emotions towards their HIV diagnosis while HIV disclosure in the camp context enables the adolescents to accept their HIV diagnosis

In nutshell, HIV disclosure to adolescents who were vertically infected with HIV creates an enormous emotional experience. The current VCT and medical context, as well as family context, services are ineffective, unfriendly to youth in disclosing HIV diagnosis; while the camp context is effective in disclosing HIV status.

**5.2.3. Experience of taking HIV treatment**

There are numerous studies that focus on adherence to ARV treatment. In this study, the researcher explored the experiences of HIV treatment and found various responses. Few participants mentioned that they have been taking medication since a young age and prior to HIV diagnosis so they are used to the treatment and therefore have no problem in taking medication and have accepted taking medication. Van Dyke (2012) highlights that early testing, diagnosis and initiations of treatment were critical for caregivers and children, and that the complexity of ARV treatment was less of a barrier to treatment.
Those participants who started treatment after HIV diagnosis reported different responses. More than half of the participants attested that they take their medication in secrecy because they cannot take their medication in front of friends or relatives if they are visiting or when playing. The secrecy is motivated by participants don’t want people to notice that they are on medication as it will reveal their HIV status. Thurston, et al. (2013) found that the role of disclosure is important in promoting adherence – some participants who experienced lack of disclosure were prevented them from taking medications at certain settings which stood in the way of adherence.

Some participants attested that taking treatment caused constraint in their social life because it limited them from engaging in activities that they would have loved to engage in freely. Piaget (cited in Van Dyke, 2012) mentions that adolescents have egocentrism, while Van Dyke (2012) adds that the egocentrism of adolescents may negatively impact on adherence to ARV treatment as adolescents may refuse to take medication at school because others will gain awareness of their illness. This leads to limited engagement in certain activities by adolescents (Van Dyke, 2012).

Other participants mentioned that taking medication on a daily basis makes the participant feel irritated and angry which has affected adherence to treatment. A study conducted by Thurston, et al. (2013) found that it is important to monitor the mood of those taking medication. One of the participants was struggling with depression and anxiety symptoms during the follow-up sessions, which had a huge impact on her adherence.

The findings also demonstrated that some participants demonstrated a lack of understanding on the importance of adhering to ARVs treatment. Mattes (2014) shows that many institutions that offer ARV treatment are understaffed by healthcare professionals, with dozens of people receiving treatment at the same time from those institutions. This may negatively impact on the quality of services provided to the patients, therefore neglecting physical examination and resulting in a lack of communication between healthcare workers and patients. The lack of communication between healthcare workers and patients may result in children and adolescents experiencing inconsistent practices and receiving insufficient information about their treatment and illness which may further evoke confusion (Mattes, 2014).
In addition, the results indicated that psychosocial interventions are important. One participant attested that she initially lacked understanding about HIV treatment; she then received explanations from psychologists and social workers to aid her to develop an understanding of the importance of adhering to treatment. According to Albelheim (2011) and Mark, et al (2006), the biopsychosocial model requires practitioners to change their perspective about using interventions at one level of a system which might be ineffective. Thus, the practitioners should work hand-in-hand and simultaneously at multi-levels, such as at biological, cognitive, behavioural and/or emotional levels in treatment planning and understanding of health and illness (Albelheim, 2011; Marks et al., 2006).

Therefore, early testing, diagnosis and initiation of treatment in adolescents who were vertically infected with HIV promotes adherence to treatment. Furthermore, adherence to treatment is impacted by social variables and psychological factors as well as medical personnel. The psychological factors are the perceptions (egocentrism leads to constraint) and mood (irritated); and the social factors (the adolescents experienced inconsistence and insufficient information from medical personnel which leads to lack of understanding) relate to secrecy (stigma and difficulties in disclosure leads to secrecy). Thus, palliative treatment is indicated in order to effectively provide services to adolescents.

5.2.4. Experiences of living with HIV

From the subtheme of prior HIV disclosure, it was evident that participants experienced difficulties in their childhood. The researcher then explored the experiences of participants in their adolescence stage and some subthemes were repeatedly expressed by the participants including medical problems and loss of loved ones. Other subthemes were also added.

Some participants reported having the responsibility of taking care of their grandmothers and having less of a social life outside the house. The study by Thupayagale-Tshweneagae, et al., (2012) also found that orphaned adolescents have difficulties in interpersonal relationships – building meaningful relationships with others seems difficult and at times impossible for them. This is as a result of many adolescents living with perinatal HIV/AIDS being in the role of young carers. Bauman et al. (2006) defines young carers as children and adolescents who take on ‘substantial and significant tasks’ with responsibilities that would normally be associated with an adult when someone, particularly a member of the household, becomes unwell. This may result in loss of time to start peer friendships (Bauman et al, 2006).
Regarding the importance of adhering to treatment in the support group, other participants reported **psycho educating** people who are HIV positive. According to Van Dyke (2012), camps are designed to foster positive relationships, competence-building opportunities, and offer support and opportunities for youth to initiate and engage in behaviour that aids in the transition to adulthood. Similarly, Fair, et al. (2012) found that group members identified the following four benefits associated with participating in the group: increased confidence, better communication skills, increased support, and a desire to share their experiences with others. In addition, the findings suggests that those participants attending support groups did not discriminate or judge themselves for taking treatment for HIV and they experienced **increased self-confidence**. Midtbo (2012) shows that Teen Club (a support group) seemed to make the adolescents confident and believe in themselves; they felt safe and secure.

In conclusion, from a biopsychosocial model, HIV impacts on multiple levels in the experiences of adolescents who were vertically transmitted with HIV. The multiple levels include social factors (loss of loved ones and sense of responsibility) and biological factors (medical problems). Adolescents who were perinatally infected with HIV are at a high risk of experiencing delays in their developmental tasks due to these biological and social factors. The biological factors include medical problems and difficulties in physical well-being; and the social factors include the experience of grief, and having limited time to form peer relationships, which is one of the developmental tasks. Anastasopoulos, et al. (2010) highlight that adolescents who were perinatally infected with HIV are unable to develop their identity, because they are unable to detach from family and attach to peers (Anastasopoulos, et al., 2010).

### 5.2.5. Knowledge about HIV

As presented in the results chapter of this study, there were some variations in the knowledge about HIV. The variations occurred between participants who are attending support groups and participants who are not attending support groups. The participants who attend the support group demonstrated **adequate information on HIV**, understanding and having information about HIV. All participants who have adequate knowledge of the disease attend support groups. Van Dyke (2012) shows that an effective peer support group creates a platform where control shifts from experts to the group members, allowing debates and
discussions among group members, developing new group norms of behaviour, and changing education to be less threatening and available to group members.

Those participants not attending support group have demonstrated **limited information and lack of information** about the disease. Thus, in a family context, the caregivers explain limited information or provide no information about the mechanism of HIV (Vaz, et al., 2010) and the lack of communication between healthcare workers and patients may result in children and adolescents experiencing inconsistent practices and receiving insufficient information about their treatment and illness, which may further evoke confusion (Mattes, 2014).

Therefore, the findings demonstrate the importance and the effectiveness of support groups as well as the ineffectiveness of family context and medical context.

**5.2.6. Challenges of living with HIV**

Punctuating from the above discussed main themes, it is evident that adolescents experienced numerous emotions towards the discovery of their HIV status. In this main theme, the findings suggest that adolescents who were vertically infected with HIV are faced with numerous challenges. In the section that follows these challenges will be discussed.

The results suggest that more than half of the participants expressed **difficulty in accepting their HIV diagnosis**. Some participants seem to be fixated on the anger of being HIV positive which prevented them from accepting their diagnosis. The above findings seem to be supported by Mutwa, et al, (2013) who indicate that once adolescents were made aware their perinatal HIV infection, they expressed confusion or anger towards their parents. Furthermore, the study conducted by Usinger and Marilyn (2010) found that adolescents who are self-absorbed, detached, angry, or overwhelmed were pre-occupied with conflicting beliefs on how others perceive them versus beliefs about their moral self which is the reflection of the ideal self-concept. The conflicting beliefs may result in the adolescent becoming fixated or stuck with an internal conflict.

In addition to reporting difficulties in accepting HIV diagnosis, other participants reported that this was due to stigma which they experienced from their social relationships. According to Rohlede, et al. (2009), stigma is a social process defined since the illness is viewed to be
preventable or controllable, or indicative of ‘immoral’ behaviours. Some people are blamed and perceived to be responsible for their own infection, resulting in active discrimination and social devaluation (Rohlede, et al., 2009). HIV stigma is perceived as discrimination pointed at people apparent to have HIV/AIDS, and the individuals, groups, and communities with which they belong to (Herek, 1999).

As shown in the previous sections, it is evident that the concept of disclosure is an enormous challenge. This concept also emerged in this main theme: numerous participants reported having a challenge in disclosure which was due to fear. The participants mentioned that fear restrained the participants from disclosing their HIV diagnosis to other people apart from those that already knew about their diagnosis. Some participants expressed that they feared being rejected, laughed at, judged, and gossiped about. Hence, this fear led to participants choosing to not disclose their HIV diagnosis.

The above results seem to be in line with previous studies that indicated that when young people disclose their HIV status, they do so with the intention of finding support. However, they are fearful of negative reactions that this disclosure may elicit (Martinez, et al., 2012; Hoogwood, et al., 2012). According to Van Staa, et al. (2008), young people utilise a strategy of normalising a chronic illness as a way of forming identity so that they are able to accept that a chronic illness was present but prevent it from dominating their lives by not disclosing their status.

The findings indicate that some participants have formed peer relationships and belong to certain crews that they associate with. However, they didn’t disclose their HIV status. Parker, et al. (2006) highlight that early adolescents form peer groups which require social skills in order to handle them effectively. Similarly, adolescents establish friendships and groups (Cobb, 2010) for the purpose of emotional support and exploration of values as well as to fulfil their need for formation of identity, belonging, building self-esteem and access to information (Jansen et al., 2012; Zarrett & Eccles, 2006; Hoogwood, et al. 2012). Although young people experience fears and dilemmas around HIV disclosure, they do not want to be associated with an identity linked to illness, contagion and death. In some ways, this desire motivates the young people not to disclose their HIV status as they choose to have a different image or identity where HIV does not belong. (Hoogwood, et al., 2012).
Other participants (two) showed a preference for playing soccer with friends but try by all means to only talk about soccer and school and not about personal issues. They also attested that attending to various activities with friends helped participants lead a normal social life, which they attested to being fun. This is supported by the study conducted by Florindo (2007) that indicates that the role of leisure in the lives of people living with HIV/AIDS has been important for coping with the negative effects of diagnosis, and increasing health and quality of life (Florindo, 2007).

Some participants reported that with their peers they get along, they never fight and argue, and they decided to avoid arguments and accept other people’s point. Thupayagale-Tshweneagae, et al. (2012) found that for the most part, the nature of problems in adolescence involves interpersonal relationships which require that individuals develop and effectively utilise social skills. However, orphaned adolescents have difficulties in interpersonal relationships and this has resulted from experiencing manipulations from their peers (Thupayagale-Tshweneagae, et al. 2012).

In addition to reporting peer relationships, other participants said they only relate well with their peers at school because their parents do not allow them to play with other children at home. Leifer and Fleck (2013) note that one of the developmental tasks, in late adolescence phase, is to care and value relationships and begin to select partners. However, in the context of HIV, Archibald (2010) found that family members, who are from families were one or more individuals are HIV infected, experienced discrimination from members of the church community due to fear of transmission, and children were not allowed to play together even after services. The adolescents expressed being warned not to hang with people living with HIV/AIDS (PLWHA). A group of members preferred their daughters not to have close friendships with someone with HIV/AIDS (Archibald, 2010). It is interesting to note that HIV stigma is a huge challenge that adolescents who are perinatally infected with HIV are faced with, and it creates many social difficulties that these adolescents encounter. Similarly, a study conducted by Kerr, et al. (2011) found that parents were being excessively protective towards their children. Thus, adolescents who were vertically infected with HIV do not experience psychosocial moratorium.

Some participants reported being socially withdrawn from their peers. Edgar, et al. (2012) found that adolescents living with perinatal HIV/AIDS experience difficulties when
developing relationships. Similarly, Usinger and Marilyn (2010) found that adolescents who are detached and/or overwhelmed may be withdrawn from societal expectations because they are being overwhelmed by personal circumstances or being deliberately withdrawn or disengaged. On the other hand, Dorrel, et al. (2009) found that these young people experience a dilemma between a desire to let people know their status and their parents’ views which sometimes results in feelings of isolation and loneliness.

Other participates attested to viewing themselves as being different from their peers. They reported that they do not understand why they are the ones suffering while other children are not. According to Piaget (cited in Van Dyke, 2012) older adolescents keep comparing themselves with adolescents with no physical illness or developmental disabilities. Similarly, within the field of social psychology (cited in Zambo, 2010), social identity refers to how we view and understand ourselves in relation to others – having a sense of who we are and where we belong in the world. This is also influenced by how others perceive us. Furthermore, a study conducted by Kerr, et al. (2011) found that people with epilepsy also reported feelings of being different from others around them; this may be due to their perception or actual experienced of being labelled as different.

The findings above imply that adolescents who were vertically infected with HIV experience difficulties in forming peer relationships and this might impact on the development of their identity (Erikson, 1968), which might result in identity crisis.

As presented in the results chapter of this study, there were some variations in the investigation of formation of intimate relationship. Few participants reported that they are involved in romantic relationship while majority of participants reported that they are not involved in a romantic relationship. Leifer and Fleck (2013) mentioned that the developmental tasks in late adolescents is to develop their own sexual identity and caring relationships; they care and value relationships and begin to select partners. In the following discussion, these variations are explored in an attempt to investigate how the background of the individuals may contribute to the differences.

The background of the participants indicated that those participants involved in romantic relationships were attending support groups while those not in a romantic relationship were not attending support groups. Those participants who reported not having any intimate and/or
romantic relationships expressed various reasons. Some reported that their caregivers did not allow them to have any romantic partners. Based on the family systems model (Jaffe, 1998), change in one of the family members will impact on the whole family system. Individuals who go through adolescence experience major changes in their lives which will impact on the whole family. This is evident through the adolescents developing their own identity, increased independence and autonomy. Consequently, the family must create a space to accommodate the changes experienced by the adolescents, especially changes in the parent-adolescent relationship (Jaffe, 1998). Hajikhani Golchin et al., (2012) point out that the conflict may result in strained parent-adolescent relationship. Parents have difficulty in recognising adolescents’ concerns; adolescents attempting to establish independence; adolescents lacking trust in the family; and parents attempting to control adolescents’ personal choices such as clothes, friends and subjects to study in school.

Others participants attested experiencing difficulties in sustaining their romantic relationships. Chinyezi (2010) found that adolescent girls who were perinatally infected with HIV lacked interpersonal skills that are necessary to form romantic relationships (Chinyezi, 2010).

Some participants also mentioned that they have difficulties in trusting their partners and this was due to past experiences were the participants disclosed their HIV status and their partners broke-up with them. Adolescents who are HIV positive are at risk of being rejected by their peers, community and the social environment (Brown & Pedder, 1991). Erikson (1968) suggests that this type of negative feedback loop may have a significant impact on this developmental stage because the adolescents may experience role diffusion. Furthermore, Pettitt, et al. (2013) also found that HIV/AIDS diagnosis has a great impact on developing sexual relationships with adolescents who have perinatal HIV/AIDS; they stand the risk of transmitting the disease to their partners, experience stigma and trust issues related to disclosing to their partners (Pettitt et al., 2013).

The above findings on intimacy indicate that adolescents who do not attend support groups experience numerous challenges which prevent them from developing romantic relationship. However, those individuals who attend support groups are able to form romantic relationships. Hence, the support group has positively impacted on adolescents who are living with perinatal HIV, in that it has equipped those adolescents to deal effectively with their
challenges and enabled them to form romantic relationships. These findings is consistent with previous research that suggests that adolescents viewed Teen Club (a support group) as a place where they could be open to one another, share problems and find support (Midtbo, 2012).

In addition to reporting various challenges, some participants attested that they experienced abuse from their caregivers. Caregivers are still using corporal punishment and they sometimes physically hurt the participants. On the other hand, other participants experienced trauma from being raped. Leifer and Fleck (2013) note that in the late adolescence phase, adolescents are faced with the developmental task of reaching independence and re-establishing family relationships in their family context. However, the study conducted by Gren-Landell, et al. (2011) found that adolescents who experienced maltreatment from parents and the community may develop an enormous fear of negative feedback in social interactions and evaluations of performance that may escalate to behaviours of avoidance and impairment, called social anxiety disorder. Similarly, the Centre for Disease Control and Prevention (Thornberry, et al., 2014) defines maltreatment as any behaviour of omission or commission by a parent or a caregiver that has an end product of harm, or potential to harm, which threatens the child or adolescent. In addition, the study conducted by Cluver et al., (2013) found that child abuse was also experienced by adolescents with perinatal HIV infection, who were exposed to severe physical, emotional and sexual abuse, as well as conflict and violence in the household.

The results further demonstrate that some participants are involved in conflict with their parents. According to Cobb (2010), the perceptions of adolescents towards their parents change. They perceive their parents as less supportive and opposing them. Similarly, Bukatko (2008) mentioned that the change in perception towards their parents resulted from the adolescents’ ability to view people with both strengths and weaknesses and to think in an abstract manner. Other participants expressed feelings of anger towards their parents which lead to participants being rebellious, acting-out and engaging in deviant behaviours. These findings are consistent with a study conducted by Mutwa, et al, (2013) that shows that adolescents that were made aware of their perinatal HIV infection, expressed confusion or anger towards their parents. This anger, in some cases, also led to the adolescents being less obedient sometimes in an attempt to punish their parents, and other times trying to come to
terms with the diagnosis, or due to confusion about their status, why this happened to them and not their siblings.

The findings indicated that some participants experienced financial constraints including having insufficient money at home that led to three participants being unable to buy the necessary food needed for them to take treatment for HIV as well as not having money to attend to their appointments at the clinics. According to Rohlede et al. (2009), children and adolescents who are infected and affected by HIV mostly grow up in poverty-stricken households. Similarly, Ssewamal, et al. (2009) reported that the death of parent may cause poverty in the family, as a prolonged parental illness and subsequent death creates a financial strain in the family resulting in poverty.

All participants identified ineffectiveness from nurses including experiencing a lack of empathy, and being impatient, judgmental and inconsistent in supporting the patients. This created distance between the participants and medical personnel. This is support by Pettitt et al. (2013) finding that suggest that clinical services for HIV/AIDS in Southern Africa are not adolescent-friendly and healthcare workers lack skills to treat adolescents, as adolescents feel uncomfortable to receive treatment in either a paediatric clinic or an adult clinic.

Other challenges which were identified in this study showed that four participants were in middle-school years (aged 16 to 17 years), and seven participants in high school years (aged 16 to 18 years). This is contrary to Jaffe’s (1998) division of sub-stages of adolescence: early adolescence corresponds with middle-school years (11–13 years), middle adolescence corresponds with high-school years (14–17), and late adolescence corresponds with college years (18 to early 20s). The study participants’ age results do not correspond with the ages of adolescents as indicated by Jaffe (1998). This is primarily due to adolescents in this study being vertically infected with HIV whereas the adolescents in Jaffe’s study (1998) were not vertically transmitted with HIV. Therefore, participants in this study were delayed in starting their schooling years. In addition, according to Piaget (Leifer & Fleck, 2013), adolescents develop formal operational thinking and shift from primary to secondary; adolescents who are prenatally infected with HIV may not reach formal operational thinking and may operate as concrete operational thinkers in their adolescence stage (Sherr et al., 2014) and this might impact on the adolescents to shift from primary to secondary school. This study’s finding is supported by Ismayilova, et al (2012) who highlights those children and adolescents who
were vertically infected with HIV are at a high risk to miss school or drop out of school. Similarly, the study conducted by Cluver et al, (2011) found that adolescents who were vertically transmitted with HIV reported experiencing disruption and difficulties in their concentration which affected their performance at school.

Some participants reported that attending monthly appointments was a challenge as it affected their academic performance. Mburu et al. (2014) found that adolescents living with perinatal HIV/AIDS may drop out of school or repeat grades due to discrimination and frequent hospital appointments (Mburu et al., 2014).

From the above, it is evident that adolescents who were vertically infected with HIV faced various challenges and this motivated the researcher to explore the coping mechanisms which are used by these adolescents. Hinshaw (2005) highlights that adolescence is a period characterised by a number of developmental tasks. To deal with the demands that confront them, adolescents draw on their coping resources, which include their problem-solving competencies and skills.

The research results indicate that participants used denial, avoidance, and hopefulness as their coping mechanisms. According to Pettit, et al., (2013), many adolescents living with HIV/AIDS suffer from self-blame and self-stigma, view themselves as lacking opportunities in their communities when compared to their uninfected peers and also live in denial about their HIV status. However, results from the study conducted by Pettitt, et al., (2013) are in contrast with the results of this study: Pettitt, et al., (2013) found that those participants who have accepted their status showed a sense of hopelessness about their future while in this study those who have accepted their status are creating meaning from living with HIV and this has helped them with accepting their HIV status. The contrast between the two studies may be a function of the context in which the study was conducted. The participants who expressed acceptance in the study conducted by Pettitt, et al., (2013) did not attend support groups and youth camps while the participants in this study attended support group and youth camps.

Thus, from the above, adolescents who were perinatal infected with HIV are faced challenges from multiple levels including social, biological and psychological factors. In addition, those adolescents who attend support groups are using coping mechanisms of creating meaning and
acceptance while those not attending support groups utilise coping mechanism of denial, avoidance, and hopefulness to being healed. Thus, adolescents who are not attending support group are missing the opportunities of benefiting from support groups.

5.2.7. Coping resources
From the above, it is evident that having to cope with HIV can be quite challenging for adolescents who were vertically infected with HIV and support is vital in helping adolescents living perinatal HIV in coping with these challenges. The researcher explored the available coping resources. The findings indicated that some participants made use of family as a coping resource. Meyer (2013) showed that millions of adolescents who were vertically infected with HIV have been orphaned or made vulnerable by HIV/AIDS. This leads to those adolescents who were vertically infected with HIV being relocated to their relatives’ homes (Rohlede et al., 2009; Meyer, 2013). Similarly, the adolescents who were vertically infected with HIV experienced loss in their family context which results in instability and further impacted on the family’s ability to support the adolescents who were vertically transmitted with HIV (Van Dyke, 2012).

Some participants reported receiving social grants for assisting them in buying healthy food and access to medication through transport. Van Dyke (2011) highlights that a loss of caregivers may result in those adolescents experiencing poverty. According to Hall and Proudlock (2011), the foster child grant was introduced with the aim of protecting the child financially.

The findings indicated that few participants were attending support groups outside Dr George Mukhari Academic Hospital, because the hospital does not have any support system for youth. Attending support groups with other young people who were vertically infected with HIV enabled some participants to discuss the challenges they experienced with living with HIV. This is in line with the study conducted by Midtbo (2012) that shows that adolescents viewed the Teen Club (a support group) as a place where they could be open to one another, share problems and find support. Similarly, Van Dyke (2012), together with Mattes (2014), highlight that many children in Southern Africa do not receive any psychosocial treatment.
From the above, punctuating from the biopsychosocial model, it is evident that adolescents who were vertically transmitted with HIV are in need of psychosocial treatment (Marks et al., 2006; Albelheim, 2011). This type of treatment aims at motivating for a high-quality life, and it rebuilds hope and basic skills to deal with daily functions (Van Dyke, 2012).

5.3. CONCLUSION
In this chapter the experiences, thoughts and challenges of adolescents who were vertically infected with HIV were discussed. The research results clearly indicate that individuals going through the adolescence stage as well as living with perinatal HIV infection are faced with an emotional and stressful situation. Furthermore, for adolescents living with perinatal HIV, HIV impacts on their social, psychological and biological factors. This leads to physical and psychosocial challenges. In addition, it is evident that physical and psychosocial challenges occur in three levels namely: prior, during and after HIV disclosure.

The findings demonstrate that adolescents who were vertically infected with HIV are in need of psychosocial treatment. The biopsychosocial treatment should be offered prior, during and after HIV disclosure. The study indicated that the majority of participants do not attend support groups; and for those who attend support groups, the support group is not offered at Dr George Mukhari Academic Hospital. According to Van Dyke (2012), and Mattes (2014), many children in Southern Africa do not receive any psychosocial treatment and there is lack and/or few such treatments tailor-made for adolescents. The findings indicated that those participants who attended the support group experienced less or no difficulties as compared to adolescents not attending the support group. This is supported by Albelheim (2011) who reported that the biopsychosocial model requires practitioners to change their perspective of using interventions at one level of a system which might be ineffective. Furthermore, it was evident that adolescents who are living with perinatal HIV infection experience unresolved emotions and are at an increased risk of developing psychological difficulties. Thus, the services of psychologist may be beneficial in addressing these psychological and emotional barriers.

In addition, the findings demonstrated that the biomedical approach is ineffective and unfriendly to adolescents who were living with perinatal HIV infection. This is consistent with Engel’s suggestion (1977) that states that from a biopsychosocial model, the medical profession is criticized and should re-examine education and care. Furthermore, the findings
illustrated that early testing, diagnosis and initiation of treatment is effective; those participants who tested, diagnosed and initiated treatment later had medical difficulties and accepting treatment as compared to those participants who tested, diagnosed and initiated treatment earlier.

5.4. STRENGTHS OF THE STUDY

- The study aimed at exploring the experiences, thoughts and challenges of adolescents who were vertically infected with HIV. It is during the process of exploring their experiences that the richness and quality of data was derived from the in-depth interviews.

- While exploring the experiences and challenges of adolescents who were vertically infected with HIV, the differences were found between the individuals attending support groups and those not attending support groups. Furthermore, the research reflected on how psychosocial treatment positively impacted on the lives of adolescents who were vertically infected with HIV.

- When exploring the participants’ challenges, the findings indicated how the biomedical approach is ineffective and not youth friendly. The research provided information that will lead to further research and the ability to improve healthcare services as well as the mental health of adolescents who were vertically infected with HIV.

5.5. LIMITATIONS

Despite the strengths of this study, as seen in section 5.4., the following limitations were also noted:

- The final sample used in the current study did not show great variability; there wasn’t an equal distribution within the different races, only black Setswana-speaking adolescents were interviewed, all the participants hailed from the same peri-urban area. The sample size was small, with participants from same clinic served one hospital. Therefore, the results may not be generalizable to the larger population. Therefore, the findings cannot account for the experiences of other adolescents who were vertically transmitted with HIV, of different races, or coming from urban and rural places, as such findings may differ from the findings of this study.
The sensitive nature of the interview questions and meeting the participants’ one-at-a-time may have impacted on the rapport and may have led to some adolescents not reporting their experiences thoroughly.

5.6 RECOMMENDATIONS
After gaining insight into the experiences and challenges of HIV-positive adolescents, the following recommendations are made:

- From the results and literature, it is evident that individuals who are living with HIV/AIDS experience numerous challenges ranging from physical, social and psychological challenges; therefore, these individuals need a palliative treatment (also called multidisciplinary team) prior, during and after HIV disclosure.

- This study also recommends the full assessment of Biomedical or Physical Treatment to adolescents who are perinatal HIV infected. This encourages early testing, diagnosis and initiations of treatment. This will ensure and address the adherence issue. This study also recommends holding workshops and training medical professionals working with HIV-positive adolescent to address negative experiences by adolescents when interacting with nurses collecting their treatment at the clinics and hospital.

- The study also recommends psychosocial treatment and support groups: HIV-positive adolescents have to develop effective skills to deal with psychosocial challenges.

The following are suggested research studies that can be explored further:

- It is recommended that future research efforts in this area should include participants from different hospitals, from wider geographic areas, and from different racial groups in order to broaden the understanding of the phenomenon.

- The time frame for the study should be expanded and increasing the number of participants is recommended in order to strengthen the findings of this study.
REFERENCES


APPENDIXES A
INVITATION TO RESEARCH STUDY

You are requested to participate in a research study which has a research topic of: An investigation into the experiences and challenges of adolescents who were vertically infected with HIV at birth and currently receiving treatment at Dr George Mukhari Academic Hospital, Garankuwa Gauteng Province

The aim of the study is: The aim of the study is to explore the experiences and challenges of HIV positive adolescents who are currently undergoing treatment at Dr George Mukhari Academic hospital, Garankuwa Gauteng Province.

The objectives of the study are:
To gain insight into the experiences, challenges of HIV positive adolescents.

Furthermore, the researcher’s objective includes exploring the current support systems of HIV positive adolescents.

The proposed research, viewed as a pilot study, aims to stimulate future research and generate debate around the importance of psychological interventions at tertiary hospitals in South Africa.

The participation of the research study is voluntary and if the participants are willing to participate in this study they will be required to ask their parents or legal guardian for agreement to allow their child to participate, and then the participant together with their parent or legal guardian should fill in their written consent by completing the informed consent form. After the filling-in the informed consent form, the participants will be interviewed by the researcher and the interview will be recorded.

The participation to this study will not cause any harm or be detrimental to the participants. The participants will be assured that they will be anonymity (not providing their names)
throughout the whole research study and even when publishing the research results. The will be no reward (being paid or given gifts) to the participants.

After reading the above invitation and having concluded to participate in this study, you should complete the consent form.
Statement concerning participation in a Research Project

Name of the Study: An investigation into the experiences and challenges of adolescents who were vertically infected with HIV at birth and currently receiving treatment at Dr George Mukhari Academic Hospital.

I have read the information on the aims and objectives of the study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this study has been approved by the Medunsa Campus Research and Ethics (MCREC), University of Limpopo (Medunsa Campus)/Dr George Mukhari Hospital. I am aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participation in this study.

………………………………….    …………………..
Name of patient/volunteer     signature of patient or guardian

………………………….  ……………………… ………………..
Place     Date     Witness

----------------------------------------------------------------------------------------------------------------

Statement by the researcher
I provide verbal and/or written information regarding this study. I agree to answer any future questions concerning the study as best as I am able. I will adhere to the approved protocol.

…………………………  ………………………… ………… ………...
Name of Researcher   Signature   Place   Date
APPENDIX C
INTERVIEW SCHEDULE

1. Before you found out you were HIV positive, describe how your life was like for you?
2. When and how did you find out about your HIV status?
3. What can you tell me about your childhood?
4. Do you remember when you first started taking your HIV treatment?
5. Are you currently receiving treatment for your HIV?
6. How do you experience taking medication on a daily basis?
7. Do you know of anyone else who is HIV positive?
8. Have you disclosed your HIV status to anyone?
9. What would be some of reasons why you would not disclose your HIV status?
10. How would you describe your social life?
11. Do you have a girlfriend/boyfriend?
12. Do they know about your HIV status?
13. How would people react if they knew about your HIV status?
14. How would you explain to people how you contracted HIV?
15. What are some the daily challenges you face?
16. Please describe your peer relationships?
17. Do you currently have any support systems?
18. What is your understanding of HIV?
APPENDIX D
(MREC APPROVAL)
APPENDIX E
(HOSPITAL APPROVAL)
MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 09/2013

PROJECT NUMBER: MREC/M/293/2013: PG

PROJECT:

Title: An investigation into the experiences and challenges of adolescents who are vertically infected with HIV and on treatment at Dr George Mukhari Academic Hospital

Researcher: Mrs V Khuto
Supervisor: Ms K Thobejane
Hospital Superintendent: Dr MC Holm
Department: Psychiatry, Clinical Psychology & Psychology
School: Medicine
Degree: MSc Clinical Psychology

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 07 November 2013

PROF GA OGUNBANJO
CHAIRPERSON MREC

The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an International Organisation (IORG0004319), as an Institutional Review Board (IRB00005122), and functions under a Federal Wide Assurance (FWA00009419).

Note:

i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.
To: Mrs. Veronica Khuto  
Department of Clinical Psychology  
P.O. Box 110  
University of Limpopo  
MEDUNSA  
0204

Date: 15 October 2013

PERMISSION TO CONDUCT RESEARCH

The Dr. George Mukhari Hospital hereby grants you permission to conduct research on "An investigation into the experience and challenges of adolescents who are vertically infected with HIV and on treatment at Dr. George Mukhari Academic Hospital."

This permission is granted subject to the following conditions:

☐ That you obtain Ethical Clearance from the Human Research Ethics Committee of the relevant University

☐ That the Hospital incurs no cost in the course of your research

☐ That access to the staff and patients at the Dr George Mukhari Hospital will not interrupt the daily provision of services.

☐ That prior to conducting the research you will liaise with the supervisors of the relevant sections to introduce yourself (with this letter) and to make arrangements with them in a manner that is convenient to the sections.

Yours sincerely

[Signature]

DR. P SHEMBE
DIRECTOR: CLINICAL SERVICES