

**Psychosocial experiences of adolescents living
with HIV and AIDS in Matlosana Sub-District,
North West Province, South Africa**

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DECLARATION

I, Boitumelo Mutloane, declare that this mini-dissertation for the award of the degree of Master of Health Sciences in Clinical Psychology at the North-West University has not previously been submitted by me for a degree at this or any other institution. I further declare that this is my own work in design and execution and that all materials contained herein have been duly acknowledged.

B. Mutloane

Date

DEDICATION

This dissertation is dedicated with love to my late son, Oamogetswe Mutloane, and most of all, my beloved husband, Baile Mutloane and my beautiful daughter, Oagile Mutloane. Your unfaltering love, encouragement, sacrifices and support throughout my studies has always been a great inspiration.

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LIST OF ABBREVIATIONS AND ACRONYMS

AAP: American Academy of Paediatrics

AIDS: Acquired Immune Deficiency Syndrome

ALHIV: Adolescents Living with HIV

ART: Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

HSRC: Human Science Research Council

PHC: Primary Health Care

SANAC: South African National AIDS Council

UNAIDS: Joint United Nations Programme on HIV/AIDS

UNICEF: United Nations Children's Fund

WHO: World Health Organisation

ABSTRACT

Background

Adolescence is an important developmental phase with many key life events happening in this phase. It is a stage of life that comes with its own challenges. Living with an extremely stigmatised disease such as HIV and AIDS is an overwhelming undertaking. Daily life is occupied with the demands of the multiple aspects of HIV management routine. Adolescents living with HIV and AIDS are even more challenged. They must not only cope with the demands of managing the disease, but also the normal developmental tasks of adolescence.

Aim

The aim of the study was to explore the psychosocial experiences of adolescents living with HIV and AIDS in Matlosana Sub-District, North West Province, South Africa.

Methodology

An exploratory qualitative method was used in conducting this study. Data was collected through interviews with 10 adolescents living with HIV and AIDS. The interviews were audio-recorded, transcribed word verbatim and translated. Thematic analysis was used to analyse the data.

Results

The findings of the study revealed that most adolescents living with HIV and AIDS struggle with psychosocial factors related to fear of disclosure and rejection, stigma, adherence to treatment and a desire to be “normal”. The results indicate that although

HIV is considered a stressor, some participants maintained hope for the future. The findings showed that support networks such as support groups had a significant impact in assisting adolescents cope with their illness.

Conclusion

It is important to provide effective and targeted psychological and social services that support the needs of adolescents to navigate safely through adolescence and improve their quality of life.

Keywords: *Adolescents, HIV and AIDS, Psychological, Social, Experiences*

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CHAPTER ONE

INTRODUCTION TO THE STUDY

1.1. Introduction

South Africa is among the countries greatly affected by HIV and AIDS in sub-Saharan Africa. According to Statistics South Africa (Stats SA, 2017), it is estimated that there are about 7.1 million people living with HIV/AIDS. According to the United Nations Joint Programme on AIDS (UNAIDS, 2017), there were 270 000 new infection in 2016 in South Africa. Although there are continued efforts to address challenges associated with the HIV pandemic, the devastating impact of the disease on children and adolescents remains a crisis. In sub-Saharan Africa, young people, particularly adolescents, remain the most at risk group disproportionately affected by HIV.

The UNAIDS (2015) estimates that in 2015, about 2 million adolescents between the ages of 10 and 19 were living with HIV worldwide; approximately 1.6 million of this number living in sub-Saharan Africa. In addition, 79% of new infections among adolescents occurred in Africa. HIV and AIDS is currently the leading cause of death among adolescents in Africa and the second leading cause of death among adolescents worldwide (United Nation Children's Fund [UNICEF], 2015). In South Africa, HIV prevalence among the youth and adolescents aged 15-24 is believed to be 4.64% (Stats SA, 2017).

South Africa faces a critical period with children born with HIV surviving into adolescents and beyond due to the provision of highly active antiretroviral therapy (ART). Similarly, sexual transmission of HIV continues to pose a challenge as the incidence and prevalence among adolescents is increasing (UNICEF, 2016; National Department of Health [NDoH] 2015). Therefore, adolescents living with HIV are

particularly a significant sub-group in the HIV and AIDS epidemic that needs to be adequately addressed.

The World Health Organisation (WHO, 2010) defines adolescence as a developmental phase of children aged 10 to 19 years. In consistence with the definition of WHO (2010), adolescence is defined for the purpose of this study as a developmental phase of children aged 10 to 19 years. Adolescence is often described as a stormy and stressful period. It is a phase of transition from childhood to adulthood, marked by major physiological, cognitive and psychosocial changes (Kuzma & Peters, 2015). Adolescence is a phase of life where self-awareness and physical appearance are important (Arnett, 2010). During this stage, adolescents pursue a range of activities outside of their homes in pursuit of autonomy and identity formation (Close & Rigamonti, 2011). Evidence suggests that the period of adolescence could be difficult as adolescents have to manage social and psychological changes, physical appearance, as well as manage the relationship with caregivers, family members as well as increased expectations from caregivers and teachers. With these changes come challenges, choices and tensions that adolescents are faced with and which have possible impacts on one's mental health. At the same time, establishing peer relations becomes highly significant in adolescence. Since social acceptance and friendships are important in adolescence, studies have shown that adolescents who perceive to be isolated or rejected, are particularly vulnerable to depression, substance misuse or eating disorders (Gowers, 2005). In this period of conformity with peers and belonging, any situation that puts an adolescent apart from others, such as an HIV diagnosis, could lead to feelings of stress and depression, which may negatively affect the psychosocial well-being of an adolescent.

Makame, Ani and Grantham (2002) define psychosocial well-being as “the social and emotional well-being of an individual and the ability to fulfill his/her potential as a human being. It includes many areas of the individual’s life, the psychological aspects, including emotional, cognitive, mental and spiritual factors; while the social aspect refers to relationships with others, the environment and the society”.

Psychosocial well-being affects every aspect of an adolescent’s life, from their ability to learn, to be healthy, productive and to relate well with other people (Tadesse, Dereje & Belay, 2014). Living with a chronic illness, particularly one associated with stigma, can bring numerous psychosocial stressors and impacts on the psychosocial well-being of adolescents (Akpa & Bamgboye 2015). Research indicates that adolescents living with HIV tend to have high levels of mental health problems (Woollett, Cluver, Bandeira & Brahmbhatt, 2017; Woollett, 2013). Research findings have found that the most common mental health disorders found among HIV positive adolescents are depression, anxiety, post-traumatic stress disorder and suicide (Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath & Ferrand, 2014; Petersen, Hancock, Bhana, & Govender, 2014). Evidence suggests that mental health problems in this population group may be associated to knowing their HIV diagnosis and disclosure of their HIV status. In addition, there are socio-emotional strains of lifelong adherence to treatment and long-term care as well as coping with stigma, fear and concerns around emerging sexuality and future course (WHO, 2014). Poor mental health problems have been found to have adverse implications on adherence to ART treatment and retention in care (Hudelson & Cluver, 2015).

The World Health Organisation (2003) defines adherence as “the ability of patients to follow treatment plans, take medications at prescribed times and frequencies and

also follow restrictions regarding lifestyles, food and other medication”. Antiretroviral treatments are an important component of the comprehensive approaches used to reduce the viral loads of people living with HIV and AIDS and in curbing HIV and AIDS (Azia, Mukumbang & Van Wyk, 2016). Optimal adherence is dependent on sustaining high rates of ART adherence of over 95% (WHO, 2003). Research on ART adherence among adolescents seems to vary widely, with some findings reporting significantly higher levels of adherence rates in African and Asian adolescents compared to those in South America and Europe (Kim, Gerver, Fidler & Ward, 2014), whereas Chandawani, Koenig, Sill, Abramowitz, Conner and D’ Angelo (2012) reported poor adherence levels among adolescents living with HIV. The literature reveals that adolescents with chronic diseases generally have lower rates of adherence to treatment compared to younger children and adults (Desai & Oppenheimer, 2011). Research conducted in resource-limited settings has documented socio-economic factors such as poverty, food insecurity and unemployment as influencing adherence (Kheswa, 2017). Similarly, socially linked factors such as stigma and discrimination have been identified to negatively contribute to ART adherence (Azia *et al.*, 2016). In a study conducted by Mutwa, Van Nuil, Asimwe-Kateera, Kestelyn and Vyankandondera (2013) in Rwanda, adolescents explained how they would avoid going to the clinic to obtain their medication because of fear of being seen and labelled as living with HIV.

According to UNAIDS (2014), HIV-related stigma is defined as “negative beliefs, feelings and attitudes towards people either living with or associated with HIV and AIDS”. Furthermore, discrimination refers to “an action based on stigmatisation”. HIV-related discrimination follows on stigmatisation; it is “an unfair and unjust treatment of an individual based on real or perceived HIV status” (UNAIDS, 2003).

Woollett (2013) states that what separates HIV and AIDS from other chronic illnesses is the stigma related with the disease. HIV-related stigma and discrimination has been described as the major barrier to disease prevention and to provide care and support for those living with HIV/AIDS. Adolescents are a vulnerable group that are most affected by HIV/AIDS-related stigma. Stigma is particularly harmful to adolescents because of their phase of development where belonging and acceptance by peers is very important (Fielden, Scheckter, Chapman, Almneti, Forbes, Sheps, *et al.*, 2006).

A study conducted by Thupayagale-Tshweneagae (2010) revealed that adolescents living with HIV and AIDS in Botswana protect themselves from the risk of being stigmatised by keeping their illness a secret; they use silence to conceal their HIV status. In the same study, adolescence described adhering to ART as important in helping them not to be sick and as a consequence reduce the stigma associated with living with HIV and AIDS. According to McHenry *et al.*'s (2017) study on the perspectives of HIV stigma from Kenyan child caregivers and adolescents living with HIV, the stigma associated with HIV was as a contributing factor for hiding and taking medication in secret. The same study showed that adolescents hide their HIV status because of fears of losing friends. Stigma can affect adolescents' sense of self regard and self-esteem and has been reported to contribute to mental health problems such as depression and anxiety (Woollett, 2013). The shame associated with HIV and AIDS can have profound psychological influence over how adolescents cope with their illness (UNAIDS, 2014).

Lazarus and Folkman (as cited in Rose & Clark Alexander, 1999) define coping as "a person's constantly changing cognitive and behavioural efforts used to manage

specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person”. Living with a chronic illness could be demanding for adults but even more for adolescents who, in addition to experiencing their own developmental difficulties, must learn to cope with the illness and incorporate it into their everyday lives (Close & Rigamonti, 2011). A lot of facets of living with HIV are potentially demanding, for example, the need for lifelong adherence, side effects of the medication and stigma (American Academy of Pediatrics, [APP], 1999).

Woollett, Cluver, Hatcher and Brahmabhatt (2016) state that HIV adds a significant burden to development and adolescents living with HIV are probable to experience increased mental health problems and psychosocial stress. In order to manage these stressful demands, individuals may make use of various coping efforts. Coping can be a key determinant of health prognosis and quality of life. According to Tadesse *et al.* (2014), psychosocial aspects are recognised as influencing coping and could explain how adolescents more or less efficiently cope with the illness.

The literature on HIV and AIDS has recorded that the psychological and social effects of HIV and AIDS are magnified in adolescents. It is in this context that psychosocial experiences of adolescents living with HIV and AIDS are explored.

1.2. Background of the study

Despite the significant developments in HIV prevention and access to antiretroviral (ARVs), the epidemic remains a cause for concern worldwide and, perhaps particularly in sub-Saharan Africa. Globally, studies show that the number of adolescents living with HIV and AIDS is increasing (Masquiller, Wouter, Loos, & Nostinger, 2012).

According to the UNICEF (2016) adolescents and young people represent an increasing part of people living with HIV worldwide. In 2015, about 1.8 million adolescents between the ages of 10 and 19 were living with HIV worldwide (UNICEF, 2016). Of the 1.8 million adolescents living with HIV, about 1.4 million (80 per cent) live in sub-Saharan Africa (UNICEF, 2016).

The UNICEF (2016) estimates that sub-Saharan Africa and South Asia are the regions with the highest numbers of HIV-positive adolescents, with adolescent girls and young women being disproportionately affected by HIV in sub-Saharan Africa.

Additionally, AIDS-related deaths among adolescents have increased over the past decade while decreasing among all other age groups, which could be largely attributed to a generation of children infected with HIV perinatally who are growing into adolescence (UNAIDS, 2016). According to UNICEF (2015), AIDS is the main cause of death for adolescents aged 10-19 years in Africa and the second globally. Majority of these deaths are among adolescents who acquired HIV as babies and survived to their adolescence years, either without knowing their HIV status or having lost out of care.

South Africa is among the countries in the world with the highest incidence of HIV (Human Science Research Council [HSRC], 2012). South Africa, like most countries in sub-Saharan Africa, has heterosexual transmission as the main mode of HIV transmission. Data from the South African National HIV prevalence of 2012 estimated that 12.2% of the population (6.4 million persons) were HIV positive, which is 1.2 million more people living with HIV than in 2008 (HSRC, 2012). The literature seems to suggest that key drivers of the epidemic are poverty, unemployment, gender

inequality, multi concurrent sexual partners and intergenerational relationships (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu *et al.*, 2012).

The NDoH (2015) has made vast strides and key interventions to improve access to antiretroviral treatment (ART) to special groups, in order to decrease the disease burden, address maternal and child mortality and improve life expectancy. This resulted in more than 2.6 million people being initiated on ART by mid-2014 (NDoH, 2015). Additionally, NDoH (2015) has also revised the eligibility criteria for ART initiation in 2015, with the following criterion: all HIV positive pregnant and breastfeeding women, regardless of CD4 count or WHO staging and children >5 years old, adolescents and adults with CD4 $\leq$ 500 cells/mm³.

Among the nine provinces of South Africa, the HIV prevalence rate of the North West Province ranks fourth among the provinces, after Kwa-Zulu Natal, Mpumalanga and the Free State provinces (South African National AIDS Council [SANAC], 2013). Among the four Districts in the Province, Dr Kenneth Kaunda carries the heaviest burden with the most number of adolescents affected by HIV/AIDS, although there is a noteworthy decline in HIV prevalence; from 37.0% in 2010 to 36.0% in 2011 and 29.1% in 2012 (HSRC, 2012).

How communities perceive and talk about HIV is likely to influence how adolescents experience HIV as an illness and meaning of living with the virus. Whether infected perinatally or during adolescence, adolescents living with HIV have a unique and very important psychosocial issues in addition to the daily challenges of adolescence.

1.3. Statement of the problem

Adolescence is an important developmental stage, with many key life events happening during adolescence. Steinberg (2008) also highlights that it is a phase that is accompanied by its own challenges such as peer pressure, initiation of sexual activity and insecurities about body image. In addition, it is a period associated with experimentation and higher rates of risk-taking behaviour, including the use of alcohol, drugs, gang involvement and unprotected sexual practices (Lowenthal *et al.*, 2014). Similarly, girls also confront the challenge of unplanned pregnancies. Sexual relationships and gender orientation issues become prominent in adolescence and young people are faced with decision-making (Fernet, Proulx-Boucher, Richard, & Joseph, 2007). Most adolescents navigate this challenging developmental stage successfully. However, some find it challenging and it may place demands on the psychological functioning of the adolescent and could likely increase stress. It is apparent that living with a highly stigmatised illness such as HIV can add a significant burden to an adolescent's psychological well-being (Mellins & Malee, 2013). The complexities of coping with HIV could be severe for adolescents at the same time, navigating the psychosocial changes associated with adolescence phase. Moreover, in South Africa, HIV takes place in the background of social factors such as poverty, unemployment, violence and parental loss due to AIDS-related deaths (Lowenthal *et al.*, 2014). Living with HIV may, therefore, impact on psychosocial development.

Adolescents living with HIV and AIDS will have fears and concerns that most of their peers do not have. The fear to be ill and hospitalised, concerns of possible death, fear of being viewed as abnormal, rejection and witnessing parental death are some of the difficulties reported by adolescents in similar studies (Lowenthal *et al.*, 2014; Galano, Turato, Delmas, Cote, de Fatima, Gouvea *et al.*, 2016).

A number of adolescents living with HIV and AIDS, who were perinatally infected, have been on treatment since early childhood and have experienced the side effects from treatment, including rashes, lipodystrophy, dizziness and other symptoms (Dawood, 2015). The side effects could be difficult to cope with and could impact on the adolescent's mental and physical health. Having side effects like rashes could result in low self-esteem. Similarly, treatment of side effects could cause psychological distress as adolescent's battle to understand the reasons for them looking different from their peers or they try to hide physical side effects that could prompt questions from peers (Dawood, 2015).

The experiences of adolescents living with HIV are unique to their developmental phase and differ from children and older young people living with HIV. Studies have emphasised that the needs of adolescents living with HIV are diverse and much more sensitive than those of adults living with HIV because at the same time, they must manage issues dealt by adults such as disclosure, practice safe sex and adhering to treatment with less life experiences than adults (Folayan, Odetoynbo, Brown, & Harrison, 2014). It is, therefore, necessary to understand the experiences, feelings, realities and difficulties that adolescents living with HIV and AIDS deal with in their daily life situations. Understanding and addressing psychosocial stressors of adolescents living with HIV would assist them cope better with the disease and improve their psychosocial well-being as they transition through adolescence to adulthood. Sufficient understanding will enable service provision that is appropriate and designed to respond to the needs of adolescents and prevent them from slipping from care due to their needs not being met. It is against this background that the researcher explored the psychosocial experiences of adolescents living with HIV and AIDS in Matlosana Sub-District, North West Province, South Africa.

In South Africa, there is research evidence with regard to the aforementioned focus area. In the North West Province, an exploratory qualitative study by Strydom and Raath (2005) focused on establishing the psychosocial needs of adolescents affected by HIV and AIDS and the responses of infected parents to the psychosocial needs of adolescents. Similarly, Li, Jaspan, Brien, Collen and Notress (2010) explored the experiences and needs of adolescents growing on treatment for HIV in Cape Town, South Africa, using focus groups interviews. Another relevant study by Mavhu, Berwick, Chirawu, Makamba, Coppas, and Dirawo (2013) focused on enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe. A mixed method research approach was used in the form of questionnaires and focus group discussions with adolescents, their caregivers, health care providers and community members. Mburu, Ram, Oxenham, Haamujampa, Lorpanda and Ferguson (2014) examined the socio-ecological determinants of adolescents' experiences of living with HIV in Zambia, using in-depth interviews and focus groups as methods to collect data from adolescents, caregivers and healthcare providers. Madiba and Mokgatle (2016) study focused on perceptions and experiences about self-disclosure of HIV status among adolescents with perinatally acquired HIV in poor-resourced communities in South Africa. The researchers used a qualitative exploratory design and in-depth interviews in their study. Qualitative studies on adolescents living with HIV and AIDS in South Africa and sub-Saharan Africa are inclined to study adolescents from the perspective of caregivers. This study, therefore, explores the psychosocial experiences of adolescents living with HIV reported by adolescents themselves.

1.4. Aim of the study

The aim of this study was to explore the psychosocial experiences of adolescents living with HIV and AIDS in Matlosana sub-district.

1.5. Objectives of the study

The objectives of this study were to:

- Ascertain the psychosocial challenges of adolescents living with HIV;
- Establish the impact of stigma in the lives of adolescents living with HIV;
- Understand the role of social support on the lives of HIV adolescents;
- Identify coping mechanisms used by adolescents living with HIV; and
- Establish the experience of HIV treatment by HIV positive adolescents overtime

1.6. Significance of the study

Conclusions drawn from this study will have practical significance for health care providers, caregivers and educators, thus contributing towards knowledge reflecting psychosocial experiences of adolescents living with HIV, thereby identifying more appropriate and effective interventions to support and strengthen their coping skills in relation to social and mental health needs.

The findings of this study would assist health care providers, caregivers and educators to recognise the emotional, cognitive and social effects of HIV on adolescents and to ensure that the continuum of psychosocial services for the benefit adolescents are provided.

Theoretically, it will add on to the existing literature on adolescents living with HIV by documenting the voices of adolescents as well as providing an understanding on how psychosocial issues are experienced and lived from the perspective of adolescents with HIV. Limitations of this study will give way to future researchers by identifying other gaps that still need to be investigated.

CHAPTER TWO

OPERATIONAL DEFINITIONS AND THEORETICAL FRAMEWORK

INTRODUCTION

The aim of this study was to explore the psychosocial experiences of adolescents living with HIV and AIDS in Matlosana sub-district, North West Province, South Africa. This chapter provides definitions of the different terms used in this study, followed by a discussion of the theoretical framework and theoretical perspectives that informed the study.

2.1. Operational definitions

2.1.1 Adolescence

Although there is no universally accepted definition of adolescence, the term is accepted and used to refer to the period between childhood and adulthood. The Oxford English Dictionary (1961) defines adolescence as the “process or condition of growing up, the growing age of human beings, the period which extends from childhood to manhood or womanhood”. The WHO (2010) defines adolescence as a “period in human growth and development that occurs after childhood and before adulthood, from ages 10 to 19”. For the purpose of this study, adolescence is a period between childhood and adulthood, between the age group of 10-19 years.

2.1.2 Psychosocial

The Oxford English Dictionary (1961) defines psychosocial as “pertaining to the influence of social factors on an individual’s mind or behaviour, and to the interrelation of behavioural and social factors”.

2.1.3 Coping

In this study, coping is defined as unique and personal strategies used by individuals to reduce the effect of stressful situations on them and or escape from adversity.

2.1.4 Adherence

Adherence to ART is “taking all ARV medication in correctly prescribed doses at the right time and in the right way while observing any dietary restrictions” (WHO, 2010).

2.1.5 Stigma

Stigma refers to “the negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. the families of people living with HIV” (UNAIDS, 2014).

2.2 Theoretical framework

2.2.1 Ecological systems theory

This study is guided by Bronfenbrenner’s ecological system theory (1979), which states that individuals develop within a complex system of relationships affected by

multiple environmental factors. Bronfenbrenner (1979) states that the environment in which a person functions, is made up of different layers of systems, which include the microsystem, mesosystem, exosystem and macrosystem and the interactions that individuals have with others and with these various systems, all have an impact on a person's development (Harkonen, 2007).

The microsystem is the innermost level, the one that is closest to the individual (adolescent). This system involves those that are part of the adolescent's immediate environment such as caregivers, siblings, peers, friends and school life. For example, within the microsystem, the adolescent may deal with the demands and challenges of taking ARV's in secret without friends and others knowing about it. This may place demands on both the adolescent and caregivers. The theory further postulates that individuals are not just recipients of the experiences that happen in the microsystem, but they also help to construct the environment (Kail & Cavanaugh, 2013).

The mesosystem involves the relationships and interactions between the microsystems in an individual's life. For instance, the experiences in an adolescent's microsystem could affect and be related to another microsystem (Harkonen, 2007). An example of this is the interaction between one's family life and their school life. This could involve interactions between an adolescent and their caregivers regarding perceived lack of support that the adolescent experiences from caregivers. This perceived lack of support can have a marked effect on how the adolescent views him/herself at school and can negatively affect developing positive relationships with peers and/or teachers. It may additionally lead to the adolescent isolating him/herself from peers out of fear of rejection that peers may not want to interact with them if the peers are to know that they are living with HIV.

The exosystem is a social setting that the individual does not actively play a part in, but which indirectly influences the individual (Harkonen, 2007). For example, if the adolescent is unable to receive his/her ARV's at the clinic due to stock outs, he/she misses out on school by having to return to the clinic and experience increased stress of having to explain their absence from school.

The macrosystem refers to the broader societal structures, as well as the overall patterns of values, belief systems, lifestyles and customs, embedded therein. The macrosystem is external to the individual and highly influential on development. For example, the social stigma that surrounds HIV can increase adolescent's experience of stress and influence the decision to disclose his or her status to others.

The final system which the chronosystem threads through the entire system, considers history and the time that shapes one's development (Harkonen, 2007). For example, poverty and hunger may have an impact on the development trajectory of an adolescent living with HIV as a result of caregivers who died due to HIV-related illnesses. The loss of parents may influence the adolescent in different systems, such as lack of financial support, poor academic performance and attachment difficulties.

HIV is influenced by multiple levels from an individual knowledge, family relations to factors beyond the individual. Adolescent's experiences, meanings and perceptions of living with HIV are continuously impacted and shaped by these various systems and how they navigate them.

2.3. Theoretical perspective

2.3.1 Erikson's theory on psychosocial development

The psychosocial development theory by Erikson (1968) is used in the study to explain how living with HIV affects adolescents at various domains, from physical, cognitive and psychosocial and how these experiences influence their identity formation.

Erikson assumes that personality develops over time and in a sequence of stages. The theory looks at the impact of social experience on individuals across their entire lifetime. The central element of the theory is the development of identity or ego. Erikson (1968) defines ego identity as the conscious sense of self that people develop through social interactions. In addition to ego identity, Erikson also believes that a sense of competence motivates behaviours and actions.

In each stage in Erikson's theory, the individual must become competent in a specific area of life. Erikson maintains that people experience a conflict or crisis during each stage. If the stage is managed well, the person will feel a sense of mastery and result in healthy identity and the acquisition of basic virtues, which the ego can use to resolve subsequent crises. If the stage is handled poorly, the person will come out with a sense of inadequacy and an unhealthier personality.

Erikson (1968) posits that the crucial development of identity occurs in the adolescent phase. It is during adolescence that individuals deal with issues of identity for the first time in their lives. According to Erikson (1968), adolescents face the life stage of identity versus role confusion in which adolescent struggle to find out who they are, what is their purpose in life and how do they fit into the world around them

(Erikson, 1968). Thus, failure to establish a stable coherent sense of personal identity in the process of identification may result in identity confusion (Erikson, 1968).

Adolescence is considered to be fascinating but at times, a stressful period in the life of most young people (Arnett, 2010). Being a transitional period from childhood to adulthood, it is characterised by extensive physical, emotional, cognitive and social changes (Arnett, 2010). Some adolescents may have a tough time coping with the rapid changes that take place. These difficult experiences, which are expected to take place during this period of development may lead to intense feelings of confusion, despair, loneliness and anxiety, which may negatively affect their psychosocial well-being (Woollet, 2013). In addition, the period is characterised by conflicts with caregivers and other people in places of authority.

Adolescents living with HIV face many of the same developmental difficulties as their HIV negative peers, that is, they experience sexual awareness, have concerns about relationships and engage in unhealthy risk-taking behaviour. However, the difficulties are intensified as they must consider issues of self-disclosure of HIV status, disease transmission, treatment adherence and stigma associated with HIV.

For adolescents living with HIV, both physiological changes and psychosocial adjustments are often interrupted by the effects of the HIV virus, the reverse is also true that adolescent development could have an impact on the disease. In the context of this study, adolescents living with HIV/AIDS may face considerable challenges in the process of forming positive self-identity. They may perceive themselves differently from others because of developmental delays such as stunting and sexual maturity resulting in increased insecurities about their body (Mutumba, *et al.*, 2015).

They may also be vulnerable to feelings of depression, low self-esteem and emotional problems, with some of them translating into mental health problems such as conduct disorder, attention deficit, hyperactivity disorder and social phobia (Zanoni, 2013). Achieving autonomy may be affected by caregivers being overprotective, which may interfere with adolescents' development of self. The social stigma linked to HIV may also affect adolescents' sense of self. He or she may define him-/herself as HIV positive and this self-definition may represent the greatest component of his or her identity, contributing to his or her own sense of stigmatisation (Mutumba *et al.*, 2015). Therefore, such situations may be difficult to cope with and can, if not properly dealt with, have a negative impact on the process of identity formation in the lives of adolescents.

2.3.3 Transactional model of stress and coping

Significant life experiences, for example, death of a loved one, illness and daily hassles such as school-related problems and interpersonal relationships (conflicts or problems with caregivers, teachers, siblings and peers) could be a considerable source of distress for many adolescents. In addition, the many changes taking place during puberty often gets many young people confused and stressed, particularly in the African context where most caregivers refrain from discussing matters of sex and sexuality with young people (Folayan *et al.*, 2014). Psychosocial stress has been identified as a risk factor for mental and behavioural problems in childhood and adolescence (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001).

The ability to adapt to adversity and stress is a central aspect of human development. Successful adaptation to stress and adversity is associated with a range of factors, which include how individuals manage their emotions and thought

processes as well as manage and direct their behaviour and act in social and non-social environments to modify or lessen sources of stress. The construct of coping encompasses all these processes (Compas *et al.*, 2001).

Coping is particularly important in adolescence as it has implications for psychological well-being (Smith & Somhlaba, 2015). Similarly, for HIV positive adolescents, the ability to cope is equally important as studies indicate that HIV places a considerable stress to development and that those infected are prone to suffer increased mental health problems and psychosocial stress (Woollett *et al.*, 2016).

Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioural efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person”. The two most widely used conceptual frameworks of coping strategies include problem-focused versus emotion-focused coping. Problem-focused strategies are aimed at altering a stressful situation while emotion-focused strategies are directed at changing one's thoughts and emotions about a stressful situation (Lazarus & Folkman, 1984). Coping strategies could be classified as adaptive or maladaptive. Adaptive coping strategies include social support, family or peer support. Maladaptive coping strategies typically cover ruminating, blame, avoidance and wishful thinking.

Lazarus and Folkman (1984) posit that the coping methods employed by an individual depend on personal attributes such as cognitive, emotional and behavioural development, as well as how he or she perceives the stressors. Folayan *et al.* (2014) argue that cultural traditions and social norms inform coping strategies adopted by adolescents, where the culture is one that promotes shame, fear, humiliation, anger, stigma and discrimination, coping with HIV infection can be overwhelming. As a result,

adolescents tend to cope by keeping their illness a secret or restrict knowledge to a few people, often immediate family members. Mofenson and Cotton (2013) believe that in their quest for acceptance and not be excluded from social spaces, adolescents are likely to cope by assuming an identity that is considered common and expected by everybody because being identified as different exposes them to judgments and causes problems in interactions with others.

Research also reveals that adolescents infected with HIV utilise several strategies to cope with the challenges of living with HIV, including treatment optimism, secrecy, avoidance, distraction and social support (Mutumba *et al.*, 2015). Given the various difficulties that adolescents experience in their daily lives, they need to develop appropriate coping mechanisms in order to adapt to all the changes of adolescence. The way in which adolescents cope with psychosocial stress can have a significant effect on their current and future psychological well-being.

CHAPTER THREE

LITERATURE REVIEW

3.1 Understanding the psychosocial experiences of adolescents living with HIV and AIDS

There is a growing call to understand the experiences and contextual circumstances of adolescents living with HIV. Studies indicate that experiences of adolescents living with HIV are shaped by a variety of factors across individual, family and peer, community and structural area (Amzel *et al.*, 2013, Mburu *et al.*, 2014). In addition, these experiences could be both positive and negative factors at each of these levels. Woollett *et al.* (2016) report that individual assets such as personal

competence, positive self-concept, resilience and a strong locus of control are important factors that shape the perception of an HIV diagnosis. Positive self-concept, communicative ability and self-efficacy have shown to promote the health of adolescents living with HIV in places such as Tanzania (Mburu *et al.*, 2014).

The literature reveals that individual resilience and positive self-concept are also influenced by the adolescent's interaction with family, peers and social networks (Amzel *et al.*, 2013). Social factors such as adolescents' relationships with peers, parents and community resources such as schools, clinics and church could influence adolescents' experiences of living with HIV (Tshuma, 2015). Evidence suggests that adolescents living with HIV tend to experience enduring adversity. They must negotiate the complex demands of treatment, social pressures and vulnerable health within the context of bereavement and disrupted care, without having necessarily developed the skills to manage these circumstances (Lowenthal *et al.*, 2014). Albright, Fair and Newman (2016) further add that living with an infectious disease also requires the adolescent to take responsibility for a range of practices that would be largely unfamiliar to their HIV-negative peers such as taking medicines, visiting doctors, monitoring health, taking caution with injuries and building skills in negotiating safer sexual practices.

Stigma and isolation are often a common consequence of living with HIV and many adolescents living with HIV, live in fear, shame and disgrace (Van Vilsteren, Haffejee, Patel & Bowman, 2011). Madiba and Mokgatle (2016) report that living in fear is a common experience for most ALHIV. For most ALHIV, the fear of being known to have the disease as well as the fear of being viewed as abnormal and the fear of rejection is always greater. Hogwood, Campbell and Butler (2013) argue that the

experiences of children and adolescents living with HIV, their knowledge and attitude towards their HIV status are affected by their caregivers who might be ill-prepared to address the issue of HIV with them. As found in studies examining disclosure to HIV infected children and adolescents, delayed and suboptimum disclosure to adolescents of their HIV status is a common experience, leaving them to cope with their disease within an atmosphere of secrecy (Michaud *et al.*, 2009). Daniel (2015) further adds that the secrecy limits opportunities that they must discuss, learn, understand and thus, accept their illness. A study by Daniel *et al.* (2007) revealed that disclosure and openness was linked to resilience and self-worth, while silence, secrecy and stigma contributed to feelings of self-hate, anxiety, hopelessness and confusion among HIV/AIDS-affected children and adolescents. However, studies have reported mixed outcomes of adolescents' disclosure to others (Mburu *et al.*, 2014).

Creating romantic and sexual relationships is a normative part of development and this aspect of adolescence is not absent from the lives of young people with HIV. However, adolescents living with HIV experience numerous challenges to establishing healthy romantic and sexual relationships due to stigma, requirements to disclose and transmission risks (Albright *et al.*, 2016). In addition, Albright *et al.* (2016) highlight that negative self-concept is common among adolescents living with HIV, who may see themselves as "damaged" or "contaminated". These experiences may result in psychosocial distress and low self-esteem and could lead to risk-taking behaviours linked with unsafe sexual practices and substance use (Thupayagale-Tshweneagae, Wright, William and Hoffmann, 2010).

3.2 The psychological well-being of adolescents living with HIV

Adolescents living with HIV face a multitude of unique issues related to the psychosocial impact of HIV, including delayed puberty, sheltered life experiences, disclosure, missed school and social opportunities, stigma, disintegration of family life and exposure to violence (Vujovic, Struthers, Meyersfeld, Dlamini, & Mabizela, 2014). It is undeniable that HIV poses risks to adolescent mental health as well as functioning and well-being (Woollett *et al.*, 2016). Growing evidence suggests that adolescents with HIV, particularly perinatally acquired are at high risk for mental health problems given exposure to genetic, biomedical, familial and environmental factors (Mellins & Malee, 2013). Research also suggests an increased prevalence of mental disorders often present for the first time in adolescence (Mellins & Malee, 2013).

HIV and mental health are often described as having bi-directional relationships, meaning that the effects of living with HIV/AIDS or having an affected family member could increase risks for mental illnesses such as depression and anxiety, while poor mental health can inspire behaviours which place individuals at risk for HIV (Betancourt, Meyers-Ohki, Charrow & Hansen, 2013). Psychological distress was indicated in a research carried out by Van Vilsteren *et al.* (2011). The findings showed that adolescents presented with symptoms of low self-esteem, anger, loneliness and depression. Their previous experiences of abuse and exposure to HIV and AIDS, real and perceived stigma and an HIV positive status seem to have contributed negatively to their psychological well-being.

Mellins and Malee (2013) state that mental health problems might compromise the ability of adolescents to manage their disease, specifically through treatment adherence and may lead to risky or unhealthy behaviours given the significant

association of mental health problems with substance use, sexual risk and poor healthcare behaviours. Smith-Fawzi *et al.* (2010) further add that in families, psychological sequelae related to HIV/AIDS have shown to predict parental depression, hopelessness and risk behaviours such as drug abuse, which may, in turn, lead to increased mental health problems among children.

The literature points out that the availability of supportive caregivers to provide nurturance and guidance is essential to the mental health and psychosocial adjustment of HIV adolescents. Similarly, parenting and family support, in particular, were associated with resilient outcomes in children and adolescents (Betancourt *et al.*, 2013). Mental health problems among ALHIV are closely related with impaired quality of life, family problems, school absenteeism, suicide risk and interpersonal difficulties, in addition to poor adherence among ART users. Neurocognitive deficits resulting from treatment or HIV disease itself could contribute to poorer mental health and later ability to adhere to medication regimens (Salama *et al.*, 2013).

3.3 The impact of stigma in the lives of adolescents living with HIV

The complexity of the social environment of adolescents living HIV is vastly undervalued. Exposure to stigma has an intense effect on their experience of living with HIV (Bernays, Jarrett, Kranzer, & Ferrand., 2014). For many adolescents living with HIV, navigating stigma remains a very challenging issue. The stigma related to HIV often erodes social supports that have traditionally supported families, children and adolescents in challenging circumstances and has implications for health and well-being (Cluver & Orkin, 2009 as cited in Smith-Fawzi *et al.*, 2010).

According to the literature, HIV stigma has been associated with increased psychological distress, poor physical health and quality of life, low social support and

risky health behaviours such as non-adherence to ART and sexual risk-taking and nondisclosure of HIV status to sexual partners (Daniel, 2015). All these results have severe public health implications, including poor virologic suppression and immunologic responses to ART, leading to drug resistance and accelerated progression to AIDS (Thoth, Tucker, Leahy, & Stewart, 2014).

Informed by the stress and coping theory, scholars have argued that stigma is a stressor that could upset the physical and psychological well-being of a person (Lazarus & Folkman, 1984). In Uganda, a study on the psychosocial challenges of adolescents with HIV revealed that adolescents identified stigma particularly in the family and school settings as a significant stressor affecting their quality of life. They described both actual experiences of stigma based on their HIV status, as well as how their fears of potential stigma affected their decisions regarding disclosure of their status (Mutumba *et al.*, 2015). Stigmatised adolescents may be socially ostracised and bullied, which is known to have detrimental mental health risks. The stigma that surrounds HIV leads to adolescents taking their treatment in secret.

Studies have documented that persons with HIV often find disclosure to be one of the most difficult aspects of living with the disease and are concerned regarding the outcomes of the disclosure (Gillard & Roark, 2012). Learning how to keep and share the secret appropriately, protecting the self in school and friendship networks and taking on responsibility for protecting family members, could be a significant stressor and a burden to carry (Albright *et al.*, 2016). Non-disclosure to anyone outside of their immediate family limits the ability to seek support for HIV-related stressors from non-familial others. The literature has also demonstrated extensive internalised stigma

related to HIV status among adolescents living with HIV, which can certainly contribute to poor self-concept to the detriment of psychological well-being. (Albright *et al.*, 2014).

3.4 The role of social support on the lives of HIV adolescents

It has been noted that a chronic illness can be very stressful and could raise the level of anxiety, worry and fear, thus leading to poor psychological well-being (Bliese & Britt, 2001; DeVries, Glasper, & Detillion, 2003). A diagnosis of HIV carries a great deal of emotions and fear of uncertainty for an adolescent. Evidence suggests that the ability to cope and adapt to changes and life stressors is closely related to the presence and quality of a social support system (Betancourt *et al.*, 2013).

Adolescence is a time of significant physical, psychological, social and emotional growth in a person's life. The literature reveals that psychological development and a healthy transition through this period is greatly influenced by the support provided from family, friends, schools and the community (Albright *et al.*, 2016). During adolescence, family support is important and contributes significantly in the adolescent's life, however, peer interactions and support cannot be overlooked as a major part of the adolescent's social network. Living with HIV increases the need for effective support and guidance in navigating this developmental phase. A diagnosis of HIV can potentially predispose an adolescent to social isolation, withdrawal and could lead to feelings of self-consciousness, rejection, fear and maladjustment.

It has been suggested that the effects of social support can have many positive benefits on the health of the recipient by improving recovery from illness. It could also play a role in specific disease progression and to buffer the effects of stress (Cohen, & Willis, 1985). A study by De Vries *et al.* (2003) revealed that the level of social

support significantly correlated with the rate of progression from asymptomatic to symptomatic stages of human immunodeficiency virus (HIV) infection in men.

Betancourt *et al.* (2013) found that adolescents who reported low satisfaction with their social support were associated with problems with depressive or psychosomatic symptoms, anxiety and interpersonal sensitivity. Family and peers were noted to influence adherence by creating an environment that enabled adolescents to adjust to new drug-taking routines and cope with side effects. This is consistent with other studies showing that support from trusted adults, parents and guardians as well as peers has a positive impact on adolescents' adherence to treatment and uptake of other services (Hodgson, Ross, Haamujompa & Gitau-Mburu, 2012; Menon., 2007) as well as on coping strategies (Midtbø, Shirima, Skovdal, & Daniel, 2012). Mavhu *et al.* (2013) report that it is essential to involve the wider family members to enhance support in the care and treatment of adolescents in order to try and reduce stigma and discrimination in the household and through that, the wider community. Holder, Young, Nadarajah and Berger (2014), found that perceived social support allowed individuals to have a more positive quality of life and to better cope with stressful life events.

Tshuma (2015) argues that due to non-disclosure, support systems are limited to parents and caregivers, which in turn, leads to caregiver burnout. Tshuma (2015) further adds that the support from family is normally in the form of physical support, for example, helping adolescents to adhere to their medication and support with aspects such as helping them to attend the clinic for disease management, however, the emotional support which is an important aspect is lacking, for example, the adolescent's feelings associated with living with HIV are not openly and freely discussed at home.

On the contrary, a study by Davey, Foster, Milton and Duncan (2009) on family support for HIV positive minority urban adolescents, revealed that adolescents infected behaviourally, had inadequate family support before being diagnosed with HIV even after their diagnosis. Their family support ranged within ambivalent or unsupportive. Davey *et al.* (2009) further maintain that adolescents often experience family-associated harm after disclosing their diagnosis, such as getting kicked out of their homes.

A study from Zambia revealed that support from peers is important in helping adolescents to take up services and remain positively engaged in care (Menon, Glazebrook, Campaign, & Ngoma 2007). A support group for adolescents living with HIV may offer an environment in which social network could be formed and strengthened. Adolescents could derive considerable benefits from being part of a support group programme. In the absence of an environment where they can talk comfortably about sexuality, a support group could provide a supportive environment where confusing messages can be consistently countered and fears and worries safely addressed. As a therapeutic tool, support groups could assist in problem-solving, reduce anxiety and promote a sense of belonging that is important in the adolescent's stages of development (Vujovic *et al.*, 2014). This is supported by findings from other studies that have noted the benefits of support groups for adolescents living with HIV (Hodgson, *et al.*, 2012). The literature supports the notion of a positive effect of social support and psychosocial well-being (Bliese, & Britt, 2001).

3.5 Coping mechanisms used by adolescents living with HIV

Psychosocial issues are important as youth progress through adolescence towards adulthood, attempting to develop a sense of self while striving for autonomy.

As relationships with parents and peers change, adolescents may experience stressful challenges, with not fully formed coping skills and/or inadequate resources. Adolescents who enter adolescence under difficult circumstances and could be ill-prepared to effectively cope with normative changes, making this period particularly challenging. For adolescents with HIV, adolescent developmental tasks are accompanied by challenges of coping with HIV as a stigmatising, sexually transmittable chronic illness, the management of medical treatment and adjustment to family loss.

Brown and Lourie (2000) also add that coping with HIV infection is a complex phenomenon related to psychological stress, personality factor and social support. Studies conducted on adults infected with HIV seem to suggest that coping style is one of several variables that may influence the onset of emotional disturbances secondary to HIV infections. Research indicates strong associations between coping strategies, mental health and resilience in HIV-positive adolescents (Woollet, 2013).

Adolescents living with HIV must cope with several conflicts. Dysphoric feelings may arise from the physiologic effects of the disease. In addition, they also must cope with the emotional pain related to social stigma, isolation and hopelessness, forced disclosure, anxiety about their medical prognosis, loss and bereavement and physical appearance and body image affected by failure to thrive and dermatologic conditions (Peterson *et al.*, 2010).

According to research, the adjustment and coping styles of adolescents living with HIV and AIDS is strongly connected to parental and family factors. Factors such as poverty, socio-cultural beliefs and multiple losses are among the family and social factors that influence coping strategies and mental health of adolescents. A qualitative

study of South African adolescents with HIV (Petersen *et al.*, 2010) revealed that family and peer support was an important factor in participants' coping with their HIV status. In addition, adolescents reported that goal-setting helped them to cope with their diagnosis (Petersen *et al.*, 2010).

Additionally, research in coping with a chronic illness also seems to suggest that maintaining a good health-worker and patient relationship is useful particularly in treatment adherence (Dibb & Kamalesh, 2012). Having a health worker that one could communicate one's need is viewed as important and enhances coping with the medication challenges. In addition to dealing with medication challenges, engaging in effective communication with health professionals encourages taking charge of their health, self-managing aspects of the illness and striving for a healthy lifestyle (Battles & Weiner, 2002).

The coping mechanisms employed by PHIV-infected adolescents to deal with stressors are directly linked to non-adherence. Specifically, those experiencing adherence problems most commonly use withdrawal and passive emotional regulation and less commonly use problem-solving or social support as coping mechanisms, possibly because of fear of stigma or unwanted disclosure. Passive coping style is also associated with depression and poorer psychological adjustment.

In a study by Beyers and Nkoane (2012), some of the participants indicated that they had been drinking more than usual since their HIV-positive diagnosis. They reached a stage where they cling to 'resources' (mostly alcohol) in order to cope with the feeling of despondency. It could be concluded that HIV-positive adolescents drink or even use drugs to escape the reality that they are confronted with. Smith-Fawzi *et al.* (2010) found that passive coping (e.g., blaming, wishful thinking, withdrawal and

self-criticism) was significantly associated with greater depression and was more frequently used by adolescents reporting medication-related stressors.

On the contrary, in a study on perinatally acquired HIV, adolescents' experiences of living with HIV and their perceptions regarding disclosure, Madiba and Mokgatle (2016) found that adolescents learned to accept and live with HIV and desired to be healthy and normal like other people. They maintained that they lived a normal life and that they were similar to other adolescents. In another study conducted with adolescents in Canada, adolescents showed a sense that they were similar to other adolescents and learned to accept and live with HIV.

3.6 Treatment adherence on the lives of HIV positive adolescents

The effectiveness of antiretroviral therapy depends on high levels of adherence yet, adherence to ART in adolescents involves many challenges like those faced by adults while others are unique to adolescents (Hudelson & Cluver, 2015). When compared with younger children and adults, ART adherence among adolescents has shown to be poor (Shroufi *et al.*, 2013). This is consistent with other studies that show that adherence to treatment of chronic illnesses has also shown to deteriorate during adolescence in other chronic diseases such as cystic fibrosis, congenital cardiac disease and diabetes and HIV is no exception (Bernays, Jarnett, Kranzer, & Ferrand, 2014).

According to the literature, factors associated with poor treatment adherence in adolescence include medication-related issues such as adverse effects, pill burden, lack of knowledge, mental health problems, changes of guardianship, attending school and absence of parental and social support (Chandwani *et al.*, 2012).

Research has also emphasised that orphan status is an important obstacle to treatment adherence. A qualitative study by Mutwa *et al.* (2013) on the living situation and adherence highlighted that social support and living situation, including living in an orphanage or foster family, was directly linked to adherence. Findings from their study also revealed that a related challenge for many adolescents was lack of privacy. This included lacking a private place to keep and take their medication, often living in congested households, boarding schools and foster care. In agreement with this viewpoint, Siu, Bakeera-Kitaka, Kennedy, Dhabangi and Kambugu (2012) report that adolescents living with HIV desire privacy but rarely have it, especially in crowded homes.

Despite the growing evidence of the benefits of disclosure to better adherence to therapy and promoting adolescents' participation and responsibility in their care studies Lowenthal *et al.* (2014); Kenu *et al.* (2014) have revealed that caregivers are hesitant to disclose the HIV positive status to their children for fear of social rejection and isolation, parental sense of guilt and fear that the children would not keep diagnosis to themselves. The WHO (2011) guidelines for disclosure of HIV-positive adolescents recommend that "children of school age should be told their HIV positive status" in order to improve health outcomes, including adherence.

Kenu *et al.* (2014) maintain that delayed and non-disclosure of HIV status to adolescents significantly affect adherence and could strain the relationship between the caregiver and the adolescent as force and persuasion are often used to get the adolescent to adhere to treatment, which may result in purposeful rebellion and non-adherence by the adolescent. Agwu and Fairlie (2013) further adds that adolescents who have been newly diagnosed or recently disclosed may be emotionally unprepared

for ART subsequently, non-adherence by the adolescent may be a way of expressing anger towards their caregivers, or the non-adherence is sometimes an attempt to punish their caregivers. The findings of a study conducted in Uganda revealed that adolescents' whose primary caregiver was the only one who knew their HIV status were more likely to be non-adherent to antiretroviral treatment. In another study on the impact of adolescent disclosure to friends, disclosure stressors ranked second to medication stressors. The data showed that disclosing to more than one friend was linked to less medication hiding and an increased CD4 count (Calabrese *et al.*, 2012). Similarly, in a South African study on associations of adolescent HIV-status disclosure and ART adherence, strong empirical support found that full disclosure to adolescents of their HIV-positive status was associated with higher ART adherence. The findings also suggest that, among perinatally infected adolescents, early disclosure prior to age twelve (12) is associated with further improved adherence (Cluver *et al.*, 2015).

Structural barriers of stigma and poverty have been linked to poor adherence. Mutwa *et al.* (2013) report that stigma influenced adolescents' adherence even within their own homes as they did not want their siblings and others to see them take their medication. As is common among adolescents, the desire to conform with peers could inadvertently lead them not only to stop treatment but could also instil in them, a distinct sense of social isolation by being marked out as different, which creates a heavy psychological burden (Lowenthal *et al.*, 2014).

According to Agwu and Fairlie (2013), lifestyle barriers such as forgetting, being away from home, busy and varied schedules, including school attendance, have been found to impact on adolescents' adherence to treatment in both resource-rich and resource-limited settings. Medication-related barriers are also common in

adolescents, particularly for perinatally acquired HIV adolescents, including treatment fatigue, complexity of regimens, pill burden and palatability of ART.

Other studies have found that the transition of adolescents from paediatric to adult HIV care services may be accompanied by significant anxiety and might increase the risk of interruption in care and non-adherence (Agwu & Fairlie, 2013). A study by Tshuma (2015) showed that ALHIV relied on their caregivers with regard to accessing care, complying with clinic visits and collecting medication and, as such, found it difficult to change from depending on their caregivers and acting independently. Evans *et al.* (2013) agree with the above and maintain that ALHIV may be less mature because their caregivers are very protective.

Despite the weariness regarding the use of medications and sometimes poor treatment knowledge and understanding of the benefits of taking medication, some studies have found that some adolescents display the importance of being healthy as a motivation for adherence and an awareness that maintaining adequate treatment is a necessary condition to maintaining good quality of life (Galano, *et al.*, 2016). Similarly, a study in South Africa on the characteristics of resilience in a group of perinatally infected HIV positive adolescents revealed that adolescents showed perseverance and encouragement for continued and consistent adherence to medication (Woollet *et al.*, 2016).

CHAPTER FOUR

RESEARCH METHODOLOGY

INTRODUCTION

This chapter focuses on the research methodology used in conducting this study. The research design, population, sampling procedure, data collection methods, analysis and ethical considerations are also examined and explained in this chapter.

Research methodology

4.1 Research design

A qualitative research approach was used in the study. The qualitative approach was found to be effective in gathering in-depth information about human experiences that helps one to understand the reasons for certain behavioural patterns (Sankar, Golin, Simoni, Luborsky & Pearson, 2006). Qualitative research also allows in exploring a phenomenon within the social environment in which it happens and from the perspective of participants. Thus, for the purpose of the study the researcher adopted the phenomenological design in order to explore the psychosocial experiences of adolescents living with HIV and AIDS. Creswell (2009) states that phenomenological research is a strategy of inquiry in which the research identifies the essence of human experiences about a phenomenon as described by participant.

4.2 Study area

The study was conducted at Matlosana Local Municipality (Gateway NM Pretorius and Empilisweni Primary Health Care Centres). Both facilities are accredited Adolescent Friendly Clinics in the sub-district.

4.3 Participants

Ten adolescents (five females and five males) enrolled in the ART treatment programme at Gateway NM Pretorius and Empilisweni Primary Health Care (PHC) facilities in Matlosana sub-district were selected to participate in the study. Participants were adolescents living with HIV and AIDS. Although it was challenging to distinguish the source of HIV infection, most had been attending the clinic since early childhood. Participants were aged between 13 and 19 years.

The identification of possible participants was based on the following criteria:

- Adolescents living with HIV and AIDS receiving ARV treatment at Gateway NM Pretorius and Empilisweni PHC;
- Adolescents who knew their HIV status;
- Adolescents aged between 13 and 19 years; and
- The caregiver must have signed the consent form and the adolescent an assent form.

4.4 Sampling method

According to De Vos, Strydom, Fouche, and Delport (2011), the overall purpose of a sampling technique in qualitative research is to collect wide and diverse data. In order to achieve this, qualitative research employs purposive sampling. Chopra and Coveney (2003) describe purposive sampling as a method based on the researcher's judgment and it is used to decide which study units should be included in the sampling sample. Purposive sampling was chosen as it enables the researcher to select participants who will be able to provide a description of the experience of living with HIV (De Vos *et al.*, 2011).

A designated HIV counsellor referred to at the PHC facilities as a community counsellor was assigned by the respective facility managers to assist to recruit participants for the study after the aim of the study and the selection criteria was explained to the facility management teams at both PHC facilities. Caregivers of adolescents accessing ART at the respective clinics were contacted telephonically by the counsellors for possible participation in the study. The counsellors obtained permission from the caregivers to disclose their information to the researcher. The information was used by the researcher to establish eligibility criteria.

The caregivers of eligible adolescents were then contacted telephonically for an initial meeting to explain the purpose of the study. The researcher visited each caregiver and adolescent individually at their residence wherein, the purpose of the study was explained to both the caregivers and adolescents and ethical considerations discussed. Caregivers and adolescents were then given an opportunity to participate in the study.

Caregivers and adolescents who agreed to participate in the study, were provided with a participant information sheet and consent form (see Appendix A and Appendix B). Signed consent and assent forms were obtained from caregivers and before the commencement of interviews. The researcher arranged with participants and scheduled appointments with them at their respective place of residence. Ten participants were interviewed during the study (five females and five males).

4.5 Data collection

Semi-structured interviews were used to collect data. The interview method is an effective method for getting participants to talk about their personal experiences and

the meaning they construct of these experiences, while providing their own perspective (Seidman, 1998). Semi-structured interviews allowed the researcher to obtain more information about the psychosocial experiences of participants with regard to living with HIV. It also assisted the researcher to elicit participants' own viewpoint in a flexible manner. Moreover, it provided an opportunity for participants to introduce issues that are important to them. It also ensured consistency and standardisation across the interviews with participants (De Vos *et al.*, 2011).

An interview guide with open-ended questions was used to collect data. The interview guide was based on the literature related to the topic. The open-ended questions allowed for probing for responses from participants where necessary in order to explore important issues (see Appendix C).

The interviews were conducted in Setswana and lasted between fifteen minutes and one hour. The interviews were audio-recorded with the consent of participants. Audio recording the interviews enabled the researcher to pay attention and concentrate on responses provided by participants. All the interviews were held at residences of participants. This was done in order to protect the identities of adolescents participating in the study. Field notes were made after each interview was completed, in order to capture the researcher's observations during the interviews. According to Greeff (as cited in De Vos, 2011) field notes are a written description of the researcher's thoughts, observations and experiences that take place in the course of the research.

4.6 Data analysis

According to De Vos (2011), data analysis is the process of bringing order, structure and meaning to the mass of data collected. Thematic analysis was used in this study in accordance with the research methodology chosen and the context of the study. It was important to analyse the transcripts within the data using themes in order to understand the psychosocial experiences of adolescents living with HIV and AIDS.

At the beginning of the data analysis, the recorded interviews were transcribed word verbatim into Setswana and then translated to English. The transcripts were carefully read several times while taking note of similar topics, which were then grouped and arranged into major themes. Thematic analysis was done on the transcripts, following the five stages of thematic analysis explained by Pope and Mays (2002) as follows: the familiarisation stage; theme identification; indexing stage; charting stage; and mapping and interpretation. In the process of familiarisation, the transcripts and field notes were read thoroughly while taking note of key words, phrases and themes that emerged from the transcripts. The identification process involved noting down and grouping together meaningful words, concepts and phrases that emerged in order to generate themes and sub-themes. During the indexing stage, concepts were put side by side while sub-themes were regrouped into major themes and the transcripts orderly arranged with numerical codes from the index. In the charting stage, similar topics were then grouped together according to the appropriate framework to which they related, thus forming the charts. In the final stage of mapping and interpretation, the identified themes were grouped and interpreted in a meaningful manner.

4.7 Trustworthiness

Trustworthiness is achieved when the results reflect as accurately as possible, the meaning as explained by participants (Lietz, Langer & Furman, 2016). The researcher attained trustworthiness by ensuring credibility, confirmability and dependability.

Credibility

In order to ensure credibility in the study, the following provisions were made: specific selection criteria were used to choose eligible participants in line with specific attributes linked to the research question; the in-depth interview process was clearly outlined to participants; participants could use the language of their choice to allow them to express and share their experiences comfortably during the interview; and field notes were assessed and integrated into the in-depth interview to enhance the quality of the data. An interview guide was developed and utilised during the course of the study to ensure consistency and uniformity across all participants and to reduce researcher bias. The researcher had supervision sessions with the research supervisor, and during such sessions, the research process and findings were discussed, thus providing an additional perspective on analysis and interpretation of the data (Moon, Brewer, Januchowski-Hartley, Adams & Black, 2016).

Confirmability

Confirmability refers to the degree to which the results are linked to the experiences of participants and not the interest and perspectives of the researcher (Moon *et al.*, 2016). Confirmability was addressed by ensuring that all the interviews were audio-recorded and transcribed word verbatim to verify the experiences and

perspectives of participants. The audio-recorded interviews and transcripts served as an audit trail and were important in the data analysis.

Dependability

Dependability refers to whether similar findings would be reached using similar participants in a similar environment and using the same research processes (Anney, 2014). Dependability was addressed by reporting on the research processes and analysis followed in the study in order to enable replication of the research in similar contexts.

4.8 Ethical considerations

Ethical approval for the study was requested and obtained from the North-West University Ethics Committee (NWU-00341-17-A9) (see Appendix D), the North West Provincial Department of Health as well as the Directorate for Policy, Planning, Research, Monitoring and Evaluation (see Appendix E).

Informed consent

Participants were given a letter containing detailed information about the research and the purpose of the study. Participation in the study was voluntary and participants had the right to accept or decline from participating. Participants were informed that they had the right to withdraw from the study at any stage. The consent and assent letters (which outlined the purpose of the study) were signed by willing and eligible participants and their respective caregivers. Participants were also informed of the audio recording of the interviews and they gave permission in this regard.

Confidentiality

All information concerning participants was handled confidentially in order to protect and be sensitive towards them. Data gathered was treated anonymously and was used solely for the purpose of this study. To ensure the confidentiality of participants, the interviews were conducted at a location that was suitable to all participants. Additionally, information that could disclose the identity of participants was removed from the research report and transcripts. The results of the study were presented in a manner that protected the identities of participants by using numbers.

Debriefing

The researcher arranged a debriefing session with social workers at the respective clinics for participants who could have been emotionally provoked during the interview in order to deal with any emotional reactions that could arise, as a means of protecting participants from harm.

CHAPTER FIVE

FINDINGS

INTRODUCTION

This chapter presents the findings of the study. The findings presented are based on the analysis of the interview transcripts on the psychosocial experiences of ten adolescents living with HIV and AIDS in Matlosana sub-district. The findings are presented as follows: the first section focuses on the demographic characteristics of participants; while the second section focuses on the themes and sub-themes derived during data analysis.

5.1 Demographic characteristics of participants

Interviews were conducted with ten participants (five males and five females) receiving health care services at Empilisweni Primary Health Care Clinic and N.M. Pretorius Gateway Clinic respectively. All ten participants knew that they were living with HIV and all of them were on antiretroviral treatment at the time of the interviews. The ages of participants ranged from 13 years to 19 years. At the time of the interviews, nine of the participants were attending school, with the exception of one participant who had already completed grade 12. All the participants were from the same geographical area (in Matlosana) and were of African origin. Below is a brief description of each participant's biographical background.

- **Participant 1**

Participant 1 is a 13 years old female. At the time of the interview, she was doing grade 6 at a local primary school. The participant is the youngest child of the three children in the family. The participant lives with her mother and older brother, her sister

is married and lives on her own. The participant's mother wanted to be part of the interview as she felt the participant was not capable of responding to some of the questions. This affected the data as the mother answered questions on behalf of the daughter. The participant kept on looking at the mother for approval. According to the participant's mother, the participant started taking ARV treatment in 2004; however, the mother claimed the participant was not perinatally infected but failed to explain how she acquired HIV.

- **Participant 2**

Participant 2 is a 14 years old female and the first-born child of two children. She has a younger brother who is seven years old. At the time of the interview, the participant was doing grade 7. The participant lives with her maternal aunt, the aunt's husband and child who is older than the participant. The participant moved to live with her aunt in Matlosana following family conflict and alcohol abuse by her parents. The participant's parents live in another town. The participant's mother was employed as a domestic worker and the father was unemployed at the time of the interview. The participant became infected with HIV through mother-to-child transmission and, therefore, was born with HIV. She had been on ARV treatment since birth. The participant's status was disclosed to her when she was 9 years old by her maternal aunt.

- **Participant 3**

Participant 3 is a 16 years old male presently completing grade 8. He stays with his grandmother, aunt and the aunt's two children, his cousin and uncles and other extended family members in an RDP house. The participant's mother passed away due to AIDS-related illnesses when the participant was an infant. He does not know

his father's whereabouts. His HIV status was disclosed to him when he was 9 years old by his grandmother. The participant has been on ARV treatment since birth. The grandmother receives old age pension, and no one works in the household.

- **Participant 4**

Participant 4 is a 17 years old male who was completing grade 9 at a local high school. The participant is the second born in a family of 4 children. He lives with his mother, grandmother, his elder sister who is 25 years old and two younger siblings (aged 7 and 9 years respectively). The participant does not know his father's identity nor his whereabouts. In 2016 when he was 16 years old, he went for circumcision at a local hospital where he tested for HIV and was found to be HIV. He then started taking treatment the same year. His mother is also living with HIV and is on ARV treatment. The participant is the only one among his siblings who is HIV positive. It was not clear how the participant was infected with HIV. He claims to remember being sick occasionally since he was young. The participant's mother was unemployed at the time of the interview.

- **Participant 5**

Participant 5 is a 16 years old male currently doing grade 7 at a local high school. The participant is the only child, his mother died of AIDS-related illness when he was young. The participant does not know the identity or the whereabouts of his father. He lives with his maternal aunt, the aunt's husband and their two children. Before living with the aunt, he was staying with his late mother's sister, but was moved because he was not properly looked after. His HIV status was disclosed to him when he was 13 years old by his aunt. The participant has been on ARV treatment since birth. The participant's aunt was unemployed at the time of the interview.

- **Participant 6**

Participant 6 is a 13 years old male currently in grade 7. He lives only with his mother. He is the only child from his mother. He has two older half-sisters from his father. The participant's parents are not married. His father is married to another woman. The participant has a relationship with his father. He was infected with HIV through mother-to-child transmission and has been on ART since birth. His mother is living with HIV and is on ART as well. According to the participant, his father is not on treatment because the participant father informed the participant that he does not have to take it. His HIV status was disclosed to him when he was 11 years old by his mother. The mother abuses alcohol and was unemployed at the time of the interview.

- **Participant 7**

Participant 7 is a 19 years old female. She completed grade 12 in 2016 and at the time of the interview, she was not studying because of financial problems. She is the last born of two children. She lives with her grandmother and her older sister (aged 22) and her extended family. The participant's mother stays in another section of the township with the participant's stepfather. The participant's biological father left when she was young. The participant acquired HIV through mother-to-child transmission. She was diagnosed with HIV when she was 7 years old while in grade 1, after repeated episodes of illness. She started taking ARV the same year (2004). Her HIV status was disclosed to her in 2010 when she was 13 years old by her grandmother. However, she was already aware of her status after a neighbour friend informed her that the pills she was taking were for HIV. Both the participant's mother and stepfather were unemployed at the time of the interview.

- **Participant 8**

Participant 8 is an 18-year old female repeating grade 9. She resides with her parents and two older brothers. She is the last-born child of 5 children. She was diagnosed with HIV when she was 9 years old after repeated illness. She was initiated on ART the same year. It was not clear how and when the participant became infected with HIV. According to the participant, her mother believes she got infected though helping a learner at school who was bleeding. The participant's HIV status was disclosed to her when she was 12 years old by her mother. One of the participant's brothers is also living with HIV but is not on treatment. Both parents were unemployed at the time of the interview.

- **Participant 9**

Participant 9 is an 18 years old female in grade 11 at a local high school. She is the last born of three children. She lives with her maternal grandparents and two older brothers and an uncle in a dilapidated two roomed shack. The participant's mother passed away in 2016 from AIDS-related illness. The father's identity is not known. She does not know when she acquired HIV, but her HIV status was disclosed to her when she was 10 years old by her late mother and she started taking ART immediately. She is the only one among her siblings who is infected with HIV. She intentionally stopped taking ARV treatment for a period of two years. She restarted with treatment in 2017 and had been on ART for just three months at the time of the interview. The participant's grandparents receive old-age grant.

- **Participant 10**

Participant 10 is a 16 years old male repeating grade 6 for the third time. He lives with his parents and his 3 siblings. He is the first born of four children. He was diagnosed in 2011 when he was 6 years old and started taking ART at the same time.

His status was disclosed to him by the doctor at the hospital but does not remember when. His mother was also diagnosed with HIV and is on ART treatment. The father's status is unknown, however, he denies that the participant is HIV infected. At the time of the interview, the mother was unemployed, and the father was a labourer.

5.2 Main themes and sub-themes

The main themes and sub-themes that emerged from analysis of interview transcripts of participants are as follows: finding out about own HIV status; knowledge of HIV; psychological challenges; social challenges; ARV treatment; and coping strategies.

Table 1: Summary of Main themes and sub-themes

Main themes	sub-themes
1. Finding out about own HIV status	How I found out about my HIV status The experience of knowing my HIV status Being sick repeatedly Denial and acceptance of the illness Keeping the illness a secret
2. Knowledge of HIV	Limited knowledge Taking unknown treatment
3. Psychological challenges	Blame Emotional experiences Denial of significant others
4. Social challenges	Poverty Fear of stigma

- | | |
|----------------------|--|
| | Abuse |
| | Inadequate support |
| 5. ARV Treatment | Experiences towards treatment |
| | Factors affecting adherence or non-adherence |
| | Side effects |
| 6. Coping strategies | Adaptive coping |
| | Maladaptive coping |

Theme 1

Finding out about own HIV status

Eight of the ten participants indicated that they found out about their HIV status from their caregivers while the other two were informed of their HIV status by the doctor at the hospital while they were seeking medical attention. Most of the participants experienced their disclosure as a once off event as captured in the excerpts below.

They were fighting at home when I heard my mother telling my aunt that she must tell me now otherwise I will know when I am a grown up, then my aunt told me that I have HIV and I cried (P2).

My grandmother told me, she just said: "Do you see that person on TV, they say she has it (HIV), you have it too" and that was it. There was no one sitting with me and explaining it to me, that is the only thing she said: you are living with it too, those pills are not for asthma" (P7).

My grandmother only said I drink HIV pills, I have a disease that is not curable (P3).

My mother only told me: "you have HIV and do not tell people (P5).

Sub-theme 1: How I found out about my HIV status

Some participants indicated that the disclosure of their HIV status was not voluntary. It was done because of the questions they asked regarding the pills they were taking and because of poor adherence as captured in the excerpts below:

She always took me there at the clinic and I would always ask her why I am drinking these pills (P3).

I did not want to take them that is the time when I was informed that I had HIV (P5).

I was asked at the clinic, I did not know and then I had to ask my mom what pills am I taking, what am I suffering from and she explained to me, that her and my dad did ... I forgot what they did, but she and I ended up taking pills, but my dad does not take them. She did not tell me how it came about (P6).

I went to get circumcised when they tested me they found it (P4).

One female participant described how harshly her HIV status was disclosed to her in the following excerpt:

I was told when there was a certain show on TV, Real Talk, on SABC 1, I think they were talking about people living with HIV and when my grandmother told me, she just said; do you see that person, they say she has it, you have it too and that was it. There was no one sitting with me and explaining it to me. That is the only thing she said; you are living with it too; those pills are not for asthma they are for HIV and that was it (P7).

Some participants indicated that they knew about their status because of recurrent illnesses as captured in the excerpts below:

It is that time when I fainted here in the house. I was taken to Tshepong and I was admitted. When they did the blood tests, they told me then, during the tests, they told that I have a certain illness (P10).

My mother took me to the clinic because I had a problem of getting sores here (pointing under the armpits and stomach) and I would perspire regularly, that is when she took me to the clinic, where I got tested. She received the result stating that I am HIV (P8).

Sub-theme 2: The experience of knowing my HIV status

Participants described varied experiences after knowing their HIV status. Most participants indicated that learning about their HIV status initially brought a range of sad traumatic experiences as follows:

I thought I was going to die. It is not a disease that you survive; it is something that kills people (P2).

She told me that I have HIV, I got scared, not believing it, I do not want HIV (P5).

One participant reported as follows: "After I knew, I even tried committing suicide and leaving home with the child from next door" (P7).

I pretended to be strong in front of my mother, as I went outside, I cried because I was hurt, the fact that I am HIV, I did not want it (P9).

Another participant revealed as follows: "I was surprised, I asked myself where I got it; they explained that I got it from my mother" (P4).

Only one participant indicated that learning about her HIV status was a positive experience, "I never panicked, I did not do anything, because my mother told me that as long as I take my treatment, I would be okay, so I never panicked or got scared" P(9).

Sub-theme 3: Being sick repeatedly

Most of participants indicated that their childhood was marked mostly by poor health due to repeated episodes of ill-health as captured in the excerpts below:

I was always sick, but I did not know what was happening. I would be cold, while it was hot(P4).

I remember well, my grandmother taking us to the clinic; she took me and my sister, the two of us, because I was sick nearly all of the time (P7).

I used to faint, and I used to get headaches frequently (P10).

My mother took me to the clinic because I had a problem of getting sores here (pointing to armpits and stomach) and I would perspire regularly that is when she took me to the clinic, where I got tested (P8).

She had always grown up giving us problems, I frequented the clinic, so that they can check her (P1).

Sub-theme 4: Denial and acceptance of the illness

Almost all participants indicated that overtime they learned to accept living with HIV, except for one participant who reported that she still found it difficult to come to terms with her HIV status.

I have not accepted that I am sick, even the last time when I went to the clinic, I burst into tears when they opened my file (P7).

Some participants spoke about accepting to live with their illness as a gradual process they had to undergo as captured in the excerpts below:

It took me a long time to accept, when people talk, I would cry and fight them whenever they speak about it, I would cry and they would ask me why am I crying and I would not say. Even at school, when a teacher teaches about it, I would cry (P2).

I accepted it this year, I realised I cannot change my situation, but just to accept and move on (P9).

Yes, I have accepted the way I am, I feel okay. I do not have a problem where I am regarding my status, so I have accepted (P8).

I am not ashamed, but when I have to take the treatment, I do take it. I am not ashamed of myself (P10).

I see myself as a normal person. I am not different (P6).

Sub-theme 5: Keeping the illness a secret

All participants indicated that they kept their illness a secret from their friends, some even from their extended members of families thus, keeping the knowledge of their HIV status to their immediate families. The fear of stigma and being treated differently by their peers and being gossiped about led to keeping it a secrecy as indicated below:

That is the choice I made, I do not want them knowing that I take pills, maybe others might spread it around, that is why I do not want them knowing (P6).

I would kill myself if people knew my status (P9).

I am not going to tell him, even my trusted friend, I do not tell him that I have it (P2).

Some participants did not feel the need to disclose their status as captured in the following excerpts:

No, it is not important to tell people (P3).

I do not want them to know that I have it (P4).

Some participants indicated that they were instructed by their parents or caregivers not to tell others about their HIV status as follows:

I remember one day we went to Klerksdorp hospital with my mother, there was a certain pamphlet next to the toilets with pills, I then told my mother that they are the same as mine, my mother screamed at me that I should keep quiet, who am I telling (P7).

My mother does not want them to know, because she does not trust relatives, there are some relatives who are heartless and will spread rumours about my name, so that is why she does not tell them (P8).

My mother said I must not tell anyone (P5).

One participant maintained that by keeping her status a secret, she was protecting herself as well as her family from stigma because disclosing her status would lead to people finding out about her parents' status.

If I were to tell them that I have HIV, they would ask me many questions, like where do you get it from? So, I will have to name my mother as well, that I got it from my mother. I would not be disclosing about myself only, my mother too, so it is not okay that way (P7).

Some participants indicated that people they attend the support group with are the only ones they have disclosed their status to. They said lack of trust in their peers was a reason for not disclosing their illness.

There is no one that I told that I have HIV, those that know are the ones from the support group (P2).

Within my friends, it is only a few, especially the ones that I am in the same support with. The ones that are also taking the treatment, they are the ones who know (P10).

I do not want people to know, only the people that I trust should know, not everyone (P9).

Theme 2: Knowledge of HIV

Most participants had basic knowledge about HIV, however, some of the younger ones could not cognitively comprehend how they got infected. Nine of the participants were perinatally infected, one did not know how she got infected but was told by her parents that it was through assisting a fellow learner at school who was infected.

Sub-theme 1: Limited knowledge of HIV

Only one participant understood how she contracted the illness, others lacked the knowledge of how they contracted the illness as captured in the excerpts below:

I know how I got it, obviously, it was from mother-to-child transmission and I got it from my mother (P7).

I asked the nurses what happened that I contracted HIV, they told me it was my mom and dad, one of them was ill (P2).

She explained to me, that she and my father did ... I forgot what they did, but she and I ended up taking pills, but my father does not take them. She did not tell me how it came about (P6).

Some participants indicated that they knew nothing about HIV before their status was disclosed to them but have since acquired some knowledge of HIV as indicated below.

I knew nothing, I was still young at the time. Now, it is when you sleep with an infected person who does not tell you and then you end up being infected (P3).

I was curious to know and asked my aunt that when I walk out there in the streets, will people know that I have it? (P2).

I knew nothing about HIV (P4).

Sub-theme 2: Taking unknown treatment

According to most participants, they have been taking ARV treatment without knowing, even before their status was disclosed to them. Some participants expressed frustration at taking pills without knowing the reason for taking them as captured in the excerpts below:

Why am I taking treatment, what is it for? I knew about the one for epilepsy, that one I know why I am taking it. Now, when I asked about this one, why am I taking this? They said because I am sick, that is why they are giving me these pills (P10).

I did not know what medication it was for, they would say it is for flu, but it is not cured (P2).

I was just taking treatment; she only told me when I was 12, when she realised that I am clever (P8).

I would always ask her why I am drinking these pills (P3).

Asking her why am I taking these pills, she did not want to tell me (P5).

I was asked at the clinic, I did not know and then I had to ask my mother what pills am I taking, what am I suffering from, what is going to happen if I do not take them, but she did not answer me (P6).

One of the participants stated that she was already suspicious that her treatment was for HIV before she knew her status as indicated below.

There was a certain pamphlet next to the toilets with pills. I then told my mother that they are the same as mine, my mother screamed at me that I should keep quiet, who am I telling. I asked myself why she was screaming, because they are for asthma and it is a normal disease. I went to the toilet, read that pamphlet and discovered what the pills that I am taking are for but did not make

too much of it, but made sense after finding the same pills at one of my friends that stayed next to our house, I told her that her pills are like mine, she told me they are not for asthma, they are for HIV, I knew from there on (P7).

Theme 3: Psychological challenges

Sub-theme 1: Blame

When describing their experience of living with HIV, some participants expressed rage and annoyance directed towards their parents whom they blame for infecting them with HIV.

I get annoyed by the fact that my life is dependent on pills. Without it, I cannot do anything and I did not bring this upon myself (P7).

I have the disease HIV, do not blame me, I was born with it (P3).

Why did she not take Nevirapine pill, what stopped her, because she seems to be enjoying what she is doing, she infected me (P7).

I would ask my mother why she did not find a place for us to stay, because we are not living well here (P9).

Sub-theme 2: Emotional experiences

Emotional distress emerged as a more common factor associated with lived experiences among participants. All participants indicated that living with HIV was emotionally difficult while some conveyed feelings of sadness, anger and unpleasant experiences of living with HIV. According to some participants, the lifelong aspects of the disease was distressing as captured in the excerpts below:

I will never live a normal life (P7).

It is because it is a disease I see it as being hard (P4).

I wish I could be like other children, just to be normal like them. I am normal, but not that normal (P3).

Sometimes, yes, most of the time, I am ashamed of myself because I am sick (P7).

Life gets hard sometimes, because at the age I am at, you need guidance about life from a mother (P9).

So and so has HIV, so and so is always at the clinic, that is the reason when I have to go to there at times, I become angry, because I go there every month. I would be asked what are you doing at the clinic? It becomes difficult for me to talk about it (P7).

The most painful thing is that my father wants me to leave school at once saying next year, you will be eighteen years old and you are still in primary school, he wants me to quit school because I have been failing. I only passed grades two, three, four, five and six. I was promoted in all these classes. For my future, I just wanted to be like other kids, being educated and having a job. That is the future that I wanted (P10).

Some participants reported that they experienced a profound sense of loneliness, depression and even suicidal ideation as follows:

There is no one that asks me if I am okay, everyone leads his or her life, no one asks me and I need someone to talk to. I even tried committing suicide (P7).

After the passing of my mother, because she died in my hands, I then went to the forest at night assuming, I would get robbed, stabbed and die, but it never happened (P9).

One participant conveyed feelings of being deprived of her childhood because of living with HIV as follows:

I am never going to lead a normal life, be like other kids. All my life when we play, I am the one that is called home to go take pills, when the other kids are playing (P7).

Sub-theme 3: Denial of significant others

Some participants indicated that their parents are yet to accept their HIV status and some parents deny its existence as captured in the excerpts below:

He did not want me to take these pills, he did not want me to take them. My father did not want, he said that thing does not exist (P10).

I asked my mom how I got it, when there is no one at home who has it; she said she does not know as well, because we as your parents do not have it, so I do not know how I got it, because at home, there is no one (P8).

She infected me and we do not know whether she is the one that infected my biological father, now she has infected the person that she stays with now. What she is doing seems to be a pattern, her pattern does not satisfy me. I wish she could talk, she does not talk about it, she seems proud (P7).

When the Dr asked whether I knew that I was HIV positive, I was surprised. When they explained to my father, my father refused, he was denying, he said there is no such thing (P10).

Theme 4: Social challenges

Socially-related factors such as stigma, poverty, inadequate social support and abuse were identified as factors that negatively shaped the experiences of participants living with HIV.

Sub-theme 1: Poverty

Poverty and unemployment emerged as significant socio-economic factors among all the participants. Several participants expressed their challenges of not always

having food and other necessities at their homes as their caregivers were unemployed and could not provide for them. At times, they had to take medication without food as indicated below:

No one works, my parents do not work, my mother lost her job and my father lost his job ages ago, my brothers do not work either. We live off from my sister, when she has food like maize meal, she shares with us and if she also does not have, we stay like that because she is the only one we depended on (P8).

We would not find food at home, everything would be a mess (P2).

I need toiletries, pads and clothes, because I do not have clothes (P9).

My mother is not working and my stepfather does piece jobs here and there. I have a sister who has a boyfriend, her boyfriend “hustles” for her (P7).

When there is no food or money, when my grandmother does not have money, I can skip them (pills) for that day (P3).

When I am hungry, I cannot cope. I cannot even think; everything just shuts down (P8).

Sub-theme 2: Fear of stigma

The fear of stigma emerged to be an important aspect that negatively influenced participants’ management of the illness and quality of life. All participants expressed their fears of being stigmatised as follows:

Sometimes, at school, if they see you skinny, they say you have HIV., When they tease each other, which is what I am scared of, if they are to find out (P6).

I am scared that if I tell them, they will say do not hang out with us (P4).

When I go to the clinic, I tell people that I have high blood (P7).

I am saying people are harsh if you tell them, “friend”, the pills that I am taking are for a certain disease. Tomorrow, he will be rude to you saying do not annoy me, you are on pills for a certain illness. That is why I do not like telling friends (P10).

There are some heartless people, when you tell them you have HIV, they end up killing you. That is what I am scared of my boyfriend, he might kill me or send people to kidnap me and take me to some forest and kill me there. Even if he (boyfriend) dumps me, it is okay, my only concern is being killed and why I have not told him long ago and only tell him now (P8),

I was not taking them in front of her and I was not taking them at the same time, so that they cannot be suspicious (P7).

I was afraid that when she tells them, they will keep telling her lots of things and she will be back to where we started (P1).

One female participant reported that she was treated differently by members of her family regarding her future aspirations due to uncertainties about her diagnosis as indicated below:

My mother favours my sister, so I feel as if I have no future to them. This is it for me, because of my sickness (P7).

Three of the participants talked about experiencing internalised stigma and indicated that they felt ashamed and perceived that people were disgusted by their status.

When I look at myself in the mirror, I feel like people can see that I have HIV (P9).

I am ashamed of myself because I am sick (P7).

I am ashamed when I meet her in the support group, I cannot even look at her (P4).

I am ashamed of going to the clinic. I do not always take the same route going to the clinic; I change routes, so that people do not see me every time I go there (P9).

Two days ago, I was wearing my sister's clothes coming from somewhere, she gave me that ugly look as if ("u ya ndinyonya") she is disgusted by me and has not spoken to me ever since. She passes and just looks at me, without saying anything and that hurts me (P7).

Sub-theme 3: Abuse

Some participants reported that they experienced incidents of abuse in their homes such as verbal abuse, family conflicts, humiliation and neglect from their caregivers who abuse alcohol while leaving all the household responsibilities to the children as captured in the following excerpts:

My uncle does not want anything to be done for us, even to be given food, my grandmother is the only one allowed to eat. My brothers and I are denied food (P9).

They would fight each day; my mother would drink alcohol each day, I had to clean after school and cook for my younger brother, wash his uniform (P2).

I think too much at home, when my mom comes home drunk and swears at me, I avoid her when she swears at me; I leave her alone (P6).

My uncle said I am going to be just like my mother and die, and he kept on saying I am going to be pregnant and not complete school, things like that (P9).

Because I am scared of them, so when you ask too many questions, you are shouted at, so I kept quiet. I did not ask them anything (P7).

I get irritated because they always argue and shout at each other (P3).

Sub-theme 4: Inadequate support

Some participants reported that they were inadequately supported at home by members of their families with regard to material and emotional support:

I do everything for myself; I go to the clinic by myself, remind myself about the treatment, no one helps me or ask about my medication and stuff (P9).

There is no one that I am able to talk to; the only thing she does is to rub it in and say you are sick take your pills (P7).

I need toiletries, clothes and pads, I need those the most (P9).

Last year, when we were visiting Joburg, they asked me if I was going to leave my treatment behind; I said no, I will not leave my treatment behind, especially the epilepsy one because the headaches I get are unbearable so I will not leave it behind (P10).

Life is just okay, even though it gets hard sometimes, because at the age (18 years) I am at, you need guidance about life from a mother (P9).

Theme 5: ARV Treatment

Majority of participants acknowledged the importance of adherence to ARV treatment and indicated the assisted in making them to remain well and healthy.

Sub-theme 1: Experiences towards treatment

Participants described varying experiences regarding ARV treatment, ranging from disliking the treatment, feeling ambivalent about treatment to feeling like they had no choice, to being encouraged to remain on treatment and to accepting the treatment. One participant expressed anger and frustration towards taking medication as follows:

I get annoyed by the fact that my life is dependent on pills. Without them, I cannot do anything and I did not bring this upon myself. All my life when we play, I am the one that is called home to go take pills, when the other kids are playing. At times, I wake up early in the morning, around half past six, before I take them at eight, the other kids will be sleeping and I wake up to take pills (P7).

The only fact I do not like is going to collect pills, it bores me and I bump into those other kids (P9).

Some participants in the study had ambivalent experiences relating to treatment:

At times, I wonder if I should take the pills or not and then, I tell myself that I am taking them (P4).

One male participant reported that he initially did not want to take treatment, however, he had to accept the treatment:

The time when I was told that I had HIV, I refused to take them, I did not want to have HIV, I did not want it, but as time went on, I started taking them and my mom told me that if I do not take pills, I am going to die (P5).

One participant expressed the desire to stop treatment:

It is my wish to stop treatment (P8).

Some participants described positive experiences relating to treatment:

The pills treat me well, when I do not take them, I do not feel well in my body (P6).

The reason why I take this treatment is that I am happy about it, I am happy about it, the more I take it, the more I realise that it is my future (P10).

If you want to live, you will take those pills (P3).

Sub-theme 2: Factors affecting adherence or non-adherence

Participants indicated an array of factors that influenced their treatment adherence and or non-adherence, such as stigma, the side-effects of medication and lack of food. All participants were on ARV treatment at the time of the interviews. Two participants revealed that their families served as a frequent source of adherence and support to them as follows:

“My female cousin reminds me not to forget the time I must cook and drink my pills” (P3)

My mother often likes to come and ask me, boy, have you taken the pills? Are your pills OK? She is very cautious (P10).

Some participants indicated that their desire to live longer and future aspirations motivated them to remain adherent to their ART treatment:

My life is what is important to me, my pills, looking after myself (P6).

I just saw myself taking pills again but I think it is because of thinking about the future and what my uncle said, the one I am staying with. It made me go back to taking them again and finish school to spite him (P9).

One female participant indicated that she adheres to treatment in order to appear “normal”, thus avoiding stigma:

I see around me that the problem is people who used to take pills and leave them end up getting sick just like my brother, he even has sores on his head because they take them and leave them again. I do not want that kind of problem that is why I stick to pills and take them. I want people to always see me this healthy because if I stop taking them, I will start to lose weight then they would notice that I am sick (P8).

The fear of being stigmatised was experienced by all participants as a difficult factor that contributed to non-adherence. Some participants described how they did not want to be seen at the clinic by community members:

At the clinic, when I pump to be checked for blood pressure, I go with my mother and she waits for me to get pumped and she would hold the file as if it is hers and they will not notice I am the sick one, they would think I have accompanied my mother to the clinic (P8).

I did not want to go to the clinic because I did not want to bump into some people (P7).

When I am at the clinic, I give my sister my clinic book, to confuse people (P3).

The fear of stigma negatively influenced adherence of participants in the study:

I do not show them when I take pills, I just grab a glass of water and take them with that (P2).

I am not disputing that it is one pill, but it is the same, they make noise the same, you cannot even visit. At eight, you disappear when people are watching TV, you are making noise with the pills in the bedroom (P7).

Most participants indicated that they, sometimes, fail to take their ARV treatment because, at times, there is no food available at home and, therefore, they have to skip treatment as captured in the following excerpts:

There are times when there is no food, I skip the pills and cannot take them when there is no food and I sometimes, ask my sister for food and she would say they have just eaten and nothing is left (P8).

At times, I did not take them, because I had not eaten, there was no food and I did not take them (P5).

Participants also cited several factors that added to non-adherence to their ARV treatment such as forgetfulness, lifestyle interference and treatment fatigue as follows:

It just comes out of my mind, I forget the pills (P4).

I do not go out, totally, like last year, I went to study, we were doing Matric, I visited my friend to study for the final exams that is when I realised that it is tough taking pills. I asked myself how am I going to manage if I go to university, because sometimes, you are required to share rooms, what if my roommate likes to gossip? (P7)

I am going to draw blood soon, so I am hoping my results come back written "none" and says that I no longer have HIV, it will be better, because I have been doing this for long now (P8).

One participant indicated that the attitude of health care professionals and the clinic setting impacted on non-adherence and compromised confidentiality.

Everybody just comes in the room and that is where people find out what we are there for. I want us to be in our own space, cleaners must not just come in and say I am mopping, I came to look for a file (P9).

"The way the nurse asked me was not okay; "when did you start ... are you using protection?" I told her I am not having sex yet, she then looked at me in a weird way. I looked at her carefully and she said to me, what pills are you taking? She then went through my old file and asked if I knew what pills I was taking, I said, yes I do. She asked what I meant when I said I am not sexually active. I told her I got it from my parents, I did not get it from being sexually active or through a needle. She said I must not lie about my mother. I cried, because I was hurt, so if she can say whatever she said, being in the profession she is in ... (weeps), if she can judge me in the kind of profession she is in, what about people who do not have the level of knowledge she has, how are they going to treat me, what kind of hurtful words are they going to say to me? (P7)

Only one participant reported past experiences of intentionally not adhering to treatment as follows:

I stopped taking pills for two years and recently, started taking them again. I used to say whether I die, or not, I do not care (P9).

Sub-theme 3: Side effects

According to participants, treatment is an important part of their daily lives and helps them feel healthy. Most of the participants expressed experiences of having side effects due to the use of ARV's treatment, and at times due to non-compliance with treatment:

I only get tired when they are finished and did not go fetch them. I get confused; I become crazy in my head, I do things I am not supposed to be doing. I sing by myself, I do not understand, they would realise that I did not take my pills. Also, when I take them on an empty stomach, I become dizzy (P2).

When I wake up in the morning, I can still feel that I am dizzy, as it drugs you at night (P4).

When I do not drink them, it is as if I lose weight, I do not have energy (P4).

They make me tired, if I did not eat (P5).

I perspire a lot at night and when I am sick with flu, I do not get well fast, it takes time, things like that bother me (P8).

It is like there is something eating me up. When I play, that thing comes fast and my bowels jump, now and then, if I did not take them that particular day (P6).

When I take the pills after I have skipped them for some days, I become dizzy (P9).

Theme 6: Coping strategies

Sub-theme 1: Adaptive coping

Almost all the participants acknowledged the positive experience of the clinic support group in helping them cope with living with HIV. They viewed the support group

as a safe haven where they could share their challenges and experiences as captured in the following excerpts:

The support group helps me a lot, I am relieved that there are people like me, we are all the same; no one is going to judge me (P7).

I like the support group, we choose topics then we talk about them, and during the discussions, the topics are quite interesting, they are suitable. The nice thing about it is that we all benefit from it, it is enjoyable (P10).

Sometimes, when I take my pills, I do ask myself why am I taking them, what happened, why am I not like the other children? But I do tell myself that there are children at our support group who take pills as well, why should I worry myself with those questions (P6).

The support group does help; they teach us what we are being taught at school, it is helpful, they give us everything, food, they teach us, even when we have homework (P2).

When we go to a support group, we talk; I say how I feel, so it helps me (P7).

One participant indicated that she viewed the clinic support group as non-beneficial:

I think it is useless honestly; I do not like to keep talking about medication and stuff. I prefer going to the clinic, collect my medication and leave (P9).

Interactions and support provided by health care providers enable some participants to cope with their illness:

At the clinic, the doctor or sister sat me down, advised me on what to do and what not to do, they do support me (P8).

One particular sister supports me mostly at the clinic; she does not like it when I spend time at home without any treatment (P10).

Some participants indicated that the support provided by their families helped them to cope with their daily lives as follows:

My mother supports me with everything, my father as well; whatever that I need, be it something that I need for school (P6).

Since I found out about my diagnosis, my parents gave me support from that day and never gave up on me and never said I should go alone to the clinic to fetch treatment, no, they are always with me (P8).

My mother always tells me that I will be okay (P5).

Some participants indicated that their coping experiences of living with HIV included writing in their journals, studying, self-motivation and attending school as captured in the excerpts below:

My education, because it is the only thing that makes sense in my life as I forget about my problems when I am at school (P9).

I study; I relief that stress by studying (P6).

I encourage myself, because I do not talk to anyone and I go to church choir, so I get to forget about everything that is happening, just because of music (P7).

I write down my feelings, I write about myself, my upbringing and the passing of my mother (P9).

Future aspirations and maintaining hope is assisting some participant to cope better:

Thinking about my future makes me hopeful and strong (P9).

I want to learn, I want to become a soldier (P2).

Sub-theme 2: Maladaptive coping

Some participants respond to stressful experiences in their lives through maladaptive ways such as use of alcohol, romantic relationships and aggressive behaviour as captured in the excerpts below:

I end up calling my boyfriend and explain to him that there is no food in the house and if he does not have money, he should send food, so that I can eat, but I cannot cope (P8).

I do drink, but not much (P3).

When a person annoys me, I beat them up and I do not want to be restrained (P2).

5.3 Summary of results

The themes that emerged from the data collected identified varied experiences; however, the common and central issues voiced by all participants were keeping their diagnosis a secret and the need to conceal their HIV status from others. The silence about their HIV positive status remains restricted to families. Disclosure of their HIV status was associated with fear of being stigmatised and fear of rejection by peers. Participants' desire to "be normal" was demonstrated by narratives that compare their daily lives to other adolescents who do not live with a chronic disease. Some adolescents were more emotionally affected by their HIV status and struggle to cope while others found the clinic support group as an effective source of support to share experiences, learn and find acceptance.

CHAPTER SIX

DISCUSSION

INTRODUCTION

This chapter focuses on the discussion of the results of this study, conclusions drawn, recommendations, limitations of the study, as well as implications for future research. The aim of this study was to explore the psychosocial experiences of adolescents living with HIV and AIDS in Matlosana sub-district North West Province, South Africa. The findings revealed six themes that described the lived experiences of adolescents living with HIV and AIDS. The discussion was done in accordance with the themes, and guided by the literature review and the theoretical framework that informed the study.

6.1 DISCUSSION OF RESULTS

Theme 1: Finding out about own HIV status

The WHO (2011) and the American Academy of Paediatrics (AAP, 1999) guidelines for disclosure to HIV-positive adolescents recommend that children of school age should be told their HIV-positive status in order to improve health outcomes. In addition, disclosure should take into consideration the level of cognitive development and psychosocial maturity of the child or adolescent concerned.

All adolescents in the study knew their HIV status, which is contrary to related literature that has reported low rates of HIV status disclosure for adolescents living with HIV and AIDS in sub-Saharan Africa (Kenu *et al.*, 2014; Mahloko & Madiba, 2012).

Similar to previous studies, disclosure was preceded by episodes of illnesses for most of participants. Most adolescents described a childhood dominated by lengthy periods of illness. They faced difficulties of not being able to go to school, frequent visits to the clinic and inability to understand what was happening to their health. The findings are consistent with what was reported in a study among adolescents in South Africa, which found that most adolescents were diagnosed after continuous periods of illness (Madiba & Mokgatle, 2016). Similarly, Daniel (2015) found that adolescents in the study experienced prolonged bouts of illness before being diagnosed HIV-positive. The findings further suggest that recurrent illness and the demands of treatment regimens significantly affected schooling and educational achievement for most adolescents.

The findings revealed that majority of cases of informing adolescents of their HIV status was not done voluntarily; caregivers often did so only in response to persistent questioning from adolescents pertaining to reasons for taking medication and mainly because of adherence to ART. This is in line with other studies Mahloko and Madiba, (2012); Madiba, (2012); Vaz *et al.* (2011) which found that disclosure was motivated by adolescents questioning why they must take medication when they did not feel sick and had problems adhering to treatment.

In the current study, the decision to disclose the diagnosis of HIV to infected adolescents seemed to have been difficult for caregivers. The reluctance by caregivers to inform HIV-infected adolescents about their HIV status could be due to several reasons as follows: inadequate skills and knowledge on how to handle disclosure; it could also be a way that caregivers protect themselves from feelings of guilt; the fear

of being blamed for infecting their adolescent with the illness; and fear of having to answer questions about past sexual behaviours.

Similar findings were reported by Idele *et al.* (2014), who described disclosure of a child's HIV status as a complex and emotional issue both for the adolescent and caregivers. In addition, Kenu *et al.* (2014) reported that informing children and adolescents that they were HIV-positive is a challenge for some caregivers because children and adolescents are frequently asymptomatic in the early stages of HIV infection, however, they need daily medication and close observation.

The findings further revealed that disclosure was experienced by adolescents as a once-off impulsive event, with some caregivers disclosing the status of patients during HIV-related programmes on TV while others did so during moments of frustration in response to adolescents' denial to take ART medication. These findings are consistent with those of a study by Vaz *et al.* (2011) who found that disclosure was largely a discrete event rather than a process. Madiba (2012) maintains that when disclosure to a child or adolescent was a once off event, children lose the opportunity to ask questions and to be taught about their disease and ART medication. The literature suggests that disclosure is not a onetime event, but a multistage process that may need several opportunities to comprehend the meaning of their status (Lee, Yamazaki, Harris, Harper & Ellen, 2015).

Adolescents in the study described disclosure of their HIV status as extremely painful; this is in line with findings by Madiba and Mokgatle (2016) who found that most adolescents experienced negative emotions such as shock and sadness. In this study, some adolescents described crying for days and contemplating suicide after learning that they had HIV and going through a range of emotional responses, including fear,

anger, disbelief and confusion as they could not understand how and why they were infected. Feelings of fear and hurt experienced by adolescents were associated with fear of death as HIV and AIDS is linked with death and dying in their communities. However, some adolescents reported that they felt indifferent following disclosure.

The findings further revealed that upon learning about their status, participants did not reveal their status to persons outside their immediate families but kept it a secret. Participants in the study indicated that they were instructed by caregivers not to disclose their status to people outside their immediate families, including extended families. In addition, all participants had disclosed neither to their friends nor to their teachers. Participants expressed anticipating negative outcomes if they were to disclose. Thoth *et al.* (2014) reported that disclosure to friends and peers is extremely difficult in adolescence as this is the phase in which adolescents are most sensitive to rejection.

Fear of stigma and rejection by peers was noted to be an important perceived barrier to disclosure in this study. The finding is consistent with the study by Hogwood *et al.* (2013) who found that the stigma associated with HIV forced adolescents and their caregivers to live in secrecy. It was also found that adolescents used secrecy to conceal going to the clinic as well as taking their ART treatment. Secrecy places an additional psychological burden on the adolescent's well-being (Mahloko & Madiba, 2012).

Furthermore, disclosure was particularly difficult for some participants in the study as disclosure implied revealing the serostatus of their biological mother and risk of being stigmatised. Similar findings were reported by Hogwood *et al.* (2013) who found that adolescents will not self-disclose to avoid family conflict and distress. Adolescents

who were in romantic relationships, expressed apprehension about disclosing to their partners, since they feared rejection. This finding is consistent with studies that examine self-disclosure by adolescents that suggest that in developing countries, disclosure to sexual partners is still lower (Siu *et al.*, 2012; Thoth *et al.*, 2014). However, despite being reluctant to disclose, this study revealed that disclosure was desirable. However, some participants thought about self-disclosure and believed it could be done at the right time, such as when they could trust their partners. Despite the low rate of disclosure, authors such as Domek (2010) have shown that disclosure has a positive outcome and is related to improved adherence to treatment, positively impacts on self-esteem and mental health as well as enhances better access to social support (Mahloko & Madiba, 2012).

All participants indicated that being diagnosed with HIV was difficult at first, but they had to learn to accept living with the disease and learn to get on with life. Most participants stated that acceptance was a process and it came about as they gained more knowledge about their illness and talking to other HIV-positive adolescents from the support group. Participants acknowledged their HIV status, however, acceptance was associated with non-disclosure.

One of the participants showed denial of her HIV status. The participant narrated her struggles with accepting her diagnosis as a result of learning about her HIV status from sources other than her biological mother, who is unsupportive and denies the participant the opportunity to openly express the challenges she experiences in her everyday life. It was also observed that the participant was struggling with anger and blame directed towards caregivers seven years after being disclosed to be HIV-positive. This could be related to the work of Van Dyk (2010), which suggests that

most people living with HIV undergo a phase of denial as it is an important and protective defence mechanism that alleviates emotional stress temporarily. The findings are consistent with what was reported by Pienaar and Visser (2012) in a study among adolescents in South Africa. The findings revealed that one adolescent denied having HIV and AIDS, because HIV was not discussed in family settings.

According to Kamen *et al.* (2012), denial is a common psychological reaction to something that is perceived difficult to a person. Kalichman (2009) adds that denial is when a challenging situation that is perceived as a threat, is considered as not true; denial helps an individual to adjust to an unpleasant situation and lessens feelings of anxiety. Several reasons could influence acceptance or denial of an HIV diagnosis, such as the manner of the initial diagnosis and the availability of immediate and subsequent support. This is confirmed by Mburu *et al.* (2014) who found that circumstances relating to how caregivers inform adolescents of their HIV positive status have important consequences as they could affect the child's or adolescent's psychosocial adjustment and development.

According to Vaz *et al.* (2011), it is important to provide children and adolescents with a platform for continuous information and communication on their illness and experiences after they have been disclosed to enhance their well-being. The findings of this study suggest that poor disclosure and an unsupportive environment could lead to limited opportunities for processing diagnosis and result in emotional difficulties for adolescents, thus making acceptance of an HIV diagnosis very difficult. Additionally, denial of one's HIV status may come as a result of stigma, which could be real or anticipated. Stigma has been previously reported to negatively influence disclosure and acceptance of HIV (Kagee & Delport, 2010).

Theme 2: Knowledge of HIV

The findings revealed that participants' knowledge was mere general knowledge without in-depth understanding of the illness. They knew that they had to take medication to be well but did not understand the implications of non-adherence. According to Kenu *et al.* (2014), having an insight and understanding of HIV among infected adolescents is essential in preventing the spread of HIV as well as addressing risks posed by HIV and AIDS. It was found that, before being told about their HIV status, most adolescents were taking ARV treatment without knowing about it. According to participants in the study, caregivers used various methods of deception to avoid telling participants about their illness and medication such as telling participants only about a co-morbid condition, for instance, asthma, epilepsy and flu and pointing out all medical needs such as a clinic appointment and blood collection to other conditions unrelated to HIV.

This finding is similar to research conducted in Uganda where some caregivers reported giving inaccurate information to their children while others did not provide their children with any information when they enquired about their illness or medication (Vaz *et al.*, 2011). Similar findings were also reported in a study by Kidia *et al.* (2014), who found that caregivers misinformed adolescents about HIV illness or concealed information regarding HIV illness from them. Tiendrebeogo *et al.* (2013) also found that caregivers who did not inform their children about their HIV status, often used deception and coercion to persuade adolescents to continue taking medication. Majority of participants indicated that not knowing what the medication they were taking was meant for, had a negative emotional effect such as constant worrying and frustration,

as they were only told to keep taking their medication and that they will be cured one day, however, the treatment did not seem to be completed.

One participant in the study reported being suspicious about the medication and the nature of her illness prior to the disclosure. The participant indicated that she discovered her status by making inferences from her surroundings (she was able to draw a connection between her pills and what she saw on a poster at the clinic). The findings may possibly reflect the constrained style of communication between caregivers and children that is characteristic of some non-Western cultures

The decision by caregivers not to tell adolescents the truth about their medication and illness may be influenced by several reasons such as concerns about a child's cognitive ability to understand the full implications of an HIV diagnosis, the wish by caregivers for a child to live a normal childhood life, fear of stigma, fear of having to explain to the child how they became infected and the rejection and blame that could result (Mutumba *et al.*, 2015). This finding is similar to the one obtained in a study conducted in Uganda on disclosure of HIV status between parents and children, which found that the decision to disclose to one's child or caregiver was a highly emotive issue involving guilt, blame and shame (Kyaddondo, Wanyenze, Kinsman & Hardon, 2013).

The findings further indicate that most participants mainly acquired information on HIV and AIDS when attending meetings of support groups at the clinic and at school during Life Orientation lessons. This may possibly be because the cultural context in South Africa does not encourage open discussion of sexuality between caregivers and children. Moreover, the idea that HIV is mainly transmitted through sex plays a significant role in the hesitation by caregivers to openly communicate. This finding is

in line with that of Pienaar and Visser (2010) who found that adolescents did not have clarity on how they contracted HIV since caregivers were reluctant to openly share such information.

Theme 3: Psychological challenges

As already stated, finding out that they were HIV-positive was painful for most adolescents who could not understand how they became infected and why them. One participant directly blamed her mother for infecting her with HIV, by failing to take precautionary measures. She expressed anger and betrayal towards her mother. Similarly, some adolescents in a study conducted in Tanzania openly attributed blame of being infected with HIV to their caregivers and harboured feelings of hatred towards caregivers (Mattes, 2014).

In the current study, most adolescents described living with HIV as highly stressful and demanding since they were expected to take responsibility for a number of things that most of their peers who did not have HIV did not worry about. The findings revealed that stressors associated with living with HIV included taking life-long medication, ongoing clinic appointments and physical effects of the disease and painful medical procedures. The findings are in line with those obtained in a study in Zambia which highlighted difficulties of living with HIV from adolescents (Hodgson *et al.*, 2012).

The findings suggest that participants experienced negative emotional experiences of being infected with HIV. This finding is in line with that of Woollett (2013), who found that children and adolescents infected with HIV were more vulnerable to behavioural and emotional problems, including anxiety, depression,

adjustment disorder and post-traumatic stress disorder. Additionally, some participants experienced a sense of loss of childhood since they were continuously ill and felt limited to engage in normal childhood activities. Participants indicated that HIV brought restrictions into their lives; normal things such as sleeping over at friends became stressful situations for them as their statuses were not known to people outside their home environment. The findings of this study are congruent with previous research on chronic illnesses in children and adolescents, thus resulting in the disruption of normalcy due to the intrusion of the illness into activities of daily living, uncertainty and disruption of the developmental tasks of peer relationships, communication and disclosure (Santis, Garcia, Chaparero, & Beltran, 2013).

It was also found that most adolescents in this study were struggling to incorporate HIV into a healthy sense of identity. Feeling “different” to other adolescents, even though they wanted to be normal was commonly reported by adolescents in this study. Albright *et al.* (2016) corroborate that a negative sense of self was common among adolescents living with HIV, who viewed themselves as “damaged” by their illness. According to Petersen *et al.* (2010), identity development is a fundamental psychosocial developmental task during adolescence and is often founded on social comparisons. Evidence suggests that most people living with HIV are likely to integrate negative stigma into their self-concept, resulting in internalised stigma (Woollett, 2013).

The findings further show that the family conditions of several participants did not allow them to express their distress due to poor parent-child relationship. They indicated that they received limited emotional support at home; furthermore, their future aspirations were barely ever discussed at family settings due to uncertainties

about their prognosis, thus opportunity for sharing their hopes and dreams was never discussed. In addition, the loss of a parent was stressing for participants who had lost their parents due to AIDS-related deaths, as it became a long-term stress factor in their lives. These factors brought about pressure and difficult psychosocial situations that adolescents must deal with in living with HIV.

Some participants reported that their caregivers denied that they were perinatally HIV infected and did not acknowledge that they might have infected their children. It is assumed that some caregivers tended to deny that their children were HIV infected as a means of coping with their guilt of infecting their children, denial could also be meant to protect the caregiver so that painful conversations about the illness could be avoided. This finding is consistent with that of Vranda and Mothi (2013) who found that most caregivers chose to deny the existence of HIV to their children and significant others because they were unable to tolerate their own guilt, regret and psychological pain. Kalichmna *et al.*, (2003) confirm that some caregivers deny the existence of HIV by explaining it away because of fear and guilt.

According to Kyaddondo, Wanyenze, Kinsman and Hardon (2013), the HIV and AIDS epidemic has become part of a moral system, a lens through which people view the behaviour of others mainly because of the commonly accepted idea that HIV infection is due to engaging in unsafe sex. This heightens caregivers' fears of explaining how one became infected, which makes some caregivers deny having the disease. In addition, caregivers have fears of losing respect and possible rejection from their children. Denial by caregivers could have implications for the adolescent, thus difficulty accepting their status or believing that they did not have HIV. This finding is consistent with that of Pienaar and Visser (2012). In their study, one participant

denied having HIV because there was denial of HIV within the family context and HIV was hardly discussed.

Theme 4: Social challenges

Poverty and unemployment of caregivers emerged as significant social challenges in the study. All participants live in low socio-economic status characterised by poverty, overcrowdedness in the home and high rates of caregiver unemployment. The findings are consistent with the works of Cluver and Gardner (2006) which found that HIV affected households were often exposed to economic deprivation. All participants indicated that their caregivers found it difficult to provide adequate food as families mainly survived on government grant. Those who were working, were involved in odd jobs. The study found that participants frequently lacked sufficient food in their households. Lack of food adversely affected participants adherence to ART as they could stop taking their medication completely. The findings also revealed that some adolescents faced discrimination and emotional abuse by some members of their families. The discriminatory practices of these members included depriving them of food. The findings are consistent with the study in Zimbabwe which found that adolescents living with HIV experienced ill treatment within their households, for instance, being given less food than others who were their own age (Mavhu *et al.*, 2013).

Abuse was also experienced in the form of insulting comments, lack of affection and not providing for their basic needs such as clothing and not supporting their daily medication intake. Adolescence is a period of “fitting in” and any situation that set an adolescent apart from other adolescents such as not having clothes combined with being HIV positive becomes a double-edged sword for any adolescent to cope with.

Palmier (2011) states that adolescents living with HIV who have little or lack psychosocial support are more likely to use destructive coping strategies such as the use of alcohol and or drugs or may attempt suicide. Alcohol abuse by caregivers and family conflicts emerged as challenges experienced by some participants in the study. In their study, Meinck, Cluver and Boyes (2015) found that households affected by HIV had considerably higher incidence rates for physical and emotional abuse than healthy households. It is likely that families affected by HIV experience additional and different stress factors such as HIV-related stigma, severe symptomology and perceived shorter life expectancy.

Participants in this study indicated that they kept their status a secret due to fear of stigma. They had heard of incidences where people infected with HIV were stigmatised in different forms. The study found that fear of stigma had considerable influence on adolescents living with HIV and their families and also had an influence on their disease management and quality of life. A study by Martinez, Harper, Carleton, Hosek, Bojan and Glum (2012) revealed the negative impact of stigma on the quality of life of people living with HIV and AIDS.

The findings of this study also show that most participants chose not to disclose their HIV status to persons outside of their immediate families due to fear of being stigmatised. This finding is similar to that of Mnisi (2015) who reported that stigma is a great impediment as it discourages people from being tested for HIV and from disclosing their status, thus making accessing care and support a challenge, if not, impossible for many. Studies of children and adolescents living with HIV have revealed that the experiences of stigma and discrimination could lead to poor mental health,

social isolation and reduced health seeking behaviour (Woollett, 2013; Mutumba *et al.*, 2015).

The findings further indicate that some participants avoided stigma by adhering to ART since the availability of ART assisted them in diminishing visible symptoms of the disease so that they appear normal thus, avoiding stigma. These findings are consistent with those obtained by Mattes (2014), who found that the importance of appearing normal and healthy was a strong motivation for being adherent to ART.

Stigma influences how these adolescents in time perceive themselves. Some participants reported experiences of internalised stigma often feeling that people knew that they are HIV infected. Woollett (2013) indicates that adolescents are at a developmental phase in which they struggle with issues of self-identity and image. As they worry much about what others think of them, they end up often accepting some of the negative social judgements that label and discredit them and projecting them on themselves. Internalised stigma has been related to a low sense of self and anger (Lyimo, Stutterheim, Hospers, & De Bruin, 2014).

Theme 5: ARV treatment

In this study, participants had varying experiences with ART treatment. Taking ARV's was like a double-edged sword for participants in this study. While some participants acknowledged the importance and benefits of treatment in their lives, that is, to live a longer and healthier life, others viewed treatment as interference in their lives. The desire to appear and feel "normal" and improved health emerged as a motivator for ART adherence for some participants. This "normal" was explained as being without the noticeable signs and symptoms of HIV, which made it possible to

hide that they were HIV positive. The findings corroborate with previous studies involving HIV infected adolescents which reported the importance of being healthy as a strong motivation for being adherent (Mutwa *et al.*, 2013; Midtbo *et al.* 2012). Adherence to ART presented some participants with a positive outlook for the future, for example, having a career and family.

However, some participants in the study faced many difficulties in their daily lives and which had an effect on taking of their ARV's medications. These challenges function at various levels, including individual, familial, social and systematic. Some participants reported that they did not like taking the ARV treatment as it interfered with their lifestyle e.g. could not go to sleep overs, they had to accept the ARV's only because they did not have an alternative choice. Participants also mentioned that ARV's were a constant reminder of being HIV-positive and of being different from their peers who were not HIV infected. Similarly, some participants in the study openly shared how they at times thought of stopping their ARV treatment. One participant reportedly defaulted treatment intentionally for two years.

Poverty and unemployment emerged as the most significant socio-economic barriers to ARV adherence as reported by all participants. All participants indicated that their caregivers found it difficult to provide for them. Lack of income meant that most caregivers were unable to buy food. Most participants reported that taking medication without eating any food worsened the side effects of medication. These results are similar with those found in a South African study in which participants attributed non-adherence to ARV treatment regularly due to food shortage in their homes (fearing the side effects if they were to take ARV's on an empty stomach) (Kheswa, 2017).

Forgetfulness to take medication due to school, visits, travelling and play was found to be a common factor to adherence to ART among participants. According to Peralta, Belzer and Palmer (2009), forgetfulness in patients could be due to various psychosocial factors such as instability in the home and emotional distress. Nebukeera-Barungi *et al.* (2015) emphasise that some adolescents tend to forget the times of taking medicines because of their playful nature as they are engaged in play, even during times of supposedly taking medicine.

Treatment fatigue was found to be another factor affecting ART adherence among participants in the study. According to Nebukeera-Barungi *et al.* (2015), adolescents, especially those who started ART when they were young, are likely to stop taking medicine because of fatigue. Treatment fatigue after several years of therapy is common and has been shown in studies of adolescent and children living with other chronic illness like cancer (Haberer *et al.*, 2012).

Most participants were found to have experienced side effects while on treatment. The side effects occurred mainly when commencing with ART but gradually decreased with time. However, none of the participants reported completely stopping their medication. The most commonly reported side effects experienced by participants included nausea, headaches, stomach cramps and dizziness. In addition, some participants indicated having had side effects such as stomach cramps and dizziness when they missed some doses of their ARV medication. Most participants indicated that it was difficult to take their medication in the view of others for fear of stigma and discrimination. Thus, they avoided doing it in the presence of others, which could lead to them missing a dose. The findings of this study agree with those of Nabukeera-Barungi *et al.* (2015) that adolescents avoid taking their medication in uncondusive

environments such as schools and other public spaces is likely to persuade adolescents to stop taking their ARV treatment.

Most participants, with the exception of one, described their interactions with health care providers as positive and helpful. One participant reported that poor health care providers' attitude and their impersonal interaction was a barrier to adherence. The findings show that lack of confidentiality at the clinic deters adolescents from going to the clinic as they do not feel comfortable going there and impacted negatively on ARV adherence and disease management. Participants, who had supportive families, were found to be faring better with adhering to their ART treatment, which is an indication of the important role of family support in the management of the disease.

Theme 6: Coping strategies

The effective use of coping strategies plays a significant role in the management of HIV and AIDS. The findings revealed that in order to manage the stressful demands associated with HIV and AIDS, participants employed different coping strategies, which have different implications for their well-being. The findings revealed that some participants used the support provided by family to cope with their illness. The support provided by family included reminding them to take their medication and clinic appointments. The findings are in line with the results obtained in a South African study on adolescents living with HIV, which found that adolescents with a wide support system, in addition to family support, seemed to cope better with HIV (Petersen *et al.*, 2010).

It was found in the current study that caregivers were often the main source of support to adolescents; however, they coped with HIV in isolation of other possible

support structures such as extended families. Thus, caregivers often managed HIV within the home environment only. In the current study, extended family did not serve as a support structure. This could be attributed to non-disclosure and fear of stigma and discrimination. It has been reported in the literature that various forms of support from family and friends could be instrumental in improving coping and promoting healthy behaviour in children and adolescents living with chronic illness (Li *et al.*, 2010). On the contrary, in the current study, friends did not serve as a support structure, mainly because participants did not disclose to friends, instead, they felt that they will be discriminated against. Daniel (2015) states that fear of stigma leads to persons living with HIV adopting coping strategies of secrecy and silence.

Several participants identified the value of attending the clinic support group, which enabled them to better cope with living with HIV. Participants reported that attending the support group allowed them to discuss issues that they normally could not discuss with their caregivers such as sex, medication and self-disclosure. In addition, being with other HIV-positive adolescents was found to be helpful as adolescents shared their experiences with other HIV-positive adolescents and did not feel alone. The findings suggest that peer support groups could play a significant role in facilitating healthy-seeking behaviour through knowledge and participation. These findings are similar to those obtained by Hodgson *et al.* (2012) in which peer support groups was found to improve coping with the disease and self-esteem, as well as encouraging the use of health services.

The findings also revealed that maintaining hope was a prominent source of comfort and helped them cope better with their illness. For example, the hope of finishing school, having a career and having their own families. The influence of hope

in coping with a chronic illness has been documented in patients with other chronic illnesses such as cancer. Mburu *et al.* (2014) reported similar results, where adolescents used hope as a coping resource in dealing with adversity.

The study also found that some participants coped with their overwhelming pain and sadness, through writing in their journals. Mattes (2014) reported similar findings wherein adolescents found their own strategies of coming to terms with feelings of distress such as keeping an 'emotional journal', while others in the study were inclined to using avoidant coping strategies such blaming their parents and using alcohol to cope with their illness. One of the participant reported that she coped with her situation by depending on her boyfriend who provided material support such as clothes, money and food. In their study, Peterson, Hancock, Bhana and Govender (2014) found that adolescents and the youth with poor coping skills reported more emotional distress, engaged more in risk-taking behaviour such as taking drugs and being promiscuous.

6.2 Conclusion

The exploration of the psychosocial experiences of adolescents living with HIV brought an awareness of the challenges and multiple stressors experienced by adolescents living with HIV. Despite the concerted efforts by government and other stakeholders to reduce the stigma of people living with HIV through incorporating HIV services into the primary health care system and awareness campaigns, stigma and discrimination is still enduring and experienced as a major challenge by adolescents. Stigma and discrimination contributes to keeping their illness a secret. Maintaining a secret is an added stress for adolescents who have to deal with their HIV diagnosis, adolescence developmental stage and adherence to ARV treatment.

Living with HIV and AIDS also influenced family communication and dynamics. The impact of HIV on the family was not only limited to concealing the status but also contributed to a dysfunctional family, including blaming parents for HIV infection or being angry with parental denial of the infection. The negative impact of poverty and unemployment was a barrier to ARV adherence.

Learning about their HIV status was viewed as a negative experience accompanied by anger, sadness, disbelief and depressive emotions. The clinic support group provided a component of coping and healing to a variety of challenges faced by adolescents. Although some participants seemed to be challenged with coping with multiple aspects of their illness, other participants learned to cope with their disease and remained hopeful about the future.

Applying Bronfenbrenner's ecological system theory to the findings demonstrated that adolescents' experiences of living with HIV emanated from how HIV was constructed in their micro environment – families, friends, school and community, which are shaped and influenced by cultural, societal and global practices and norms with regard to health and HIV. Thus, how adolescents navigate issues of stigma, disclosure and how to make sense of disease-related experiences is continuously shaped and influenced by the social environment within which adolescents find themselves in.

6.3 Limitation of the study

The study was based on the opinions of participants and was carried out at two adolescent friendly clinics with a small sample size of ten adolescents. Thus, the findings cannot and does not seek to represent the experiences of all adolescents

living with HIV in Matlosana sub-district. All participants were black adolescents from disadvantaged family backgrounds and, as such, the findings cannot be generalised to other racial groups and socio-economic levels.

Exploring the experiences from the perspectives of adolescents and not including those of caregivers also constituted a limitation in the study as only one-sided experiences were sought. Interviews with caregivers could have provided a valuable dimension to this study.

The use of a clinic accredited as an “adolescent friendly clinic” may also have influenced the range of psychosocial experiences of adolescents.

Furthermore, the study limited its focus to the psychological and social processes experienced by adolescents.

Another limitation was the fact that the caregiver of one participant wanted to sit through the interview and felt that the participant was not capable of responding to the questions. This affected the data as the caregiver responded to some of the questions on behalf of the participant who kept on looking at the caregiver for approval.

6.4 Recommendations

Following the findings discussed above, the following recommendations are made.

To provide counselling intervention to enhance caregivers’ skills and knowledge on disclosure processes in efforts to help caregivers to disclose to children in ways that enhance the well-being of the child.

To provide more interventions to assist adolescents living with HIV to develop a positive sense of identity that is not based just on their HIV status.

Provision of psychological intervention by clinical psychologists to prevent negative mental, behavioural and social health outcomes of HIV and to explore adaptive coping skills.

To promote and intensify the use of peer-based support programmes as coping structures and improve supportive networks.

Therapeutic interventions to improve parent-child relationship to enhance emotional support by caregivers.

6.5 Implications for future research

The findings of this study point to the important need for developing programmes that not only address the clinical needs of adolescents but also effective psychological health and support interventions for their overall well-being.

Clinical psychologists, social workers, educators and other health care workers could make use of the findings to gain understanding of the psychosocial experiences of adolescents living with HIV that could inform therapeutic intervention.

Future qualitative research conducted with a mixed-race profile of adolescents could explore the psychosocial experiences of living with HIV.

It may be necessary to consider exploring experiences from both caregivers and adolescents' perspectives to provide a more valuable dimension.

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APPENDIX A: Guardian information sheet and consent form

My name is Boitumelo Mutloane and I am doing MA studies in Clinical Psychology with the North West University (Mafikeng Campus). As part of my Master's dissertation, I am doing a research study on the psychosocial experiences of adolescents living with HIV and AIDS. I would like to request permission for your child to participate in the research study.

My research aims to explore the psychosocial experiences of adolescents living with HIV and AIDS. If you agree to allow your child to take part in this study, the interview will take approximately one hour.

During the interview, I will ensure that any emotional stress or disturbance to your child is minimized. Your child will have access to professional counselling if needed during the research process.

If your child agrees, the interview will be audio recorded. This will help me remember what I talked about with your child. The audio tape will be kept locked in a safe cabinet and only I will have access to listen to it and audio tape will be destroyed after the research study. You will not be able to listen to the audio tape.

Participation in the research study is entirely voluntary. Your decision whether or not to allow your child to participate will not affect the treatment, care and support services that your child receives at the clinic. Even if you give your permission, your child is free to refuse to participate and can end his or her participation at any time in the study process.

Your child's identity will only be known by me. She/he will not be paid for being in the research study but she/he will be given a total amount of R50.00 for transport to come to the clinic and back to your home when the interview is over.

If you have any questions or you are unsure of anything about the research, you can contact me at 082 406 3828. If you are unsure of anything about the research study and have any concerns about the ethical aspect of the research, please contact UNW Department of Psychology at 018 389 2635.

If you permit your child to participate in the research, please sign the guardian consent form below

Date: -----

Ms. Boitumelo Mutloane
(Researcher)

GUARDIAN CONSENT

Yes, I give permission for my child to participate in this study on exploring the psychosocial experiences of adolescents living with HIV and AIDS.

- ☐ The study has been explained to me and I understand what it involves.
- ☐ I understand that my child's participation in the research study is voluntary.
- ☐ I understand that even if I give my permission, my child can choose not to participate in the study.
- ☐ I understand that neither my child's name will be revealed in any reports.

Signature of the guardian

Name of the guardian

Name of the child

Date

APPENDIX B: Adolescent information sheet and assent form

Hello, my name is Boitumelo Mutloane. I am a MA student from the North West University (Mafikeng Campus). I am doing a research on the psychosocial experiences of adolescents living with HIV and AIDS

As part of my research study I would like to speak to you about your life history of living with HIV. The interview will be conducted by me. The interview should take approximately one hour. Things you tell me in the interview will be confidential. Your name will not be mentioned in any report.

During the interview, if you allow me, I will use an audio recorder, which means that what we talk about during the interview will be recorded. This is so that I can remember what we talked about. The audio tape will be kept locked in a cabinet and only me will be allowed to listen to the audio tape. It will thereafter be destroyed.

Some of the questions that I may ask might be uncomfortable. If you do not want to answer just tell me, I will not force you to answer them. I will ensure that any emotional stress or disturbance to you is minimized. You will have access to counselling if needed during the research process.

I have asked permission from your caregivers for you to participate in the research study and they have agreed. Am not however going to inform them what you say in the interview unless you decide to tell them.

You will not be paid for being in the research study but you will be given transport money totalling R50.00 for your transportation to and from the clinic for the interview. You will not be forced to participate in the research if you do not want to. You will not get into trouble with the clinic if you say no. You may also stop in the research study at any time.

I will be happy to answer the questions you have about the research study. My contact number is 082 406 3828. If you are unsure of anything about the research study and have any concerns about the ethical aspect of the research, please contact North West University Department of Psychology at 018 389 2635.

If you wish to participate in my research study you can sign the assent form below.

Date: -----

Ms. Boitumelo Mutloane (Researcher)

YES, I want to take part in this study.

- ☐ I was invited to participate in the above mentioned research project which is undertaken by Boitumelo Mutloane, a Masters student at North West University (Mafikeng Campus)
- ☐ This research study aims to explore the psychosocial experiences of adolescents living with HIV and AIDS. The information will be used as part of the requirements for the MA in Clinical Psychology. The results of the study will be presented in a dissertation.
- ☐ My identity will not be revealed in any discussion and description by the researcher.
- ☐ My participation is voluntary. My decision regarding participation or non-participation in the study will in no way affect my lifestyle.
- ☐ No pressure was exerted on me to consent to my participation and I understand that I may withdraw from the study at any stage without being penalized.
- ☐ Participation in this study will not result in any cost or financial gain for me or my guardian(s).

Signature of participant

Name of participant

Date: -----

APPENDIX C: INTERVIEW GUIDE

Section A: Biographical Details of the participants

1. Age:

2. Gender:

Male	
Female	

3. Language:

Setswana	Xhosa	Sotho	Other (specify)

4. Educational Level

Primary Education	Secondary Education	Tertiary Education	Other (specify)

Section B: Self

5. Where do you live?
6. Can you tell me about what you do during a day? –How a 'normal' day would look like?
7. Which parts of the day do you enjoy the most?
8. What things do you think you are good at?
9. Who do you live with?
10. How many siblings do you have? (Do you all live together or are some of the siblings living elsewhere?)
11. How is the relationship with your family/caregivers?

Section C: Knowledge of HIV

12. Can you tell me about how you got to know that you have HIV?
13. When were you told of your HIV status?
14. How did you feel?
15. What was your reaction when you find out about your HIV status?
16. Did you know anything about HIV/AIDS before you were told about your status?

Section D: Disclosure

17. What do you think was good or right about how you were told about your disease?
18. Do you feel that you can talk freely with your parents/caregiver about HIV, and that you get answers to your questions?
19. Do you think it is important that you were told about your status? Why?
20. Who knows about your disease apart from your caregiver? (do you talk to people outside of where you get treatment about HIV/AIDS?)
21. If yes whom did you disclose to and how long did you take to disclose your status?

- 22. What was their reaction to the news?
- 23. How did their reaction make you feel?
- 24. What prompted you to disclose your status to them?
- 25. If you have not disclosed, why have you not disclosed to anyone?

Section E: Treatment

- 26. Are you currently on ART?
- 27. If yes, how long have you been on treatment?
- 28. How do you experience the treatment in general?
- 29. Knowledge regarding treatment?
- 30. Factors affecting adherence /non adherence on treatment
- 31. Experience of non-adherence to treatment
- 32. Independence in taking treatment

Section F: Stigma/Discrimination

- 33. What do you think are the challenges you experience living with HIV? What things are the most difficult in your situation?
- 34. Describe how those challenges affect your day-to-day living?
- 35. How do you handle/cope with them?
- 36. How do people that know you have HIV treat you?
- 37. Have you experienced to be discriminated against or in other ways been treated badly by other people? If yes, how do you react/what do you do?
- 38. Have you ever felt unsafe due to your status? Why?

Section G: Care and Support

- 39. What are the needs you have as an adolescent living with HIV/AIDS?
- 40. How do you feel about yourself?
- 41. What things are important to you?
- 42. What/Who do you think is your most important source of support?
- 43. What advice would you give another adolescent who has just discovered that he or she is HIV positive?
- 44. Generally how do you experience your life? /What are your goals and wishes for the future?
- 45. What makes you feel safe?

Section H: Service Delivery

- 46. How often do you visit the clinic to collect your treatment?
- 47. Your perception about the clinic?

APPENDIX D: NWU Ethical Clearance Certificate



ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by the Human Sciences Research Ethics Committee (HSREC) on 13/02/2017, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby approves your project as indicated below. This implies that the NWU-IRERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: The psychosocial experiences of adolescents living with HIV and AIDS in Matlosana District, North West Province.																
Project Leader/Supervisor:	Dr M Maepa															
Student:	RB Mutloane															
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>3</td><td>4</td><td>1</td><td>-</td><td>1</td><td>7</td><td>-</td><td>A</td><td>9</td></tr></table>	N	W	U	-	0	0	3	4	1	-	1	7	-	A	9
N	W	U	-	0	0	3	4	1	-	1	7	-	A	9		
Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation																
Application Type: Master's																
Commencement date: 2017-02-13	Expiry date: 2020-02-13															
Risk:	N/A															

Special conditions of the approval (if applicable):

- Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HSREC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HSREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principle investigator) must report in the prescribed format to the NWU-IRERC via HSREC:
 - annually (or as otherwise requested) on the progress of the project, and upon completion of the project
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
 - Annually a number of projects may be randomly selected for an external audit.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the HSREC. Would there be deviation from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-IRERC via HSREC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-IRERC and HSREC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the HSREC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.
- HSREC can be contacted for further information via Estle.Emtoch@nwu.ac.za or 018 280 2873.

The IRERC would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the IRERC or HSREC for any further enquiries or requests for assistance.

Yours sincerely

**Prof LA
Du Plessis**

Digitally signed by
Prof LA Du Plessis
Date: 2017.02.21
16:00:55 +02'00'

Prof Linda du Plessis

Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)

APPENDIX E: Letter of Approval from North West Department of Health



POLICY, PLANNING, RESEARCH, MONITORING AND EVALUATION

Name of researcher : Ms. B. Moutloane
North West University

Physical Address _____
(Work/ Institution) _____

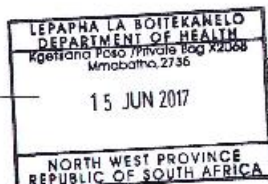
Subject : Research Approval Letter – Exploring the Psychosocial
experiences of adolescents living with HIV and AIDS in Matlosana
sub-district, North West Province.

This letter serves to inform the Researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The Researcher is expected to arrange in advance with the chosen facilities, and issue this letter as proof that permission has been granted by the Provincial office.

This letter of permission should be signed and a copy returned to the department. By signing, the Researcher agrees, binds him/herself and undertakes to furnish the Department with an electronic copy of the final research report. Alternatively, the Researcher can also provide the Department with electronic summary highlighting recommendations that will assist the department in its planning to improve some of its services where possible. Through this the Researcher will not only contribute to the academic body of knowledge but also contributes towards the bettering of health care services and thus the overall health of citizens in the North West Province.

Kindest regards,

Dr. FRM Reichel
Director: PPRM&E



15/06/2017
Date

Researcher

19/06/2017
Date

Healthy Living for All

APPENDIX F: Certificate of Language Editing



Faculty of Humanities

Department of English

18 May 2018

TO WHOM IT MAY CONCERN

CERTIFICATE OF LANGUAGE EDITING

I, Paul Nepapleh Nkamta, confirm and certify that I have read through and edited the mini-dissertation: "Psychosocial experiences of adolescents living with HIV and AIDS in Matlosana sub-district, North West province, South Africa" by Boitumelo Mutloane, student number: 16299388, submitted to the Faculty of Health Sciences, in fulfilment of requirements for the Degree of Master of Health Sciences in Clinical Psychology, at the North-West University, Mafikeng Campus.

Boitumelo Mutloane was supervised by Dr MM Maepa of the North-West University.

I hold a PhD in English Language and I am qualified to edit academic work of such nature for cohesion and coherence.

The views and research procedures detailed and expressed in the mini-dissertation remain those of the researcher/s.

Yours sincerely

Paul Nepapleh Nkamta (PhD; MA; PGCE; BA Hons)
Tel: 018 389 2895
Cell: 073 970 7514

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