

**THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS LIVING WITH HIV &
AIDS IN THE NORTH-WEST PROVINCE**

By



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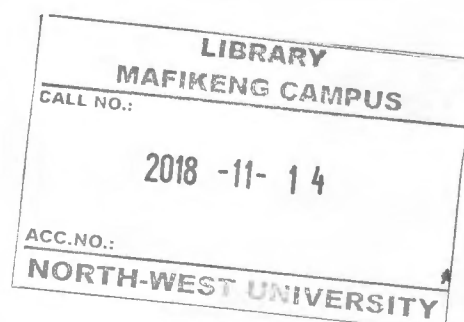
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Declaration

I, Cherise Nicolle Sander, hereby declare that this mini-dissertation for **MSOCSC in Clinical Psychology** at North West University-Mahikeng Campus hereby submitted, has not previously been submitted for a degree at this or any other University, it is my own work in design and execution, and all the material contained herein has been duly acknowledged.

Signature:

Date:

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ABSTRACT

Objectives: This study aimed at investigating the psychosocial experiences of adolescents who are living with HIV & AIDS within the North-West Province of South Africa.

Method: A qualitative methodological approach was employed, using a combination of five perinatally and horizontally infected adolescents, aged 16-19 years. Semi- structured interviews were employed to draw data from the adolescents in this study and a convenient purposive sample was employed in this study.

Results: The main themes which emerged included (1) negative experiences, (2) experiences in relation to ARVs and (3) coping strategies. The negative psychosocial experiences included sickness and pain; feelings about the participant's death, negative self-concept, poor romantic relations; fear of disclosure, social rejection, stigma and discrimination and social isolation. Experiences in relation to ARVs included positive experiences such as protecting the body and negative experiences included inconvenience, side-effects and adherence. The adolescents in this study coped through employing positive coping strategies such as self-acceptance and seeking psychosocial support.

Conclusion: In conclusion, the adolescents in this study largely identified with negative social and emotional/psychological experiences and the use of ARVs proposed both positive and negative experiences for them.

Recommendations: Individual psychological services should be customized for HIV positive adolescents with the purposes of facilitating the complicated grieving processes which this population face; to develop more positive self-constructions, and teach more effective disclosure amongst such populations. Interventions promoted at the community level as an effort to reduce stigma and discrimination from community members.

Keywords: *HIV & AIDS, Adolescents, Psychosocial experiences, Negative experiences, medication/ ARVs, Coping Strategies*

CHAPTER 1

INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 Introduction

Adolescence is a separate developmental stage of life which commences between 11 to 13 years and reaches its conclusion between 17 and 21 years (Louw, Van Ede & Louw, 1998). Travelling through the adolescence developmental life stage entails passing through dramatic and turbulent biological, psychological and social developmental changes (Louw, Van Ede & Louw, 1998; Stang & Story, 2005; Papillia, Olds & Feldman, 2007; Beksinska, Pillay, Milford & Smit, 2014). The major developmental tasks of adolescence (amongst others) include developing a personal identity, sexual exploration and possible engagement in sexual intercourse (Santrock, 2004); constructing a sense of self, (Newman & Newman, 2004) and accepting one's altered physical appearance as a result of puberty (Louw, Van Ede & Louw, 1998). These already existing complex developmental milestones of adolescence may be furthermore complicated by the HIV virus within the HIV positive adolescent.

HIV (Human Immunodeficiency Virus) & AIDS (Acquired Immune Deficiency Syndrome or Acquired Immunodeficiency Syndrome) is a medical condition which alters the immune system, making the individual much more vulnerable to infections and diseases and which may in some cases result in a patient's untimely death Nordqvist, (2016) has adapted a biopsychosocial approach which emphasizes that a combination of biological, psychological and environmental or social domains of an individual's functioning collectively work together in determining an individual's existence as an organism; similarly these dimensions should be acknowledged when attempting to understand and intervene in disease or illness (Engel, 1980). As a result of the biopsychosocial nature of HIV & AIDS, and the numerous

physical, psychological and social milestones of adolescence there may be an inevitable and unique impact of HIV & AIDS upon the lives of adolescents who are infected by this illness.

Some authors have proposed that these turbulent yet normal biological, psychological and social milestones of adolescence have been further complicated by the biopsychosocial nature of HIV & AIDS, due to issues such as stigma and discrimination, causing a unique set of psychosocial experiences for the HIV positive adolescent (Engel, 1980; Li, 2009; Bravo, Edwards, Rollnick, & Elwyn, 2010; Vranda & Mothi, 2013). Or at the least has implications upon the psychological and social domains of an adolescent's development (Brown, Lourie & Pao, 2000). While coping with the biological, psychological and social milestones of adolescence, these individuals must simultaneously cope with the additional burdens which are associated with HIV & AIDS. For these reasons this study aims at establishing an in-depth understanding of the unique experiences of the HIV positive adolescent's psychological development in the manner of how it interacts with his/her social environment (psychosocial experiences). For the purposes of this study, adolescents of the age 13-19 years who are vertically (mother-to-child-or infant infection) or horizontally (i.e. sexual activity, blood transfusion, etc.) infected will be the focus of this study.

Thus far adolescent HIV & AIDS has become an increasingly noticeable epidemic in South Africa. UNAIDS (2013) estimated that a total 320 000 of adolescents were living with HIV & AIDS in South Africa. According to UNAIDS (2014) 13 % of the world's adolescents who are infected with HIV & AIDS reside within South Africa (UNICEF, 2016). Petersen, Bhana, Myeza, Alicea, John, Holst, McKay and Mellins (2010) also state that in a country like South Africa, the psychosocial experiences of HIV-positive adolescents may be unique to more developed countries due to issues such as parental loss, the late rollout of ARVs, poverty and other negative social circumstances within this unique social context.

1.2 Problem Statements

The psychosocial impact of HIV & AIDS and the coping strategies which are used to cope with challenges amongst adolescents living with HIV & AIDS is an unexplored area of research both in South Africa and internationally (Mutumba, Baumeister, Musime, Byaruhana, Francis, Snow & Tsai 2015; Mavangira & Raniga 2015). In addition to this, Petersen et al., (2010) propose that the lack of such data on the psychosocial experiences of HIV-positive adolescents manifests itself as a barrier in the development of psychosocial support programmes as a means of improving mental health amongst HIV-positive adolescents within South Africa. In addition to this, there have been only a few qualitative studies which have been conducted within South Africa which focused on the psychosocial experiences of adolescents living with HIV & AIDS, and those which have been conducted, were administered within larger cities and have neglected to cover the psychosocial experiences of HIV positive adolescents who reside in semi-rural areas in South Africa (Petersen et al., 2010; Black, 2009; Strydom and Raath, 2005). Hence the undertaking of this study which will attempt to fill the gaps left out by previous studies.

1.3 Significances of the study

The significances of this study will be explored within the three broad areas of practical, methodological and theoretical.

Practical significance: The results gathered in this study will be used to inform psychosocial support programmes which aim at promoting psychological health outcomes amongst adolescents who are living with HIV & AIDS within the South African context and inform clinical psychologist who practices within the HIV & AIDS field in a semi-rural area.

Methodological significance: A qualitative approach was employed as this methodological paradigm aims at achieving a 'complex' and intricate understanding or meaning of real-life social or psychological issues, or problems within a real-world-setting (Creswell; 2007; Hancock, Ockelford & Windridge, 2009; Yin, 2011). Applying a qualitative approach in this study will not only close the gaps in qualitative research but will also allow for the researcher to extract deeper meanings from the data in order to more effectively understand the essence of the individual's experiences in order to effectively to develop psychosocial intervention programmes.

Theoretical significance: This data gathered in this study will additionally contribute towards closing the gaps in literature both nationally and internationally in reference to the psychosocial experiences of HIV positive adolescents within the academic field of adolescent HIV & AIDS.

CHAPTER 2

OPERATIONAL DEFINITIONS AND THEORETICAL FRAMEWORK

2.1 Operational Definitions

2.1.1 Adolescence

Seifert & Hoffnung (1987) define adolescence as the stage of development that leads a person from childhood to adulthood which begins at around age twelve and lasts until the completion of physical growth, which normally occurs at around twenty. Louw, Van Ede and Louw (1998; 384) postulate that adolescence as a separate developmental stage varies from about 11 to 13, while the age at which it ends is between 17 and 21. Louw et al., (1998) furthermore emphasize that “since the age boundaries of adolescence vary, it more acceptable to demarcate the adolescent developmental stage on basis of specific physical and psychological developmental characteristics and socio-cultural norms rather than chronological age.”

In this study, an adolescent is defined as an individual who falls within the ages of 13-19 years of age, and who is in the process of experiencing the physical, psychological and emotional and psychological milestones which are relevant to his/her age.

2.1.2 Living with HIV & AIDS

In this study HIV and AIDS refers to adolescents who have tested for HIV & AIDS and who have received a seropositive status for HIV and AIDS.

2.1.3 HIV & AIDS

In this study HIV refers to a microscopic organism which is referred to as a virus, which gradually attacks the human body's immune system, which is our body's natural

defence against illness and infections (Avert, 2015). The Human Immuno-Virus does this through the method of attacking a type of T-helper (CD-4) cells and makes copies of it (Avert, 2015). HIV is transmitted from one person to another through bodily fluids. AIDS refers to the most progressed stage of HIV, characterized by an extremely low CD—4 count. This advanced stage of HIV is indicative of an extremely weakened immune system, implying an additional reduced capacity of the immune system to fight infections, which could result in death if left untreated (Avert, 2015).

2.1.4 Psychosocial experiences

In this study, psychosocial experiences refer to those experiences which relate to one's psychological and social functioning.

2.2 Theoretical Framework of the study

2.2.1 George Engels's Bio-psychosocial model (1977)

The biopsychosocial model was developed by George Engel (1977). In Engel's capacity as a theorist, he opposed the assumptions established by the biomedical model, which he concluded as incomplete and limited in terms of the understanding and treatment of medical disease/s or illness. According to Engel (1977) the original model of health, the biomedical model postulated that medical disease or illness is solely accounted for by dysfunctional somatic processes and neglected to incorporate the individual with his/ her qualities as an individual, with his/her psychological and social dimensions of functioning when treating disease or illness within a patient and consequently apply these assumptions in the treatment or care of the patient.

Engel (1977) therefore sought the need for a more inclusive scientific medical model and established the biopsychosocial model which attempted to close these gaps in the

biomedical model. The biopsychosocial model emphasized the importance of acknowledging all biological, psychological and social dimensions when attempting to understand, care for and treat illness in human beings.

Central to this paradigm is the systemic principle which emphasizes that no phenomenon exists in isolation (Engel, 1980). Engel made reference to the basic scientific natural systems theory which was originally developed by Weiss and von Bertalanffy. According to Engel, (1980) Weiss and von Bertalanffy all observed in their capacity of scientists that the system of nature comprises of different units which occur across a continuum from the smallest and least complex unit to the largest and most complex unit (Engel, 1980). Engel (1980) identifies these units in ascending order starting with subatomic particles, atoms, molecules, organelles, cells, tissues, organs/organ systems, nervous system, person, two-people, family, community, culture, society-nation and biosphere. Engel (1980) furthermore communicates that these units are simultaneously a component of a higher unit, both a whole and part of a unit and part of a higher level unit or system. The abovementioned statements highlight the interdependent nature of these units and the fact that they simultaneously influence one another and he looked at illnesses from a holistic viewpoint. In an attempt to understand the functioning of one unit, one must understand and intervene at all the different levels of functioning. An attempt to understand natural phenomena such as diseases and illness requires an understanding of the biological (i.e. organs systems) psychological (i.e. person) and social (i.e. community) levels/units of functioning within an individual. In support of the biopsychosocial model devised by Engel (1977), this study emphasizes that the process of treating HIV & AIDS as a biological disease should also be incorporated with the psychological and social aspects of the HIV-positive patient and emphasizes the interdependent nature of biological, psychological and social factors when treating HIV & AIDS as these units all influence each other during the course of HIV &

AIDS. In order to understand and treat HIV & AIDS as a disease, both psychological and social factors should be incorporated. In attempting to understand and treat an individual who is HIV-positive, one should not only consider the biological domains of functioning, but should also consider the psychological and social units of functioning in order to effectively develop understand and intervene for the adolescent who is living with HIV & AIDS. This study hereby attempts to incorporate the psychosocial experiences of the HIV-positive adolescents as a means of treating an adolescent who is living with HIV & AIDS.

2.3 Theoretical Perspectives

2.3.1 Sigmund Freud's Psychoanalytic theory of development

Sigmund Freud's psychoanalytic theory which was developed in 1923 is a broad theory which holds numerous critical concepts which Freud regards as indispensably explicative to personality development. In this theory, Freud conceptualized three revolutionary concepts, namely (1) the structural hypothesis, (2) anxiety and defence mechanisms and (3) the five psychosexual stages of development, as crucial in the journey of human development. In Freud's structural hypothesis, he divided the human psyche into three psychic structures, each with its own set of priorities, functions and agenda (Lemma, 2003). Freud identified these structures as the Id, the Ego and the Superego. According to Lemma (2003), Freud attributes 'normal personality functioning' to the smooth interaction of psychic energy between these three psychic structures. Furthermore, Lemma (2003) states that personality challenges are a manifestation of the potential conflicts between the demands of these various structures.

Lemma (2003) furthermore elaborates that the abundance of our sexual and aggressive biological drives which we were born with are found within the Id. According to Lemma (2003) that the Id is not in touch with reality, is unamenable to the phenomenon of

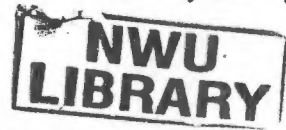
reality, morality, reasoning and logic and most importantly, its inborn and main function is to increase pleasure and reduce pain.

According to Lemma (2003), the ego is more in touch with reality as compared to the id (via the use of senses) and its purpose is to therefore acknowledge this reality without excessively employing defence mechanisms in doing so. Schultz and Schultz (2009) postulate that due to its awareness of reality, the ego assists the id in determining more socially appropriate and acceptable means of reducing the tensions built up by the id. The function of the ego is therefore to serve as a mediator between the id and reality (Lemma, 2003). Lemma (2003) additionally specifies that the ego is obligated to control voluntary thoughts and actions and is engaged with other the mental functions such as judgement, reality testing, perception, sense of time and thinking.

The superego is the psychic structure that criticizes or inhibits an individual's drives, fantasies, feelings and actions (Siegfield, 2014) and is the structure which evokes the absolute image of who we ought to be, moral principles and rules (Lemma, 2003). Lemma (2003) additionally comments that the superego criticizes if our behaviour is not acceptable or satisfactory.

Anxiety is a core concept in Freud's psychoanalytic theory. Corey (2009) defines anxiety as a feeling of dread that results from repressed feelings, memories, desires and experiences that emerge on the surface of awareness and can be considered a state of tension which motivates us to do something. When the ego experiences feelings, thoughts and desires which threaten or overwhelm it or it experiences this anxiety as traumatic, it may employ a wide range of defense mechanisms which are aimed to assist the ego in reducing this traumatic anxiety and danger through distorting reality (Schultz and Schultz, 2009; Corey, 2009). Although defences can be used to assist in reducing psychological and emotional pain

and trauma, Corey (2009) emphasizes that the excessive use of defences by the ego may prevent the individual from facing reality.



In addition to this, Corey (2009) furthermore states that the type of defenses which are employed by an individual are dependent upon the individual's degree of threat or anxiety and the level of their development. Many HIV-positive adolescents may experience trauma as a result of being diagnosed with a life-threatening illness such as HIV & AIDS. This trauma is similar to that experienced by those who have lost a parent due to the disease. Such experiences may be so painful and consequently require ego defense mechanisms to assist him/her in coping with the emotional or psychological pain of these experiences. Maswikiti (2010) states that during the stage of late adolescence, the adolescent realizes that aspiring to be an ego ideal is an incessant process which is paramount in their development. She additionally elaborates that the end of this phase is also the emergence of stable character formation which can be achieved by meeting distinct developmental challenges, dealing and coping with traumatic experiences, being able to accept one's past and being able to move forward and have a future (Maswikiti, 2010). However, this can be difficult if defence mechanisms prohibit such a process from taking place.

The third significant concept of Freud's theory refers to his identification of the psychosexual stages of development. In Freud's view, sexual instincts are present from birth, which led him to develop these psychosexual stages (Lemma, 2003). Freud identified these stages as the oral, anal, phallic, latency and genital psychosexual stages of development. Lemma (2003) additionally states that at each of these stages our psyche directs this libidinal energy to a specific area of the body which serves a pleasure.

Hefner (2015) states that it is during this stage that an individual's psychic energy is focused on the genitals with the primary focus of attaining pleasure at this part of the body.

This need to attain sexual pleasure at the genital areas is likely to initiate interest in sexual relationships, sexual exploration and/or sexual intercourse in most adolescents, which in most cases occurs with peers of the opposite sex. A study conducted by Marteleto, Lam and Ranchodd (2008) revealed that most adolescents in urban South Africa are sexually active whilst still enrolled in high school. Considering the fact that the adolescent exhibits a natural interest/ inclination towards sexual exploration may impose challenges for the adolescent who is living with HIV & AIDS for various reasons.

Considering the fact that HIV & AIDS is a sexually transmittable disease would impose various complications on the standard sexual developmental milestones of adolescence. Firstly, the adolescent may experience difficulty in disclosing their HIV-positive status to an actual or prospective romantic or sexual partner because he or she may fear the possibility of experiencing rejection. Secondly these adolescents may also withdraw or postpone any romantic or sexual involvements as a result of the fear or risk which is associated with infecting a romantic or sexual partner when making physical contact with him or her.

2.3.2 Chaudoir and Fischer's (2010) Disclosure Processes Model (DPM)

The disclosure processes model posits that the process of disclosure (particularly for the individual with a strongly stigmatized identity such as HIV and AIDS) is multi-layered and complicated (Chaudoir and Fischer, 2010). This is largely derived from the basis that disclosure may yield either favourable (i.e. social support) or unfavourable outcomes (i.e. social rejection or discrimination). These processes include (1) antecedent goals, (2) the disclosure event itself, (3) mediating processes, (4) outcomes, and (5) the feedback loop (Chaudoir & Fischer, 2010). These processes all work intricately and hand in hand in

determining whether disclosure will or will not be of benefit to the discloser (Chaudoir & Fischer, 2010).

In addition to this, this model advances early disclosure theories through emphasising the importance of delineate two types of motivations (namely approach versus avoidance motivations). According to Chaudoir and Fischer (2010) these models considerably influence the discloser's decision to disclose at each of the abovementioned stages.

These 5 processes will be briefly described below:

1. Antecedent goals: Chaudoir and Fischer (2010) mention that antecedent goals may affect what happens later in the disclosure process. Disclosure is a goal-directed behaviour in which individuals have a wide range of goals and people will disclose only when they perceive disclosure to be an effective tool in obtaining their specific goal of interest (Chaudoir & Fischer, 2010). The individuals will then consider whether disclosure is appropriate for the purpose of attaining these specific goals.
2. Disclosure event: according to Chaudoir and Fischer (2010), characteristics such as the 'depth and breadth of information disclosed', the time span taken to disclose the identity, the method of disclosure used (face-to face conversation, email, etc.) and the depth of private information disclosed during the event may affect how the actual event goes down and how the confidant may react (Chaudoir & Fischer, 2010). For example, disclosers who may reveal extensive private or sensitive information during their first meeting with their confidants may provoke feelings of discomfort from their confidants, which may also cause the confidant to respond by displaying feelings of hostility towards the discloser (Chaudoir & Fischer, 2010). The discloser is then likely to sense such hostility and may in return refrain from disclosing information any further (Chaudoir and Fischer, 2010). In essence, both the confidant and discloser can influence one another's reactions during the disclosure event.

3. Mediating processes and outcomes will be explained together in this theory. According to Chaudoir and Fischer (2010) the three mediating mechanisms (the alleviation of inhibition of a stigmatized identity, social support and changes in social information) are likely to affect outcomes across three areas of functioning (the psychological, behavioural and physiological areas of functioning). Although these authors postulate that although concealing a stigmatized identity can have either negative or positive or both effects for different individuals of functioning (i.e. psychological), they furthermore elaborate that concealing a stigmatized identity may be more beneficial (or have more beneficial outcomes) for the psychological functioning of some individuals (i.e. one's who possess avoidance focused goals) as compared to others (i.e. those who possess approach focused goals). For instance Chaudoir and Fischer (2010) state that because individuals with avoidance focused goals possess avoidance motivational systems which are chronically active, they are more inclined to repress information to avoid recurrent intrusive thoughts which in turn cause them psychological stress.

4. Feedback loop- ultimately, the DPM views disclosure events as an perpetual process of manipulating stigma, therefore the experiences of previous disclosures affect the likelihood of an individual to disclose or not to disclose again (Chaudoir & Fischer, 2010). For example, if an individual's disclosure event elicited negative outcomes such as discrimination, rejection, etc., this result may decrease the likelihood of the individual disclosing any information regarding their stigmatized identities in the future (Chaudoir & Fischer, 2010).

Chaudoir and Fischer (2010) elaborate that individuals who possess stronger culturally stigmatized identities such as HIV & AIDS are less likely to benefit from disclosure due to the potentially high possibility of negative social treatments such as stigma, discrimination and rejection. These individuals may consequently be aware of the high risk

of potential rejection, stigmatization and discrimination which may occur against them, preventing them from disclosing their HIV status (Chaudoir & Fischer, 2010).

2.3.3 Carl Rogers's person-centred theory (theory of the self-concept)

According to Rogers, all human beings possess a strong, fundamental, inherent tendency (self-actualization) which entails striving to do the best for ourselves regardless of the challenges which we are faced with (Rogers, 1951; Casemore, 2011). This inherent tendency can however be either built or destroyed based on the interactions which we receive with the environment, i.e. specifically significant others.

A central component of Roger's theory is the self-concept, which he emphasizes is largely determined by an individual's interaction with his/her environment. Central to an individual's feelings sense of worth and self-concept is the phenomenological condition of "unconditional positive regard". Rogers (1957) defines unconditional positive regard as the acceptance of an individual's bad qualities, attributes and downfalls in a similar manner in which he or she may accept the good attributes of an individual. This demonstrates acceptance of an individual, regardless of their shortcomings. When an individual receives unconditional positive regard from their environment, this automatically increases their own self- regard, sense of worth and self-concept and self-acceptance, regardless of shortcomings which he/she possesses as an individual (Iberg, n.d; Wilkins, 2000). However, in instances wherein the individual receives conditional positive regard or acceptance (acceptance only when he/she meets "good", the individual will only learn to love oneself if he she meets the standards which are set by the significant other/s, rather than when the individual actually actualizes his/her actual potential), he or she internalizes or incorporates the values which significant others place on him/herself, whether negative or positive and their self-concept is determined by values which outsiders place on the individual. So where *conditional positive*

regard is given, the individual's sense of worth is determined by the input which he/she receives from others and not determined by him/herself (incongruence) making him/her more likely to develop partial self-acceptance and a poor self-concept.

Individuals who are living with HIV & AIDS and who do not receive unconditional positive regard from others but rather receive negative feedback from individuals in their environment such as stigma, discrimination rejection, and teasing are more susceptible to develop negative self-concepts through the negative feedback which they receive from these individuals. They also base their self-concept on this feedback from the environment.

2.3.4 Elisabeth Kubler-Ross stage theory of grief

Dr Elisabeth Kubler-Ross (1969) formulated a theory of grief which aimed to highlight the emotional and psychological responses which individuals experience in relation to loss in general. According to Kubler-Ross, individuals who experience loss go through the psychosocial stages of denial, anger, bargaining, depression and lastly acceptance (Sanchez, 2007). Although these stages are identified in the abovementioned order, they may not necessarily be experienced in this stringent order, as some stages may pass others or be omitted.

Denial, which is the first psychological reaction of the patient, functions as a psychological defense mechanism to assist the individual to cope with the emotional pain and shock and protects the individual against experiencing overwhelming feelings (Snyder, n.d). Sanchez (2007) furthermore states that anger is usually a substitute for denial. When denial cannot be maintained any longer, it is replaced with feelings of anger, envy, resentments and rage (Kubler-Ross, 1969). Synder (n.d) states that anger may be indicative of the commencement of the acknowledgement of reality. Kally (2015) describes bargaining as trying to make a deal with a higher power as a result to resolve or reverse the situation or

loss. Upon realizing that the bargaining and anger will not reverse the loss, the individual will sink into depression (Patricelli, 2016). Patricelli (2016), specifically highlights that depression is the initial realization that the loss or inevitable event is irreversible and it is during this stage that the individual may experience symptoms such as feelings of hopelessness, changes in eating or sleeping habits, withdrawal from relationships, crying, etc. The final stage, which Kubler-Ross demarcated as “acceptance”, will occur once the individual has processed their initial grief emotions, is able to accept that the loss has occurred and cannot be undone, and are once again able to plan for their future and re-engage in daily life (Patricelli, 2016). Sanchez (2015) additionally emphasizes that external signs of contentment such as smiling and laughing during this stage should not be mistaken for happiness and the individual is not okay with the loss. However, they have accepted the permanent reality of fate or the future (Sanchez, 2015). Van Vliet (2013) emphasizes that, after some time, the individual will resume taking up other activities again and fit back into their daily schedules.

This theory has implications for adolescents who are living with HIV & AIDS. Firstly these stages are significant in understanding the emotional and psychological processes which an HIV-positive individual may pass through after learning about his/her HIV-positive status. Secondly Maswikiti (2010) mentions that these stages should show that death is not imminent for the HIV-positive individual, however understanding how the individual is living after accepting his or her HIV positive diagnosis is important in a study of this nature.

2.3.5 Lazarus and Folkman’s transactional model of stress, appraisal and coping

This model was developed to demonstrate how stress, appraisal and coping theories were combined to explain how individuals respond to circumstances which are psychologically taxing. Lazarus reconstructed a psychological model of stress through

building on Seyle's physiological model of stress and defined stress as a relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources (Lazarus & Folkman 1986).

Central to this model is the concept of appraisal. Lazarus and Folkman (1984) described two types of appraisals. These are the primary appraisal and the secondary appraisal. Matthieu and Ivanoff (2006) describe a primary appraisal as one's evaluation of the amount of harm or danger which a situation or event may impose on his or her welfare and furthermore describe a secondary appraisal as one's estimation of his or her personal capability to manage the stressful circumstance. Matthieu and Ivanoff (2006) continue to elaborate that meanings and feelings are produced as a result of appraising the actual stressful event or circumstance which consequently produces a cognitive or behavioural reaction which is aimed at reducing the gap in between an individual's perceived circumstantial demands and his or her personal resources. These actions or reactions are referred to as coping strategies. Lazarus and his colleagues thereafter differentiated eight categories of coping strategies which included confrontative coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, problem-solving, and positive reappraisal (Krohne, 2002).

Furthermore Lazarus (1999) additionally states that an individual employs coping strategies in one of two ways, by problem-focused coping, which is actively or behaviourally altering the external person–environment relationship, or emotion-focused coping, which is altering the personal or internal meaning or relationships. Lastly Lazarus postulated that individuals may use these coping strategies to behaviourally modify the relationship between the individual and his or her environment (problem-focused coping) and / or to modify his or her personal meaning or relationship (problem-focused coping) (Lazarus, 1993; Matthieu & Ivanoff, 2006). Adolescents who are infected with HIV & AIDS may be predisposed to

numerous stressful and challenging situations as a result of the negative experiences and psychosocial complications which are induced as a result of a HIV-positive diagnosis. Applying effective coping skills is very important amongst this group of individuals as an attempt to assist them in successfully coping with the burdens of HIV & AIDS.

CHAPTER 3

LITERATURE REVIEW

3.1 Introduction

The following literature review probes the psychosocial experiences of adolescents living with HIV & AIDS globally. It specifically focuses on both positive and negative psychosocial experiences of adolescents, their experiences in relation to medication (ARVs) and the coping mechanisms employed by adolescents living with HIV & AIDS.

3.2 Literature Review

Psychosocial experiences include amongst others identity, disclosure, stigma and discrimination, self-concepts, emotional and psychological experiences.

Research has demonstrated that among the psychosocial experiences of HIV-positive adolescents have been the death of one or both biological parents (Black, 2009; Petersen et al., 2010; WHO, 2014; McClearly-Sills, et al, 2014). Many of these findings were established within the South African context and furthermore revealed more specific emotional and psychological experiences within the theme of parental loss such as emotional pain (Petersen et al, 2010); isolation within the process of grieving parental death and insufficient time to effectively grieve the death of a parent as a result of HIV & AIDS, inevitably leading adolescents to being trapped in the process of grieving (McClearly- Sills, Kanesathasan, Brakarsh, Vujovic, Dlamini, Namisango, Nasaba, Fritz, Wong & Browsky, 2013; Black, 2009). Ramjohn (2012) who investigated the progress involved in identity exploration amongst a sample of HIV-positive youth within New York reported that a large portion of this sample delayed their identity exploration processes with the intent of making sense of their HIV-positive diagnosis (Ramjohn, 2012). This author furthermore reported that most of

these adolescents possessed poor self-concepts (Ramjohn, 2012). In contrast to these findings, a Canadian study conducted by Risio, Ballantyne, Read and Bendayan (2011) revealed that adolescents expressed more positive self-constructions. In addition to positive self-concepts, a strong sense of resilience appeared to be a common theme amongst a group of adolescents who resided within South Africa, regardless of their HIV diagnosis (Black, 2009).

Stigma and discrimination appear to be prevalent amongst adolescents who are infected with HIV & AIDS (Strydom & Raath, 2005; Midtbo, 2012; Dube & Ross, 2012; Gachanja, 2015; Mburu, Ram, Oxenham, Haamujompa, Iorpeda, & Ferguson, 2015). Authors Deacon and Stephney (2007) suggest that some respond to stigma through internalizing it and concur with the negative perceptions which other people hold towards them. This form of stigma (internalized stigma) appeared to be prevalent amongst a sample of Zambian adolescents who were living with HIV & AIDS (Mburu et al., 2014). Stigma and discrimination also appear to have a negative impact upon disclosure processes amongst HIV- positive individuals.

Amongst other psychosocial experiences, self-disclosure is an integral part of living with HIV & AIDS, however, it has been identified as one of the most challenging components of having HIV & AIDS both by individuals who are HIV-positive and their health care providers (Leonard, Markham, Bui, Shegog and Paul, 2010; Thoth, Tucker, Leahy & Stewart, 2014). Disclosing one's HIV-positive status as an adolescent or young person is highly significant as it yields more positive outcomes such as social support and assists in the task of combatting new HIV infections (Chaudoir & Fischer, 2010; Thoth, Tucker, Leahy & Stewart, 2014). More specifically, from a developmental perspective, Wiener and Battles (2006) state that the task of self-disclosure may be most challenging during adolescence as it is during this life-stage that the individual is most sensitive to rejection. Mutwa, Van Nuil,

Asiimwe-Kateera, Kestelyn, Vyankandondera, Pool, Ruhirimburu, Knakuze, Reiss, Geelen, Van de Wijgert & Boer (2013) report that adolescents in Kigali, Rwanda faced difficulties in disclosing their HIV status, as they fear that disclosing their status would solicit stigmatization. In addition to this Galano, Turato, Delmas, Cote, Gouvea, Succi and Machado, (2016) confirmed this notion through stating that disclosing one's HIV-positive status appeared to be a major hurdle to the majority of adolescents who participated in their study. These authors specifically cited factors such as a lack of courage, potential feelings of discomfort, embarrassment and the potential risk of being rejected as common reasons behind the participant's disclosure difficulties (Galano et al., 2016). In some instances, the challenges related to disclosure may even extend into the romantic and sexual domains of life of an individual living with HIV & AIDS (i.e. disclosure to a romantic partner or sexual partner). This hypothesis was confirmed in a study conducted by Ferrand, Miller & Jungman (2007) who reported that among HIV-positive adolescents in relationships, the task of disclosure to a partner occurs as a major hurdle to adolescents most of the time. In agreement with these finding, Childs and Maxwell (2009) who explored the sexual practices amongst a group of HIV-infected adolescents in the United States also reported that most adolescents experienced difficulty in disclosing their HIV status to their sexual partners. The fear of being potentially rejected and the fear of the potential negative reactions which these adolescents anticipated prevented them from disclosing their status. Similarly, other HIV-positive adolescents report non- disclosure of their HIV status due to the fear of possible abandonment and negative responses from their confidants (Mburu et al, 2010).

In addition to this, HIV-positive adolescents are confronted with numerous and significant difficulties which impact their decisions related to their sexuality (Childs & Maxwell, 2009). An interesting Canadian study which identified the experiences of HIV-positive adolescents within a supportive environment revealed that, regardless of the support

which this group received, they still anticipated future difficulties in disclosing their HIV status to a prospective romantic or sexual partner due to the possibility of being rejected or ostracized by them (Risio, Ballantyne, Read & Bendayan, 2010). Risio et al., (2010) furthermore report that these adolescents in their study additionally experienced feelings of fear and guilt about potentially infecting a sexual partner in the future. Most perinatally infected adolescents in the U.S.A furthermore experienced a difficulty in the task of mediating condom use amongst sexual partners (Childs & Maxwell, 2009). An additional experience described by this group of adolescents included the delay in the initiation of sexual activity as a result of the fear of infecting a potential partner (Childs & Maxwell, 2009). Common themes which appeared included a concern about infecting a sexual partner and difficulties in initiating relationships due to a fear of being rejected by a romantic partner due to their HIV-positive status (Hosek, Harper and Domanico, 2000). Galano et al., (2015) report in relation to deciding which romantic partners could be trusted with information regarding their HIV-positive status. These authors furthermore reported difficulties in establishing when would be the most appropriate time to disclose their HIV-positive status to a partner. These authors furthermore reported the principle difficulties in this study were linked to fears of abandonment and prejudice and the view that the confidant might breach confidentiality after disclosing their secret. Hindrances around engaging in both sexual or romantic relationships and activities such as dating as a result of ones HIV status has been a common phenomenon in a study amongst HIV positive adolescent clinic attendees in the United States (Childs & Maxwell, 2009).

Kang, Mellins, Kee, Robinson, & Abrams (2008) proposes that establishing autonomy as an adolescent who is living with HIV & AIDS is difficult. Some studies have demonstrated that adolescents who are living with HIV & AIDS experience severe feelings of anxiety, uncertainty and pessimism regarding their future (Punpanich, Detels, Gorbach and

Leowsrisook, 2008; Ramjohn, 2012; Li, 2009 & Li et al, 2009); trauma (Brown, Lescano & Laurie, 2001; Radcliffe, Landau, Hawkins, Tanney, Kasam-Adams, Ambrose & Rudy, 2007); depression (Brown, Lescano & Laurie, 2001; Strydom & Raath, 2005; Vilsteren, Haffeejee, Patel & Bowman, 2011; Mutwa et al., 2013) and aggression (Vilsteren. et al., 2011; Beyers & Nkoane, 2012) and experiences of physical and sexual abuse (Martinez, Hosek & Carleton, 2009; Kadivar, Garvie, Sinnock, Hestony & Flynn, 2006; Nugent, Brown, Belzer, Harper, Nachman & Naar-King, 2010). In contrast to the previous findings, Li et al., (2009) reported that some adolescents do possess positive views in relation to their futures, which comprise of general feelings of happiness (Li et al, 2009 & Gachanja, 2015). Gachanja (2015) furthermore cited acceptance of their HIV-positive status as a positive experience amongst HIV-positive adolescents in Kenya.

On the other hand, Ramjohn (2012) who conducted a qualitative investigation on the identity process amongst a group of female adolescents infected with HIV & AIDS in the United States of America established a significant portion of this sample experienced feelings such as 'hopelessness and devastation' about their HIV diagnosis, which consequently prevented them from thinking and planning for their future (Ramjohn, 2012). Bullying (Li., 2009); rejection (Punpanich, Detels, Gorbach & Leowsirook, 2008) and poor scholastic performance (Maswikiti, 2010) are also experiences which were identified amongst HIV-positive adolescents.

Medication as a general phenomenon is a central part of the life of any individual who is living with HIV & AIDS including adolescents. Good medication adherence has been noted amongst some teenagers who are HIV- infected (Lawan, Amole, Jahan & Abute, 2015; Gachanja, 2015), while some adolescents experience difficulties in adhering to the rigid medication regimes (Hosek, Harper & Domanico, 2000; Ledlie 2001; Chandwani, Koenig, Sill, Abramowit. Conner, & Dangelo, 2012; Merzel, Van Devanter and Irvine, 2008). Studies

have demonstrated that the ramifications of ARVs extend into the psychosocial realms of adolescents functioning (Patel, Kassaye, Gore-Felton, Wyshak, Kadzirange, Woelk, & Katzenstein, 2009; Agwu & Farlie, 2013). ARVs have been noted to induce several inconveniences amongst HIV-positive adolescents. Gachanja (2015) who measured the experiences which adolescents had faced after learning their HIV statuses in Nairobi, Kenya, reported that ARVs have been cited to interfere with the everyday lives of most adolescents in this sample. Similar to these findings, authors Galano et al., (2016) state that having a HIV-positive diagnosis and using ARVs prevented most adolescents from engaging in social activities with friends such as attending parties and engaging in other social activities with their peers.



Other forms of inconveniences which are manifested from ARVs include unpleasant physical side effects which include amongst others nausea, stomach aches and fatigue have been cited in numerous studies (Maswikiti, 2010; Gachanja, 2015; Galano et al, 2016). In some instances, these unpleasant physical symptoms have progressed to more serious illnesses which sometimes resulted in hospitalization amongst South African adolescents who were HIV-infected (Maswikiti, 2010). This study furthermore revealed that ARVs also improved the health of adolescents and provided them with hope and a sense of security in relation to their health and allowed them to focus on pursuing other life goals which were not related to HIV & AIDS (Maswikiti, 2010).

Coping strategies are an integral part of the lives of HIV-positive persons due to the numerous taxing and negative psychosocial experiences. Matthieu and Ivannoff (2006) define coping as the constantly changing cognitive and behavioural efforts to manage specific demands that are appraised as potentially taxing or exceeding a person's resources. According to Salama, Morris, Armistead, Koenig, Demas, Ferdon., & Bachanas (2013) coping mechanisms can be divided into two broad categories which include positive and

negative coping strategies. Positive coping mechanisms include active attempts to adjust or change the stressor or its meaning (Pearlin and Schooler as cited in Salama et al., 2013). Salama et al (2013) furthermore identify positive coping mechanisms such as problem-solving, seeking social support and cognitive restructuring. These authors furthermore describe negative coping mechanisms as those which do not directly address the stressor Dempsey (as cited in Salama et al., 2013) and include engaging in activities which will distract oneself, directing blame to others, and wishful thinking (Blaauwbroek as cited in Salama et al, 2013).

Literature has revealed the use of coping mechanisms such as social support (Petersen et al, 2010; Mutwa et al., 2013; Mburu et al., 2014); medication (Petersen et al., 2010; Mutumba et al., 2013); avoidance, distraction (Mutumba et al., 2015); praying, being close to someone you care about, sleeping, trying on your own to deal with problems, engaging in sedentary activities (Lewis & Brown, 2002) amongst adolescents who were living with HIV & AIDS in dealing with the emotional, psychological and physical demands of the illness.

The literature in relation to the psychosocial experiences of HIV positive adolescents has revealed to have neglected to distinguish more specific differences in psychosocial experiences amongst males and females. There also appears to be less in-depth literature in relation to specific phenomenon such as sexuality, dating and self-esteem amongst HIV positive adolescents. Furthermore the data/studies which focused on the challenges or negative experiences of adolescents appeared to have outweighed the studies on the more positive psychosocial experiences of HIV positive adolescents.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 Research Approach

A qualitative research method was employed in this study. Qualitative research aims at “providing an in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstances, their experiences, perspectives and histories” (Ritchie and Jane, 2003; p. 4). A qualitative research method was employed in this study, considering the fact that the aim of this study was to investigate or establish the experiences of adolescents who are living with HIV and AIDS in the North-West Province.

4.2 Research Design

A phenomenological research design was employed in this study as to allow the researcher to thoroughly explore the psychosocial experiences of the five adolescents who are living with HIV and AIDS in this study.

4.3 Sampling and Participants

Although the researcher aimed at using eight adolescents for this study, only a number of five adolescents were used as a result of the difficulties which the researcher had in accessing this group of adolescents. The researcher chose to employ a convenience sample due to time constraints and recruited participants according to their availability and accessibility which was through community workers who were already in contact with this sensitive group of individuals. During the recruitment process, some of the adolescents who the researcher had intended to use were difficult to locate as they had moved to other places

and were difficult to trace. The researcher did however, attempt to recruit other participants who met the criteria for participation in the study; however this group of individuals appeared to be very scarce, unless the researcher approached hospitals and clinics. This process was impossible due to the complicated, time consuming procedures, particularly concerning consent which was required to use participants from hospitals and clinics within the South African context and due to the limited time constraints which the researcher had. However, other studies within this same area of study and in related areas within the South African context also employed a small number of participants within their qualitative studies. These studies include the works of Jenna, (2014) who conducted a study which was titled 'exploring the lived experiences of adolescents living with vertically acquired HIV'. In her study, Jenna (2014) used a sample of five participants. In addition to this study, in another study conducted by Maswikiti (2010) which was titled: "Antiretroviral treatment adherence in South Africa: An adolescent perspective," a total number of six adolescents who were infected with HIV & AIDS were interviewed to draw findings about this topic.

Ultimately the entire sample comprised of 5 participants. The sample consisted of a mixed sample of perinatally and horizontally infected adolescents (3 African, Setswana speaking females, 1 African, Setswana speaking male and one Coloured, English speaking male). Some of them were orphaned and others were not. The adolescents who participated in the study varied from the ages of 16 years to 19 years with a mean age of 17 years and 8 months. This placed the sample at a stage of late adolescence. The participants in this study were purposively sampled. Perinatal HIV infection refers to the direct transmission of HIV from a mother to the embryo, foetus, or baby during pregnancy, child-birth or breastfeeding. Horizontal HIV infection refers to the acquisition of HIV through any non-mother- to – child routes of transmission which occur through numerous modes of contact such as sexual

intercourse; sharing a needle or exposure to semen, vaginal fluid, or blood of an HIV-infected partner.

Tongco (2007) states that the purposive sampling technique, also called judgment sampling, is the deliberate choice of an informant due to the qualities the informant possesses. The inclusion criteria for participants for this study were:

- Adolescents who fell within the age range of 13-19 years.
- Received a seropositive status for HIV & AIDS.
- Resided within the Mafikeng area within North-West Province in South Africa.

4.4 Procedure

The process of recruiting participants began once the researcher attained ethical clearance for the study. At the initial stages of recruiting the participants, the researcher did not approach the adolescents directly as this might have exposed the HIV-positive status and identities of those adolescents who wished to keep their status a secret. The researcher approached community workers and one non-governmental organization who had already established contact with adolescents. These agencies thereafter referred adolescents who had met the criteria for participation in the study to the researcher.

As such, the researcher met with the NGO manager; the support group leaders and community workers and requested them to inform the adolescents about the study on behalf of the researcher. The N.G.O is was institution which belongs to a larger religious affiliation within the Mafikeng region. Amongst other humanitarian services, this institution provides psychosocial care to numerous children, adolescents and adults who are living with chronic illnesses such as HIV & AIDS, high-blood pressure, sugar diabetes, etc. out. Amongst other psychosocial services provided by the N.G.O are those of providing psychoeducation of

various chronic illnesses, providing home-based care and meals to their attendees on an out-patient care basis. The adolescents who were part of the N.G.O had attend these services every fourth-night. The adolescents who volunteered to participate in the study then contacted the researcher telephonically and a follow up meeting was arranged and conducted where the researcher explained the purpose, rationale and conditions of participation in the study and informed consent was obtained verbally. Face-to-face meetings were arranged prior to the data collection process where the purpose and nature of the study was explained more intricately. This also provided the participants with the opportunity to ask any questions which they had which related to the study. During this process, the adolescents were also ensured of their choice to withdraw from participation in the study at any point of the study. Confidentiality and anonymity were also maintained through omitting the names of the participants during the process of the study, analysis and the final research document. Informed written parental consent was also attained from the guardians/parents of the two adolescents who were under the age of 18 years and informed consent was also attained from the adolescent themselves.

4.5 Data Gathering

In this study, semi-structured, in-depth interviews were employed as a means of obtaining a comprehensive and in-depth understanding of the psychosocial experiences of the sample of adolescents who are living with HIV and AIDS. A topic guide was also used as a means of exploring the areas of relevance to the study. Although a topic guide was employed to guide the researcher, the structure of the interview remained flexible as it permitted the adolescents to introduce new areas of discussion which were most relevant to the adolescent's experiences at that particular time (yet which were still relevant to the study). In addition to this, the topics for discussion were also discussed in a manner which was most

suitable for the adolescent, to allow their responses to be fully probed and to allow the researcher to be responsive to relevant issues raised spontaneously by the interviewee (Jane & Ritchie, 2003). The interviews which were conducted with the participants from the NGO were conducted at an office within the NGO centre on the days when the adolescents met for their weekly support groups while the interviews with the other adolescents were conducted in a common venue which was convenient for the participant. A voice-recorder was used to record the interviews during the interview process.

A total of two interview sessions were conducted with each participant. The rationale behind this was that the researcher used a large portion of the first session to establish a rapport with the adolescents and used the remaining duration of the first session and the second session to explore more in-depth issues relating to the study. The interval between the first and second session with each participant did not exceed one week. At the end of every session, snacks and refreshments were made available for each participant.

4.6 Data analysis

A thematic content analysis technique was utilized to analyse data in this study. This approach was chosen as it allowed the researcher to interpret the results of the study in a way which highlighted the deeper meanings or essences of the experiences of the adolescents who are infected with HIV and AIDS in the North-West Province of South Africa. The analysis for this study was conducted manually.

The process of analysing data was guided by Braun and Clarke's (2006) model of thematic analysis. The researcher began familiarizing herself with the raw data through the process of immersing herself in the data. This was carried out through the act of repeatedly reading through the raw data in a way which elicited interpretation and establishing the meanings which underlie the data extracts (Braun & Clarke, 2006). Formal codes were

thereafter marked on the raw data extracts and were thereafter divided into broader themes. The act of transforming codes into themes involves determining how the available themes can be amalgamated/ integrated to form overarching themes (Braun & Clarke, 2006). These themes were furthermore divided into themes and sub-themes. Once this was done, these themes were then reviewed and named (Braun & Clarke, 2006).

4.7 Ethical considerations

The researcher received ethical clearance from Human Research Ethics Committee of the North-West University (NWU-00436-15-A9).

Ethical Guidelines in reference to conducting research with HIV-positive adolescents within the South African context are as follows:

The ethical considerations in relation to autonomous and parental informed consent in this study were founded on the principles of the Human Sciences Research Council of 2009 which state that every person younger than 18 years requires a legal guardian to assist them with decisions with legal consequences, such as consent to research participation. In addition to this, Singh, Karim, Karim, Mlisana, Williamson., Gray and Govender, (2006) state that even though ethical review committees in other countries have renounced the requirement of parental consent for adolescents who participate in research and who are under the age of 14 years, ethical review committees in South Africa remain uncertain and dubious about the act of renouncing parental consent for adolescents who are 14 years of age, and even as old as 17 years of age. Singh et al (2006) furthermore mention that a complication in the South African context is a guideline by the South African Medical Research Council (MRC) research ethics guidelines who authorize the age of 14 as the autonomous age of consent for therapeutic research in instances where the research may not induce any physical and psychological harm to the adolescent (Singh et al, 2006). In keeping within the parameters of safety in the

abovementioned regulations in relations to conducting research amongst adolescents in South Africa, the researcher in this study required all participants (adolescents) who were under the age of 18 years to attain informed parental consent.

Written and verbal informed consent to recruit adolescents from the centre/ N.G.O study was sought and granted by the director of the Non-profit Organization before the researcher began the recruitment process. Written informed consent was also sought from the guardians and parents of adolescents who were under the age of 18 years before any interviews took place.

The researcher also explained the purpose, significance and implication/risks for participation in the study to the N.G.O director. Topics which raised sensitive issues, were addressed through asking clear and direct questions, so that the participants were not drawn through ambiguity or confusion into subjects they would prefer to avoid (Ritchie & Lewis, 2003). During the process of obtaining informed consent from the adolescent, the purpose of the study was explained to each adolescent. The sensitive nature of the research was explained to the adolescents including the type of topics which would be discussed during the interview process (e.g. exploring the loss of a parent, stigmatization, how the illness was acquired, etc.) to ensure that participants were aware of the emotional risks which could occur through participating in the study. This was done so that the adolescents were not deceived by the nature of the research conducted. The adolescents were also assured that the information which was collected during the study would be used for the sole purpose of research, and no other purposes. It was made clear to the adolescents at the stage of recruitment and obtaining informed consent that their participation in the study was completely voluntary and that he or she would be able to withdraw from the participation at any time during the course of the study. This included providing them with information

about the purpose of the study, who the research team is, how the data will be used, and what participation will require of them.

As a means of ensuring anonymity amongst the participants of the study, the names of the participants were omitted during the process of data analysis and in the final research report. The researcher furthermore maintained confidentiality of the participants through omitting comments or characteristics of the participants which could make them identifiable to the public through disclosing any information in the interviews such as place of residence, family dynamics, and other unique identifiable characteristics.

The researcher also ensured that transcribed data obtained in the study was well secured. The voice recorder which was used to record the interviews and transcribed interviews was well secured by the researcher who alone had access.

Due to the sensitive nature of this study, careful consideration was given to the ways which may protect the adolescent from experiencing any harm which may have manifested as a result of the sensitive topics discussed during the research process (interview process). Participants were given a clear understanding of the issues which the study addressed before being asked to participate in it (Ritchie & Lewis, 2003). The researcher also used her judgement to delineate what is and is not relevant and must avoid prurient or irrelevant detail for each participant during the interviews (Ritchie & Lewis 2003).

During the interview process, the researcher engaged with the participants in a manner which was sensitive to the well-being of the participants.

The permission to use a voice recorder during the interview process was also sought and obtained from the participant's during the process of obtaining informed consent and the participants were informed that these recordings and transcriptions of the study would be safely secured by the researcher.

During the process of recruiting the participants, the researcher did not approach the participants directly as this would have exposed the adolescent's HIV positive identity to the researcher without their consent. In this instance, the researcher however approached community members who were aware of any adolescents who met the inclusion criteria for the study and then introduced them to the study, making the participation voluntary and it also protecting the identity of the prospective participants. Community workers were provided with the information of the study and there-after divulged this information to adolescents who they knew who had met the study criteria. Those adolescents who were interested in the study and consequently volunteered to participate in the study communicated such to the community workers who thereafter provided the researcher with the participants contact numbers with the permission of the participants. The community workers were not part of the N.G.O, but where individuals who were known within a specific community who took personal responsibility in caring for children and adolescents who were orphaned and were struggling with social problems. These community workers where recommended to the researcher by a secondary source. The names and identities of the participants were at no point in time communicated by the community workers to the researcher, but this was divulged by the participants themselves once telephonic contact was established between the researcher and participant. Direct contact to the participants, without volunteering to participate would have been a breach of their confidentiality regarding their HIV-positive identity. Hence only once the participants who indicated a desire to participate in the study were contacted by the researcher.

CHAPTER 5

FINDINGS

5.1 Background overview of the study

Although the researcher had planned to include eight participants (four males and four females), in the end individual interviews were conducted with five HIV-infected adolescents around Mahikeng, two males and three females. The adolescents were from two race groups, one colored and four blacks. The adolescent's age ranges from 16 to 19, categorizing them under late the adolescence developmental stage. Three participants contracted HIV perinatally while two of them, one male and one female, both 19 contacted it through sex with partners who were positive. Three participants were still attending school at the time of the interviews and two participants were not in school. Of the two who were not in school, one participant dropped out at grade eight while the other one dropped out at grade 11.

5.2 Brief background information of participants

Participant 1

Participant 1 was a 17 year old female in grade 10, she was of black ethnicity and acquired HIV perinatally. The participant was orphaned as a result of HIV/AIDS. The participant's father passed away when she was four years of age, followed by the passing of her mother in 2008. Both of the participants parents had passed away from HIV-related illnesses. The participant had a younger sister (14) who is also living with HIV & AIDS. Both the participant and her younger sister resided with their maternal grandparents and their two maternal uncles in a village in Mafikeng. Although the participant was perinatally infected with HIV and has been on ARV's for ten years, she had only become aware of her HIV status

six years ago, when joining the support group. She heard about her status through discussions in the support group.

Participant 2

Participant 2 was 19 year old female who was of black ethnicity. The participant had dropped out of school at grade 8 and had been moving from place to place since the loss of her mother. Since then, the participants living conditions had been challenging and turbulent as she described being estranged from her maternal family. The participant lost her mother in 2007 and her brother as a result of HIV & AIDS and currently has one sister (26) who is also infected with HIV; however she resides in a different town. The participant contracted HIV through a former lover, with whom she has a child. The participant was diagnosed with HIV last year and had been on medication for approximately 6 months at the time of the interview.

Participant 3

Participant 3 was a 16 year old, black male who is currently in grade 9. The participant acquired HIV perinatally. The participant was the youngest of many siblings, in a family which he described as “complicated” stating that he has many step-brothers and step-sisters, however, he described his older sister (26) as someone who has been consistently available for him, regarding everything he wanted and needed. The participant resided with this sister who has taken care of him since the death of his parents. Both of the participant’s parents were deceased as a result of HIV. Even though, he had no recollection of his mother as she passed away during his infancy, he reported having good memories of himself and his father who also passed away.

Participant 4

Participant 4 was an 18 year old black female who was doing grade 11, who acquired HIV through vertical transmission (from her mother) who was still alive. The participant

resided with her mother, younger sister (16) and step-father. She described her family as close. The participant learnt about her HIV status at age 14 from her own observation and from nurses. She had been on medication since a very young age but wasn't aware of her status.

Participant 5

Participant 5 was a 19 year old coloured male who has completed grade 11 and is currently not working. The participant contracted HIV horizontally via a sexual partner. He resided at home with his parents and two younger sisters and described his family as supportive and understanding. The participant had been diagnosed with HIV since early last year (2015) and learnt about his illness while attending a routine medical check-up at a local clinic and had been taking ARVs since his diagnosis.

Table 1

Title: Characteristics of Participants (Background Information of Participants)

Participant	Age	Gender	Race	Mode of Infection	Parental Status
1	17	Female	Black	Perinatal HIV Infection	Orphaned (Both Parents Deceased)
2	19	Female	Black	Horizontal HIV Transmission	Orphaned (Residing with Grandparents)
3	16	Male	Black	Perinatal Transmission	Orphaned (Residing with older sister)
4	18	Female	Black	Perinatal Transmission	Participant has mother
5	19	Male	Coloured	Horizontal Transmission	Participant has both parents

5.3 Themes

Three themes were identified in the data which are: the negative experiences of living with HIV & AIDS; the experiences with medication and coping experiences. The data revealed that the psychosocial experiences set out by the adolescents differed on the basis of the individual' background and situational experiences. The three themes and their sub-themes are tabulated separately below.

Theme one: The negative experiences of living with HIV and AIDS

Table 2

Theme 1: The negative experiences of living with HIV & AIDS

THEME	SUB-THEME
The negative experiences of living with HIV and AIDS	First time experiences
	Emotional experiences
	- <i>Feelings about the parents' death</i>
	- <i>Negative self-concept</i>
	- <i>Poor romantic relations</i>
	- <i>Fear of disclosure</i>
	Social experiences
	- <i>Social rejection</i>
	- <i>Stigma and discrimination</i>
	- <i>social isolation</i>

Table 1 shows theme 1 extracted during data analysis which is; The negative experiences of living with HIV & AIDS

The negative experiences of living with HIV & AIDS

The adolescents' negative experiences of living with HIV & AIDS were revealed in three different ways depending on the individuals. These negative experiences were identified as first time experiences; emotional experiences; social experiences of living with HIV & AIDS.

First time experiences

Taking unknown medicine. Almost all the participants who got infected through perinatal infection did not even realize what was happening,

"I was taking these other tablets since 2007, It's 9 years back... Like I thought it was for TB (Tuberculosis) for like... My grandparents never told me what the medicine was for, they didn't tell me exactly what killed my parents...one day we were at a camp and the leader said we should play a game of children who are affected and infected with HIV and AIDS... one girl said ... (inferring participants name), the medicine you are taking is for HIV and not TB... the other children's don't drink the pills... some of us, we are taking them, ok... that means I'm one of those who are infected but the other ones who are not taking them are affected...." [P1]

Another indicated that, *"They used to give us medication...I remember like the nurses and my mum would always tell me I have to take these pills if I want to be strong and healthy... like I didn't realize it at once, like there were so many things that did not make sense ... Then the next year like when I was like in early high school, the nurses told me about something that's in my blood..." [P4]*

They are just fine with it, *"I am fine with it" [P1]*

Sickness and pain. Those who got infected through horizontal infection realized through sickness, *Eish... I find out when I was sick...my body, body's too small (thin) I was asking myself questions like, why? ...why are you getting so thin? ...going to the clinic to test, I found out I was HIV positive...* Feeling of pain after knowing the status, *"... I was shocked (shaky voice)... they told me that I'm HIV positive and I started crying it was painful."* [P2]

Another participant stated, *"I knew three years back so i just accepted it although it was very hard [P3]: I had sores that used to come out on my body...so as time went by I tested and was told I am HIV ... great pain"*

Emotional experiences

Feelings about the parents' death. Some adolescents have gone through different emotional experiences after the death of their parents.

Great pain from the death of parents. *"It's very hard, it's painful (lowered voice and tearing)." [P2]* One participant felt like she lost her heart, *"I feel like something was taken out of my heart ... it's like my heart was taken out of my chest."* [P1].

Its hurts because both my parents are dead, eventhough my sister ... she takes good care of me and I know she does her best, but sometimes when I think about my parents, its painful [P3].

Hard. To some it is hard, *"like usually when there's a parents meeting in school it becomes hard for me like when I see my friends with their families it becomes hard but I just live with it because it's the way life it is ..."* [P3]

Abandonment by other family members. *"...it was very hard because after he passed away he's family, they didn't... (trembling voice) they didn't take care of us so only my mother's mum took care of us ... they abandoned us and left [P3]*

Another added, *"...like after she passed away... like I had to move from Klerksdorp to come here... because my aunt sent us away ...she told us to leave, my aunt just she does not like me and my sister, [P2]*

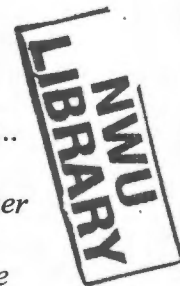
Fear. *"who's going to protect me again... who am I going to talk to? [P1]*

Hurts. *"You can't talk to a granny about other things, like when you are growing... you get to a stage where you are dating or being attracted to someone. You can't talk to her about that and it hurts... I just wish my mother was here so that I could talk to her because she had a lot of experience of what I'm going through..." (With tears). [P1]*

Mixed emotional feelings about the parent's absence. one participant stated emotionally that, *" ... every child deserves a mother love , no matter what... anyway its ok, its ok, she's gone... she was a drunkard, she used to leave us at home, alone we'll be eating left-overs, sometimes they would be rotten. we are now living a good life, and maybe if my mother was here I would not be living this life,, maybe I would be like other kids who don't have support system from their parent... but here at home like, I can even talk to my uncles, we talk its ok...[P1]*

Negative self-concept. Some participants experienced stress which lead to emotional feelings revealed negativity towards the self and hence suicidal thoughts. According to one participant, *"I will stress myself and then end up wanting to commit suicide. Like I did last year... I drank Jik. I drank it because one day one guy at my class said my back look like someone who lift up the weights so it was very hurtful (crying) because they don't know where I'm coming from and how I got that thing on my back...(crying). [P1]*

One indicated that, *"...at first it's difficult because it is like you shutting yourself out there... you hate yourself... [P5]* Some feelings of anger and frustration are also experienced. *"It is difficult because sometimes you have funny feelings, but you just have to act as if they are not*



there. You don't know what you do. It's like you get angry, frustrated, so many things (looking hurt). [P5]

Poor romantic relations. The status of the participants complicates things when it comes to romantic relationships. One participant highlighted that, *"I just don't even date because it makes everything so complicated..., I am afraid if things start to become serious he will leave me if I have to tell him that I am positive... [P4].*

I won't have a boyfriend because if I tell him, he's going to run away [P2].

Now it takes longer for me to start dating a girl because that person needs to know before anything goes on. It can take about three months because when I think of telling that person my status so many things come to my mind...like maybe she's not gonna understand and run away [P5].

Some wish they could date but feel nobody wants them, *"Like my friends are dating and then with me sometimes I don't have a boyfriend... my friends will be called when when we walk on the street and with me it does not happen... [P1]* Feelings of not loved takes away confidence, *"(low tone) we are human beings, we have feelings, we have crushes. Like, I will be like I wish that guy will come and approach me one day, but it won't happen... but now he doesn't see me the way I want him to see me.... sitting on my bed fantasising how good or how will I be treated if I had a boyfriend". [P1]*

Some participants have experienced rejection after disclosing their status. *"...When I told him...he broke up with me [P2]*

Thoughts of the individual infecting the partner also have led to some participants refusing to be in an intimate relationship. *"There is someone who tried to kiss me, but I said emm.. no... I have fears that when I kiss him there will be blood somewhere... and I am he is going to be infected... [P2].*



Fear of disclosure. There is still fear of some experiences of environmental change in disclosing the status to the public. *...Like I want to disclose... and I'm still at school... what if the reaction of my peers and schoolmates change? Maybe they will want to treat me like a sick person or someone who will die soon... I don't want them to have fear for me. I want to be treated the way I'm being treated now...like if you tease me, go on and tease me then.* [P1]

Some participants have fear of gossip and rejection around them, *"It's not easy, I want to tell my friend, but I can't tell her, I'm scared (with a shivering voice) that she will gossip about me ...I once called her at my home and when she arrived, I tried to tell her but eish it was scary."* [P2]

Another added, *" It's only my secret ...I am not ready to tell anyone ...they are going to gossip about me ... and say you see oh, she is HIV positive and I don't want to be around her"* [P3]

With some participants the fear is about people setting boundaries for them, *"...if I tell this person he's going to react this way and then that is when the boundaries starts.* [P5]

Social experiences

Social rejection. The data has revealed that fear of social rejection by the participants is one of the negative experiences. One participant stressed that he has been rejected and now feeling isolated, *"I have only disclosed to my family and very few friends... and now the people that I thought were my friends have changed so obviously I feel out of place... I'm not wanted around them and things like that, they really bring me down."*

Continuing he states, *"...like I had tons and tons of friends, but I'm left with only five. The people that I can say are my friends because they don't judge me others have rejected me.* [P5]

Stigma and discrimination. Stigmatisation has been also experienced by some participants, ... *some people do treat you like nothing and as a human being you feel it, like...maybe, I'm not wanted here or because a lot of people they are not educated about HIV* [P4]

Another indicated, "...*they just don't know, like they are even scared to talk to you and some act different, it's almost like they afraid to come close to you or talk to you the way the used to you can even see that they look at you in a funny way.*" [P5]

Social isolation. Just feeling alone, "*No one... I am just alone...nobody wants to be with me.*" [P1]

Table 3

Theme 2: Experiences with the ARV (Anti-Retroviral) medication

THEME	SUB-THEME
Experiences with ARV medication	Positive experiences - Protects the body Negative experiences - inconveniences - socialisation - Side effects and adherence medication -<i>Deforms the body, leading to emotional pain.</i> - Suicidal ideation - Cause other sicknesses

Table 2 shows theme 2 extracted during data analysis of the findings; Experiences with the ARV medication

Experiences with the ARV (Anti-retroviral) medication

All the participants in the study are on ARV (Anti-Retroviral) treatment. Although they go through different experiences, the data has revealed that their experiences with the ARV medicine are both negative and positive. On the other hand, some even go through mixed feelings about the medicine.

Positive experiences. According to participants the medicine protects their body. ...
"I was just thinking about my medicine I will be fine, I'm going to be fine and I'm going to get my body back. [P2]

A strong relationship has been built between the participants and their medicine as they regard it (medicine) as a friend. *"Even if I would go kilometres and then forget them at home, I will just run back and take them... they help me because now I know my viral load has dropped to less than 25mbecause of them, they help me... I've grown up to like them, so I feel like they are my friends and if I don't walk with them then something is wrong," [P1]*

Another indicated that, *"I know if I take my medication I will be ok and it's up to me to be healthy... I just like them." [P5]*

To some participants the medication is like a baby that they have to be with and never separate with. *"It's my little baby... my first-born...it is building a wall, a barrier that protects the parts that are uninfected, so when you skip, you are creating a crack... the medication helps me... it's like a baby, if I look after it, it will look after me....[P4]*

Medication gives direction and hope of life to some of the participants, *"...medication is giving me direction because now I can focus more on my life than my social life and have hope." [P4]*

Negative experiences

Although the participants have no alternative but to accept medicine as their life support and companion in their life journey, there is still the other side of it whereby it gives them some negative side effects. Data has revealed that most of them have are going through one challenge or the other as they continue taking the medicine.

Inconveniences. There are some inconveniences caused by the medicine as they cannot visit around and socialise easily due to the fear that they may miss the actual appointed time for medicine taking. *“... I don't go out to play with friends, I am just an indoor person I stay at home ...not because I want to, but because of medication... you get left out with time because sometimes your cell phone might be having some problems so it becomes hard to keep up with the time when I'm outside ... so eish yes, it stops you from doing quite a few things yes...(taking a deep breath) a lot of things”* [P3]

Another participant added that, *...taking the pills in front of my friends like... will reveal my status... maybe they will start asking question or pull away from me.* [P1].

Side effects and adherence to medication. There has been a notification of adherence to medication by almost all the participants since they feel they have no choice but to take it in order to live healthy despite the side effects.

Deforms the body, leading to emotional pain. The medicine has gone to the point of causing some body deformation to some of the participants which they regard as the most hurting part of their HIV and AIDS experience and is lowering their self-esteem. One of the participants indicated sadly that, *“...this medicine has bad side effects, side effect like you see...it made me have... (Silent a bit and taking a deep breath) ...the hunched back... it hurts because others mock me”* [P1]

Suicidal ideation. The thought of not being able to stop the medicine that deforms their body leaves them with suicidal ideation. *"...sometimes I ask myself why me... why should I have this thing... other children, who are in the same medication as me ... (choking with hurt) don't have hunch backs like me (with a hurting voice) ...that is why I once tried to commit suicide because other children are teasing me with this thing..."* [P1]

Cause other sicknesses. Some participants are experiencing different types of sickness due to taking the ARV medication. One participant stressed that he is bored because of the side- effects of this medicine. *"It makes me feel dizzy and tired and tend to be forgetful somehow at times... It bores me to death because I know it's this thing... Yes like its boring seriously it is, most of the times... because I have no choice but to take it"* [P4]

On the other hand, another participant experience sleeplessness, *"Sometimes I don't sleep... your thinking, everything becomes tired. It's like your whole body is not yours, it's like somebody is just putting something heavy on you... Some of the days you don't even feel like taking them because they are uncomfortable"* [P4]

Table 4

Theme 3: Coping experiences

THEME	SUB-THEME
Coping experiences	Self-acceptance Social support - Family - Friends - Health Services - Church and religious organisations.

Table 3 shows theme 3 extracted during data analysis of the findings; Coping experiences

Coping experiences

Although there has been a lot of negative experiences emotionally, physically, psychologically, socially the participants have revealed some coping experiences with themselves, family, friends, the community, health services as well as the church.

Self-acceptance. The participants have revealed a sense of self-acceptance which has kept them going on with life, some even indicated that it is not a life sentence. *"I took it very well after getting the results because I didn't see it as a bad thing or a life sentence"* [P3]

Life is still normal with the participants, *"My HIV positive status does not change my way of seeing my future. I can still live a normal life I will still become a businessman and own my own restaurant one day... if I take my meds every day, I can have a normal, happy life."* [P5]

No threats about it life is still normal as the participant has self-contentment, *"...I don't feel threatened by anything ... I see my future as fairly good... I can still live a normal life."* [P4]

Another participant believes the status cannot stop him from doing what he wants to do *"I told myself that I don't care, as long as I'm on medication. It helped me a lot, improved my health. I know what I want, when to get it and how to get it ... I believe it is part of my life. If I don't accept then I will always be on a back foot...So I have accepted my HIV status."* [P5]

Social support. The participants are experiencing a lot of support from different people around them being; Family, Friends, The community, Health Services and Church.

Family. The participants experience different forms of support from their families, *"...but I've realized that my family is here... my uncles...they say that if we want to talk, we should talk to them... I told them that one day I'm going to disclose my status and I want them to be there beside me when I talk about it..."* [P1]

More support for the participants, *"At home they are there for me, they are nice people, they treat me well, anything I want they buy me."* [P2]

"I have an elder sister who took me in as her child... there is a very good communication between the two of us ...like when I have troubles I speak to her because she also went through the same thing, she guides me... she's the one who took me in as her own child...we are a family, and we help each other." [P3]

Friends. Despite the fact that some participants have gone through bad experiences after disclosing to their friends the remaining ones are there for them and some of still get support from the friends they disclosed to. *"My friends treat me well and they accept that I am sick... they are always there for me."* [P2]

My friends are there for me...I feel free to speak about anything and they won't judge me." [P4]

Health Services. Some health services offer good support and counselling for the participants. *"I was at the clinic they counselled me and after that I accepted the situation* [P2] ...

At the children there, at ward 6, children's ward in the hospital... (stressing the point) they are very supportive...they were my friends, they even yes...you will feel very happy there... The relationship with the nurses...helps me... gives me confidence and strength to love myself and my life." [P1]

Church and religious organisations. To those participants who go to church there has been a lot of support from their church members, mostly the older members and other religious organisations. *"One granny in church once said, don't let what other children say to you get into your head. Let it bump like a tennis ball... since then all they say teasing me*

bump just like a ball. The pastor's wife as well always asks me as to whether i have not forgotten to take the medicine." [P1]

Religious organisations as well play a very supportive role to the participants who happen to be part of them. *"The support help here...coming here to caring for kids (Caring for Kids Christian Action Group: serving the poverty stricken community) helps me emotionally and physically ...It helped me to realize that I'm not the only one who needs help with my status or the way I live. I wish Caring for kids action group could go nationally to help those other kids who are suffering."* [P3]

CHAPTER 6

DISCUSSION

6.1 Discussion of results

The aim of this study was to explore the psychosocial experiences of five adolescents who are living with HIV & AIDS in the North-West Province of South Africa. The sample was of a mixed sample of adolescents who were either perinatally infected or horizontally infected with HIV & AIDS.

The first area of discussion in this study focused on the negative psychosocial experiences (challenges) of this group of adolescents. The second focus area included this samples experiences in relation to ARV's (HIV & AIDS related medication) and the third area discussed the coping strategies which were employed by these adolescents in an attempt to cope with living with a demanding and life threatening disease and as an attempt to understand how they manage with the negative experiences or challenges of this group. The discussions of the findings are presented below.

6.1.1 Theme 1: Negative psychosocial experiences (difficulties or challenges)

The principle outcome of this study fell under the first focus area of the study- *negative psychosocial experiences*. Generally, the data has revealed that there appears to be differences amongst the negative experiences of those participants who acquired HIV & AIDS through vertical (perinatal) routes of infection as compared to those adolescents who acquired HIV through horizontal infection. The vertically infected participants appeared to have accepted their HIV-positive status more easily than the horizontally infected participants. Most of these participants are the ones who do not have problems with their

families and friends since the family look at them as innocent children who got infected because of the parents. On the contrary, the horizontally infected participants are judged by those who know about their status. They also seem not to have accepted their status as easily like others. The group seem to be going through more negative experiences (challenges) than the other group.

Within the sub-theme *emotional experiences*, there appeared to be a contrast with some studies which demonstrated more severe negative affective experiences such as trauma (Brown, Lescano & Laurie, 2001; Radcliffe, et al., 2007); depression (Brown, Lescano & Laurie, 2001; Strydom & Raath, 2005; Vilsteren; 2011; Mutwa et al., 2013); anger/aggression (Vilsteren, Haffeejee, Patel & Bowman, 2011; Beyers & Nkoane, 2012) and feelings of anxiety, uncertainty and pessimism regarding their future (Punpanich, Detels, Gorbach and Leowsrisook, 2008; Ramjohn, 2012; Li, 2012 & Li et al, 2009) amongst HIV positive adolescents. The adolescents in this study did not experience any of the abovementioned emotional states, however the enduring experience of parental loss in this study (Black, 2009; Petersen et al., 2010; McClearly-Sills et al., 2013; WHO, 2014) gave rise to numerous negative affective experiences such as *intense emotional pain in relation to losing a parent* to HIV & AIDS. The emotional pain cited by most of the sample in this study is congruent with the findings of Petersen et al., (2010) who established that a large portion of adolescents who were infected with HIV in South Africa experienced intense emotional pain from losing a parent. The experiences of adolescents who had lost a parent in this study also concurred with the works of Black (2009) and McClearly-Sills et al., (2013) who demonstrated that the processes of HIV-positive adolescents who had lost their parents grieving remained incomplete. The perinatally infected adolescents in this sample also expressed no anger or resentment towards their parents for infecting them and a possible explanation for this could be due to the fact that these adolescents have already accepted their

HIV status and also due to the fact that they were born with their status indicates that it is a part of their lives and something which they have also had.

A potential explanation as to why these adolescents may not be experiencing such severe emotional experiences may be as a result of the *social support* which they receive from various agencies and the effective counselling which they received from the health care facilities during and after being told their HIV status which made them understand the benefits and the security which medication they learnt and experienced had contributed to their lives. The social support and counselling which was experienced by adolescents also facilitated the phenomenon of “acceptance” of their HIV status’ and their new HIV positive identities which concurs with Kubler- Ross’ final stage in her model of loss/grief. During the interviews it became evident that the adolescents believed that the medication which they were using provided security for their health statuses and they therefore did not view HIV as a death sentence. The security in relation to their health and prolonged life which these adolescents found from the medication had caused them to maintain more positive views on their future and could be a potential explanation for the lack of depression, anger and bleak view of the future which was noticeable amongst adolescents in other studies of this nature. This security which medication offered adolescents can be seen in the works of Maswikiti (2010) who found that medication provided adolescents with a sense of hope in relation to their lives and provided them with a sense of security against early death and illnesses caused by HIV & AIDS.

Perhaps there is a need for future studies to explore the dynamics of grief amongst adolescents living with HIV & AIDS.

Some of the findings under the theme ‘*negative experiences*’ furthermore concurred with other studies such which demonstrated that living with HIV & AIDS furthermore

complicated selected standard psychological and social developmental milestones amongst adolescents infected with HIV & AIDS (Kang, Mellins, Kee, Robinson & Abrams, 2008; Li, 2010; Childs & Maxwell, 2009; Ramjohn, 2012). In this study, many of these *negatives experiences* interfered with the normal developmental milestones of adolescences such as establishing sexual or romantic relationships with the opposite sex and the development of a self-concept were detrimentally affected as a result of positive serostatus for HIV & AIDS, as cited in the works of Childs and Maxwell (2009).

The findings under the sub-sub- theme of '*poor romantic relations*' support the view of Childs and Maxwell (2009) who proposed that a HIV-positive diagnosis during adolescence hinders the normal sexual developmental milestones of adolescence. In keeping up with the findings of Hosek, Harper and Domanico (2000) & Risio, Ballantyne, Read and Bendayan, (2010), who reported that HIV-positive adolescents feared the possibility of infecting a romantic or sexual partner and fear disclosing their HIV status due to the possibility of experiencing rejection by romantic or sexual partners. In this study, these experiences were present however, they were extreme, to the point where these fears prevented adolescents from engaging in any form of dating or sexual intimacy. In contrast to some studies which revealed that HIV- infected adolescents experienced psychosexual challenges with more practical tasks such as disclosing their status in relationships and difficulty in mediating condom use as identified by Childs and Maxwell, (2009) and not being able to determine an appropriate time to disclose their HIV positive status to their partners and determining which romantic partners could be trusted with their diagnosis (Galano et al, 2015), the adolescents in this study experienced challenges which were more inclined to the anticipated long-term negative consequences of engaging in sexual or romantic relations. Generally, these findings were indicative of adolescents who experienced a sense of isolation in relationship to dating and engaging in intimate relationships.

The *negative self-concepts* which were prevalent amongst most of the adolescents in this study appeared to be a manifestation of the unconditional positive regard which this sample received from significant others within their context Rogers, (1957) and in some cases internalization of stigma (internalized stigma) as acknowledged in the works of Deacon & Stepheny (2007) and Mburu et al., (2014).

Furthermore, within the context of this study, which was strongly characterized by orphaning and in some instances, distant family relations with extended members of their family (i.e. through rejection and abandonment from existing family members and poor emotional relationships with them) for some of the adolescents, an additional potential explanation of the *negative self-concepts* which were found amongst this sample of adolescents could possibly be the result of a lack of strong quality of family relations and emotional closeness which should exist between family members in order for individuals to develop a good construction of self as cited in Papini, Selby and Clarke (as cited in Tshenkeng, 2009). These findings in relation to the sub-sub-theme of poor self-concepts furthermore concur with those findings of Ramjohn (2012) and Ferrand et al (2010) who found that *negative self-concepts* were a common experience amongst most participants within their studies. The adolescents who possess *negative self-concepts* in this study would potentially benefit by developing more deep emotional bonds with individuals who they can trust, and who provide unconditional positive regard, even if it outside of the family context such as in psychotherapy. These findings oppose the findings of Risio et al (2011) who established more positive self-identities amongst adolescents.

Most of the social experiences in this study are in accordance with the findings of many other studies. These social experiences include that of *rejection* (Punpanich, Detels, Gorbach & Leowsirook, 2008), *stigmatization and discrimination* (Dube & Ross; 2013;

Midtbo, 2012; Strydom & Raath, 2005; Gachanja, 2015 & Mburu et al, 2015) and were prevalent amongst this sample, in alignment with adolescents in other studies.

The sub-sub-theme '*fear of disclosure*' which was recognized in this study is in line with the disclosure process model of Chaudoir and Fischer (2010). These theorists proposed that individuals who are living with more strongly stigmatized identities such as HIV & AIDS are less likely to disclose their stigmatized identities due to the increased risk of experiencing stigmatization, discrimination or rejection. The adolescents in this study expressed strong feelings of fear and apprehension in relation to disclosing their HIV status. These findings also concur with the results of studies conducted by Galano et al (2016) Ferrand, Miller and Jungman (2007) and Mutwa et al (2013) who all established that self-disclosure was difficult for most adolescents within their studies. More specifically, these findings are keeping up with the notion of Wiener and Battles (2006) who state that disclosure might be more difficult during adolescence due to hypersensistivity/ fear of rejection.

6.1.2 Theme 2: Experiences in relation to ARVs

The second focus of this study was to investigate the experiences of adolescents who are living with HIV & AIDS in relation to ARVs. The findings under this sub-theme reveal numerous points, some of which contradicted some findings in literature and others which concurred with them.

Firstly, the findings in this study demonstrate that ARV usage affected this sample in both positive and negative ways.

The findings in relations to the use of ARVs concur with the works of Maswikiti (2010) and Galano et al., 2016) who cited physical discomfort and (Galano et al, 2016) who cited the

inability of HIV positive adolescents to socialize as desired with their peers as major *inconveniences* which were linked to the use of ARVs.

However, regardless of this experience, most of the adolescents in this study had reported both physical and social inconveniences which were induced as a result of using ARV's, these adolescents still managed to adhere well to the specific and rigid regimes of ARV's and did not default (medication adherence here refers to keeping up with the proper prescribed time limits and dosages of their medication. These good adherence behaviours in relation to medication have been cited in the works of Amole, Jahan and Abute, (2015) and Gachanja, (2015). These findings furthermore oppose the works of Chandwani et al., (2012); Merzel, VanDevanter and Irvine, (2008); Ledlie (2001) and Hosek, Harper & Domanico, (2000), who found medication adherence to be a challenge amongst HIV positive adolescents.

A possible explanation for good medication adherence which was identified in this study, in spite of the inconveniences which the medication caused amongst this sample may be linked to the proposition made by Agwu and Farlie (2013) who state that "*the coping mechanisms employed by PHIV-infected adolescents to deal with the stressors are directly linked to non-adherence.*"

These authors additionally elaborate that social support as a coping mechanism contributes positively towards good medication adherence (Agwu and Farlie, 2013). In regards to this quotation and in relation to the findings within the specific context of this study, the provision of *social support* which was provided by various agencies to adolescents in this study in the form of providing both practical assistance (i.e. keeping up with rigid time schedules and frequent doses of medication) and assisting in everyday emotional demands

related to a HIV-positive diagnosis may be a possible explanation for the good adherence patterns which were prevalent amongst this sample.

Furthermore, although medication was not explicitly stated under the theme of “coping strategies” it became evident that adolescents also viewed their ARV’s in a positive light (*positive experiences*), as shown in the works of Maswikiti (2010) who emphasized that HIV positive adolescents viewed medication as a source of hope for their future and allowed the adolescents to focus more on their goals which were not related to HIV& AIDS. Adolescents in this study here understood the significance and benefits of medication and this is one way in which ARV’s were viewed positively. For example, some of the adolescents mentioned:

“medication is giving me direction because now I can focus more on my life than my social life and have hope.” [P4].

“I was just thinking about my medicine I will be fine, I’m going to be fine and I’m going to get my body back.” [P2]

In one instance, medication was cited as a cause of an individual’s poor self-concept due to the fact that it has deformed her body and caused her to develop a negative self-image.

6.1.3 Theme 3: Coping Strategies

The coping strategies of *self-acceptance* and *social support* which were identified in this study by adolescents to assist them with managing with the emotional and practical implications of HIV & AIDS concurred with numerous studies such as Mutwa et al., (2013); and Petersen et al., (2010). Both of these coping strategies were also identified in Lazarus and colleagues’ Ways of Coping Questionnaire (WOCQ) as cited in (Krohne, 2002). The notion of self-acceptance also concurred with the final stage of Kubler-Ross’ final stage of grief

(1969) titled acceptance which demonstrates the acceptance of reality of tragic news, which in the instance of this study referred to an acceptance of a HIV positive diagnosis. Self-acceptance of an HIV-positive diagnosis was also demonstrated in the works of Gachanja (2015).

The fact that the adolescents in this study demonstrated self-acceptance and an acceptance of their HIV-positive status facilitated them to more openly accept the responsibilities which accompanied a HIV positive diagnosis such as being able to adhere to the rigid medication regimes associated with ARVs. The self- acceptance of a HIV positive status consequently allowed the adolescents in this study to maintain more positive outlooks on the future and life (Li, 2010), pursue their personal goals and maintain a general feeling of happiness about life in general (Li, 2010 & Gachanja, 2015) in spite of the fact that they were infected with HIV&AIDS. Such positive outlooks on life amongst HIV positive individuals have kept up with the works of (Li, 2010). In other words, self-acceptance as a coping mechanism assisted adolescents in coping with the practical demands of HIV & AIDS and the emotional difficulties (i.e. maintaining a positive view on the future) amongst adolescents in this study.

The findings furthermore revealed that this sample was able to employ positive coping strategies as identified by Petersen et al., (2010), Mutwa et al., (2013) and Pearlin & Schooler, (1978) as cited in Salama et al (2013) in contrast to some studies such as Mutumba et al., (2015) and Lewis and Brown (2002) which revealed more negative coping strategies such as avoidance and distraction amongst HIV-positive adolescents in other studies. In essence, both behaviourally-focused coping strategies together with emotion-focused coping strategies were simultaneously employed in the coping processes of these adolescents, which appeared to work well for adolescents who used them together. Furthermore, this study revealed that there is a potential link between good medication adherence and coping

strategies such as social support, however there is limited knowledge on this topic, therefore warranting further research on this topic.

6.1.4 Conclusion

In this study, it was revealed that HIV positive adolescents experienced various forms of negative experiences, some of which were emotional and others were social. Emotionally, demonstrated difficulties were in relation to romantic and intimate relationships, emotional pain and complications around mourning the death of a parent, anxiety in disclosing their HIV status, and developing a poor sense of self. Furthermore, it was evident that although ARVs provided a sense of hope for the future, it also demonstrated that the medication stood as a barrier for them to socialize and caused negative physical side effects. The adolescents here managed to cope effectively with some of their experiences of living with HIV & AIDS through the use of social support and self-acceptance, however they still need assistance in coping with some of the difficulties cited earlier.

6.2 Limitations of the study

The use of a convenient sampling technique in this study imposed many limitations on the generalizability of the findings in this study as a convenient sample of only five participants within the North-West Province was insufficient to generalize the psychosocial experiences to all adolescents who were HIV positive within this Province. Case studies used in this study are a relatively small sample from which to generalize findings to all adolescents within the North-West Province. Secondly insufficient time was available to explore the deeper emotional experiences which were related to the adolescents grieving processes in relation to losing a parent. Lastly, adolescents who originated from the black racial group were over-represented in this study.

6.3 Implications for future research

In this study, it became evident that HIV & AIDS has the potential to impact upon some of the standard developmental milestones of adolescence (i.e. sexual exploration and development of the self-concept). In the future, more qualitative methodological studies could explore the impact which HIV & AIDS could have on the specific, standard developmental milestones of adolescence.

The emotional impact of losing a parent or both parents as a result of HIV & AIDS also emerged as a key area of concern in this study, however the researcher did not have ample time to probe sufficiently into the deeper emotional aspects of the death of a parent/s amongst this group. Future studies could be developed which focus specifically on the grieving processes which are related to parental loss amongst HIV positive adolescents.

Additional studies of the same nature could be conducted, using larger sample.

6.4 Recommendations

In developing programmes for HIV positive adolescents, developers should intervene at both individual and societal levels. On an individual level, adolescents must be provided with environments which will offer them unconditional positive regard which will assist them to develop positive identities about themselves which are not linked to a HIV-positive status. Developing more positive self-concepts will help show adolescents that they have other positive aspects which are not linked to a HIV-positive diagnosis.

Other areas such as complicated / incomplete grief processes amongst these adolescents should be addressed as a means of facilitating disclosure in the grief processes and to reduce the emotional impact which the loss of a biological parent comes with. It is also recommended that mental health workers provide individual and/or group grief

psychotherapy for adolescents who are trapped in the process of grieving the loss of their parents.

Support groups were cited as a major source of coping both emotionally and physically, therefore it is recommended that more support groups which cater for HIV-infected youth be developed so that these adolescents could also be provided with a sense of emotional and physical support (i.e. psychoeducation on medication and HIV itself). The findings of this study were shared with the NGO leaders with the permission of the participants at the conclusion of the study.

Future studies of similar nature could also include more male participants.

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APPENDIX 1



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ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by the Human Resource Research Ethics Committee, Mafikeng Campus, 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: Investigating the psychosocial experiences of adolescents living with HIV and AIDS in the North West Province.																
Project Leader:	Mrs N Matamela															
Student:	CN Sanders															
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>4</td><td>3</td><td>5</td><td>-</td><td>1</td><td>5</td><td>-</td><td>A</td><td>9</td></tr></table>	N	W	U	-	0	0	4	3	5	-	1	5	-	A	9
N	W	U	-	0	0	4	3	5	-	1	5	-	A	9		
Legend: S = Submissions, R = Re-submissions, P = Physiological Assessments, A = Assessments																
Approval date: 2015-10-20	Expiry date: 2018-10-20															
Category:	N/A															

Special conditions of the approval (if any): None

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 (principal investigator) must report in the prescribed format to the NWU-IRERC:
 - annually (or as otherwise requested) on the progress 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.
- 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 NWU-IRERC. 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 and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-IRERC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - 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 NWU-IRERC 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.

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 for any further enquiries or requests for assistance.

Yours sincerely

Linda du
Plessis

Digitally signed by Linda du Plessis
DN: cn=Linda du Plessis, o=NWU,
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Prof Linda du Plessis

Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)

APPENDIX 2

1065 Hector Petersen Drive

Unit 5

Mmabatho

05/12/2016

This is to certify that the dissertation entitled

**PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS LIVING WITH HIV AND
AIDS IN THE NORTH WEST PROVINCE**

Submitted by

CHERISE SANDER

For the degree of

**MASTER OF SOCIAL SCIENCE
(CLINICAL PSYCHOLOGY)**

In the

**FACULTY OF HUMAN AND SOCIAL SCIENCE
MAFIKENG CAMPUS
NORTH WEST UNIVERSITY**

Has been edited for language by

Mary Helen Thomas (B.Sc. Hons. PGCE)



APPENDIX 3

Parental Informed Consent Form

Investigating the Psychosocial Experiences Adolescents living with HIV and AIDS within the North-West Province

Dear Parent or Guardian

My name is Cherise Sander and I am a registered student at the North-West University (Mafikeng campus- student number: 17068126) under the course titled: Master's in Clinical Psychology). As a requirement of this degree, I am conducting a research project which aims at investigating the psychosocial experiences of adolescents who are HIV positive.

Adolescent HIV/AIDS is a separate epidemic and needs to be handled and managed separately from adult HIV as adolescents not only face problems in accepting their HIV status, need for long life, treatment and other positive family members but some also have sad memories about their lost parent and a big question mark in the future, regarding their health (Naswa and Marfatia, 2010).

The quality of life of people with HIV extends beyond the physical realm to affect psycho-social-spiritual wellbeing (O 'Connell, Skevington and Saxena, 2003) and, in addition to this many intervention programs for HIV-positive adolescents focus largely on the medical/physiological aspects of HIV, and very little research and intervention focuses on addressing the psychological needs of HIV positive adolescents. HIV-positive adolescents face unique psychosocial experiences and it is important that we identify and address them as a means of assisting this group of individuals on an individual level and at community levels,

however, this has been difficult within the South African context as a result of the lack of information regarding on this topic.

The information gathered in this study will be used to help close the current gaps in knowledge regarding the psychosocial experiences which HIV-positive adolescents within the South African context may experience and may also assist us as researchers to contribute towards developing a custom-designed psychosocial intervention programme for HIV-positive adolescents within South African community, which may assist mental health professionals in treating HIV-positive adolescents on a psychosocial level in the future.

I, the researcher will use the method of individual face-to-face interviews to gather information in this study, which will be conducted by myself, the researcher, and a voice recorder will be used to record the interviews. The interview will be conducted by myself, Cherise Sander and it will involve only myself and your child.

Protecting the identity of the participants in this study is very important to the researcher and for this purpose, numerous steps shall be taken to ensure that the participant's identity may not be exposed. Firstly, within the process of data analysis, the research team which involves the researcher and one other researcher will be in contact with the raw data (i.e. voice records and transcribed conversations). Within the process of the final report, personal information such as the names, surnames and any personal information which might put the participant at risk of being personally identified by the public will be omitted so as to maintain confidentiality. The voice recorder which will be used in this study will be kept safe and remain solely in the researchers possession. It will only be made available to the researcher herself and one other psychologist.

Participation in this study is of a voluntary nature and this means that regardless of the informed consent which may be obtained from you, the parent or guardian, your child may

not participate in this study if he or she decides not to. Furthermore, the adolescent may withdraw from participating in this study during any stage of the research process and will not be forced to participate if he or she indicates such.

Some of the topics which may be addressed during the interviews may be sensitive (i.e. discussing the death of a parent, rejection, dating and intimacy). However, the adolescent is not obliged to engage in the discussions of such topics or issues if he or she is uncomfortable with them or indicates this.

If your child chooses to participate in the study, he or she will not be paid, however, he or she will receive a small stipend which will be used to cover any transportation costs which may be incurred as a result of getting to the interview venue. In addition to this, refreshments and snacks will be provided to the adolescents during the interview sessions.

This study has been approved by the Human Resource Research Ethics Committee, Mafikeng Campus and the researcher will adhere to the prescribed ethical guidelines as approved.

Please contact me using the information below if you have any further questions related to the study.

Cherise Sander

The North-West University

Phone: 0832988403

Email: talk2cherise@yahoo.com

Guardian/ Parental permission

- I have understood the conditions and implications which apply if my child participates in this study.
- I hereby give permission for my child to participate in this research.

Signature of parent/guardian
guardian

Printed name and surname of parent/

Date

APPENDIX 4

Child informed consent form

Investigating the psychosocial experiences of adolescents who are living with HIV & AIDS in the North-West Province

Hello, my name is Cherise Sander and I am a psychology student at the North West University in Mafikeng. I am doing a research project about the psychosocial experiences of adolescents who are living with HIV & AIDS within the North-West Province of South Africa. The reason I am doing this research is because here in South Africa, there is little information to help us understand how teenagers who are living with HIV & AIDS experiences their day-to-day lives and we would like to know more about this.

The information which we get from these interviews is going to help us to learn more as to how HIV & AIDS affects your life as a teenager (both in a good way or a bad way), and will help us to understand how we can help you better cope with some of the difficulties you have with these issues.

The interviews will be done in a place where you feel comfortable. For teenagers who attend the support group, the interviews will be done at the support group on the days when you meet for your support group meetings. If you chose to participate in the study, two interviews will be done for each teenager and each will last for about one hour. During the interview we may discuss topics which you may find are sensitive such as dating, your feelings, your parents, and other issues which you yourself feel are important for us to talk about but, if you find it difficult to speak about any of these topics or you are not happy to speak about them, you do not have to speak about them and will not be forced to do so. You will also decide how much information you want to share with me and if for any reason, you decide that you no longer want to be part of the study, you will be allowed to stop participating in it at any time.



The interviews will be done by myself alone, Cherise and I will also need your permission to record the interviews with a voice-recorder. The reason why I will need to use a voice recorder is so that I can better remember what we have discussed during conversations. I myself, and another psychologist will be the only two people who will know your names and surnames who and listen to your interviews from the recorder. When we write our research document we will not put your names and surnames and other information which might show who you are so that people who are reading the document do not know who is talking. I, the researcher will also make sure that the voice-recorder which we will use to record the interviews is kept safe and that no-one else besides the other psychologists will listen to the interviews. Myself and the other psychologist also promise that we will not tell anyone else your names or surnames during the study and after the study.

You will not be paid any money to take part in this research study but you will be given a small amount of money which will help you to pay for any transport fees which you may need to get to the place where we will do the interview. During the interviews you will also be given something to drink and some snacks.

If you are under the age of 18 years and you wish to take part in this research, I will also need to ask your parents for permission to allow you to take part in this study.

Thank you for giving me some of your time.

If you have any questions about this study, please contact me with the information mentioned below.

Thank you once again

Cherise Sander
The North-West University
0832988403
Email: talk2cherise@yahoo.com

- I have understood everything that will happen and what I am allowed to do if I take part in the study.
- I hereby choose to take part in this research study

Signature of child

Printed name and surname of child

Date

APPENDIX 5

Title: Investigating the psychosocial experiences of adolescents living with HIV and AIDS in the North-West Province

Question guide

1. Please tell me about yourself
2. Please tell me more about your family
3. How did you discover you are HIV positive?
4. Do you know how you became HIV positive and what do you understand about being HIV positive?
5. Have you disclosed your HIV positive status to anyone? OR
6. Are you confident in disclosing your status?
7. How do you think people in your community think about HIV or people who are HIV positive?
8. Do people in your community know about it and if so how do they relate with you?
9. Are there those who are infected in your neighbourhood and do they relate together?
10. Are you on medication for HIV? Tell me more about this medication, (example: does it help you? are there any negative things about the medication that you take? Are there any side effects that the medication and are you committed to taking the medication)
11. How do you experience relationships with the opposite sex?
12. How do you see the future?

13. Do you think being positive can stop you from achieving your future goals/ what are your future goals.
14. Is there anything which makes you feel sad?
15. Is there anything which makes you feel happy?
16. Peers: how do you view yourself in relation to your peers? How do you feel when you are with your peers?
17. Are there any positive experiences you have? tell me more about them
18. How do you view yourself in relation to your peers/ friends?

Thank you