

Exploring the lived experiences of adolescents living with vertically acquired HIV

by

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DECLARATION

I, Pretty Patience Jena (Student no: 50809148) hereby declare that **EXPLORING THE LIVED EXPERIENCES OF ADOLESCENTS LIVING WITH VERTICALLY ACQUIRED HIV** a dissertation of limited scope submitted in partial fulfilment of the requirements for the Master's Degree in Social Behavioural Studies in HIV/AIDS to the University of South Africa is my own independent work and has not been previously submitted for any other degree or examination at any other university.

Pretty Patience Jena

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ABSTRACT

This qualitative study explored the **lived experiences** of **adolescents living with vertically acquired HIV** receiving treatment, care and support services at Dora Nginza Wellness clinic, in Port Elizabeth, South Africa.

Six adolescents living with vertically acquired HIV (four females and two males) between the ages of 16-17 years participated in in-depth semi-structured open-ended individual interviews. Tesch's (1990) method of data analysis for qualitative research was used to analyse the interviews.

Adolescents that participated in the study spoke widely about the outlook on their illness and their lives both in the past and present. They depicted fear, anxiety, pain and sadness in their lived experiences. They were anxious about their own death and had experienced illness and death of parents, siblings and close relatives due to **HIV and AIDS**. They described painful and traumatic life events related to their illness which included knowing their own HIV status and severe health problems and hospitalisations. They all learnt about their HIV status in early adolescence and choose not to disclose their status to people outside the family due to fear of rejection, stigma and discrimination. Taking **ARVs** was challenging to the participants due to side effects and strict medication schedules. Their school attendance and performance was affected by their illness. Family was an important resource of support. The participants had good experiences of HIV treatment at the Wellness clinic.

The findings suggest that adolescents living with vertically acquired HIV faced a number of challenges in dealing with their disease and its treatment. They need intensive care and support services that enhance their positive self, facilitate self-disclosure and decrease and discourage stigma and discrimination at school and within their communities.

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ACRONYMS AND ABBREVIATIONS

AIDS Acquired Immune Deficiency Syndrome

ALHIV Adolescents Living with HIV

ART Anti-Retroviral Treatment

HAART Highly Active Anti-Retroviral Therapy

HIV Human Immunodeficiency Virus

PLHIV People Living with HIV

SEM Social Ecological Model

SRH Sexual Reproductive Health

SSA Sub-Saharan Africa

UK United Kingdom

UNAIDS the Joint United Nations Programme on HIV and AIDS

USA United States of America

WHO World Health Organisation

CHAPTER 1: SITUATING THE RESEARCH PROBLEM

1.1 Introduction and background of the study

South Africa, like other countries in sub-Saharan Africa (SSA) faces a critical period with its first generation of children born with Human Immunodeficiency Virus (HIV) maturing into adolescence. Adolescence, defined by the World Health Organisation (WHO) 2010, as a developmental phase between the ages of 10 and 19 is a period of physiological, cognitive and emotional development mainly characterised by sexual maturation, an increased participation in risk taking behaviours and an increased desire for independence (Swayer, Drew, Yoe & Britto, 2007). Consequently this developmental phase becomes an added complexity should the adolescent involved is already living with a highly infectious and stigmatizing infection such as HIV (Jaspan, Li, Johnson & Bekker, 2009).

For most of the history of the Acquired Immune Deficiency Syndrome (AIDS) pandemic, it was believed that the majority of the children born with HIV in resource poor settings did not survive past infancy, let alone adolescence (Brahambhatt Kigozi, Wabwire-Mangen, Serwadda, Lutako, Nulugoda, Sewankambo, Kiduggavu, Wawer & Gray, 2006; Chilongozi, Wang, Brown, Taha, Valetine, Emel, Sinkala, Kafulafula, Noor, Read, Brown, Goldenberg & Hoffman, 2008; Little, Thorne, Lozi, Bunders & Ngongo, 2007). However, recent data has emerged to challenge this misconception as children who acquired HIV infection via vertical routes are now entering adolescence in Southern Africa. An estimated one-third (36%) of HIV infected infants have slow progressing disease and a median life expectancy of 16 years even without accessing treatment. Further, a significant number of children born with HIV at the peak of the HIV epidemic in the 1990's are presenting to clinical services for the first time in adolescence (Ferrand, Luethy, Bwakura, Mujuru, Miller & Cobertt, 2007; Ferrand, Bandason, Musvaire, Larke, Nathoo, Mujuru, Ndhlovu, Munyati, Cowan, Gibb & Corbett, 2009a; Ferrand, Corbett, Wood, Hargrove, Cowan, Gouws, Williams & Ndhlovu, 2009b; Ferrand, Munaiwa, Matsekete, Bandason, Nathoo, Ndhlovu, Munyati, Cowan, Gibb & Corbett, 2010a;

Ferrand, Lowe, Whande, Munaiwa, Langhaug, Cowan, Mugurungi, Gibb, Munyati, Williams & Corbett, 2010b).

Advances in HIV testing for exposed infants and children and the national roll-out of antiretroviral therapy (ART) in South Africa since 2004 has led to an increased access to highly active antiretroviral therapy (HAART). This has increased the life expectancy of children living with HIV, making it possible for them to reach adolescence and adulthood (Anderson & Seedat, 2009). The population of adolescents living with vertically acquired HIV is expected to grow significantly (Jaspan et al. 2009). While adolescents aged between 10-19 years accounted for 1% of the total number of patients receiving HAART in South Africa in 2008, this proportion is expected to grow exponentially to approximately 5% by 2020, mainly due to vertically infected children surviving into adolescence (Boulle, Bock, Osler, Cohen, Channing, Hilderbrand, Mothibi, Zweigenthal, Slingers, Cloete & Abdulla, 2008). With approximately 330 000 children between the ages of 0-14 years living with HIV in South Africa in 2009 (Joint United Nations Programme on HIV and AIDS (UNAIDS) 2010), prevention, treatment, care and support for adolescents living with vertically acquired HIV will become increasingly important over the next decade.

This research study therefore aimed at exploring the lived experiences of adolescents living with vertically acquired HIV who were receiving HIV treatment, care and support services at Dora Nginza Wellness clinic in Port Elizabeth, South Africa and determine care and support services developmentally appropriate for this population.

1.2 Research problem

Although the phenomenon of HIV and AIDS has prompted increased research interest in adolescents and young adults who constitute about 21% of people living with HIV in SSA (UNAIDS, 2012), very little attention has been given to adolescents living with vertically acquired HIV in the region. Much of the research on adolescents living with HIV (ALHV) in SSA has been confined to the epidemiology

of sexually acquired HIV infection amongst 15-24 year olds with considerable emphasis on primary prevention of HIV infection among adolescents and minimal attention on lived experiences of adolescents who are already infected. Furthermore when the issues of ALHIV are discussed, they rarely distinguish those adolescents who are vertically infected from those who sexually acquired HIV, choosing instead to broadly discuss ALHIV as a single population.

Adolescents living with vertically acquired HIV (10-19 years) emerge as a unique population of people living with HIV (PLHIV) in SSA. Descriptive studies on ALHIV in Southern Africa demonstrate that clinical status varies by transmission i.e. vertical or sexual (Nachega, Hislop, Nguyen, Dowdy, Chaisson, Regensberg, Cotton & Maartens, 2009; Nglazi, Kranzer, Holele, Kaplan, Mark, Jaspan, Lawn, Wood & Bekker, 2012). Adolescents who acquire HIV infection sexually during adolescence enter HIV treatment and care without obvious symptoms of HIV but with moderate immune dysfunction. In contrast, adolescents living with vertically acquired HIV are likely to have advanced AIDS disease with a history of opportunistic infections (Dolfus, Le Chenadec, Faye, Blanche, Briand, Rouzioux & Warszawski, 2010; Ferrand et al. 2007; Ferrand et al. 2009a; Ferrand et al. 2010a; Frederick, Thomas, Mascola, Rakusan, Mapson, Weedon & Bertolli, 2000).

To date, studies on lived experiences of adolescents living with vertically acquired HIV in SSA are limited. As a result issues and information about this growing population of adolescents are poorly understood and documented in SSA. Several research studies have highlighted the need to investigate and address emotional and social issues affecting adolescents who acquired HIV vertically in resource poor countries (Ferrand et al. 2010b; Jaspan et al. 2009). Knowledge gained from this study will therefore contribute to the empirical knowledge of lived experiences of adolescents living with vertically acquired HIV in resource poor settings like South Africa.

1.3 Rationale of the study

Adolescents living with vertically acquired HIV are becoming a significant proportion of the population of South Africans living with HIV and AIDS. However very little social research exists on the lived experiences of adolescents living with vertically acquired HIV. Being the first generation of long-term survivors of HIV in South Africa who have carried the virus since birth, adolescents living with vertically acquired HIV emerge as an increasingly important and unique population whose experiences need to be known and understood.

This shift in the pattern of the HIV and AIDS epidemic in adolescents requires social service providers to recognize and address the issues of the growing population of ALHIV. Consequently, an in-depth understanding of the lived experiences of adolescents living with vertically acquired HIV is critical to determining developmentally appropriate services aimed at improving their psychosocial well-being, continued health and overall quality of life.

Qualitative studies on adolescents living with vertically acquired HIV in South Africa tend to research adolescents from an adult/caregiver or service provider perspective (Heeren, Jemmott, Sidloyi, Ngwane & Tyler, 2012; Madiba, 2012; Mahloko and Madiba, 2012). Adolescents' own experiences tend to be under-represented in the literature of adolescents living with vertically acquired HIV in South Africa and SSA as a whole. However Eder & Fingerson (2003) highlighted the importance of adolescents' participation in research processes concerning issues that concern them. Other researchers (Deacon & Stephney, 2007) have observed that the caregiver reports may be an inaccurate measure of adolescents' perception on their lived experiences.

This study therefore explored the lived experiences of adolescents living with vertically acquired HIV with a view to build a holistic picture of their experiences formed by the words reported by the adolescents themselves.

1.4 Aim of the study

The aim of this study was to explore the lived experiences of adolescents living with vertically acquired HIV receiving treatment, care and support services at Dora Nginza Wellness clinic. This was done in order to enhance understanding of the meanings the adolescents attribute to their experiences of living with HIV since birth and determine care and support services developmentally appropriate for this population based on the study's findings.

1.5 Objectives of the study

The following objectives are outlined to accomplish the aim of the research study:

- i. To explore the lived experiences of adolescents living with vertically acquired HIV receiving treatment, care and support services at Dora Nginza Wellness clinic.
- ii. To determine care and support services developmentally appropriate for adolescents living with vertically acquired HIV.

1.6 Research questions

The main research question guiding this study may be formulated as follows: *What are the lived experiences of adolescents living with vertically acquired HIV and what kind of care and support would be developmentally appropriate for these adolescents?* In order to explore the main research question fully the following sub-questions will be explored:

- i. What are the lived experiences of adolescents living with vertically acquired HIV receiving treatment, care and support services at Dora Nginza Wellness clinic?
- ii. What care and support services would be developmentally appropriate for adolescents living with vertically acquired with HIV?

1.7 Study context

This case study on the lived experiences of adolescents living with vertically acquire HIV was conducted at Dora Nginza Hospital Wellness clinic, which is one of the Dora Nginza Hospital's departments. Dora Nginza Hospital is a large provincial government funded hospital, situated in a black urban residential township of Port Elizabeth in South Africa. The hospital was established in 1979 and is the only hospital that has a paediatric disease clinic in the Eastern Cape Province. Dora Nginza Wellness clinic was established in 2005. It shares half of the responsibility of providing HIV treatment, care and support services to people living with HIV (PLHIV) in the Nelson Mandela Metropolitan. The multi-disciplinary team that performs various functions maintains ongoing disease management to PLHIV. The adolescent division of the clinic was formed in 2009. It was formed due to the growing need to serve the first group of children growing up with HIV entering adolescence.

1.8 Research methodology

A qualitative, exploratory case design was used as the research design. The population for the study comprised of adolescents living with vertically acquired HIV receiving HIV treatment, care and support services at Dora Nginza Wellness clinic. A purposive sampling method was used to select study participants. Information was gathered directly from the participants' by means of in-depth semi-structured open-ended individual interviews. An interview schedule was used as a data collection instrument. All interviews were audio recorded. Data analysis was conducted using Tesch's method of data analysis for qualitative data, which encompasses reading and re-reading verbatim transcripts of all interviews conducted, listing all topics, coding and categorizing themes. A detailed description of the research methodology is given in Chapter 3.

1.9 Trustworthiness of the study

The researcher used strategies adopted by Lincoln & Guba (1985:290) to establish the trustworthiness of the research data. These strategies include credibility,

dependability, conformability and transferability, which will be discussed in detail in Chapter 3.

1.10 Ethical considerations

In order to reduce the risks of ethical violations in the research process, the researcher maintained ethical principles (as identified in De Vos, Strydom, Fouché & Delport, 2005: 58-67; De Vos, 2001:24-34). The following core ethical principles of avoidance of harm, informed consent, voluntary participation, and confidentiality were ensured during the study.

1.11 Definition of key terms

Acquired Immune Deficiency Syndrome (AIDS) is an epidemiological disease based on clinical signs and symptoms caused by HIV. AIDS is caused by HIV (UNAIDS, 2011).

An **adolescent** is defined by WHO as an individual in the 10-19 age group (WHO, 2010). In this study an adolescent refers to a person between the age of 10 and 19 years of age who contracted HIV through vertical transmission.

Antiretroviral therapy (ART) is a medical treatment which consists of a combination of one or more different class antiretroviral drugs (ARVs) to suppress a retrovirus and one of the retrovirus is the HIV which causes AIDS. Antiretroviral therapy slows down replication of the virus and can greatly enhance quality of life (UNAIDS, 2011).

Human Immunodeficiency Virus (HIV) is a retrovirus that causes AIDS. HIV destroys the body's ability to fight off infection and disease, which ultimately leads to AIDS (UNAIDS, 2011).

Living with HIV refers to a condition when antibodies against HIV have been detected on a blood test or a gingival exudates test. Synonym: seropositive (UNAIDS, 2012)

Vertical transmission of HIV is the transmission of HIV from an infected pregnant woman to her newborn child. HIV transmission can occur at any time during pregnancy, delivery or breastfeeding (WHO, 2010). The same definition applied in this study.

1.12 Overview of chapters

Chapter 1 gives an introduction and background of the study. The research problem, the rationale of the study, objectives of the study, research questions, the study context, and a brief discussion of the research methodology are discussed in this chapter.

Chapter 2 reviews literature pertaining to the study. It provides an analysis and examination of both national and international information sources related to ALHIV with specific reference on adolescents living with vertically acquired HIV. It concludes with a discussing of the theoretical framework which guided the study.

Chapter 3 describes the research design and methodology employed in the study. Qualitative research methods adopted for this study are described. The chapter encompasses the steps and actions that the researcher took in conducting the study and analyzing the data. The chapter concludes by discussing the research ethics that were adhered to in conducting the study.

Chapter 4 presents the findings of the study. The findings are discussed in accordance to the two research questions posed by the study (Refer to Section 1.5). A description of the biographical information of the study participants and themes that emerged during data analysis related to participants' lived experiences

are discussed together with the care and support services determined from the study findings.

Chapter 5 concludes the study. It gives a summary of study findings and the limitations of the study. The chapter concludes with suggestions for further research and recommendations for policy and practice.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter discusses research pertaining ALHIV globally with specific reference to adolescents living with vertically acquired HIV in SSA and in particular, South Africa. The literature review covers significant content areas related to the study's key research interests on lived experiences of adolescents living with vertically acquired HIV. The chapter concludes by discussing the Social Ecological Model (SEM) which provides the theoretical framework of this study, and situates SEM in the context of adolescents living with vertically acquired HIV.

2.2 Adolescents living with HIV in sub-Saharan Africa

Sub-Saharan Africa remains the region in the world heavily affected by HIV and AIDS, with Southern Africa remaining at the epicentre of the epidemic. The United Nations Children's Fund (UNICEF, 2011) has reported that 2.2 million adolescents (10-19 years) have been living with HIV as of 2010. An estimated 1.2 million ALHIV lived in SSA. Countries with the highest HIV prevalence with over one in 20 adolescents living with HIV, were South Africa (292 000), Zimbabwe (104 000), Mozambique (89 000), Malawi (81 000), Zambia (80 000), Lesotho (19 800) and Botswana (14 600), (UNICEF, 2011).

Sohn & Hazra (2013) have highlighted the lack of knowledge regarding the global numbers of adolescents living with vertically acquired HIV over the age of 15 years because global reporting does not differentiate between adolescents living with vertical and behaviourally acquired HIV. They have noted that the lack of a global surveillance system or mechanism for tracking children living with vertically acquired

HIV as they transit to adulthood results in a lack of understanding of whether they are retained in care or lost to follow up.

Nonetheless, surveys conducted in South Africa, Botswana, Zimbabwe, Zambia, and Swaziland have reported a substantial burden of vertically acquired HIV between the ages of 10-19 years (Ferrand et al. 2009a; Ferrand et al. 2009b; Ferrand et al. 2010a; Gray, 2009; Jaspán et al. 2009; Mahloko & Madiba, 2012). Results from a study conducted by Ferrand et al. (2009b) have predicted a substantial epidemic of HIV in vertical adolescent survivors in South Africa and Zimbabwe with the prevalence of vertically acquired HIV among 10 year olds estimated to increase from less than 0.2% in 2000 to 3.3% by 2020 in South Africa (Jaspán et al. 2009). In 2009, there were 334 000 children (0-14 years) living with HIV in South Africa (Department of Health, 2010).

Very few studies have investigated the lived experiences of this unique, emerging population of adolescents living with vertically acquired HIV in South Africa. Various authors stress that the growing population is poorly served by care and support services largely because of under estimation of the extent of the nature of adolescents living with vertically acquired HIV in SSA (Birungu, Obare, Mugisha, Evelia & Nyombi, 2009; Hodgson, Ross, Haamujompa & Gitau-Mburu, 2012; Cataldo, Malunga, Rusakaniko, Umar, Teles & Musandu, 2012).

2.3 Adolescents living with vertically acquired HIV

Research done in SSA indicates that it is more common than previously thought for vertically infected children to live into adolescence even without access to ART and often being unaware of their HIV status (Ferrand et al. 2007a; Ferrand et al. 2009a; Ferrand et al. 2010a; Mahloko & Madiba, 2012). These studies show that there is a significant number of adolescents living with vertically acquired HIV in Southern Africa including adolescents who are long term survivors of vertically acquired HIV who remain undiagnosed until they develop advanced AIDS.

As in the case in all Southern African countries, the population of South African children born with HIV is ageing into adolescence and young adulthood as a result of maturing HIV epidemic, earlier paediatric diagnosis and provision of ART (Jaspan et al. 2009). Descriptive studies demonstrate that adolescents living with vertically acquired HIV inherit more than just the HIV virus, but a complex web of biological, social and psychological vulnerabilities (Frederick et al. 2000; Futterman, 2004). Vertically infected adolescents unlike adolescents infected via behavioural routes are more likely to be in advanced stages of HIV, with a history of opportunistic infections (Ferrand et al. 2007; Ferrand et al. 2009a; Ferrand et al. 2010a; Ferrand et al. 2010b), more complicated co-morbidities (Little et al. 2007), orphaned (Ferrand et al. 2007; Mavhu, Berwick, Chirawu, Makamba, Copas, Dirawu, Willis, Araya, Abas, Corbett, Mungofa, Laver & Cowan, 2010), with different mental health support needs (Kamau, Kuria, Mathai, Atwoli & Kangethe, 2012; Kang, Mellins, Ng, Robinson & Abrams, 2008) and on complex treatment regimens related to both long-term HIV and ART exposure (Nachega et al. 2009; Nglazi et al. 2012). HIV interferes with the normal developmental process of puberty by delaying physical and intellectual development (Buchacz, Rogol, Lindsey, Wilson, Hughes, Seage 3rd, Olesk & Rogers, 2003; Lowick, Sawry & Meyers, 2012). The combination of HIV related issues of life expectancy, death, bereavement, orphanhood, change of caregivers, poverty, stigma, family silence, disclosure, transmission of the virus to others and the rapid changes of adolescents create an exceptional and formidable challenge to adolescence living with vertically acquired HIV (Ferrand et al. 2010b; Kamau et al. 2012; Petersen, Bhana, Myeza, Alicea, Johns, Holst, McKay & Mellins, 2010).

2.4 Adolescence and HIV and AIDS

Adolescents living with vertically acquired HIV embark on a new phase both in their lives and in the course of their disease as they transit from the paediatric to adult HIV care and treatment programmes (Birungi et al. 2009). A dual crisis occurs as the adolescent try to cope with illness related stressors and the normal stressors associated with adolescent development (Bakeera-Kitaka, 2006).

While adolescents living with vertically acquired HIV are familiar with illness, that is, the lay experience of being sick, it is only upon disclosure which usually takes place during the adolescence phase that they are really able to confront their disease as a clinical phenomenon (Fielden, 2005). For these adolescents, the ill-self is familiar but the HIV positive self is not. This new information as well as the new phase of adolescence, elicits responses to illness, making sense of their disease and integrating an HIV identity to their emerging adult selves (Kang et al. 2008). With this knowledge about their HIV diagnosis they confront the cultural and societal definitions of HIV and AIDS, which now pertain to them. They must embark on a quest to discover what HIV means to them in a society and culture where the definition of HIV and AIDS provokes stigmatising associations and labels (Deacon & Stephney, 2007). As such the quest for meaning and identity may be arduous and psychologically demanding.

For any adolescent, the formulation of meaning and identity is novel and potentially confusing (Balk, 1995). For an adolescent living with vertically acquired HIV, identity development can be negatively impacted by illness (Hosek, Harper & Domanico, 2005). Some adolescents living with vertically acquired HIV have had difficulties with their HIV identity because they do not want to be associated with other adolescents and adults who were infected behaviourally through stigmatised behaviours such as promiscuity, drug use and homosexuality (Kang et al. 2008).

For adolescents living with vertically acquired HIV, transition into adulthood includes an important shift towards medical independence which includes activities such as self management, scheduling appointments and refilling medications (Murphy, Greenwell & Hoffman, 2002; Roberts, 2000). Their development of autonomy is a complex issue affected by an unexpected future they now have and by the effort of parents or caregivers to delay the normal course of growth and maturing as well as the knowledge of their disease (Battles & Weiner, 2000). Marlink & Teitelman (2009) have acknowledged that many adolescents with chronic illnesses are at

higher risk than their peers for unnecessary dependency. Autonomy as competence may also be challenged by a complicated family dynamic where one or more members are also living with HIV and have died or might die. Knowing that AIDS has taken family members or severely burdened the family may affect how much the adolescent can believe in their own abilities to act, plan and strive (Steel, Nelson & Cole, 2007).

Cohort studies in Southern Africa have shown that ALHIV are less likely to adhere to antiretroviral drugs (ARVs) than adults (Bygrave, Mtangirwa, Ncube, Ford, Kranzer & Munyaradzi, 2012; Nachega et al. 2009; Nglazi et al. 2012) and have lower survival rates compared to younger children (Bakanda, Birungi, Mwesigwa, Nachega, Chan, Palmer, Ford & Mills, 2011). These studies and others (Chandwani, Koenig, Sill, Ambramowitz, Conner & D'angelo, 2012; Ferrand et al. 2010b; Shroufi Gunguwo, Dixon, Nyathi, Ndebele, Taziwa, Fereyra, Vinales & Ferrand, 2013) clearly show that adolescents are not adhering to ARV medication and this is a major concern as non-adherence to ART can increase the risk of drug resistance and morbidity.

Several qualitative studies in SSA have identified a number of psychosocial factors associated with poor adherence and non-adherence among ALHIV. These include stigma, delayed disclosure, depression, stigma, alcohol use, difficulty in identifying with HIV-negative peers, anxiety about sexual relationships and future planning, low self-esteem and feelings of hopelessness which are sometimes compounded by the adolescent having to head a family, and having to take care of ill relatives and siblings (Bakanda et al. 2011; Chandwani et al. 2012; Ferrand et al. 2010b; Li, Jaspán, O'Brien, Rabie, Cotton & Natrass, 2010; Nglazi et al. 2012). Other studies have found structural factors outside the adolescents' control which include ARV stock outs, lack of access to the clinic, transportation difficulties and poverty as barriers to ART adherence (Atuyambe, Neema, Otolok-Tanga, Wamuyu-Maina, Kasasa & Wabwire-Mangen, 2008; Nachega, Leisegang & Bishau, 2010).

The issue of stigma is linked to various issues, such as when the main caregiver is away there is fear of disclosure and some caregivers face difficult decisions about whom to ask to support drug adherence for their child in their absence; or the death of a caregiver, leaving no one to administer ARV treatment to the child; or even the child being away visiting relatives could cause problems in adherence to drugs, as the responsibility is then left to the child (Chi, Cantrell, Zulu, Mulenga, Levry, Tambatamba, Reid, Mwangi, Mwinga, Bulterys, Saag & Stringer, 2009).

2.5 HIV status disclosure to children and adolescents living with vertically acquired HIV

Issues regarding HIV diagnosis disclosure take an additional importance as children living with vertically acquired HIV reach adolescence (Steele et al. 2007; Throne, Newell, Botet, Bohlin & Ferrazin, 2002). As adolescents living with vertically acquired HIV reach puberty and become sexually active, they carry great risk of transmitting HIV to others and may even result in a second generation of children to which HIV is transmitted vertically. Therefore, knowing about their HIV status is an essential part of HIV prevention within the larger population.

The South African Department of Health (Department of Health, 2010) and WHO (2011) recommend informing children of their HIV diagnosis. Several studies from SSA suggest that disclosure of HIV status to children and adolescents has positive outcomes on their lives, compared to keeping the HIV diagnosis as a secret (Biadgilin, Deribew, Amberbir & Deribe, 2009; Brown, Oladokun, Osinusi, Ochigbo, Adewole & Kanki, 2011; Bulter, Williams, Howland, Storm, Hutton & Seage 3rd, 2009; Heeren et al. 2012; Kallem, Renner, Ghebremichael & Paintsil, 2011; Menon, Glazebrook, Campaign, & Ngoma, 2007; Vaz, Maman, Eng, Barbarin, Tshikandu & Behets, 2011). According to the findings of these studies disclosure increases the knowledge and understanding of HIV and AIDS, helps facilitate adolescent's adjustment to the illness, improves psychosocial well-being and adherence (Biadgilin et al. 2009; John-Stewart, Wariua, Beima-Sofie, Richardson, Farquhar, Maleche-Obimbo Mbori-Ngacha & Wamalwa, 2012; Kallem et al. 2011; Vaz, Eng,

Maman, Tshikandu & Behets, 2010), boosts self-esteem and decreases risk behaviours (Vaz, Corneli, Dulyx, Rennie, Omba & Kitetele, 2008) .

Furthermore, within children's and adolescent's own experiences of living with HIV and adherence to ARVs, disclosure helps to maintain their right to know and participate in their care (Bikaako-Kajura, Luyikira, Purcell, Downing, Kahazura, Mermin & Bunnell, 2006; De Baets, Sifovos, Parson & Pazvakarambwa, 2008; Heeren et al. 2012; Vaz et al. 2010). In these studies children and adolescents indicate negative effects of delayed disclosure and positive effects of disclosure. They have reported the desire to know their HIV status and for honest and open talk about their illness (Bikaako-Kajura et al. 2006; Blasini, Chantry, Cruiz, Ortiz, Slabbarria & Scalley, 2004; Heeren et al. 2012; Hodgson et al. 2012; Mellins, Brackis-Cott, Dolezal, Richards & Nicholas, 2002; Vaz et al. 2010; Vaz et al. 2008). In a qualitative South African study, children who had been informed of their HIV diagnosis at a mean age of 12 years expressed that they thought it would be better if their caregivers had informed them around the age of five (Heeren et al. 2012). Adolescents report to perceive more support from their social network after being informed about their status (Hodgson et al. 2012).

Despite these benefits, growing evidence found extremely low full HIV disclosure rates and high rates of partial HIV disclosure rates among children and adolescents living with vertically acquired HIV in SSA (Abebe & Teferra, 2012; Biadgilign, Deribew, Amberbir, Escudero & Deribe, 2011; Biadgilign et al. 2009; Brown et al. 2011; Kallem et al. 2010; Mahloko & Madiba, 2012; Vaz et al. 2010). In a sample of Ugandan children living with HIV between the ages of 5 and 17 years, only 29% of the children knew their HV diagnosis (Bikaako-Kajura et al. 2006). Another Ugandan study found a slightly higher disclosure rate of 59% in children between 8 and 18 years (Nabukeera-Barungi, Kalyesubula, Kakitiinwa, Byakika-Tusime & Musoke, 2007). In a Zambian cohort of adolescents between 11 and 15 years, only 37.8% of the adolescents had undergone disclosure (Menon et al. 2007). In a cross-sectional survey of caregivers of children living with HIV in South Africa, 61% of children were

disclosed to between the ages of 10 to 13 years (Madiba, 2012). In a Congolese study, disclosure did not occur until a mean age of 15 years (Vaz et al. 2008), though this figure was influenced by late diagnosis of vertical transmission until adolescence.

While there are significant variations in the above findings in SSA, in 3 out of the 5 of these studies, disclosure occurred later than studies in North America (Throne et al. 2002; Wiener, Mellins, Marhefka & Battles, 2007). On the other hand, these results fall more in line with research done in other resource-limited settings, such as India (Oberdorfer, Puthanakit, Louthrenoo, Sirisanthana & Sirisanthana, 2006) where disclosure of HIV status to children living with vertically acquired HIV occurs between the ages of 10 and 16 years. Differences suggest that context plays an essential role in the decision whether and when to tell children about their HIV positive diagnosis, and highlight significant challenges that disclosure poses to caregivers and health care providers in SSA (Heeren et al. 2012; Madiba, 2012).

Studies in South Africa report that caregivers of children living with HIV who have the prerogative to disclose HIV diagnosis commonly do not disclose information to the children (Heeren et al. 2012; Madiba, 2012; Mahloko & Madiba, 2012; Kouyoumdjian, Meyers & Mtshizan, 2005; Moodley, Myer, Michaels & Cotton, 2006). Caregivers have cited numerous barriers to disclosure of children's and adolescent's HIV status and these barriers have been found to be similar across SSA.

Among caregivers, the most common reason for non-disclosure is that the child is too young or immature to understand his or her diagnosis (Heeren et al. 2012; Madiba, 2012; Mahloko & Madiba, 2012; Moodley et al. 2006). However, there is no general consensus on what qualifies a child to be too young to understand HIV diagnosis. In a South African study, caregivers thought that a mean of 11 years and 12 years were the most appropriate ages for partial and full disclosure respectively (Moodley et al. 2006). Conversely health workers recruited from the same site

favoured partial disclosure at the age of 6 and full disclosure at 10 years. In another South African study, caregivers agreed that children aged between 5 and 6 years should learn about their HIV diagnosis (Heeren et al. 2012). In rural Zimbabwe, community members and health care workers preferred a mean age of plus 10 years for partial disclosure and plus 14 years for full disclosure (De Baets et al. 2008). In a study in Kenya the median preferred age of disclosure preferred by caregivers was 12 years (John-Stewart et al. 2012) and 13.4 years in Nigeria (Brown et al. 2011).

Apart from age, caregivers also cited lack of knowledge and skills to disclose to children and to handle the children's reactions (Heeren et al. 2012; Kouyoumdjian et al. 2005; Madiba, 2012; Mahloko & Madiba, 2012), parental discomfort talking about their own HIV status, parental feelings of guilt about infecting their child (Lee & Johann-Liang, 1999) and concern that disclosure will have negative psychological effects on the child (Heeren et al. 2012; Madiba, 2012; Vaz et al. 2011; Vreeman, Nyandiko, Ayaya, Walumbe, Marrero & Inui, 2010). However findings from USA and Zambia (Butler et al. 2009; Menon et al. 2007) suggest that disclosure does not have a negative impact on children's and adolescents' mental health.

According to Deacon & Stephney (2007), stigma and discrimination play an important role in parental/caregiver decision on disclosure of HIV status to children and the process of disclosure. Fear of discrimination, fear of social rejection and isolation and fear of being judged as promiscuous or associated with a disease of gay people were some of the barriers for disclosure identified by parents/caregivers (Biadgilin et al. 2009; Kallem et al. 2011; Kouyoumdjian et al. 2005; Moodley et al. 2006; Vaz et al. 2008; Weiner & Battles, 2006). Caregivers in South Africa fear that disclosure to the child will lead to accidental disclosure by the child and adversely the family HIV status to other children, extended family and neighbours (Heeren et al. 2012; Madiba, 2012; Mahloko & Madiba, 2012; Moodley et al. 2006) and causing discrimination against the child or the whole family.

On the other side, the most common motivators for HIV disclosure to children and adolescents have included caregivers' belief that a child had a right to know their HIV diagnosis (Moodley et al. 2006; Vaz et al. 2010; Vaz et al. 2008), fear that the child might learn his or her diagnosis from other sources (De Baets et al. 2008; Mahloko & Madiba, 2012), concern that the child will become sexually active and might infect others (Vaz et al. 2008; Vaz et al. 2011), older age (Vaz et al. 2011), medical reasons; either because they were not taking their medication properly or because they were about to start their regime (Madiba, 2012; Mahloko & Madiba, 2012; Vaz et al. 2010).

For South Africa, the country with the largest paediatric ART programme in the world with 105 123 children on ART in 2010 (Statistics South Africa, 2011), it is imperative that researchers and specifically health care providers understand why, when and how caregivers disclose HIV to their children living with HIV and develop programmes to support caregivers in disclosure. The development of effective programmes to assist parents/caregivers to disclose HIV diagnosis to children and ALHIV requires an understanding of parents/caregivers beliefs about HIV disclosure as well as those of children and ALHIV. Several researchers have called for a shift in emphasis from whether or not to disclose to children and ALHIV to providing culturally appropriate support to parents/caregivers and developmentally appropriate information to children and adolescents (Kallem et al. 2011).

2.5.1 Adolescents disclosure of their HIV status

Adolescents living with vertically acquired HIV deal with disclosure issues on multiple levels from finding out their own HIV positive status, to deciding to disclose their status to others. Literature on adolescents living with vertically acquired HIV disclosing their own HIV status to others is still limited in SSA. Most of the South African studies on HIV disclosure to children and adolescents living with vertically acquired HIV have researched issues around HIV disclosure from the parent, caregiver or health care provider perspective (Kouyoumdjian et al. 2005; Madiba,

2012; Mahloko & Madiba, 2012; Moodley et al. 2006) hence there is very little literature on adolescents' point of view.

Nonetheless, adolescents are quite articulate about their entitlement to control disclosure of their HIV status to others (Heeren et al. 2012; Mburu, Hodgson, Teltschik, Ram, Haamujompa & Mutali, 2013). A qualitative study in Uganda reviewed that most ALHIV did not disclose their HIV status (Siu, Bakeera-Kitaka, Kennedy, Dhabangi & Kambugu, 2012). While many adolescents shared their HIV status with family, they were reluctant to tell peers at school (Hodgson et al. 2012; Obare, Birungi, Katoaire & Kibenge, 2011a). Adolescents also shared positive and negative experiences of disclosing their HIV status to their peers, friends and family (Hodgson et al. 2012; Li et al. 2010; Michaud, Suris, Thomas, Kahlert, Rudin & Cheseaux, 2009; Sherman, Bonanno, Weiner & Battles, 2000; Siu et al. 2012; Thupayagale-Tshweneagae, 2010; Weiner & Battles, 2006). In these studies fear of stigma and discrimination along with the associated problems of rejection, abandonment, abuse and isolation were commonly cited barriers and determinants of the number of people adolescents disclose their HIV status to.

Partner disclosure proves to be most challenging as adolescents fear rejection and loss of respect if their status is known (Siu et al. 2012; Weiner & Battles, 2006). However, findings from USA suggest that those adolescents who chose to disclose report greater self-competence with their partners and peers (Battles & Weiner, 2000; Weiner & Battles, 2006), increased social support and decreased problem behaviour (Battles & Weiner, 2000). On the contrary, it has been found that self-disclosure is not related to self-concept or problem behaviour but the same study found a significant increase in CD4 count of adolescents who had disclosed their HIV status (Sherman et al. 2000). This finding might imply that self-disclosure is positively related to self adherence to ART treatment considering the increase in CD4 count.

The above review of literature on disclosure indicates gaps in research on experiences of HIV disclosure by adolescents living with vertically acquired HIV. Attempts have been made in this study to further investigate the identified phenomenon. This study explores the lived experiences of adolescents living with vertically acquired HIV and investigates disclosure of HIV status on the perspective of the adolescents looking at when and who informed the adolescents about their HIV status, the circumstances leading to disclosure, their reactions to the disclosure and to whom the adolescents disclose their status to and the motivations or barriers to self disclosure.

2.6 Mental health of adolescents living with vertically acquired HIV

Adolescence is an important period for mental health development. Global figures indicate that within this developmental phase, 20% of individuals suffer from a clinically significant mental illness and suicide is the third leading cause of death (Belfer, 2008). Mental health disorders have been shown to occur with increased frequency among adolescents living with vertically acquired HIV (Hazra, Siberry & Mofenson, 2010; Malee, Tassiopoulos, Huo, Siberry, Williams & Hazra, 2011). Adolescents living with vertically acquired HIV are affected by the normal pressures of adolescence, along with a number of additional complex interacting biological, psychological and social stressors, which are related specifically to living with HIV (Brown, Lourie & Pao, 2000; Veinot, Flicker, Skinner, McClelland, Saulnier, Read & Goldberg, 2006; Lee, Gortmaker, McIntosh, Hughes, & Oleskel, 2006). In addition, as prior stated, adolescents living with vertically acquired HIV reach puberty later than their negative peers, raising questions about personal identity.

Clinical reports from the USA indicate substantive mental health problems in adolescents who acquired HIV vertically such as attention-deficit hyperactivity disorder, depression, adjustment disorder, post-traumatic stress disorder and anxiety, relative to their uninfected peers (Brown et al. 2000; Murphy, Moscicki, Vermund & Muenz, 2000). A study which explored the psychological stressors and manifestation of psychiatric dysfunction of 84 children living with vertically acquired

HIV by Brown et al. (2000) found an association between poor emotional functioning, social support and school performance. Mellins, Brackis-Cott, Dolezal & Abrams (2006) have investigated psychiatric symptoms in adolescents living with vertically acquired HIV aged 9-16 years. Results of this study have revealed a 55% prevalence of psychiatric disorder, primarily in the anxiety and behavioural domains. A cross-sectional study of Zambian ALHIV of school going age range of 11-15 indicated that Zambian ALHIV had increased mental health problems compared to a British sample (Menon, Glazebrook & Ngoma, 2009).

Qualitative investigations conducted in South Africa with ALHIV indicated that an ALHIV experience similar psychosocial challenges and concerns to those in developed countries (Li et al. 2010; Petersen et al. 2010). Challenges include lack of disclosure of HIV status, erratic drug taking, stigma, difficulty in identifying with HIV negative peers, anxiety about sexual relationships and low self-esteem. Adolescents living with vertically acquired HIV in both SSA and USA also reported emotional problems such as feeling angry and fearful of HIV, depression, emotional pain due to stressful life events like severe illness and death of parents, siblings or close relatives, worrying about who will take care of them, poverty, social withdrawal, loneliness, anger, crime, violence and stigma (Ferrand et al. 2007; Kamau et al. 2012; Li et al. 2010; Mavhu et al. 2010; Murphy et al. 2000; Petersen et al. 2010).

This often translates into high rates of depression, conduct disorder, social phobia and attention deficit hyperactivity disorder among adolescents living with vertically acquired HIV (Kamau et al. 2012; Mellins et al. 2006). AIDS severity also appears to affect many psychological disorders. A study by Nachman, Chernoff, Williams, Hodge, Heston & Gadow (2012) found that adolescents with lower CD4 percentages had more severe conduct disorder symptoms. The same study found that higher viral load was associated with more severe depression symptoms.

Comparably recent studies have also found contrasting evidence to the average described situation of children and adolescents living with vertically acquired HIV as being subject to psychosocial problems. Studies in Botswana and Tanzania report that adolescents living with vertically acquired HIV on ART live healthy and normal lives and view themselves with positive identities in spite living with a chronic illness (Midtbo, Shirima, Skovdal & Daniel, 2012). Similarly, a study in France revealed that adolescents living with vertically acquired HIV who were followed since birth, had physical development and school achievement similar to nationwide statistics (Dollfus et al. 2010). Research studies like these which compares the psychosocial functioning of adolescents living with vertically acquired HIV to that of control groups from the same communities is particularly important given the importance of research on psychosocial wellbeing adolescents living with vertically acquired HIV.

In conclusion, a review of literature on the mental health of adolescents living with vertically acquired HIV offers mixed findings, with some studies finding greater levels of psychosocial problems among adolescents living with vertically acquired HIV, whilst others find no significant differences between adolescents living with vertically acquired HIV and their peers who are HIV negative. The reason for these mixed findings might be that some of these studies are based on health care professionals' or caregivers' reports which might not give a perspective of adolescents' real experiences.

2.7 Sexual and reproductive health of adolescents living with vertically acquired HIV

Sexual activity is often initiated during adolescence, with risk taking and experimentation being considered normal and many adolescents not taking necessary HIV preventative measures (Futterman, 2004), thus increasing the risk of HIV infection. For adolescents living with vertically acquired HIV, important developmental tasks may be interrupted with sexual development being impeded, subsequently putting strain on meaningful peer relationships (Sherr, 1997) and normal coping mechanisms. Additionally, adolescents living with HIV need to come

to terms with their future sexuality and integrate a new adult body image (Sherr, 1997).

Addressing sexual and reproductive health (SRH) needs of adolescents living with vertically acquired HIV introduces a complex chapter in the fight against HIV and AIDS mainly because of the intricate relationship between sexuality and the main modes of HIV transmission. Adolescents living with vertically acquired HIV have the same SRH needs as other adolescents and do not lose their desire for sex or to have families (Baryamutuna & Baingana, 2011; Birungi et al. 2009; Mburu et al. 2013). Many have had sex or intend to in the future, have numerous unanswered questions relating to sex (Birungi et al. 2009) and have concerns about infecting others, having children safely and disclosing to partners (Li et al. 2010; Obare, Van der Kwaak, Adieri & Owuor, 2010; Birungi et al. 2009).

The desire to have children and a family by adolescents living with vertically acquired HIV has also been extensively documented in SSA (Baryamutuna & Baingana, 2011; Birungi et al. 2009; Busza, 2011; Cataldo et al. 2012; Hodgson et al. 2012; Li et al. 2010; Mburu et al. 2013; Obare et al. 2010). In a Ugandan study of adolescents living with vertically acquired HIV, only one-third of the respondents had never had sex, and of these, 86% intended to have sex in future (Birungi et al. 2009). In a Kenyan study, three quarters of participants wanted to have children in future, although most wanted to delay this to later in life (Obare et al. 2010). Despite this, low rates of contraceptive use (66%) were reported, 68% of sexually active female respondents had already been pregnant and three-quarters of those were unintended pregnancies (Obare et al. 2010). Other studies in Eastern Africa have reported the same findings (Bakeera-Kitaka, Nabukeera-Barungi, Nostinger, Kekitinwa & Colebunders, 2008; Beyeza-Kashesya, Kaharuza, Ekstrom, Neema, Kulane, & Mirembe, 2011; Busza, 2011) including unsafe sexual behavior (Busza, 2011; Birungi et al. 2009). Similarly in a study from the United Kingdom (UK) of female adolescents living with vertically acquired HIV, one-fifth had been pregnant and 75% of these were unplanned pregnancies (William, 2010).

A large multi-country cross-sectional observational study of ALHIV in Malawi, Mozambique, Zambia and Zimbabwe has revealed that SRH needs of adolescents living with vertically acquired HIV in Southern Africa remain largely unaddressed by existing HIV and AIDS programmes (Cataldo et al. 2012). Hodgson et al. (2012) maintain that HIV services in this region reveal significant gaps in age-appropriate support regarding sexuality and relationships including inadequate support for ALHIV as they embark on sexual and love relationships. This is mostly because such services promote young people living with HIV to refrain or postpone sexual activity. Consequently stigma, fear of discrimination, secrecy and lack of privacy at local clinics were the main setbacks to accessing reproductive health services in local clinics in qualitative studies of ALHIV which focused on reproductive and sexual health issues (Birungi et al. 2009; Busza, 2011; Cataldo et al. 2012; Hodgson et al. 2012).

Findings by (Baryamutuma & Baingana, 2011; Hodgson et al. 2012) reinforce the observation from studies from developed countries (Fielden, 2005; Fielden, Scheckter, Chaman, Alimenti, Forbes, Sheps, Caldells & Frankish, 2006) that adolescents living with vertically acquired HIV need SRH education interventions designed to address their particular needs at different stages of their development. Based on their findings on sexual behaviour and procreational intentions of such adolescents, (Williams, 2010) recommend innovative intervention programs offering reproductive health education including procreational choices and considerations.

This suggests that interventions designed to reduce the risk of sexually transmitting HIV by this population require developmentally appropriate psychosocial approaches that target stigma, perceptions of peer influence and separate SRH services for adolescents living with vertically acquired HIV. However the almost exclusive focus on the negative implications of HIV tends to hinder initiation of programmes aimed at addressing the SRH of adolescents living with vertically acquired HIV. This problem is accompanied by the false assumption that

adolescents living with vertically acquired HIV in SSA may be too few to justify targeted programming and the reluctance to acknowledge that it is natural for them to have sexual desires and needs and therefore act upon them (Birungi et al. 2009).

2.8 Theoretical framework

The study is based on the Social Ecological Model (SEM), which recognizes the intertwined relationship existing between an individual and their environment. The SEM developed from the work of Urie, Bronfenbrenner's Ecological Systems Theory (1979) which focused on the relationship between the individual and the environment, identified the core assumptions which underpin the SEM.

Using the SEM, this study recognizes that whereas adolescents living with vertically acquired HIV are responsible for instituting and maintaining life styles necessary to improve their well-being and reduce HIV transmission, their behaviour is influenced by factors at different levels namely, the microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1979). Each level contains and influences the prior level and directly and indirectly affects adolescents living with vertically acquired HIV. Consequently in this study the lived experiences of adolescents living with vertically acquired HIV are viewed from a social ecological perspective since the adolescent and HIV are embedded within the family and the family is embedded within a social and cultural context.

In Bronfenbrenner's (1979) perspective, the microsystem of an adolescent living with vertically acquired HIV refers to all the settings the adolescent personally interacts and is influenced. These consist of the social network of intrapersonal relationships involving direct face-to-face interactions with whom the adolescent has lasting relationships which includes the family, peers, hospitals and clinics and the school. It also includes the individual adolescent's psychological and cognitive factors like personality, knowledge, attitudes, skills and beliefs (Hosek, Harper, Lemons &

Martinez, 2008). In this study the microsystem extends to also include HIV since it places demands on the adolescent, the family and entire community.

For an adolescent living with vertically acquired HIV, identity includes, the HIV and AIDS identity, because HIV will always be a part of the adolescent for life. How the adolescent integrates an HIV identity will have an impact on how she or he responds to lifelong disease management such as adherence and disclosure (Kazak, Segal-Andrew & Johnson, 1995). The denial or avoidance of the HIV identity is one of the stages of developing adolescent identity, where one has not explored, acknowledged or accepted the HIV identity as part of self (Hosek, Harper & Robinson, 2002).

Meaning making and identity development occur within the context of the adolescent's cultural and societal systems which in turn "are human creations, continually recreated and re-imagined by individuals with diverging experiences and motives" (Buckser, 2008:168). Meaning is an individual dynamic construction that is embedded in the person's particular social and cultural context (Fife, 2005; Thorne, 1999) so the adolescent living with vertically acquired HIV may assign different meanings to HIV as his or her experience varies in changing contexts.

In the social ecological perspective, the family is the closest and most durable part of the microsystem for children and adolescents (Bronfenbrenner, 1979). There is theoretical and empirical consensus that suggests that the family context has an important influence on the adolescent's ability to successfully negotiate important developmental tasks such as ego identity development as described by Erickson in 1963 (Balk, 1995). HIV and AIDS is a family disease which disrupts the normal parent child relationships on which most adolescents depend on (Cluver, Gardner & Operario, 2007). Unfortunately, this unique characteristic of HIV and AIDS for adolescents living with vertically acquired HIV is its presence in the family, an infected mother and possibly also a father and siblings with HIV. Several studies in SSA show that HIV and AIDS is destructive and erode the family structure resulting

in poor family support structures, fragile connections and broken bonds for many adolescents living with vertically acquired HIV especially those orphaned by the epidemic (Ferrand et al. 2010b; Mavhu et al. 2010; Petersen et al. 2010).

The majority of adolescents living with vertically acquired HIV in Southern Africa have lost one or both parents, a sibling, a guardian or a close relative to HIV and AIDS (Cluver et al. 2007; Ferrand et al. 2009a; Ferrand et al. 2010b; Hodgson et al. 2012; Mavhu et al. 2010; Meyers, Yotebieng, Kuhn & Moultrie, 2011; Petersen et al. 2010). A review of children attending Harriet Shezi Children's Clinic at Chris Hani Baragwanath Hospital (South Africa) in 2010 indicated that more than 50% of children over the age of five years had lost at least one biological parent (Meyers et al. 2011). For this reason, there are many family configurations for adolescents living with vertically acquired in SSA like living with a related kin such as grandmothers, living with foster parents or living in a children's home (Ferrand et al 2010b; Mavhu et al. 2010; Meyers et al. 2011; Petersen et al. 2010). Adolescents living with vertically acquired HIV who are orphaned are therefore likely to be deprived of a strong psychological base to explore who they are and to eventually develop to what they are meant to be. A qualitative study among ALHIV in Zambia has shown that many adolescents do not have a strong family support mainly because of orphanhood (Hodgson et al. 2012). Other qualitative studies done in Zimbabwe and South Africa established that most adolescents living with vertically acquired HIV experience stress and trauma related to death of parents and family due to HIV and AIDS (Mavhu et al. 2010; Petersen et al. 2010).

In this study the mesosystem of an adolescent living with vertically acquired HIV comprises of interrelations among settings in which the adolescents actively participate such as relations among parents or caregivers, family members, the hospital or clinic, the school and peers. These interactions are essential and provide social identity and role definition to the adolescent (Marcia, 1968). The interactive elements are bidirectional hence adolescents are influenced not only by their parents or caregivers attitude about HIV, but also by the parents or caregivers'

attitude towards HIV and in turn are affected by the manner in which the adolescent responds. The richer the medium of communication in this level, the more influential it is on the adolescent and the more positive his or her lived experiences with HIV are. Open effective communication between parents or caregivers and health care providers can have a positive effect on the adolescent's adherence (Brown et al. 2000; Bikaako-Kajura et al. 2006).

The family situation has implications for the adolescent's success at adherence and the relationship between the adolescent and the parents or caregivers has an influence on how she or he will adhere to ART treatment (Rehm & Franck, 2000). Further, a parent's or caregiver's attitude towards her or his own adherence may be important regarding how the adolescent adapts to this aspect of disease management (Pontali, 2005). Thus, the family's overall attitude towards their health is very important in the care and support of adolescents living with vertically acquired HIV.

Furthermore, the relationship between the health care provider or practitioner and the adolescent greatly influences the adolescent's HIV management and adherence to ART (Hammani, Nostlinger, Hoeree, Lefevre, Joncheer & Kolsteren, 2004; Pontali, 2005). The health care system can be a convenient environment to navigate or it can confound the adolescent at every turn (Dodds, Blakley, Lizzotte, Friedman, Shaw, Martines, Siciliano, Walker, Sotheran, Sell, Botwinick, Johnson & Bell, 2003) and the degree of availability, affordability and cultural appropriateness of health care services determines the degree to which adolescents are able and willing to comply with medical counsel. For adolescents transitioning from paediatric to adult care, the new health care system can provoke considerable anxiety and lead to suboptimum compliance or falling out of health care (Weiner et al. 2007). The adolescent health care system is therefore crucial to the success of the young person's management of HIV, both by providing the necessary information for correct adherence and by providing support that adolescents need (Pontali, 2005).

For adolescents living with vertically acquired HIV, the exosystem is primarily the consideration of the parents', caregivers', siblings' and friends' networks and the extent to which the adolescents' HIV status impacts those networks (Kazak et al. 1995). The adolescent is not an active participant, but settings in which events occur affect the setting containing the adolescent. The exosystem also includes policies and informal structures that may directly impact treatment, care and support services for the adolescent and the family. In many developing countries, South Africa included, some policies that relate to adolescent health are in place though most of them lack specific reference to adolescents living with vertically acquired HIV (Birungi et al. 2009; Ferrand et al. 2009a; Ferrand et al. 2010a; Jaspan et al. 2009).

Lastly the macrosystem of the adolescent living with vertically acquired HIV consists of larger societal structures and values (social, cultural, religious and political) that the adolescent lives in as a whole. According to Bronfenbrenner (1979), these are not solely geographical or physical, but also emotional and ideological. These influences are more easily seen than other factors, mainly due to the magnitude of the impact of HIV and AIDS.

According to Brown et al. (2000), the cultural context of HIV transmission is an important factor in the care and support of ALHIV. Cross cultural studies of psychological processes triggered by HIV infection suggest that people of different backgrounds cope with HIV and AIDS according to their own social morals and cultural perceptions about HIV and AIDS. Culture describes not only the beliefs and values that are attached to HIV and AIDS, but also to the symbolic interactions that the adolescents engage in with peers, family, health care system and the larger community. In SSA, HIV and AIDS has been associated with extreme reactions of shame, humiliation, fear and anger (Deacon & Stephney, 2007; Ferrand et al. 2007). Consequently, the cultural context of PLHIV must be understood in order to improve care and support services of ALHIV.

Using the SEM, as an analytical lens, this study explores the lived experiences of adolescents living with vertically acquired HIV at the adolescents' microsystem, mesosystem, exosystem and macrosystem levels.

2.9 Conclusion

This chapter has highlighted research conducted on adolescents living with vertically acquired HIV in SSA. The literature revealed that there is limited research on the lived experiences of adolescents living with vertically acquired HIV in SSA and in South Africa in particular. The chapter concluded with a discussion of the SEM as the theoretical framework guiding the study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter focuses on the research methodology employed to explore the lived experiences of adolescents living with vertically acquired HIV. It describes the research design, population, sample and sampling technique, data collection techniques, data collection instrument, data collection process, data analysis and interpretation and finally, the ethical consideration that the researcher took into account in the implementation of the research process.

3.2 Research design

The design of a study refers to the plan or steps followed to collect, analyse and interpret data (Creswell, 1994:12). It guides planning and implementation of the study in order to achieve the objectives of the study (Creswell, 2007:33). The function of a design is to ensure that the evidence obtained enables us to answer the initial research questions as explicit as possible (De Vaus, 2001:9).

The study was conducted within a qualitative paradigm employing an exploratory case study design to allow for a deep understanding of the lived experiences of adolescents living with vertically acquired HIV. Qualitative approaches focus on exploring and understanding the way individuals or groups interpret and make sense of their experiences, behaviours, interactions and social contexts in the world which they live (Atkinson, Coffey & Delamont, 2001:7). Thus the qualitative approach is most appropriate in this study since the aim is to explore the lived experiences of adolescents living with vertically acquired HIV.

The study corresponds to (Stake, 1995:3) definition of an instrumental case study, where the focus of the research is “upon providing an insight into an issue” and in this case the lived experiences of adolescents living with vertically acquired HIV. Yin (2003:5) has offered three conditions for selecting a research design, (i) the type of research questions posed, (ii) the extent of control an investigator has over actual behavioural events and (iii) the degree of focus on contemporary as opposed to historical events. The research questions that guided this study were “what” questions:

- ⇒ What are the lived experiences of adolescents living with vertically acquired HIV receiving treatment, care and support services at Dora Nginza Wellness clinic?
- ⇒ What are the care and support services that are developmentally appropriate for adolescents living with vertically acquired HIV?

Yin (2003:6), has stated that a “what question is a justifiable rationale for conducting an exploratory case study.” Looking at Yin’s second condition, the extent of control over behavioural events, if the researcher has no control over behavioural events, Yin argues a case study is preferred. In this study the researcher has no control over the lived experiences of adolescents living with vertically acquired HIV, thus indicating the use of case study design over other types of research designs. The final condition Yin (2003:7) has identified when determining a research is the degree of focus on contemporary as opposed to historical events. He has further stated that an exploratory case study design facilitates in-depth investigation of a distinct contemporary phenomenon characterized by a lack of detailed preliminary research within its real-life context bringing out details from the view points of participants (Yin, 1994:13). This study investigates lived experiences of adolescents living with vertically acquired HIV which is a recent emerging population of PLHIV in South Africa (Jaspan et al. 2009). Merriam (1998:33) stated that a case study design is selected for its uniqueness, for what it can reveal about a phenomenon, knowledge we would not otherwise have access to. Little research exists on the

lived experiences of adolescents living with vertically acquired HIV in South Africa, thus knowledge gained from this study will contribute to the empirical knowledge of this unique emerging population.

In addition, a qualitative exploratory case study design was regarded as the most appropriate for this study as exploration of lived experiences of adolescents living with vertically acquired HIV involves sensitive, emotional and personal topics that are best captured through careful probing using qualitative in-depth semi-structured individual open-ended interviews (Henn, Weinstein & Foard, 2006:162). Data was gathered within the adolescents' natural setting allowing them to share their own experiences of living with HIV since childhood in their own words therefore facilitating in-depth understanding of their lived experiences. The design allowed for interpretation of the adolescents' stories around the guiding questions affording the opportunity to develop and understand meanings and experiences of these individuals (Anderson & Arsenault, 2002:119). The exploratory case study design also allowed the researcher to determine support services developmentally appropriate for adolescents living with vertically acquired HIV from the findings of the interviews.

3.3 Population, sample and sampling techniques

Bless & Higson-Smith, (2006:98) have referred to a population as “the entire set of objects or people which is the focus of the research study, and about which the researcher wants to determine some characteristics.” According to (Punch, 2005:101), a sample refers to the actual group included in the study from which data is collected, while a sample is drawn from the population. The sample is studied, in order to assist in explaining some facts of the population. It is not feasible to expect to be able to study the entire population.

Purposive sampling, a non-probability sampling approach which entails selecting participants composed of elements that contain the most characteristic or typical attributes of the population that serves the purpose of the study best (Grinnel &

Unrau, 2008:153) was used to recruit participants for this study. The identification of possible participants was based on the following criteria:

- Adolescents who contracted HIV through vertical transmission receiving HIV treatment, care and support services at Dora Nginza Wellness clinic;
- Male and female adolescents aged between 16 and 19 years;
- Must be aware of his/her HIV status; and
- Must have signed an adolescent assent form and the caregiver signed the guardian consent form.

The sample in this study was drawn from twenty-three adolescents living with vertically acquired HIV receiving HIV treatment, care and support services at Dora Nginza Wellness clinic in 2013. Out of the population of twenty-three, only eleven adolescents met all criteria for selection. However, only six adolescents agreed to participate in this study. The participants comprised, four females and two males.

3.3.1 Participant recruitment process

The recruitment of participants commenced when the ethics approval of the study had been attained from the University of South Africa's Higher Degree's Committee. Permission to conduct the study at Dora Nginza Wellness clinic was obtained from the Department of Health, Nelson Mandela District and the CEO of Dora Nginza Hospital. Once permission was attained, a meeting was set up to meet the staff working at Dora Nginza Wellness clinic that included doctors, nurses, a social worker and a counsellor. At this meeting the researcher explained the aims and objectives of the study and the inclusion criteria of adolescent participants. The researcher was assigned to a counsellor who facilitates a support group program for adolescents living with vertically acquired HIV at Dora Nginza Wellness clinic.

The counsellor was instrumental in facilitating a meeting between the researcher and eleven adolescents living with vertically acquired HIV who belong to a support group of adolescents aged between 16 and 19 years. The researcher was introduced to the adolescents and given an opportunity to present her study. The

researcher explained the aims and objectives of the study to the adolescents and informed them that taking part in the study would mean they would be interviewed about their personal experience of living with HIV and the interviews would be audio recorded with their permission. The researcher also made it clear that their consent to be part of the study was voluntary and that the researcher would also need their guardian consent for adolescents below the age of 18 years to participate in the study.

An open invitation to participate in the study was thereafter offered to all the eleven adolescents who met the inclusion criteria of the study who were present during the briefing of the study. They were informed that they should approach their support group counsellor if they were interested in participating in the study. Only six adolescents approached the counsellor and indicated their willingness to participate in the study. The counsellor then contacted their caregivers and invited them to Dora Nginza Wellness clinic for a briefing of the research study with the researcher. The counsellor introduced caregivers to the researcher and the researcher explained the purpose and nature of the research study, the methods and possible outcomes to each caregiver. All the six caregivers agreed for children in their care to participate in the study and gave written guardian consent. Caregivers were reimbursed R50.00 for tax fares which they had used to travel to the clinic by the researcher.

Issues of assent and consent are described in Section 71 of the National Health Act No: 61 of 2003 of South Africa. The researcher had to follow the guidelines in creating the guardian information sheet and consent form and adolescent information sheet and assent form and recruiting participants for the study. In these guidelines children under the age of 18 years are referred to as minors who renders them dependent upon adults around them. They are therefore legally unable to make independent decisions about whether or not to take part in a research. In this regard, children require a legal guardian to assist with decisions with legal consequences, such as consent to research participation. This means the guardian

agrees to allow their child to participate in a research after they receive details about the purpose and nature of the research, the methods and possible harms and outcomes. The child then assents meaning she or he gives affirmative agreement to participate in the research study after understanding the purpose and nature of the study and is willing to participate.

Scheduling of the interviews was done through the caregivers. The researcher contacted the caregivers since they sent the adolescents to the clinic for the individual interviews and this was seen as also giving consent for the adolescents to participate in the study, even though all of them had already signed written guardian consent forms. Adolescent participants signed their written assent forms before the interviews commenced to show that they agreed to be part of the study. Before signing the adolescent assent forms, the researcher carefully explained again to the participants the purpose and nature of the research study and the possible outcomes. Participants were also given time to read through the assent forms, where details about the study and their rights were written down. The researcher also read to the participants all the most important details such as participating in the study was voluntary, their right to withdraw from the study at any time, that choosing not to participate would have no negative implications, that they did not have to answer any questions which they were uncomfortable answering and that their identity would be protected. The researcher also made sure that the adolescents understood that they could refuse to participate in the study even when their guardian had given consent.

3.4 Data collection technique

In this study, data was collected directly from the six adolescents living with vertically acquired HIV by means of in-depth individual semi-structured open-ended interviews. The interviews were audio recorded. This technique was chosen because, as Seidman (1998:3) stated “At the root of in-depth interviewing is an interest in understanding the experience of other people and the meaning they make of that experience”. Tutty, Rothery & Grinnell (1996:52), further asserted that

“interviews provide researchers with an opportunity to learn about that which you are able unable to directly observe in a person’s natural environment, and that is particularly true when you are interested in learning about a person’s experiences, behaviour, thoughts and feelings”. Cherrington (in Nel, Gerber, Haasbroek, Schultz, Sono & Werner, 2001:246-247) also added that the interviewer has two purposes; to get information from the participants, and to judge the informants on the basis of the information.

The semi-structured interview design was appropriate for this study as it permitted a focused exploration of a specific topic (Fossey, Harvey, McDermolt & Davidson, 2002) and also allowed the researcher to be aware of non verbal cues which were valuable for interpreting the participants’ feelings towards certain questions and around various responses they gave. The semi-structured interview design does not restrict the interviewer to a prescribed interview schedule, yet it gives the interviewer the opportunity to ask the same questions to all the participants (Sommer & Sommer, 1997).

The interview schedule was used as a flexible instrument during the interview process facilitation exploring and sharing so that an understanding of the adolescents’ lived experiences is reached by both the participant and the researcher. The questions were open-ended to allow participants’ own views to be expressed freely. Questions were formulated around adolescents’ personal experiences of growing up living with HIV and included the adolescents’ biography information, experiences of disclosure of their HIV status, experiences of disclosure to others, experiences of disease management, traumatic experiences related to their HIV status, social support available to them, relationships, their aspirations and what they think can be done for them to realize their full potentials (*Appendix D*). These questions were informed by the literature that was read on this related topic.

3.4.1 Data collection process

The six individual interviews were conducted in a consultation room provided by the Wellness clinic in November 2013. The setting provided a private, familiar and comfortable environment for the adolescents as they were used to having counselling sessions in this room.

The interviews lasted between 40 minutes to an hour and were mostly conducted in English, as all participants were comfortable with being interviewed in English. However there were moments within the interviews where questions had to be translated into Xhosa. The researcher was able to translate questions and answers when needed into Xhosa which is known by the researcher. A translator was not needed in this research as the participants were for the most part fluent in English and the researcher could speak Xhosa.

The interviews were face to face, which allowed the researcher an opportunity to observe other valuable factors such as general appearance, overall health, non-verbal behaviour and other individual traits (Sommer & Sommer, 1997). A pocket sized audio recorder was used to record all the interviews with the permission of the participants. Audio recording the interviews allowed the researcher to concentrate and pay full attention to the adolescents' response to the interview questions on their lived experiences, without having to take detailed notes.

The use of probes, prompts and a questioning style which is flexible (Henn et al. 2006:162) enabled the researcher and the participants to engage in dialogue, with the researcher eliciting personal aspects of the adolescents' lived experiences that were pertinent to them and therefore facilitating understanding of their unique issues. Baker, Costa and Shalit (1997:45) mentioned that probing creates the opportunity for clarifying ideas, explaining difficult terminology and different interpretations. It, therefore gives the participant the opportunity to query some of the questions, and the researcher the opportunity to explain or eliminate ambiguity. Both researcher and participants could therefore make sure that they created a shared understanding or meaning of their lived experiences.

The interview commenced with a general inquiry into the biographical information of the participants serving as introduction. Thereafter the participant's experiences of learning their HIV status were explored. After establishing how, where, who and when the participants learnt their status, the participants were asked to describe how they received their HIV diagnosis. Experiences of sharing their HIV status with people outside their families were also discussed with participants paying attention on facilitators and impediments of self-disclosure. Participants' experiences of disease management at home, school and at the clinic were also discussed. The interviews were concluded by exploring the participants' sexual relationships, future plans and their views on what can be done by people around them to ensure that they realized their full potential.

Immediately after each individual interview was complete the researcher made detailed notes in the form of field notes of her observations during the interviews, such as how participants responded and reacted to the questions asked and themes explored. According to De Vos et al. (2005:298), field notes assist researchers to remember and explore the process of the interview in a relative manner. Observation offers a unique way of collecting data by not only focusing on the spoken words of the participants, but also by taking note of their body language (Denscombe, 2003:192).

3.5 Data analysis

Data analysis for qualitative research is the non-numerical process of examining, and interpreting data, in order to elicit meaning, gain understanding, and develop empirical knowledge (Babbie, 2007:378; Corbin & Strauss, 2008:1). Babbie & Mouton (2001:108) reiterated this sentiment by stating that qualitative data analysis involves the breaking up of data into manageable patterns, relationships, trends and themes. The goal of analysis is to know the various constructive elements of one's data through an examination of the connections between concepts, constructs and

to see whether there are any trends that could be identified or isolated, in order to establish themes in the data (Bless & Higson-Smith, 2006:98).

The six audio recorded interviews were analysed using Tesch's method of data analysis for qualitative research (Tesch, 1990). The steps of developing an organizing system as explained by Tesch (1990:142) were utilized. This entails a process of segmenting and categorizing as well as decontextualizing and contextualizing data (Tesch, 1990:142).

Firstly the researcher typed the field notes and all the six interviews were transcribed verbatim from the audio recordings into six Microsoft word documents. The point was made of using only the participants' respective statements. The researcher listened to the audio recordings carefully and read and re-read each of the six transcripts so that she became familiar with the data. The second step was to identify specific topics in the interviews. The researcher selected one interview, and went through it asking, "What is this about?" She then thought about the underlying meaning in the information. The identified topics were written in the margin of the document. The researcher repeated the above with all the six interview scripts and a list was compiled of all the topics that came up. The researcher took the list and returned to the data. The topics were abbreviated as codes, and the codes were written next to the appropriate segments. Similar topics were clustered together, and formed into columns that might be arranged into major topics and outliers.

The major topics and the unique topics were thereafter used to create a preliminary organising system. The researcher found the most descriptive wording for the topics, and turned them into themes. She endeavoured to reduce the total list of themes by grouping together topics that relate to each other. Lines were drawn between the categories, to show inter-relationships. The researcher made a final decision on the abbreviation of each theme, and alphabetizes the codes. The data

material which belonged to each theme was assembled in one place, and a preliminary analysis was performed.

The researcher decided to construct an organising system from the data and not from the theoretical framework that guided the study. Different authors have different views on the construction of an organising system. According to Tesch (1990:119), interpretive qualitative researchers rarely use the theoretical framework to construct an organising system, while Miles & Huberman (1994:55) assert that conceptual frameworks and research questions are important for preventing overload. The data was coded and organized into common and recurring themes derived from participants' lived experiences. The themes were developed in accordance with the purpose and objectives of the study in order to answer the research questions. The themes that emerged from data analysis are dealt with in detail in Chapter 4 where findings of the study are discussed.

The decision to conduct data analysis manually was influenced by the number of participants who took part in the study and the researcher's willingness to learn the process of data analysis manually. The intimacy with data gained by this process gave valuable insight into the lived experiences of adolescents living with vertically acquired HIV.

3.6 Ensuring trustworthiness

Establishing the trustworthiness of a research study lies in the heart of issues conventionally discussed as reliability and validity also being central to any conception of the quality of qualitative research. Establishing trustworthiness gives assurance that the research instruments were capable of providing accurate and meaningful answers to the research questions and when qualitative research accurately represents the experiences of the participants (Curtin & Fossey, 2007:56). Trustworthiness of this study was enhanced by employing the four criteria of trustworthiness namely credibility, dependability, conformability and transferability proposed by Lincoln & Guba (1985: 300).

3.6.1 Credibility is the confidence in the truth of data and interpretations of them (Mertens, 1998:180-184). Credibility was enhanced by prolonged and substantial engagement of research participants during interviews. Participants were encouraged to remain open and comfortable, so as to facilitate the process of sharing and exploring their understanding of their lived experiences. Credibility was also enhanced by comparing data collected from the six interviews with each other.

3.6.2 Dependability refers to the degree to which the reader can be convinced that the findings did occur, just as the researcher states that they did happen (Van der Riet & Durrheim, 2006:93) and there can be no credibility in the absence of dependability (Neuman, 2003:179). An audit trail which is a transparent description of the research steps taken by the researcher from the beginning of the study to the development and reporting of findings (Lincoln & Guba, 1985: 319-320) has been given in this chapter as a means of ensuring dependability of the study.

3.6.3 Conformability refers to the neutrality of the data, that is, the data and their interpretations were not interventions of the researcher's imagination (De Vos, 1998:350). Lincoln & Guba (1985:303) suggest a conformability audit to confirm that data can be traced to the original sources, and that the process of synthesizing the data to reach conclusions can be verified. Conformability in this study was enhanced by the availability of raw data on the audio recorder and transcripts to verify the themes. The interviews were audio-recorded to capture verbatim accounts by participants. This was important in analyzing data, as facts were recorded.

3.6.4 Transferability refers to the extent to which findings from the data can be applied to other settings or groups (Kelly, 2006: 381). In general, qualitative studies are not generalisable, but findings should be transferable, in that results can be compared with those of other studies and experiences and encourage further investigations in those areas (Curtin & Fossey, 2007:92). A detailed description of the context in which the study was undertaken and explanation of the research

methodology and verbatim quotations taken from interviews and descriptions of the findings of this study provides sufficient information to permit replication in a similar context.

3.7 Ethical considerations

A consideration of ethical issues is necessary in any research involving human subjects and especially when working with minors. Ethical considerations concern principles and guidelines which researchers must follow in order to ascertain that they do not violate the physical, psychological and emotional state of the participants of the study during the data collection process. For results to be acceptable, the researcher is obliged to follow certain ethical principles. De Vos (2002:63) define ethics as:

“a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and participants, employers, sponsors, other researchers, assistants and students”.

Ethics should, thus, be understood as a set of rules that prescribe how the researcher must behave towards people involved in the study. The participants in this study are included in the category of “vulnerable groups” (WHO 2011) as they are adolescents below the age of 18 years and are living with HIV. The study was thus sensitive to this fact and a number of steps were followed in order to ensure the rights of participants were protected.

Ethical clearance for the study was obtained from the Higher Degrees Committee of the Department of Sociology in the College of Human Sciences at UNISA (*Appendix E*). Permission to conduct the study was given by the Department of Health Nelson Mandela District and the CEO of Dora Nginza Hospital (*Appendix F*).

3.7.1 Avoidance of harm: Participants were protected against emotional and physical harm, within reasonable limits. In this study, the potential risks were emotional, rather than physical; and they could arise from the participants being asked to recount stressful or painful experiences relating to the death of close relatives and disclosure of their HIV status. A social worker was available for counselling if the need arose. There were no incidents of emotional upsets during the study.

3.7.2 Informed consent: Participants and their caregivers were given detailed information regarding the purpose and nature of the research including possible advantages and disadvantages or any dangers to which they might be exposed to both verbally and in writing. Adolescent information sheet and assent forms (*Appendix C*) and guardian information sheet and consent forms (*Appendix B*) were also developed by the researcher clearly stating the above, which were signed by willing and eligible adolescents and their respective caregivers. Participants were informed of their right to decline to participate in the study or withdraw from the study at any stage of the interview. Based on this information, potential participants and their caregivers were able to make decisions on whether to volunteer their participation.

3.7.3 Confidentiality was of outmost importance in this study, in order to protect and to be sensitive towards the participants. Data gathered was confidential, treated anonymously, and used for the purpose of the study only as the participants. Participants identifying information was removed from the transcripts and the research report and pseudonyms were used.

3.7.4 Debriefing of participants: Participants were given an opportunity to reflect on the experience of being part of the study. This was an opportunity to resolve possible misconceptions, or emotional reactions, which could result from the interview. In cases where participants appear emotionally affected, appropriate referrals were made, but this was not necessary.

3.7.5 Recording: Participants were informed that an audio recorder would be used and they were free to opt out or refuse to use the audio recorder if it made them uncomfortable.

3.8 Pilot study

Mitchell & Jolley (2001:13-14) have stated that a pilot study is used to fine-tune the main study and throw up unanticipated problems the researcher could encounter in the actual study and the difficulties that the researcher can iron out before the actual study. De Vos et al. (2005:210-215), have further stated that the value of the pilot study entails giving a researcher an opportunity to check the suitability of the interview schedule, to test and adapt the measuring instruments, to determine the number of codes per question, to assess the suitability of the sampling frame, to be aware of the expected non-response rate or percentage, to estimate the lengths of the main investigation, to ensure the involvement of the researcher, to analyse the data and to evaluate the study entirely.

A pilot study was conducted for this research, in October 2013 after feedback of the research proposal was received. Two interviews were held with participants who met the inclusion criteria of the study. During these pilot interviews no issues with regards to the interview questions emerged. The two participants who participated in the pilot study understood all the words in the questions posed. However they responded to open questions with very short, vague answers and it was decided that in the main study, a more probing focus would be applicable. De Vos et al. (2005:302) have stated that probing refers to attempts made by the researcher to deepen the responses to questions or to increase the quality of the responses given by the interviewee. A number of probing methods, as suggested by De Vos et al. (2005:302) were used and these included direct questioning, encouraging and acknowledging.

3.9 Conclusion

In this chapter the research methodology was described outlining how the research was conducted. The research stemmed from a qualitative approach employing an exploratory case study design. Purposive sampling was used to recruit adolescents who met the inclusion criteria of the study. Individual semi-structured open-ended interviews were conducted with six adolescents living with vertically acquired HIV receiving HIV treatment, care and support services at Dora Nginza Wellness clinic. Interview scripts were used as the main data source. Data analysed using Tesch's 1990 qualitative data-analysis approach. Trustworthiness was confirmed through Lincoln & Guba (1985) model and ethical considerations focused on the protection of participants' and their identities. The next chapter will look at the findings of the study and these will be discussed in detail and verified against the existing literature on ALHIV.

CHAPTER 4: FINDINGS

4.1 Introduction

This chapter presents the findings of the study. The findings reflect the information gained from the analysis of the participants' interview transcripts as well as the researcher's observational notes regarding the lived experiences of six adolescents living with vertically acquired HIV receiving HIV treatment, care and support services at Dora Nginza Wellness clinic. I report on the findings related to each of the research questions, as mentioned previously.

The discussion of the study findings will be presented as follows: biographical information of the research participants will be presented firstly. This will be followed by the themes and sub-themes, as identified during the process of data analysis to answer research question 1 and 2. These are backed up by quotations from the participants, where applicable; and they are subjected to a literature control, in order to compare and contrast the findings in relation to the existing body of knowledge.

4.2 Biographical information of the participants

Six adolescents (four female and two male) living with vertically acquired HIV receiving HIV treatment, care and support services at Dora Nginza Wellness clinic took part in this study. All the participants were of African origin and were between the ages of 16 and 17 years. A summary of each participant's biographical information is represented below. Pseudonyms have been used to protect the identity of participants.

Sonwabiso

Sonwabiso is a 17 year old boy currently repeating Grade 9. He is in the foster care of his maternal grandmother and also lives with his older sister who is 22 years old, the sister's two children and his maternal aunt and her three children. His mother passed away in 2007 and he does not know the identity or whereabouts of his father. He does not know when he was diagnosed with HIV but he remembers being sick occasionally since he was young. Sonwabiso thinks he started taking ART treatment in 2006. His HIV status was disclosed to him in 2010 when he was 14 years old by the doctor. His grandmother receives old age pension and a foster care grant on his behalf. The sister and the aunt are employed and also receive child support grant for their children.

Sipho

Sipho is a 16 year old boy currently completing Grade 9. He is in the foster care of his maternal grandmother and also lives with his two siblings and six cousins and nephews. His mother died in 2011 and his father died in 2002. He was diagnosed with HIV in 2011 and his HIV diagnosis was disclosed to him by his grandmother the same day he was diagnosed. He was 14 years old. He has been taking ART treatment since 2011. The grandmother receives old age pension and foster care grants for him and his two siblings.

Lihle

Lihle is a 16 year old girl repeating Grade 7 for the third time. She stays with her paternal aunt and the aunt's three children. Her mother died when she was an infant and her father died in 2012. She was diagnosed with HIV in 2007 when she was 10 years old. Her HIV status was disclosed to her when she was 12 years old by her maternal aunt who was her caregiver at the time. Unfortunately the maternal aunt died in 2010 and Lihle moved from Queenstown to stay in Port Elizabeth with her paternal aunt. She started ART treatment in 2008. The paternal aunt is employed and one of the aunt's daughters is also employed.

Noluthando

Noluthando is a 16 year old girl completing Grade 10. She is in the foster care of her maternal aunt and stays with the aunt and the aunt's four children. Before she was staying with her maternal grandmother and after the grandmother died in 2010 her aunt took her. Her mother passed away in 2008 and she does not know the identity or whereabouts of her father. She had a sister who also passed away in 2007. She is not sure when she was diagnosed with HIV but she started ART treatment in 2007 when she was 10 years. She accidentally heard about her status by a neighbour in 2009 when she was 12 years. The maternal aunt is employed and also receives a foster care grant for Noluthando.

Musa

Musa is a 17 year old girl repeating Grade 9. She lives with her maternal uncle and his family. Her mother passed way in 2008 and she does not know the identity or whereabouts of her father. She used to stay with her maternal grandmother before the grandmother died in 2011. She thinks she was diagnosed with HIV in 2008. Her HIV status was disclosed to her in 2009 by her grandmother when she was 12 years old. She also started ART treatment in 2009. Both the uncle and his wife are employed.

Okuhle

Okuhle is a 16 year old girl currently doing Grade 8. She is in the foster care of her maternal grandmother. She stays with her grandmother, a younger sister and her four cousins. Her mother died in 2010 and her father died in 2002. Her younger brother passed away in 2004. She does not know when she was diagnosed with HIV. She started taking ART treatment in 2005. She was informed about her HIV status in 2010 by her grandmother when she was 13 years. The grandmother is a recipient of old age pension and foster care grants for Okuhle, her sister and her cousin.

4.3 Emerging themes from participants lived experiences

Three main themes, with accompanying sub-themes emerged from the information given by the participants with regards to their lived experiences. The overview of themes and sub-themes is presented in the table below.

Table 1: Summary of themes and sub-themes

Themes		Sub-themes	
4.3.1	HIV infection	4.3.1.1	Being sick
		4.3.1.2	Fear of dying
		4.3.1.3	Living with loss
4.3.2	Disclosure of HIV status	4.3.2.1	Knowing my HIV status
		4.3.2.2	Keeping it a secret
		4.3.2.3	Avoiding friendships
4.3.3	Copying with HIV	4.3.3.1	Family support
		4.3.3.2	Visiting the Wellness clinic
		4.3.3.3	Taking ART treatment
		4.3.3.4	Going to school
		4.3.3.4.1	Absenteeism from school
		4.3.3.4.2	School pupils attitudes
		4.3.3.4.3	Teachers' attitudes
		4.3.3.5	Sexual relationships
4.3.3.6	Future plans and aspirations		

4.3.1 Theme 1: HIV infection

Generally all participants depicted HIV as having a negative impact on their lived experiences. They expressed feelings of anxiety, fear, sadness and loss which are related to their illness. This main theme contains essentially three sub-themes namely being sick, fear of dying and living with loss.

4.3.1.1 Being sick

All participants have experienced long-term ill health whilst growing up and two participants reported at least one hospital admission during the past year. Participants reported experiencing recurring or serious illnesses and recall multiple hospital admissions with much of their childhoods disrupted by ill-health and clinic or hospital visits:

In 2012 I had TB. I was at Empilweni Hospital for months but ... even before that I remember always being sick and sick and going to the hospitals and clinics (Lihle).

I have always been sick since I was young but last year I was very sick. I had infection in the chest so I stayed in hospital for a while (Noluthando).

I had pneumonia so we went to the hospital with my grandmother. I was tested and when we got home my grandmother said the results showed I had HIV (Sipho).

My flue and coughing would never end. I always came to the hospital at times staying here for weeks (Okuhle).

This finding supports findings from previous studies from Zimbabwe and South Africa (Ferrand et al. 2009a, Ferrand et al. 2010a; Ferrand et al. 2010b) which reported a heavy burden of chronic complications in adolescents living with vertically acquired HIV which were associated with an increased risk of hospitalization. In these studies like in this study the most frequent diagnosis among participants was chronic lung diseases like tuberculosis, pneumonia, and cardiac infection.

Okuhle and Lihle complained about people's stigmatising reactions to their physical appearance:

People say bad things about umm my skin and my hair so I always wear a hat when am going out of the house (Okuhle).

Everyone comments that am skinny and small for my age and some people even think am ten years old. You know I don't like it when people comment on such things about me (Lihle).

Consistent with key reports on pronounced stunting, growth failure and pubertal delay of children and adolescents living with vertically acquired HIV (Buchacz et al. 2003; Ferrand et al. 2009a; Ferrand et al. 2010b) this finding confirms physical developmental delays amongst adolescents living with vertically acquired HIV. Another study of school-age South African children who started ART after clinical and immunological disease progression has demonstrated that up to 90% of them have significant developmental delays than uninfected controls (Lowick et al. 2012).

4.3.1.2 Fear of dying

All participants expressed fear of dying and reported feeling anxious about death most of the time. In most parts of the interviews they would refer to death or dying:

HIV is always in my head, it's there whatever I do, or if I sleep, when I wake up it's there. Everyday am thinking about dying and I even dream of myself being very sick or dying (Sipho).

I try but am scared of dying. Everyday am reminded of dying either by the pills or anything that has to do with AIDS (Noluthando).

You know am always worried about if I'm going die tomorrow or next week (Musa).

I have been sick quite a lot. When I fall ill, I get stressed, you know I think the worst and I think I am not going to survive this time (Lihle).

Similar to previous studies (Hodgson et al. 2012; Li et al. 2010; Petersen et al. 2010) participants in this study had difficulty incorporating HIV in their lives. Participants closely associated living with HIV with dying and although they acknowledged that taking ART treatment would prolong their lives and were still very much aware that they could still die and they were worried and scared of dying. The lifelong nature of illness was also distressing for most participants. Okuhle said the most difficult part of her life was *“the fact that I will always have HIV, it has no cure so I know I will die eventually”*.

4.3.1.3 Living with loss

Loss of biological parents, sibling or a close family member was a common experience in the lives of participants and these losses reinforce the reality to the participants that they may be the next to die. All participants reported that their parents were deceased and half of the participants reported death of both mother and father. Two participants reported death of a sibling and all participants reported death of a close family member.

All participants conveyed feelings of pain and sadness related to the death of their parents or family members. When asked to elaborate on what was painful about the death, for some participants the circumstances surrounding the death of the parent(s) or family member(s) appeared to influence how they experienced the loss with some having observed the illness at first hand:

I came from school and saw her dead on the bed. She was not very sick you know, but she was HIV positive. Later my father also died. He was very sick for some time. My brother, my aunt and my uncle have also died over the years and you you can never get used to it. So when anyone dies in the family am reminded of my parents and brother's death and all the sad feelings come back all again (Okuhle).

My mother was sick for a very long time and every day she would look more sick. She died in 2008. When my mother died my grandmother took me and she got sick again and also died two years ago. I felt more stressed when my grandmother died and I was worried that no one will look after me (Musa).

My sister was always sick. One day she had a headache and that night she could not sleep. She got very very sick and started having fits so they took her to the hospital. I didn't sleep that night waiting for them to come back but they only came in the morning and they said she was dead. [Sighs]. I cried. I loved her so much (Noluthando).

My other aunt who looked after me in Queenstown was like a mother to me. She told me she had HIV like me and we used to take our pills together. It's very painful she died (Lihle).

In this study, orphanhood is a common experience. Previous studies conducted in Southern Africa amongst adolescents living with vertically acquired HIV have shown tremendous burden of HIV on the family, with a high proportion of adolescents participating in the studies having had experienced parental, sibling and family illness and death due to AIDS (Ferrand et al. 2007; Ferrand et al. 2009a; Mavhu et al. 2013; Meyers et al. 2011; Petersen et al. 2010). Experiences of death of parents has been shown to be distressing and related to concerns about social support, financial security, school attendance and health in other studies (Ferrand et al.

2010a; Li et al. 2010; Mavhu et al. 2013; Obare et al. 2011a). However the participants of this study did not raise such concerns.

All participants lived in households that were not headed by their parents and only Sonwabiso had always lived in his current household. Among those who had changed households, Siphon, Musa and Okuhle moved once and Lihle and Noluthando had moved more than twice, mostly due to caregiver's illness and death.

4.3.2. Theme: 2 Disclosure of HIV status

In this theme participants reported on their experiences of HIV disclosure from both a perspective of being informed about their own HIV status and disclosing their HIV status to others. Two main sub-themes emerged namely; knowing my HIV status, keeping it a secret and avoiding friendships.

4.3.2.1 Knowing my HIV status

All participants in the study knew their HIV status which makes them an unusual group, as previous studies report on low HIV status disclosure rate for children and adolescents living with vertically acquired HIV in SSA (Biadgilign et al. 2011; Kallem et al. 2011; Madiba, 2012; Mahloko & Madiba, 2012; Menon et al. 2007; Moodley et al. 2006; Vaz et al. 2011).

Participants were informed about their HIV status between the ages of 12 – 14 years and the mean age of disclosure was 13 years. Similar to previous studies (Madiba, 2012; Mahloko & Madiba, 2012; Kouyoumdjian et al. 2005) this study confirms delayed HIV disclosure among children and adolescents living with vertically acquired HIV in SSA. In many studies the age of the adolescents was found to be a determinant factor for the adolescent's knowledge of the HIV status. In a South African study, more than half of the caregivers reported disclosing to children's HIV status between the ages of 11-17 years (Mahloko & Madiba, 2012).

In addition, it has been documented that caregivers view children over the age of 12 years as emotionally mature for disclosure of HIV status (Bikaako-Kajura et al. 2006; Weiner & Battles, 2006). This could be due to the caregiver's belief that at an early age, the child lacks the emotional and cognitive maturity needed to understand the diseases and its implications.

All participants described disclosure as a once off event where the caregiver or doctor explained to the adolescents that they were living with HIV and the infection was passed on to them by their parents during birth or breast feeding.

She just told me I had HIV and it was an incurable disease which my mother had given it to me when she gave birth to me (Noluthando).

My aunt told me. She asked me if I knew anything about HIV and I told her what I had learnt at school about it. She then said you have that disease and you were born with it (Lihle).

Sonwabiso, Noluthando and Okuhle did not know when they were diagnosed with HIV. Lihle, Musa and Sipho were diagnosed at the ages 10, 13 and 14 years respectively. This finding confirms previous studies from Southern Africa which reported a huge burden of undiagnosed vertical HIV infection among adolescents' long-term survivors whose HIV infection was unrecognized during infancy and become symptomatic in adolescence (Ferrand et al. 2007; Ferrand et al. 2009a; Ferrand et al. 2009b; Ferrand et al. 2010a; Madiba, 2012). Ferrand et al. (2009b) report that at least a third of infants living with HIV in Southern Africa had slow progressing disease with a 50% probability of surviving to adolescence even without ART treatment.

Participants in the study were asked about their experiences of learning their HIV status. Musa, Lihle, Okuhle and Sipho were informed about their HIV status by their

caregivers and disclosure occurred within a home setting, Sonwabiso was informed by a doctor and disclosure took place at Dora Nginza Wellness clinic and Noluthando accidentally found out from a neighbour and disclosure also occurred in a home setting:

I was fighting with her grandchild and I bite her arm so she went home bleeding. The grandmother came to our house angry and she shouted at me and said why did I want to give her granddaughter my AIDS (Noluthando).

Musa and Sonwabiso reported that the main reasons of disclosure by either their caregivers or doctor were related to medical adherence:

I was tired of taking the treatment so I threw the pills in the toilet and when she found out she explained why it was necessary for me to always take the treatment (Musa).

The doctor told me when I was 14 years. I was sick again and he asked me if I knew why I was sick. I said no and he told me it was because I was not drinking my treatment properly and he explained why I must take the treatment everyday in the morning and at night (Sonwabiso).

The above information is consistent with other findings on paediatric HIV disclosure in SSA where improving treatment adherence was identified as the most common reason for HIV disclosure (Brown et al. 2011; Heeren et al. 2012; Kallem et al. 2011; Madiba, 2012; Madiba & Mahloko, 2012; Menon et al. 2007; Moodley et al. 2006; Vaz et al. 2008; Vaz et al. 2010; Vaz et al. 2011; Vreeman et al. 2009).

Apart from parental illness and death, participants reported that becoming aware of their own HIV status was the second most traumatic life event they had ever

experienced. Participants reported that the initial experiences of learning their HIV status brought an array of negative emotions such as feelings of sadness, despair, hopelessness and anger, coupled with a sense of imminent death:

After knowing I had HIV, I kept thinking about dying. I was angry with my grandmother for not telling me and angry with my mother for giving it to me. I couldn't eat, I locked myself up in the bedroom and cried myself to sleep, I didn't go to school for days (Noluthando).

I could not believe it. I felt sad. I I was afraid. I thought so am I going to die (Sipho).

It was a big blow. I was angry with my family for not telling me. I was hurt and very sad and could not see the purpose of living so I just slept. I thought if I had HIV am going to die because that what people said (Sonwabiso).

Negative outcomes of HIV disclosure to adolescents living with vertically acquired HIV in SSA are not as many as the positive outcomes, but as established from studies from the Democratic Republic of Congo (Vaz et al. 2010) and South Africa (Mahloko & Madiba, 2012; Madiba, 2012; Petersen et al. 2010) as is the case with this study, caregivers and adolescents themselves reported that disclosure initially evoked feelings of sadness, worry, anger and hopelessness with some adolescents withdrawing from previous social groups and activities (Mahloko and Madiba, 2012; Petersen et al. 2010). Some of the reasons for these negative emotions were specifically due to the stigmatising nature of HIV (Vaz et al. 2010). For participants in this study, the initial experience of learning about their HIV status and the need to adhere to ARVs seemed to be quite overwhelming and emotionally difficult. Noluthando and Sonwabiso were angry with their families for not disclosing their HIV status to them and Noluthando was even angry with her mother for infecting her.

Similar to previous studies involving children and adolescents living with vertically acquired HIV, (Bikaako-Kajura et al. 2006; Heeren et al. 2012; Mahloko & Madiba, 2012; Menon et al. 2007; Vaz et al. 2008; Vaz et al. 2010) participants in this study found it very important to know their status for several reasons including knowing why they were sick, why they took medication every day, why they visited the Wellness clinic frequently and in order to be able to take care of themselves:

Because now I know I have HIV I can take care of myself, if I didn't know I wouldn't be caring about myself and taking these pills everyday (Noluthando).

We have to know we have HIV so that we can be careful and avoid infecting others (Sipho).

So that I can accept my status and be comfortable and accept everything that happens in my life (Musa).

I didn't understand why I was taking so many pills every time when my sister wasn't and why we always came here to get more (Okuhle).

Being informed about their own HIV status influenced the participants' life positively including being able to take care of themselves, to understand their life situation and accepting the status. Participants reported that some aspects of their lives were difficult to understand prior to the disclosure, such as taking ARVs everyday and frequent visits to the Wellness clinic. Disclosure enabled the participants to make sense out of these routine activities and also helped them to see them as significant and important. Okuhle and Noluthando reported that knowing their HIV status contributed significantly to their ART adherence, confirming the findings of other studies that have explored the links between disclosure of HIV status to children

and adolescents living with vertically acquired HIV and adherence (Bikaako-Kajura et al. 2006; Brown et al. 2011; Heeren et al. 2012; Kallem et al. 2011; Menon et al. 2007; Vaz et al. 2011).

4.3.2.2 Keeping it a secret

Secrecy was a pivotal in discussions about participants disclosing their HIV status to others. Maintaining their HIV status a secret remained an overriding concern with all participants in the study as they considered information about their HIV status private. Similar to other studies of adolescents living with vertically acquired HIV (Heeren et al. 2012; Obare et al. 2011a) all participants stated their wish to have full control over who had knowledge of their HIV status as they considered their HIV status personal hence they just sought to keep it to themselves:

I just don't want to talk about it. It's my secret (Sipho).

No I have never told anyone. It's private and doesn't concern anyone but me (Noluthando).

Ferrand et al. (2007) describe adolescents living with vertically acquired HIV as a "hidden population". Participants in this study are best characterised as a population "in hiding" due to fear of HIV related stigma and discrimination. Musa, Sipho, Sonwabiso and Noluthando reported that they had never disclosed their HIV status to anyone outside the family and they wanted their HIV status to remain a family secret because of fear of stigma and discrimination. Lihle and Okuhle reported they had disclosed their HIV status to people outside the immediate family, namely teachers, so that the teachers would understand why they were sick and missed school often:

I told my teacher so that she could understand why I missed school so much otherwise I have kept it a secret (Lihle).

Am not at school occasionally and I miss out a lot of school work. I therefore decided to tell her the reason why am not at school so that she could give me a chance to catch up with things taught when am not at school (Okuhle).

This finding is in line with other reports where disclosure of HIV status to teachers was reported to mostly provide greater academic support with the school being more understanding with the adolescent's situation (Fielden et al. 2006; Obare et al. 2011a; Petersen et al. 2010).

Self-disclosure of HIV status for participants in this study was related to a perceived lack of trust in the peers, teachers and other people to keep the secret and fear of stigma and rejection. Some participants were very clear about not trusting their peers enough to disclose their status, as they feared their peers would stop playing with them or tell other people in their community or at school about their HIV status who would end up gossiping about them or using their HIV status against them:

I have considered telling some of my friends but I don't trust them, they will not play with me and maybe they will go around and tell other people who will be mean to me (Musa).

Am afraid to tell any of my friends because they talk a lot and they won't be able to keep the secret. I think what if they start avoiding me at school and everyone will know. No I won't tell them, I don't trust them at all (Sipho).

A lot of people know who I am. I don't really want to be like one of those children who are a centre of attention at school and everybody is like,

“Oh look at that girl who has AIDS”. I did rather people see me as Musa than them saying “Oh Musa with AIDS” (Musa).

Previous studies conducted in SSA documented low levels of HIV status disclosure among adolescents living with HIV (Hodgson et al. 2012; Midtbo et al. 2012; Petersen et al. 2010; Siu et al. 2012; Thupayagale-Tshweneagae, 2010) with over half of the adolescents having never disclosed their HIV status beyond their immediate family due to the fear of stigma and discrimination along with the associated problems of rejection, abandonment, abuse and isolation.

Some participants talked about the assumptions surrounding HIV transmission that served to impede disclosure. They expressed their worry that if their HIV status was known, they could be accused of unacceptable behaviour. The existence of these assumptions within society was spoken about from the participant's direct experience, but they also created their own assumptions on what they expect others to think about the source of their HIV infection. Perceived beliefs were associated with HIV being only a sexually transmitted disease. Three participants expressed their worry that if their HIV status was known, they would be accused of being promiscuous, as if they were personally responsible for acquiring the infection. The end result of such perceptions would be stigmatisation and discrimination:

They won't understand that I got the HIV from my parents. They will think I was sleeping around with older men (Lihle).

Most people don't understand how HIV is transmitted and I know if I tell most of them will think, oh she is a prostitute that why she got it. They won't believe my mother gave it to me (Musa).

People will never believe I inherited AIDS from my mother. It's like they don't even know that my mother died of AIDS. If they somehow discover I have it they will think am lose and am to blame for having it (Noluthando).

Like in other studies of adolescents living with vertically acquired HIV (Hazra et al. 2010; Kang et al. 2008), participants in this study do not want people to assume that they acquired HIV behaviourally through stigmatised behaviours like being promiscuous. Some participants pointed that people lack adequate knowledge about vertical transmission of HIV which leads to assumptions that HIV is only behaviourally acquired resulting in stigma and discrimination therefore impeding self-disclosure of HIV status. This finding is consistent with other findings (Buseh, Park, Stevens, McElmurry & Kelber, 2006; Michaud et al. 2009) where adolescents also referred to lack of knowledge about HIV within the general population causing discrimination and a fear to disclose HIV status to others. Adolescents therefore protected themselves by keeping their status a secret and thereby avoiding stigma. In this study this was also an action of protecting their families as participants like Noluthando did not want people to know her mother died of AIDS.

Three participants reported that their caregivers discouraged them from disclosing their status to other people, sometimes including extended family members, friends, school teachers and community members for fear of stigma and discrimination:

My aunt wants to keep it a secret, because she doesn't like how people react (Lihle).

My other extended family do not know am positive because I was told by my grandmother not to tell anyone (Sipho).

My aunt says it's a secret and I must not share with other people otherwise I will also disclose my mother's secret (Noluthando).

These findings mirror those of other studies on HIV disclosure to children living with vertically acquired HIV in South Africa where caregivers reported that they told children and adolescents living with vertically acquired HIV not to disclose their status (Heeren et al. 2012; Madiba, 2012; Mahloko & Madiba, 2012; Moodley et al. 2006). Caregivers in these studies reported concerns that once children told others about their HIV status they would be socially rejected, mocked, teased, isolated by peers and the family's HIV status would be made public. For Noluthando, the aunt fears that if she discloses her HIV status to people outside the family she will therefore disclose her mother's HIV status.

However even the other three participants who did not report being instructed to keep their HIV status a secret by caregivers still kept their HIV status a secret. This phenomenon was also identified by Hejoaka (2009) who has argued that children keep the diagnosis secret because of their awareness of the secret nature of HIV and AIDS. Children and adolescents living with vertically acquired HIV as well as children living with family members with HIV are likewise subject to gossip, discrimination and hostility because of their association with HIV (Deacon & Stephney, 2007).

Although most participants initially spoke of disclosure as something that they do not want to happen ever and something that initiated a lot of fear for them, throughout the interviews there was evidence that disclosure was desirable in some instances or inevitable at some point in future:

I would never tell anyone but maybe one day I will have to when I have a boyfriend (Musa).

But if I get married to that man and am obviously going to have children with him so I will have to tell him (Okuhle).

Both male participants revealed they were involved in romantic relationships and they have not disclosed their HIV status to their girlfriends yet. They stated that they had been encouraged by the doctor and counsellor at Dora Nginza Wellness clinic to disclose their HIV status to their girlfriends, but they had not as they are worried the girlfriends might reject them:

I really don't know how to tell her. Am still working on it and when maybe we decide to sleep together I will tell her. I know she loves me but she might not understand and maybe leave me but I hope she loves me enough to stay with me (Sipho).

She doesn't know I have HIV, I haven't told her yet. You know there has been no need to tell her coz we are not sleeping together yet but in future, if I'm still dating her and we eventually want to sleep together, I'm going to tell her because you know she deserves to know before we sleep together. Besides the counsellor says I should and I will, it's just that am also not sure she will still love me after I have told her (Sonwabiso).

Previous studies conducted in SSA reveal that disclosing HIV status to partners is most challenging as adolescents fear rejection and loss of respect if their status is known (Bakeera-Kitaka et al. 2008; Birungi et al. 2009; Siu et al. 2012). Participants in this study also saw no urgency of telling their partners as they were also not engaged in any sexual activities with their partners and they both saw the need for disclosure when they decide to have sex.

4.3.2.3 Avoiding friendships

Some participants in this study seemed to avoid peer relationships in order to keep their HIV status a secret. Three participants reported isolating themselves and fear of others learning their status often overshadowed their need for friendship:

To make friends is too much effort, too much risk of being known you have HIV. A friend will want to know too much about you. They will want to visit you at home and maybe come and sleep over and I don't want that so yeah I don't have friends (Noluthando).

I don't allow other kids to get too close to my life, I know my life is complicated and I don't want to answer any questions regarding to my illness so don't invite them to my house (Lihle).

I don't have friends. I talk to my sister she is like a friend to me. When I come from school, I stay in the house and I don't go anywhere (Okuhle).

This finding is consistent with other research studies in South Africa which found that adolescents living with HIV isolating themselves from peers and more likely to experience peer problems (Li et al. 2010; Menon et al. 2007; Petersen et al. 2010; Thupayagale-Tshweneage, 2010). Living with HIV affected social interactions, separating participants from their peers.

4.3.3 Theme 3: Copying with HIV

Participants reported that after knowing about their HIV status, they went through a process of accepting their new reality, and integrating having HIV into their sense of self, their daily routines and their plans for their future. Participants had similar experiences of copying with HIV which included family support, frequent visits to the Wellness clinic, taking medications and attending school. Sub-themes that emerged in this theme were family support, visiting Dora Nginza Wellness clinic, taking ARVs, going to school, dating and future plans.

4.3.3.1 Family support

All participants were in the care of family members with four participants in legal foster care. Three participants were in the care of grandmothers, two with aunts and one with an uncle and his wife. Participants recognised the central role their families played in helping them cope with both their illness and life in general. They felt love and support from their caregivers, siblings, aunts, uncles and other family members who were staying with them:

They give me all the support I need and they care and love me and it makes life a bit easier just knowing they care (Musa).

I have had closer relationship with my family because I have needed them more since I was diagnosed with HIV (Sipho).

At home they help me with everything and give me all the support I need. It helps me get through knowing they love me (Noluthando).

Participants stated that their families assisted them to take their ARVs and stay healthy. Okuhle whose caregiver is also living with HIV describes how she and her grandmother both remind each other of taking their pills and how this has facilitated her adherence to ARVs:

We take our pills the same times so we always remind each other. When she takes hers, she calls me to take mine (Okuhle).

My sister and grandmother always encourage and remind me to take my treatment. They emphasize how important it is for me to be healthy and to live longer. I really feel loved and cared for (Sonwabiso).

My uncle bought me a cell phone last year to help me take my treatment. Although my phone alarm reminds me to take it he still asks to see if I have taken the treatment (Musa).

For some participants, relationships within the family appeared to replace peer relationships which are typical of their developmental stage. When asked about their peers, three participants replied that family members such as a sibling or cousin were their best friend:

My sister is my best friend. She understands what am going through and I don't have to explain anything to her (Okuhle).

I play with my cousins, they are my best friends (Sipho).

Family support was not limited to the domain of HIV, but was also perceived being instrumental in the broader aspects of life like providing food, shelter, clothes, paying school fees and giving guidance in life:

My family helps me with everything. They guide me and protect me and I always feel safe because I know they are there for me (Sipho).

They correct me when am wrong and advice me so that I don't make wrong decisions (Noluthando).

Several studies have pointed to out the importance of a supportive family in enabling children and adolescents living with HIV to cope with HIV (Hazra et al. 2010; Li et al. 2010; Petersen et al. 2010). For participants in this study family meant having people who loved them unconditionally despite their HIV status, people who understood their illness and where they never had to hide their illness.

4.3.3.2 Visiting the Wellness clinic

Most participants spoke about their long-term positive experience of receiving treatment, care and support services at Dora Nginza Wellness clinic which they described as routine. They all visited the Wellness clinic alone once a month for their monthly scheduled check-up and all participants saw it very important not to miss these visits. During the visit participants reported that they saw their doctor, collected their ART treatment, and attended the support group session. They described the processes, procedures and personal interactions with staff at the Wellness clinic that govern their experiences of visiting the Wellness clinic as follows:

We come here every first Friday of the month. We are supposed to be here by half past seven and collect our files from the reception and wait for our doctor who usually comes at eight. Each one of us sees the doctor at times together with a nurse. The doctor does the regular tests on our blood and urine. Once in three months the doctor takes blood and checks the CD4 count and tells you the CD4 results. After seeing the doctor we give our files to the nurses who fetch the medicine and whilst we are waiting for our medicine if you want you can talk to the social worker about all kinds of things going on in our life. Sometimes she invites other people with HIV to come and speak to us about life and last time there was a guy who came to talk to us about circumcision. After everyone finishes with the doctor we have a support group with the counsellor(Sonwabiso).

All participants identified visits to the Wellness clinic as a central feature of their childhood and adolescence experience. Okuhle and Noluthando reviewed their past and perceived attending the Wellness clinic attendance as part of their lives and therefore deemed it normal:

I always came here [Wellness clinic] since I was very young, so coming here is part of my life (Okuhle).

I know that at least once every month I must come here [Wellness clinic]. It's been like that for years now (Noluthando).

All participants stated that they enjoyed visiting the Wellness clinic and like the fact that they had their own day each month on which they were alone as adolescent patients living with vertically acquired HIV at the Wellness clinic. They mentioned that it was helpful being part of a group in which difficult explanations about their status were not required and where they did not hide their HIV status:

The experience is that when am at home I feel like am the only one taking the ARVs but when I come here I see children like me who also take the treatment (Musa).

Coming here made me see that there are other children like me and when they share what they go through, I feel much better and know that after all, am not the only one (Sipho).

You do not feel lonely here because you are with other children who are just like you and you don't have to explain anything (Sonwabiso)

Here I meet others like me and I don't have to pretend when I come here (Lihle).

The above statements show how it can be strengthening to engage with others who have a similar illness and life experiences as oneself, which can prevent feelings of depression and loneliness in one's situation and enhance the feeling of belonging, a finding also supported in other studies (Midtbo et al. 2012; Petersen et al. 2010).

Similar to previous findings (Shirima, 2012), participants in this study enjoyed the relaxing and non-threatening nature of the Wellness clinic which separates their check-up visits with those for children and adults living with HIV.

Participants described positive interactions they had with the Wellness clinic staff which include nurses, doctors, a social worker and a counsellor. Participants reported that these interactions are very casual making it easy for them to communicate any issues with all the Wellness clinic staff:

I got to know my doctor and he also got to know me. He wants to know what's going on in my life and every time he asks me if I have any questions about my HIV and the treatment. If I need advice on anything I ask him. He makes me feel like an equal (Sipho).

Every time I come here I always get like more information about HIV. They explain everything so I know exactly what is going on (Sonwabiso).

Everyone here is nice and they make us feel comfortable taking their time always to treat us. I regard them as friends and family (Okuhle).

The strengths of tailored age-specific HIV and AIDS services offered at the Wellness clinic by the clinic's multi-disciplinary team comprising of a doctor, nurses, a social worker and a counsellor emerged as important to the participants' disease management. The clinic's successes in addressing informational needs of adolescents were evident in the adolescents' discussions about their illness. This finding contrasts previous studies from SSA which have reported a glaring gap in the health care system, where there are neither specialised HIV clinics for adolescents nor specialists to cater for adolescents living with vertically acquired HIV (Ferrand et al. 2009b; Hodgson et al. 2012; Jaspan et al. 2009). Other studies (Baryamutuma & Baingana, 2011; Hodgson et al. 2012) have identified poor health workers' attitude towards adolescents living with HIV, lack of communication, formal

and impersonal interactions between adolescents living with HIV and medical staff as barriers to disease management.

Participants talked about how Wellness clinic staff helps them to understand their illness specifically matters regarding HIV and AIDS including issues on relationships, sex, family planning and pregnancy. They generally reported finding discussions about sex and relationships in the clinic useful and well handled by the social worker and counsellor:

I always feel better when I come here [Wellness clinic]. I feel better because everyone here cares. They always explain to us about HIV and the importance of taking the medicine, using condoms and having a healthy child (Musa).

I know about my virus load, CD4 count and the social worker and counsellor have discussed issues of sex, having children and family planning with us (Noluthando).

We have got that relationship where I can just tell them [doctor, nurses, social worker and counsellor] anything at all (Musa).

Its good because they don't tell us don't do that and don't have a girlfriend. It's more like advice on how to protect yourself and your girlfriend (Sipho).

Contrary to other studies that report neglect of the SRH needs of adolescents living with vertically acquired HIV by health care services (Baryamutuna & Baingana, 2011; Birungi et al. 2009; Busza, 2011; Cataldo et al. 2012; Li et al. 2010), participants in this study were very well informed about their SRH issues and they reported that they could receive SRH services at the clinic if they wish. The Wellness clinic was talked about as a place where the participants could ask

questions with regards to their health, HIV, sex, family planning, child bearing and general life issues providing adjunct support in addition to family support.

4.3.3.3 Taking ART treatment

Many participants commenced ART treatment in early adolescence and all of them have been receiving treatment for at least two years or more. They all expressed that taking ARVs forms a fundamental part of their everyday life. They all reported that they take their ARVs twice everyday in the morning and during the night and most of the participants identified taking medication everyday as a challenge which reminded them they were living with an incurable disease. However they all knew that being healthy required diligence about ART adherence:

I only have a chance to live if I take my pills everyday and eat healthy (Noluthando).

If I don't take the pills, I will get more sick and die (Lihle).

Participants reported ARVs as very important in their lives and taking ART treatment consistently was related to being able to live a longer healthy life. This finding is consistent with other studies (Bikaako-Kajura et al. 2006; Li et al. 2010; Menon et al. 2007; Midtbo et al. 2012) where children and adolescents expressed similar attitudes to their ART treatment, trusting the ARVs will keep them healthy. In a South African study, adolescents living with HIV identified availability of life prolonging medication as assisting them to cope with HIV (Petersen et al. 2010).

All participants reported a number of factors that contributed to their negative experiences of taking and adhering to their ARVs and these included taking ARVs every day, ART regimes being changed, size of the ARVs, figuring the most

appropriate time to take the ARVs and dealing with side effects from ARVs which led them to default their treatment at times:

I have taken many types of treatments. Most of them were changed because they made me very sick when I took them. I would feel dizzy and sometimes vomit. The doctor changed the treatment until I had one which didn't make me vomit (Musa).

It was difficult when I started them. I would get stomach pains when I drink them and at times vomit a lot and so I would throw them in the toilet and pretend I drank them. The ones am taking now are better (Okuhle).

I have to wake up very early each morning so that I can eat and take the pills. I don't like waking up early but I have to (Lihle).

Taking the treatment in the morning is very difficult for me. I must take them before I go to school but they make me sick if I take them early in the morning, but I also cannot take them at school (Sipho).

I have to drink the pills every day whether am sick or not and they taste horrible you know. They are big so sometimes they get stuck on my throat and its painful (Noluthando).

Physical side effects like nausea, dizziness, rashes, oversleeping and inability to sleep, weakness and other symptoms create a complicated relationship between the participants and their bodies. Similar to these findings, medication related barriers such as treatment fatigue, dosing frequency, pill burden, side effects of ART treatment have been cited as reasons for poor adherence among adolescents living with HIV (Chandwani et al. 2012; Hosek et al. 2005; Moodley et al. 2006).

All participants reported it was difficult to take their medication in a public place so instead they had to remove themselves from social situations making it more likely they might miss a dose. All the participants were very open about how they sometimes think of defaulting or actually default their ART:

I visited my friend and couldn't get a chance to be alone to drink the treatment. I ended up sometimes taking them late or not taking them. I don't want him to know that am sick (Sonwabiso).

Last week I was like, no today am not taking pills. I wanted to wake up early and study for my exam and the pills make me oversleep. So I didn't drink them otherwise I was not going to wake up early and study (Noluthando).

Lifestyle barriers such as forgetting, worrying about disclosure of HIV status, being away from home were common amongst participants in this study.

You end up thinking too much and at times you now feeling like I don't want to take the treatment (Musa).

At times I forget taking the pills you know when there is no one to remind me (Lihle).

I am happy to have the treatment. Am not sick today because take treatment but on the other hand, when I feel so well, then I don't always want to bother about taking it regularly (Sipho).

Missing one's drugs increases the risk of a person's viral load and for him or her to become resistant to ARVs. Findings of this study clearly show that adolescents living with vertically acquired HIV do not consistently adhere to their ART treatment.

Previous research has revealed that adolescents in Southern Africa have poor adherence than adults (Bygrave et al. 2012; Nachega et al. 2009; Nglazi et al. 2012; Shroufi et al. 2013). Several qualitative studies in SSA have identified a number of psychosocial factors associated with poor adherence and non-adherence among ALHIV and these include stigma, delayed disclosure, depression, stigma, alcohol use, difficulty in identifying with HIV-negative peers, anxiety about sexual relationships and future planning, low self-esteem and feelings of hopelessness which are sometimes compounded by the adolescent having to head a family, and having to take care of ill relatives and siblings (Bakanda et al. 2011; Bygrave et al. 2012; Chandwani et al. 2012; Ferrand et al. 2009b; Mavhu et al. 2010; Nglazi et al. 2012).

4.3.3.4 Going to school

All participants were attending public schools in the local community. They all reported school was important to them and they all wanted to finish school and go to university. Within their experiences of going to school participants reported school absenteeism, stigmatising attitudes of other school pupils towards them and unappreciated attention from teachers.

4.3.3.4.1 Absenteeism from school

They all reported missing school regularly due to illness and medical appointments.

I was very sick in 2011 and didn't go to school most of the time (Sipho).

Every first Friday of the month we come here so it's like I miss a school day each month (Noluthando).

This has implications in their school performance which in turn influences progression from one grade to another. Lihle, Okuhle, Sonwabiso and Musa were a grade or more behind their age and they all reported repeating grades. Poor

performance caused by illness and absenteeism were the major reasons of repeating a grade:

I was hospitalized with TB for a whole year last year so I ended up repeating Grade 7 again (Lihle).

I was sick most of the time and missed school a lot. I failed my exams and had to repeat (Okuhle).

Missing school due to illness causes them to be behind in their learning, and trying to make up for the work that they missed and or do not understand is quite overwhelming and frustrating. These findings correlate with other findings (Kamau et al. 2012; Obare et al. 2011a) which found that HIV and AIDS has an impact on school attendance and performance on children and adolescents living with vertically acquired HIV which could even be a hindrance for a successful healthy future.

4.3.3.4.2 School pupils' attitudes

Participants who were symptomatic reported being isolated, shunned and stigmatized by other students:

They don't want to associate with me and some always make insulting comments about HIV in my presence (Lihle).

They call me nasty names like snake, poison and comment a lot about my hair (Okuhle).

Other participants also reported experiencing the full extent of children's fear and ignorance about HIV and AIDS from cruel jokes to active discrimination within

school environments, suggesting that approaches that normalise living with HIV and educate school children about HIV must be intensified:

At school they say people with HIV are always sick and die quite easy. So each time they say this I feel affected and most of the time I keep quite or move away (Noluthando).

Children at school talk about AIDS in negative ways. They even say they will never play or touch kids who have AIDS (Musa).

4.3.3.4.3 Teachers' attitudes

Okuhle and Lihle reported that some teachers, while trying to be kind, give them unwanted favouritism by giving them special attention such as asking after their welfare or giving them food. Although offerings were viewed as generous, the participants said they did not want being singled out among other children in class:

If you are not sick, you maybe like to be treated special, but if you have a disease like mine, you just want to be treated normal (Okuhle).

I don't like when my teacher give me favours and ask me every time how am feeling (Lihle).

These wise and incisive statements capture the essence of some participant's experiences of living with HIV within the school setting. Participants do not want to be dominated by an identity linked to HIV. They long first and foremost to be seen as children with the assurance that their identity remains larger than their HIV status. Most participants like Musa reported that they had not disclosed their HIV status to teachers or anyone within the schools because they did not want any special attention towards them and wanted to be treated normally just like other learners.

4.3.3.5 Sexual relationships

With respect to experiences of dating, all the four female participants reported that they had never been in a relationship and had never engaged in any sexual expression such as kissing, touching or fondling. They however all reported a desire to date and have sex in future. Both male participants reported that they were in relationships and had engaged in at least one sexual expression with their current partners:

We have not slept together yet but we do touch and kiss (Sipho).

We just do the other staff but not the real staff (Sonwabiso).

Studies have reported mixed findings regarding sexual activity in adolescents living with vertically acquired HIV with some studies reporting delayed penetrative sex (Mellins et al. 2011), increased sexual behaviour among adolescents living with vertically acquired HIV just like their HIV negative peers (Baryamutuma & Baingana, 2011) and no association between HIV status and sexual risk behaviour (Obare et al. 2010). In a Ugandan study of adolescents living with vertically acquired HIV, only one-third of the respondents had never had sex, and of these, 86% intended to have sex in future (Birungi et al. 2009).

Previous studies have reported that in developing countries, HIV and AIDS programmes and services are designed around paediatric and adult care (Birungi et al. 2009; Baryamutuma & Baingana, 2011; Busza, 2011; Cataldo et al. 2012; Hodgson et al. 2012) and cannot adequately address the SRH of adolescents living with vertically acquired HIV. In this study, the Wellness clinic seemed to play a major role in providing relevant information about sexual and reproductive health to adolescents as participants in this study were very knowledgeable about these issues.

4.3.3.6 Future plans and aspirations

In spite of the challenges with school absenteeism, grade repetition and dealing with uneducated and discriminatory attitudes of other school children, all participants considered education constructive. Like in other studies (Hazra et al. 2010; Li et al. 2010; Petersen et al. 2010) finishing school and having good grades was associated with a better future and the majority of participants reported this as a motivation of attending school:

I want to be someone in future, a person that people admire and respects and going to school is my stepping stone (Noluthando).

Am building my future and passing my Grade 12 will enable me to go to university, and have a good job (Sipho).

I know my future depends on my education (Musa).

Although many participants reported fearing death they also showed a positive view of their future and neither their past nor present challenges seemed to have much impact on this outlook. Most participants actually found hope in their dreams of leading normal lives in future. They also believed it possible for them to finish school, have good careers, marry and start families. All four female participants stated they would like to find a life partner and start a family once they had completed their education and fulfilled their ambitions:

I definitely want to be married and have my own family and children too when I finish my studies (Okuhle).

I want to finish Grade 12 and go to university and be a doctor. I hope I will find a good man to marry me and we can have children (Noluthando).

I would want to have my own family but am not thinking much about that now. I must get educated first. I would want to be a social worker (Lihle).

Maybe I will be a nurse but I will also take any job which I can work in a hospital. If I get the right man to marry me, maybe someone like me, I would love to have a family and have children (Musa).

Participants in this study aspire for better lives just like their HIV negative counterparts. A positive life view has also been reported in previous studies on adolescents living with vertically acquired HIV (Bakeera-Kitaka et al. 2008; Baryamutuma & Baingana, 2011; Birungi et al. 2009; Li et al. 2010; Mburu et al. 2013; Obare et al. 2010). Participants desire to have careers, families and children and recognize the importance of schooling towards achieving that better life and the majority of participants in this study reported this as a motivation for continuing with education.

4.4 Care and support services appropriate for adolescents living with vertically acquired HIV

This section addresses care and support services developmentally appropriate for adolescents living with vertically acquired HIV based on the lived experiences shared by the adolescents in this study. The study participants had an opportunity to share what they thought could be done for them to ensure they realise their full potential and this is incorporated in the determined care and support services discussed below.

4.4.1 Scheduling monthly clinic visits after school hours or during weekends

Okuhle and Noluthando reported that they would want their monthly checkups at the Wellness clinic to be scheduled on a weekend or after school hours so that they do not miss school often:

It would help if we can come on a Saturday instead of a Friday. In high school Friday is an important day and most tests are written on a Friday, and I miss some of the tests because I have to be here (Okuhle).

I wish the check-up visits could be after school hours or weekends so that I don't miss any school work (Noluthando).

The Wellness clinic must try to schedule the adolescent appointments to see the doctor and collect medicine after school hours. Participants in the study reported that they all finished school at three o'clock and could arrange to be at the clinic around this time to see the doctor and collect their ART treatment. Support group sessions at the clinic could therefore be conducted on a Saturday. This would minimise school time lost for disease management.

4.4.2 Facilitate adolescent peer support outside the Wellness clinic

Participants in this study repeatedly noted the need for opportunities to interact more with other adolescents living with vertically acquired HIV besides during monthly clinic appointments:

We don't always have a chance to be together like this except when we come here for our visits. It would however be good if we meet often (Sipho).

I know there are a lot of children like me with HIV and it will be good for us to know each other and be able to support each other even when we are at home or at school (Musa).

Given that social identities are formed in relation to others, developing a healthy social identity for adolescents living with vertically acquired HIV also requires involvement of peer social groups at the community level that can challenge the

pervasive negative attributions projected onto people living with HIV. Peer support services providing treatment education, support for adherence, opportunities to boost self-esteem, support for dealing with HIV-related stigma and mentoring are critical for adolescents living with vertically acquired HIV (Menon et al. 2007; Midtbo et al. 2012; Petersen et al. 2010). In other settings peer support groups have been shown to improve confidence and uptake of health services (Hodgson et al. 2012; Watt, Maman, Anne, Eng, Setel & Golin, 2009). The use of peer education and group activities could potentially be integrated into home-based care programmes or linked through referrals to widen adolescents' access to sources of information and support (Hodgson et al. 2012).

4.4.3 Decrease and discourage stigma and discrimination

The need for measures that decrease and discourage stigma and discrimination experienced by adolescents within their immediate circles of care such as the school was something that all participants in the study felt strongly about. They emphasised the need for teachers to teach more about HIV and AIDS and other methods of HIV transmission besides having unprotected sex in order to educate pupils and eliminate discrimination against them:

Most kids don't know that there are people of my age that were actually born with HIV. The teachers need to teach about children like us so that other kids understand this type of HIV with have. Until other kids understand about people like me, I will not disclose my HIV status (Noluthando).

Given the frequency of harmful attitudes and influences in schools and communities where the participants reside, it is important that all people and programs involved in HIV related services address stigma and discrimination against adolescents living with vertically acquired HIV while building the capacity of adolescents and their families to address stigma directly. Approaches include supporting targeted interventions to address negative situations in schools and the general community.

This can be achieved through comprehensive education on HIV and AIDS within schools by teachers to help raise awareness (particularly around methods of HIV transmission) and challenge stigma.

4.4.4 Support adolescents disclose their HIV status

All participants in this study expressed the need to be better prepared to manage their own life like knowing when, to whom and how to disclose their HIV status. Self-disclosure of HIV status to people outside the family was a common challenge for all participants in this study and even for participants who had disclosed their HIV status to teachers such as Lihle and Okuhle. They both continued to consider further disclosure and talked about worries and dilemmas connected to it: *“I only told my teacher because I had just started high school and I wanted her to understand why I was absent from school most of the time, otherwise I can’t tell other people”* (Okuhle). Support around disclosure should therefore be an ongoing process throughout adolescents’ lives, particularly paying attention to age and developmental stages like beginning secondary school, dating or sexual relationships so that disclosure can be discussed and considered at different times and when challenges arise. Health care professionals should discuss disclosure more intensively with adolescents and create ongoing systematic support to assist adolescents living with vertically acquired HIV in developing their skills for disclosure and help them understand how to deal with its consequences. Attention is often paid towards families where the adolescent has not been informed of his/her HIV status yet, but this study suggests that self-disclosure is just a big dilemma for adolescents, for which they would benefit from the various forms of support. This support may most effectively take the form of peer support, in sharing ideas and experiences and thinking about how they can approach the subject with other people.

4.5 Conclusion

In this chapter, the research findings have been presented and subjected to literature verification. The researcher first provided a biographical information of the participants, in order to give the reader a background and contextual information relating to participants' families, diagnosis of HIV, disclosure of HIV and when they started taking ARVs. The researcher then proceeded to discuss the themes which emerged from the process of the data analysis with regards to the lived experiences of the adolescents. The first theme, HIV infection, dealt with adolescents' perceptions about HIV and it was divided into three subthemes, namely being sick, fear of dying and living with loss. The second theme dealt with disclosure of HIV status and was divided into three subthemes which are knowing my HIV status, keeping it a secret and avoiding friendships. The third theme, coping with HIV had six sub-themes which are family support, visiting the Wellness clinic, taking ARVs, going to school, dating and future plans. The last section of the findings presented the determined care and support services for adolescents living with vertically acquired HIV based on the research findings. Four care and support services were identified namely scheduling clinic appointments after school hours or during weekends, establishing peer support groups outside the Wellness clinic, decreasing and discouraging stigma and discrimination and supporting adolescents disclose their HIV status. Based on the research findings of the study, a summary, conclusion and future recommendations will be presented in the next chapter.

CHAPTER 5: CONCLUSION

5.1 Introduction

This final chapter of the research report presents the summary of the study findings together with the limitations, recommendations and conclusion of the study.

For this qualitative study, an exploratory case design was implemented, drawing on the social ecological theory which recognises the connected relationship existing between an individual and their environment. Two research questions were addressed: Research question 1; What are the lived experiences of adolescents living with vertically acquired HIV receiving treatment, care and support services at Dora Nginza Wellness clinic? Research question 2; What are the care and support services developmentally appropriate for adolescents living with vertically acquired HIV? Through in-depth individual semi-structured open-ended interviews with six adolescents (four female and two male) aged between 16 and 17 years experiences of living with HIV since birth were identified in three themes and from the study findings, the researcher determined four care and support services developmentally appropriate for the adolescents.

5.2 Summary of the study findings

Themes that emerged from the study findings were related to HIV infection, disclosure of HIV status and coping with HIV. Based on the study findings, four care and support services were determined for adolescents living with vertically acquired HIV. These are:

- **HIV infection**

Participants regarded HIV as a negative part in their lives, conveying feelings of sadness, fear and anxiety about their illness. At a personal level, participants described HIV as physically and emotionally painful. All participants have experienced severe long-term illness, numerous hospitalisations, and loss of parents, siblings and family members due to HIV and AIDS. Experiences of death of parents and family members have shown to be distressing and related to concerns about their own death. Some participants presented physical and developmental delays as a consequence of their disease. They were very anxious about death. Some have had multiple caregivers due to illness and death.

- **Disclosure of HIV status**

Despite being born with HIV, the participants learnt about their HIV status during early adolescence. Learning about their HIV status is clearly an emotional and pivotal point in the adolescents' life. Participants reported reacting with sadness, anger, hopelessness, withdrawal, imminent sense of death and worry about what their HIV diagnosis meant for their future. Some participants revealed that their caregivers discouraged them from revealing their HIV status to others outside the family. Their HIV status is a secret kept within the family. Secrets appeared to be an everyday part of participants' lives as it was difficult for them to trust what others may do with the information about their HIV status. This fear was linked to the awareness that HIV is associated with stigma. They understood their responsibility to protect their partners but feared that disclosure would lead to rejection or stigmatisation.

- **Copying with HIV**

Participants report on how they had integrated living with HIV in their daily lives and described experiences of family support which helped them to cope with the infection. They also reported on their positive experiences of visiting the Wellness clinic regularly and their good relationships with the health professionals which

made the routine clinic visits enjoyable. Participants were provided with safe and supportive health care services that are adolescent friendly, confidential and allowed them to receive comprehensive treatment, support and care services including sexual and reproductive health services. Treatment adherence was raised as a concern by all participants. They viewed experiences of taking ARVs as a demanding as well as tedious process that involved waking up early, challenging medication schedules, dealing with side effects and reminded them they were terminally ill. All participants were attending school at the time of the interviews. Issues of absenteeism, repeating grades and stigma as well as discrimination by other pupils were a common challenge amongst the participants. The most commonly cited reasons for missing school and repeating a grade were illness, going for check-ups at the Wellness clinic and poor performance. All participants were not involved in sexual relationships but some are dating. They all aspire to finish school, have families, children and careers.

The following care and support services were determined for adolescents living with vertically acquired HIV-; They include 1) scheduling clinic appointment after school hours and during weekends, 2) establishing peer support groups outside the Wellness clinic, 3) decreasing and discouraging stigma and 4) discrimination and supporting adolescents disclose their HIV status.

5.3 Limitations of the study

This study is based on participants' perceptions and was confined to one HIV clinic in the high density suburb of Port Elizabeth, an area dominated by people of African origin using a sample of only six adolescents living with vertically acquired HIV between the ages of 16 and 17 years who knew their HIV status. It is acknowledged that the study findings are restricted to these specific adolescents from this suburb in this community and may not be generalised to a wider population of adolescents living with vertically acquired HIV in South Africa and beyond.

Furthermore, the use of a multidisciplinary clinic that specialises in HIV services may also have favoured the range of adolescents' lived experiences. All adolescent participants were accessing comprehensive treatment, care and support services in a clinic where staff had specialised training and experience in the field of HIV and AIDS. This may be unlike the rest of this population of adolescents living with vertically acquired HIV who are attending tertiary hospitals which are not well resourced as support services may not always be available at all hospitals.

5.4 Suggestions for further research

It is recommended that a larger randomly selected sample, covering a larger geographical area be drawn in future research studies in order to improve the generalisability of the findings. In addition, the inclusion of caregivers, health care providers and teachers in a follow up study would provide a valuable holistic view on the lived experiences of adolescents living with vertically acquired HIV.

As the study focused mainly on adolescents between 16-17 years adolescents, future research studies could incorporate older adolescents. The experiences of older adolescents are important especially considering that high risks behaviours become increasingly common in late adolescence. Unfortunately this group was not adequately represented in this study.

5.5 Recommendations for policy and practice

Based on the findings, the following recommendations are suggested for adolescents living with vertically acquired HIV:

- **Improve adolescents' positive sense of self**

There is need for intensive support, whether it is social or spiritual in nature to help adolescents develop a positive sense of self that is not based only on their HIV status. The personal wellbeing of participants in this study is affected by HIV, and unsurprisingly, most of them felt sad, anxious and angry about their HIV status.

Strong support networks enhance the ability of adolescents to overcome the multiple stressors in their lives and adolescents living with vertically acquired HIV with positive self-concepts reported fewer emotional problems and performed better in school (Li et al. 2010; Midtbo et al. 2012).

- **Enhance ART adherence**

Since adherence to ART is integral to attaining and sustaining positive virological and immunological outcomes (Nglazi et al. 2012), adolescents living with vertically acquired HIV needed support to manage their ART treatment. Caregivers of adolescents tended to be heavily involved in providing practical and instrumental help of taking ARVs. However adolescents must take increasing responsibility for taking ARVs as they do for their monthly clinic visits. Adolescents may therefore need to be targeted with interventions which enhance adherence to ART and promote responsible treatment management.

- **Facilitate adolescent peer groups outside the Wellness clinic**

The Wellness clinic needs expand the continuum of care to include more community based resource persons and partners to meet the psychosocial needs of adolescents while maintaining a central point person to monitor and coordinate the care (Wellness clinic social worker or counsellor) like peer outreach, mentoring and support groups for adolescents living with vertically acquired HIV. These need to be resource-intensive and could benefit from being decentralized from the Wellness clinic by being brought into the community and led by adolescents and their caregivers. Interactive sessions might simply bring together adolescents and must be formed around specific activities.

- **Address stigma and discrimination against adolescents living with vertically acquired HIV in schools**

The Department of Education needs to collaborate with school officials to formulate policies that outlines measures aimed at discouraging stigma and discrimination of in-school adolescents living with vertically acquired HIV. Such measures include

disseminating comprehensive information about HIV and AIDS transmission during Life-Orientation lessons and programmes aimed at sensitizing school students on the consequences of discrimination and stigmatization on other pupils living with HIV and PLHIV in general, as well as advocacy to have school management allocate resources for anti-AIDS campaigns within a school's budget. This could in turn, increase the propensity to disclose one's HIV status by adolescents and ensure an appropriate and timely response to the needs of students living with HIV by school officials.

5.6 Conclusion

This study explored the lived experiences of six adolescents living with vertically acquired HIV receiving treatment, care and support services at Dora Nginza Wellness clinic. The exploration of their lived experiences brought an awareness of various challenges and obstacles the adolescents' experienced. There is need for the implementation of appropriate care and support interventions in creative, coordinated, multilevel approaches where adolescents and community stakeholders can potentially work together. Adolescents need intensive care and support services that enhance their positive self, facilitate self-disclosure and decrease and discourage stigma and discrimination at school and within their communities.

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APPENDIX A: Application for permission to conduct a research study

27 September 2013

The Superintendent
Department of Health Eastern Cape Province
Conyngham Road
Parson Hill
6001

Dear Madam

Re: APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH STUDY ON ADOLESCENTS LIVING WITH VERTICALLY ACQUIRED HIV RECEIVING HIV TREATMENT, CARE AND SUPPORT SERVICES AT DORA NGINZA WELLNESS CLINIC

Research topic: EXPLORING THE LIVED EXPERIENCES OF ADOLESCENTS LIVING WITH VERTICALLY ACQUIRED HIV.

I hereby apply for permission to conduct a research study on adolescents living with vertically acquired HIV receiving HIV treatment, care and support services at Dora Nginza Wellness clinic.

My name is Pretty Jena. I am a registered qualified social worker and am doing a masters degree in Social Behavioural Studies (HIV/AIDS) with the University of South Africa (UNISA). In partial fulfilment of the requirements of my degree I am required to undertake a research study in the area of HIV/AIDS and my field of interest is adolescents living with vertically acquired HIV.

The research study aims to explore the lived experiences of by adolescents living with vertically acquired HIV and to determine care and support services developmentally appropriate for this population.

With the assistance of a counsellor who runs a support group for adolescents living with HIV at Dora Nginza Wellness clinic, I would like to recruit five male and five female adolescents living with vertically acquired HIV between the ages of 16 and 19 years who are attending the clinic. Adolescents of any ethnic or gender group will be included as participants. The inclusion criteria for the sample of adolescents are as follows:

- Must be living with vertically acquired HIV.
- Must be aware of his/her HIV status.
- Male or female between the ages of 16 – 19 years.
- Must be willing to participate in the study and has signed the adolescent assent form (for adolescents below 18 years and their guardian(s) signed the guardian consent form) and adolescents above the age of 18 years has signed adolescent consent form.

Participation in the research study is entirely voluntary. Guardian permission will be sought for prospective adolescent participants below the age of 18 years for the adolescent's inclusion in the research study. The adolescents who will consent to be part of the research study will be required to avail themselves for in-depth individual semi-structured open-ended interviews with the researcher for approximately one hour long in November 2013 at Dora Nginza Wellness clinic consultation room.

The questions that will be covered during the interviews will relate to the lived experiences of growing up with HIV. Any emotional stress or disturbance to participants will be minimized. Participants will also have access to a professional social worker at Dora Nginza Wellness clinic if needed during the research process.

Adolescents who will participate will have the right to withdraw from the research study at any point of the research process and their decision will be respected and no pressure will be placed upon the individual.

Strict confidentiality will be applied during the research process and information gathered will be used for research purposes only. Names of the participants will not be mentioned in any report. Copies of the transcribed individual interviews will be securely stored and locked in a cupboard at my house where I only have access to them. On completion of the research study, I will destroy them. A feedback session of the research findings will be organized by the researcher after the completion of the data analysis.

There is unfortunately no payment attached to adolescents' involvement in the research study. The researcher will only provide transport money totalling R50 for the research participants to visit the clinic both for briefing of the interviews.

If you need any clarity with regards to the research study or if you have any concerns about the ethical aspect of the research you can contact me or contact Maki from UNISA; Department of Sociology at 012 429 6587.

Your permission for me to conduct the research study will be greatly appreciated.

Yours sincerely

.....

Pretty Jena

Contact no: 041 453 0441/ 078 4111967; patiencejena@yahoo.com

APPENDIX B: Guardian Information Sheet and Consent Form

My name is Pretty Jena and I am a registered qualified social worker and am doing MA studies in Social Behavioural Studies in HIV/AIDS with the University of South Africa (UNISA). As part of my Master's dissertation, I am doing a research study on the lived experiences of adolescents living with vertically acquired HIV receiving HIV treatment, care and support services at Dora Nginza Wellness clinic. I would like to request permission for your child to participate in the research study.

My research aims to explore the lived experiences of adolescents living with vertically acquired HIV and determine care and support services developmentally appropriate to this population. If you agree to allow your child to take part in this study, I will interview the child at Dora Nginza Wellness clinic consultation room in November 2013. The interview will take approximately one hour.

During the interview, I will ensure that any emotional stress or disturbance to your child is minimized. Your child will have access to a professional social worker at Dora Nginza Wellness clinic if needed during the research process.

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

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

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

If you have any questions or you are unsure of anything about the research you can contact me at 078 4111967. If you are unsure of anything about the research study and have any concerns about the ethical aspect of the research please contact Maki from UNISA; Department of Sociology at 012 429 6587.

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

Date: -----

Ms. Pretty Jena (Researcher)

GUARDIAN CONSENT

Yes, I give permission for my child to participate in this study on exploring the lived experiences of adolescents living with vertically acquired HIV.

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

Signature of the guardian

Name of the guardian

Name of the child

Date: -----

APPENDIX C: Adolescent Information Sheet and Assent Form

Hello, my name is Pretty Jena. I am a registered qualified social worker and an MA student from the University of South Africa (UNISA). I am doing a research on the lived experiences of adolescents who were born with the HIV.

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

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

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

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

You will not be paid for being in the research study but you will be given transport money totalling R50.00 for your transportation to and from Dora Nginza Wellness clinic for the interview.

You will not be forced to participate in the research if you do not want to. You will not get into trouble with Dora Nginza Wellness clinic if you say no. You may also stop in the research study at any time.

I will be happy to answer the questions you have about the research study. My contact number is 078 4111967. If you are unsure of anything about the research study and have any concerns about the ethical aspect of the research please contact Maki from UNISA Department of Sociology at 012429587.

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

Date: -----

Ms. Pretty Jena (Researcher)

ADOLESCENT ASSENT

YES, I want to take part in this study.

- I was invited to participate in the above mentioned research project which is undertaken by Pretty Jena, a masters student at UNISA.
- This research study aims to explore the lived experiences of adolescents living with vertically acquired HIV. The information will be used as part of the requirements for the MA Social Behavioural Studies in HIV/AIDS. The results of the study will be presented in a dissertation.
- My identity will not be revealed in any discussion and description by the researcher.
- My participation is voluntary. My decision regarding participation or non-participation in the study will in no way affect my lifestyle.

- No pressure was exerted on me to consent to my participation and I understand that I may withdraw from the study at any stage without being penalized.
- Participation in this study will not result in any cost or financial gain for me or my guardian(s).

Signature of participant

Name of participant

Date: -----

APPENDIX D: Interview guide

- Can you me about yourself? (Age, schooling, family make up, socioeconomic situation)
- Can you share with me how you first became aware of your status, (who told you, when, where, what were the circumstances?)
- How did you feel when you learned about your diagnosis?
- Tell me what it is like for you living with HIV? (Physical effects, illnesses and hospitalizations, medical care and providers, family support, social support, social difficulties)
- Have you disclosed your illness to your friends or any other person? (For those to whom you have disclosed, how did you choose these people to share your HIV status? What were the circumstances? How did the person react to this news? For those not disclosed to, why have you not disclosed to these people?)
- Can you describe any difficult or traumatic experiences in your life related to your status?
- Do you attend any support group for people living with HIV?
- Do you have a boyfriend/girlfriend? (How old is she/he; Does he/she know about you HIV status; Are you in a sexual relationship; Are you practicing safe sex?)
- What do you think can be done by your family, friends, nurses, doctors, social workers, teachers and the larger community to ensure that you realise your full potential?
- What are your goals and plans for the future, do you plan to have a family, a job, where do you see yourself in ten years to come?

APPENDIX E: UNISA ethical clearance letter



Department of Sociology
College of Human Sciences
27 September 2013

Proposed Title: Exploring the lived experiences of adolescents living with vertically acquired HIV
Principle investigator: Ms PP Jena (Student number 50809148)

Reviewed and processed as: Class approval (see paragraph 10.7 of the Unisa Guidelines for Ethics Review).
Approval status recommended by reviewers: Approved

The Higher Degrees Committee of the Department of Sociology in the College of Human Sciences at the University of South Africa has reviewed the proposal and considers the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed. Approval is hereby granted for the candidate to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa.

In addition, the candidate should heed the following guidelines,

- To complete and sign a Supervisor-Student Agreement form, which is a code of conduct guiding the research process,
- To start the research study only after obtaining the necessary Informed Consent,
- To carry out your research according to good research practices and in an ethical manner,
- To maintain the confidentiality of all data collected from or about research participants, and maintain safe procedures for the protection of privacy and when storing such data,
- To work in close collaboration with the assigned Supervisor and to ensure the way in which the ethical guidelines as suggested in the reviewed proposal has been implemented in your research,
- To notify the Committee immediately in writing if any change/s is proposed to the study and await approval before proceeding with the proposed change,
- To immediately notify the Committee in writing if any adverse event occurs.

Regards,

Dr. Chris Thomas
Chair: Department of Sociology
Tel: 0027 (0)12 429 6301

**GOEDKEURING VAN TITEL
APPROVAL OF TITLE**

Student	Jena PP	No	5080-914-8
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Graad/Degree	MA Social Behaviour Studies in HIV and AIDS
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Dr Chris Thomas	Bylyn/Ext: 6301
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U aanbeveling ten opsigte van die volgende title en die benoeming van 'n studieleier/promoter asb.
Your recommendation regarding the following proposed title and the nomination of a supervisor/promoter please.

Titel/Title: Exploring the lived experiences of adolescents living with vertically acquired HIV.


Studieleier/Promotor
Supervisor/Promoter: Dr KC Motha

Personeelnommer
Personnel Number: 52239624

Medestudieleier/-promotor
Joint supervisor/promoter:

Personeelnommer
Personnel Number:

Adres, indien ekstern
Address, if external

Handtekening/Signature:  Datum/Date: 27 September 2013

Prof G E Du Plessis	Bylyn/Ext: 6507
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Vir goedkeuring namens UKK asseblief
For approval on behalf of ECC please

Handtekening/Signature: _____ Datum/Date: _____

Vorberei deur
 Prepared by: Gretchen du Plessis

Bylyn.....Datum
 Ext 6507 Date 2013/09/27

APPENDIX F: Permission to conduct study



DG 25 • 1st Floor • Dora Nginza Hospital • Spondo Street • Zwide • Port Elizabeth • Eastern Cape
Private Bag X11951 • Algoa Park • Port Elizabeth • 6005 • REPUBLIC OF SOUTH AFRICA
Tel.: +27 (0)41 406 4211 • Fax2email: +27 (0)86 528 2204 • Email: Felicia.hendricks@impilo.ecprov.gov.za

From:	Dr. B. Mbulawa-Hans
To:	Ms. Pretty Jena
Cc:	Dr. C. Thomas (UNISA)
Date:	15th November 2013
SUBJECT:	REQUEST TO PERFORM RESEARCH

Dear Ms. Jena

Your request dated 27th September 2013 refers,.

Permission is hereby granted provided that you supply this institution with the findings of your research.

Regards


Dr B. Mbulawa-Hans
Acting CEO
Dora Nginza Hospital

United in achieving quality health care for all
24 hour call centre: 0800 0323 64
Website: www.ecdoh.gov.za



