

THE CHALLENGES FACED BY ADOLESCENTS WITH PERINATAL HIV/AIDS

By

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DECLARATION

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I hereby declare that **“The challenges faced by adolescents with perinatal HIV/AIDS”** is my own work. All the sources consulted and quotes used have been indicated through the appropriate referencing style. I did not submit this dissertation for a degree at another University.

Signature:

Date: 2015/11/30

DEDICATION

This study is dedicated to all the children who are living with perinatal HIV and AIDS in South Africa, Sub-Saharan Africa and the whole world. You are the heroes of our generation and the leaders of tomorrow because you have survived this pandemic. The worst is over and you are victims turned into victors. I am proud of you all.

*“You can’t get HIV/AIDS by hugging, kissing, holding hands. We are normal. We are human beings. We can walk, we can talk. We have needs just like everyone else. We are all the same.”*Nkosi Johnson, 2000.

“No child should be born with HIV; no child should be an orphan because of HIV; no child should die due to lack of access to treatment,” Ebube Sylvia Taylor.

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This journey has not been easy. The mountains I had to climb loomed in front while the storms looked impossible to calm. However, the journey seemed endless and the destination nowhere in sight, you kept me going. For that, I am eternally grateful. I give all the glory back to you; Almighty, Faithful God. Had it not been for your loving kindness, there is no way I would have pulled through.

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To everyone who made this research a success, thank you.

Finally, to me Sue; you made it against all odds. This is just the beginning.

God bless!!!

ABSTRACT

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DEPARTMENT: SOCIAL WORK AND CRIMINOLOGY

DEGREE: MSW SOCIAL HEALTH CARE

HIV and AIDS has, over the years, wrecked havoc and once threatened human existence. Despite experiments over the years to find HIV and AIDS treatment and management strategies, HIV still claimed lives and left many infected. Parents faced the inevitable agony of giving birth to HIV positive children who normally would not survive beyond their toddler years. Experiments for solutions continued and highly active antiretroviral therapy (HAART) was rolled out in South Africa in the new millennium (Li, Jaspán, O'Brien, Rabie, Cotton & Natrass, 2009:751; Human Sciences Research Council, 2005:4). This gave hope to the new generation as it meant people could live longer with this disease as long as they adhered to treatment. This study was informed by a concern that these adolescents are transitioning into adulthood, yet they are incapacitated and are facing many challenges in dealing with their HIV status.

The goal of this study was to investigate challenges faced by adolescents with perinatal HIV and AIDS. The researcher conducted the study using a qualitative approach by conducting face-to-face semi-structured interviews with 12 (twelve) adolescents with perinatal HIV from Hammanskraal Jubilee Hospital's Wellness Clinic. A purposive non-probability sampling technique was used to select the participants for the study.

The study findings revealed a range of challenges these adolescents are facing and experiencing in their everyday lives. These include stigma, discrimination; lack of education and information on perinatal HIV and AIDS. There is also a challenge of non-disclosure of HIV status to the infected child and pressure not to disclose the status to significant others. The adolescents are also struggling with issues of compliance and adherence to medication, lack of awareness on available support systems as well as failure to utilise the systems due to non-disclosure. At one time, this disease did affect academic progress of some of the adolescents, as the researcher observed that some were in their late teens and still in primary schools. The researcher concluded that adolescents with perinatal HIV and AIDS indeed have dilemmas in their day-to-day lives; hence, they need support from all sectors.

In light of these findings, the recommendations include the need for education on the HIV and AIDS pandemic as well as perinatal HIV and AIDS. There is also need to establish supportive services for these adolescents by creating platforms for supporting each other and sharing experiences. It is also recommended that a comprehensive education on HIV and AIDS to the caregivers and schoolteachers of these adolescents is given in order to empower and equip them to deal with this unique and demanding age group and also be empowered in treatment management. Furthermore, the study recommends an anti-stigma awareness in the communities to create a comfortable interaction between the HIV-positive people and the community at large. It is also recommended that further research must explore the experiences of and challenges faced by the caregivers and significant others.

KEY WORDS

Perinatal HIV and AIDS;

Adolescents;

Bio-psychosocial;

Antiretroviral therapy (ARV);

Highly active antiretroviral therapy (HAART);

Caregivers;

Stigma;

Discrimination;

Prevention of mother-to-child transmission (PMTCT);

Support systems

ACRONYMS

ADHD	Attention Deficit Hyperactive Disorder
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral drugs
BPS	Bio psychosocial
CDC	Centres for Disease Control
IASSW	International Association of Schools of Social Work
IFSW	International Federation of Social Workers
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
PMTCT	Prevention of Mother-to-child Transmission
SALC	South African Law Commission
UNAIDS	The Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organisation

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CHAPTER ONE

GENERAL INTRODUCTION AND ORIENTATION OF THE STUDY

1. INTRODUCTION

Increased availability of highly active antiretroviral therapy (HAART) has meant that children with perinatal Human Immunodeficiency Virus (HIV) have a better chance to survive into adolescence and adulthood (Li, Jaspan, O'Brien, Rabie, Cotton & Natrass, 2009:751). The availability of antiretroviral treatment (ART) also ensures that the disease is now manageable and patients can survive for a long time, (Baryamutuma & Baingana, 2011:212). This is a big breakthrough in the fight against the HIV pandemic because tremendous advances have saved lives and transformed a fatal disease into a chronic one (Zanoni, 2013:15). However, the long-term challenges of the HIV infection on these survivors are a cause for concern and the long-term consequences that come with it cannot be overlooked.

Although highly active antiretroviral therapy was publicly available in South Africa in 2004 (Li et al., 2009: 751), the prevalence and progress of perinatal HIV infection in older children and adolescents in South Africa is poorly captured (Gray 2009:3). This is why the experiences of this particular group are unknown compared to other groups of people living with HIV and AIDS. The Centres for Disease Control (CDC) (2007:1) points out that in America alone, 67 of 68 children who were diagnosed with HIV in 2005 had perinatal HIV. This statistic shows that perinatal transmission is the commonest way children get infected with HIV. In 2003 in South Africa, about 96 228 babies were estimated to have perinatal HIV (Department of Health, 2003 in Human Sciences Research Council, 2005:3) and approximately 704 829 children were living with HIV and AIDS in 2005 (Human Sciences Research Council, 2005:3). These statistics are evidence that a decade later these children are now fairing into adolescence and adulthood.

These children are growing into adolescence and adulthood and due to the relatively large numbers, they are a significant group to look at in terms of their health, psychological and social needs. When children living with HIV grow into adulthood, they are usually stigmatised and discriminated on the premise that they were

irresponsible and acquired the virus through risky sexual behaviour (Meyersfeld & Vujovic, 2011:2). Adolescents with perinatal HIV and AIDS also face the same challenges faced by any other adolescents, before they can even consider challenges of being born with HIV. This is why Woollett (2013:23) points out that HIV and AIDS adds a significant burden to adolescent development through issues like orphan-hood, stigma, bereavement, poverty, increased risk taking behaviour, among other social ills. This suggests that the adolescents with perinatal HIV and AIDS are facing a plethora of challenges in their life. This study therefore explored the various challenges of growing up with HIV and the day-to-day experiences of adolescents with perinatal HIV in the Hammanskraal area.

1.1. DEFINITION OF KEY CONCEPTS

1.1.1. Adolescence

Mosby's Medical, Nursery & Allied Health Dictionary (2002:14) defines adolescence as, "the period between the onset of puberty and adulthood. It usually begins between 11 and 13 years with the appearance of secondary sex characteristics and spans the teenage life, terminating between 18 to 20 years of age with the completion of the development of the adult form". For the purposes of this study, adolescence ranged from 11 to 19 years.

1.1.2. Perinatal HIV and AIDS

Perinatal refers to the time and process of giving birth or being born (Mosby's Medical, Nursing & Allied Health dictionary (2009:1424). Therefore, perinatal HIV and AIDS refers to acquired immune-deficiency syndrome acquired by infants and children from their mothers; either during pregnancy, labour and delivery or during breastfeeding (CDC, 2007:1).

1.2. LITERATURE REVIEW

Mellins and Malee (2013:1) indicate that globally, children born with HIV and AIDS are reaching adolescents in large numbers. Hattam (2010:1) and CDC (2007:1) postulate that vertical transmission of mother to child is the dominant route of HIV

transmission to children. This might sound threatening to the human race, however, use of highly active antiretroviral therapy (HAART) has intensified hence children are surviving perinatal HIV and AIDS (Mellins & Malee 2013:1). Hattam (2010:1) point out that in South Africa, the first meaningful intervention against HIV and AIDS took place in 1994 and hence these children with perinatal HIV and AIDS have been afforded a chance to live longer. Most of these survivors are in their adolescence and some already adults.

As children are growing up living with HIV and AIDS, they face various challenges in their lives. Mellins and Malee (2013:2) argue that adolescents coping with HIV since birth experience a lot of difficulties including, 'on-going medical treatment, hospitalizations, exposure to pain and sheltered life experiences. They also face a host of unique issues related to the psychosocial impact of HIV, a highly stigmatized and transmittable illness that may make transition through adolescence difficult. It is therefore important that the daily experiences of these survivors be explored so as to equip service providers on intervention strategies when working with adolescents with perinatal HIV and AIDS.

Adolescence is a stage where an individual is no longer a child and yet not an adult as well and this causes adolescents to be caught in an identity crisis. Matshili (2011:3) argues that this is the stage where one desires independence and is more influenced by friends than parents. This stage cuts across all adolescents regardless of their HIV status. However, adolescents with perinatal HIV and AIDS might find themselves stuck in a dilemma where they have to withdraw from parental dependence naturally like any other adolescent, and yet depend on the same parents and family members for support regarding living with HIV and AIDS. Matshili (2011:8) indicates that HIV and AIDS influences how individuals experience and progress through this stage of adolescence. It is therefore important to understand the needs of adolescents with perinatal HIV and AIDS and how they experience living with HIV in their day to day lives.

The next chapter will give a detailed literature study on adolescents with perinatal HIV and AIDS. The literature study helps in understanding the challenges faced by these survivors as well as their experiences of living with HIV and AIDS.

1.3. THEORETICAL FRAMEWORK

The researcher utilised the bio-psycho-social model as the theoretical basis for the study. The bio-psycho-social model stems from the general systems theory, which assumes that systems exist within systems, and that nothing exists in isolation. The general systems theory postulates that an individual's behaviour can only be understood in relation to the context within which it occurred (Vorster, 2003:5). In light of this, the challenges of adolescents with perinatal HIV and AIDS are viewed from the family where the infection took place and is centralised.

The bio-psycho-social model recognises that the biological, psychological and socio-cultural forces act in unison to determine an individual's health (Straub, 2012:16). In this research, the assumption was that the challenges faced by adolescents with perinatal HIV could be explained in their physical, psychological being and their day-to-day interactions within the systems of family, church, schools and peers. Furthermore, the bio-psycho-social model is also sometimes referred to as the holistic view, because it focuses on the whole picture of a person, the body and mind as whole as well as external environmental and social factors of the person (Cowles, 2000:12). Ross and Devereil (2010:14) also refer to the bio-psycho-social model as 'psycho-socio-environmental' model, whereby its focus is said to be the "promotion and maintenance of health through socio-environmental and behavioural changes". This shows how the bio-psycho-social model serves to look into the person as a whole in relation to their surroundings.

In the bio-psycho-social model, health and wellness has to be explained in multiple contexts (Straub, 2012:16). Ogden (2000:4) assert that illness can be caused by a combination of biological (for example virus), psychological (for example behaviours, beliefs) and social (for example employment) factors. The biological component of

the model seeks to understand how the cause of illness stems from the functioning of the human body. In the case of this study, the existence of the HIV virus in the body and its effects on the biological function of a human body will be considered. The psychological component looks at the belief that health and illness are subject to psychological influences (Straub, 2012:17). Potential psychological causes and effects for a health problem like HIV and AIDS will include emotional turmoil, stress management, negative thinking and poor coping skills. Social factors include social systems like churches, school and the society as a whole; placing emphasis on how these social systems relate with the individual. These social factors are more reliant on lack of social support and high levels of responsibility at home, school or the community at large.

The bio-psycho-social model assisted the researcher to develop a better understanding of the challenges faced by adolescents with perinatal HIV and AIDS. The researcher concurs that being HIV-positive comes with many biological, social and psychological challenges, besides having the virus to deal with. The challenges include disturbed physical and cognitive development, discrimination, stigma; constant absenteeism from school to attend health care centres, and issues of disclosure. The focus was on biological, psychological and social factors that affect these adolescents. Therefore, the researcher deems this model appropriate for this study.

1.4. RATIONALE AND PROBLEM STATEMENT

HIV and AIDS is one of the much researched topics in the world. Deacon and Stephney (2007:1) point out that there are always attempts to address the needs of children living with HIV and AIDS, with much focus on material needs like poverty alleviation and education. However, little information has been sought on the personal experiences of adolescents who have survived the virus throughout childhood (Gray, 2009:1). Adolescents have a number of physical, psychological, emotional and social needs but material needs are given preference over psychological and emotional needs, like dealing with stigma and overall acceptance.

Adolescents with perinatal HIV are also developing cognitively, physically and socially but they are more affected by social problems than other HIV and AIDS subgroups (Deacon & Stephney, 2007:2). Birungi, Obare, Mugisha, Evelia and Nyombi (2006:725) reported that the reproductive and sexual health needs of adolescents with perinatal HIV remain largely unaddressed by existing HIV and AIDS programmes. This shows how much the unique needs of these survivors are not addressed. In this regard, this is why the bio-psycho-social model was used in this study to look at the different challenges this particular group is facing.

The researcher consulted EBSCO Host, Google Scholar and the University of Pretoria library. There was limited literature on challenges faced by children and adolescents with perinatal HIV and AIDS, especially in South Africa and Africa as a whole. As has been noted before, Gray (2009:1) confirmed that little is known about African children living with HIV beyond the age of five. Chances are high that little is known about how these children managed to survive into adulthood. This could be the reason why those who survive because of antiretroviral therapy are forgotten and ignored, since they were never expected to survive.

Therefore, the focus of this research is justified as it might shed light on the plight of this group and the need for them to be considered in policy and strategy making at national level.

The research question was: **What are the challenges faced by adolescents with perinatal HIV/AIDS?**

1.5. GOAL AND OBJECTIVES

The goal of the study was to explore and describe the challenges faced by adolescents with perinatal HIV and AIDS.

The objectives of this study are:

- To describe and contextualise perinatal HIV and AIDS,

- To determine the adolescents' knowledge of HIV and AIDS,
- To establish their attitudes towards lifetime treatment of HIV and AIDS,
- To establish their needs regarding living with HIV and AIDS,
- To determine their challenges of living with HIV and AIDS,
- To determine the availability of support systems and utilisation thereof,
- To provide recommendations on how to help adolescents with perinatal HIV and AIDS.

1.6. RESEARCH METHODOLOGY

The qualitative research approach was used in this study. The research is applied and exploratory in nature. The collective case study design, which is popular in qualitative research as it allows an in-depth exploration of a phenomenon was used. The population of the study were adolescents with perinatal HIV and AIDS in the caseload of the Wellness Clinic at Jubilee Hospital in Hammanskraal. The primary data was collected through semi-structured interviews. A more detailed description of research methodology as well as ethical aspects applicable to the study will be discussed in Chapter 3.

1.7. LIMITATIONS OF THE STUDY

Although this study achieved its initial aims, some limitations were encountered. Firstly, getting participants was challenging, as some of the participants initially selected refused to be interviewed hence the process had to be repeated more than once to get the 12 (twelve) participants. Secondly, the age range of 11 to 19 years was too broad because it included pre-teen and teen-age adolescents whose experiences with HIV might differ significantly. However, the in-depth interviews conducted presented an opportunity to probe into the challenges faced by adolescents growing up with this disease. Thirdly, most of the participants speak SeSotho, thus could not adequately communicate in English, IsiZulu or isiNdebele, which the researcher preferred. Therefore, there were communication barriers because the researcher can understand SeSotho but cannot converse fluently in the language. Lastly, the interviews ran for an average 15 minutes instead of the

expected 45 minutes to an hour. This was attributed partly to communication breakdown and other factors like participants being in a hurry, not engaging the researcher much or they were unaware of their status hence some questions became irrelevant. However, despite this limitation, the researcher managed to collect adequate information from the study.

1.8. DIVISION OF THE RESEARCH REPORT

The final product of this research is a report with the following structure:

Chapter 1: General introduction to the research study

- Introduction
- Definition of concepts
- Literature review
- Theoretical framework
- Rationale and problem statement
- Goal and objectives
- Research Methodology
- Limitations of the study
- Outline of the research report

Chapter 2: Literature study

- Introduction
- Theoretical framework of the study: bio-psychosocial theory in context of adolescents with perinatal HIV and AIDS
- Prevalence of perinatal HIV and AIDS in Sub-Saharan Africa
- Challenges associated with perinatal HIV and AIDS in adolescents
- The role of social workers in assisting adolescents with perinatal HIV and AIDS
- Policies and guidelines for perinatal HIV and AIDS.

Chapter 3: Research methodology

- Introduction
- Research methodology
- Ethical aspects
- Empirical findings/results of the study
- Summary

Chapter 4: Conclusions and recommendations

- Introduction
- Goal and objectives of the study
- Key findings of the study
- Conclusions
- Recommendations

CHAPTER TWO

LITERATURE REVIEW ON PERINATAL HIV AND AIDS WITH REFERENCE TO ADOLESCENTS

2.1. Introduction

This chapter focuses on the subject of perinatal HIV and AIDS with reference to adolescents in detail. Perinatal HIV and AIDS in adolescents is one aspect that reminds health professionals that the fight against mortality resulting from HIV and AIDS infection on children has been won but there is still a greater fight to deal with survivors of the pandemic as they go through the different stages of growth; from teenage through adolescence to adulthood. It is important to note that perinatal HIV and AIDS in adolescents is a global challenge that requires a holistic approach. In this chapter, the prevalence of adolescent perinatal HIV and AIDS globally, in Sub-Saharan Africa as well as South Africa will be examined. The chapter will also focus on the role of social work profession as well as policy stipulations in dealing with adolescents with perinatal HIV and AIDS.

In light of this, the challenges faced by adolescents with perinatal HIV and AIDS are discussed using the bio-psychosocial model (BPS) framework. The bio-psychosocial model acknowledges that the HIV and AIDS pandemic is not only about the physical health aspects of the individual but also the social and psychological aspects. In this chapter also, perinatal HIV and AIDS in adolescence in relation to the biological, psychological and social aspects that affect the individual on a daily basis will be explained. The bio-psychosocial model will guide the researcher to examine how HIV and AIDS affects these adolescents' daily lives and their interaction with their families, the society and the community as a whole.

2.2. The bio-psychosocial model in the context of adolescents with perinatal HIV AND AIDS

The researcher utilised the bio-psychosocial model as the theoretical basis for this study. This model recognises that the biological, psychological and socio-cultural forces act in unison to determine an individual's health (Straub, 2012:16). Dogar (2007:11) reiterates that this model encourages training of medical practitioners in the study of psychosocial aspects alongside bio-determinants of the disease. In this regard, the aim is to extend health care beyond the patient to include the family and the community.

The biological component of the model seeks to understand the anatomical, structural and effects of a patient's biological functioning, how the cause of illness stems from the functioning of the human body, (Dogar, 2007:11). In this regard, the study at hand considered the HIV virus, its existence in the body and its effects on the biological function of a human body. The psychological factor looks at the effects of psychodynamic factors, potential psychological causes and effects for a health problem like HIV and AIDS which include emotional turmoil, stress management, negative thinking and poor coping skills, motivation, personality and reaction to illness, (Dogar, 2007:12). Social factors included cultural, religious, environmental and familial experiences on the expression of illness (Dogar, 2007:13). Social systems like churches, school and the society as a whole put emphasis on how these social systems relate with the individual and contribute to health and disease, Straub (2012:18).

The psychological aspects of the bio-psychological model came out through the questions on stigma and non-disclosure. Ross and Deverell (2010:109) point out that adolescents living with HIV and AIDS not only face a bleak future, but they are also living in fear of being found out to have HIV and AIDS. These authors attribute this to the fact that HIV and AIDS carries a double stigma of being terminal as well as sexually transmitted. As a result, there are psychological effects on the patient. In this regard, the aspects of non-disclosure, non-adherence and stigma were broadly explored with the participants.

The social aspects were explored on issues like the adolescent's social support systems available. This involved asking about the participant's interaction and support received from friends, family, the school, the community and the health care system as a whole. This enabled the researcher to explore these adolescents' challenges from all biological, social and psychological aspects to obtain a full account of the challenges faced. It is important for health care providers to conduct assessments that uncover different aspects of an individual including family backgrounds. Some families have deep complications that go beyond HIV and AIDS, which may influence intervention, experience or coping capacities of the adolescent in many aspects.

2.2.1. The bio-psychosocial aspects of perinatal HIV and AIDS in adolescents

The following section will briefly discuss the aspects of perinatal HIV/AIDS from the bio-psychosocial view. It has been mentioned that health and illness can be explained in terms of the biological and psychological functioning of a human body, as well as the socio-cultural factors of the patient.

2.2.1.1. The biological aspects of perinatal HIV and AIDS in adolescents

The fight against child mortality due to perinatal HIV and AIDS infections was won with the introduction of HAART. This brought a new hope that HIV and AIDS is manageable and hence children born with the virus had a chance at life than they had in the previous decade. However, it should be noted that this virus has adverse effects on the body of the adolescents as they grow with the virus including the development of infectious diseases. In a study conducted by Gray (2009:1), adolescent HIV accounted for half of hospitalisation in adolescents. Gray (2009:1) maintains that most of these cases were suffering from immune-suppression and the major route of HIV infection was perinatal. Some of the hospitalised adolescents were cases of tuberculosis, pneumonia, cryptococosis and septicaemia.

ART decreased mortality by delaying the progression of AIDS; however these therapies are associated with a number of complications. Houghton (2013:1) and Gray (2009:2) agree that continued intake of antiretroviral treatment has physical side effects like wasting, stunted growth, scarring, skin blemishes and pubertal delays. Close (2010:3) adds that due to delays in treating the disease, adolescents with perinatal HIV and AIDS have delayed development and hence may look smaller than other adolescents. This affects their confidence as well as self esteem. Studies of Lipshultz, Miller, Wilkinson, Scott, Somarriba, Cochran & Fisher (2013:12) reveal that HIV infection is a primary cause of acquired heart disease, especially accelerated atherosclerosis, symptomatic heart failure and pulmonary artery hypertension. In this case, children are exposed to HAART and ART at an earlier age while their cardiovascular system is still developing and this eventually leads to adolescents who have a lower cardio-respiratory fitness, lower extremity strength and flexibility than their HIV negative counterparts.

Studies of Barlow-Mosha, Eckard, McComsey and Musoke (2013:1) reveal that the improved survival of HIV patients due to ART is unfortunately associated with serious metabolic complications like lipodystrophy and bone disease among others. Lipodystrophy has a significant impact on mental health of older children and adolescents which leads to poor self image, depression and eventually perpetuate non-adherence. Most children and adolescents who grow up with HIV are at times cognitively impaired or suffer from learning disabilities. This is said to be a result of the long term stay of virus in the body leading to brain damage. As a result, these complications affect the quality of life of these adolescents who are at a very important stage of life where major decisions are made.

2.2.1.2. The psychosocial aspects of perinatal HIV/AIDS in adolescents

Close (2010:319) and Zanoni (2013:16) note that with the roll-out of effective antiretroviral therapy, HIV and AIDS is increasingly being more a chronic than a terminal illness. However, this transition has many psychosocial effects, which require various psychological adjustments, especially in the adolescent, and paediatric populations (Close, 2010:319). These psychosocial aspects are

intertwined and affect each other. It must be noted that adolescence is generally a difficult stage, which is characterised by significant physical, social, cognitive and emotional changes, the need to disentangle oneself from the family's influence and identity crisis, (Mellins, 2010:3). Among other challenges, being an adolescent battling with perinatal HIV/AIDS has added challenges like poor body image, death of parents and siblings, lifetime treatment and pill fatigue (AIDS Education & Training Centres, 2004:17).

Stigma is one social aspect that affects everyone infected and affected by HIV and AIDS. Close (2010:322) states that stigma is a negative, moral or judgemental definition of a person or social situation, often connected to discredit, disgrace, blame and ascription of responsibility for the condition. In this light, the victims of HIV/AIDS find themselves also as victims of stigma, and there is no escape. Stigma has adverse effects on the disease progression as it can affect or lead to non-adherence (Close, 2010:322) and non-disclosure (Levin, 2012:43), especially when they become sexually active and one needs to disclose to their sexual partner.

Woollett (2013:23) also refers to what she coined self or internalised stigma, where individuals take on the perceived stigma of others and begin to stigmatise themselves. This is common in adolescents as they are struggling with issues of self-image and self-identity. The pressure to avoid disclosure by caregivers and family also perpetuates internalised stigma. Woollett (2013:23) maintains that in the process of trying to enforce non-disclosure to avoid stigma, the family actually becomes self-stigmatised. Self-stigma has a danger of having lasting effects on the adolescents' social and psychological functioning, including denial of their diagnosis (Close 2010:322). In turn, denial affects adherence.

Adherence is quoted as one of the most difficult tasks as persuading adolescents with perinatal HIV and AIDS to take their medicine consistently is challenging. Hill (2012), points out that generally, adolescence is a stage where health is not a priority and adolescents with perinatal infection are no different. So, they cannot be

expected to have outstandingly organised lives and take their medication. Such expectation is generally unfair to them. Therefore, pill fatigue also affects adherence.

Levin (2012:33) described pill fatigue as a condition occurring overtime to chronically ill patients who take a lot of medication. The patient stops taking pills because of stress and monotony of constant swallowing of pills. This is one of the hardest aspects of antiretroviral treatment, where one has to take pills for a lifetime. Levin (2012:34) postulates that antiretroviral therapy is monotonous and some patients experience side effects, which leads to added burden.

Adolescents with perinatal HIV are also prone to mental health disorders (Levin, 2012:43). Such disorders include attention deficit hyperactivity disorder (ADHD) which Levin says has a negative impact on disclosure and adherence. This is often associated with depression and poor self-image; hence, the adolescent acts abnormal to acquire attention.

Adolescents with perinatal HIV and AIDS also find themselves in a dilemma as they are expected to lead a double life. In a newspaper article interview of adolescents with perinatal HIV, Hill (2012) reported that one of the interviewees said that the society is expecting them to live two lives. Personally, one has to be completely honest and accept their own status while on the other hand, they cannot disclose about their status to the society or close people. This expectation is one of the reasons of non-adherence. One young adult also spoke of the pain of having to take medicine in secrecy for the rest of one's life. Most children grow up confused about being fed medicine and having to submissively take them in secret. As a result, they are expected to cope with the new knowledge of their diagnosis, knowing that one still cannot share the diagnosis with friends.

2.3. The prevalence of perinatal HIV and AIDS globally

There are about 3.3 million children below the age of 13, globally, who are infected with HIV and AIDS (UNICEF 2011:12). Heresi (2011:4) highlights that a third of

these children acquired the disease perinatally. The Centres for Disease Control (2007:1) reports that in US alone, about 10,000 young people were living with the virus; 76% of them were between the ages of 13 and 20. The findings of the UNAIDS Global Report (2013) in (Elizabeth Glaser Paediatric AIDS Foundation, 2014:1), also reveal that approximately 700 children under the age of 15 years are infected with HIV and AIDS every day, mostly through mother to child transmission. Even though efforts to curb mother to child transmission to avoid perinatal HIV and AIDS are under way, the existing generation of adolescents with perinatal HIV and AIDS need immediate interventions, as they are the mothers and fathers of the future generation.

Close (2010:319) also notes that in 2007, there were approximately 2, 1 million children under the age of 15 years infected with HIV and AIDS worldwide. From the 35, 3 million infected people by end of 2012, 2.1 million were adolescents aged between 10 and 19, and these estimates include both vertically and horizontally acquired HIV and AIDS (Idele, Gillepse, Porth, Suzuki, Mahy, Kasede & Luo, 2014:56). This shows that this pandemic is far from over as these children are growing up to become adults. Unless there is a considerable improvement in diagnosing older children exposed to HIV, perinatal HIV will remain a much bigger challenge among a previously unanticipated sub-population in Sub-Saharan Africa, (Sohn & Hazra, 2013:2).

2.4. The prevalence of perinatal HIV AND AIDS in Sub-Saharan Africa and South Africa

In sub-Saharan Africa, it is reported that 2, 9 million children were living with HIV and AIDS (UNAIDS Global Report, 2013). Pienaar and Visser (2012:66) state that South Africa has the largest HIV and AIDS population in the world and HIV in adolescents is a cause for concern as service delivery tends to side-line this group. In 2003 in South Africa, about 96,228 babies were estimated to have perinatal HIV and approximately 704,829 children were living with HIV and AIDS in South Africa (Human Sciences Research Council, 2005:3). This is evident that these children are

in their adolescence decade later; thanks to the roll-out of the ARVs in South Africa in 2004, (Human Sciences Research Council, 2005:4).

HIV and AIDS prevalence in children and adolescents is reported to have fluctuated over the years in Sub-Saharan Africa. Sohn and Hazra (2013:2), indicate that Sub-Saharan Africa constitutes over 90% HIV and AIDS cases in children below the age of 15, of which 85% are adolescents with HIV and AIDS in Sub-Saharan Africa (Idele et al, 2014:57). South Africa has the highest incidence of children living with HIV and AIDS (50%), followed by Zimbabwe at 35% (Sohn & Hazra, 2013:2). Armstrong, Pungula, Sobantu, Cheserem and Moshal (2013:26) state that in 2009, data in South Africa estimated that between 264,000 and 322,000 of 10 to 19 year olds were living with HIV and AIDS.

However, these statistics do not differentiate between vertical and horizontal infection. The average age of sexual debut for a South African adolescent is 15 years (Armstrong et al, 2013:27); hence, it is possible that some of the infections are behavioural. Baryamutuma and Baingana (2011:212) also highlight that the exact numbers of young people living with HIV and AIDS are difficult to determine as HIV data is usually disaggregated between adults and children.

Few data evaluating the outcomes of the prevention of mother-to-child transmission of HIV, (PMTCT), program exists (Meyers, Moultrie, Naidoo, Cotton, Eley, & Sherman 2007:1). This shows that it possibly was also not really captured how many children were born with the virus. Mofenson and Cotton (2013:5) confirms this by pointing out that the lack of epidemiologic data to better define this population is a cause for concern, and the reason why there are few researches on this particular group of adolescents.

Many children in Sub-Saharan Africa may not know their HIV status when they reach adolescence (AIDSTAR 2012:9) and this may have an effect on classifying them as

perinatally or behaviourally infected. There is much concern amongst scholars that as much as the vast majority of children were perinatally infected, reporting on older children is combined with adolescents and youth who were behaviourally infected; making it difficult to keep track of their outcomes (Sohn & Hazra 2013:6).

It is worth noting that this group of adolescents has received little attention globally. Mofenson and Cotton (2013:1) point out that there is still lack of data to define perinatal HIV and AIDS in adolescents globally. Sohn and Hazra (2013:1) and Zaroni (2013:16) also point out the lack of knowledge of the statistics on children with perinatal HIV and AIDS over years, as most reporting does not differentiate between vertical and horizontal transmission in young people. Gray (2009:1) also indicates that there is limited research in South Africa on the prevalence of perinatal HIV and AIDS in adolescents and older children.

This lack of systems for tracking of data on children with perinatal HIV and AIDS is likely to result in unpreparedness and lack of knowledge as well as failure to recognise opportunities in treatment and management of this disease (Sohn & Hazra, 2013:6). Reporting of perinatal HIV and AIDS has to be separate as it highlights infection before development of immune systems (Sohn & Hazra, 2013:6). The findings of Zaroni (2013:16) reveal that the little data available on the subject of perinatal HIV and AIDS in adolescents also leads to limited effective interventions for them. As a result, it is unknown what kind of interventions can be considered to enhance the lives of adolescents with perinatal HIV and AIDS.

As has been pointed out before, there is also no clear-cut reporting and differentiation between perinatal and behavioural infections in adolescents. Sohn and Hazra (2013:6) note that unless there are mechanisms to track the survival of this subgroup, the number of children with perinatal HIV surviving into adulthood will remain unknown, as thousands of them will be lost in the crowd. Gray (2009:3) also adds that in Zimbabwe, the data shows a burden of undiagnosed adolescents with perinatal HIV and AIDS. In Tshwane, South Africa, Feucht (2009:5) indicated that

there were between 14,000 and 19, 000 diagnosed HIV cases in adolescents that were missing from ART outreach. This shows a gap in capturing accurate statistics concerning perinatal HIV and AIDS in adolescents in Sub-Sahara Africa, as well as few interventions in reaching out to them for administration of antiretroviral therapy.

2.5 Adolescents with perinatal HIV AND AIDS

Vranda and Mothi (2013:19) assert that children with perinatal HIV and AIDS are fairing into adolescents due to availability of highly active antiretroviral therapy (HAART). Initially, the assumption was that children infected with perinatal HIV and AIDS will barely live beyond 5 years, and hence such children were not expected to live longer (AIDSTAR, 2012:1; Houghton, 2013:4). However, the roll-out of ARVs made a remarkable difference and amidst the excitement of victory, it was overlooked that this group would live long enough to experience adolescence and adulthood, which unavoidably leads to sexuality and childbearing issues. In this light, a whole new set of challenges in the HIV sector emerged from the victory over mortality of children due to HIV and AIDS (Zanoni, 2013:15).

Living in fear is a norm for most adolescents with perinatal HIV and AIDS. Ross and Deverell (2010:6) assert that adolescents with HIV and AIDS not only face a bleak future but are also afraid of being known to have the disease. The fear of rejection is always greater than the fear of dying of HIV and AIDS. Ross and Deverell (2010:6) also point out other reactions such as depression, inability to cope, the unavoidable future relationships, which lead to anxieties resulting in poor school performances and isolations. Zanoni (2013:16) adds that one of the severe effects of perinatal HIV and AIDS is significantly lower full-scale intelligent quotient and learning disorders. Coupled with mental health issues associated with perinatal HIV and AIDS, frequent disruptions of social, occupational and academic activities because of clinic appointments and/or hospitalisations often lead to feelings of anxiety and depression (Zanoni, 2013:17).

Compared to adolescents with behavioural infections, it should be taken into consideration that adolescents with perinatal HIV and AIDS have different clinical, social and psychological needs (AIDSTAR, 2012:2). These conditions include physical and developmental delays, vulnerability to opportunistic infections, battling with one or multiple loss of parents and caregivers due to the pandemic (Gray, 2009:2). The adolescents are also likely to originate from child headed households. However, all adolescents need care and support, important care and support is needed for those living with perinatal HIV and AIDS. They are different because they are dealing with psychosocial, disclosure and stigma issues arising from the fact that they acquired their infection perinatally and have been living with the virus all their lives.

Several authors (Gray, 2009:2; Mofenson & Cotton 2013:1; Sohn & Hazra, 2013: 1; Zandoni 2013:16) point to the fact that there is limited research in South Africa on the prevalence and disease pattern of perinatal HIV in older children and adolescents. The same can be said regarding the rest of the world. This group has not been planned for, hence, it took medical personnel by surprise and they are still 'finding their feet' in terms of researching on the needs. Most studies done in relation to the current study are the ones that either looked at adolescents with HIV and AIDS generally or were doing other research on adolescents infected or affected by the pandemic. Little specific research has been done on adolescents who are living with perinatal HIV and AIDS.

There was a research done in Kalafong that focused on experiences of adolescents living with HIV and AIDS. In the research, Pienaar and Visser (2012:67) discovered that adolescents have an increased need for independence and acceptance into their group. The research findings indicated that generally, adolescents with HIV and AIDS are struggling with issues of disclosure, adherence and lack of support among others (Pienaar & Visser, 2012:66). The study findings of Baryamutuma and Baingana (2011:215) concur with the findings of Pienaar and Visser (2012:66) which revealed that disease management is constrained by lack of communication and

impersonal interactions between health workers and adolescents living with HIV and AIDS.

The current research looked at the experience of all young people with perinatal HIV and AIDS, drawing the conclusion by this researcher that previous research still overlooked those unique aspects of adolescents with perinatal HIV and AIDS. It is worth noting that this research was carried out in a semi urban area, where the services are not specialised and the study population is characterised by underprivileged families who come from a background with many social problems besides dealing with HIV and AIDS related challenges.

2.5.1. Characteristics of families of adolescents with perinatal HIV AND AIDS

Although perinatal HIV and AIDS is a global challenge, it has been noted that the hardest hit are the minority groups and in most countries, children born with HIV and AIDS are from vulnerable minority and disempowered families (Mellins, 2010:5). Heresi (2011:21) points out that poverty is one of the characteristics of families of adolescents with perinatal HIV and AIDS, and this gets intertwined with all other challenges such as parents with substance abuse histories, chronic diseases and trauma. Vujovic (2012:10) states that most families of adolescents with perinatal HIV and AIDS are from fractured households characterised by low psychosocial support as a result of absent parents or single parent set up. This has a negative effect on the role of family system in dealing with their diagnosis.

2.5.2 Challenges associated with adolescent perinatal HIV AND AIDS

Adolescence is generally a difficult stage of life; mostly characterised by identity crisis and confusion (Meyersfeld & Vujovic, 2011:1). All adolescents, regardless of whether they have perinatal or behavioural HIV and AIDS, have more or less the same challenges. However, for the purpose of the study, the focus was placed on adolescents with perinatal HIV infection, as their challenges are more complicated, owing to the fact that they had a lifetime commitment to medication. Houghton (2013:5) argues that this group of children have had their whole lives dependent on

pills and this becomes monotonous. This is one of the reasons leading to non-adherence in adolescence.

Lifelong treatment also causes changes on body image for adolescents with perinatal HIV and AIDS. This is substantiated by Houghton (2013:6) and AIDS Education Training Centres (2004:17), who indicated that the virus has a number of effects on a teen's body. The effects include short stature for the age, wasting, obesity, lipodystrophy, nephropathy and encephalopathy, all owing to the medication. Gray (2009:2) also argues that HIV in children and the intake of antiretroviral drugs (ARVs) have adverse effects on their day-to-day life, including cognitive and pubertal delays.

Improved access to antiretroviral therapy has a positive impact in reducing the decline in HIV-related mortality. This is a positive development. However UNAIDS and WHO (2009:16) argue that the epidemiological effect is that prevalence will be higher compared to when therapy is not available. It is in this light where one positive aspect is taken for granted, since the focus is placed on curbing mortality, not the disease progression.

Zanoni (2013:15) reiterates that although the roll-out of antiretroviral therapy has made tremendous advances towards saving lives and transforming HIV and AIDS from being fatal to being chronic, considerable long-term consequences of HIV infections have been previously overlooked. Armstrong et al. (2013:27) also notes that health care workers involved in paediatric and adult HIV and AIDS often find themselves with limited resources, experience and feel under-equipped to address the needs of infected adolescents. Thus, adolescents with perinatal HIV and AIDS are left in limbo as they grow up in the health care system that suddenly leaves them when they graduate from childhood.

Since adolescence is a stage where an individual is trying to find him or herself, there is a need to rely on the social system, but this may be difficult in the case of perinatal HIV and AIDS. In addition to the background of families characterized by

poverty and substance abuse, most of these families face caregiver burnout. It is revealed that these are cases of deaths of parents or siblings (Heresi, 2011:23), or the child might be caring for a sick parent (Gray, 2009:2).

Issues of non-disclosure may also lead to caregiver burnout and exhaustion of support system, since only those aware of the status will be involved in provision of social support. In this light, non-disclosure is one of the greatest challenges faced, and it is a cause for concern. Adolescents do not disclose their status due to reasons ranging from norms learnt from a parent who was also HIV-positive but kept it a secret, never took their medicines and ended up dying (Heresi, 2011:29), to fear of stigma and discrimination from family and community as a whole.

Stigma has been mentioned as a cause of non-disclosure, which also makes adherence hard (Heresi, 2011:31). Non-disclosure means intake of medication will be a secret only known by a few privileged family members. This makes consistency in medication intake irregular, which is hazardous to one's health. Non-adherence may also be a result of non-disclosure to sexual partners (Heresi, 2011:32). Where one is afraid to disclose their status or intends to keep it a secret, they forgo the medication. Naturally, adolescents with perinatal HIV and AIDS also have sexual, reproductive rights just like their HIV-negative counterparts (Baryamutuma & Baingana, 2011:211). Because it is a challenge to uphold these rights, the infected adolescents might resort to non-disclosure to their sexual partners for fear of rejection and discrimination. Gray (2009:3) highlights that disclosing one's HIV and AIDS status has health benefits. Hence, non-disclosure can be associated with anxiety and depression as well as absence of possible social support.

Woollett (2013:24) also points out that in South Africa, youth friendly services in the public sector are not adequate. This leads to adolescents being lost in adult care systems or worse, where they fall out of care and their needs are unmet eventually, as seen in Feucht's findings (2009:5). This has a negative impact on disease progression because once they lose touch with the health care system, they are likely to fall into non-adherence, engage in risky sexual behaviours as well as non-disclosure. This will perpetuate infections and re-infections eventually.

Adolescents with perinatal HIV and AIDS face problems with the suffocating health care system. Baryamutuma and Baingana (2011:215) indicate that health care centres are frustrated by shortage of staff members, who are also working under pressure. At the end of the day, patients are affected as they have to spend long hours awaiting health attention. This becomes hard for adolescents living with HIV as they risk being seen at HIV clinics, especially if disclosure is still outstanding. This also hampers school attendance, as they have to take time off school to attend to medical appointments and medication collection.

Studies involving adolescents living with HIV and AIDS have judgementally documented their concerns regarding health care workers (Armstrong, et al., 2013:27; Baryamutuma & Baingana, 2011:215; Nkwanyana, 2013:21). Baryamutuma and Baingana (2011:215) note that most health workers still have the perception that people with HIV and AIDS should be asexual, which, as they argue, is total disregard of the sexual and reproductive rights of this particular group. In addition, Armstrong et al., (2013:27); Nkwanyana (2013:21) point out that the attitude of health care personnel has a lasting effect on adolescents living with HIV and AIDS. These attitudes might lead to a disconnection between adolescents who are HIV-positive and the health care system, which inevitably has adverse effects on disease management, adherence and disclosure. This diverts focus from addressing the real issues on how they deal with sexual and reproductive problems and merely concentrating on their medication, which breeds problems as adolescents are at a stage of risk taking. Mellins (2010:29) indicates high rates of mental health and adherence problems and challenges related to normative experimentation with sex and substance use, which are risky for one's health. Armstrong et al. (2013: 30); Baryamutuma and Baingana (2011:215) reiterate that adolescents with HIV and AIDS need a team of respectful, non-judgemental, adequately trained health care personnel who will create a conducive platform for them to discuss sexual and reproductive health issues openly.

Adolescents with perinatal HIV and AIDS would have had a fair share of grief by the time they reach adolescence. Woollett (2013:24) asserts that many adolescents who

were infected through mother to child transmission are mostly orphaned by the time they reach adolescence. This will have a bigger impact on efforts to curb psychosocial effects of the pandemic. Woollett (2013:24) notes that as long as this population is overlooked and their clinical, psychological and social needs are poorly understood, adolescents living with HIV and AIDS will remain one of the most affected by this pandemic. (Woollett 2013:24) adds that unless measures are put in place to address the bio-psychosocial needs of this population, not only are the lives and welfare of this group threatened, but the efforts made thus far in paediatric HIV will be jeopardised also.

Adolescents with perinatal HIV and AIDS also have behavioural problems. This group of adolescents are characterised by massive psychological and emotional stress, which is bound to reflect in many ways (Zanoni, 2013:15). All these result from many complex interacting biological and psychological factors, the adolescents experience overlapping behavioural problems, including risky sexual behaviours. Zanoni (2013:16) notes that behavioural problems increase as they reach adolescence. Heresi (2011:33) and Zanoni (2013:16) concur that experimenting and risk taking becomes their main game.

All adolescents' behaviour is characterised by risk taking and sexual activity. Baryamutuma and Baingana (2011:216) reported that condom use is not consistent in this age group and Pienaar and Visser (2012:67) state that adolescents with HIV and AIDS have a deep need for independence and acceptance by peers more than their families. As a result, they are under pressure to take risks if it means peers will accept them. In such situations, there will be no room for disclosure or adherence to medicine as it may hamper the chances of acceptance by one's peers. Mellins (2010:6); Heresi (2011:20) agree that perinatal HIV may lead to adolescents feeling like social misfits as medication disturbs normal life. In order to fit in society, one will have to forgo their health needs and resort to non-adherence to avoid disclosure.

It is worth noting that one of the biggest challenges is transitioning from dependency to independency as expected of all adolescents growing into young adulthood. This transition also means a shift towards medical independence (Woollett, 2013:24; Mofenson & Cotton 2013:1; Agwu & Fairlie 2013:10). They assert that the transition to independence may seem good but adolescents struggle with coping without support and it amounts to abandonment as adolescents had been used to more support at paediatric level. Woollett (2013:24) notes that the transitioning into adolescence and adulthood involves an important shift in medical dependence, which unfortunately sees a decrease in the involvement of both the health care system and the family system. All these have serious implications for the health of the adolescent.

The AIDSTAR (2012:4) states that the needs for adolescents with perinatal HIV and AIDS are specific psychosocial, disclosure and stigma issues that are related to the fact that they were infected by their parents. Mofenson and Cotton (2013:5); Sohn and Hazra (2013:8) agree that this success in ensuring survival of young people with perinatal HIV infection, who have been expected to die, has been accompanied with unanticipated needs. These needs include the sexual and reproductive health of the group, having to cope with managing long-term medications and the complications thereof. Other needs are mental health needs, as well as having to consider issues of career choices, higher education and future families.

2.5.3. The role of social workers in adolescent perinatal HIV and AIDS

The International Federation of Social Workers (IFSW) General Meeting and the International Association of Schools of Social Work (IASSW) General Assembly approved the following definition of social work in July 2014:

“Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing (IFSW, 2015:1)

In respect of this definition, the IFSW calls on all governments, world and regional bodies to ensure the human rights of those who live with HIV and AIDS are respected, do not suffer discrimination, and are treated equally. The IFSW also calls for recognition of the unique role of social work in all, including HIV and AIDS interventions and improved resources for education and training.

In HIV and AIDS, social workers are at the forefront of the battle to provide effective care, counselling and support to those infected and affected, and to develop new interventions to prevent the spread of infection. Harber (1999:3) notes that in HIV and AIDS interventions, adolescents and young people should be involved at all stages of planning and implementing programmes. Information about HIV and AIDS is not enough. Young people need to develop social and life skills that give them protection from infection. They also need to have access to good quality, confidential welfare and health services. In this light, Harber (1999:2) identifies the roles of social workers in working with children and adolescents living with HIV and AIDS to include:

- Establishing policies regarding HIV testing of children,
- Provision of sexual abuse counselling, where appropriate,
- Promote the development of policies that children who are HIV positive should not be discriminated by crèches, schools, etc.,
- Develop special foster/adoptive schemes for children who are HIV positive,
- Devise HIV prevention programmes that involve youth at all stages,
- Mobilise and train young people as peer educators,
- Promote life-skills programmes that emphasise survival skills (e.g. health, nutrition and negotiating skills), which prepare adolescents for adult roles,

- Assist parents and other adults in contact with youth to develop greater openness about sex,
- Help to dispel myths about HIV and AIDS and promote attitudes that will ensure that youth living with HIV are not subjected to discrimination.

The Children's Institute (2004:42) alludes to the fact that there are key role players involved in delivering services to children with HIV and AIDS. It is important to note that social workers are involved with all role players involved in delivering services. These role players include the government, the health sector, NGOs, offices of rights of children, even the education sector. It is therefore important that the role of social workers in delivering services to this group be mentioned as they play a pivotal role in the multidisciplinary team. The study site, Jubilee ART and wellness clinic has a full time social worker employed. She serves to provide psychosocial intervention, means testing, support services, referrals, assisting to apply for identity documents as well as grants and facilitating the support groups.

2.6. Policies and guidelines for perinatal HIV AND AIDS

Studies of several literature sources cited in previous sections in this chapter have pointed out that perinatal HIV and AIDS has received limited attention from policy makers. As efforts were on the availability of the HAART to ensure people could live longer, the children who were surviving this pandemic due to the ART being administered were neglected. Perinatal HIV and AIDS is manageable, thus allowing children who are HIV positive to grow up. Eventually, these children are introduced into schools and the community, where they have to live with other people. There is therefore need for policies to protect their rights in their daily interaction with their societies. In South Africa, the youngest ever HIV and AIDS activist, Nkosi Johnson, was initially denied acceptance at a public school in Johannesburg because of his HIV-positive status. His story became one of the driving forces to formulating legislation in this regard (Nkosi's Haven, 2015)

The Constitution of the Republic of South Africa Act (1996:1257), section 29(1) (a) provides that every person has a right to basic education and equal access to educational institutions. Unfair discrimination is prohibited. It should be noted that in as much as it is a right to basic education for everyone and to be admitted at schools regardless of their health status, it is also imperative that strategies be put in place to ensure minimal or no transmissions at school as a result thereof. However, in all this, the South African Law Commission (1998:4) notes that forced testing of all children as a basis for admission at school and any form of discrimination could not be justified, unless that particular child posed a significant health risk to others.

The Commission was aware of the fact that HIV education was a controversial matter involving complex issues. The questions which arose were about the philosophical, political and religious tenets of sex education, the appropriate age level at which this type of information should be supplied (SALC 1998:9). As a result, the Commission concluded that a real need for a uniform national policy regarding HIV and AIDS in schools existed, in which aspects such as continued school attendance, management of persons with HIV infection, confidentiality of AIDS-related information, and HIV and AIDS education were addressed.

At that time, the Commission made the following preliminary recommendations and ensured that legislation should confirm that:

- HIV testing may not be a prerequisite for admission to schools or for continued school attendance,
- A child may not be barred from continued school attendance solely on the grounds of his or her HIV infection,
- Confidentiality of AIDS-related information must be maintained,
- The education authorities be compelled by legislation to provide AIDS information and education as part of the compulsory curriculum to primary and secondary school children, but that the parent or guardian of a child is permitted to refuse in writing that the child concerned attend such a programme,

- The education authorities establish a clear and comprehensive national policy regarding the management of children with HIV infection,
- In such a policy document aimed at the education corps; principles and practical guidelines should be set out and the confidentiality of AIDS-related information,
- Continued education for children with HIV infection, the application of relevant universal precautions, and ensuring the supply of information and education on HIV and AIDS (SALC, 1998:10).

The South African Constitution, Section 28(1) (c) asserts that all South African children have a right to basic health care services and social services, and this includes children with HIV and AIDS. In line with the obligations set out in Article 24 of the Convention on the Rights of the Child, a very comprehensive strategy is required from government to adequately cater for the range of health care and other social needs of children with HIV-infection (Children's Institute 2004:13). Due to reasons like poverty, terminally ill parents, or absent parents, many children infected with and affected by HIV live in circumstances where parents and caregivers are unable to adequately care for them. Therefore, the state has a responsibility to ensure such children have access to and support from health and social services (Children's Institute, 2004:15).

Children with chronic illnesses, HIV and AIDS included, need a comprehensive health service response. The proposed functions of health services for children are:

- Effective primary level identification,
- Good and timely referral and communication with secondary and tertiary levels of care for diagnosis,
- Specialised investigation and development of a long term management plan
- Continuity of care,
- Availability of medication support on an ongoing basis at a facility closest to the child,
- Adequate family/caregiver support,
- A multi-disciplinary and inter-sectoral team approach,

- A patient-retained card to reflect ongoing management and assessment that will enable the child to be treated at facilities outside of their residential area if necessary. (Children's Institute, 2004:18).

It is important that service providers for children with HIV and AIDS are aware of the provisions of policies concerning service provision. Policy frameworks will also ensure that the HIV-positive children will also access services without fear of prejudice and discrimination.

2.7. SUMMARY

Although efforts have lately been made to curb perinatal HIV and AIDS, its prevalence before the successful introduction of prevention of mother to child transmission (PMTCT) cannot be ignored. The children born before this great achievement have since grown and are in their adolescence, some in adulthood. These are the subjects of this research. This chapter has outlined and explored literature that has been written on the subject of perinatal HIV and AIDS in adolescents. This chapter also explored the use of the bio- psychosocial theory in relation to perinatal HIV and AIDS. It is outlined how the biological, psychological and social aspects work together in relation to an individual's sense of self-health and esteem. In addition, the chapter looks at the role of social work professionals as well as policy guidelines in interventions with children and adolescents with perinatal HIV and AIDS. The next chapter will focus on the research methodology and empirical findings of the study.

CHAPTER THREE

RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS OF THE STUDY

3.1. INTRODUCTION

The aim of the study was to explore challenges faced by adolescents with perinatal HIV and AIDS; looking into their experiences regarding living with HIV and AIDS, how they experience a lifetime of medication and how being born HIV-positive has and how it continues to affect their lives. This chapter outlines the research methodology that was used in this study focussing on the research approach, type of research, research methods, research design, study sampling, techniques and the ethical considerations in the study. In the second section are the empirical findings as well as themes that emerged from the process of data collection and analysis. This section of research methodology is concluded with a chapter summary.

3.1.1. Research site

This research was conducted at Jubilee General Hospital in Hammanskraal. Jubilee is a big government hospital and it services the greater part of Hammanskraal. Hammanskraal is a semi urban area located north of Pretoria City. Jubilee ART and wellness clinic is a primary health care facility providing HIV, AIDS and TB related treatment, care and support services to patients as well as their vulnerable families, (info4africa, 2015:1). Jubilee Hospital is a very big establishment with different specialised clinics, including the ART and wellness clinic which specifically deals with HIV and AIDS, TB and related cases, and this clinic was the specific study site. ART and Wellness clinic services people from different villages in Hammanskraal namely Unit D, Unit C, Temba, and Wintervelt, Maubane, Portion 9, Kanana, Marokolong, Makapanstad, Dilopye, Leboneng, Mandela and Ramotse, (Info4Africa, 2015:1).

The wellness clinic has staff members who are involved in service delivery on a daily basis. The members of the staff include the clinic manager who is responsible for the overall running of the clinic, the matron who is the assistant to the manager, doctors who attend to patients and give out medicine as well as nurses who also alternate at

the reception for administrative issues. The clinic also has a dietician who serves to assist patients with the recommendations on dietary requirements and also distributes some food packages to the needy. Lastly, the clinic has a social worker who deals with the psychosocial needs of the patients, offering assistance with grant applications, therapeutic and referral services. The social worker also facilitates a weekly support group for TB and HIV positive patients, among others (Info4Africa, 2015:1).

3.2. RESEARCH METHODOLOGY

3.2.1 Research question of the study

The research question that this research aimed to answer was:

What are the challenges faced by adolescents with perinatal HIV and AIDS?

In answering this question, the researcher deduced questions from the objective and some of these questions included:

- What are the attitudes of adolescents with perinatal HIV towards lifetime treatment of HIV and AIDS?
- What are the challenges of living with HIV and AIDS?
- What are the recommendations for service delivery on adolescents with perinatal HIV and AIDS?

Creswell (2009:133) argues that a research question seeks to inquire about the relationship amongst variables that the researcher seeks to know. In this regard, the research question was justified as it sought to explore the different challenges adolescents with perinatal HIV and AIDS are facing in their day-to-day life. The research question acknowledges that these young people have physical, social and psychological challenges emanating from living with HIV and taking medications. The biological challenges include wasting and affected general body image, social problems like stigma and discrimination, which Close (2010:322) mentions they can also lead to issues of adherence and acceptance of treatment for the rest of their lives.

3.2.2 Research approach

The researcher used the qualitative approach. Thyer (2001:257) states that “a qualitative research aims at describing, making sense of, interpreting or

reconstructing in terms of the meanings that the subjects express.” Hence, it was important that qualitative research be utilised for this study. Nieuwenhuis (2007: 75) also adds that a typical characteristic of case studies is that they strive towards a holistic understanding of relationship and interaction among participants in a specific situation and they tend to give meaning to a phenomenon under study. The approach also enabled the researcher to find answers to research questions that provide a more comprehensive understanding of a social problem from an intensive study of a few people (Fouché & DeVos, 2011:91).

This paradigm was appropriate since the researcher was able to use a range of methods that use qualifying words and descriptions to record and investigate aspects of social reality (Bless & Higson-Smith, 2000:156). Babbie (2010:270) also points out that a qualitative research is especially appropriate for the study of those attitudes and behaviours best understood within their natural setting. Therefore, this research approach was significant in the exploration of the challenges that adolescents with perinatal HIV and AIDS face in their day-to-day life.

3.2.3. Type of research

The applied research method aims to contribute towards the issue of problem solving, decision making, policy analysis and community development (Blanche, Durrheim & Painter 2006:45). This research was exploratory in nature as the topic looked for insights (Fouché & DeVos 2011:95) in the phenomena of perinatal HIV in adolescents. Moreover, the need for the study had arisen from lack of information on the researched topic (Fouché & DeVos, 2011:95).

3.3 RESEARCH DESIGN AND METHODS

The research design and methodology used in the study will be discussed in this section.

3.3.1 Research design

The case study design was utilised in this research, specifically the collective case study design. The collective case study design enabled an in-depth exploration of the challenges adolescents with perinatal HIV and AIDS face in their day-to-day lives (Blanche et al., 2006:459). The collective case study research also enabled the researcher to find patterns in the lives of research participants, their actions and words (Fouché & Schurink, 2011:320). In case of the proposed study, it must be noted that these adolescents have different experiences of life. Hence, their challenges are different to a certain extent. The collective case study design allowed the uniqueness of every individual to be realised; enabling, the researcher to make comparisons between cases and allow for extension of theories (Fouché & Schurink, 2011: 322).

3.3.2. Study population

The study population refers to the people who are the focus of the study (Lapan, Quartaroli & Riemer, 2012:83). In the case of this study, the study population was all adolescents with perinatal HIV in Hammanskraal area who were on the caseload of Jubilee Hospital ART and Wellness Clinic from December 2014 to January 2015.

3.3.3. Sampling

Neuman (2007:141) and Nieuwenhuis (2007:79) assert that sampling is a small collection of units or cases from a much larger collection or population. The wellness clinic has a huge number of HIV and AIDS patients on their database, including adolescents with perinatal HIV and AIDS. With this big number, it was not feasible to include every adolescent with perinatal HIV and AIDS in the study. The researcher used purposive sampling. Nieuwenhuis (2007:79); Strydom (2011a:228) both points out that qualitative research is generally based on non-probability sampling. In purposive sampling, the sample contained characteristic representation of the population of adolescents with perinatal HIV and AIDS (Strydom, 2011a:232; Nieuwenhuis, 2007:79).

Due to the sensitivity of the topic under study, the researcher selected the study participants indirectly. The sister-in-charge selected the participants who fit the description and were willing to participate. The participants' selection criteria included:

- Being on the Jubilee Hospital ART and Wellness clinic database for December 2014 and January 2015,
- Should have contracted HIV through perinatal transmission,
- Individuals of ages 11 to 19 years,
- Female and male individuals,
- Voluntary participation and accompanied by consent and assent forms,
- Participates should be able to speak or understand English and IsiZulu/IsiNdebele.

The patients come in anytime to collect medicine, so the first 12 who were willing and fit the description were selected. After the participants gave their consent to the sister in charge, they were referred to the researcher for the interviews.

3.3.4 Data collection method

The researcher used a semi-structured one-to- one interview as a data gathering method. Interviews were particularly handy in enabling the researcher to get the story behind a participant's experiences. This is because in an interview, the interviewer could pursue in-depth information around the topic of perinatal HIV and AIDS. This method was hence more flexible and allowed the researcher to gain a detailed picture of the participants regarding the perinatal HIV and AIDS in adolescents (Greef, 2011:351). The semi-structured one-to-one interviews allowed the researcher to probe the participants further about perinatal HIV and AIDS. As a result, the data and information collected is a detailed account of how the respondent feels about the topic at hand (Greef, 2011:351).

An interview schedule was used as a data collection tool. This schedule assisted to guide the interview and it allowed the researcher to have a set of predetermined

questions (Greef, 2011:352). The researcher had one interview session with each participant as the next hospital visit was going to be in three months' time. The average length of each interview was about 15 minutes, with the shortest interview resulting from participants that were not very much aware of their status (due to non-disclosure); hence, some questions became irrelevant in that regard. The researcher used an audio recorder to record 12 (twelve) participants during the interviews.

The researcher sought permission from the participants through consent forms. Recording permission was also sought verbally as well as through signed consent forms. The researcher started the conversation outside where she introduced herself and then in the interview room, the interview would build on the initial conversation; starting with general questions like age and level at school. This helped ease the participants so that they could be calm throughout the interview session.

Using semi-structured interview data collection method has its advantages and disadvantages. Advantages of using this interview method are that it gives room for probing. Neuman (2011:345) reiterates that the researcher can repeat the question, the reply, pause or use probes involving gestures like tilting of head and raising eyebrows, which come in handy in interviews as it allows non-verbal communication to be used in probing further. Greef (2011:360) reiterates that the interviews were particularly useful in this study because large amounts of data were quickly obtained. The researcher was also able to probe and observe non-verbal cues of the participants. One of the limitations is that interviews involve personal interaction, hence, they rely on effective participation (Greef: 2011:360). If a participant is not cooperating, the whole process will be affected. The researcher faced this challenge with a few participants and used probing methods to try to get the participants to cooperate.

3.4 Data analysis

Schurink, Fouché and De Vos (2011:399) assert that qualitative data analysis refers to the examination and interpretation of observations for the purposes of discovering

the underlying meaning and patterns of relationships. Lapan, et al. (2012:98) add that the analysis of qualitative data progresses through the classification of ideas, themes, topics, activities, types of people and other categories relevant to the study. In this research, the guideline as set out by Schurink, et al. (2011:403-418) was used. The specific aspects of this guideline which were applied are:

Planning for recording of data

Planning should consider that data is to be recorded in a systematic manner which is appropriate to the settings and participants (Schurink et al., 2011:404). In the proposed research, the researcher observed non-verbal communication in addition to verbalised cues to analyse data. The researcher took a few notes but made sure it did not distract the flow of the interview process or disturb attention of the participant (Schurink et al., 2011:404). An audio recorder, in form of a cell phone, was used in recording data and the consent of the participants in this regard was sought beforehand. The recorded data was later transferred to the laptop and was later put on a disc for safekeeping.

Data collection and preliminary analysis

Qualitative data collection is two-fold; first in the field during data collection and secondly, away from the field after data collection. The first analysis is not in-depth as it happened during the course of the interview. The second data analysis enabled the researcher to reflect on the interview and listen to the recorded data (Schurink et al., 2011:405). Listening to the recorded data helped the researcher to link notes taken during the interview and recorded data for each individual participant. The researcher then transcribed the recording and translated the data recorded, as some interviews were conducted in SeSotho and Zulu languages.

Data management

Managing data involved crosschecking the data after it was transcribed. The researcher had to crosscheck if she has all the data she needs or had to collect

additional data. Arranging for additional collection of data proved to be difficult as the study participants were only going to come back for medication after three months. Hence, the researcher hence had to work with the data she had already collected. The researcher then categorised and labelled the data into meaningful groups.

Reading and writing memos

This step involved reading the data and trying to understand it. It was easy to understand this data as it was already in written form. The aim of the researcher was to familiarise herself with the data and she was making short notes in the process.

Generating categories and coding the data

This step involves an awareness of the data by the researcher and the researcher was now very informed about the data. This awareness of the data enabled the researcher to draw up common themes, ideas and patterns of identifications that characterise the case more broadly. Eventually, the researcher managed the data by classifying it into themes and sub-themes to ensure clear interpretation. These themes and sub-themes will be discussed broadly later on in this chapter.

Testing emergent understanding and searching for alternative explanations

This step involved evaluating the data. The researcher evaluated the data to enable her to determine how useful the data collected is in answering the questions being explored, and how central they are to the phenomenon being studied. This helped the researcher to reach a conclusion to the truthfulness of the data collected in answering the question. To apply this in the study, the researcher considered information that could have or have not come out during the course of the study and then made observations on the meanings of gathered data. The researcher realised that the information on needs of adolescents did not come out as expected and this observation brought about a conclusion that will be discussed in the section under themes.

Interpreting and developing typologies

This is the step when the researcher made sense of the data collected. This produced interpretations of the data and conclusions were drawn that may have implications beyond the specific case that has been studied. The conclusions and recommendations were drawn here and they will be discussed in detail in Chapter 4.

Presenting the data

This is the final step of the process where the researcher presents the data. Since this research seeks to explore the challenges faced by the adolescents, the data will be presented in form of pie charts and bar graphs. This form of presentation allows the researcher to show the themes that came up during the study. The research findings are presented later on in this report.

3.4.1. Trustworthiness of qualitative data

The concept of trustworthiness is very important in qualitative research as justifies whether it is necessary to carry out the research topic under study. In view of this study, three aspects of trustworthiness were taken into consideration: credibility, dependability and conformability.

Credibility

Credibility involves establishing that the results of the research are believable. Schurink, et al., (2011:420) argue that the goal of credibility is to ascertain if there is a match between the views of the participants and the way the researcher represents the data. The strategies were employed to ensure credibility in this study and these are reflexivity and prolonged involvement. Reflexivity involves the researcher deconstructing them self and the ways in which their beliefs, experiences and identity interact with that of the participant, (Lietz, Langer & Furman, 2006:447). Lietz and Zayas (2010:198) explain that reflexivity refers to a thoughtful consideration of how a researcher's standpoint can influence the research. This

researcher acknowledged that she has her own views regarding this study and had to ensure her own views did not have an effect on the progress of the study. In this case the researcher was honest in conducting the study and ensured that her beliefs and views did not influence the flow of the study, (Lietz et al. 2006:453). The researcher also utilised prolonged involvement through-out the study. This was achieved through familiarising herself with the topic as well as getting to know the participants better by engaging with participants before interviews to increase rapport between participants and researcher, (Lietz et al. 2006:453).

Furthermore, Shenton (2004:69) asserts that examination of previous research findings is a key strategy in ensuring trustworthiness. The researcher cited key contributors and writers on related topics in the literature review (Saldana, 2011:135) by relating her findings to an existing body of knowledge, which makes the study credible and trustworthy. The researcher then made necessary comparisons whether the data pointed out to the same conclusions (Nieuwenhuis, 2007:80; Schurink et al., 2011:420). The researcher managed to conceptualise and record the participants' challenges the way they explained them during the interviews. The researcher also ensured that the population under study was accurately identified and described (Schurink et al., 2011:386).

Dependability

Schurink et al. (2011:420) asserts that dependability means the researcher asks whether the research process is logical, well documented and audited. Shenton (2004:71) also indicate that dependability attests to the fact that if the research were to be repeated under the very same circumstances and with the same participants, similar results will be obtained. To ensure dependability the researcher reported the processes of the study in detail which enables the reader to assess the extent to which proper research practices have been followed (Shenton 2004:71). This detailed report includes more details on how the researcher handled data gathering, analysis and the research designs. As a result, future researchers can depend on this report to conduct the same or similar studies (Shenton, 2004:71).

Confirmability

Lietz and Zayaz (2010:197) postulate that confirmability refers to the ability of others to confirm or corroborate the findings. In this study, confirmability has been reached because the findings of the study are a result of experiences and ideas of participants than the preferences and characteristics of the researcher, (Shenton, 2004:72). The researcher recorded the participants and transcribed the voluminous data. In the study, thick descriptions were used to ensure a thorough representation of the phenomenon of inquiry and its context as perceived and experienced by the study participants (Lietz & Zayas 2010:198). The researcher admitted her own predispositions in the study and this maximised trustworthiness of the study (Shenton, 2004:73). The results of this research are therefore a detailed account of the experiences of the participants.

3.4.2. Pilot study

The researcher conducted a pilot study with two participants possessing the same characteristics as those in the main investigation. The idea was to ascertain certain trends (Strydom & Delport, 2011:394); to test the data gathering instrument and address the goals and objectives, resources, research population, procedures of data collection and possible errors (Strydom & Delport, 2011:395). The pilot study also allowed the researcher to gain insight into the research and helped identify and fix possible errors before embarking on the main study.

3.5. Ethical considerations

Ethical issues are an important aspect of social research which involves human subjects (Babbie, 2010:75). Permission was sought from the University of Pretoria. Since HIV and AIDS is a highly sensitive medical problem, the researcher also obtained permission from the Jubilee Hospital as well as the Department of Health before conducting the research. In this regard, data collection was consistent with ethical considerations in the research (Leedy & Ormrod 2013:151).

The following ethical considerations were made during the research and data collection methods:

3.5.1. Avoidance of harm

Leedy and Ormrod (2013:152) indicate that an important principle of social research is that it must not expose participants to any undue physical, emotional or psychological harm. This study involved a very sensitive health issue of HIV and AIDS and the target population is an equally delicate group. Hence, emotional harm had to be expected or provided for. In research, participants may be harmed physically or emotionally, thus it is important that harm is avoided (Strydom, 2011b:115). Strydom (2011b:115) adds that participants must be made aware of potential harm.

In this study, the researcher minimised potential emotional harm by ensuring the respondents were aware that they will be sharing sensitive information and their consent and voluntary participation was sought. The study participants were also aware they had a right to withdraw from the research anytime, if they deemed necessary (Rubbin & Babbie, 2011:77). Although the research also made available resources for counselling (the medical social worker and psychologist) in case there was any harm encountered, there was no incident of harm physically or emotionally to the participants during the study.

3.5.2. Informed consent

De Vos, Strydom, Fouché and Delport (2005:78) indicate that informed consent implies that all possible or adequate information on the goal of the investigation procedure, the disadvantages and dangers that the participants might meet are well explained to the subjects. It is very important that the participants are aware of what is happening in the research. This research ensured that the participants were well aware of the nature of the study and were willing participants (Leedy & Ormrod 2013:151). For participants who were younger than 14 years of age, their parents

and guardians were consulted and permission was sought from them before any interviews with the children.

Bless and Higson-Smith (2000:106) also point out that participants have the right to know what the research is about and how it will affect them, the risks as well as benefits of participation. They must also be aware that they have the right to decline to participate in the study if need be. Strydom (2011b:117) reiterates that the participants must be aware of the advantages and disadvantages of the research, the expected time span, the goals of the investigation and the procedures that will be taken. This information was communicated in the consent and assent forms as well as verbally. The participants and their guardians were also informed of non-economic gains. They were also informed that the interview was recorded and they gave permission in that regard. Furthermore, they were informed that the data would be stored in the University of Pretoria for the period of 15 years. Later, those who were willing to participate in the study signed the informed consent forms and guardians signed informed assent forms to give permission for their children to participate in the study.

3.5.3. Violation of privacy, anonymity and confidentiality

The researcher protected the participants' right to privacy by ensuring that any data collected would not be traceable back to the participants (Leedy & Ormrod, 2013:151), as every individual has a right to privacy, confidentiality and anonymity. Strydom (2011b:119) points out that every participant has a right to decide when, where, to whom and to what extent their personal information can be revealed. Henceforth, the researcher ensured the privacy of participants and kept their identities anonymous by use of pseudonyms. A digital recorder was used in recording data. The researcher also ensured that the records of the interview sessions were handled anonymously and will not be traced back to the individuals. The researcher sought participants' verbal and written permission to use a digital recorder and take notes during the interviews. The participants' real names and any identifying details were not mentioned before, during or after the interviews.

3.5.4. Voluntary participation

This ethical consideration acknowledged that no participant must be coerced to participate in a research against his or her will (Strydom, 2011b:116). In this respect, the participants were told of their right to withdraw from the research any time when they feel like. Hence, the researcher made sure that the adolescents under study participated on their own free will and were aware of their legal rights as participants. Written consent was also sought from parents and guardians of some participants who could not give their own consent.

3.5.5. Debriefing of participants

Debriefing is when the participants get to work through their experiences after the study (Strydom, 2011b:122). The researcher debriefed the participants after the interview process. Debriefing also gave the researcher an opportunity to answer any questions that might have arisen during the study (Strydom 2011b:122), and arrangements were made with the clinic social worker for counselling if the need arose. The researcher referred one participant to the clinic social worker for counselling.

3.5.6. Deception of subjects

Strydom (2011b:118) describes deception as misleading participants, deliberately misrepresenting facts or withholding information from participants in-order to ensure participation from them when they would have otherwise refused to participate. In the study, the researcher ensured that no form of deception was inflicted on the respondents (Strydom, 2011b:119). The researcher was open with the participants regarding the research, the use of audio-recorder and asked for the participants consent beforehand.

3.5.7. Actions and competence of researcher

Researchers are ethically obliged to ensure that they are competent, honest and adequately skilled to undertake the proposed investigation (Strydom, 2011b:123).

This was a sensitive research and it required that the researcher be competent. The researcher was competent, as she had passed a research theory module as part of her post-graduate course work. The researcher also had approval by the University of Pretoria's ethics committee. The researcher was also competent and honest in acknowledging information from other sources and avoiding plagiarism.

3.6. SECTION ONE : EMPIRICAL FINDINGS OF STUDY

The findings of the empirical study are presented in detail in this section, starting with biographic profile and followed by the presentation of themes and sub-themes that emerged during the interviews with the participants. The themes and sub-themes are presented in form of a table, followed by a thorough discussion of these themes and sub-themes supported by the participants' voices.

3.6.1. Biographic profile of participants

The profiles were drawn from information from the participants' age, gender, level of education and years on treatments as well as knowledge of their own status. The biographic profile will be presented in table 3.1 below:

Table 3-1: Profiles of participants

Participant	Age	Gender	Level of education/ Grade	Number of years on treatment	Knowledge of own status
Participant 1	12	F	7	6+	Yes
Participant 2	13	M	5	4	Yes
Participant 3	13	F	7	3	Yes
Participant 4	15	M	6	3	No
Participant 5	16	M	11	6+	Yes
Participant 6	15	M	10	6+	Yes
Participant 7	16	M	7	3	Yes
Participant 8	16	F	11	6+	Yes
Participant 9	19	F	Tertiary	6+	Yes
Participant 10	16	F	11	6+	Yes
Participant 11	11	F	5	6+	No
Participant 12	17	M	10	2	Yes

The pie charts and bar graphs below present the information on gender, age, number of years on treatment, knowledge on treatment and comparison of participants' age, educational level and number of years on treatment.

3.6.1.1 Gender

The research had 12 (twelve) participants with 6 (six) males and 6 (six) females

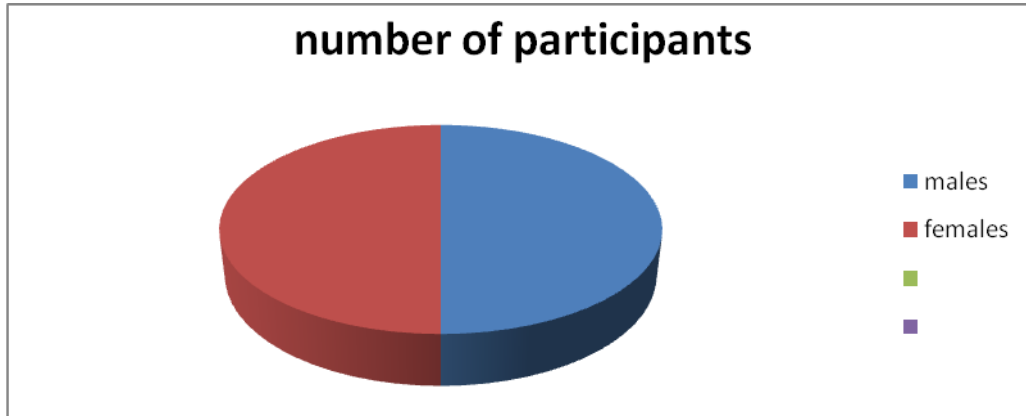


Figure 3-1: Gender of participants

3.6.1.2 Age of participants

Participants' ages ranged from 11 to 19 years, though there was none who are 14 and 18 years old. Only two participants were between the ages of 11 and 12. Four participants were 16 years old while only two participants were 13 and 15 years old each. Only one participant in the 17 to 19 age range was interviewed. A similar study carried out at Kalafong hospital involved the same age group (Pienaar & Visser, 2012:67). This distribution of ages enabled the capturing of data from both lower and upper adolescent groups. This information is presented in the bar graph below.

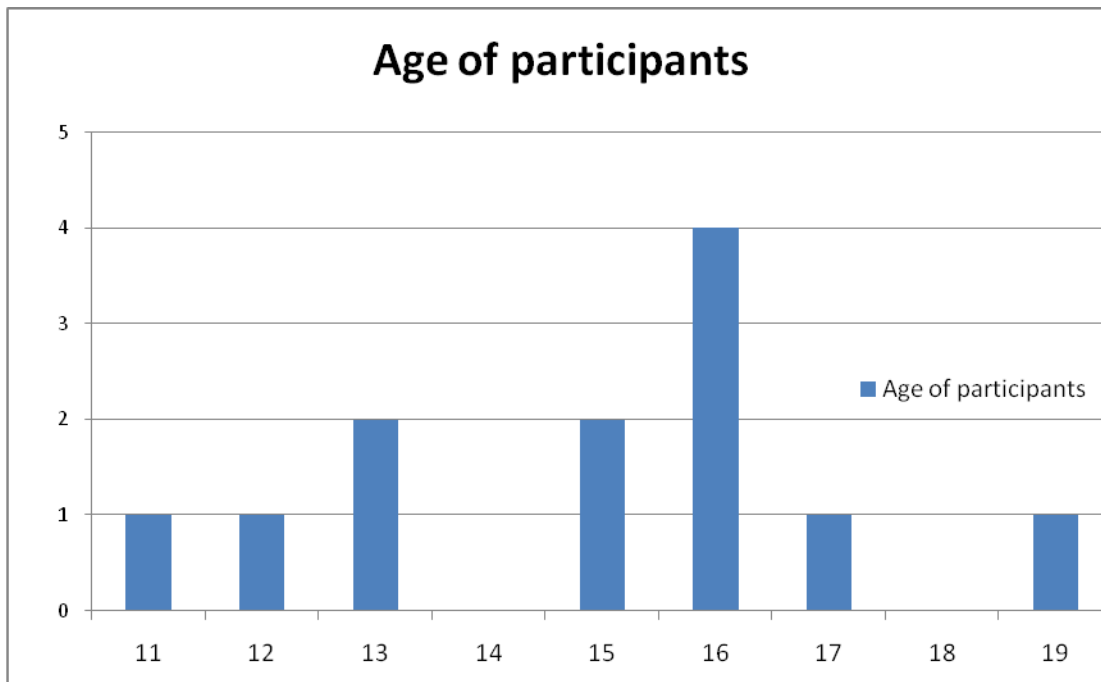


Figure 3-2: Age of participants

3.6.1.3 Number of years on treatment

The pie chart below represents the number of years participants have been on antiretroviral treatment. Only one participant has been on treatment for at least two years and three participants have been on treatment for at least three years. The majority of participants have been on treatment for 6 years or more. Most of the adolescents who have been on treatment for more than 6 years are the older adolescents.

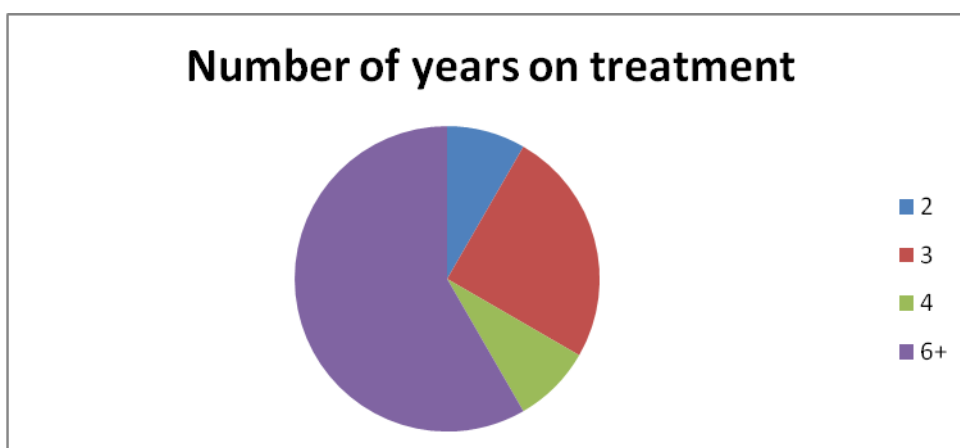


Figure 3-3: Number of years on treatment

3.6.1.4 Knowledge on treatment

Of the twelve (12) participants interviewed, only two (2) did not know their HIV status. They were told they are taking medicine so they can be well. The rest were told of their HIV status and are aware of the reason for their medication intake. This profile corresponds with Pienaar and Visser (2012:72) studies where one out of 6 adolescents was not aware of their status.



Figure 3-4: Participants' knowledge of their status and treatment

3.6.1.5 Comparison on participants' age, educational level and number of years on treatment.

The research findings reveal a correlation between age and number of years on treatment. It was also revealed that those participants who have been on treatment for more than 6 years were not affected in their academic life. For instance, participants 1, 5, 6, 8, 9, and 10 have been on treatment for more than 6 years and are in the right school grades for their ages. A discrepancy to this finding is participant 12 who has only been on treatment for two (2) years but his studies seem to have not been disturbed. Participants 4 and 7 are too old for primary school and they have been on treatment for lesser years. This could mean that they missed part of school because of late diagnosis of their status, thus delaying treatment. The graph below shows the correlation between age, grade and number of years on treatment.

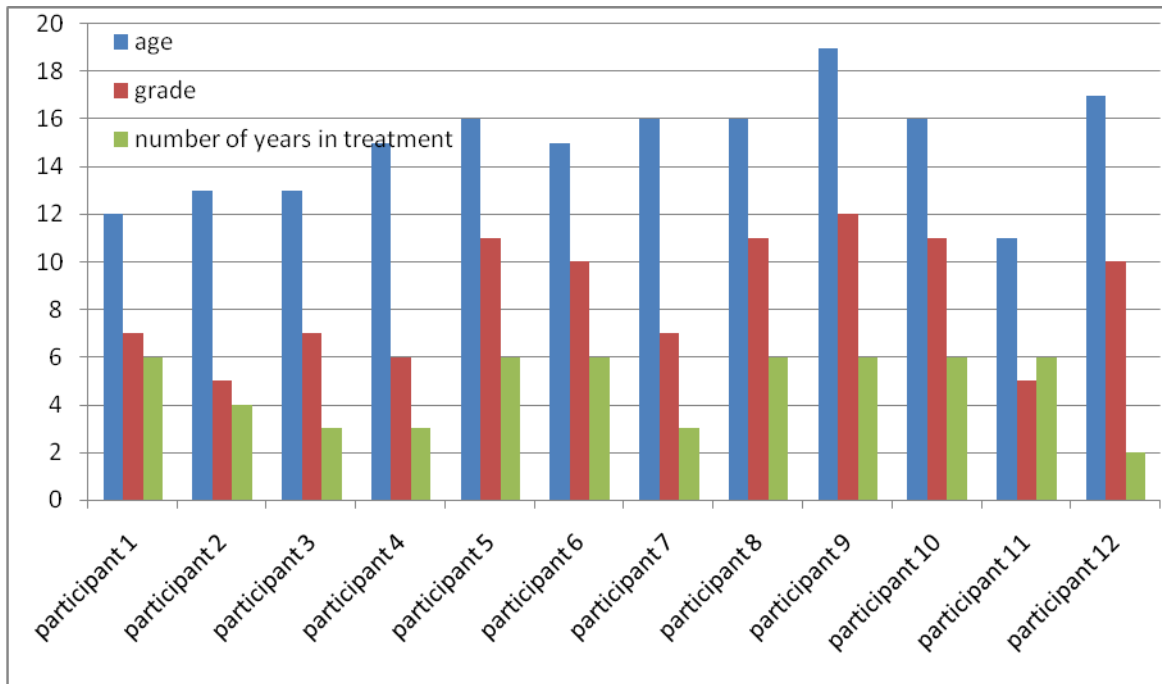


Figure 3-5: Comparison of age, grade and number of years on treatment

3.7 SECTION TWO: EMPIRICAL FINDINGS OF STUDY

Themes and subthemes

During data collection and analysis, themes and subthemes emerged and these will be presented below in a table format and discussed afterwards. As they are discussed, the voices of the participants will be quoted to justify the emerging themes. The themes and sub themes are summarised in table 3-2 below.

Table 3-1: Themes and Sub-themes

Themes	Sub-themes
1. Disclosure of HIV status	1. Knowledge of own status 2. Disclosure to family and significant others 3. Acceptance / denial of status
2. Challenges of living with perinatal HIV and AIDS	1. Knowledge on perinatal HIV and AIDS 2. Challenges of being HIV-positive 3. Adolescents' coping strategies
3. Needs of adolescents with perinatal HIV and AIDS	
4. Adolescents' views on treatment	1. Attitude towards treatment 2. Commitment to treatment 3. Knowledge regarding treatment 4. Factors affecting adherence/ non-adherence on treatment 5. Experiences of non-adherence to treatment 6. Independence in taking treatment
5. Stigma and discrimination	1. Fear of being stigmatised and discriminated 2. Internalised stigma
6. Support systems	1. Knowledge of availability of support systems and use thereof 2. Views on service delivery 3. Recommendations on service delivery

3.7.1 Theme 1: Disclosure of HIV status

Of the twelve participants, only two participants were not aware of their status. The participants mentioned that their HIV status was disclosed to them by their family members. In this study, disclosure emerged as one of the key concerns in adolescence living with perinatal HIV and AIDS.

Subtheme 1.1: Knowledge of own status

In the study, ten of the twelve participants indicated that they were aware of their status. Only one participant found out about her status on her own, the other nine were told by their families that they are HIV positive. Most of the participants also indicated that they were diagnosed after repeated sicknesses, which led to them seeking medical attention. The following were quoted from participants:

- *“I was very sick and they take me to the clinic and then they take me to test for TB and all the diseases and they found out that I am HIV-positive”.*
- *“Always when I’m at school, I feel dizzy and my class teacher take me home until my aunty go with me to the clinic and at the clinic they tell my aunty that I had to test and then I test and I find out that I’m positive...”*
- *“Me and my mom go to the doctor to do a test and after the test, my mum told me am HIV-positive.”*

It is important to note that contrary to what related literature says, there is an increase in disclosure of status to adolescents with perinatal HIV. Pienaar and Visser (2012:72) carried out a similar study and the findings revealed that five out of 6 participants were aware of their HIV status. However, to a lesser extent, there is still a concern of cases of non-disclosure to children who are HIV-positive. This is indicated in these following responses:

- *“My mother says, eish, I have a growth, in my heart, and I asked why I’m drinking pills, she said you have a growth so I left it like that.”*
- *“I don’t have HIV, treatment is for protecting me...from many diseases...”*

It is interesting to note that the parents of the two participants who are not aware of their HIV status actually gave their consent for their children to participate in the research.

A case of non-disclosure to the sick child is also found in a study by Pienaar and Visser (2012:69) who reported on a 13-year-old participant in their research who was not aware of her status and thought she took the medication to stay healthy. One of the interviewees reported in an article in the Guardian paper by Hill (2012) was also recorded saying he accidentally found out about his status when he was in his teenage years and had always been taking medication under the pretext that they are sweets. In this regard, the study findings revealed that some parents and guardians of adolescents with perinatal HIV and AIDS are reluctant to disclose the status. Instead, they explain the treatment in relation to other illnesses. Woollett (2013:23) also noted that between 25% and 90% of school aged children who are HIV-positive are unaware of their own status despite going to clinics every three months for their treatment.

Subtheme 1.2: Disclosure to family and significant others

All participants communicated that their closest family members are aware of their HIV status. Even two participants who are not aware of their status pointed out that their families are aware that they are on medication. Seven (7) participants mentioned that they could not disclose their status to their friends and teachers because they are afraid of being stigmatised. However, there is an exception of two participants who mentioned that they have disclosed to their teachers and one who disclosed to a trusted friend and another disclosed to her boyfriend. The following quotes confirm this finding:

- *“It’s my family only...my mother, grandmother, grandfather, sister and brother.”*
- *“It’s fine that they don’t know because they will laugh at me at school”.*
- *“No, it is something that is like; they knew it before me because I was born HIV-positive.”*
- *“Only one knows... he didn’t tell anyone he is a good friend”.*

It should be pointed out that there are differing viewpoints when it comes to disclosure outside the family structure because HIV and AIDS is still treated with secrecy. Although adolescence is a stage, where one relies more on friends for assurance, it is sad that only two participants were comfortable to share this part of their lives with friends. The study findings also revealed that non-disclosure to significant others are widely influenced by family members than the adolescents themselves in these ways. This shows that these adolescents have little influence in running their own lives, which is contrary to popular opinion that adolescents generally have a sense of independence. The following quotes confirm this observation:

- *“But friends don’t know. They said I must keep it secret.....even doctors told me that I must keep secret because children out there, I’m made fun. If I can tell them, everyone will know, so I must stay secretly.”*
- *“No I’m not planning to tell them... because obviously if you are HIV-positive, some learners will take you otherwise, like they won’t treat you the same”.*

Ross and Deverell (2010:6) confirm this finding in saying that adolescents with perinatal HIV and AIDS fear rejection for having the disease. This shows how challenging disclosure is as these young people would rather hide their HIV status because stigma is still vibrant in the communities. Pienaar (2010:126) indicates that most families are aware of adolescents’ HIV status, which means disclosure in families is not much of a problem. However, openly discussing HIV and AIDS issues is limited in families and the family has considerable influence on disclosure outside the family structure. The provisions of the bio-psychosocial model that social systems like the family, school and community contribute to health and illness, have been confirmed in this finding as it is evident that the family set up has an impact on how adolescents view and treat their diagnosis.

Sub theme 1.3: Acceptance vs denial of HIV and AIDS status

Nine (9) participants have accepted their HIV status except for one who has not accepted his status. None of the other participants directly blamed their parents for

the infection, instead they owned their status. The participants mentioned that being diagnosed with HIV was not easy to swallow but eventually they had to accept. Some explained that the positive reaction and support from their families helped them to accept their status. Two of the participants said:

- *“I have to, it’s my status there is nothing I can do about it.”*
- *“Ah I didn’t feel very bad I just accepted it, like it’s nobody’s mistake that am positive, I’m born with this disease. I don’t know how I felt. Realising it I just moved on with life, no stress no worries about how to live.”*

It shows that the participants have come to accept their HIV-positive status and learnt to live with it. However, it becomes ironic in that these participants have accepted their own status and yet are afraid to disclose. This is also pointed out in previous literature study where Hill (2012) writes about an adolescent who said that society expects them to live two lives. Personally, one has to be completely honest and accept their own status while on the other hand; they cannot disclose their status to the society or close people. This is bound to have lasting effects on the patients, which might lead to self-stigma.

Two of the participants showed denial of their status. One mentioned that when he was diagnosed he could not accept his status as he was thinking what his future will turn out like if he has HIV. He had to go for counselling to assist him with acceptance. Another participant even denied having HIV and AIDS His denial showed that even his mother is also in denial as the participant was already 15 and yet his mother still made him believe he is taking medicine just to remain well. These participants’ responses were:

- *“At first I didn’t accept it....I was thinking a lot about my future...my future, my children, their children”.*
- *“I don’t have it... I don’t have HIV.”*
- *“I just know that they are protecting me...(the pills)”.*

Denial is real in HIV and AIDS cases and it is one of the causes of non-adherence. Pienaar and Visser (2012) study findings reveal that one participant in their study is facing denial in the family as the topic of HIV and AIDS is never raised (Pienaar &

Visser, 2012:69). The bio-psychosocial model helped in understanding these findings as it stipulated that poor coping skills, reaction to illness among others reflect the psychological framework in relation to the sickness (Dogar 2007:12). This model hence helped in understanding such findings in the study.

3.7.2 Theme 2: Challenges of living with perinatal HIV and AIDS

Participants in this study revealed a number of challenges they face in their everyday life. The participants did mention that living with perinatal HIV is not easy. This will be discussed under the following sub themes.

Sub theme 2.1: Knowledge on HIV and AIDS and perinatal HIV and AIDS

All participants in the study noted that they have some knowledge on HIV and AIDS and how it is spread. Only a few had an idea on what perinatal HIV and AIDS is. However, most participants are aware that they were infected via their mothers but they do not seem to understand how. Only one participant who understood actually explained non-availability of HAART during the time she was born compared to the current times. The following quotes were their responses on what perinatal HIV is:

- *“Like at the time we were born, for us to be HIV, it is because like now there is a vaccine that helps kids not to get that infection. There is a treatment that prevents unborn babies from getting HIV from their mothers if they are still young and at the time they are born. So the time that I was born, there was no vaccine. There was no cure, that’s what I understand.”*
- *“They told me that I have HIV and I must get treatment from Jubilee. So they told me that I found this from my parents, since I was born. I was born with it.”*
- *“I understand that I was born with it.”*

However, some participants could not explain their understanding of perinatal HIV/AIDS. The researcher believes it could be a result of non-familiarity with the terminology. One participant who did not even know his own status asked:

- *“What is perinatal HIV?”*

Two participants seemed confused as to how they were infected:

- *“I understand the virus that it can get into anyone.....When you are having unprotected sex.....When you touch the blood of the other person who is positive.”*
- *“I know that it is spread through people sleeping together...and one must use condom to help them otherwise they mustn’t sleep together...Also don’t touch anyone’s blood. Use gloves if you have to, otherwise you will be infected because you never know if that person has HIV or not.”*
- *“Because I didn’t want to get HIV-positive, I don’t know how it got to me.”*

Literature confirms that most adolescents are aware of their status and have a certain level of knowledge as far as HIV and AIDS is concerned. In their study of six HIV-positive adolescents in Kalafong, Visser and Pienaar (2012:67) found that only one of them was not aware of HIV and AIDS. This shows that currently, there is a general knowledge of HIV and AIDS among adolescents. Although adolescents are generally aware of HIV, it is evident that they do not know much about perinatal HIV. As seen in the above quotes, most of the adolescents do not comprehend how they acquired this disease. Study findings of Pienaar’s (2010:113) concur with this finding. It indicates that the families are reluctant to disclose such information to the adolescents. Hence, there are various explanations given to adolescents on how they contracted the disease. Such findings bring out the relevancy of the bio-psychosocial model which seeks to understand bio-determinants of the disease as well as the anatomical, structural and effects of a patient’s biological functioning (Dogar, 2007:11). This model will assist medical personnel and social workers in their role in explaining in detail what perinatal HIV and AIDS is.

Sub theme 2.2: Challenges of being positive

Participants pointed out a number of challenges they face in living with HIV and AIDS. Four participants complained that being on medication disturbs their personal lives. Their interaction with friends at home and school is affected by medication.

The participants complained that being on medication makes their live very difficult. Here are some of the responses:

- *“Sometimes when I was drinking three pills I had to stop during the day and go drink pills.”*
- *“Yes, it affects me because sometimes when I’m doing something, I have to go and get the medicine and drink...When you are playing with your friends, sometimes you must tell them you are going when it’s still early to go home”*
- *“Sometimes if you are going to holidays, you may forget them. And as you are a teenager, you go for clubbing, you see, and you have to come early before time.”*
- *“There are many challenges that are affecting me in my life and sometimes you believe that some people know your status and you feel sad to talk to them”.*

From the above statements, it is shown that being positive has adverse effects on the day-to-day lives of these young people. They have to alter their lifestyle to suit their status in order to keep up with their medication. The literature study in chapter 2 also confirmed these findings, where Mellins (2010:6) and Heresi (2011:20) agree that perinatal HIV may lead to adolescents feeling like social misfits since medication disturbs normal life. Visser and Pienaar (2012:67) also agree that medicine intake may stop the patients from going for sleep-over, especially where disclosure has not been addressed. It is also evident that in trying to keep their status secret, adolescents have to compromise their wellbeing. One participant reported that he was stuck when he had to fill in forms at school; he highlighted one such scenario as follows:

- *“Yes, I have problems because at school they bring forms to fill up and there is a question that says ‘Do you take treatment or not’ and I don’t know what to write.”*

Such instances become tricky when one decides to hide that they are on medication, which may put them at a disadvantage of accessing the necessary assistance at the same time an adolescent might not be brave enough to inquire clarity from others,

especially knowing they might compromise their secret. These challenges have a direct bearing on disease management. The bio-psychosocial model helped in terms of understanding how these participants' social life is disturbed by their status and also it shows that there is a link between non-disclosure and lack of social support. This means since these adolescents barely disclose to their social circles they hence cannot expect support from the same.

Subtheme 2.3: Adolescents' coping strategies

In this study, few participants mentioned their coping mechanisms; two male participants stated that they play soccer to escape their internalised agony. One participant stated that he talks to his family members and it helps him. The other participants avoided sharing about how they cope and instead said they concentrate on taking their medicine. This is evident in the following quotes:

- *"I play soccer to release stress."*
- *"Sometimes you feel sad, sometimes you may talk to your mother or sister. That's the best way to deal with that, maybe they will understand you."*
- *"...I'm drinking my pills, the way they told me to take it."
"I don't know what to say...I don't know".*

Just like any other medical and social ill, HIV and AIDS needs one to develop coping strategies in order to deal with emotional aspects that come with being HIV positive. However, contrary to findings in this study, the studied literature does not point out positive coping strategies for adolescents living with HIV and AIDS. Zaroni (2013:16) reiterates that feelings of depression, withdrawal, loneliness and anger are common with adolescents struggling with HIV and AIDS. Gray (2009:2) states that most of these adolescents are either nursing their sick parents or living in child headed households, which leave no room for any coping strategies. The picture Gray (2009:2) paints is one of an overwhelmed adolescent, who is dealing with their own HIV-positive status, and taking responsibility over the home.

These findings concur with the provisions of the bio-psychosocial model, specifically the psychological effects of HIV and AIDS in adolescents. As Zanoni (2013:16) revealed, due to frustration and anger of failure to cope with treatment, these adolescents turn to negative coping strategies and resort to behavioural problems of drug abuse, high rates of depression, conduct disorders, social phobia, attention deficit, and hyperactivity disorder among others.

3.7.3 Theme 3: Needs of adolescents with perinatal HIV and AIDS

Four participants in the study mentioned healthy living as their main need. One participant pointed out that that they are in need of support in disease management. The participants were quoted saying:

- *“Maybe I need healthy food.”*
- *“I need to live healthy and eat healthy food. Drink my medication, exercise to be healthy.”*
- *“I need to be educated, I need to take my pills according to the way they told me to do. I have to protect the ones who are dear to me, the loved ones. Maybe, they must wear gloves so they will not be affected too. ...I need to eat healthy.”*
- *“I need them to protect us from this, help us stay on our medicine... To people who take medicine everyday and they feel like tired, then they don't want to take them anymore, they must get them to take them always because when you stop taking them, you end up being or you end up dead.”*

The participants reiterated on the need for healthy living and adherence. The study area is a semi-urban area and most dwellers in Hammanskraal are living below the poverty datum line and possibly access to food might be a problem for these adolescents. It should be noted that these particular participants spoke in their own context and due to their background, healthy food is a priority amongst their needs. The studied literature, for example Mellins, (2010:5) also revealed that children born with HIV and AIDS are from vulnerable minority and disempowered families. Thus,

there is need to provide them with healthy food in-order to complement their medicine.

3.7.4. Theme 4: Adolescents' views on treatment

The participants had different views regarding treatment. All adolescents do not like the treatment but some do understand it is important to take this treatment to be well. Their views and attitude towards antiretroviral treatment is discussed under the following subthemes:

Subtheme 4.1: Attitude towards treatment

Participants acknowledged the importance of this medication. However, a few mentioned that they do not like the medicine but they drink it because it is important to do so. The two younger participants verbalised their dislike for treatment. It was evident that they are taking the treatment just because their parents expect them to. Three of the participants had this to say:

- *"I feel bad bad...I don't want to take the pills."*
- *"The pills are big, and I can't drink it..."*
- *"I don't feel so good like taking pills for the rest of my life sometime they are annoying like...."*

However, the older participants appreciated the role of ART in their lives. This is what two older participants had to say concerning their treatment:

- *"I'm fine about the treatment because if I wasn't drinking these pills, where will I be now?"*
- *"I feel good because treatment keeps my body strong. It can't show to passing people. If you are not drinking medicine, anyone can see you have a problem but if you drinking medicine, you will be better. So I feel good taking the medicine."*

Most literature study records negative attitude towards ART by young people, mostly owing to the fact that taking this treatment has adverse effects on their day-to-day life. As has been recorded before, there are various social and psychological factors responsible for a certain attitude towards treatment and these include non-

disclosure and stigma (Rao, Kekwaletswe, Hosek, Martinez, Roderiguez, 2007:31). Vijayan, Benin, Wagner, Romano and Andiman (2009:1224) note that one of the reasons adolescents have negative attitude towards ART treatment is that taking pills every day, even when they feel ill, is a constant reminder of their disease.

In this study, there were participants who were actually appreciative of the treatment and were not complaining about its life-long intake. The researcher notes that this positive attitude towards treatment by older participants compared to the younger ones is because the older participants have deeper understanding of HIV and AIDS and the benefits of adherence.

Subtheme 4.2: Commitment to treatment

All participants pointed out that at the time of interviews they were adhering to their treatment. Some participants mentioned that they rarely forget to take the pills but when they do, they ensure they make up for the missed tablets. The following are some of the participant's responses regarding adherence:

- *“No yho...I make sure if I go, I take it and I drink.”*
- *“No, I’m not doing that...”*
- *“Yeah I drink them everyday...”*
- *“I have... (defaulted) Then I felt ill. Then was admitted in the hospital”.*

The participants have embraced the importance of the treatment in their life, and it seems it is their motivation for living. They have placed their hope in knowing that as long as they adhere to the medication, they will be well. One thing that was uniform with all the participants is that they know exactly how many pills they drink and at what time. Most of them were also very accurate as to when they started taking the pills. This showed that this medication is becoming a significant part of their life that they cannot forget about it.

In literature, Houghton (2013:5) reveals that this group of children have had their whole lives dependent on pills and this becomes monotonous. It is one of the reasons leading to non-adherence in adolescence. As has been pointed out, these adolescents with perinatal HIV and AIDS are adhering to treatment partly because their parents and guardians are monitoring them. Once the adolescents come to a point of independence in pill administration, they might opt for non-adherence.

Subtheme 4.3: Knowledge regarding treatment

Most participants had very limited or no knowledge at all about their treatment. Of the twelve (12) participants interviewed, only two (2) know the treatment by its names. Some do know how the treatment works in their bodies, otherwise the rest are not aware of the names of their treatment. This is possibly a cause for concern considering they are the ones taking the medication. The information they gave was:

- *“Abacavir, nevirapine and...”*
- *“Efavirenz, lamivudine, tenofovir ”*
- *“Yes I know at least it’s supposed to try and fight the viruses...”*

The literature study revealed that most of these adolescents generally rely on their caregivers. In the study done by Vijayan et al. (2009), only 5 out of 18 participants could articulate the names of their treatment. Vijayan, et al., (2009:1224) maintain that most adolescents depend on caregivers to help them administer the medication hence they have no idea what medicine they are taking at a given time. The same was observed in this study; that adolescents are not aware of their own medicine. They take it for granted that their caregivers should know.

Subtheme 4.4: Factors affecting adherence and non-adherence

Most participants mentioned that they are adhering to the medicine because they were told to drink or else they will die. The desire to live is the main motivation for taking the pills. The study findings also revealed that some of the participants have had to accept the medication only because they do not have another option. The following quotes indicate responses of some participants:

- *“I don’t feel so good like taking pills...I just think I have to accept, I have to take this medication for the rest of my life.”*
- *“It’s that if I default, I might get sick and the treatment will reject you”.*
- *“...I will get sick. I will end up dead”.*
- *“After that they told me if I don’t drink my pills I am going to die”.*

Furthermore, most participants have at one time forgotten, skipped or decided not to adhere to their medicines, all for various reasons. Some participants deliberately made the decision to stop taking their medication and most reasons concur with the sentiments of Agwu and Fairlie (2013:2) of critical thinking and risk taking:

- *“It has been a long time since I have not been taking treatment...I didn’t really understand I’d be positive, I just have got this thing in my mind that I’m healed, like one pastor prayed for me and I believe that I’m healed I had no stress, no worries about this disease.”*
- *“When, last time I was in grade 6. I think that I could stop them but my mum told me that I if I could stop them my life would be end. ...It’s just they are too big that I can’t drink them.”*
- *“It’s that time they told me I have HIV... I was afraid....I was thinking a lot about my future...”*

It should be noted that adherence and non-adherence are greatly determined by factors such as experience of a particular individual. The study revealed that the biggest reason for adherence on treatment is the fear of death, which is being drummed into the adolescents by their parents, caregivers and health care workers.

Agwu and Fairlie (2013:2) agree that adolescence is a risky stage that is characterised by physical and psychological evolution, which involves concrete thinking and risk taking. Therefore, non-adherence is likely to be higher in this age group. It is reported that achieving 100% adherence in perinatally infected adolescents in Sub-Sahara Africa was reported only in about 20% of cases (Agwu & Fairlie, 2013:2). This shows there is a big challenge in successful administration of ART in adolescence. Spies (2005:97) indicates that the factors that motivate good adherence include the understanding that poor adherence will lead to resistance.

This information is also a driving factor to adherence in the study group as seen in the verbatim quotes above.

Subtheme 4.5: Experiences of non-adherence to treatment

In almost all cases of non-adherence, participants pointed out that it was voluntary. Four of the participants did confess that at one time they had stopped to take their medications and after getting sick they had learnt the dangers of non-adherence. All participants agreed that non-adherence is wrong. After learning the hard way, they have since chosen to adhere to their treatment. Although it might seem far-fetched, these experiences seem to be a good motivation as far as adherence is concerned. The participants mentioned that:

- *“Then I felt ill. Then was admitted in the hospital.”*
- *“If I don’t take them I feel dizzy.”*
- *“I got sick and I sleep in hospital for months.”*

All participants in the study were aware of the negative implications of defaulting on their medication. This is because some had once defaulted and got sick. Thus, they are now aware that non-adherence is a ‘nonstarter’.

There was particularly interesting observation of one participant. Despite her knowledge of HIV, she decided to default after a pastor prayed for her. The participant believed she did not have to take medicine anymore. This participant confessed:

- *“I didn’t really understand I’d be positive...I just have got this thing in my mind that I’m healed, like one pastor prayed for me and I believe that I’m healed. I had no stress no worries about this disease. ... I believed that I’m positive but I did not take it seriously. I believed that I can live being positive and not taking treatment.”*
- *“I believed that I’m positive but I did not take it seriously, I believed that I can live being positive and not taking treatment”.*

This case illustrates that discussions on HIV and AIDS should also acknowledge the effects of other social factors like cultural and religious beliefs. This is one area that studies have overlooked but can have a significant bearing on medication intake generally. Ross and Deverell (2010:26) mention that various aspects that determine health behaviours include religion, race, ethnicity as well as western versus traditional healing methods. The bio-psychosocial model in this regard helped understand the extent to which religion can influence health and illness. In this regard, it was observed that religious beliefs have a certain degree of influence on HIV and AIDS perception and adherence issues. It is important to note the role religion plays in the lives of individuals, and for social workers to be able to know how to consider religious and cultural beliefs in the treatment plan of every individual.

Sub theme 4.6. Independence in taking treatment

All participants, but one, mentioned that they rely on their family members when taking treatment. The one who was an exception claimed that he also comes alone to collect his medicine from the clinic. The rest of the participants noted that either they are given the tablets to drink or they are reminded when it's time for medication and in most cases they are closely monitored by an adult. This is how they explained their pill intake routines:

- *“No, she gave me a phone to set an alarm for 6:30, when it rings I eat then drink pills.”*
- *“Every day they ask me if I had my tablets, by my aunty.”*
- *“I’m taking them then I will show her then I drink.....”*

One interesting case was an 18 year old who had just matriculated and would be going to University, away from home, yet she still could not take medication unsupervised. She was still relying on her maternal aunt for administering the treatment. This is what she had to say when asked how she will cope when she moves to university:

- *“I have to. It’s my status; there is nothing I can do about it ...I will teach myself then...”*

Agwu and Fairlie (2013:10); Mofenson and Cotton (2013:1) agree with the findings under this sub theme in that adolescents living with HIV and AIDS find it difficult to

transition from dependency on their caregivers to independence and eventually when they are expected to act independently, they regard it as abandonment. However, the researcher points out that although there is a general reliance on caregivers, some of the participants were being slowly trained to be independent. Such strategies like setting an alarm for medicine times help the adolescent to get used to the routine.

In addition to the studied literature which revealed that these adolescents are not involved in their own treatment plans, the AIDS Education and Training Centres (2004:19) asserts that these adolescents are not involved in decision making that affects their lives. It can be concluded that there are different factors causing adolescents to be dependent or independent in taking their medicine but one scenario cannot be generalised. However, it is imperative to note a contradiction in the findings where adolescents with perinatal HIV are seen depending on their caregivers of which at this stage they should be thriving to break free from the caregivers' grasp.

3.7.5 Theme 5: Stigma and discrimination

Participants cited the fear of stigma as a hindrance in their day-to-day lives. The participants indicated that they are afraid of being stigmatised mostly in schools. It is noted that none of the participants had personally experienced stigma, however, they believed that the community would stigmatise against them if they knew their HIV status.

Subtheme 5.1: Fears of stigma and discrimination

Most of the participants have not disclosed and are not planning to disclose their HIV status to anyone outside their families. Only four of the twelve participants have disclosed to others beyond their family circles. The rest of the participants attributed their lack of disclosure to fear of stigma by others. The following quotes confirm this finding:

- *“Even doctors told me that I must keep secret because children out there, I’m made fun, if I can tell them, everyone will know. So, I must stay secretly.”*
- *“Maybe I don’t want to.... I decide to tell my friends but some friends are gossip.”*
- *“I cannot trust friends...some people can’t live with you if you have HIV.”*
- *“Because obviously if you are HIV-positive, some learners will take you otherwise; like they won’t treat you the same. According to the way I know.”*
- *“It’s fine that they don’t know because they will laugh at me at school. They will be calling me names and they won’t play with me again.”*
- *“If at home you are being discriminated. Then you feel somehow, then you let go the pills.”*

It is noted that stigma has a very big effect on how these adolescents would perceive themselves eventually. Even literature mentions stigma as a leading factor contributing to fear in HIV and AIDS patients. Ross and Deverell (2010:6) state that for these adolescents, the fear of being rejected is always greater than the fear of dying of HIV and AIDS. Hence, some opt for non-adherence, if taking the treatment exposes their secret. Baryamutuma and Baingana, (2011: 211) also echo these sentiments by noting that the infected adolescents might resort to non-disclosure for fear of rejection and discrimination.

Sub theme 5.2: Self-stigma

Three participants pointed out that they have fears of their own. They pointed out that they are aware that being HIV positive makes them different from other people. Some of the participants explained that even without disclosing, they just feel like people are aware of their status. Self-stigma was identified in the following quotes from the participants:

- *“There are people that you think they know you and know your status and you are afraid to talk to them. You think they will expose you from playing with them and do things with them”.*
- *“I feel bad, because I’m different to other people. I can’t do what people do outside ...”*

- *“Sometimes it’s fine but not always. I will be feeling, maybe, I’m not part of that family.”*

In these statements, it is noted that the participants have thought about their situation and reached a conclusion about perceived community attitudes. It has been mentioned before by Woollett (2013:23) that adolescents struggle with issues of self-identity and image. As they worry much about what people think of them, they end up projecting the same stigma on themselves. It should be noted that self-stigma results mainly from the pressure of non-disclosure. Woollett (2013:23) also adds that as the adolescents and the family concentrate on non-disclosure, they are perpetuating internalised stigma by constantly being paranoid of what the ‘unknowing’ people think of their status. The bio-psychosocial model came in handy as it enabled the researcher to understand how the various psychosocial effects, including self-image and self-identification affect how these adolescents perceive themselves.

3.7.6 Theme 6: Support systems

The participants acknowledge that their immediate family members are available to give them support in their lives. Discussions with participants revealed that it is only the family that is viewed as a support system and hence the only place where this support is normally sought. This theme is broadly discussed in the following subthemes:

Subtheme 6.1: Knowledge of availability of support systems and use thereof

All participants mentioned their immediate family as the main source of support available. None mentioned any support structure beyond the family and to a lesser extent the school system. The following quotes indicate participants’ responses:

- *“It’s my family...my brother, my father, my sister and my baby sister...”*
- *“My sister...”*
- *“My sister, my grandmother, my grandfather and my aunts and uncles.”*

One particular participant seemingly did not acknowledge the importance of his family’s support. He pointed out that he felt out of place even when they try to show

him support. He was asked how the support of his family makes him feel and he said:

- *“Sometimes it’s fine but not always...I’ll be feeling maybe I’m not part of that family.”*

There is a split amongst the participants on their awareness of the availability and use of support systems. Those who mentioned family as their sole support system attributed this to non-disclosure which the families had enforced. The participants had pointed out that their family members had warned them to be discreet about their HIV status. As long as the participants keep their status secret, chances of getting support from outside their family set up are low. However, some did mention that beyond their immediate families, they have the support of teachers. Three of the 12 (twelve) participants actually mentioned that they have disclosed to their teachers and have no difficulty discussing their status with teachers and doctors:

- *“I tell them everything about my life.....the doctors...at school I tell the teachers so that they can help me.”*
- *“My teachers.....I told only a few....They treat me so well.”*
- *“....even my mam knows what time I drink my pills and she treats me special and lets me go home.”*

Although some participants have extended support from their teachers, it is not enough support for adolescents with perinatal HIV. They need additional support from friends and the community as a whole. In their research on HIV infected adolescents, Pienaar and Visser (2012:73) also discovered that support was generally limited to the family and extended family system. Scholars argue that due to non-disclosure, the, support systems are limited to the parents and caregivers, which in turn leads to caregiver burnout. It is also important to note that this support received from the family is usually in form of physical support. Hence, emotional support which is an important aspect in administering treatment is lacking (Pienaar & Visser, 2012:73).

Subtheme 6.2: Views on service delivery

In the study, most participants were hesitated to answer the question on service delivery and some did not have any comments to make on service delivery. Most of them said they are satisfied with the service delivery. This made it hard to conclude whether this meant the service delivery is satisfactory or the adolescents themselves are not aware of what to expect from the service providers. The participants said:

- *“They handle me well; there is nothing to complain about...”*
- *“Their service is fine, no problem.”*

These findings are contrary to the literature study, which revealed that there is an identified conflict between HIV-positive adolescents and the health systems. Baryamutuma and Baingana (2000:215) assert that, adolescents with perinatal HIV and AIDS face problems with the suffocating health care system, where health care centres are frustrated by under-staffing and working under pressure. As a result, patients have to endure long waiting hours. The researcher observed that patients waited a considerably long time in long queues when they come for their medication. These long queues are usually observed from the time the clinic opens its doors until lunchtime. This is the reason why on the date for collection, the adolescents have to take the day-off school as they have no guarantee of a quick service.

Subtheme 6.3: Recommendations on service delivery

In this study, only a few older participants understood and had views on what they expect or would recommend for service provision. Three of the participants said:

- *“I think maybe for the teenagers there have to be a day, only for teenagers only coming for check-up.”*
- *“I wish the hospital could just take one year for the (collection) of treatment.”*
- *“I need them to protect us from this, to help us stay on our medicine, to people who are when everyday they take medicine and they feel like tired then they don't want to take them anymore, they must get them to take them always because when you stop taking them you end up being sick or you end up dead.”*

As noted in the quotes above, one participant believed that the system can put in place programmes to support patients by assisting them with adherence to medication. Spies (2005:298) echoes this sentiment by stating that there is a need for the government to look into and make provision for patients' individual circumstances. The recommendations from participants in this group are all different, and they have to be treated and addressed in their difference. Spies (2005:305) recommend that service delivery should involve assessment of the patients' bio-psychosocial circumstances. The bio-psychosocial model enables social workers working with adolescents with perinatal HIV and AIDS understand the unique needs of every individual patient. For instance, the psychosocial assessment might reveal that one particular participant's psychosocial circumstances deprive him psychosocial support, which another participant might be getting from family and friends. In this regard, adequate treatment plans will be drawn for such a patient.

3.8. Summary

The study was carried out at Jubilee Hospital ART and Wellness Clinic in Hammanskraal, which is a semi-rural residential area outside Pretoria Central. This study site was chosen because of its rural set up and the possible high cases of perinatal HIV and AIDS, also bearing in mind that there is possibly less intervention on adolescents with perinatal HIV and AIDS, because of their location.

A qualitative design was used for the study. Adolescents with perinatal HIV and AIDS were purposely selected for the interviews with the help of the Jubilee ART and Wellness Clinic's Sister-in-Charge. In total, 12 (twelve) respondents were interviewed and in-depth interviews which were guided by an interview schedule were used to collect data. Data analysis was done using Creswell's stages of data analysis, which involved transcribing and interpreting the data, regrouping it into themes and sub themes for easy referral. This section later focused on the different themes that emerged from the study. The themes were explained using direct quotes from participant. The bio-psychosocial model played a key role in understanding how biological, psychological and social factors affected attitudes, reactions and perceptions of adolescents with perinatal HIV. The next chapter will focus on the key findings, conclusions and recommendations of the study

CHAPTER FOUR

CONCLUSIONS AND RECOMMENDATIONS

4.1. Introduction

This chapter will generally present how the goals and objective were achieved in the study. A presentation of the key findings of the study will follow, from which conclusions and recommendations are drawn.

4.2. Goal and objectives of the study

The study goal was to explore and describe the challenges faced by adolescents with perinatal HIV and AIDS. This goal was achieved through the following objectives:

Objective 1: To describe and contextualise perinatal HIV and AIDS

This objective was achieved through the literature reviewing chapter 2. The objective is also achieved through sub theme 2.1, which is one of the themes that emerged from the collected data. In chapter 2, this objective is largely described when perinatal HIV and AIDS is explained in detail. This includes a detailed presentation of global statistics on perinatal HIV and AIDS as well as statistics on Sub-Saharan Africa. This section also mentioned the extent of perinatal HIV and AIDS in adolescents; looking at the perpetuating factors leading to the existence of this particular group. Theme 2, sub theme 2.1 also describes how these adolescents perceive perinatal HIV and AIDS as well as how they perceive HIV and AIDS generally. The whole aim was to ascertain the adolescents' knowledge of perinatal HIV in the context of their own experiences of growing up living with HIV and AIDS.

Adolescents with perinatal HIV and AIDS resulted from the fight against child mortality, creating a whole new generation of adolescents growing up HIV positive. It is noted that as focus was made on curbing infant deaths due to HIV, the emerging group of adolescents was overlooked. These adolescents were unfortunately born before there was effective prevention of mother to child transmission (PMTCT) programmes. However, by surviving the pandemic, which would have otherwise killed them at an early stage, they are now the beneficiaries of antiretroviral therapy. Some participants in this study indicated that they have some knowledge of perinatal

HIV and one even mentioned that they were born before there was effective PMTCT programme.

Objective 2: to determine the adolescents' knowledge of HIV and AIDS

This objective was discussed in Chapter 3, under sub theme 2.1 and it was generally realised that these adolescents have been HIV-positive since birth but most of them know so little about the pandemic that is part of their life. It seems there is a general lack of important education on HIV and AIDS. Most of the participants just understand a few facts about HIV and AIDS such as how it is spread and that it is a life time disease. The information they have is derived from the little knowledge that they learn about in school. For children who have had to live with HIV and AIDS for as long as they can remember, they have to know in detail about the pandemic. It was observed that even some older adolescents could not explain what perinatal HIV and AIDS is, let alone know about HIV and AIDS.

Objective 3: To establish their attitudes towards lifetime treatment of HIV and AIDS

This objective has been discussed briefly in Chapter 2, and broadly in Chapter 3, under sub-themes 4.1 and 4.2. In the literature study, it was revealed that these adolescents are heavily burdened by the intake of pills. It was discussed that because of the nature of pills, which also have some negative effects on their bodies, like body image and pubertal delays, this treatment, although beneficial, has its own shortfalls. The discussion with the participants also revealed that they do not really like this treatment and the adolescents are taking the treatment just because they have no choice and the fear of death is stronger than their hatred for the treatment. Most of them have accepted that they will have to drink the medicine for life as long it keeps them healthy, despite their dislike of the treatment.

Their attitude towards lifetime treatment is also discussed under sub theme 4.3 and 4.6, about their knowledge of the treatment as well as independence in pill administration. The discussions with research participants revealed that only a small number of adolescents know their medication by name. Almost all of them do not even know the effects of the treatment on their body, except for the fact that it is meant to make them well. It is important that they should be aware of every

medication one takes; what it is fighting in their bodies. Antiretroviral treatment includes vitamin pills at times, but none of the adolescents even mentioned those. This lack of knowledge regarding their treatment 'speaks volumes' about their attitude towards treatment; that they have no knowledge about the very thing that is going to be part of their everyday life. However, it is important to note that, this lack of knowledge is to a greater extent due to lack of education on HIV and AIDS.

It was also revealed that some of these adolescents have at least failed or decided not to adhere to the tablets once in their lifetime (in sub theme 4.4). Most of the reasons for non-adherence were the dislike of the treatment and denial of their HIV status. The fact that this medication disturbs their day-to-day life was also mentioned and this shows that this medicine is likely to be always loathed by these adolescents as its continuous intake has an adverse effect on their day-to-day activities. The treatment takes away their freedom to associate with others and to live their lives to the fullest without having to care about treatment at given times of the day.

Objective 4: To establish their needs regarding living with HIV and AIDS

The objective was discussed in the literature study in chapter two and under theme 3 (three) in Chapter 3 (three). It was established during the literature discussion that these adolescents with perinatal HIV and AIDS have needs that are unique to them as a subgroup of HIV and AIDS patients. Some of these needs are the need for support and provision with adequate food.

The discussions revealed that their core needs are mostly for support with healthy eating to supplement their medication. It is concluded that there is a recognisable lack of healthy eating among these adolescents, which may be due to poor incapacitated family backgrounds, where one or both parents are deceased or unemployed. One participant mentioned the need for support from the government to encourage them to take pills and fight non-adherence by young people.

Objective 5: To determine their challenges of living with HIV/AIDS

The challenges faced by these adolescents were discussed in chapter 2 as well as chapter 3, under theme 2. The challenges faced by adolescents with perinatal HIV infection are many, including non-disclosure, adapting to treatment, stigma and

discrimination. As described in chapter 2, these adolescents are facing challenges with their body image and developmental delays, which the researcher observed during the study. Some of the participants had sores and warts on their faces and for others their bodies were relatively small for their age. There was another worrying observation, where some participants are still in lower primary grades at school and yet they are in their late teens (see figure 3.5). The study findings also revealed that most of the adolescents were already orphans who are being raised either by their grandparents, older siblings or other family members.

The discussion with participants also revealed that most challenges encountered concern treatment (sub theme 4.1), where their day-to-day lives are disturbed by intake of treatment. These adolescents revealed how their whole life is centred on treatment in such a way that when it is medication time, everything else has to stop. In the literature study in Chapter 2 (two), it was mentioned that these children could not have a sleep-over, especially where there was non-disclosure. One of the participants also mentioned that if one needs to go for holidays or go clubbing like other teens, they have to come home early for the treatment.

Objective 6: To determine the availability of support systems and utilisation thereof

This objective was discussed in Chapter 2 (two) and in subtheme 6.1 in Chapter 3 (three). It was noted that there is a strain on the family and caregiver system as it is the only one involved in supporting these adolescents with perinatal HIV/AIDS. This caregiver-burnout has been explained as being caused by non-disclosure (discussed in subtheme 1.2). Therefore, they cannot expect support from significant others. Some of the adolescents are also not able to use the school system as a support structure for fear of rejection. One participant mentioned that teachers had told them not to touch sick children as they will be infected. Although three participants indicated disclosing to their teachers, it is also noted that the majority of cases cannot trust their teachers enough to disclose their status.

The adolescence stage is known for its high reliance on friendships than any other relationship. In the case of adolescents with perinatal HIV/AIDS, friendship is the last place they will look for support, let alone share their status (as mentioned in sub

theme 1.2). Another significant lack of use of support uncovered through discussions with the adolescents revealed that they are not aware of the hospital as a support system. None of the study participants directly mentioned the hospital as a support system and this can be attributed to lack of education on this pandemic to these children. It would be beneficial for them to be taught of available support systems beyond the family.

Objective 7: To provide recommendations on how to help adolescents with perinatal HIV/AIDS

The objective was discussed in Chapter 2 in the section on the bio-psychosocial theory, where it discussed on how to tackle HIV/AIDS using this theory. This objective was achieved to a certain extent by recommendations made by participants during the study. It should be noted that due to lack of knowledge concerning HIV/AIDS (stated under subtheme 2.1), and limited or lack of knowledge regarding support systems beyond the family (subtheme 6.1), it is understandable that these participants could not come out with a range of recommendations for themselves. However, these challenges, as observed by the researcher, will form part of the recommendations to assist and care for this sub-group of adolescents with perinatal HIV/AIDS.

4.3. Key findings and conclusions

This section will present the key findings of the study and the recommendations thereof. The findings and recommendations emanate from the data gathered during the interviews as well as the observations by the researcher. These findings are based on the challenges faced by these adolescents who are living with perinatal HIV/AIDS. The following were the findings in the study conducted:

- There is a split in terms of awareness of perinatal HIV/AIDS amongst adolescents. Although a few participants had little knowledge on perinatal HIV/AIDS, most participants could not fully conceptualise perinatal HIV/AIDS, although they are living with the virus.
- ❖ It can be concluded that adolescents with perinatal HIV/AIDS are not well informed of the disease that affects their day-to-day life. These adolescents

are expected to live with and accept their circumstances, yet they do not have a full comprehension of how and why they were infected.

- There is a serious concern over adolescents who are not aware of their own HIV status. In the study, there were two (2) adolescents who have been on antiretroviral treatment for a considerable time, yet they did not know the reason for their medication. They were told it is to keep them well and that is what they believed.
- ❖ It can be concluded that a serious problem exists for adolescents who are born and grow up with HIV. Some reach their teens unaware of their status. This is tricky as this may contribute to negative reactions like denial when they eventually learn of their status. Such adolescents might resort to anger and denial which will have adverse effects on adherence to medication in the future.
- The study findings indicate that adolescents have considerably limited knowledge of their own medicine. Only a few participants know at least the names of their treatment. The participants took for granted that their treatment is the right one and that it makes them well. To them, the knowledge of treatment is not as important as taking the treatment, which is what most of them seemed to focus on. This limited knowledge concerning their treatment disempowers the adolescents
- ❖ It can be concluded that the adolescents' lack of knowledge on treatment is a cause for concern. These adolescents need to know their medicines by name and be aware of how they function to keep them well. This information will empower them and enhance adherence to treatment.
- The research findings also indicate that non-disclosure is a serious challenge in the lives of adolescents with perinatal HIV and AIDS. These participants pointed out that it is mostly their closest family members who know their status. Otherwise, in most cases, all the significant others, including extended family members, friends and teachers, are not told of the child's status. The research findings revealed that in most cases non-disclosure is forced upon

the adolescents by families who encourage them to be discreet about their HIV status.

- ❖ It can be concluded that total disclosure will remain a challenge as these adolescents still find it hard to confide in their best friends. Non-disclosure means fewer people know about the status and less support is received.
- Most of adolescents with perinatal HIV and AIDS are struggling to accept their status. It is observed that most participants acknowledge their HIV status but have not accepted it fully.
- ❖ The researcher concluded that these adolescents do not fully embrace their positive status. These adolescents continue to take medicine because they have no choice. Most of them have once risked their lives by not adhering to treatment.
- The findings of the study revealed that these adolescents are struggling with issues of adherence to treatment. The study findings revealed that some of these adolescents once decided or actually stopped taking the medicine because they could not cope anymore.
- ❖ It can be concluded that adolescents with perinatal HIV and AIDS are not happy with lifetime treatment. They are finding it hard to cope with taking medicine for the rest of their lives.
- The researcher found through observation that long-term treatment has physical and psychological effects on the body. Some of the adolescents interviewed had visible signs of wasting, warts and sores on their bodies, while some looked too small for their ages. The researcher attributed this to the side-effects of medication and the disease in their body. The researcher also noted a general lack of confidence amongst the participants when they could not even answer questions they were asked, for fear of the unknown.
- ❖ The conclusion drawn from this observation is that the HIV treatment has physical effects on the body image of these adolescents and once their body image is distorted, it has inevitable psychological effects on their self-esteem and eventually their confidence levels drop.

- Findings of this study revealed a disparity in that as much as adolescence is a period of seeking independence, adolescents with perinatal HIV and AIDS are still dependent on their caregivers. They depend on their caregivers for administration of their treatment and in some instances, collection of the same.
- ❖ In this regard, it can be concluded that these adolescents do not have control over their own lives and their caregivers determine almost everything for them. This is detrimental to their psychosocial well-being and growth. Instead of transitioning to independence, most of them will remain dependent on their caregivers for long.

- The findings indicate that these adolescents have limited social support. The family system is the only overall support system that is being utilised. These adolescents have chosen or been told to keep their status secret, hence they cannot have a support system that is not aware of their HIV status. This only leaves the close family unit as the sole source of support for these adolescents.
- ❖ The conclusion drawn from this finding is that non-disclosure may be viewed by the adolescents and their family members as beneficial and a way of keeping their secret. However, it has adverse effects of denying these adolescents the benefits of having multiple relevant support systems like friends, the school and the general community.

- Findings of the research indicate that the family plays a big role in supporting these adolescents; however, it does not have the necessary capacity to offer comprehensive support. The study findings revealed that some loopholes in how the family at times manages this disease, which might have serious implications in the future.
- ❖ The researcher concludes that the family system is incapacitated to provide much support to these adolescents as witnessed through lack of disclosure of status to adolescents themselves. The family needs input from different support systems like the health care system and the education system to be able to offer relevant support to these adolescents with perinatal HIV and AIDS.

- The findings of this study indicate that stigma and discrimination against people living with HIV and AIDS are still challenges in the society. As a result, adolescents with perinatal HIV and AIDS live in fear of being stigmatised if their status is known.
- ❖ The researcher concludes that stigma and discrimination are social ills that need to be dealt with in the society if the fight against HIV and AIDS is to be won. It is important to accept and support the HIV-positive in our societies and make them feel as important and productive as their HIV-negative counterparts.

Overall, the study managed to explore and uncover the various challenges faced by adolescents with perinatal HIV and AIDS. The challenges have been discussed above and relevant recommendations made below. It is important to note that challenges faced by these adolescents can be taken as individual as well as group scenarios as each case has to be dealt with in its uniqueness.

The theoretical framework of this study, the bio-psychosocial model played a great role in understanding the study. In exploring the challenges faced by adolescents with perinatal HIV and AIDS the researcher looked at the biological, psychological and social factors that have a bearing in the experiences of the participants under study. The researcher learnt that lack of understanding of the biological functioning of their bodies is one of the reasons participants still cannot comprehend what perinatal HIV is and how exactly they were infected or how the treatment works in their bodies. The model also helped to explore and understand that psychological effects of HIV and AIDS contributed to issues of self-stigma, non-adherence and many others. The social contexts of the model were depicted in how social relations with families, friends and the community affected the adolescents' attitude towards the disease. The recommendations to curbing the identified challenges will be discussed in the next section.

4.4. Recommendations

After the research was conducted, themes of the findings were formulated and reported, the recommendations were deduced and they are presented below:

4.4.1 HIV and AIDS education on children with perinatal HIV

The study findings revealed that these adolescents are not well equipped with information concerning perinatal HIV and AIDS. It is important that as these adolescents grow with HIV and on treatment, they may be well aware of the condition they are living with. It is also important that this education be meted on the significant others, especially the family and the teachers at school to be empowered on perinatal HIV and AIDS in adolescents so that they may know how to handle such issues. Family members need to be empowered so that they can be a strong support to these adolescents, also educating them about this pandemic even in the confines of their own homes.

Perinatal HIV and AIDS also need to be explained to teachers so that they are aware of how to deal with such cases at school, and how to structure their HIV and AIDS education curriculum at school so that they are sensitive to adolescents who are on medication. This education should also be directed to prominent figures like chiefs, village heads, ward councillors and religious leaders as they have great influence in their communities. The social workers in the hospitals, clinics and community has the role to educate everyone involved on HIV and AIDS and ensure people are equipped in disease management of HIV and AIDS.

4.4.2. Educating and empowering caregivers of these adolescents on the pandemic

The study findings revealed that there is a high reliance on the caregiver's views than on what is in the best interest of the adolescents. The same caregivers are not 'coming out clean' to these adolescents concerning their HIV status. Some adolescents are growing up taking medicine every day, unaware of what the medicine does in their bodies. Therefore, it is important that the caregivers of adolescents with perinatal HIV and AIDS are empowered on HIV and AIDS and how they can handle these adolescents. The caregivers also need to be educated on the advantages of disclosing the status to their children so that they are aware of what is happening to them all the time. These caregivers should also be knowledgeable and be in a position to offer the all-round support these young people might need without having to go to the clinic for assistance. In this case, the social workers play a

supportive role on these caregivers by educating as well as offering debriefing and counselling where necessary.

4.4.3. Education on availability of alternative social support

The study findings revealed that these adolescents are not aware of alternative support systems besides the family. If these adolescents and their caregivers could be educated on the availability of schools, peers, the health care system and community support systems, then the burden maybe lessened on them and their caregivers, as they can receive psychosocial support from different sources. In this regard, the social worker plays a role of resource mobiliser, mobilising resources for adolescents with perinatal HIV and AIDS as well as referrals to different service providers.

4.4.4. Provision of support group services

The findings of the study revealed that adolescents with perinatal HIV and AIDS are struggling with issues of disclosure and lack of social support systems. It is recommended that there be a set time for a support group for the adolescents who are HIV-positive. This will help them to share experiences, share fears and strengthen each other as young people facing the same predicament. Formulating and facilitating support groups will also be beneficial to the hospital, as it will also provide good insight on programmes to assist these adolescents. It is also recommended that a support group for caregivers of these adolescents be established. This will assist in sharing ideas, sentiments and strategies on how to deal with and raise this group of adolescents. There is a need for caregivers to understand that they are not alone in raising these young people, therefore seek psychosocial support in this regard. The social worker's role will be in formulating, facilitating and supporting the support groups by providing education and linking the support groups with necessary service providers.

4.4.5 Provide comprehensive education on ART.

The study findings revealed that most participants are less equipped with information concerning their medication. Therefore, it is recommended that these young people be educated on the logistics regarding their treatment. The researcher recommends education on the different medicines that form the ART, their specific names as well

as their functions in the body. This will assist the patients to be involved and to be aware of why they are taking the medication and what role it plays in making them well. This education will also empower patients to share information with others who might need it at home. The social worker plays an educative role in this regard and also encourages other professionals working with these adolescents to be involved in information dissemination. The social worker becomes part of a team involved in education of adolescents with perinatal HIV and AIDS on administration of ART.

4.4.6. Anti-stigma awareness

The findings of this study indicated that stigma and discrimination is a great challenge in the lives of adolescents with perinatal HIV and AIDS. Once these adolescents feel they are being stigmatised, they are likely to feel threatened, presenting different problems in their day-to-day lives. The researcher recommends anti-stigma awareness campaigns to be intensified in a bid to educate and advice the community against stigma and discrimination towards people living with HIV and AIDS. The campaigns should also educate on different ways of contracting HIV and AIDS in-order to smother the association of HIV and AIDS with sexual behaviours hence making people treat children born with HIV and AIDS more fairly. The social workers have a role to set up and facilitate such campaigns, which can reach the communities through various channels like social media, open-air campaigns, fliers and workshops.

4.4.7. Conducting further research

There is still great need to conduct further research on experiences of adolescents with perinatal HIV and AIDS. The study findings revealed that these children growing up with perinatal HIV and AIDS are not surviving in isolation, but rely on the family and significant others. The researcher recommends that future research involve all significant others like the family system; specifically the caregivers of these adolescents, peers, the community, the schools and the health care system, in trying to understand these adolescents better. It is also recommended that these researches be done in different areas and provinces so there can be rich knowledge regarding the experiences of these adolescents as they grow with HIV and AIDS. Such research will help map out intervention strategies for these adolescents as well

as conceptualise the extent of adolescent perinatal HIV in Africa, which literature shows such data has been found to be limited.

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APPENDICES

Appendix 1: SEMI-STRUCTURED INTERVIEW SCHEDULE

Goal of this study

To explore and describe the challenges faced by adolescents with perinatal HIV/AIDS

SECTION A: BIOGRAPHICAL DETAILS OF THE PARTICIPANTS

1. Age :

2. Gender :

Male	
Female	

3. Language

Sepedi	Tswana	Sotho	Tsonga	Venda	English	Afrikaans	Other(specify)

4. Education level

Primary education		Secondary education		Tertiary education		Other(specify)	

5. Number of years being on treatment

< 1 yr		1yr		2yrs		3 yrs		5yrs		6 yrs+	

SECTION B: KNOWLEDGE OF HIV

1. What do you know about perinatal HIV/AIDS?
2. When did you find out about your HIV status?
3. How did you find out?
4. What was your reaction when you found out about your HIV status?

DISCLOSURE

1. Have you disclosed your HIV status to anyone yet?
2. If yes, whom did you disclose to and how long did you take to disclose your status?
3. What was their reaction to the news?
4. How did their reaction make you feel?
5. What prompted you to disclose your status to them?
6. If your answer to 1 is no, why have you not disclosed to anyone?

TREATMENT

1. For how long have you been on treatment?

2. Explain the importance of taking the medication each day as prescribed.
3. What challenges do you experience from taking the medication?
4. What happens when you do not take the medication as prescribed?
5. Are you being assisted with collection and taking of treatment? If so, by who?
6. When do you see yourself taking treatment without supervision?
7. What challenges do you have associated with your treatment?
8. How do you feel about the lifetime treatment?
9. What happens if you do not take medication?

CHALLENGES

1. What are the challenges of having perinatal HIV?
2. Describe how these challenges affect your day-to-day living?
3. How do you deal with the challenges you mentioned above?
4. What are the needs you have as an adolescent with perinatal HIV?
5. How do you feel about yourself?
6. Who are your support systems, in your family and community?

7. How often do you visit the hospital or clinic to collect your treatment?
8. What is the community's attitude towards people with HIV/AIDS?
9. Do you experience stigma or rejection from the community or school regarding your illness?

RECOMMENDATIONS

What are your recommendations regarding provision of adolescent Perinatal HIV health care services in the hospital or clinic?

Appendix 2- Permission from Department of Health



Kuyasheshwal Gauteng Working Better

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

243 Pretorius Street, Cnr. Thabo Sehume & Pretorius Street, Manaka Building, Pretoria 0001 South Africa.
Tel: +27 12 406 0237
Enquiries: Mr. Peter Silwimba.
e-mail: peter.silwimba@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE

CLEARANCE CERTIFICATE

Meeting: N/A

PROJECT NUMBER: 41/2014

Title: Challenges faced by adolescents with perinatal HIV/AIDS
Researcher: Tshuma Sukholulhe
Co-Researcher:
Supervisor: Mr M Chimange
Department: Social Work and Criminology

DECISION OF THE COMMITTEE

Approved

**NB: THIS OFFICE REQUESTED A FULL REPORT ON THE OUTCOME
OF THE RESEARCH DONE**

Date: 18th September 2014

Mr. Peter Silwimba
Chairperson Tshwane Research Committee
Tshwane District

Mr. Pitsi Mothomone
Chief Director: Tshwane District Health
Tshwane District 2014.09.22

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedures as approved by the committee.

Appendix 3: ETHICAL CLERANCE LETTER FROM UNIVERSITY OF PRETORIA



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

3 July 2014

Dear Prof Lombard

Project: The challenges faced by adolescents with perinatal HIV/AIDS
Researcher: S Tshuma
Supervisor: Ms Nj Bila
Department: Social Work and Criminology
Reference number: 12236439

Further to our letter of approval, please note that this approval will be rescinded should the hospital not grant Ms Tshuma permission to conduct the research. Written proof of hospital's approval is therefore required.

Sincerely

Prof. Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karen.harris@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Actign Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergil; Prof GM Spies; Dr Y Spies; Prof E Taljard ; Dr P Wood

Appendix 4: Letter of informed assent

Researcher's name : Tshuma Sukholuhle

Contact details : 0718269948

Email : sukholuhletshuma@yahoo.com

Institution: Department of Social Work and Criminology, University of Pretoria

INFORMED ASSENT

Title of the study: The challenges faced by adolescents with perinatal HIV/AIDS

Purpose of the study: The purpose of the study is to explore the challenges faced by adolescents with perinatal HIV/AIDS.

- 1. Procedure:** I will be requested to take part in a face-to-face interview about my experience of perinatal HIV/AIDS. The interview will take place at the hospital during non-teaching hours and will take approximately 60 minutes. The Clinical Manager has given permission for the interviews to take place at the hospital. The interview will be tape-recorded and Sukholuhle will take notes during the interview. Only Sukholuhle and her supervisor will have the permission to listen to the recordings and read the notes. The recordings and the notes will be handled with strict confidentiality and, at the completion of the research, will be securely stored at the Department of Social Work and Criminology, University of Pretoria, according to the policy of the University.
- 2. Risks:** I understand that the interview will be about my experiences with regards to perinatal HIV/AIDS. There are no foreseen risks related to my participation in this study. However, I realise that this may be a sensitive topic for me. Therefore, if I may experience any emotional distress because of the interview, I will have an opportunity for counselling with a qualified social worker.
- 3. Benefits:** I understand that there are no direct benefits to me for participating in the study. However, my participation will help professional persons to gain better understanding of how adolescents experience perinatal HIV/AIDS.

4. **Participant's rights:** I understand that my participation in the study is voluntary and that I can withdraw at any time with no negative consequences.
5. **Confidentiality:** The information received from me will be treated confidentially and no one will be able to identify me from the study. If I decide to withdraw from the study at any stage, the information from the interview will be destroyed. The results from this study will be published in the researcher's final research report or in a professional journal, but my identity will not be made known.

If I have any concerns, I can contact the supervisor. I understand my rights to voluntarily participate in the study and withdraw at any time. I agree that I willingly participate in the study. I understand what the study is about as well as how and why it is being done. I am aware that the data will be stored for 15 years at the Department of Social Work and Criminology, University of Pretoria, according to policies of the University.

I have received a copy of this consent form.

Participant: -----

Date: -----

Researcher: -----

Date: -----

Appendix 5: Letter of informed consent

Researcher's name : Tshuma Sukholuhle

Contact details : 0718269948

Email : sukholuhletshuma@yahoo.com

Institution: Department of Social Work and Criminology, University of Pretoria

INFORMED CONSENT

Title of the study: The challenges faced by adolescents with perinatal HIV/AIDS

Purpose of the study: The purpose of the study is to explore the challenges faced by adolescents with perinatal HIV/AIDS.

- 1. Procedure:** My child will be requested to take part in a face-to-face interview focusing on his/her experience of perinatal HIV/AIDS. The interview will take place at the hospital during non-teaching hours and will take approximately 60 minutes. This will be done with the permission of the Department of Health and the clinical manager at the hospital. The interview will be tape-recorded and the researcher will take notes during the interview. Only the researcher and her supervisor will have the permission to listen to the recordings and read the notes. The recordings and the notes will be handled with strict confidence and at the completion of the research, will be securely stored at the Department of Social Work and Criminology, University of Pretoria, according to the policy of the University.
- 2. Risks:** I understand that the interview will be about my child's experiences with regards to perinatal HIV/AIDS. There are no foreseen risks related to my child's participation in this study. However, this maybe a sensitive topic and if my child does experience any emotional distress because of the interview, he/she will have an opportunity for counselling with a qualified social worker.

3. **Benefits:** I understand that there are no direct benefits for me or for my child for participating in the study. However, my child's participation will help professionals to gain better understanding of adolescent perinatal HIV/AIDS.
4. **Participant's rights:** I understand that my child's participation in the study is voluntary and that she/he can withdraw at any time with no negative consequences.
5. **Confidentiality:** The information received from my child will be treated confidentially and his/her identity will not be revealed at any stage. Should my child decide to withdraw from the study at any stage, he/she can do so with no negative consequences and information that was obtained from him/her will be destroyed. The results from this study will be published in the researcher's final research report or in a professional journal, but my child's identity will not be made known.

If I have any concerns, I can contact the supervisor. I understand my child's rights as a research participant and I agree that he/she willingly participates in the study. I understand what the study is about as well as how and why it is being done. I am aware that the data will be stored for 15 years at the Department of Social Work and Criminology, University of Pretoria, according to policies of the University.

I have received a copy of this consent form.

Parent: -----

Date: -----

Researcher: -----

Date: -----

Appendix 6: Editor's Letter



Online Editorial Services

17 July, 2015

To whom it may concern

I have over 8 years free-lance experience of editing academic theses for post-graduate students and work-related reports. I confirm that I edited this thesis; *'The challenges faced by adolescents with perinatal HIV/AIDS'* by Sukholuhle Tshuma.

1. I checked compliance with the guidelines which the author provided:

Font: Arial, 12 point

Spacing: 1.5

Language: South Africa English

Thus, the grammar, punctuation and spellings were corrected according to the South African English dictionary in Microsoft Word. Punctuation anomalies were corrected. Suggestions for correction of long and wordy sentences were made as 'comments'. It is the author's discretion to accept or reject those editorial suggestions.

2. I also checked compliance with the Harvard Reference style for in-text and the Reference List. I used the guidelines from the University of Johannesburg and the University of Stellenbosch to correct the referencing inconsistencies which were detected.
3. I also checked the 'flow' in the document, paying particular attention to the sequencing of the sections, paragraphs and sentences. Changes were made where it was appropriate.
4. For the document layout, section headings were defined in order to generate an automatic Table of Contents.

Regards,

Eunice Mwandayi

Tel: 084-593 2014

Email: mwandayie@gmail.com

