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EXPERIENCES OF ADOLESCENTS WITH PERINATALLY ACQUIRED HIV IN THE LIMPOPO PROVINCE

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DECLARATION

I, Ngwashesenge Francinah Malungani,

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declare that:

"EXPERIENCES OFADOLESCENTS WITH PERINATALLY ACQUIRED HIV IN THE LIMPOPO PROVINCE"

is my own unaided work and has not been previously submitted by me or anyone at any other university. All efforts to acknowledge sources used in this study were taken.

Signed

22/10/2018

Date

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ABSTRACT

TITLE: EXPERIENCES OF ADOLESCENTS WITH PERINATALLY ACQUIRED HIV IN LIMPOPO PROVINCE

INTRODUCTION

HIV remains a global health concern despite the efforts by different countries to combat the infection. Perinatally acquired HIV affects a large number of children who are growing into adolescence due to the widespread availability of antiretroviral treatment (ART). Adolescents with perinatal HIV face a high rate of disease burden, health complications, greater need for ART and high mortality rate than those who got infected during adolescence. The duration of HIV in the adolescents' bodies contributes to the long history of HIV complications and social stressors. The adolescents who acquired HIV in their teens are likely to have a higher CD4 cell count and less chances of viral resistance.

PURPOSE

The aim of this study was to explore and describe the experiences of adolescents with perinatally acquired HIV in Limpopo Province.

METHODOLOGY

This was a qualitative study using a descriptive phenomenological approach, which seeks to understand the experiences of the adolescents with perinatal HIV from their own viewpoint. The design allowed the adolescents to describe their experiences as lived, and how they construct meaning of their lives. A sample of 20 adolescents, males and females with acquired perinatal HIV was selected purposefully to participate in the study.

In-depth unstructured individual interviews were used to collect data from the participants, which were audio-recorded with the participants' permission. This was followed by probing questions which obtained a rich, detailed data from the participants. This study utilised Giorgi's method of data analysis and three main themes and subthemes emerged from the study. All steps of Giorgi's method of analysis were employed.

FINDINGS

The study findings revealed the various and difficult challenges that are faced by the adolescents with perinatal HIV throughout their lives. Themes that emerged out of this study were as followed: Acknowledgement of negative effects of perinatally acquired HIV, disclosure of HIV status and distressing and disruptive social effects of HIV.

CONCLUSION

The adolescents with perinatal HIV emerge as a unique part of the society with special health care needs related to them.

KEYWORDS

- Experiences;
- Adolescents;
- Human Immunodeficiency Virus (HIV);
- Acquired Immune Deficiency Syndrome (AIDS);
- Perinatal HIV;
- Antiretroviral Therapy.

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ABBREVIATION	MEANING
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
DoH	Department of Health
HIV	Human Immunodeficiency Virus
NDP	National Development Plan
PHC	Primary Health Care
RDP	Reconstruction Development Programme
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme for HIV and AIDS
WHO	World Health Organisation

CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Perinatally acquired Human Immunodeficiency Virus (HIV) is defined by the World Health Organisation (WHO) as the passage of the virus by the mother to the baby during pregnancy, labour, delivery, and breastfeeding (WHO, 2016). Across the globe, children who acquired HIV and Acquired Immunodeficiency Syndrome (AIDS) perinatally, are estimated at more than 3 million (Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath & Ferrand, 2014:627). Among these children, 90% live in Sub-Saharan Africa (Lowenthal, et al. 2014:627). South Africa alone has approximately 1.3 million children and adolescents who are infected with HIV according to the Department of Health of South Africa (Department of Health (DoH), 2012:9).

A study conducted in Ghana revealed that there were 30 401 children who acquired perinatal HIV in 2011 (Ghana AIDS Commission 2014:15). A large number of children who acquired HIV perinatally survive into adolescence due to the widespread availability of antiretroviral treatment (ART) globally (Mellins & Malee, 2013:1). Many of these adolescents face years of taking medication, parental loss or illness, and numerous psychological and physical concerns that are HIV related (Enmil, Nugent, Amoah, Norman, Antwi, Ocran, et al. 2016:460). Adolescents with perinatally acquired HIV are likely to have a history of HIV complications, less autonomy, more disease burden, and a higher mortality risk than those who acquired HIV in their teens (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2016:12). The newly infected adolescents are likely to have a higher CD4 count, have less chances of viral resistance, and they benefit from simple treatment regimens (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2016:12).

The WHO (2013:26) confirmed that adolescents and young adults who are living with HIV from birth face a number of stressors related to disclosure of their status and discrimination due to the infection. Midtba, Shirima, Skovdal and Daniel (2012:261) added that HIV-related stigma has a more significant impact on the psychological and general health of adolescents and young adults who acquired HIV perinatally, than those who acquired HIV through lifestyle. This is the reason why one of the goals of the National Strategic Plan (2012-2016) of the Republic of South Africa is to reduce the stigma related to HIV and Tuberculosis (TB) by at least 50% (National Strategic Plan on HIV, STI and TB, 2012-2016:12).

Forming and sustaining an intimate relationship with a partner is important at the adolescent stage of development (Greenhalgh, Evangeli, Frize, Foster & Fidler, 2016:283). This proved to be a massive challenge for adolescents with perinatally acquired HIV because they find it hard to disclose their status to their partners due to fear of being rejected. Some of these adolescents will choose to be single, whereas others choose not to disclose or end the relationship if they come across negative attitudes (Greenhalgh, et al. 2016:283).

The WHO (2013:23) recommended strategies to tackle the challenges affecting adolescents living with HIV, which may be of significant benefit to them. This includes community-based approach strategies and healthcare workers receiving training on how to support the adolescents on disclosure of their HIV status to others. The WHO further acknowledged that services tailored for adolescents living with HIV pose a great challenge for most healthcare settings, due to healthcare workers' lack of training on this phenomenon (WHO, 2013:23).

The DoH of South Africa developed some guidelines for healthcare workers with regard to the psychosocial support of children and adolescents infected and affected by HIV. Yet, healthcare workers of South Africa often complain that the workload is too much and they do not have time to manage patients' needs, let alone the additional workload of supporting adolescents with perinatally acquired HIV (DoH, 2012:9).

The South African government has made great progress with regard to HIV treatment programmes. The progress came after a decade of tragic and complex denialism that resulted in severe loss of life for South African citizens. To date, the country has enrolled more than two million people on ART programmes. This is, by far, the largest national antiretroviral programme in the world (Simelela & Venter, 2014:249).

In South Africa, programmes like Primary Health Care (PHC) re-engineering were put in place, which involved the restructuring of services in order to improve and enhance the health of South African citizens. One of the elements of this programme is home and community-based care, where services are provided to patients in their homes. The president of South Africa also launched a programme called “Operation Phakisa”, which seeks to improve and enhance the quality of life of people in the country as rapidly as possible. It was launched in order to implement the National Development Plan (NDP) of the country (Department of Planning, Monitoring and Evaluation, 2014).

1.2 RATIONALE

Adolescence is an integral stage of human development because of the physical and psychological changes in the body. Some adolescents find the stage difficult to cope with. It is a stage where they attempt to develop a sense of self-worth, strive for autonomy and decision-making. The long-term existence of HIV in their bodies may exacerbate the stage-associated stressors. Most research on adolescents with perinatal HIV focused on their educational needs, alleviation of hunger, and biomedical outcomes (Tshuma, 2015:5). Yet, there is evidence that adolescents with perinatally acquired HIV experience psychosocial issues as they progress from adolescence into adulthood (Mellins & Malee, 2013:2). The researcher aimed to come to a deeper understanding of the lived experiences of these adolescents. The rationale behind conducting the study was to discover how the adolescents with perinatal HIV create meaningintheir lives. An understanding of the adolescents’ experiences assisted the researcher to describe the adequacy of the care provided.

1.3 PROBLEM STATEMENT

Being born with HIV and having to live with it may become a serious health concern for adolescents (Mellins & Malee, 2013:2). The long-term existence of HIV infection in the adolescents’ bodies comes with a number of long-term adverse consequences. The social, emotional, and economic effect of HIV was also highlighted by the Department of Health of South Africa (DoH, 2012). According to the report by the Joint United Nations Programme for HIV and AIDS (UNAIDS), the majority of adolescents who are infected with HIV, acquired it perinatally, and this might negatively affect their development (UNAIDS, 2013:6).

This phenomenon of HIV and AIDS has attracted research interest in adolescents and young adults who, according to UNAIDS (2014:17), constitute 29% of the 4 million youth living with HIV. Less attention has been given to those with perinatal HIV. Instead, most of the research has focused on the epidemiology of HIV and AIDS among adolescents (Jena, 2014:2). Mellins and Malee (2013:1) added that the majority of studies that were conducted on adolescents with perinatal HIV had focused primarily on the biomedical outcome, and yet there is increasing evidence that children with perinatal HIV are at risk of mental health problems. A study conducted by Lowenthal, et al. (2014:631) revealed that adolescents and children with perinatal HIV have a higher rate of hospital admissions due to mental health issues like depression, compared to the general adolescent population.

Having acquired HIV perinatally poses a risk of negative psychosocial implications. There are ramifications of hospitalisation, such as missed school days due to hospital visits from recurrent infections. They also miss social opportunities and experience delayed puberty because of the long-term effects of the virus in their bodies (Mellins & Malee, 2013:2). Therefore, there is a pressing need to explore and describe the experiences of adolescents with perinatal HIV so that recommendations can be made for high-quality care beyond specialist level at all healthcare facilities.

1.4 SIGNIFICANCE OF THE PROPOSED STUDY

Adolescence is a critical part of human development as it is a transition from childhood to adulthood. It is a complex stage of life where young people take on new responsibilities and experience independence. This stage can be extremely difficult if it is coupled with the presence of HIV, due to the long-term effects of the virus in the body. The findings of this study might contribute towards the implementation of evidence-based practice in nursing, and will enhance the rendering of high-quality care to adolescents with perinatal HIV because their health needs will be identified and acted upon. Healthcare staff will be empowered on how best to provide care to adolescents with perinatal HIV.

The findings of this study may add value to the body of knowledge of nursing education. It will serve as a basis for future research on the treatment needs of these adolescents. The findings of this study may also contribute towards the development of policies, guidelines, and health promotion strategies for adolescents with perinatally acquired HIV. Therefore, the study is significant as there is a need to explore and describe the experiences of adolescents with perinatally acquired HIV.

1.5 RESEARCH QUESTION

The primary research question in this study was:

What are the experiences of adolescents with perinatally acquired HIV in Limpopo Province?

1.6 PURPOSE

The purpose of the study was to explore and describe the experiences of adolescents with perinatally acquired HIV in the Limpopo Province in order to contextualise the meaning attributed by the adolescents and develop services tailored to their needs based on the findings.

1.7 OBJECTIVE

The objective was to explore and describe the experiences of adolescents with perinatally acquired HIV in Limpopo Province, South Africa.

1.8 CONCEPT CLARIFICATION

Concept clarification defines concepts used in a research report and denotes the characteristics and general theoretical meaning of the concepts (Brink, van der Walt & van Rensburg, 2012:91).

1.8.1 Experiences

Experiences focus on how individuals make meaning of their lives and interpret their world within their given context (Polit & Beck, 2017:466). In this study, experiences relate to how the adolescents with perinatally acquired HIV make meaning of their own lives and how they interpret their world.

1.8.2 Adolescent

The WHO (2016) defines 'adolescence' as the period of human growth and development that occurs after childhood and before adulthood, from ages 10 to 19. In this study, an adolescent was a person from the ages of 18 to 19 with perinatally acquired HIV. This age group is more mature and these adolescents have lived long enough to have experienced the full-term effects of living with perinatally acquired HIV.

1.8.3 HIV

The Human Immunodeficiency Virus (HIV) is a retrovirus that infects cells of the immune system, destroying or impairing their functions. As the infection progresses, the immune system becomes weaker and the person becomes more susceptible to infection (WHO, 2016). In this study, HIV refers to a Human Immunodeficiency Virus that attacks the adolescent's immune system, making it weaker and more susceptible to opportunistic infections.

1.8.4 AIDS

Acquired immune deficiency syndrome (AIDS) is a progression of HIV infection where the immune system becomes weak, and is characterised by the occurrence of more than 20 opportunistic infections and related cancers (WHO, 2016). In this study, AIDS refers to the occurrence of opportunistic infections in the adolescents who acquired HIV infection from their mothers during pregnancy, birth or breastfeeding.

1.8.5 Perinatally acquired HIV

Perinatally acquired HIV, also called mother-to-child-transmission of HIV, occurs when an HIV-positive woman passes HIV to her baby during pregnancy, labour, delivery, or breastfeeding (WHO, 2016). In this study, perinatally acquired HIV, which is also known as vertical transmission, means that HIV was passed on to these adolescents at an early age, either in the uterus, during labour or delivery, or during breastfeeding.

1.9 PARADIGM

A paradigm is an accepted set of beliefs and values that direct a research study (Botma, Greeff, Mulaudzi & Wright, 2015:40). This study was based on the constructivist paradigm which assumes that reality is multiple and subjective and exists within a context of those who lived it. Reality is a result of the participants' social and psychological construction. Polit and Beck (2017:09) stated that constructive studies focus mainly on the human experience as it is lived. This paradigm believes that knowledge is relative and it can only be obtained from the people involved. The paradigm seeks to understand the participants' lived experiences of a particular phenomenon (Polit & Beck, 2017:09). The emphasis is on the fact that human life is dynamic, holistic, and has individual aspects that the researcher is attempting to capture in its entirety. Therefore, the constructivist paradigm was relevant to this study as it seeks to gain a deeper understanding of the experiences of adolescents with perinatal HIV. The emphasis was on how the participants draw meaning in their lives regarding living with HIV. The adolescents with perinatal HIV were a source of information for this study as they are the ones with such lived experience. The paradigm is discussed under the ontological, epistemological, and methodological philosophical assumptions.

1.10 PHILOSOPHICAL ASSUMPTIONS

1.10.1 Ontological assumptions

Ontology is defined as the branch of philosophy dealing with the nature of reality. It is concerned with how the world is viewed (Terre Blanche & Durrheim in Botma, et al. 2015:40). The researcher is a professional nurse who works with adolescents with perinatal HIV on a daily basis. From the researcher’s observations, the reality regarding the phenomenon is that it is difficult to live with HIV and can be worse for adolescents as they are in a transition period from being children to becoming adults. Being born with HIV comes with some challenges that affect them in all aspects of their lives.

1.10.2 Epistemological assumptions

Epistemology is a branch of philosophy that deals with the nature of knowledge (Botma, et al. 2015:40). The epistemological position of the researcher is that detailed and rich data is contained within the adolescents with perinatal HIV. The study allowed the adolescents born with HIV to construct their own knowledge on the phenomenon through the reflection of their own experiences.

1.10.3 Methodological assumptions

Methodology refers to the steps, procedures and strategies for gathering and analysing data in a study (Polit & Beck, 2017:735). Methodology provides guidance and direction for the researcher on the methods to use in order to obtain knowledge (Botma, et al. 2015:41). This was a qualitative study that employed a descriptive phenomenological approach. In-depth, unstructured individual interviews were used to collect data from the participants. Giorgi’s (1985) method of data analysis was employed in this study (Polit & Beck, 2017:540).

1.11 DELINEATION

In this study, the researcher focused only on adolescents aged 18 and 19 years, both males and females, who acquired HIV infection perinatally, and who reside around Waterberg district in Limpopo Province.

1.12 RESEARCH DESIGN AND METHODS

A qualitative, descriptive phenomenological research design was used in this study. The population consisted of all adolescents with perinatally acquired HIV in the Limpopo Province. A purposive sampling technique was employed to select the most suitable participants who fitted the study criteria. Data were collected using in-depth unstructured individual interviews, which were audio-recorded with the participants' permission. Data analysis was done using Giorgi's (1985) method of analysing data. More details are provided in Chapter 2.

1.13 ETHICAL CONSIDERATIONS

This study was approved by the Ethical Clearance Committee of the University of Pretoria. Permission to conduct the study was obtained from the Department of Health in the Limpopo province**.** The following Ethical Principles were adhered to:

1.13.1 Respect for human dignity

This principle implies that human beings are autonomous and possess the right to self-determination and the right to full disclosure (Polit & Beck, 2017:140). In this study, the participants were respected at all times. Full information on what the study entailed was given to the participants so they could decide whether or not to take part in the study. The participants in this study received consent form to sign if they chose to participate (Refer to Annexure B).

1.13.2 Beneficence

The purpose of human research should be the production of benefits to the participants (Polit& Beck, 2017:139). This principle gives the participants the right to freedom from harm and discomfort, as well as the right to protection from exploitation. In this study, all efforts were employed to minimise harm, especially emotional harm, as participants were revisiting their painful past experiences. All the participants in this study were protected from any form of exploitation. A social worker who is based at the facility was on standby in case there was a need for counselling during interview sessions.

1.13.3 Justice

The principle of justice involves the participants' rights to fair treatment and the right to privacy (Polit & Beck, 2017:141).

1.13.4 The right to fair treatment

Fair treatment includes the researcher's ability to keep all the promises that were made at the beginning of the study (Brink, et al.2012:37). The researcher in this study honoured all appointments with the participants as scheduled. Punctuality and time management during interview sessions were observed. All participants in this study were treated equally, fairly, and with respect. The participants were not exploited or manipulated in any way.

1.13.5 The right to privacy

The participants possess the rights to determine the extent to which their personal information will be shared or withheld from others (Polit& Beck, 2017:141). Participants have the right to expect anonymity from the researcher, which refers to keeping the participants' identities a secret (Brink, et al. 2012:37). Participants were recruited without divulging their HIV status to anyone. Confidentiality was ensured at all times. The names of the participants were not used in this study; instead, pseudonyms were used and the list of participants' real names was destroyed.

1.14 ORGANISATION OF THE STUDY

The final structure of this research study is as follows:

CHAPTER 1: Overview of the study.

CHAPTER 2: Research design and methods.

CHAPTER 3: Presentation and discussion of results.

CHAPTER 4: Summary of results, recommendations, limitations and final conclusion.

1.15 CONCLUSION

This chapter highlighted that according to research, adolescents with perinatally acquired HIV face challenges that affect all facets of their lives. Having acquired HIV from birth affected their normal childhood and development, as well as their transition from childhood to adulthood. The purpose of this study was to explore and describe the experiences of adolescents with perinatally acquired HIV in the Limpopo Province. A descriptive phenomenological approach was applied in this study in order to obtain detailed information through unstructured interviews. The study used Giorgi's (1985) method of data analysis and all ethical principles were adhered to throughout this study.

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

This chapter outlines a research methodology that was employed in this study to explore and describe the experiences of adolescents with perinatally acquired HIV in the Limpopo Province. The chapter describes the research design, the context of the study, the population, sampling and the sampling technique used; inclusion criteria, data collection, data analysis, as well as the criteria to ensure trustworthiness that were taken into consideration.

2.2 RESEARCH DESIGN

In this qualitative study, a descriptive phenomenological approach was used. This approach seeks to understand the experiences of the adolescents with perinatally acquired HIV in the Limpopo Province. The design further understood the world from the participants' point of view, where the meaning of their experiences unfolded. Phenomenology is defined by Botma, et al. (2015:190) as a strategy in which the researcher identifies the essence of human experience. Descriptive phenomenology asks questions like "what is it like to experience that?" (Brink, et al. 2012:121).The root of phenomenology in this study understood the phenomenon in the participants' own terms. This was done to provide a description of human experience as it is experienced by the participants themselves, allowing the essence to emerge. In this study, data were collected from the participants using unstructured individual interviews which were audio-recorded with permission from the participants. Participants were interviewed at their respective clinics as planned. The following descriptive phenomenological research processes were adhered to during data collection in this study as outlined in Brink, et al. (2012:122): bracketing, intuiting, analysing, and describing.

2.2.1 Bracketing

Bracketing or reduction is an interactive process whereby the researcher holds back any beliefs and preconceived ideas regarding the phenomenon being studied (Polit & Beck, 2017:471). Bracketing was done to ensure objectivity and transparency. In this study, the researcher put aside any preconceived ideas, beliefs and opinions that might have affected the data regarding the experiences of adolescents with perinatal HIV. The researcher regarded the data in its own context. Essentially, the researcher achieved bracketing through the use of a reflective journal by way of preparing, evaluating, and providing organised feedback from the participants, while she also noted her own opinions on the study phenomenon.

2.2.2 Intuiting

The researcher developed an awareness of the lived experiences of the participants. The researcher remained totally immersed and open regarding the meaning related to the phenomenon by those who experienced it (Polit & Beck, 2017:472). In this study, the researcher was open to the meaning that participants attached to the phenomenon. Participants were requested to elaborate on the information that they were providing regarding their experiences. Individual participants described their feelings in their own respective ways.

2.2.3 Analysing

Analysing involves identification of the essence of a phenomenon that will be investigated, as well as how data will be obtained and presented (Streubert & Carpenter, 2011:81). In this process, the researcher repeatedly reviews all the data until there is a common understanding. Data were analysed so that the essence and the constituents of the phenomenon being studied could be understood. The essence represents and reflects the whole phenomenon. It made the phenomenon what it was (Polit & Beck, 2017:472). As the participants described their experiences to the researcher, the essence of the phenomenon as a whole gradually emerged.

2.2.4 Describing

The researcher communicated the description and critical elements of the phenomenon to be studied (Streubert & Carpenter, 2011:82). A detailed description of adolescents' experiences of living with perinatally acquired HIV was presented in this study. This phase occurred at the point where the researcher came to the full understanding and definition of the phenomenon (Polit& Beck, 2017:472). At the end of each individual interview, the researcher came to a full understanding of what it is like to be born and live with HIV as an adolescent.

2.3 RESEARCH METHODS

2.3.1 Context

A context or study setting refers to the place where data collection takes place. This study of exploring the experiences of adolescents with perinatally acquired HIV was conducted in Waterberg district in Limpopo Province of South Africa. The data collection was conducted at different clinics in the district. The local area consists of 10 clinics serving 19 000 population (Mapela local area, 2017). It is situated 20 kilometres away from Mokopane Hospital, which is a referral hospital.

2.3.2 Population

The population is defined as a complete set of persons or objects that possess some common characteristics that are of interest to the researcher (Brink, et al. 2012:216). In this study, the population was represented by all adolescents who acquired HIV from birth who are currently residing in Limpopo Province.

2.3.3 Sampling and selection of participants

Sampling refers to the selection of participants from the entire population to obtain the information about the phenomenon (Brink, et al. 2012:132). Purposive, non-probability sampling was used in this study to select the most appropriate sample, and access key individuals who had the potential to provide rich sources of data. The researcher accessed the participants from the database of the relevant primary healthcare facility after permission to conduct the study was granted by the Department of Health. The researcher went through the records of the participants and avoided participants with mental health issues to avoid exacerbating their conditions. The researcher liaised with the staff at the facilities to inform them of the purpose of the study and to gain their co-operation. The social workers and councillors based at the different clinics were informed of the interview sessions to be held at their clinics. This was done so that they could provide appropriate counselling to participants who became emotional during the sessions.

The researcher was familiar with the programmes at the local area clinics. The selection of participants who fitted the criteria was done without divulging their HIV status because the researcher was in her usual nursing uniform, issuing medications to all patients with chronic conditions without segregation. All chronic medications were issued in one room as usual, which facilitated the selection of participants without segregation. Privacy and confidentiality were maintained during the recruitment process. The selection of the participants was treated like an ordinary day for participants. Participants were informed of voluntary participation in the study and the right to withdraw from the study at any time. All the risks and benefits were communicated to the participants. No information was withheld from the prospective participants, so they made an informed decision.

2.4 INCLUSION CRITERIA

Participants in this study were expected to fit into the set criteria. Twenty adolescents aged 18 to 19 years were selected because they were mature and had lived long enough to have experienced the full effects of living with perinatally acquired HIV. Both males and females were included in the study. Those whose healthcare records showed that they started taking anti-retroviral drugs from birth or at a young age were selected. These participants resided around in Waterberg district. They had to be willing to sign a consent form voluntarily. The participants had to be able to speak English or Sepedi fluently as the researcher is fluent in those languages.

2.5 EXCLUSION CRITERIA

Participants who were excluded in the study were the following: those who acquired HIV during their teens, adolescents who were not aware of their HIV status, adolescents who lived outside Waterberg district, participants who were unable to speak English or Sepedi and those who were not willing to sign a consent form to participate.

2.6 DATA COLLECTION

In this study, data were collected directly from participants using in-depth individual interviews which were also referred to as unstructured interviews. This technique allowed the researcher to ask a broad question and still be able to probe further to obtain more detailed information (Brink, et al. 2012:158).

On the day of data collection, the venue was organised to be free from threats. The counselling room at their respective facilities was used, as participants were familiar with the surroundings. The purpose of the study was communicated to the participants during their first contact. The researcher established a rapport with the participants to make them feel at ease. The broad question that was asked was: *How has it been living with perinatal HIV; may you please share your experiences with me?* The researcher was able to probe further in order to obtain more detailed information from the participants. Probes also allowed the participants to elaborate on the topic (Brink, et al. 2015:158). Subsequent probing questions were guided by the participants' responses (Polit & Beck, 2017:280). The researcher also employed observations, paraphrasing, listening skills, as well as seeking clarity by requesting that the participants elaborate on certain issues. A total number of 20 participants were interviewed. The naïve description of the participants was taken in a natural attitude as narrated by the participants. An additional data collection method used by the researcher was the taking of field notes to include data that was not recordable. The participants signed the consent form before they took part in the study and the interviews were audio-recorded with their permission. By audio-recording the interviews, the researcher had the opportunity to pay full attention to the participants' responses and to observe any non-verbal cues and behaviours. The participants were engaged for a period of 30 minutes to an hour until saturation was reached.

The social workers and councillors at the respective clinics were made aware of the interviews in order to provide counselling if necessary. At the end of the interviews, the participants were thanked for their participation.

2.7 PILOT STUDY

A pilot study is a small-scale version or a trial study which is conducted prior to the main study (Polit & Beck, 2017:624). A pilot study was conducted with two participants who fitted the criteria of this study. The pilot study enabled the researcher to acknowledge that it was not easy for the participants to talk openly about their HIV status. Therefore, the researcher ensured that the participants were more relaxed during the interviews due to the sensitivity of the topic. This was done by establishing rapport and ensuring that the interview was as private as possible. Confidentiality was maintained throughout the research study.

The pilot study also encouraged the researcher to do more probing as the participants were ashamed to talk about their conditions.

2.8 DATA ANALYSIS

Polit and Beck (2017:725) define data analysis as the organisation and synthesis of research data. Giorgi's (1985 in Polit & Beck, 2017:540) method of data analysis was used in this study.

2.8.1 Reading the data

All data was repeatedly read in order for the researcher to familiarise herself with it and to make sense of the whole (Polit & Beck, 2017:540). All the audio-recorded interviews underwent verbatim transcription. The naïve description of the participants was taken in a natural attitude as narrated by the participants. At the end of this step, the researcher was familiar with the data as narrated by the participants.

2.8.2 Discrimination of units from participants' description of the phenomenon

After reading all the transcripts, the researcher attended to the individual description of the phenomenon to extract significant statements. Each description was broken down into separate units. This was done so that the data could be dealt with in more manageable portions. Different meanings within the data were marked (Polit & Beck, 2017:540). The researcher was not forced to commit to the initial discrimination of the units. It was acceptable to combine or divide meaning units and place them where they are most appropriate and suitable.

2.8.3 Articulating the psychological insights in each of the meaning units

Each unit was then transformed from the language in which it was spoken, into a 'psychologically sensitive' meaning. This was based on the individual experience of the participant. In this where data were changed into an analytic process. It was the process where data were placed into identified units according to its meaning. In some instances, new information emerged and required a new unit to be formed (Polit & Beck, 2017:540).

2.8.4 Synthesising of all the transformed meaning units into a consistent statement regarding the participants' experiences

During this stage the synthesis of the psychological structure of the experiences took place. It could be expressed on a general or specific level. The final structure served as an ideal representation of the phenomenon being studied (Polit & Beck, 2017:540); it was the outcome of the entire analysis.

2.9 TRUSTWORTHINESS

The trustworthiness of this study was ensured by employing the five criteria of trustworthiness as outlined by Lincoln and Guba (1985 in Polit & Beck, 2017:559). These are credibility, dependability, confirmability, transferability, and authenticity.

2.9.1 Credibility

Botma, et al. (2015:233) refers to credibility as truth-value. The findings of the study are credible if they reflect the experience and perceptions of participants (Moule & Goodman, 2014:455). In this study, credibility was ensured by prolonged engagement, persistent observation, and triangulation. The participants in this study were engaged in data collection for a period of four months. Prolonged engagement was essential in establishing a rapport and trust between the researcher and the participants (Polit & Beck, 2017:559). Credibility was also ensured in this study by using persistent observation of the participants' behaviour and non-verbal cues during the interview process. Triangulation was attained using different data collecting methods. These included individual unstructured interviews, which were audio-recorded and supplemented with field notes of non-verbal behaviour which could not be recorded.

2.9.2 Dependability

Dependability criteria refer to the stability (reliability) of data over time and conditions (Polit & Beck, 2017:559). The dependability question would be whether it is possible to get the same results if the study was to be conducted again with the same participants at the same study setting. In this study, the consistency of the data collected from the study participants was ensured. Processes such as bracketing and reflexivity were used to ensure dependability (Polit & Beck, 2017:471). The researcher was able to collect detailed, rich data by using unstructured individual interviews.

2.9.3 Confirmability

Confirmability refers to the objectivity that is the potential for congruence between two or more independent people about the data accuracy, relevance or meaning (Polit & Beck, 2017:559). The raw data collected will be kept as evidence that the study has indeed taken place. In this study, all data provided is traceable to its original source. The process of synthesising the data to reach conclusions is available for verification.

2.9.4 Transferability

Transferability refers to the potential possibility for the data to be used in another setting or with other groups. It is the ability to generalise from the findings to the larger populations (Botma, et al. 2015:233). In this study, a rich description of data was kept safe in order to permit replication. The data is in a sufficiently detailed form to attract its use in other similar contexts.

2.9.5 Authenticity

Authenticity refers to the extent to which the researcher fairly and faithfully shows a range of realities (Brink, et al. 2012:127). It is revealed in a report as it conveys the feeling tone of the participants. This study was made authentic by describing, in detail, the feelings, emotions and experiences of adolescents with perinatally acquired HIV using their own description as lived experiences.

2.10 CONCLUSION

This chapter highlighted descriptive phenomenology as a research design that was used. The population were all the adolescents with perinatal HIV in the Limpopo Province. A purposive, non-probability sampling method was used to select the appropriate sample. Data collection took place through the use of unstructured individual interviews which were audio-recorded with the participants' permission. All the steps of Giorgi's data analysis method were employed in this study. The five criteria of trustworthiness as outlined by Lincoln and Guba (1985) were also followed. The next chapter will focus on the empirical findings of this research study.

CHAPTER 3

PRESENTATION AND DISCUSSION OF RESULTS

3.1 INTRODUCTION

The previous chapter addressed the methodology of the study. The focus of this chapter is the findings from the interviews conducted with the adolescents with perinatally acquired HIV regarding their lived experiences.

This study employed a qualitative, descriptive phenomenological design. Twenty participants were interviewed. The participants were purposively selected and fitted the selection criteria. Data were collected using unstructured individual interviews in order to obtain more detailed information. All the steps of Giorgi's 'method of data analysis' were adopted in this study.

3.2 BIOGRAPHIC DATA OF PARTICIPANTS

Twenty participants who met the inclusion criteria in Limpopo Province (males and females) were interviewed in this study. No new information emerged after the twenty interviews were conducted. All participants were African in origin and aged 18 to19 years. All participants were still in high school, and some were in the lower grades as a result of having repeated some grades. They all lived with extended families, mostly due to orphan hood related to HIV. Each of the participants' biographic information was summarised below. No names were mentioned in this biographical information for the protection of the participants' identities.

Participant No 1

Participant no 1 was an 18-year-old female who was living with her grandparents, mother, little brother, aunt, and her cousin. She did not know the identity or whereabouts of her father. She was currently in Grade 10. She repeated Grades 8 and 9 due to ill health. She did not remember when she was diagnosed with HIV but she remembers that it was when she was very young. She was sick and was taken to the clinic by her grandmother. She was tested for HIV and was told that she was infected. There was no one who was employed at home. They relied on a child support grant for her, her sibling, and her little cousin.

Participant No 2

Participant no 2 was an 18-year-old male who was currently in high school doing Grade 8. He was an orphan who lost his mother while he was still a baby. He only had pictures of his mother as shown to him by his grandmother who was currently looking after him. His grandmother told him that his mother died because she was very sick. His HIV status was disclosed by a doctor at the hospital he attended because he was suffering from TB. He did not have any siblings. He lived with his grandmother, his uncle and his uncle's wife. The only person who was employed as a domestic worker was his uncle's wife. They relied on the grandmother's pension money and the child support grant for him.

Participant No 3

Participant no 3 was an 18-year-old male who was in high school in Grade 8. He also repeated Grade 8 due to being recurrently sick. The participant was orphaned when he was still a very small baby. He had no recollection of his mother. He did not know his father or his whereabouts. He lived with his two aunts, their children, and his uncle. He did not have any siblings. The only member of his family who was employed was his uncle. The rest of the family relied on the child support grant of the children in the house. The participant was informed of his HIV status when he was 8 years old, during a severe case of TB. He was taken to the hospital where he had an HIV test, and was informed that it was positive.

Participant No 4

This participant was an 18-year-old female who was in high in Grade 10. She had one sibling and lived with her mother who was employed as a domestic worker, together with her two aunts and their children. Both of her aunts were employed. The participant's HIV status was disclosed to her by her mother when she was 13 years old. Her mother told her that she was born with HIV and that was the reason why she was taking medication on a daily basis.

Participant No 5

Participant no 5 was an 18-year-old female who was orphaned by AIDS when she was 8 years old. She expected her mother to be discharged from the hospital but she died just before she could be released from the hospital. The participant completed Grade 12 the previous year, but she did not pass it very well. She was planning to upgrade her Grade 12 in the coming year. She did not have any siblings. She lived with her grandmother and her aunt who had two children. No one was employed in their household. They relied solely on the grandmother’s old age pension and the child support grant of her aunt’s children.

Participant No 6

This participant was an 18-year-old male who was in high school in Grade 10. He was an orphan who was still angry and blaming his deceased mother for passing the virus onto him. He found out about his HIV status when he was 7 years old. He was told by his mother’s sister at home, but he did not really understand the implications of having HIV. His testing and disclosure were preceded by sickness as he was taken to the hospital. He lived with his grandmother, his aunt, his sister and his aunt’s two children. Their financial support was from the government in the form of social grants.

Participant No 7

Participant no 7 was a 19-year-old female who lived with her maternal grandmother and her aunt. She was in high school doing Grade 10. She repeated both Grades 9 and 10. She had been taking medications ever since she could remember. She could recall her grandmother giving her medications on a daily basis, and she only discovered that the medications she had been taking all this time were for HIV when she was 9 years old. She was informed by a counsellor at the hospital. She was also informed by her grandmother to keep it a secret. Her mother died when she was 2 months old.

Participant No 8

Participant no 8 was an 18-year-old male who was living with his maternal aunt and her 3 children, as well as his grandmother. The participant's mother died when he was very young. He does not remember how old he was at the time. He started taking medications in 2009 when he was 10 years old. His HIV status was disclosed to him by the doctor at the hospital where he was admitted with some severe illness. He does not remember what illness he had at the time. He was in Grade 9, which he was repeating due to his inability to attend classes regularly.

Participant No 9

Participant no 9 was an 18-year-old female residing in one of the villages in Waterberg district. She was a high school student doing Grade 11. She was an orphan, who lived with her grandmother and her 3 older siblings. She was the youngest of the four children. Her mother died when she was 5 years old. She was informed of her HIV status at the age of 16 by the nurse at the clinic, because her grandmother was feeling uncomfortable to disclose her HIV status to her.

Participant No 10

Participant no 10 was an 18-year-old female who lived with her twin sister, her grandmother, and her maternal aunt who had three children. She was in high school doing Grade 11. Her mother died when she was still young and she was looked after by her grandmother and her aunt. Her father was living in another province and he was married to another woman. He has not contacted the participant or her twin sister in a long time. She found out about her HIV status when she was in Grade 7 when she was informed by the nurse at the mobile clinic.

Participant No 11

This participant was an18-year-old female who had a twin sister who was also HIV positive. She lived with her grandmother and her maternal aunt who had three children. She was in Grade 11. Her mother died when she was still young. Her HIV status was disclosed to her by a nurse at the mobile clinic where her twin sister was treated for minor ailments. After a positive HIV test of her twin sister, she was also tested, even though there was nothing wrong with her at the time. She also tested HIV positive.

Participant No 12

Participant no 12 was an 18-year-old male whose parents died when he was 1year and 3 months old. He was in Grade 9, and had failed two grades in high school. His maternal grandmother rejected him and abandoned him on the day of his mother's funeral because he was a sickly child. He was adopted by his paternal grandparents and was still living with them at the time of the interview. He had been taking HIV medications all this time, but he was told that it was to treat TB because his grandparents were reluctant to tell him due to fear of how he would react. He only discovered that he was HIV positive in 2017. He was told by a nurse who informed him that she was also HIV positive.

Participant No 13

Participant no 13 was an 18-year-old female who was in Grade 11 at one of the high schools in her village. She was the youngest of two siblings. She is currently living with her mother; her brother is at a tertiary institution. Her father passed away in 2006. She was informed about her HIV status by her mother, but she did not believe her. She eventually confirmed her status at the hospital.

Participant No 14

This participant was an 18-year-old male who was orphaned, and does not know the whereabouts of his father. He was living with his aunt who was taking care of him. He was an only child. He was attending high school doing Grade 10. He did not really remember his mother as the only person who has always been around was his maternal aunt. His HIV status was disclosed to him by the health staff at the hospital where he was admitted with a chest infection.

Participant No 15

Participant no 15 was a 19-year-old female who was a Grade 11 student. She was living with her elderly maternal grandmother who was unable to look after herself due to old age. The participant was actually looking after her grandmother as her mother passed away when she was still very young. She had always been looked after by her grandmother. Disclosure of her HIV status was done by her grandmother, who has been supportive ever since the participant can remember.

Participant No 16

This participant was an 18-year-old female who was living with her sibling who was 13 years old in an RDP house in one of the villages not far from the local clinic. The participant lived with different members of her extended family, until she decided that she was old enough to stay in her mother's house and look after her sibling. The participant lost her mother when she was 7years old, and does not know her father. She was in high school doing Grade 11. The participant was informed of her HIV status by a nurse at the clinic when she was 14 years old. Her case is different because her HIV disclosure was not preceded by any sickness. She was informed of her HIV status when she went to the clinic for reproductive health services.

Participant No 17

Participant no 17 was an 18-year-old male who was in high school doing Grade 10. The participant was living with his grandmother, his aunt, and her 2 children. His mother was living elsewhere, but in the same village. He does not know the whereabouts of his father as he was not in his life. He remembered taking antiretroviral medications since the age of 10 years. The participant accidentally discovered his HIV status by reading the information in his medical file. He was shocked and confronted his mother when he got home. She confirmed that he was born with HIV.

Participant No 18

This participant was an 18-year-old male who was an orphan. He was living with his uncle and his uncle's wife. He had a sibling who was also on ART. The participant was doing Grade 8 for the third time. The disclosure of his HIV status was done by his uncle at home. The participant was not compliant with the treatment prescribed to him and he disregarded his clinic appointments several times. The importance of adhering to ART was emphasised.

Participant No 19

This participant was an 18-year-old male who was living with his grandparents and uncle in an RDP house at the village. His mother was working in another province. The participant was in high school doing Grade 8, and he reported that he was in that grade because he could not go to school regularly due to being ill. Both his grandmother and mother were on the same treatment. His HIV status was disclosed to him by his mother who explained to him that he was born with the virus. The participant was aware of his father's whereabouts, but reported that since childhood he never took care of him.

Participant No 20

Participant no 20 was a 19-year-old male student in Grade 11, which he was repeating that year. He was diagnosed as having HIV at the clinic where he went for a consultation at the age of 16. His disclosure was preceded by illness. He was living with his mother, his two sisters, and his nephew. His mother had been in denial about his status for a long time and he had been getting support from his sister. The participant moved to another province, but he is still getting his treatment at the original clinic where he was diagnosed.

3.3 DISCUSSION OF RESULTS

Three main themes and subthemes emerged from the analysed data collected from the 20 participants who were interviewed in this study. All quotes in this chapter were from the participants. A summary of the themes and subthemes are presented in Table 3.1.

TABLE 3.1: SUMMARY OF THEMES AND SUBTHEMES OF ADOLESCENTS' EXPERIENCES OF LIVING WITH PERINATALLY ACQUIRED HIV IN THE LIMPOPO PROVINCE

THEMES	SUBTHEMES
1. Acknowledgement of negative effects of perinatally acquired HIV	• Recurrent sickness • Fear of dying • Treatment adherence
2. Disclosure of HIV status	• Learning of own HIV status • Fear of disclosing HIV status • HIV/AIDS stigma • Avoiding sexual relations
3. Distressing and disruptive social effects of HIV	• Orphan hood leading to poverty • School attendance disruptions • Social / Family support

3.3.1Theme 1: Acknowledgement of negative effects of perinatally acquired HIV

All the participants who took part in this study acknowledged that having acquired HIV perinatally had a negative impact on their lives. They all experienced some life challenges associated with the presence of HIV in their bodies. Generally, perinatally acquired HIV affected them in all aspects of their lives, including physically, socially and psychologically. This was confirmed by Persson and Newman (2012:658) who described adolescents with perinatally acquired HIV as youth living with a condition that has been historically difficult to treat. These adolescents are facing multiple challenges including physical complications related to their HIV infection, medications, as well as impaired neurocognitive development. Under this theme, three subthemes emerged, namely: recurrent sickness, fear of dying, and treatment adherence.

3.3.1.1 Recurrent sickness

All participants in this study experienced recurrent episodes of illnesses associated with HIV infection, ranging from moderate to severe. The majority of participants recalled being diagnosed with TB at some point in their lives. The participants alluded that being born with HIV has caused many health problems for them. Some participants reported multiple hospital admissions, as well as clinic visits. They also acknowledged that their childhood was disrupted by recurrent illnesses.

> *“I do not remember some of the details of my sickness but I was always very sick and has been hospitalised too many times I lost count”* (Participant no 2).

> *“My body was aching and I had Flu too many times, at some point I was diagnosed with TB and one time I was so sick that I could not even walk”* (Participant no 1).

> *“It was at the time when I was very sick when I was coughing up blood and then my aunt took me to the hospital where they told us that I had a severe case of TB and they also tested HIV and told us that it was positive”* (Participant no 3).

> *“I was suffering from TB and then they decided to test me for HIV as well and that is how they found out that I was having it as well. So the doctor at the hospital told me that I have HIV”* (Participant no 17).

"I have been sick for as long as I remember" (Participant no 15).

Participants in this study mentioned that as a result of being born with HIV, their health and childhood were greatly disrupted. They all experienced recurring illnesses and multiple hospitalisations, compared to their age group counterparts. These claims are supported by the findings reported by Mellins and Malee (2013:1) and Persson and Newman (2012:658), who indicated that adolescents coping with HIV from birth face ongoing treatments and its effects, as well as multiple hospitalisations due to recurrent illnesses associated with HIV infection. In addition, it was emphasised that longstanding HIV infection, which was acquired when the immune system was not yet developed, results in severe chronic health complications.

Lowenthal, et al. (2014:5) also confirmed in their study that adolescents with perinatally acquired HIV suffer the additional burden of chronic health complications. Ferrand, Bandason, Musvaire, Larke and Nathoo (2010:5) further reiterated that health complications like lung and cardiac diseases were among the causes of increased risk of hospitalisations and hospital-related deaths in adolescents with perinatally acquired HIV. These findings were also supported by Weber, Gie and Cotton (2013:2), who highlighted that the prevalence of chronic lung disease is increasing in adolescents with perinatal HIV. The authors further reiterated that the heavy burden of chronic complications is severe due to immunosuppression.

Lowenthal,et al. (2014:5) revealed that adolescents with perinatal HIV are at high risk of TB infection and disease due to immunosuppression and widening of social contact during teenage years. They further noted that the burden of TB in adolescents with perinatal HIV might be underestimated because there has been an increased report on longstanding chronic respiratory symptoms. Moreira-Silva, Zandonade and Espinosa (2015:10) also agreed that there is an increased rate of morbidity and mortality in adolescents with perinatal HIV. The study also acknowledged that the infection in this group is always in severe form. Recommendations were made to monitor these adolescents to promote their quality of life and survival time.

3.3.1.2 Fear of dying

The participants in this study depicted that as soon as they were told of their HIV status, they all thought they were about to die. This was due to countless lives being claimed by HIV-related conditions since its emergence. These participants expressed that death was always on their minds as a result of having HIV in their bodies. Having to take daily medications also reminded them of their HIV status and death.

There is no denying that fear of death remains a front-line barrier for effective and complete treatment of HIV-related diseases among infected children and adolescents. This singular challenge stems from their limited knowledge about the disease. The same reason is responsible for them holding on to the belief that HIV/AIDS is a terminal disease. They tend to justify this stance by claiming that despite the increased availability of highly effective ART, many people lose their lives to HIV/AIDS. These beliefs form the basis of their fear of dying.

> *"I was just confused and wondering how that was possible, I thought I would not be able to get home alive, I thought I would go home inside a coffin being dead"* (Participant no 2).

> *"I was so afraid that I thought I was going to die at a young age. I thought that was the end of it all, because I have heard people say people with HIV die prematurely"* (Participant no 1).

> *"It is because anyone can die at any time but the situation is worse when one is HIV positive"* (Participant no 3).

> *"When they told me that I had HIV, I was afraid because I thought that I could die at any time."* (Participant no 13).

> *"Well..., I was crying because I was scared and wondering on how I got HIV, since I am still little and I do not know anything about boyfriends and all those things. And got me wondering if I am going to die, then I started crying since I was so scared, I don't want to die I still want to live just had to accept that I will live with* it *forever"*(Participant no 5).

It is clear that participants associated HIV with death because they heard a lot of stories from people about HIV claiming lives. This factor remained real in their lives because some of them lost their parents to HIV. They all displayed signs of fear and anguish when they talked about dying. As a result, the participants regarded death as inevitable, and there seemed to be no escape route for them.

A study conducted by Madiba and Mokgatle (2016:4) confirmed that adolescents with perinatally acquired HIV found it very hurtful and shocking when their HIV status was disclosed to them. They thought they were going to die and also felt like dying at the time of disclosure. These findings concur with the research study conducted by Hogwood, Campbell and Butler (2012:52), which highlighted that some adolescents who were born with HIV felt that having to live with HIV was equivalent to death. The study further revealed that the media is aggravating the fear of death associated with HIV as mortality statistics associated with HIV is constantly displayed.

Lichtenstein, Rogers, Marefka, Hindson, Cook-Heard, Rygiel, et al. (2017:13) also affirmed these findings by acknowledging in their study that HIV-positive adolescents were faced with a fear of dying. The study further revealed that there is a need for counselling for the adolescents living with HIV regarding fear of death as a result of the infection.

3.3.1.3 Treatment adherence

The participants in this study declared that having to take medications on a daily basis wears them down at times. The majority of participants confessed that they had been non-compliant with treatment at some point in their lives, particularly at the beginning of their treatment. The majority of the participants in this study have accepted their HIV status and were now adhering to treatment.

> "*It was very hard at the beginning because they were making me dizzy and I was vomiting and that was the reason why I was not taking them, I would pretend to take them and hide them in my hand and then go out and dig a little hole and throw them out"*(Participant no 3).
>
> "*Well...... when I started taking medication, I was taking two tablets and took them out and I would just stare at them and I asked myself that do I really have to take this? Ok, and I would just take them but they would get stuck in my throat and I would find it hard to swallow them*

> *but I told myself that I have to take these things, then I would just drink water then they would go, it was not that bad really but even up to now when I think of taking them (madi aka anotshaba) because I think oooh!!, here comes the pill"* (Participant no 5).

> *"Mmmm, I was sad and wanted to be like other girls, not taking medications everyday but only taking medications when I am sick, just a little illness and not taking it every day, sometimes I would just cry like and ask myself why do I have to take this thingseveryday, why can't I get a break? But there is no break, taking a break will only bring myself backwards, I might get sick of I might even die in the process so I would tell myself No!!, I don't have to do this to myself, I must take care of myself. This is what I am and there is nothing I can do about it other than taking my medications"* (Participant no 15).

> *"I do not like taking medications because sometimes it disturbs me since no one knows about my status except my family". I cannot leave my house to sleepover at anyone's house because people will see me taking medications and they will start asking questions"* (Participant no 12).

One participant in this study was still not complying with the treatment prescribed. He was still harbouring anger towards his deceased mother for infecting him with HIV. He felt that it was her fault for getting infected and he blamed her for passing it on to him. This participant failed to honour clinic appointments and defaulted a few times. He received continuous counselling services at the clinic. These findings are similar to the study findings by Jena (2014:59), who highlighted that when disclosure of HIV status took place, some participants reacted in anger for getting infected. They felt that their mothers must have been careless with their lives for them to get infected.

> *"I don't understand why I should be taking medications for the rest of my life because of someone else, this is nothing to do with me!! (referring to the mother, participant displayed signs of anger towards the deceased mother who passed the virus to him). I got to a point where I got tired of taking medications especially because I take them twice a day, sometimes I just stare at them"*(Participant no 6).

Adolescence is a critical and sensitive stage of development, characterised by a high surging of hormones which bring changes in this population group. It gets more complicated if it is accompanied by a highly stigmatised infection like HIV. Treatment adherence is challenging for adolescents with perinatally acquired HIV because at this stage they want to fit in with their peers (Agwu & Fairlie, 2013:2). This was also supported by Fick, Fairlie, Moultrie, Woollett, Pahad, Thompson, et al. (2015:147), who stated that the adolescents with perinatally acquired HIV are a special and unique group of the population with different needs from others. This is purely because the stage is associated with an increased need for experimentation, independence, rebelliousness, defiance against authority, as well as emotional changes like anxiety, moodiness, insecurities, and overconfidence at times. Factors such as denial, and fear of stigma and discrimination may negatively impact their adherence to treatment.

A report by Slogrove, Mahy, Armstrong and Davies (2017:12) described the need for adolescent-friendly services in order to retain them in care and continuing with treatment. Adolescents are in a vulnerable position because they are in a state of transition from child health services to the adult services. The authors highlighted that these adolescents are too old for paediatrics and too young for adult health services, thus they fall through the cracks at a time when they need the health workers’ attention.

The stigma attached to HIV contribute towards poor adherence to treatment where adolescents would miss their doses to avoid disclosure. These findings concur with Madiba and Mokgatle’s (2016:2) study, which highlighted that disclosure, gives meaning to adherence, as knowing about their HIV status is the main contributing factor towards adherence. The study revealed that participants desire a healthy life and would like to stay alive; this is the reason for ensuring that they take their treatment regularly. Some of the adolescents with perinatally acquired HIV acknowledged and appreciated the availability of antiretroviral drugs as they feel that it keeps them alive.

3.3.2 Theme 2: Disclosure of HIV status

Participants in this study found it difficult to cope when they learned that they were born with HIV in their bodies. They expressed feelings of sadness, anxiety, and fear related to HIV. All participants in this study alluded that self-disclosure is a difficult, if not impossible, task. None of them disclosed their HIV status to anyone outside their family structure. This tends to affect some aspects of their lives as they find it hard to live with the secret, and to ensure that it is kept a secret. Their freedom becomes constrained. Four subthemes emerged from this theme namely: learning of own HIV status, fear to disclose HIV status, HIV/AIDS stigma, and avoiding sexual relations.

3.3.2.1 Learning of own HIV status

Disclosure of HIV statuses to children is necessary, according to the Children's Act of South Africa (Act no 38 of 2005). The Act recognises the rights of children to participate in the decisions affecting their healthcare, and the right to privacy about the disclosure of their own status.

All participants in this study described negative feelings after they were informed of their HIV status. They were all afraid, confused, and were having thoughts of death which seemed imminent. Their HIV status was disclosed to them at a time when they were sick, which instilled and aggravated the fear of death in the participants.

> *"I was so afraid that I thought I was going to die at a young age. I thought that was the end of it all."*(Participant no 1).

> *"I was just confused and wondering how that was possible" I thought I would not be able to go home alive, I thought I would go home inside a coffin being dead"* (Participant no 2).

> *"I was only 14 and they told me that I am HIV positive, I was like... (shocked expression) HIV positive? I started crying and asking myself how I got it, I am just 14 and they explained that I got it through the mother-to-child-transmission"* (Participant no 11).

> *"And they also told me that my mother was also HIV positive and died from it. And since then I have been taking my medications but it was kind of weird since I thought I was normal just like other girls, my life just changed I had to come back to being this person I don't know, I had to take medication at 7, so I had to wake up early in the morning and get some to eat so that I can take my medications, but it was kind of weird until I accepted that I am HIV positive"* (Participant no 12).

Participant no 4 became very angry when he was told about his HIV status andhe blamed his deceased mother for infecting him. At the time of the interview he had not recovered from that state. He had not accepted his HIV status, and was not compliant with treatment. He was receiving continuous counselling.

> *"I am very angry with my mother (even if she is dead) for infecting me with this virus, I do not like the fact that I have to take medications for the rest of my life because of her carelessness, I am not impressed at all"* (Participant no 4).

Participants in this study narrated that they experienced a range of feelings when disclosure of their HIV status took place. They experienced feelings of pain, sadness, anger, fear, shock and disbelief. Some had a fear of death which was aggravated by their disclosure being preceded by sickness at the time.

Jena (2014:59) affirmed this finding in her study where participants displayed some anger and blaming attitudes towards their biological parents for infecting them with the virus. This is also consistent with the findings by Joshi, Mithilesh, Venkatnarayan, Dalal and Mathai (2017:20) and Perrson and Newman (2012:658), who reported that children born with HIV who survive into adolescence are at risk of developing psychological disturbances as a result of long-term HIV and its related stressors, together with the long-term effects of medications.

Kenu, Obo-Akwa, Nuamah, Brefo, Sam and Lartey (2014:844) affirmed that disclosure promotes better adherence to therapy and encourages good clinical outcomes. Their study further asserted that disclosure normally tends to ensure a high degree of psychological adjustment and a reduction in the risk of HIV transmission when the young person becomes sexually active. The National Department of Health in South Africa acknowledged the fact that there are ramifications associated with disclosure of HIV status to children and adolescents, thus, they recommended strategies for successful and effective disclosure (DoH, 2016).

3.3.2.2 Fear of disclosing HIV status

The majority of the participants in this study were raised knowing their HIV status. They were also informed to keep it a secret as none of them ever disclosed to anyone. The level of stigma and discrimination in society was so high that none of the participants in this study was willing to disclose their status to anyone. Their HIV status is only known to the members of their household.

> *"I did not disclose my HIV status to my partner because she will leave me and tell everyone about it and no girl would want to be with me"* (Participant no 8).

> *"I am afraid that people will start talking about me and even some won't want to come near me."* (Participant no 1).

> *"I have not disclosed my positive HIV status to anyone because I am afraid that they will tell others about it and everyone will eventually know about it"* (Participant no 2).

> *"Well...everyone has got their own opinion, that is why I think they might have their own opinion about this, so I thought like ok, I won't tell them, this is me, it's all about me and not us, even if you are friend, my best friend, my closest friend, this is my secret, you might see me take things but you will not know what they are for, If you happen to ask I will just tell you that I have got this stomach ache or headache I will just say I am not feeling very well, that's all you will get"* (Participant no 14).

> *"I will not disclose my HIV status to anyone because if it happens that we have a disagreement with that person then they can just easily tell other people about it and people will treat me differently, they might think that I acquired HIV through sex and not from my mum"* (Participant no 6).

Participants in this study were still harbouring fears of disclosure because they grew up knowing that their statuses are to be kept a secret. They did not want to be the subject of gossip. The basis of non-disclosure was associated with how people would react to finding out about their condition. The disclosure terrified them to an extent that they were not willing to do it. It was clear that the stigma associated with HIV played a significant role in the decision process.

These findings are consistent with Grainger's (2017:37) findings that adolescents with perinatally acquired HIV are afraid of being alienated by their peers if they find out about their status. The author further highlighted that the fear of self-disclosure is associated with the stigma attached to HIV. They have a fear of rejection, discrimination, isolation, and possible violent attacks from society that might take place if they disclose their HIV status to anyone.

A study by Hogwood, et al. (2012:50) indicated that self-disclosure seems to be a complex decision to make, which is dependent on factors such as societal attitudes towards HIV. The authors further declared that the adolescents seem to go to extreme ends in order to maintain the secrecy about their HIV diagnosis. They come up with excuses to justify their absences from school and other activities. The study further reported that some adolescents are reluctant to disclose their HIV status due to the unpleasant comments they heard from others with regard to HIV. Kidia, Mupambireyi, Cluver, Ndhlovu, Borok, et al. (2014:1) acknowledged in their study that disclosing an HIV-positive status is one of the most difficult events of life for adolescents with perinatal HIV.

Findings from a study conducted by Madiba and Mokgatle (2016:1) revealed that self-disclosure by adolescents with perinatally acquired HIV to sexual partners and friends is very low. Their HIV status is kept a secret because they do not see a need to disclose, and fear being the subject of gossip. Stigma associated with HIV progress into discrimination, which takes away the freedom of people living with HIV.

However, it is encouraging to note that the WHO recognises the fact that HIV status disclosure to others is a challenging task for adolescents. This led to a policy, providing recommendations on how to support adolescents in their disclosure to others. It was recommended in the policy that "adolescents should be empowered and supported to decide if, when, how and whom to disclose" (WHO, 2013). The way to support adolescents in the difficult process of disclosure remains a research gap, particularly in low and middle-income countries.

3.3.2.3 HIV/AIDS stigma

Stigma attached to HIV is causing significant challenges and problems for adolescents with perinatally acquired HIV. This was discovered during the interviews with the participants in this study.

> *"No, I am not really going to tell anyone I think people will judge because people are so judgemental, aah, I think what will be going through their minds will be that I am on to boys I think that would be the first thing that will come to their minds"* (Participant no 16).

> *"I am afraid that people will start talking about me and even some will not want to come near me, because people still think that one might contact HIV by just touching people living with HIV"*(Participant no 1).

> *"No one knows about my HIV status except my family because if I tell people, they will not treat me the same way, they will gossip about me, some might not want to come near me my friends will abandon me and not want to eat with me at school"* (Participant no17).

Participants were concerned about becoming the subjects of gossip in their communities if the news about their HIV infection comes out. The reason for secrecy regarding HIV status is the stigma attached to it. All of the participants were afraid of how society would react if they find out about their status. Participants were reluctant to disclose their status because people might automatically assume that they got infected due to lifestyle or promiscuity. It was all about maintaining the secrecy of their HIV status. Adolescents were afraid that if they disclose their HIV status to one individual, they might run a risk of other people finding out about their status without their permission.

Joshi, et al. (2017:20) highlighted the fact that a major factor that distinguishes HIV/AIDS from other chronic diseases is the stigma attached to it. The authors also mentioned that affected children and adolescents often live in fear and shame because of HIV, as they try by all means to keep the diagnosis hidden from their relatives, and society at large. More often than not, the adolescents would not want to be seen taking their ART. These adolescents try to conceal their HIV status from people as much as possible. Consequently, the secrecy of the diagnosis continues to pose challenges in all aspects of their lives.

The findings are consistent with the claims by Madiba and Mokgatle (2016:2), who found out that self-disclosure among adolescents, might be constrained by negative parental attitudes towards disclosure in the first place. The study further revealed that adolescents experienced discrimination, rejection or isolation following self-disclosure of their HIV status to some of their friends, among other stigma-related problems.

3.3.2.4 Avoiding sexual relations

In this study, most of the participants were not engaged in a sexual relationship with anyone. Some participants were in a relationship, but had not yet been sexually active. Three participants were sexually active and were not consistent in using protection during sexual activity. Those who were in relationships had not disclosed their statuses to their partners. The majority of the participants chose not to engage in sexual relations due to fear of infecting their partners. In that way, they avoided disclosing their HIV status to their sexual partner. Some felt that if they enter into a sexual relationship, that might warrant disclosure and they were not willing to share their HIV status with anyone outside their nuclear family at that moment. However, some of the participants acknowledge that the need to disclose was inevitable in the future. The participants alluded that their peace of mind is temporarily ensured if they are not in a relationship with anyone. This is another way of safeguarding their secret and avoiding having to explain themselves to anyone.

> *"Because, if I do not have a girlfriend I will live my life happily, look well after myself and not share my money with anyone, avoid a dilemma of telling anyone about my HIV status, even if I die no one will cry because I won't be having any girlfriend"* (Participant no 3).

> *"I avoid having a relationship because I would not know how to tell my girlfriend that I am HIV positive"* (Participant no 2).

> *"Yes my friends have boyfriends but I do not have one because of my problem and also my mother told me that boys will waste my time"* (Participant no 1).

Most of the participants in this study avoided getting into a sexual relationship to avoid having to disclose their HIV status to their partners. Those who were in a relationship reported that they were in a predicament, resulting in fear of infecting their partners. All the participants in this study acknowledged, to some extent, the mode of HIV transmission and prevention.

Galano, Turato, Delmas, Cote, Gouvea, Succi, et al. (2016:174) concurred with the findings of the current study and indicated that the adolescents had strong concerns regarding transmission to their sexual partners. As a result, they avoid getting into a relationship. The authors further commented that adolescents who were not yet in a sexual relationship also had the same concerns about the risk of infecting their partners in future. They all agreed that HIV status secrecy becomes less compatible in a romantic relationship. The major concern is the fear of losing a partner as a result of the disclosure.

However, the findings in a study by Kaushik, Pineda and Kest (2016:3) revealed that the majority of adolescents with perinatal HIV were engaging in unprotected sexual relations. While attention was focused on the benefits of disclosure, healthcare workers for HIV-positive adolescents tend to ignore the inherent associated fears and risks. Studies by Toska, Cluver, Hodes and Kidia (2015:56) also confirmed this claim. Their findings challenged the assumptions that disclosure is automatically protective in sexual and romantic relationships for HIV-positive adolescents, who may be ill-equipped to negotiate safer sex.

3.3.3 Theme 3: Distressing and disruptive social effects of HIV

Participants indicated that the social effects of HIV could be disruptive and distressing for adolescents with perinatally acquired HIV, and it can make transition into adulthood difficult. The participants further emphasised that adolescence is characterised by a need for independence and involvement in risk-taking behaviour. It was also revealed that community attitudes towards people living with HIV could cause irreparable damage to the growth and development of adolescents who were born with HIV. The participants indicated that ongoing stigma attached to HIV could prevent adolescents with perinatally acquired HIV from seeking social and medical services. In most rural areas, it is a taboo to talk about HIV to others.

In this study, participants alluded that HIV has robbed them of their normal childhood due to parental loss, since the majority of adolescents lost one or both parents. HIV has clearly contributed towards an increased number of orphans in South Africa. Three subthemes emerged under this theme, namely: orphan hood leading to poverty, School attendance disruptions, and social/family support.

3.3.3.1 Orphan hood leading to poverty

The majority of the participants in this study were orphaned by HIV/AIDS and were living with their extended families. Most had no recollection of their parents' identities. They only knew their mothers from the photos shown to them by their family. The fathers were not in their lives. Two participants, who were twins, reported that their father used to care for them buthe no longer contacts them. It was also commented that orphan hood as a result of HIV/AIDS serve as a reminder of looming death as their parents died of the same condition. Orphan hood resulted in poverty due to the absence of the financial provider. All participants in this study were from poverty-stricken families. This was identified through an inquiry on their family's financial situation. They were all on child support grants and most of the participants reported that no one was employed in their families. The very same support grant from social services was soon due to be terminated as they now turned 18, and it had already been terminated for the 19-year-olds. That aggravated poverty as the financial relief was eliminated. Those whose family members had jobs were employed as labourers. Orphan hood put the participants in a difficult position in which they are at risk of exploitation, increased sexual vulnerability, loss of educational opportunities, and child labour.

> *"It is only me and my sister, we are both in school, our mother died after a long period of being ill and I used to take care of her because she was very sick"* (Participant no 16).

> *"I do not know my mother, she died when I was still very little, I have only seen her pictures."* (Participant no 3).

> *"My mother passed away in 2007 when I was 8 years old, she died because she was HIV positive"* (Participant no 19).

> *"My mother died when I was still very little, my grandmother told me that my mother died because she was very sick"* (Participant no 7).

The majority of the participants in this study were orphans. Most of them did not know who and where their fathers were. One of the most painful events in life is the loss of one or both parents at a young age, regardless of the cause of death. Being orphaned by HIV/AIDS posed a burden on orphans as their survival, growth, and development were threatened. This condition put them in vulnerable positions. Most of the participants were in difficult home situations. They all miss growing up with their parents. The participants expressed a sense of loss as they spoke about their parents.

This view was supported by findings by Campbell, Anderson, Mutsikiwa, Madanhire, Skovdal, Nyamukapa, et al. (2014:13) and Nsagha, Bissek, Nsagha, Asson, Kamga, Njamnshi, et al. (2012:246), who stated that AIDS-orphans face immense challenges in the absence of significant support from adults. Their welfare, growth and development were threatened as they were in vulnerable positions and at risk of exploitation, abuse, and lack of education. Lowenthal, et al. (2014:8) agreed with this study's finding, since their study revealed that orphan hood had significantly increased together with HIV, and that 50% of AIDS-orphans are adolescents.

Children orphaned by AIDS became the responsibility of the extended family. This arrangement tends to put some children in vulnerable positions, and some end up living on the streets (Lombe, Mabikke, Enelamah & Chu, 2017:8). Campbell, et al. (2014:10) expressed the sad truth about the negative impact of HIV/AIDS on the welfare of children and adolescents. Most of them with perinatally acquired HIV were orphaned by HIV/AIDS and were looked after by relatives who tended to abuse and exploit them. Lombe, et al. (2017:2) agreed that the labels of “AIDS-orphans” and “vulnerable children” had unintended negative social and psychological effects on the children involved.

3.3.3.2 School attendance disruptions

Participants in this study reported that HIV contributed significantly towards their schooling disturbances. The majority of the participants in this study were in the lower grades for their age, and they all blamed it on HIV and its effects. Some appeared to have difficulties comprehending or understanding when spoken to.

> *“I have not been attending school regularly because I have always been a sickly child ever since.”*(Participant no 8).

> *"I do not remember some of the details of my sickness but I was always very sick and has been hospitalised too many times I lost count and I could not go to school then"*(Participant no 13).

> *"It was kind of tricky going to school knowing that in the middle of the month I would have to go to the clinic to fetch medications, sometimes I would have to miss school but they told me that I should come on weekends and after that it was okay because my studies were not disturbed anymore"* (Participant no 20).

The participants narrated how difficult it has been at times to attend school fully due to HIV-related challenges. Frequent visits to the healthcare facilities for various reasons had an effect on their schooling process. Some participants had to collect medications during school hours, which had an impact on their education. Long-term and frequent hospitalisation also contributed towards the loss of school hours.

Watkins, Sello, Cluver, Kaplen and Boyes (2014:112) supported this assertion by saying that a major consequence of poor school attendance is that educational attainment begins to deteriorate even before children were orphaned. This is due to the fact that these children were obliged to look after their sick parents. There are high rates of school disruption and dropping out due to parental death, as there was no provider. Some of the children are forced to drop out of school to get financial help. At times, they drop out of school to look after their siblings and other sick relatives. Poverty also contributes towards school disruption by the lack of school equipment, lack of food, school fees, and uniforms. Frequent visits to the health clinics due to ill health, routine HIV check-ups, and collection of medications also influence school disruptions for adolescents with perinatally acquired HIV (Breckenridge, Black-Hughes, Rautenbach& McKinley, 2017:12).

These findings are consistent with the findings of the study conducted by Lowenthal, et al. (2014:9), which emphasised the prevalence of issues with schooling among adolescents with perinatally acquired HIV. The study stated that they experience schooling issues like absenteeism due to recurrent sickness and clinic appointments. The study also revealed that the affected adolescents encounter stigmatisation and experience isolation at school from both the teachers and their classmates.

A study conducted by Watkins, et al. (2014:112) revealed that there is a high rate of school disruption and drop-out due to orphan hood related to HIV and AIDS. The authors further noted that orphan hood perpetuate poverty which, in turn, results in adolescents dropping out of school for several reasons. Some of the factors affecting educational attainment according to the same authors, are the inability to afford school fees and school uniforms. The study further highlighted that, as an orphan, some of the adolescents were stigmatised for being HIV positive and also for looking after the remaining parent or sibling who was also affected by the virus. They tend to drop out of school due to an inability to cope with the workload. Some orphans were forced to relocate to their extended families which contributed to their school disruption as they had to start afresh.

3.3.3.3 Social/family support

All participants in this study lived with their extended families. They all got support from their relatives; even the three participants who were living with their mothers and their grandparents. They were not aware of any existing support groups in the community and were not willing to join any as they were worried about disclosure of their HIV status to anyone other than their immediate family. None of the participants got any societal support because of the perceived attitudes from society towards HIV.

> *"I stay with my grandmother, aunt, my nephew and my niece, my aunt looked after me after my mother passed away"* (Participant no 16).

> *"I stay with my two aunties and my uncle, my aunt is the one looking after me, making sure that I* take *my medications properly"*(Participant no 3).

> *"I stay with my grandmother and she has been a pillar of strength to me as long as remember"* (Participant no 15).

The societal attitude towards HIV makes it difficult for these adolescents to be free; they seem to live in an isolating situation. Stigma remains an enormous issue in the lives of the participants as they are more concerned about people finding out about their HIV status than taking care of themselves.

> *"I am afraid that people will start talking about me and even some won't want to come near me."*(Participant no 11).

> *"I did not tell them and I do not think it is really necessary for me to tell them because I think they might judge"* (Participant no 5).

Participants in this study got support from their immediate families as well as healthcare workers. They were not aware of any existing support from society. They all declared that even if they were aware of any support groups, they would not have joined due to fear of the possible consequences of self-disclosure.

Mellins and Malee (2013:16) highlighted the importance of support for adolescents with perinatally acquired HIV from different sectors of their lives which lessen anxiety, depression, and behavioural problems. Research has revealed that adolescents with perinatal HIV experience a significant amount of mental health problems associated with the long-term presence of HIV in their bodies, which affect their brain development, as well as their lifelong need for treatment (Mellins & Malee, 2013:2).

There is a great need for continuous support and monitoring following disclosure of HIV status by way of identifying and dealing with issues that may arise as a result of disclosure. The adolescents should be provided with time to ask questions and seek clarity where needed. Follow-up sessions are required to evaluate the state of the adolescentspost-HIV disclosure. The follow-ups can be on a one-on-one basis, in support groups, or on a patient-caregiver basis (DoH, 2016).

A study conducted by Zanoni, Sibaya, Cairns, Lammert and Haberer (2017:3) reported that support and care tailored specifically for adolescents with HIV yielded positive and beneficial outcomes. The services focused on adolescents who were born with HIV, and resulted in improvement in viral suppression, less school absenteeism, and retention in care. This was witnessed in those clinics that were rendering such services. In this way, there is improved quality of life.

3.4 FIELD NOTES

Field notes are a form of record keeping where the researcher takes note of the events and observations in the field (Polit & Beck, 2017:521). The researcher took field notes during interviews with the permission of the participants. The field notes of this study follows:

3.4.1 Observational notes

Observational notes are objective descriptions of observed events and conversations in the field of study (Polit & Beck, 2017:521). In this study, the researcher observed that all participants presented as shy, timid and lacking confidence. This was solely associated with the nature of their conditions. The participants were initially embarrassed to discuss their HIV statuses with the researcher. The mode of transmission of HIV contributed towards their behaviour.

3.4.2 Personal notes

These are the comments about the researcher's own feelings in the field (Polit & Beck, 2017:522). As the interviews continued, the researcher came to the realisation of how difficult life was for the adolescents with perinatal HIV. Being born with HIV was one of the injustices of life. The participants found themselves in difficult situations, which is not their fault.

3.4.3 Methodologic notes

These are reflections about observational strategies (Polit & Beck, 2017:522). In this study, the establishment of rapport before the actual interview proved to have made the participants more relaxed. The sensitivity and nature of this study required all efforts to ensure that the participants were comfortable. The researcher showed some interest in the personal aspects of the participants and gained their trust in the process.

3.4.4 Theoretical notes

These are the researcher's thoughts about how to make sense of what is going on (Polit & Beck, 2017:522). All participants in this study acknowledged the bio-psychosocial difficulties of being born with HIV and having to live with it. All aspects of their lives were affected.

3.5 CONCLUSION

The findings in this study revealed that being born with HIV and having to live with it for the rest of one’s life comes with a range of challenges that proved to rob the participants of their normal childhood, welfare, and development. The participants were put in an enclosed shell due to their efforts to maintain the secrecy of their HIV diagnosis. This deprives them of their complete freedom as they have to constantly be vigilant in order to keep their diagnosis a secret. The stigma attached to HIV is a major contributing factor towards their lack of freedom.

CHAPTER 4

SUMMARY OF RESULTS, LIMITATIONS, RECOMMENDATIONS AND FINAL CONCLUSION

4.1 INTRODUCTION

This is the final chapter of this research study which includes a summary of results, limitations, recommendations, and a final conclusion. In this qualitative study, a descriptive phenomenological approach was employed where participants were interviewed on an individual basis. The main question asked was: "How has it been living with perinatal HIV; may you please share your experiences with me"? Probing questions, which were directed by the participants' responses, followed. A total of 20 participants – both males and females – were interviewed in this study. Three main themes emerged, and these are as follows: Acknowledgement of perinatally acquired HIV, Disclosure of HIV status, and Distressing and disrupting social effects of HIV.

4.2 RESEARCH OBJECTIVE

As stated in Chapter 1, the research objective was to explore and describe the experiences of adolescents with perinatally acquired HIV in the Limpopo Province, South Africa.

4.3 SUMMARY OF RESULTS

A total of 20 participants were interviewed in this study using the unstructured interview method. The three themes that emanated from this study on completion are briefly discussed next.

4.3.1 Acknowledgement of negative effects of perinatally acquired HIV

The participants in this study acknowledged that having acquired HIV at a young age came with a number of challenges that disrupted their normal childhood. They displayed feelings of sadness, fear, anger and blaming attitudes towards their mothers, whom they held responsible for infecting them with the virus. They reported that recurrent illness was disruptive to their childhood as they would frequently be taken to healthcare settings to be treated for different ailments. Historically, HIV is associated with death due to the significant number of lives claimed over the years. The participants also depicted fears of dying following disclosure of their HIV status. Fear of death became a reality in their lives when they lost members of their families due to HIV-related Illnesses.

Some participants have accepted their status, but having to take medications daily served as a reminder of their status and a looming sense of death. On the other hand, some of the participants still found it hard to accept their status and to take medications on a daily basis for the rest of their lives. This had a negative effect on their HIV management. They failed to honour clinic appointments and gave numerous excuses for not attending clinic sessions. Their adherence to treatment was also badly affected.

4.3.2 Disclosure of HIV status

From a young age, participants in this study were taught never to disclose their HIV status to anyone. They grew up knowing that it was a secret they must take to their grave. None of the participants in this study disclosed their status to anyone outside their family structure. As a result, they developed a fear of disclosing their HIV status. In cases where accidental disclosure occurred, it caused emotional turmoil for the participants. It was difficult, if not impossible, for the participants in this study to disclose their status.

The foundation of non-disclosure was solely based on the stigma attached to HIV. The stigma associated with HIV played an important role in the lives of those who were affected. It kept them in an enclosed and isolated situation as they were always protective and on guard to ensure that the secret remained in place. All participants alluded that they would not disclose their HIV status because of fear of discrimination and rejection by fellow human beings. They went as far as avoiding sexual relationships because they did not want to disclose their HIV status and had concerns about infecting their partners. They claimed to find life easier when they were not involved in a sexual relationship, because it lessens any burden of disclosure.

4.3.3 Distressing and disrupting social effects of HIV

Adolescents with perinatal HIV are social beings living within a society. Participants in this study experienced various social disruptions related to HIV. Some of the social effects of HIV made their transition from childhood to adulthood difficult. Some participants had support from their caretakers and members of their immediate families, whereas others found themselves in difficult positions. They learned to integrate living with HIV into their daily lives. They learned different ways to cope with HIV among their peers. Nineteen participants in this study were still at school at the time of interviews. The schooling of the participants was affected due to HIV-related absenteeism, repeating of grades, and discrimination from peers.

Participants relayed both positive and negative encounters with healthcare workers at different health settings. The majority of adolescents in this study were orphaned by AIDS. Orphanhood led to poverty due to the lack of a financial provider. Parental absence contributed to child-headed families, exploitation, and abuse of some of the participants. Most of the participants in this study came from poverty-stricken families and lived with their extended families.

Failure to disclose their HIV status due to fear of discrimination contributed towards a lack of support from society. None of the participants was aware of any support groups available in their communities.

4.4 LIMITATIONS OF THE STUDY

Limitations that the researcher encountered in this study included:

4.4.1 Lack of transferability

The researcher acknowledges that the results of this study are the perceptions of the adolescents based in the rural area in Waterberg district. The findings do not represent the adolescents in other provinces of South Africa. Therefore, the results cannot be transferable.

4.4.2 Non-disclosure of HIV status to the prospective participants

The researcher came across two potential participants who were aged 18 and 19 years, who were not aware of their HIV status. No one has ever disclosed their HIV status to them. They only knew that they were taking vitamins and medications for TB. The disturbing factor about these adolescents was that they were already sexually active. Family members confirmed that these adolescents were being protected from the negative impact of knowing their HIV status, hence the non-disclosure. The recommendation was to facilitate disclosure to adolescents as they need to take care of themselves and adopt a healthy lifestyle as they embark on romantic relationships.

4.4.3 Difficulty in tracing and locating participants

Some of the prospective participants were difficult to locate because they changed their addresses and contact numbers, yet their clinic records were not updated. A few had relocated to other areas and the system was not updated with regards to their whereabouts**.** Some of the preselected participants had died before they could be interviewed. This served as a limitation because it was out of the researcher’s control.

4.4.4 HIV status denial/acceptance

Some participants in this study were still in denial about their HIV status. This contributed towards non-adherence to clinic appointments. Some of the participants found it difficult to discuss their HIV status. They were unable even to mention the abbreviation “HIV”. They would just call it a disease or ‘a thing’ because they still found it hard to accept. This was a limitation because some were unable to be free and discuss the full impact of the virus on their lives. One prospective participant was not included in the study because she stated that she believes that she did not have the virus, even though she was informed about her status and was on treatment.

4.5 RECOMMENDATIONS

Recommendations that were deduced from this research study upon completion were as follows:

4.5.1 Provision of effective strategies to address HIV and AIDS stigma are necessary through awareness campaigns

There is a great need to intensify and address the HIV and AIDS stigma as it is still causing havoc in the lives of those affected. This can be done through campaigns, workshops and various channels of social media.

4.5.2 Development of programmes and services tailored specifically to the adolescents living with HIV

There is a need to develop services specifically for adolescents with HIV as their needs are unique. These services will provide the empowerment that they require to succeed in life. The empowerment will enhance their self-esteem and improve their confidence.

4.5.3 There should be education and empowerment for school children about HIV and AIDS, including its consequences

Based on the findings in this study regarding the way HIV is perceived at school, there is a need for more education about HIV prevention, transmission and the management of HIV and AIDS. There is also a need to address the stigma attached to HIV in our schools. This can be achieved through collaboration of government departments such as Department of Health, Education and Social Development.

4.5.4 Healthcare workers and society should regularly support adolescents with perinatal HIV

- There is a great need for psychosocial support for the adolescents with perinatal HIV as they go through difficult times associated with HIV.
- There is a need for continuous counselling and monitoring of these adolescents.
- The effective and safe transition from being children to being adults with regard to HIV management and care is required; this can be achieved through development of programs and health care strategies by members of the health care team targeted specifically at adolescents living with HIV
- Support should come from members of the multi-disciplinary team, as well as from the empowered society. There is a need for more support groups in the communities as well as encouraging those affected to get involved as they will be empowered and benefit from their involvement.
- There is a need for government to follow up and identify those children who were orphaned by HIV/AIDS and those in child-headed positions in their families.

4.5.5 Adjustment and extension of clinic hours to suit the needs of the adolescents

This will allow adolescents to be able to collect their medications at convenient hours and school disruption will be minimised. The recommendation is for the adolescents to be given appointment dates that will not interfere with their school attendance and other activities.

4.6 RECOMMENDATIONS FOR FURTHER RESEARCH

Recommendations for further research on the topic include:

- Conducting research studies that cover a larger sample and a larger geographical area. The study should extend to both rural and urban parts of South Africa in order to facilitate generalisation of the results.
- Future research should include younger adolescents in order to obtain a holistic view of all adolescent age groups.
- Healthcare providers and caregivers should be included in future research studies to obtain their experiences regarding care of the adolescents with perinatal HIV.

4.7 CONTRIBUTION TO THE BODY OF KNOWLEDGE

- The findings of this study might contribute towards the implementation of evidence-based practice in nursing and will enhance the rendering of high-quality care to adolescents with perinatal HIV. Services tailored specifically to the adolescents with perinatal HIV, will be developed.
- Healthcare staff will be empowered and undergo training on how best to provide care to adolescents with perinatal HIV.
- The findings of this study may add value to the body of knowledge of nursing education. It will serve as a basis for future research on the treatment needs of these adolescents.
- The findings of this study may contribute towards the development of policies, guidelines and health promotion strategies for adolescents with perinatal HIV.

4.8 FINAL CONCLUSION

This research study explored and described the experiences of adolescents with perinatal HIV in the Limpopo Province. The findings from this study revealed that adolescents who acquired HIV at a young age experience multiple challenges throughout their lives. HIV causes complications towards the transition process from childhood to adulthood. The participants found themselves in a situation that is not their fault. They are living with a highly stigmatised chronic condition associated with shame, prejudice, and social exclusion. This calls for a more extensive programme to assist them to cope with the infection and its effects. They emerged as a unique part of the population who were living with the challenges associated with the long-term survival of HIV. There is a need to empower these young people to facilitate a sense of self-worth, confidence, healthy lifestyles, and avoiding an isolated life as a result of the HIV infection. A tailored sensitive approach to provide bio-psychosocial care is required.

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ANNEXURE A

INTERVIEW GUIDE FOR ADOLESCENTS WITH PERINATALLY ACQUIRED HIV

QUESTION
1. How has it been living with HIV; may you please share your experiences with me?

ANNEXURE B

CONSENT FORM

PARTICIPANT'S INFORMATION & INFORMED CONSENT DOCUMENT

STUDY TITLE: EXPERIENCES OF ADOLESCENTS WITH PERINATALLY ACQUIRED HIV IN LIMPOPO PROVINCE

Principal researcher: N.F. Malungani

Institution: University of Pretoria

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Day time numbers: 0722009175

After hours :0722009175

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

DD	**MMM**	**IVY**

:
TIME

Dear participant

1) INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate in the study. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy about all the procedures involved. In the best interests of your health, it is strongly recommended that you discuss with or inform your personal doctor of your possible participation in this study, wherever possible.

2) THE NATURE AND PURPOSE OF THIS STUDY

You are invited to take part in a research study. The aim of this study is to explore and describe the experiences of adolescents who were born with HIV.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This involves answering question from the researcher for a period of up to an hour. There might be more than one session. The interview will be recorded with your permission.

4) RISK AND DISCOMFORT INVOLVED.

The risk and discomfort might be emotional upset because the study requires you to revisit your past, which might be unpleasant. All efforts to minimise harm will be instituted.

5) POSSIBLE BENEFITS OF THIS STUDY.

This study may allow health care staff to provide a more improved health care from what you might have received, thus the nursing practice will be improved based on the findings and the health needs identified.

6) I understand that if I do not want to participate in this study, I will still receive standard treatment for my illness.

7) I may at any time withdraw from this study

8) INFORMATION If I have any questions concerning this study, I should contact:

RESEARCHER: Miss Malungani…… Tel: 015 413 0906……or cell: 0722009175 email: leratohlatli@yahoo.co.uk

SUPERVISOR: Prof M.D. Peu email:doriccah.peu@up.ac.za.

FACULTY OF HEALTH SCIENCES RESEARCH ETHICS COMMITTEE: 012 356 3085

9) CONFIDENTIALITY

All records obtained while in this study will be regarded as confidential. Results will be published or presented in such a fashion that patients remain unidentifiable.

10) CONSENT TO PARTICIPATE IN THIS STUDY.

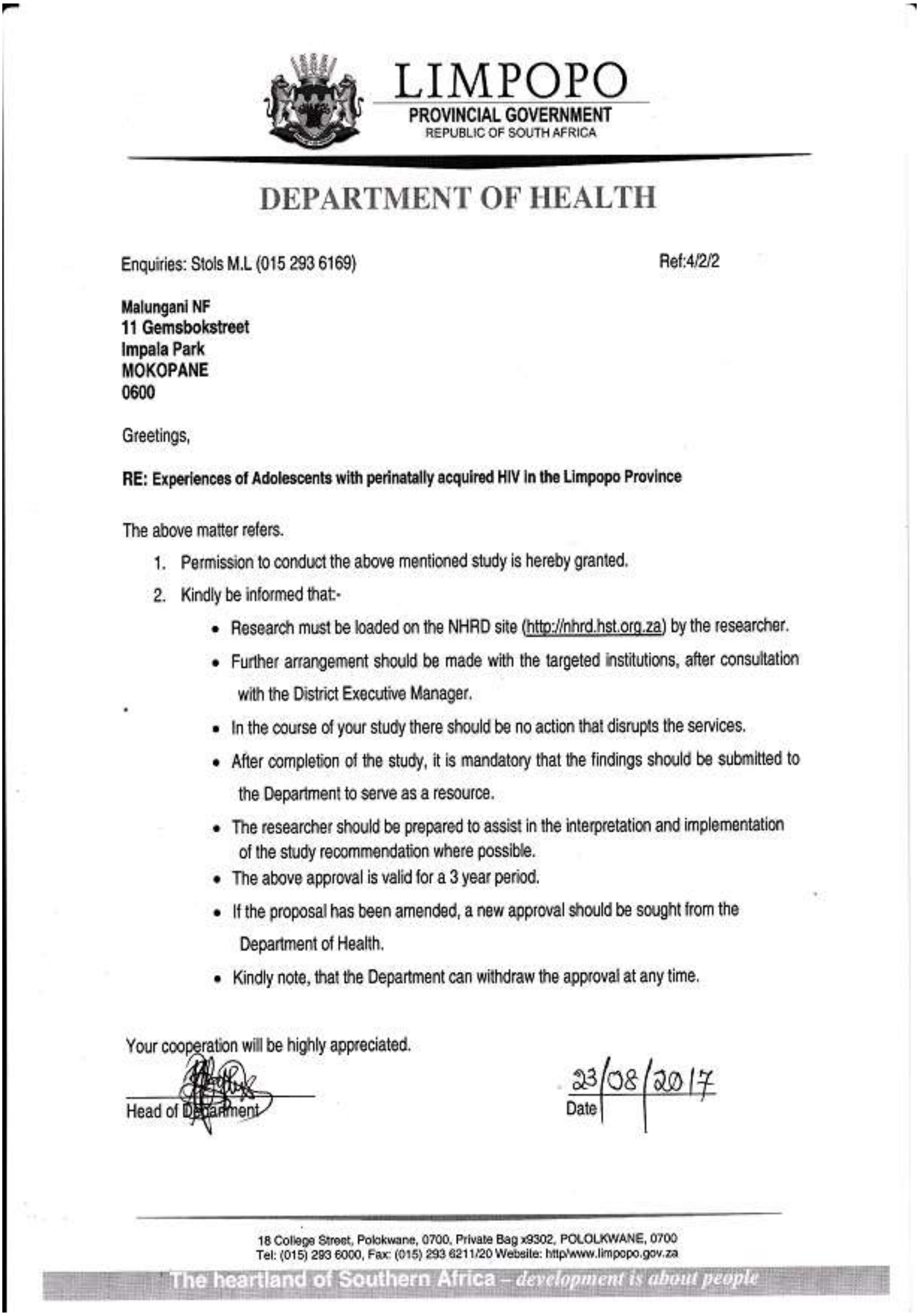
I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

Participant name	**Date**
Participant’s signature	**Date**
Researcher’s name	**Date**
Researcher’s signature	**Date**
Witness name and signature	**Date**

ANNEXURE C

PERMISSION FROM DEPARTMENT OF HEALTH



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stols M.L (015 293 6169) Ref:4/2/2

Malungani NF
11 Gemsbokstreet
Impala Park
MOKOPANE
0600

Greetings,

RE: Experiences of Adolescents with perinatally acquired HIV in the Limpopo Province

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
    - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
    - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
    - In the course of your study there should be no action that disrupts the services.
    - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    - The above approval is valid for a 3 year period.
    - If the proposal has been amended, a new approval should be sought from the Department of Health.
    - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department

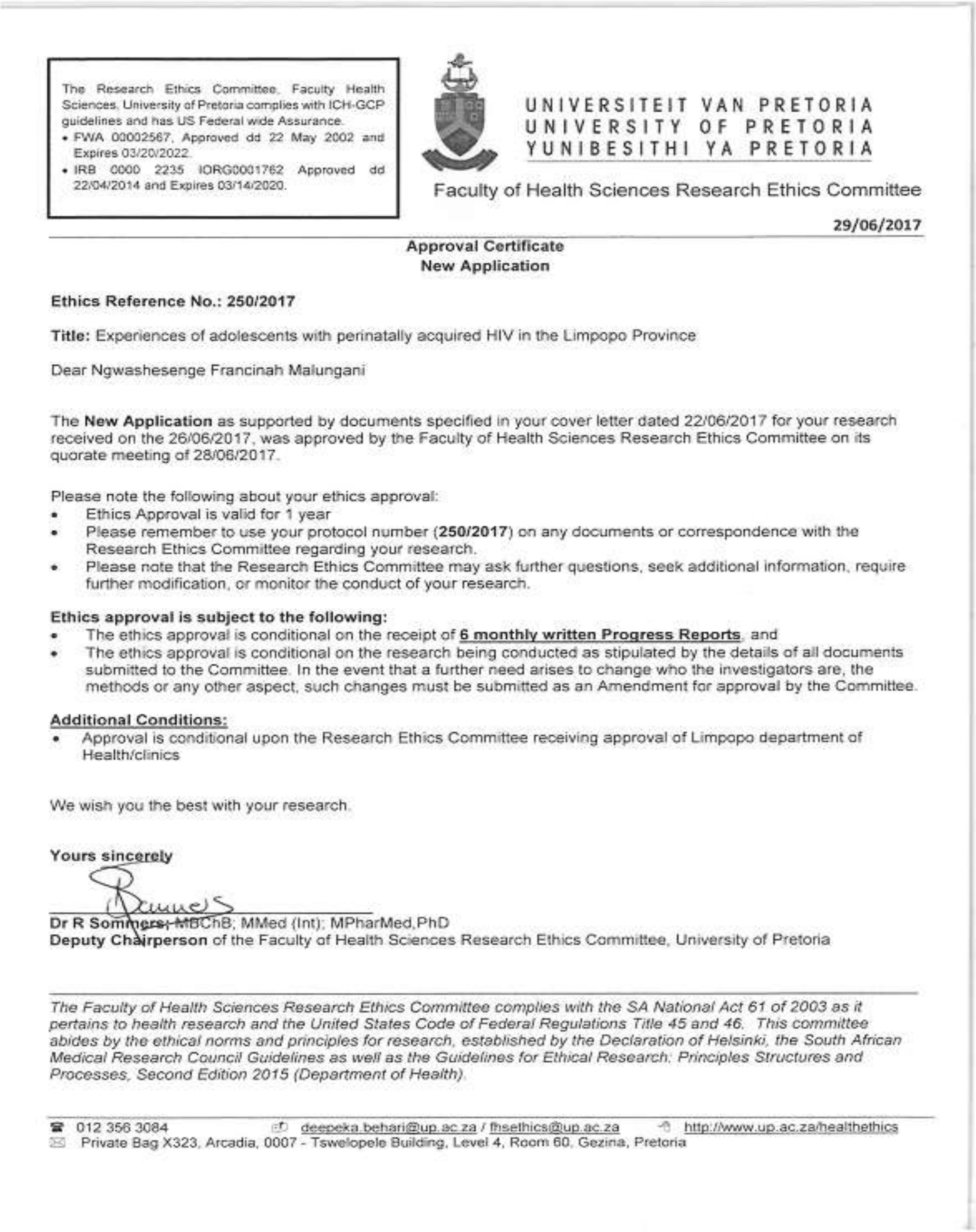
23/08/2017
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http/www.limpopo.gov.za

The heartland of Southern Africa – *development is about people*

ANNEXURE D

ETHICAL CLEARANCE CERTIFICATE



The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

29/06/2017

Approval Certificate
New Application

Ethics Reference No.: 250/2017

Title: Experiences of adolescents with perinatally acquired HIV in the Limpopo Province

Dear Ngwashesenge Francinah Malungani

The **New Application** as supported by documents specified in your cover letter dated 22/06/2017 for your research received on the 26/06/2017, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 28/06/2017.

Please note the following about your ethics approval:
- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (**250/2017**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Additional Conditions:
- Approval is conditional upon the Research Ethics Committee receiving approval of Limpopo department of Health/clinics

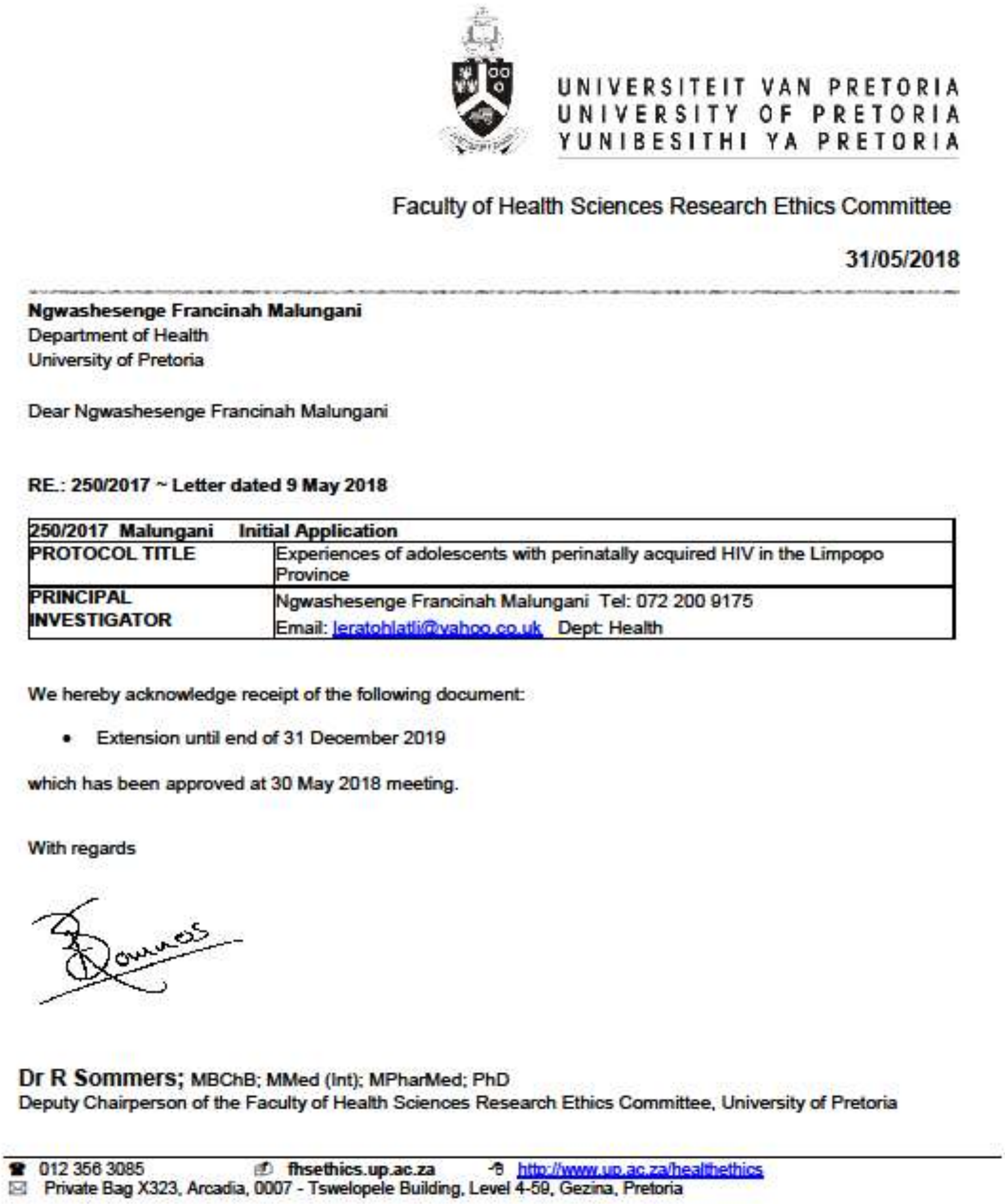
We wish you the best with your research.

Yours sincerely

Dr R Sommers; MBChB; MMed (Int); MPharMed,PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

☎ 012 356 3084 ✉ deepeka.behari@up.ac.za / fhsethics@up.ac.za http://www.up.ac.za/healthethics
✉ Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60, Gezina, Pretoria



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

31/05/2018

Ngwashesenge Francinah Malungani
Department of Health
University of Pretoria

Dear Ngwashesenge Francinah Malungani

RE.: 250/2017 ~ Letter dated 9 May 2018

250/2017 Malungani	**Initial Application**
PROTOCOL TITLE	Experiences of adolescents with perinatally acquired HIV in the Limpopo Province
PRINCIPAL INVESTIGATOR	Ngwashesenge Francinah Malungani Tel: 072 200 9175 Email: leratohlatli@yahoo.co.uk Dept: Health

We hereby acknowledge receipt of the following document:

- Extension until end of 31 December 2019

which has been approved at 30 May 2018 meeting.

With regards

Dr R Sommers; MBChB; MMed (Int); MPharMed; PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

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