CHALLENGES FACED BY MOTHERS WITH HUMAN IMMUNODEFICIENCY VIRUS POSITIVE CHILDREN IN PIETERSBURG HOSPITAL, LIMPOPO PROVINCE SOUTH AFRICA

by

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DISSERTATION

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DECLARATION

I, Segoale Nare Okney, declare that the dissertation titled "**CHALLENGES FACED BY MOTHERS WITH HUMAN IMMUNODEFICIENCY VIRUS POSITIVE CHILDREN IN PIETERSBURG HOSPITAL, LIMPOPO PROVINCE SOUTH AFRICA**, is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references; and that this work has not been submitted before for any other degree at any other institution.

Full names: Segoale Nare Okney Date: 29 October 2020

Signature:……

DEDICATION

This dissertation is dedicated to my two parents: my late father, Mr Michael Lesetja Matshela, and my mother, Mrs Jane Raesetja Matshela. In memory of my father I say: You are loved beyond words and missed beyond measure. To my mother, I say: You are far the strongest woman I have ever known.

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ABSTRACT

The purpose of the study was to identify and explore the challenges faced by mothers with HIV positive children and who were admitted to Pietersburg Hospital, Limpopo Province, South Africa, during the period of study. A qualitative research methodology was used in the study based on exploratory and descriptive designs.

The population for the study included all mothers of children who are HIV positive and had been admitted to the Paediatric Ward of Pietersburg Hospital, Limpopo Province, during the period of study. Non-probability purposive sampling was used to draw a sample of twelve (12) HIV positive participants from the research population. Data was collected from twelve participants through the use of semi-structured in-depth interviews, guided by an interview schedule. Fields notes were captured for non-verbal communication and a voice recorder was used to capture all the audio record of the interview sessions.

Ethical clearance for the study was obtained from Turfloop Research Ethics Committee (TREC); and permission to collect data at the Pietersburg Hospital was obtained from the Limpopo Department of Health as well as the hospital's Chief Executive Officer and from the Operational Manager of the Paediatric Ward.

The findings from the study indicated that mothers of HIV positive children experienced numerous psychosocial and economic challenges on a daily basis. These challenges include accepting their own and their children's HIV positive status; and also disclosing the status to their children. They also had to deal with opportunistic infections that the HIV positive children are more susceptible to, as well as challenges of ensuring that their children did not default on the medication schedules. Poverty and the lack of finances to pay for the various special needs of HIV positive children were also other key challenges experienced by the mothers.

In light of these findings the study recommends the need for HIV/AIDS education, support from families and significant others as well as from the government. The study also recommends that well-coordinated and integrated inter-departmental intervention programmes are required to help mothers cope with their challenges.

Keywords: Challenges, HIV/AIDS, Mothers, Children

DEFINITION OF CONCEPTS

Challenges

A challenge is the situation of being faced with something, which needs great mental or physical effort, in order to be done successfully and therefore tests a person's ability (Cambridge English Dictionary, 2016). In this study challenges referred to all issues that affected mothers with HIV positive children.

Mother

A mother is a female parent, who performs the role of bearing some relation to her children (Hejoaka, 2009). In this study, the term mother refers to both "biological mothers'' and "substitute mothers" (Hejoaka, 2009) caring for children who were admitted at Pietersburg Hospital, Paediatric Ward, in the Limpopo Province.

HIV

HIV is a virus that belongs to Retroviridae family, which is considered as highly evolved and can replicate in host cells by Reverse Transcription process. Virus enters the body, damages the immune system and causes various diseases in humans. HIV is a virus that causes Acquired Immunodeficiency Syndrome (Preeti, 2016).

Children

The Convention on the Rights of the child defines a child as a human being below the age of 18 years. Children evolve through distinct developmental stages including infancy (0-6 years), middle childhood (6-10 years), and early adolescence (10-14 years) and late adolescence. In South African law, children under 18 years are legal minors who are not fully capable of acting independently without assistance from parents and legal guardians (Strode, Slack & Essack, 2010). In this study children refers to minors less than 18 years and are HIV positive.

LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-Retroviral Therapy
DNA	Deoxyribonucleic Acid
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HCT	Human Immunodeficiency Virus Counselling and Testing
IMCI	Integrated Management of Childhood Illness
IPV	Inactivated Polio Vaccine
PCR	Polymerase Chain Reaction
PLWH	Persons Living with HIV
PMTCT	Prevention of Mother to Child Transmission
TB	Tuberculosis
UN	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

HIV/AIDS is the biggest challenge facing the global health care system today (Nwaozuzu & Dozie, 2014). The Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO) state that there are 34 million people living with HIV across the world (Oliver & Petty, 2012). The burden of the AIDS epidemic is greatest in resource poor settings; in particular, 22, 5 million of the 33, 2 million individuals infected with HIV globally live in Sub-Saharan Africa (Levy, Webb & Sellen, 2010).

The majority of adults, 60%, living with HIV infection in Sub Saharan Africa are women (Ezugu, Chukwuemeka, Nkwo, Ezegwui, Akabueze & Agu, 2016). One study reported that 90% of HIV positive women in Asia were infected by their husbands or long term male partners (Raes, Syed, Ali & Muhammed, 2013). An extensive body of research has documented a range of negative reproductive health consequences arising from women's experiences with IPV which includes unintended pregnancy, foetal loss, maternal morbidity and mortality, and increased vulnerability to sexually transmitted infections, including HIV (Falb, Annan, Kpebo & Gupta, 2014).

South Africa is experiencing one of the largest HIV epidemics in the world. HIV sero-prevalence among pregnant women attending government antenatal clinics was 29, 1% 2007 and vertical transmission has resulted in a large burden of paediatric HIV disease and reversal of gains achieved in reducing child mortality. In Limpopo Province, the antenatal HIV seroprevalence was 20,7% in 2009 (Horwood, Voce, Vermaak, Rollins & Qazi, 2010). HIV related infections causes over 40% of children's deaths. HIV related illnesses and deaths have had a devastating effect on households and communities (Horwood et al., 2010).

Women, as mothers, bear a disproportionate share of the burden and this, in turn, increases risks of paediatric infection. Despite increasing access to highly efficacious combination antiretroviral therapy for PMTCT, hundreds of thousands of children continue to contract HIV from their mothers each year (WHO, 2013).

Initial interventions in paediatric HIV/AIDS focused on the medical urgency and terminal nature of the disease (Avabratha, Kodavanji & Vaid, 2011). Understandably, there was little attention given to challenges faced by the mothers of children with HIV/AIDS (Todres, 2009).

In 2010, the UN launched the Global strategy for Women's and Children's Health, which sets out a plan to save the lives of millions of women and children. It calls for a bold, coordinated effort that builds on what has been achieved globally (Mamogobo, Lekhuleni & Mothiba, 2014).

The Millennium Development Goal number 4 requires a two-thirds reduction in under-five mortality. For years, paediatric HIV was a neglected aspect of the epidemic with little attention and inadequate treatment (Kerber, Tudome-Nkhasi, Dorrington, Brodshaw, Jackson & Lawn, 2012). The WHO and the UNICEF developed the Integrated Management of Childhood Illness (IMCI) strategy to improve child survival in poor resources settings (Horwood et al., 2010). IMCI was adopted by the South African Government in 1997, as the gold standard for delivery of child health services at primary level (Horwood et al., 2010).

Doctor Aaron Motsoaledi, South Africa's former Minister of Health, told the Lancet that during the 1990s, the diagnosis of HIV infection was like a death sentence. There are still a lot of obstacles to face and a lot of work to do, but the progress is good (Maurice, 2014). The development of highly active antiretroviral treatment in the 1990's has prolonged survival for HIV infected women extending their time for bearing and raising children. Research has shown that chronic illness is a major stressor for the entire family, and illness severity has been linked to higher levels of psychological distress in chronically ill adults and their children (Murphy, 2009).

People living with HIV are often stigmatised because behaviours leading to infection are considered avoidable. HIV infection particularly affects women, and the external stigma is experienced more by women, against whom most blaming is directed. This often leads to depression among women (Horwood et al., 2010). A study conducted by Mamogobo et.al, revealed that rural women were fearful of disclosing their HIV positive status as this may lead to losing their sexual partners (Mamogobo et al., 2014).

Management of HIV-infected children is a challenge for mothers. Illness and grief interfere with parents' ability to provide constant care for their children. In many African cultures, women are not independent decision-makers, but they need family support. Openness in families is not self-evident and discussions are met with many barriers (Jaana, Suominem & Valimaki, 2010). The need for intervention to assist both children and mothers affected by HIV is recognised widely. Studies ignore the wellbeing of the mother as the primary caregiver and the interaction between mother and child (Ramanathan, Swendeman, Comulada, Estrin & Rotheram-Borus, 2012).

With the above background, the researcher was motivated to conduct a research study about the challenges faced by mothers with Human Immunodeficiency Virus positive children in Pietersburg Hospital, Limpopo Province, South Africa.

1.2 PROBLEM STATEMENT

There have been few studies characterising the impact of HIV infection on the mother, and even fewer from rural African settings (Naniche, 2009). Anyone diagnosed with HIV faces the physical and psychological challenges of living with a chronic disease (Murphy, 2009). The challenges include various matters, for example, poverty, hospital admissions, stress and stigma. HIV positive mothers living with HIV positive children are facing challenges every day. The researcher observed that on a monthly basis, over a period of 12 months, on average 10 children were admitted in the Paediatric Ward of Pietersburg Hospital for HIV related diseases. Mothers feel the impact of HIV and AIDS (Todres, 2009). They have to deal with the burden of their own disease and also that of taking care of their infected children. Therefore, the study sought to explore and describe the challenges faced by mothers with Human Immunodeficiency Virus positive children in Pietersburg Hospital, Limpopo Province, South Africa.

1.3 THEORETICAL FRAMEWORK

In this study, Abraham Maslow's hierarchy of needs theory was adopted as a theoretical framework to explore and describe challenges faced by mothers with HIV positive children. Maslow used the terms "physiological", "safety", "belongingness" and "love", "esteem", and "self-actualization" to describe the pattern that human motivations generally move through. Mothers with HIV positive children move through these patterns although the challenges they face while raising children diagnosed with HIV/AIDS compromises their own needs as time progresses. The needs of their

children progressively take precedence over theirs. Maslow sees all the needs as essential for survival.

Maslow suggests that genetically, we have needs within us to “build”, like instincts. Figure 1.1 below illustrates the different survival needs that each individual needs to be fulfilled in order for one to thrive.

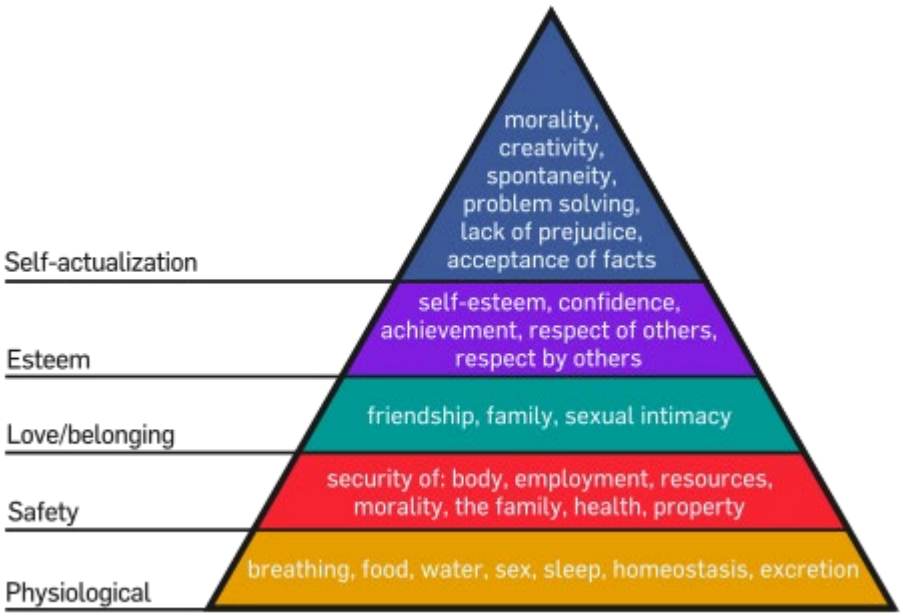

Figure 1.1: An interpretation of Maslow’s hierarchy of needs, represented as a pyramid with the more basic needs at the bottom.

The explanations of each of the needs reflected in Figure 1.1 above are presented below.

- **Physiological needs**

Physiological needs are the physical requirements for human survival. If these requirements are not met, the human body cannot function properly and will ultimately fail. Air, water, and food are metabolic requirements for survival in all animals, including human beings. Despite their positive HIV status, mothers and their children need to satisfy these basic needs.

While maintaining an adequate birth rate shapes the intensity of the human sexual instinct, sexual competition may also shape the said instinct. According to Murphy (2009), HIV positive women desire love, children and intimacy.

- **Safety needs**

With their physical needs relatively satisfied, the individuals' safety needs take precedence and dominate behaviour. Clothing and shelter provide necessary protection from various elements of danger. This level is more likely to be found in children because they generally have a greater need to feel safe. HIV positive mothers are regarded as vulnerable and also need to feel safe. Safety and security needs include personal security, financial security, health and well-being, safety net against accidents/illness and their adverse impacts (Cherry, 2018).

- **Love and belonging**

According to Maslow, human beings need to feel a sense of belonging and acceptance among their social groups, regardless whether these groups are large or small. Deficiencies within this level of Maslow's hierarchy – due to hospitalism, neglect, shunning and ostracism, can impact the individual's ability to form and maintain emotionally significant relationships in general, such as friendship, intimacy and family. Mothers living with HIV experience fear, anger, blame and stigmatization from families and friends (Cherry, 2018).

- **Esteem**

All human beings have a need to feel respected, and this includes the need to have self-esteem and self-respect. Esteem presents the typical human desire to be accepted and valued by others. Psychological imbalances such as depression can hinder the person from obtaining a higher level of self-esteem or self-respect. Murphy (2009) found that HIV positive mothers reported higher levels of depression, health-related anxiety, alcohol abuse and poor medical outcomes.

- **Self-actualisation**

This level of need refers to what a person's full potential is and the realization of that potential. Maslow describes this level as the desire to accomplish everything that one can, to become the most that one can be. HIV positive mothers may have the strong desire to become ideal parents. Given the severe challenges mothers with HIV/AIDS face, and the relatively poor outcomes for their seropositive children, interventions are needed for this population to help them meet their full potential.

1.4 PURPOSE OF THE STUDY

The purpose of this study was to explore and describe the challenges faced by mothers with HIV positive children in Pietersburg Hospital, Limpopo Province, South Africa.

1.5 RESEARCH QUESTIONS

The research questions, which guided the researcher throughout the study, were:

- What were the challenges faced by mothers with HIV positive children in Pietersburg Hospital, Limpopo Province, South Africa?
- What coping strategies were developed to support mothers with HIV positive children in Pietersburg Hospital, Limpopo Province, South Africa?

1.6 OBJECTIVES OF THE STUDY

The objectives of the study:

- To explore the challenges faced by mothers with HIV positive children at Pietersburg Hospital, Limpopo Province, South Africa.
- To describe the challenges faced by mothers with HIV positive children at Pietersburg Hospital, Limpopo Province, South Africa.
- To develop support strategies for mothers with HIV positive children at Pietersburg hospital.

1.7 OVERVIEW OF RESEARCH METHODOLOGY

1.7.1 Research Design

Since the aim of the study was to understand the challenges faced by mothers with HIV positive children in Pietersburg Hospital, a qualitative research design was deemed relevant since it could provide the in-depth knowledge needed. Qualitative research focuses on aspects such as meaning, describing, promoting and understanding rich detailed human experiences from the view point of the participants in the context in which the action takes place (Polit & Beck, 2012).

The exploratory and descriptive designs were used in the study. Exploratory research investigates the full nature of the phenomenon, the manner in which it is manifested and the other factors to which they are related. Descriptive designs provide a picture

of a situation as it happens. Challenges faced by mothers with children who are HIV positive were explored and described in the study (Burns & Grove, 2015).

Semi-structured in-depth interviews were used to collect the required data. These interviews were guided by an interview schedule which contained the main themes to be explored. Twelve (12) mothers living with HIV were purposively sampled and interviewed at Pietersburg Hospital. The researcher collected data over a period of three months at the hospital.

The data collected were analysed using open coding, whereby data was reduced, organised, interpreted and given meaning. Bias was minimised by utilising three types of data collection methods through the use of interviews, voice recorder and field notes. The interviews were recorded using a voice recorder and transcribed verbatim in order to retain the authenticity of the participants' experiences. A detailed discussion of the methodology is provided in Chapter 3 of the dissertation.

1.7.2 Ethical considerations

Turfloop's Research Ethics Committee approved the study, and the research ethics clearance certificate is attached hereto as Annexure 6. Similarly, the Limpopo Department of Health gave permission for data collection at the hospital, and the formal letter granted the permission which is attached hereto (Refer to Annexure 4).

Furthermore, the following ethical considerations were observed in the course of the study:

- The research participants were informed that their participation in this study was on a voluntary basis. They had to confirm their volition to participate by signing a consent form, a copy of which is attached hereto as Annexure 3. In cases of illiterate participants, they had to give verbal consent which was given recorded on audiotape.
- Confidentiality and anonymity were maintained as the researcher was the only person who could access the data and pseudonyms were used in the dissertation to protect the identity of participants. The interviews took place at Polokwane Hospital in a private room to ensure a confidential environment.
- The research posed minimum psychological risks to the participants. Adequate information was provided to the participants before the study by discussing the study with them beforehand.

1.8 SIGNIFICANCE OF THE STUDY

The results of the study identify challenges faced by mothers with HIV positive children. The findings provided a good and sound basis for developing measures to assist the mothers who face these challenges to cope with their own HIV status and that of their children. The Department of Health may utilise the findings of the research to improve the quality of life for both mothers and their children. Similarly, the hospital may use the findings of this study to improve the quality of care for mothers with HIV positive children.

1.9 OUTLINE OF THE DISSERTATION

Chapter 1

Chapter one introduces the study, provides background information, defines the problem statement and presents the theoretical framework, which is about the Maslow's hierarchy of needs, to understand the challenges faced by mothers with children who are HIV positive. The Chapter also states the purpose of the study, outlines the research questions and the objectives of the study, and provides an overview of the research methodology. It further describes the significance of the study, and outlines the structure of the dissertation.

Chapter 2

Chapter two focuses on a review of the relevant literature on challenges faced by mothers with children who are HIV positive.

Chapter 3

Chapter three presents the research methodology, describing the study site, the research design, population and sampling, data collection methods, data analysis, and measures employed to ensure trustworthiness. It also explains the ethical considerations that guided the study, and the measures undertaken to eliminate bias.

Chapter 4

Chapter four presented the research findings.

Chapter 5

Chapter five discusses the summary of the study. It also presents the conclusions and recommendations drawn from the findings of this study. Limitations of the study are discussed in the same chapter.

The very last part of the dissertation consists of Annexures.

1.10 CONCLUSION

Chapter one has provided an overview of the study, problem statement, theoretical framework, purpose of the study, research questions, objectives of the study, research methodology, significance of the study and ethical considerations. The next chapter discusses the topic through a more in-depth literature review on challenges faced by mothers with HIV positive children.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

According to Burns & Grove, 2015 and Brink, van der Walt & van Rensburg (2012), literature review is an organized written presentation of what has been published on a topic by scholars in the selected field of study. A thorough literature review provides a foundation on which to base new evidence, and is usually conducted before data are collected (Polit & Beck 2012). In this context, the purpose of this chapter is to provide a brief history of HIV/AIDS in order to contextualise the challenges faced by mothers with children who are HIV positive.

Literature on the subject is reviewed so as to gain a greater understanding of the topic as well as identify the gaps in the research to date. It also provides a more understanding of the application of Maslow's needs theory to the study.

2.2 BRIEF HISTORY OF HIV/AIDS

Globally HIV and AIDS are considered to be a major health and developmental challenge facing humanity (Dhashini, 2013). Currently, close to half of the 37 million adults living with HIV/AIDS worldwide are women, and many of them are in their reproductive years (UNAIDS, 2016). After 30 years, the HIV remains an epidemic of global concern; with sub-Saharan Africa bearing the heaviest burden (Mathur, Romo, Rasmussen, Nakyanjo, Nalugoda & Santelli 2016). South Africa is an epic centre of the HIV epidemic with an estimated 6.4 million South Africans living with HIV, and more than half of these are females (Cooper, Harries, Moodley, Constant, Hodes, Matthews, Morroni & Hoffman, 2016).

HIV prevalence is high amongst South African women of reproductive age and transmission of HIV from mother to child is a major concern and remains a public health priority (Haffajee, Ports & Mosavel, 2016). According to a UNAIDS report, 95% of HIV infected pregnant women in South Africa received some antiretroviral therapy intervention for PMTCT in 2010 (UNAIDS, 2012).

While progress has been made, there are still several challenges in scaling up PMTCT services in the South African public health care centres (Mnyani & McIntyre, 2016). Despite the global up-scaling of interventions for PMTCT, there still remain high

paediatric HIV infections, which result from unequal access in resource- constrained settings (Dako-Gyke, Dornoo, Addo, Atuahene, Addo & Yawson, 2016). Children represent more than 15% of new HIV infections worldwide, and approximately 90% of children become HIV positive through MTCT (Haffejee et al., 2016). Paediatric ART programmes have demonstrated good outcomes with increasing treatment initiation in younger children and infants, in response to South Africa and WHO guidelines expanding recommendations for immediate ART from infants to all children (Davies M, 2015).

Literature suggests that, many women who live with HIV/AIDS desire to become mothers and indeed many of them have gone to become mothers (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios & Onoya, 2012). Motherhood, in the context of a chronic and stigmatizing illness such as HIV, brings with it many unique challenges (Willcocks, Evangeli, Anderson, Zetler & Scourse, 2016). Literature also suggests that women who are living with HIV/AIDS and who are mothers carry a triple burden of being HIV infected: they are HIV positive themselves, they are mothers to HIV positive children, and are often caregivers to their partners who live with HIV/AIDS (Liamputtong & Hantavorn, 2014).

A study by Yates (2011) described the experiences of mothers as a challenge and a struggle. There are numerous challenges of motherhood, many of which are exacerbated by HIV (Yates, 2011). Motherhood seems to have been an incredibly overwhelming experience for all mothers. Mothers have to put their children's needs before their own, and sometimes struggle to provide for their children (Yates, 2011). Women infected with HIV are a vulnerable population (Webel, Dolansky, Henry & Salata, 2012). Although little research has been done on the impact of terminal illness in HIV/AIDS infected children, research on other diseases indicates challenges of children living with terminal illness (Shisana, 2012). In a study by Khunga, some mothers and community members believed that a child with marasmus had HIV/AIDS and this was said to increase stigma for both the mother and the child (Khunga, 2014). Clinically diagnosed Pneumocystis pneumonia and severe acute malnutrition are highly predictive of death in children infected with HIV (Avabratha et al., 2011).

The prevalence of the Human Immunodeficiency Virus is high among South African women of reproductive age, and transmission of HIV from mother to child is a concern (Horwood et al., 2010). Male partners appeared to be barriers to disclosure. Women

feared accusations of infidelity, abandonment, discrimination or violence (Jaana et al., 2010). Various studies have provided evidence that maternal HIV infection in the family compromises the healthy development of children (Le Doare, Bland & Newell, 2012).

Poverty, lack of affordable housing, racism, stigma, and discrimination, all contribute to the progression and management of HIV (Greene, Ion, Kwaramba, Mwalwanda, Caswell, Guzha & Carvalhal, 2015). Many women face barriers to accessing services including limited transportation, caregiving responsibilities, employment, drug coverage, housing instability, immigration, HIV stigma, and relationships with multiple providers in multiple locations (Logie, James, Tharao, & Loutfy, 2013).

2.3 HIV RELATED CHALLENGES FACED BY MOTHERS

Raising HIV positive child or children among HIV negative children increases the stress experienced by mothers (Mhlanga, 2013). This chronic and stigmatized condition can affect the overall functioning and lifestyle of affected mothers and their children (Avabratha et al., 2011). Infected women must learn to live with the unique challenges and stressors related to HIV. HIV related challenges include poverty, unemployment, intimate partner violence, hunger and lack of access to transportation (Oliver & Petty, 2012). Most of the responsibilities of caring for children living with HIV/AIDS falls on family members, in particular, women. Women as mothers are involved in the caregiving process, leading to them being overburdened with responsibilities in the form of care and support roles (Mocke, 2010). Somalia is a country where after twenty years of war many Somali women have been left in sole charge of their children (Alvarez & Lally, 2014).

The mothers feel that they have no control over the situation has been found to be a predictor of stress in studies of mothers of children with HIV (Mhlanga, 2013). Violence against women and gender inequalities are commonplace in South Africa. Stigmatisation reinforces these power hierarchies and gender stereotypes (Horwood et al., 2010). Many people feel ashamed and embarrassed, when they are diagnosed with HIV infection. Gender inequality, in its multilevel and culturally diverse manifestations, contributes to violence against women and is a driver of the HIV pandemic among women and girls. A Brazilian study found that women with HIV were

more likely to report severe and recurrent experiences of violence than they were prior to diagnosis (Kendall, van Dijk, Wilson, Picasso, Lara & Garcia, 2012).

Women face unique challenges in managing HIV diseases including dealing with family roles, higher levels of poverty and inadequate access to health care resources (Centre for Disease Control and Prevention, 2010). In Pakistan, women suffer abuses right from before they are born, as there is infanticide of female babies; followed by harmful ritual customs, including acid attacks, forced marriages, even at a very young age, punishments by stoning and other physical abuses. According to the Commission for Human Rights for Pakistan, every year more than a thousand women and girls are the victims of so-called “honour killings” (Alvarez & Lally, 2014).

A study by Yates (2011) found that each mother had her own experiences that are unique and distinct from others. However, while their experiences differed, there were a number of common challenges that the mothers identified. Several factors, including sociocultural, economic and biological, continue to render women susceptible to HIV in Africa (Durojaye, 2014). Mhlanga (2013) in her study highlighted the following stressful factors associated with raising a child with HIV: financial cost, emotional demands and logistical complications. As HIV services were not originally created by or for women, it appears their unique issues have not been considered in programme design and implementation, thereby limiting services that would specifically address their needs. Although tailored services that respond to women's unique needs are critical in improving health outcomes, the notion of women-specific HIV/AIDS services remains poorly conceptualized in the literature (Greene, Ion, Kwaramba, Mwalwanda, Caswell, Guzha & Carvalhal, 2015).

2.3.1 Stigma and discrimination

Stigmatization is an attitude, but discrimination is an act or behaviour (Avabratha et al., 2011). Among the effects of HIV/AIDS related stigma and discrimination are blame, denials and difficulty in adhering to treatment. HIV related stigma and discrimination are ingrained in societal structures (Koodibetse, 2015). HIV infection particularly affects women and accordingly external stigma is experienced more by women, against whom most stereotype description applied to people living with HIV/AIDS are directed (Horwood et al., 2010). Studies indicate that sexual stigma takes place at multiple levels, including the family, church and community as well as via in laws and policies (Poteat, Logie, Adams, Mothopeng, Lebona, Litsie & Baral, 2015).

Stigma negatively affects people's physical and mental health. Despite efforts to reduce stigmatization at social level, it persistently and continuously threatens the mental health of people living with HIV and their family members. Social stigma towards people living with HIV and their family members include rejections, social isolation, and reduced social opportunities and social support (Chi, Li, Du, Tam, & Zhao, 2016). With strong cultural taboos, stigma and secrecy, HIV has a unique social context that adds to the complexity of interventions with affected populations. In fact, HIV has been described by many researchers as a "social disease" due to the stigma and marginalization of affected individuals. These two factors can make accessing traditional forms of social support particularly difficult for individuals and families living with or affected by HIV (Hyba, 2016).

Increasing numbers of people living with HIV/AIDS shoulder the burden of lack of support and need for secrecy. As the blame persists they are also deprived of their rights as human beings (Koodibetse, 2015). Perceived HIV-related stigmatization not only influences mental health but also physical health. In a recent study conducted by Chi at al. (2016) perceived stigmatization has been found to go under the skin to negatively affect the stress response systems and hypothalamic-pituitary adrenal axis functions. Despite advances in HIV treatment, HIV/AIDS diagnosis still carries significant stigma (Tessmer–Tuck, Poku & Burkle 2014). In South Africa, the ending of apartheid brought with it an improvement in women's conditions, but violence continues to be one of the commonest forms of discrimination, going beyond any barriers of race and class. Between 2010 and 2011, more than 66,000 cases of sexual aggression were recorded in South Africa, where one woman is killed by her partner every six hours. Furthermore, cases of HIV among women run at double the rate among males (Alvarez & Lally, 2014). In a study undertaken in Lesotho, it was found that discrimination in religious institutions was common place and was reflected in community norms (Poteat, 2015). A study undertaken in Mexico indicated that most of the women stated that they had suffered HIV-related discrimination from a health care provider (Kendall et al., 2012).

The root of this discrimination has persisted into the twenty-first century. In some countries it is much more dangerous to be born female than in others (Alvarez & Lally, 2014). According to studies, up to today, 186 countries have ratified the Convention on the Elimination of All Forms of Discrimination against Women, a positive advance achieved after years of protests, mobilizations and activism. However, much would

seem still to remain to be done (Alvarez & Lally, 2014). Research shows that increasing knowledge about HIV/AIDS can contribute to the alleviation of HIV/ AIDS-associated stigma (Terzic-Supic, Santric, Mirkovic, Svetlana & Soldatovic, 2015).

2.3.2. Intimate partner violence

Intimate partner violence against women is a serious public health concern, with multiple impacts on women's physical, mental and reproductive health. Intimate partner violence may take a variety of forms including physical, sexual and emotional violence (Kyegombe, Abramsky, Devries, Michau, Nakuti, Starmann, Musuya, Heise & Watt, 2015). For HIV positive women, managing the disease is a major concern – particularly in cultures where women have little power to regulate their sexual availability to men and are thus at increased risk for exposure to HIV (Wang, Chen, Zhang, Bao, Zhao & Lu, 2016). In Afghanistan, 80% of women are forced to accept arranged marriages (Alvarez & Lally, 2014).

A study on Haitians in the United States revealed that although the incidence of AIDS cases was decreasing among Haitian men, it was increasing among Haitian women. Most of the research done on HIV and mothers indicate that women are infected by their partners. In China, heterosexual sex is currently the most common transmission route for HIV (Wang et al., 2016). The main route of HIV infection for women in the United States of America is through heterosexual contacts (Kowala-Piaskowska, Mania, Baralkiewicz, Zeromski & Mozer-Lisewska, 2010). Among Haitian women it was found that 88% had been infected through heterosexual contact (Glemaud, Illa, Echenique, Bustamente- Avellanede, Gazaba, Villar-Loubet, Rodriguez, Potter, Jayaweera, Boulanger & Kolber, 2014).

Many factors have contributed to this increase, including the inability to negotiate safe sex, limited HIV knowledge, gender inequality in heterosexual relationship and domestic violence, which also often lead to barriers in HIV treatment and affected HIV disclosure (Glemaud et al., 2014). Several international studies have linked sexual and physical violence from a male partner to higher rates of HIV infection among women (Kendall,van Dijk, Wilson, Piccasso, Lara & Garcia, 2012). Intimate partner violence affects 30% of all ever-partnered women in the world and has grave health consequences for affected women and their children (Perova & Reynolds, 2016).

Gender violence is the most widespread violation of human rights, taking multiple forms: domestic violence, sexual abuse of girls, harassment at work, human

trafficking, and rape by husbands or by strangers, in refugee camps, or as a tactic in war, and others (Alvarez & Lally, 2014). A Chilean study found that low-income women who experienced intimate partner violence were more likely to report risk behaviours for HIV acquisition than those who did not experience intimate partner violence, primarily unprotected sexual intercourse and intercourse with a partner of unknown HIV-status (Kendall et al., 2012). The 2016 Uganda Demographic and Health Survey indicate that only 22% of married women independently decide on their own health: many women lack the authority to make and act on decisions on their own health, which places sexual autonomy beyond their reach (Nampewo, 2017). With the lack of control over one's own body and health, HIV as a key health concern takes on a woman's face. A South African study concluded that sexual violence and its relationship to HIV occur against the backdrop of inequalities in South Africa, where gender, sexuality, race and class powerfully intersect to reinforce poor woman's vulnerability (Mills, 2016). Sexual violence has been associated with higher rates of HIV acquisition.

2.4 DISCLOSURE OF HIV STATUS

A study exploring experiences of disclosure among a cohort of women receiving HIV treatment at Chitungwiza, National Hospital in Zimbabwe, identified fear of stigma, violence or divorce as barriers to disclosure to partners (Zamodia-Haas, Mudekunye-Mahaka, Lambadin & Dunbar, 2012). In the Shona culture of Zimbabwe, a high demand for childbearing contributes to strong pressure from partners and families to have children. For young women living with HIV, disclosure of HIV status can be a central strategy to garner support for controlling fertility (Zamodia-Haas et al., 2012). When individuals discover that they are HIV-positive, one of the first things they decide is whether to tell their family and friends.

Approximately 14% of caregivers interviewed admitted that they have not revealed either their own or their child's HIV-positive status to their extended family members (Avabratha et al., 2011). Some mothers expressed fears about lack of confidentiality from the nurses, and that receiving HIV-related services could lead to unintentional disclosure of their HIV status (Horwood et al., 2010). A cross-sectional survey conducted in antenatal clinics in Soweto, South Africa, indicates that the various reasons for non-disclosure to the partners, include fear that the partner would leave,

be violent, or accuse the woman of being unfaithful and infecting him with HIV (Mnyani & McIntyre, 2016).

Some women did not disclose their own status and that of their babies because of poor relationship with other household members, and fear of stigmatization and rejection of themselves and their babies (Lazarus, 2010). The women experienced stigma and ostracism from in laws. Stigma and disclosure are intricately linked, and women hesitated to disclose their status due to fear of rejection, isolation, stares, name calling and gossip (Alomepe, Buseh, Awasom & Snethen, 2016). Studies by Modiba (2015) indicated that the shame associated with HIV is a major obstacle to its prevention, and the stigma that surrounds people is compounded by discrimination against women. The stigma and discrimination lead to women avoiding testing and treatment services for fear of abandonment and other repercussions from husbands, families, communities and health providers (Modiba, 2015).

2.5 PSYCHOSOCIAL SUPPORT FOR MOTHERS

Literature has shown that social support assists mothers with coping, lowers stress levels and increases the mothers' confidence (Yates, 2011). Mothers of children living with HIV receive little or no support for the challenges that they are faced with which made the experiences difficult. The support that these mothers either receive or lack seems to have been an important buffer for their challenges. Living with HIV requires many self-management tasks including treatment adherence, daily symptom monitoring, frequent engagement with one's health care provider, managing family responsibilities, dealing with the impact of stigma, preventing sexually transmitted diseases, and managing the interaction of HIV and other chronic diseases (Webel et al., 2012).

Women are disadvantaged through poverty, gender discrimination and absence of support in their role as sole responsible adults for their children (du Toit, 2012). Yates, in his studies defines resilience as the balance between risk and protective factors. He found resilience in neighbourhood, parenting, family, friends, money, personal characteristics and spirituality. Although women have a right to bear children, in the case of women with HIV/AIDS, having a child is not a simple matter (Yates, 2011). They have to deal with the psychological, social and cultural issues associated with the disease and death as well as the processes of becoming a mother (Liamputtong

& Haritavorn, 2014). The concerns for Chinese women living with HIV include stigma, sero-status disclosure, medication access, medication adherence and continuation of family obligations (Wang et al., 2016). There have not been many studies dealing with the intersection of HIV-related stigma and gender (Terzic-Supic et al., 2015).

2.5.1 Spousal support

Men are heads of households, making decisions on financial matters, as well as sexual and reproductive issues (Alomepe et al., 2016). Mhlanga, in her study states that many mothers disclosed their grief over having the fathers of their children abandon their families because they could not accept their children had HIV (Mhlanga, 2013). She supports this finding, stating that stressors of having a child with HIV frequently leads to marital conflict as well as conflict with other relatives. A study conducted by Mamogobo et al., (2014) revealed that rural women were fearful of disclosing their HIV positive status as this may lead to losing their sexual partners.

Majority of women in Thai contracted HIV from having sex within monogamous relationships with partners who engaged in high risk behaviour. When a woman is labelled as having HIV, she is treated with suspicion, her morality is questioned, and often blame is placed on her (Liamputtong & Haritavorn, 2014). Women are likely to experience violence and human rights abuses when their partners become aware of their HIV status (Durojaye, 2014). Mathur (2016) in a study noted that women received more HIV/AIDS education throughout their lifetime. They received it more directly through interpersonal interactions from healthcare providers. The effectiveness of an HIV prevention message is clearly dependent on the actions of both partners (Mathur, Romo, Rasmussen, Nakyanjo, Nalugoda, & Santelli, 2016).

2.5.2 Family support

Despite recurrent periods of stress, many families are able to sustain themselves; some finding a greater closeness through standing by each other in difficult times (Casale, Cluver, Crankshaw, Kuo, Lachman & Wild, 2015). Many reports on chronic illness in children paint a bleak picture for the children and their families. However, this picture is not always a true representation of their experiences. Many families take the illness in their stride, doing what needs to be done and living a life as normal as possible. Without disclosure, the typical HIV positive female will not get the support she needs. Disclosure initiates family support, which has a positive effect on family dynamics and self-efficacy skills (Wang et al., 2016). Mothers of HIV positive babies

tended to seek medical attention, confirmation or reassurance even for relatively minor ailments. Studies indicated that for some women, the HIV positive status of their babies had not affected how they took care of their own health. Most women believed that their babies' status strengthened their determination to safeguard their own health, so that they could care for their babies in the present and in the future (Lazarus, 2014).

Stress and the lack social support account for 40% of the cases of depression in mothers. Stress in this instance refers to a negative impact on mothers' psychological wellbeing due to their subjective experience of the demand placed upon them by their surrounding environment (du Toit, 2012). A Chinese study revealed that after disclosure, the family support women received not only facilitated their self-management but also helped them adhere to their daily ART regimen (Wang et al., 2016). HIV and AIDS infected individuals and their families have to cope with a multitude of stressors. This chronic and stigmatized condition can affect the overall functioning and lifestyle of the affected children and their families. Illness and grief interfere with the parents' ability to provide constant care for their children (Avabratha et al., 2011).

A woman is often a mother and the primary caregiver of her family. In these roles, someone is depending on the woman for support, time, resources and energy. However, women living with HIV also have increased physical and emotional needs that require them to escape from these competing demands and find time to care for themselves (Webel, Dolansky, Henry, & Salata, 2012). Families living with a member who has a chronic illness (especially HIV) vacillate between hope and despair, between suffering and possibility (Wang et al., 2016).

Studies involving caregivers who were related to and lived with HIV infected children, such as Fawzi (2010) and Demmer (2011) in Dhashini, found that caregivers experienced depression at times when caring for HIV infected children. Fawzi (2010) further concluded that parental depression further influenced the extent of "anxiety, anger, depression and loss of concentration" experienced by the HIV infected child (Dhashini, 2013). It was recommended that family-focused interventions were required to deal with the psycho-social and physical experiences of parents and their HIV infected children. It has been noted that families of HIV-positive persons often display initial negative attitudes towards HIV which is altered by means of education, making

them more accepting of the family member living with HIV (Terzic- Supic, et al., 2015). Home, for many women, is understood as a place of refuge and an idealised site of safe affective networks. Secrecy and stigma surrounding HIV often prevented family members from accessing HIV-related social support from outside the family (Hyba, 2016).

2.5.3 Community support

Studies by Mathur et al. (2016) indicated that HIV/AIDS remained a major health concern in the community. There is new evidence identifying poverty, lower educational levels, and high rates of incarcerations in communities as ecological risk factors of infection for American women (Webel et al., 2012). There are few things in life that gives as much joy and pleasure to adults as children laughing and smiling. These cannot be taken for granted. Throughout the span of childhood, globally, nationally, in communities and household contexts, there are many threats to children's happiness.

The health of children demands serious commitment by all, but especially by those specifically engaged in activities directly related to child health (Kibel, Westwood & Saloojee, 2012). Studies by Webel, Dolansky, Henry & Salata, (2012) indicate that women living with HIV face unique challenges to managing their illnesses as they balance their work as mothers, wives, employees and caregivers while managing multiple chronic conditions (Webel et al., 2012). A South African study indicates that HIV positive women are treated as impure and without rights, and may experience increased trauma through practices of silencing and isolation. Thus, fear of violence, virus and stigma has been a real tragedy in this community, and paralyzed solidarity and constrained body and agency to openly stand up against AIDS (Stewart & Strathern, 2014).

HIV care needs to take place within a holistic framework that attends to the social, psychological and physical wellbeing of the individual. The role of the household members and community support structures must be recognised and supported. Hyba (2016) indicates that the single bond of HIV status is sufficient to create a community, as the group is "united by the desire to find a safe place to deal with AIDS in their lives" (Hyba, 2016). Care has shifted from the hospital to the community for people living with HIV and offering comprehensive services to PLWH in community settings has proven effective (Green et al., 2015).

A study conducted in Cambodia concluded that it is critical to reach the most vulnerable and marginalised mothers and their children (Willis, Onda & Stoklosa, 2016). Over the past decades, many countries in southern Africa have focused on improving the health response to those living with HIV (Webel et al., 2012).

2.5.4 Financial support

Households' income is affected because of the cost of illness and death of HIV/AIDS in the family. Medical and funeral expenses are increased, and household savings are affected because of increased financial needs, leading to deep poverty and increased borrowing (Mocke, 2010). Financial hardship is considered the primary factor associated with poor mental health in mothers in a study done in Australia.

Some studies found that poverty is associated with increased risk of HIV infection. A study in Kenya found that economic independence could enhance a woman's ability to negotiate safe sex with her partner and protect herself from HIV (Muchomba, Shu-Huah Wang & Agosta, 2014). Lack of finance has a negative impact on mothers. They are unable to provide for their children as they would like to. They therefore rely on others for financial support and this leads to stress and feelings of inadequacy as mothers (Yates, 2011). A study conducted in Limpopo revealed that caring for children on ARV medication often resulted in mothers borrowing money, accumulating and living in debt, and hiking for lifts to get access to the health facilities for follow-up visits (Mafune, Lebese & Nemathaga, 2017). Some of the financial burdens include transport costs during follow-up visits to the health facilities, costs of normal household food as well as of lunch boxes during school days or during days of follow-up visits to the health facilities; and the cost of clothing for the children in need of care.

Most challenges are a result of pre-existing social living circumstances including unemployment and lack of funds. In many societies women have lower social and economic status, while also assuming primary care of the family (Wang et al., 2016). Parents have communicated financial strain as a major stressor due to the many needs, medical check-ups, and diet, involved in caring for a child with HIV. All these stressors have impacts on the family as a whole. The stressors negatively affect the siblings of the children with HIV who tend to struggle to cope with the greater attention given by the mothers to the sick children. Children with HIV also experience many stressors, which include various physical challenges and emotional problems. All

these diverse experiences are worthy of further investigation (Mhlanga, 2013). For the purpose of this study, the researcher focused on the challenges faced by mothers.

2.5.5 Professional support

Contact with health services during pregnancy is a critical opportunity for women to learn about their HIV status and, if they are living with HIV, to access medical care and treatment for their own health and to prevent vertical HIV transmission. Scaling up access is an integral part of achieving the Millennium Development Goals of reducing HIV- related maternal and child mortality (Rivero & Kendall, 2015). There is evidence to suggest that the patient/provider relationship may have an effect on decision-making during the antenatal period, and on the uptake of PMTCT interventions (Mnyani, 2013).

The study by Haffejee, Ports & Mosavel (2016) revealed that women were treated badly by a health worker because of their HIV status. Some responded that they lost their jobs, denied care by family and rejected by family. Some studies suggest that health workers lack skills and confidence to provide integrated HIV care. Inadequately trained health workers are more likely to report negative attitudes (Horwood et al., 2010).

Some healthcare providers were supportive of HIV-infected children and their families. However, in some cases there was a history of discriminatory behaviour because of the possibility that a healthcare could contract the disease from the patient (Avabratha et al., 2011). In South Africa, high HIV prevalence has profoundly affected work environment of health workers. Fear of occupational HIV exposure may lead to the implementation of non-rational and stigmatising techniques to prevent contamination, and fear of being stigmatised by association of working with AIDS patients, may make nurses reluctant to combat AIDS stigma (Horwood et al., 2010). A study by Achema & Ncama (2016) concluded that giving empathic-supportive care to children living with HIV would help them cope with the challenges of HIV.

They recommended that caregivers, nurses and others involved in the care of these children should have a listening ear and implement holistic care with empathy (Achema & Ncama, 2016). HIV clinicians will need to improve their skills and expertise in this area as caring for more of these vulnerable infants become their responsibility. In turn, neonatologist and paediatricians already caring for this clinical population will need to enhance their skills and expertise in HIV related interventions (Kuhn & Kroon,

2015). In the coming years, there is bound to be great demand for counselling services for families with children affected by HIV/AIDS. Hence the aim of the study was to explore the challenges faced by mothers with children who are HIV positive (Avabratha et al., 2011).

2.6 ANTE-RETROVIRAL THERAPY

The WHO recommend that women with HIV should begin ART prophylactically in pregnancy, irrespective of CD4 count, and continue this treatment for life (Doherty, Ford, Vitoria, Weiler & Hirnschall, 2013). The number of people living with HIV is increasing owing to population growth and drug treatment, which is prolonging life (Avabratha et al., 2011). Paediatric ART programmes have demonstrated good outcomes with increasing treatment initiation in younger children and infants, in response to South African and WHO guidelines expanding recommendations for immediate ART from infants to all children 5 years old (Davies, 2015). Following the promulgation of the 2013 national guidelines, an increasing number of young HIV infected infants and children are initiated on ART during hospitalisation (Klein, Palma, Luzuriaga, Pahwa, Nastouli, Gibb, Rojo, Borkowsky, Bernardi, Zangari, Calvez, Compagnucci, Wahren, Foster, Munoz-Fernández, De Rossi, Ananworanich, Pillay, Giaquinto, & Rossi, 2015).

This intervention is aimed at reducing MTCT, and is used in conjunction with daily ARV administration in the neonate for 4-6 weeks postnatally (Doherty, et al 2013). In Zambia alone, almost 10 000 children are infected with HIV annually. Suboptimal adherence to ART among HIV positive mothers increases the likelihood for maternal HIV related disease progression and drug resistance for both the mother and her child (Hampanda, 2016). Achieving high treatment adherence remains a challenge in many settings globally. A South African study by Pillay et al., shows that ART-naïve HIV infected children are still very much at risk of HIV related morbidity and mortality (Pillay et al., 2015).

The Integrated Management of Childhood Illness strategy was adopted in 1988 as the country's primary strategy for reducing deaths in young children. South Africa was the first country to include identification and management of HIV infection in children in the IMCI Chart Booklet. One of the key shifts in the South African HIV programme is that ART for children should be provided at all public sector health facilities. The

National Department of Health recommends that nurses should be at the forefront of initiating and following-up children on ART (Republic of South Africa, 2010). Successful treatment of HIV-positive children requires a high level of adherence, at least 95% to highly active antiretroviral therapy. Psychosocial factors contribute substantially to the successful outcomes of ART, in particular counselling of caregivers before and during ART initiation (Pillay et al., 2015).

Studies by Ricci, Netto, Luz, Rodamilans & Brites (2016) suggested that optimal adherence to therapy can be affected by several child-related factors, including bio-medical psychosocial, and antiretroviral therapy and caregiver characteristics.

2.7 CARE OF THE SICK CHILD WHO IS HIV POSITIVE

Effective antiretroviral treatments for mothers and babies are available in many sub-Saharan African countries, for example, in Tanzania, Uganda, and South Africa through their national programmes. PMTCT programmes have made it possible to reduce the risk of infection. In South Africa, the PMTCT guidelines recommend that diagnostic testing in infants be performed as early as 4 - 6 weeks of age, so that highly active antiretroviral treatment (HAART) is initiated early, thereby reducing the deaths of infants (Shipalana & Ntuli, 2016). Without care and treatment, one third of infants die in the first year of life and about a half of children by the second year of life (Le Doare et al., 2012). Early diagnosis of HIV infection enables immediate HIV care and initiation of ART as recommended by World Health Organisation. This significantly reduces mortality and hospitalisation (WHO, 2010). Several authors have reported that growth retardation due to HIV could be corrected with ART initiation (Leroy& Jesson, 2015). Studies indicate that vulnerable children living with HIV conditions used compassionate care from their family members, nurses and other stakeholders in health care in order to cope with the HIV condition.

HIV/AIDS is a chronic disease that needs the full understanding and cooperation of parents or guardians to take the children for lifelong treatment (Shipalana & Ntuli, 2016). Caregivers of HIV infected children are faced with the added responsibility of ensuring that these children have access to life-saving health care at all times (Achema & Ncama 2016). A Brazilian study by Ricci et al. (2016) indicates that some characteristics of the caregivers can affect children’s adherence to treatment. In the case of mother-to-child transmission, death or severe disease of biological parents

may enable them to take care of the child. This is especially true for mothers, who usually have to deal with the guilt associated with HIV transmission and many have other comorbidities such as depression, which result in delayed care of the children (Ricci et al., 2016).

An exploratory study on the experiences of caregivers in KwaZulu-Natal, with 13 female caregivers and 12 professionals who worked with caregivers and HIV infected children, concluded that poverty and stigma impact greatly on the caregivers' ability to provide care for the HIV infected children (Dhashini, 2013). Caregivers who are responsible for the health and wellbeing of HIV infected children face constant challenges in their caregiving role and this has implications for the quality of care of the children. The needs of HIV infected children are complex but vital to meeting those needs is the administration of antiretroviral therapy.

2.7.1 The nutritional needs of a child living with HIV

Nutrition forms an integral part of any care plan for children living with HIV/AIDS. It is also important in the provision of ART to achieve full benefits (Leroy & Jesson, 2015). The WHO recommends the avoiding breastfeeding only in situations where replacement feeding is acceptable, feasible, affordable, sustainable and safe (WHO, 2010). Children living with HIV and AIDS have increased energy needs compared to uninfected children. These children experience a deficiency in micronutrients (Leroy & Jesson, 2015). In a study undertaken in Tanzania it was found that mothers found it difficult to adhere to either exclusive breastfeeding or replacement feeding due to cultural norms enforced by older generations (Oliver & Petty, 2012).

Infant feeding in communities with a high prevalence of HIV and AIDS is a potential challenge to mothers who must ultimately decide how to feed their infants within contexts that constrain their choices (Levy, Web & Sellen, 2010). Studies in HIV-positive mothers showed that those neonates who were exclusively breastfed showed significantly lower rates of diarrhoeal diseases and had lower rates of hospitalisation (Sepeng & Ballot, 2015). Malnutrition is associated with more than one third of all deaths in children under 5 years of age worldwide. The first of the Millennium Development goals that targets extreme poverty and hunger by halving malnutrition is far from achieved (Leroy & Jesson, 2015). Malnutrition is a common complication associated with HIV and AIDS. It adds stress to an already weakened immune system and may complicate the treatment of the disease by negatively affecting the ability of

the intestinal tracts to absorb drugs, proteins, carbohydrates and fats (Leroy & Jesson, 2015).

2.8 CHILDREN LIVING WITH TERMINAL ILLNESSES

"A child's chronic illness variables are its daily effects yet ever a threat to the child's survival, a chronic illness is inescapable. For both child and family, it is a perceptual demanding companion; a lifelong associate; a constant shadow" (Shisana, 2012). Examples of chronic illnesses that children may suffer from include muscular dystrophy, spina bifida, congenital heart disease, sickle cell disease, or leukaemia. A child with a chronic illness stays a developing individual, needing love and care. However, the recurrent experiences that characterize the child's illness punctuate his life (Ruddle, 2011). Strong mother-child relationships can contribute to enhanced psychological resilience in children (Visser, Finestone, Sikkema, Boeving-Allen, Ferreira, Eloff & Forsyth, 2012). The repeated medical procedures, accompanied by pain, and boredom or feelings of anxiety, may come with waiting in a clinic or at the hospital (Ruddle, 2011).

2.8.1 Breastfeeding versus Bottle-feeding

Optimal breastfeeding is essential for a child's survival and development because breast milk has all the necessary nutrients for healthy growth; and it also provides significant protection from childhood diseases (Marinda, Chibwe, Tambo, Lulanga & Khayeka-Wandabwa, 2017). For women with HIV, infant feeding decisions can be complex (Murphy, 2009). Several women felt that due to the expectation of breastfeeding within their cultural setting, to formula feed carries the risk of inadvertently disclosing their HIV status to those around them. Therefore, cultural norms and expectations of African women living with HIV may influence feeding decisions (Oliver & Petty, 2012). Health education and counselling should be given whenever mothers visit the clinics in order to raise awareness on feeding-related issues; and to also respond to and clarify on the questions that arise from the mothers (Marinda et al., 2017).

A case study was conducted by Petty and Oliver (2012) about an African woman in the United Kingdom. She was advised to formula feed her baby. She felt that formula feeding was culturally considered a signal of being HIV positive and carried an undesirable stigma (Oliver & Petty, 2012). In sub-Saharan Africa it is difficult for

women with HIV to adhere to a chosen infant feeding method due to pressure from family members. It is nearly impossible to adhere to exclusive bottle feeding and exclusive replacement feeding regimen because both are alien concepts in African societies where mixed feeding is the norm (Modiba, 2015). Furthermore, Morgan (2010) studied a sample of 18 Botswana women with HIV, taking highly active antiretroviral therapy (HAART), who had chosen to breastfeed. Breastfeeding, especially exclusive breastfeeding in the first months of life, is the cornerstone of good infant nutrition, health and survival (Morgan, 2010).

The various benefits are not for the child only, but also for the mother. Such benefits extend beyond infancy, as they also provide protection against common non-communicable diseases in adult life (Kuhn & Kroon, 2015). Human milk is uniquely composed to meet the needs of the human infant, and has been established as the optimal form of nutrition for neonates (Sepeng & Ballot, 2015). Avoiding breastfeeding is not realistic in developing countries and a large proportion of HIV positive women breastfeed their infants due to social pressure (Hafejee et al., 2016). A study conducted in Cambodia, shows that the country's national policy recommended exclusive breastfeeding in consideration of the population's lower income level, which hinders the sustainability of formula feeding. Complimentary breastfeeding (combination of breastfeeding and replacement feeding) represents an important source of risk for infants born to HIV infected mothers. A study conducted in Nigeria, indicated that formula feeding has been associated with higher risk of infant mortality than breastfeeding (Nwaozuzu & Dozie, 2014).

And the WHO recommends that infants born to HIV positive mothers receive either exclusive breastfeeding or exclusive replacements feeding in addition to early weaning (Nwaozuzu & Dozie, 2014).

2.9 HIV/AIDS AWARENESS

Studies indicate that the population of children with HIV is growing due to increased life expectancy; and the anticipated quality of life for children with HIV has progressed due to advancement in healthcare and societal integration. In support of these mothers, there is ongoing research on HIV/AIDS and mothers. As there is no cure for HIV infection, lifelong ART is required to allow HIV-infected individuals to lead healthy lives (Sued, Figueroa, & Cahn, 2016). Children with HIV infection are at risk of

developmental and behavioural challenges. With treatment, HIV positive children are growing up and reaching adolescence. The introduction of effective new antiretroviral therapies in the early 90s provided improved health and increased life expectations for HIV infected children (Sherr, Croome, Castaneda, Bradshaw & Romero, 2014).

Initial interventions in paediatric HIV/AIDS focused on the medical urgency and terminal nature of the disease (Ricci et al., 2016). Understandably, there was little attention given to long term psychosocial issues and adjustment. Improvements in medical treatment however have resulted in a decline in the incidents of AIDS and mortality in both children and adults. These children, who were initially not expected to survive, are now facing academic, social and emotional issues related to living with a chronic health condition (Avabratha et al., 2011).

HIV has both physical and psycho-social impact on individuals. The latter often being a neglected aspect of intervention (Dhashini, 2013). HIV positive children are plagued by physiological challenges such as acute weight loss, failure to thrive, prolonged fever, recurrent thrush, chronic diarrhoea, tuberculosis, pneumonia, recurrent bacterial infections, dermatitis, neurological abnormalities such as seizures and other AIDS defining conditions. A further challenge is that HIV infected children are often not as responsive to medical treatment as non-infected children. As a result, they are likely to struggle with life-threatening complications (Dhashini, 2013).

These physiological experiences can be frightening and traumatic for the HIV infected children because they could require extensive periods of hospitalisation. Thus providing for the health and welfare of HIV infected children can be emotionally and physically draining for their mothers (Dhashini, 2013).

A South African study that analysed post-natal deaths under 12 months of age identified a peak in mortality between one and three months owing to HIV infection. In 2013 SA recommended birth HIV DNA PCR testing for HIV exposed low birth weight infants, and the 2014 National Consolidated HIV guidelines recently extended birth testing to new-borns deemed to be at high risk of antenatal or intrapartum HIV infection (Elley, 2015). Managing HIV infected children is complex. The social issues that have caused poor access to prevention programmes often persist and complicate management. Many experienced paediatricians grapple with these issues. And there is currently no consensus on the best approach (Demas, Rabie & Cotton, 2014). South African clinicians are grappling with the prevention, diagnosis and management of HIV

infection in neonates and there is a limited body of evidence to guide them (Elley, 2015).

2.10 BELIEF SYSTEM

Fatima & Suhail (2010) measured the impact of mothers' belief system on their emotional experience and concluded that one's personal belief system is a personal supportive resource when facing both normal and adverse life circumstances. Literature studied throughout the years, illuminates on the participants' expression of faith as a meaningful coping mechanism that has contributed to the positive experience of mothers of children with HIV (Mhlanga, 2013).

HIV prevalence is high among South African women of reproductive age and transmission of HIV from mothers to children is a concern. South Africa has made strides in reducing the number of new HIV infections through a National Strategic Plan for HIV/AIDS with priorities in expanding access to treatment and support services (Haffajee et al., 2016).

2.11 BURDEN OF HIV/AIDS

After 30 years, the HIV remains an epidemic of global concern with Sub-Saharan Africa bearing the heaviest burden (Mathur et al., 2016). HIV is thus influencing women's lives more deeply, as they are more susceptible to the disease at an age when they are experiencing rapid social development (Wang et al., 2016). Women and children are the most vulnerable groups that need special attention. HIV/ AIDS is a leading factor that has contributed to the rise in under-5 morbidity and mortality rates and had made it impossible for South Africa to achieve the Millennium Development Goal 4 by 2015 (Shipalana & Ntuli, 2016). Studies shows that despite concerted health education efforts over the last decades in Rakai, there are gaps in health information, ways the messages are used, and their salience. If ignored, these gaps could hamper future HIV behavioural and biomedical prevention efforts (Mathur et al., 2016).

Women in developing countries are disproportionally burdened by HIV disease. This has impacted their abilities to perform a core role of taking care of their families. Cameroon's society is patriarchal and societal norms about masculinity and gender give men control over women. Women in Cameroon are caregivers for their families and communities, but HIV infected women must also deal with living with the virus

(Alomepe et al., 2016). HIV has a huge impact on individuals and community structures such as families (Mocke, 2010). HIV positive children are more prone to neglect by their families and friends. The impact of HIV/AIDS includes deepening poverty and psychosocial defects in the family. Family members are often traumatised and have a variety of psychological reactions to illness and death of family members including stigmatisation in the family, and separation from associations and siblings.

According to studies by Colvin, HIV positive patients have more contact with healthcare services than HIV negative patients. The current HIV epidemic in South Africa affects the health system mainly in the form of low staff morale and loss of staff due to illness. HIV infection increases hospital admissions, leading to overcrowding of wards. According to a study conducted in Soweto, HIV positive children were hospitalised for an average of eight (8) days compared to an average of six (6) days in HIV negative children (Colvin, 2010).

HIV has a dramatic effect on the mortality of the population. Worldwide, a child under 15 years dies of an AIDS-associated illness every minute of every day (Mocke 2013). Although HIV does not change identities of women, it does threaten their ability to continue functioning in their traditional gender-based roles. Facing multiple social expectations and obligations, HIV positive women may come to doubt their personal worth and feel that they brought shame on themselves (Wang et al., 2016). In spite of the growing numbers and pressing needs of this population, still there is limited knowledge about the mothers themselves, the impact of illness on parenting and on their children, and how to provide effective support services for these mothers.

2.12 LEGISLATION RELATED TO HIV AND WOMEN

Many countries have taken legislative measures to address the legal and human rights issues related to HIV. In sub-Saharan Africa, the majority of countries adopted HIV-specific legislation. As of August 2014, 27 Sub-Saharan countries had adopted such laws (Eba, 2016). In the countries where human rights of women are not respected, the risk of HIV infection is much greater (Kowala-Plaskowska et al., 2010). Studies indicate that biomedical interventions alone cannot curb the HIV epidemic among young women and girls in sub-Saharan Africa. The history of the global response to HIV is rife with political failures to address deep-seated human rights violations. Gender inequality which ranges in its manifestations from persistent failures to

recognize the sexual and reproductive health and rights of women to economic injustices perpetuated through law—allows HIV to flourish among young women and girls (Mcgovern, Fine, Crisp & Battistini, 2017).

Women's sexual health and reproductive health and wellbeing are dependent on a complex array of socio-economic and healthcare factors (Cooper et al., 2016). Two decades after the advent of democracy, South Africa remains a highly unequal society socio-economically (Cooper et al., 2016). Women are more likely to experience violence and human rights abuses when their partners become aware of their HIV status (Durojaye, 2014). South Africa is often seen as a beacon of hope for upholding sexual rights. After South Africans transition to democracy, people's rights become more actionable assurance of equality given by the 1996 Constitution (Daly, Spicer & Willan, 2016). Global and regional human rights treaties including the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa provide for specific protections of the human rights of women and girls (Mcgovern et al., 2017).

In the South African context, where the right to health is enshrined in the Constitution, health policy developments provide unique opportunities to air concerns about even the most marginalised citizens, women included (Daly et al., 2016). Studies conducted in Lesotho found that women did not have access to the core human rights described in the United Nations Human Rights Commission's "Born free and equal" report (Poteat et al., 2015). South African laws and policies support a rights-based framework and are aligned with internationally confirmed documents, and health and development frameworks including the 1994 International Conference on Population, the 1995 Beijing Conference on Women, the Millennium Development Goals (MDGs), the Sustainable Development Goals (SDGs), and the Global Family Planning 2020. South African women have full equality in terms of the legislation, but unequal power relations continue to undermine women (Cooper et al., 2016).

The South African National Strategic Plan for 2012-2016 was developed in 2011 to focus on key populations vulnerable to HIV, including women (Daly et al., 2016). Eba, (2016) in his studies indicated that even the smartest HIV-related legislation will have little impact unless it is accompanied by financial and other measures to support its implementation and enforcement (Eba, 2016). A study of African countries such as

Botswana, Lesotho, Swaziland, Namibia and South Africa came up with the Protocol to the African Charter on Human and Peoples Rights on the Rights of Women in Africa (Durojaye, 2014). The protocol allowed for great opportunities to exist for African governments to address the gender dimension of the HIV epidemic. The protocol contains provisions to advance women's fundamental rights in general, and sexual and reproductive rights, in particular (Durojaye, 2014).

In June 2016, the South African AIDS Council launched the US government-funded "DREAMS'' campaign to reduce HIV among girls and young women. The campaign aims to link problems of HIV teenage pregnancy, school 'drop outs' and gender-based violence and create economic opportunities for young women (Cooper et al., 2016). Under international human rights law, states are required to take steps to progressively achieve the full realization of the right to sexual and reproductive health (Mcgovern et al., 2017).

2.13 CONCLUSION

Chapter two has provided a critical review of relevant literature that relates to the current study. The chapter commenced with a global, African and South African overview of HIV and AIDS together with the government's response to HIV in South Africa.

This was followed by challenges and stigma faced by mothers with children who are HIV positive. Support for mothers has also been discussed, followed by ART and care for children with HIV. Subsequently, HIV/AIDS awareness, belief system, the burden of HIV, and legislation related to HIV and women, have also been discussed. The next chapter presents the research methodology.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter, the methodology used to conduct the research on challenges faced by mothers with HIV positive children is presented. The focus is on the research setting, the research design, sampling strategy, methods of data collection, data analysis and the relevant ethical considerations.

3.2 STUDY SITE

The study site for this research was the Paediatric Medical Ward at Pietersburg tertiary hospital situated in South Africa, Limpopo Province, Polokwane under Capricorn District (See figure 3.1).

The hospital offers amongst others, ART, HCT, PMTCT and other specialist services. There is a HOPE Clinic within the hospital dedicated only to the care of HIV/AIDS patients. There are similar clinics within district hospitals in the Limpopo Province. Patients with HIV/AIDS-related complications from hospitals around the province are referred to the HOPE Clinic of Pietersburg Hospital for specialist management. Around ten (10) HIV positive children are admitted to the Paediatric Medical Ward with HIV-related illnesses on a monthly basis. Mothers lodges in the ward to look after their children.

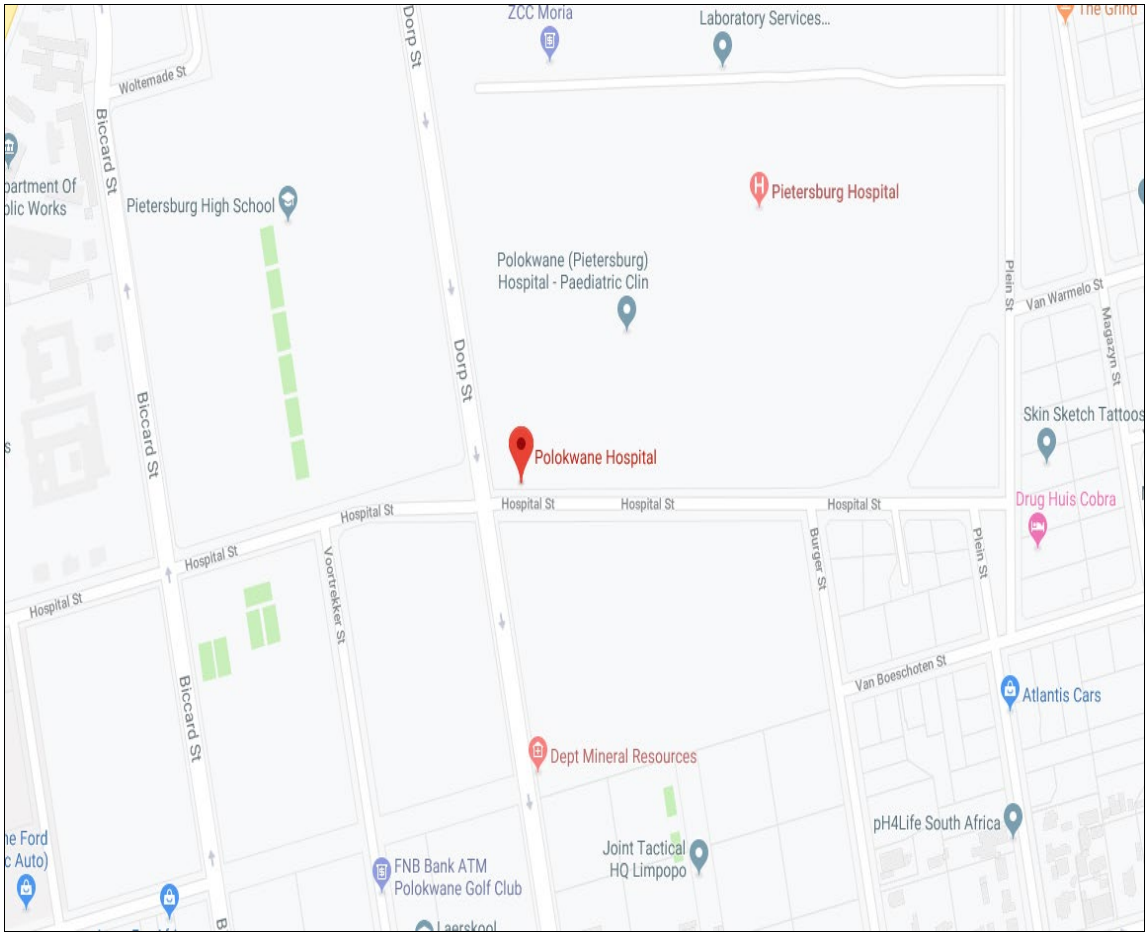

Figure 3.1: Area map of the research site

3.3 RESEARCH DESIGN

A research design provides the structure for the research methods and design decisions that must be taken to plan a study (Botma, Greef, Mulaudzi & Wright, 2010). It enables a researcher to anticipate what appropriate research decisions should be taken so as to maximise the validity of the eventual results (Botma et al., 2010).

A qualitative, exploratory and descriptive design was used in the study. Qualitative research involves investigation of a phenomenon, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design (Polit & Beck, 2012). In such research, a systematic, interactive and subjective approach is used to describe life experiences and give them meaning.

A common method for collecting the relevant information in qualitative research is that of unstructured interviews. Mugivhi (2010) in her study argued that, at the root of unstructured interviewing is interest in understanding the experiences of other people and the meaning they make of those experiences. HIV-positive mothers experience

various problems and a qualitative methodology offers the opportunity to seek depth in the understanding of complex challenges rather than seeking the breadth of findings that a quantitative design offers (Mugivhi, 2010).

The purpose of exploratory designs is to develop an initial, rough understanding of a phenomenon (Botma et al., 2010). Exploratory research begins with a phenomenon of interest, but rather than simply observing and describing it, such research investigates the full nature of the phenomenon, the manner in which it is manifested and the other factors which it is related to (Polit & Beck, 2012). Descriptive designs are used where more information is required in a particular field through the provision of a picture of the phenomenon as it occurs naturally (Botma et al., 2010). The researcher does not manipulate variables, and makes no effort to determine the relationship between them. The researcher searches for accurate information about the characteristics of a single sample or about the frequency of occurrence of a phenomenon (Brink, Van der Walt & Van Rensburg, 2012).

In this study, the researcher explored and described the challenges faced by mothers with children who are HIV positive at Pietersburg Hospital, Limpopo Province, South Africa.

3.4 POPULATION AND SAMPLING

Population is the entire group of persons or objects that is of interest to the researcher, and which meet the criteria the researcher is interested in studying (Brink, Van der Walt & Van Rensburg, 2018). The population for the study included all mothers of children who were HIV positive and were admitted to the Paediatric Ward of Pietersburg Hospital, Limpopo Province, during the period of the study.

Sampling is a strategy that researchers employ to select a representative group of few individuals drawn from the broader research population. The actual study is then focused on the representative group of few individuals, commonly referred to as the sample population, and the findings are extrapolated and generalised to the entire research population. In this study, a non-probability purposive sampling strategy was employed to select the research sample. Non-probability purposive sampling is a technique of drawing sample populations from research populations based on the judgement of the researcher regarding participants that are representative of the study phenomenon, or who are especially knowledgeable about the question at hand (Brink,

Van der Walt & Van Rensburg, 2012). Twelve HIV positive participants who were mothers of HIV positive children who were admitted at to the Paediatric Ward at the Pietersburg Hospital during the period of this study were selected to form the sample. In the study, the term 'mother' was used to refer to any individual playing the role of a mother to an HIV positive child. It therefore turned out that out of the twelve (12) mothers, two (2) were biological grandmothers to the respective children, one (1) was a guardian to the respective child. The remaining nine (09) were biological mothers to the respective HIV-positive children.

3.4.1 Inclusion criteria

Although the initial intention was to focus on mothers to children who were below five years old, because the majority of the children were five and more years old, a decision was taken to widen the scope of the study to include positive HIV mothers to HIV positive children of any age admitted at the hospital. In this study, the term mother refers to both "biological mothers'' and "substitute mothers" (Hejoaka, 2009) caring for children who were admitted at Pietersburg Hospital, Paediatric Ward, in the Limpopo Province. The twelve (12) in the sample were those who had expressed their availability and willingness to take part in the study. This specific number of mothers was sufficient to enable the researcher to identify problems faced by HIV-infected mothers, but still manageable for one researcher to collect in-depth information from, within a limited time. Data were collected over a period of three (3) months from April to June 2017. The participants were interviewed until the point of saturation in terms of information was reached. Data saturation is the point at which new data no longer emerge during the data collection process (Brink et al, 2018).

3.4.2 Exclusion Criteria

All HIV positive mothers with HIV negative children admitted in Paediatric Ward during the study were excluded because the study focus was on both HIV positive mothers and their children. The study specifically sought participants who were willing to share their challenges and shed light on the phenomenon in question.

3.5 DATA COLLECTION

It is a requirement in research that data should be valid and capture the meaning of what a researcher observes. Data collection is the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions or

hypotheses of a study (Burns & Grove, 2015). In this study, qualitative data were collected through the use of semi-structured in-depth interviews. Fields notes were captured for non-verbal communication and voice recorder was used to capture all the interview sessions.

The central question that was asked in the same way for all participants was: “What are the challenges that you face as mothers with children who are HIV positive? Probing questions were asked to allow the researcher to explore further on the challenges that HIV positive mothers face. The participants were encouraged to elaborate more on the challenges they face with their HIV positive children. Data was collected until no new information was emerging from the interviews. Data saturation was reached at participant number 12.

The researcher collected data over a period of three months at the Paediatric Ward of Pietersburg hospital after obtaining permission from the hospital’s Research Committee and the Operational Manager. Voluntary informed consent was obtained in writing from the participants. Interviews were conducted with individual HIV positive participants of HIV positive children in the private room to ensure confidentiality of participants. Each interview lasted for about 30 to 45 minutes. The interviews were conducted in Sepedi, a language used by the majority of people in and around Polokwane.

3.5.1 COMMUNICATION TECHNIQUES

In this study, the following communication techniques were used during the semi-structured interviews:

3.5.1.1 Listening

A researcher is expected to have good listening skills. Mothers with HIV positive children were given the opportunity to talk and describe their challenges without interference. The researcher also observed non-verbal and facial expressions.

3.5.1.2 Encouragement

The participants were encouraged to pursue a line of thought. They were encouraged to elaborate on their challenges with HIV positive children.

3.5.1.3 Clarification

Clarification embraces the method that seeks further explanation of unclear statements. The researcher asked follow-up questions to gain more insight and a better understanding of the responses provided.

3.5.1.4 Probing

This is the technique used to persuade the participant to provide information about the issue under discussion. This assisted the researcher to get a detailed response to a question, to increase the richness of the data being obtained, and to give clues to mothers about the level of response that was desired.

3.5.1.5 Paraphrasing

Paraphrasing involves a verbal response when a researcher repeats the essence of what participants are saying to confirm that the statements are correctly understood. The researcher tried to obtain accurate meaning by asking the mothers of HIV positive children the same question in a different manner, using the same words the participants used.

3.6 DATA ANALYSIS

Data analysis is conducted to reduce, organize and give meaning to data (Burns & Grove, 2015). The individual responses of mothers were analysed, compared, categorised and interpreted to draw conclusions. The following Techs's open coding methods as outlined in Cresswell (2009) were adhered to during data analysis:

- The researcher obtained the sense of the whole by reading all the transcripts carefully. The ideas that came to mind were jotted down.
- The researcher selected one interview, for example the shortest one, and went through it asking: "What is this about?"
- The researcher completed this task for several participants; a list was made of all the topics. Similar topics were clustered together and formed into columns that were arranged into major topics, unique topics and leftovers.
- The researcher found the most descriptive wording for the topics and turned them into categories. The researcher reduced the total list of categories by grouping together topics that relate to each other. Lines were drawn between categories to show interrelationships.

- The researcher made the final decision on the abbreviations for each category and alphabetises the codes.
- The researcher assembled data material belonging to each category in one place and performs a preliminary analysis.
- The researcher recoded the existing data.

Data were collected during interviews and audio-taped. The audio recordings were transcribed verbatim, then repeatedly listened to in order to familiarise with the content and any intonations. Data were coded to enable tracing themes and quotes. Comments and reflections were recorded on the transcriptions.

In order to identify themes and supporting quotes from the text, areas of concern to the participants were identified and linked with the participants' expressed experiences. Themes were identified and grounded in the text. Themes illustrating similar concepts were then grouped together. These sub themes were represented under a main theme, again grounded in the text. Any patterns that emerged were included at this level.

Finally, a table with main themes supported by sub themes was constructed to illustrate the main findings. After data analysis and discussion, a comparison was done between the participants' lived experiences and literature regarding challenges faced by mothers with HIV-positive children. Similarities and discrepancies were identified and discussed.

3.7 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness is the degree of confidence qualitative researchers has in their data, assessed using the criteria of credibility, transferability, dependability and confirmability (Polit & Beck, 2012).

3.7.1 Credibility

Credibility refers to the believability of the data (Polit & Beck, 2012). In this study, credibility was ensured by triangulating data collection methods. A voice recorder was used to capture interviews. Sessions field notes supplemented the voice recorder where non-verbal communication was noted. Prolonged engagement was ensured by staying in the field until data saturation was reached (Brink et al., 2012). The

researcher allowed the participants to describe challenges they faced as mothers with HIV positive children through verbal interview, voice recording and field notes.

3.7.2 Transferability

Transferability is defined as the ability to apply the findings to other participants (Brink et al., 2012). The researcher purposefully sampled HIV positive participants of HIV-positive children who were able to describe their challenges. Participants were interviewed until no new information was emerging. Other researchers would be able to conduct similar studies in different contexts as observations were defined within the specific contents in which they appeared.

3.7.3 Confirmability

Confirmability guarantees that the findings, conclusions and recommendations are supported by the data and that there is internal agreement between the investigators' interpretation and the actual evidence. This is accomplished by incorporating an audit procedure (Brink, Van der Walt & Van Rensburg, 2012). The researcher collected data from the mothers of HIV positive children. The data reflected the voice of the participants, and not the researcher's biases and perceptions. Confirmability was also achieved by incorporating an independent coder, who was used for quality checks (King & Horrocks, 2010).

3.7.4 Dependability

Dependability refers to the stability of data over time (de Vos, Strydom, Fouche & Delport, 2013) The researcher asked mothers with HIV positive children to explain and describe their own views and experiences regarding the challenges they face. The researcher provided evidence such that if the study were to be repeated with the same or similar participants in the same or similar context, the findings will be similar & (Brink et al., 2018).

3.8 ETHICAL CONSIDERATIONS

Ethics is a moral value system that is concerned with the adherence of professional, legal and social obligations to the study participants. Ethical behaviour is important in research. When human beings are used as study participants, care must be exercised to ensure that their rights are protected (Polit & Beck, 2017). The researcher must understand the importance of protecting research participants. The benefit of the

research must outweigh its risk (Brink et al., 2018). Ethical guidelines also serve as standards, and a basis upon which each researcher ought to evaluate her or his own conduct (de Vos et al., 2013).

3.8.1 Ethical clearance

Ethical clearance was obtained from Turfloop Research Ethics Committee (TREC). Permission to conduct the study was obtained from the Limpopo Department of Health, the Chief Executive Officer and Paediatric Ward Operational Manager of Pietersburg Hospital.

3.8.2 Informed consent

Written informed consent was obtained from participants. The nature and purpose of the study were clearly explained to the participants before the study commence. participation was voluntary and the participants had a right to withdraw from the study at any time without any penalty. Participants were provided with opportunity to raise any concerns or questions (Brink et al., 2012). The consent form was signed by participants before the interview. Participants who could not write used finger print instead of signature on the consent forms. The participants' permission to be audio-recorded was obtained before starting with the interviews.

3.8.3 Protection from harm

The right to protection from discomfort and harm from a study is based on the ethical principle of non-maleficence. which states that one should prevent harm and, above all, do no harm. In research, discomfort and harm can be physical, emotional, social or economic (Burns & Grove, 2015). The researcher observed the participants for any signs of distress during the interviews. The participants were given a chance to ask questions and verbalise if they feel uncomfortable during the interviews. A social worker and a psychologist were on standby for participants that would need counselling due to the sensitive nature of the topic.

3.8.4 Anonymity and Confidentiality

Anonymity refers to a researcher's act of keeping the identities of participants concealed to an extend that the researcher cannot link individuals with the information provided (Brink et al., 2012; Polit & Beck, 2018). Confidentiality refers to a researcher's commitment to non-disclosure of private information shared by participants (Burns & Grove, 2015).

According to De Vos et al., (2013) “every individual has the right to privacy and it is his or her right to decide when, where, to whom and to what extent his or her attitudes, beliefs and behaviour will be revealed”. The researcher kept the identity of the participants anonymous by conducting interviews in a private room. Similarly, the research data was handled in strict confidence by using code names and not revealing it to other persons. The researcher ensured the anonymity of the participants by not directly identifying them at any time during the research process. Codes and pseudonyms were used instead. The researcher assured the participants of their confidentiality throughout the research process.

3.9. BIAS

Bias is an influence that produces an error, which can affect the quality of evidence in qualitative studies. Bias can occur at, and within any step of the research process (Brink et al., 2012). Any component of the study that deviates from true measures leads to distorted findings (Burns & Grove, 2015)., the researcher minimised bias by not including personal opinions and views in the study. The researcher did not allow her prior understanding about the problem to influence the research process and its findings.

A sample of 12 HIV positive participants was selected for the study as such participants represented the study phenomenon, and were presumed to be knowledgeable about the question at hand. The local spoken language (Sepedi researcher was used during data collection to facilitate participants understanding. Furthermore, triangulation was used during data collection to strengthen bias minimisation.

3.10 CONCLUSION

This chapter has presented the qualitative research methodology adopted for this study on challenges experienced by mothers with children who are HIV positive. Face-to-face, semi-structured interviews were used with the help of an interview guide. Mothers were purposefully sampled in the Pietersburg Hospital by accessing women whose children were admitted to the Paediatric ward. The data collection and analysis procedure have been presented. The chapter has also explained the process of reflexivity that was employed to enhance the trustworthiness and authenticity the research process, the information collected. Finally, the ethical considerations specific

to this study have also been highlighted. The next chapter presents, interprets and discusses the research findings.

CHAPTER 4

RESEARCH FINDINGS AND LITERATURE CONTROL

4.1 INTRODUCTION

The previous chapter presented the methodology used to conduct the research on challenges faced by mothers with HIV positive children. This chapter presents the findings of data that was collected from the twelve (12) participants who were purposively sampled to describe challenges faced by mothers with HIV positive children, and who were admitted at the Pietersburg Hospital in Limpopo Province at the time of the study.

Table 4.1: Demographic characteristics of participants

Number	Relation to child	Participants' age	Marital status	Employment status	Time of child's diagnosis	Child's present age
1	Guardian (Female)	38 years	Single	Employed	At birth	10 years
2	Mother	36 years	Widow	Unemployed	At birth	9 years
3	Mother	41 years	Married	Employed	At birth	8 years
4	Grandmother	72 years	Widow	Pensioner	At birth	7 years
5	Mother	34 years	Single	Unemployed	At birth	11 years
6	Mother	38 years	Married	Unemployed	At birth	11 years
7	Mother	41 years	Single	Employed	At birth	8 years
8	Mother	45 years	Single	Unemployed	At birth	10 years
9	Grandmother	68 years	Widow	Pensioner	2 months	7 years
10	Mother	40 years	Single	Unemployed	At birth	3 years
11	Mother	33 years	Single	Unemployed	At birth	6 years
12	Mother	36 years	Single	Unemployed	At birth	5 years

The participants included the nine biological mothers, one female guardian and two grandmothers. The marital status of the participants varied: two mothers were married one was a widow and six were single; the one female guardian was single; both of the

two grandmothers were widowed. Four of the participants were employed, six unemployed and two were pensioners. Eleven of the participant's children were diagnosed HIV positive at birth, and one at two months of age. The age of participants' children varied from three (3) to eleven (11) years. The age of the children was an important variable in the study because it indicated the time period that the respective mothers were living with challenge of giving care to their children.

4.2 DISCUSSION OF RESULTS

The findings on the challenges faced by the mothers were categorized under four main themes and eleven sub-themes. These four main themes and the associated sub-themes are summarized in Table 4.2. The verbatim statements made by the participants are presented in italics in the discussion parts of the chapter.

Table 4.2: Themes and sub-themes related to the challenges faced by mothers with children who are HIV positive

Theme	Sub-theme
1. Disclosure of HIV positive status	1.1. Disclosure of HIV positive status to child 1.2. Disclosure of HIV positive status to teachers at school
2. Taking care of an HIV positive child	2.1. Hospital visits for regular check-ups 2.2. Financial burden 2.3. Opportunistic infections 2.4. Child defaulting on the treatment schedule 2.5. Isolation from social life
3. Fear of stigma	3.1. Stigmatisation of HIV positive child

4. Challenges in accessing support	4.1. Family support system 4.2. Financial support 4.3. Available support structures for mothers of HIV positive children

4.2.1 THEME 1: DISCLOSURE OF HIV POSITIVE STATUS

The information obtained from the semi-structured interviews from participants with children who were HIV positive in Pietersburg Hospital in the Limpopo Province, revealed that some participants found it very difficult to tell their children of their HIV positive status. This finding is similar to a study conducted in rural Zambia by Tsuzuki, Ishikawa, Miyamoto, Dube, Kayama, Watala & Mwango (2018). The study found that although parents and caregivers of children living with HIV said that disclosure of positive status was a necessary process and good for their children, disclosure rates were, however, low. The parents and caregivers therefore could not inform their children of their HIV positive status although they continued to give them their ARVs as expected. Two subthemes emerged from this theme and were outlined as follows:

4.2.1.1 Sub-theme 1.1: Disclosure of HIV positive status to child

The study revealed that some of the mothers of HIV-positive children experienced challenges regarding disclosure of the HIV positive status to their respective children. They therefore failed to make the children aware that they were living with HIV. However, the mothers continued to administer ARVs to the children. Some of the participants felt that they were ill-equipped to handle the possible consequences of making their children know that they were living with HIV. They indicated that they needed assistance from the doctors and nurses or counsellors to disclose this information to the children. One participant explained that she felt she did not have the right to disclose the status to the child. Some of the participants were worried how their children would react after knowing that they were HIV positive and other participants were afraid that the children would react in a negative manner once they knew that they were HIV positive. One participant explained that she had informed her child that he was HIV positive.

Below are verbatim extracts of interview answers on the question of disclosing to the children the information that they were HIV positive.

Participant 1 said: Sometimes when I administer the medication, I ask the child, "my child, what is this medication for? Do you have headache"? He would reply and say he does not have a headache. I say to him: "Do you just take the medicine without feeling any headache? He would say, "Yes". Then I would say, "Okay". I would not tell him; I do not have the right to tell the child; …? Mmm! Okay! This means I ought to tell the child so that he can know the purpose of the medicine.

Participant 6 also said: That before you first divulge the information regarding the child's HIV status, I have fears regarding the approach I should use because some when they find out that they are HIV positive, they may get affected mentally and psychologically. Mostly, the news that they are HIV positive needs to be broken by the parent in the absence of doctors or nurses. They [doctors and nurses] ask you if you told the child about the condition. And (coughing) my other fear is that we have not disclosed his status to teachers at School as teachers are not the same. You may disclose to some and they end up treating the child badly. Conversely, you may disclose to others [teachers] and find that they are alright. Other than that, we have disclosed his HIV status at home and every family member knows; mmmh! He is the only one among the four children I have who is HIV positive. Questions arose and even as he grows up at school they are taught about these. They suggested that we should inform him of his HIV status when he is 12 years old, but I could see that by 11 years he was ready, and we sat down with him and explained his HIV status. Fortunately, we never experienced any problem. Okay!

Participant 8 concurred: *For example, it was difficult for us to disclose to him that he is HIV positive because he is only 10 years old. He does not yet understand. It would be a good idea for other patients as well to have a doctor or someone with adequate training to speak to this child until he fully understands his condition so that when he starts dating he will be equipped with knowledge to protect himself and the partner because as parents it is difficult to discuss with him as we are not sure how he will react to the news.*

Participant 12 also said: The doctor and I did the explanation. We entered into a private room where the doctor asked if he knew [that he was HIV positive]. By then, we had

no yet revealed to him the reason he was taking medicine. That's when the doctor and I did the explanation.

Studies by Haffejee et al., (2016) have reported that HIV disclosure comes with different sorts of stigma and discrimination. Women face bad treatment from health care workers, family members, partners and society. These factors could make people more secretive about their HIV status, which is a further challenge in the fight against HIV. Close relatives are more likely to be empathetic, maintain confidentiality and less likely to stigmatize. Individuals are afraid of rejection by significant others or stigmatisation by the wider community (Doyal, 2014). Close relatives are also the prime sources of psychosocial and practical support as shown by this study.

Motherhood, in the context of a chronic and stigmatizing illness such as HIV, brings with it many unique challenges (Willcocks et al., 2016). For HIV positive parents, informing an older child on her status may entail disclosure of their own HIV infection (DeSilva, Penwill, Sabin, Gifford, Li, Fujie, Weiwei, Yongzhen, Hongyan, Xuemei, Barnoon, Gill & Bonawitz, 2018). For HIV-positive mothers, coping with a lifelong and life-threatening condition is complicated by the responsibilities of parenting. Qualitative studies have reported that mothers experience HIV-related discrimination (Treisman, Jones, & Shaw, 2014), and the dual challenges of caring simultaneously for themselves and their children (Willcocks et al., 2016).

Studies done on parental disclosure in China have indicated that the majority of HIV-infected parents were reluctant to disclose their sero-status (Caiola, Barroso & Docherty, 2018). Stulac, Jean-Baptise, Mathews & Mukherjee 2016 in their study indicated that disclosure has been associated with increased adherence, improved clinical outcomes, and safer sex practices; but in some cases, it is also associated with stigma and risk of violence. A primary concern for HIV-infected parents all over the world is the issue of making a decision about whether to, when to and how to disclose their HIV status to their children (Simoni, Yang, Shiu, Chen, Udell, Bao & Lu, 2015). This study also revealed that participants find it is easier to disclose their own positive HIV sero-status to close persons such as parents and sisters than to disclose to their children. From a public health point of view, disclosure can benefit the public by reducing the transmission of the virus. However, from the HIV-positive person's social point of view, disclosure has many negative implications (Wright & Mwinituo, 2010).

Some participants in the study indicated that they needed help from healthcare workers such as counsellors, nurses or doctors to facilitate disclosure to their children. In this study disclosure was further associated with emotional and behavioural challenges when the child found out about their status. A study in Malawi reported on emotional and behavioural difficulties among children living with HIV (Kalembo, Kendall, Ali & Chimwaza, 2019). The study in Malawi found that the behavioural and emotional difficulties in children living with HIV were associated with other factors but not disclosure, while this study in Limpopo Province of South Africa showed that the behaviour of children changed upon discovering that the treatment they were taking was for HIV.

Although disclosure was hard, the parents and caregivers managed to disclose to their children with a few being assisted by health professionals. Those who did not disclose to their children wished to be helped by professionals when they eventually disclosed. Discomfort with HIV disclosure was related to Maslow's need for love and belongingness. The caregivers feared that their children might face rejection when their HIV status is known, particularly by school teachers. According to Maslow, the need for love and belonging is threatened when people are not accepted by others. The study participants had some need for loving and belongingness.

4.2.1.2 Sub-theme 1.2: Disclosure of HIV positive status to teachers at school

The study found that some participants experienced challenges in relation to disclosing the HIV positive status of the children to the teachers of the children at school. They felt challenged by questions that the teachers at school asked because they wanted reasons for the children's regular absence from school. The participants also felt that the teachers wanted to know confidential information about the nature of ailment that the children had been diagnosed of. The children were also troubled by the teachers wanting to know more confidential information about their diagnosis. One participant indicated that she had disclosed her child's positive status to the teachers. These sentiments were expressed as follows:

Participant 2 said: *Mmm, as a parent, it is not easy to raise an HIV positive child. The child himself does not know that he is infected with HIV. It is only the parent who knows about him being infected with this kind of disease. So, it is an emotional challenge for her. Mm!*

Participant 8 also said: Yes…The other issue relates to schooling. You may find that the teacher interrogates the child at school. The teacher asks probing questions and the child comes back home offended as the teacher would like to know why he visited the hospital digging for confidential information. Sometimes, this is what I think troubles the child at school because the child is too close to me and confides in me.

Participant 11 said: Since he has already done blood tests, he can only go back after six months and sometimes I request that he be scheduled during days when he is not writing tests or examinations. Even at school they have never given me any problem. When he started each grade at school, he just completed the form. Each time he goes to a new grade, he explains that he is sick, and he will do this until grade 7… They keep checking. When he is consulting the doctor, they know he went to the doctor. The problem is when you keep it as a secret and not complete the form confirming that the child is sick, this is where you will have a problem. But since I started collecting medication on his behalf, I am not experiencing any challenges.

The participants in this study indicated that they found it difficult to disclose the HIV positive status of the respective children to teachers at their children's schools and felt the need to have qualified professionals, like doctors, to assist them in this regard. In India, the National AIDS Control Organisation, in its guidelines for care and treatment of paediatric HIV recommends that disclosure should take into consideration the levels of maturity of the children, their ability to cope with the information, as well as the family dynamics (Mehta et al., 2016).

Mothers may be reluctant to disclose information to teachers and other third parties regarding the HIV positive status of their children for numerous reasons including concerns about negative emotional reactions, fear of resentment, feeling of guilt in transmitting the virus, and discomfort in discussing HIV transmission. For HIV positive parents informing an older child on her status may entail disclosure of their own HIV infection (Desilva et al., 2018).

In the process of serving the intention of keeping HIV-affected children from depression, discrimination, bullying and potential embarrassment, by not disclosing their HIV positive status to teachers and other professional; parents end up inadvertently distancing these HIV- infected children from professional helpers such as teachers, health care providers and social workers (Zhang et al., 2016).

In an attempt to protect their children from rejection and discrimination, the participants were selective about who they disclosed their children's status to. Close family members who would likely offer support and acceptances were made aware of the children's infection as opposed to school teachers and the school environment. Maslow postulates that for one to feel loved, she or he needs to belong to a group and be accepted by that group. This is also evident in the participants' responses where they had a desire for their children to belong to a support group. They indicated that support groups should not be made available only for adults living with HIV but that hospitals should also have support groups for children living with HIV. Some of the children in the sample were reported to be isolated, keeping mainly to themselves as well as to their primary caregivers. This could mean that they did not feel that they belonged with peers but rather with those who knew about their infection.

4.2.2 THEME 2: TAKING CARE OF AN HIV POSITIVE CHILD

The information obtained from study indicates that the participants found taking care of their HIV positive children as a challenging experience. The challenges relate to frequent visits to the hospital as the children get sick or suffer opportunistic infections, financial burdens, and conforming to the requirements of HIV treatment programme. They indicated that the children had to miss school at least once every month because they had to go to the hospital for check-up and also to collect medication. Five sub-themes emerged from this theme and these are presented and discussed below.

4.2.2.1 Sub-theme 2.1: Hospital visits for regular check-ups

Some of the participants identified the regular visits to the hospital for the monthly check-ups and to collect medication for the child as an onerous and therefore challenging routine. Besides the hassle of travel, this monthly routine also meant that the children had to miss school and the mothers or guardians had to be absent from work because they had to accompany their respective children to the hospital. The participants expressed these sentiments as follows:

Participant 2 said: Okay. The main challenge I experience as I raise the HIV positive child is that of frequently coming to the hospital. Mmm, when the child comes for the check-ups at the hospital, he misses school and I have to take leave at work.

Participant 4 added: I stay only with children, this one and his brother. We are only three at home. So the way you travel a long distance because of the sickness you just told yourself to accept the status quo. Yes. Yes. I no longer tell people that I am HIV positive because they would stigmatise and detest me as they are afraid of HIV.

The participants saw the regular visits to the hospital as a challenge because it disrupted school and work schedules for the child and caregivers who were in employment. Folayan, Caceres, Sam-Agudu, Odetoyinbo, Stockman, & Harrison (2017) in their study in Nigeria also found that regular hospital visits were a cause of stress to the adolescents living with HIV. Besides causing the children to be regularly absent from school, and the mothers or guardians to regularly take leave from their workplaces, the regular visits to the hospital also have cost implications in terms of bus or taxi fares. A number of the participants stated that the use part of their social grants to pay cover the transport costs incurred on the monthly trips to and from the hospital.

4.2.2.2 Sub-theme 2.2: Financial burden

The study revealed that some of the participants were experiencing financial challenges because they had to accompany their children to the hospital at regular intervals for check-ups.

Some of the participants explained that they had no regular source of income and therefore found it very difficult to cover the cost of taking their children to and from the hospital. The participants also identified the need for the provision of nutritious balanced diet to HIV positive children as another burdensome factor in taking care of HIV positive children. The challenge is that such a diet is costly and the mothers, particularly those who were unemployed or had no regular source of income, were forced to use part of their social grants to buy the required food. Unfortunately, the social grant is not sufficient to enable the mothers or guardians to provide the required balanced diet for the full month. Knizek, Mugisha, Osafo & Kinyanda (2017) found similar results in their study conducted in among the caregivers of children living with HIV and AIDS in Uganda.

These sentiments are aptly expressed by the participants. *Participant 3 said: My main challenge is that I run out of money because I am unemployed. As a result, sometimes I struggle. The little money I receive as a social grant is from their deceased father…*

Participant 6 said: Yes! The children must be supported with food. They should be given nutritious food and treatment.

Participant 7 said: Mmmh!!! I have no other challenges I have encountered. I just bring him to the hospital to collect his treatment and also do check-ups

Participant 10 concurred: One needs to take care of him by ensuring that he eats when he wakes up; he needs to eat well.

These findings are consistent with those of a study conducted by Li, Harrison, Fairchild, Chi, Zhao & Zhao (2017) which revealed that people living with HIV frequently experience stigma, disruption in caregiving, reduced educational access and financial hardship. A study conducted in Limpopo also revealed that caring for children on ARV medication often resulted in mothers borrowing money, accumulating and living in debt, walking long distance to and from hospitals or hiking for lifts to get access to the health facilities (Mafune, Lebese & Nemathaga, 2017). Travel costs in relation to the regular visits to hospitals, the costly nutritious diet required by HIV positive children, and the costs of clothing and general child maintenance, are the factors that cause the financial distress among the mothers or guardians of HIV positive children.

Most of the participants are not from within the city of Polokwane, where the hospital is situated. Some come from areas that are less accessible by buses or taxis. Ricci, et al., (2016) in their qualitative study on adherence to the treatment programme requirements, indicated that mothers with HIV provided information about their own non-adherence, which negatively influence children's adherence. The findings of this study are similar to the study conducted by Avabratha et al. (2011), who also found that financial aspects of medical therapy need to be considered. Haffejee, Ports & Mosavel, (2016) also reported that a major challenge in accessing health care was the long distance to clinics, the lack of personal transport and insufficient funds to use public transport to access facilities. In the interest of accessing HIV/AIDS services on

monthly basis, the mothers have to travel to the Pietersburg Hospital, from their respective villages and small towns.

4.2.2.3. Sub-theme 2.3: Opportunistic infections

The majority of the participants stated clearly that children living with HIV were more susceptible to opportunistic infections than HIV negative children. These sentiments were expressed as follows:

Participant 10 said: *Sometimes he coughs a lot and often has high temperature. But this occurs sometimes, not all the time. He coughs a lot. When he gets sick it is more severe.*

Participant 12 concurred: We then called the ambulance to take him to hospital. When the doctor examined him, he was diagnosed that he has HIV. They then examined the mother who was also found to be HIV positive. Then the father started getting sick. They forcefully helped him to take medicine along with the tea prescribed by the church. He refused to take the pills and he eventually died.

Participant 5 explained: He spent months in ICU [Intensive Care Unit]. I just accepted! What could I say? They said HIV was the reason he was hospitalised and admitted at ICU. The disease was accompanied by another opportunistic infection relating to incessant coughing. He was diagnosed with TB when he was born. Yes!

Participant 7 agreed: *As a parent raising an HIV positive child, my experience is that he contracted TB (the one affecting lungs, now being referred to as bronchitis). After that, he became better as he was taking medication. Nevertheless, he has lung bronchopneumonia.*

The participants opined that the severity of any illness or disease is amplified manifold in children living with HIV relative to their HIV negative counterparts. Children living with HIV exhibit severe illness symptoms even with what would normally be considered as minor sicknesses, such as coughs.

Once a child has been diagnosed with HIV infection, careful follow-up is critical. Growth and development monitoring should be performed monthly with careful attention to ruling out opportunistic infections, particularly TB. Children who are diagnosed with HIV infection should receive prophylaxis for opportunistic infections. For children co-infected with TB, ART is generally deferred until at least 2 months after TB therapy has been started, or until TB treatment is completed (Stulac et al., 2017).

The finding that children living with HIV are more susceptible to opportunistic infections is consistent with findings of a study conducted by Dhaka, Sherwal, Saxena, Rai & Chandra, (2017) which revealed that children who were HIV positive were more prone to contracting respiratory infections. Fever with cough was the presenting symptom in the children, suggesting the infection of the upper and lower respiratory tract.

4.2.2.4. Sub-theme 2.4: Child defaulting on the treatment schedule

The majority of the participants indicated that one of the challenges they encounter was that as the children grew they would sometimes forget to take their medication especially when the parents were not around. Some participants indicated that sometimes their children would refuse to strictly follow the treatment schedule. These frustrations were aptly expressed in the following ways:

Participant 3 said: *The only challenge is that he is growing up and beginning to be streetwise. He tends to no longer take the medication and when I ask him, he says he's tired of taking medication.*

Participant 12 concurred: The only problem is when he refuses to take his medication. Yes. He gives me stress by being stubborn. I need to chase him around first just as I have explained that I chase him first. Yes. That is the problem I encounter.

Currently it is widely recognised that the early treatment of HIV results in better long-term outcomes for children and adults (National Institutes of Health, 2015). HIV-related paediatric morbidity and mortality was significantly decreased after introducing anti-retroviral treatment in resource limited countries (Leroy & Jeson, 2015). However, to appreciate the benefits associated with the use of ARV drugs, patients are required to focus on long-term commitment to taking at least 95% of the treatment as prescribed, given that poor adherence is linked with multidrug resistance, and even death resulting from opportunistic infections (Azia et al., 2016).

This study showed that some of the children missed doses of their medication. The participants reported that this trend was observed particularly when they were away from home. Low levels of HAART adherence can lead not only to a decrease in the effectiveness of treatment, but also to the emergence of resistant forms of HIV, where resistance develops quickly to all pharmacological group (Shilovskaya, 2014). ARV medications generally require frequent dosing and are supplied in formulations that may be difficult for children to tolerate, including as large pills, bitter tasting liquids and gritty powders. Adults may remind the children to take their medication and check

medications to determine whether the children take them as per schedule. These practices can instil a sense of self-responsibility into the children, but this cannot be achieved if the children had no knowledge about their HIV status (Mafune et al., 2017).

4.2.2.5. Sub-theme 2.5: Isolation from social life

Most of the participants expressed concern that that their HIV positive children did not want to socialise with their peers in terms of age groups and/or gender. Their experience was that their children tended to isolate themselves from other children in the same age groups, and that they essentially lived lonely lives. One participant stated that her child wanted to always spend time with her alone and no other person. Other participants indicated that they being would not even allow their children to visit relatives without the mothers being with them because of the need of them to monitor and ensure that the children did not default on the treatment schedule when they were away. These sentiments were expressed as follows:

Participant 8 said: What I have noticed is that he lives in close proximity with me. I have realised that the child fails to associate with other children, like going [to visit relatives].

Participant 10 added: In some day he gets very lonely. When you look at him, one could see he's so lonely. Mmmh! He would look sad. Yes, he just sits.

The study found that children living with HIV tend to isolate themselves from other children and that some of these children keep to themselves and appear very sad and lonely. The participants also indicated that relatives were not informed about their children's HIV positive status and therefore if they were to see the children taking medication, they would ask many questions. Studies conducted by Hyba (2016) found that the tendency not to disclose the status of HIV positive children to relative, social workers, nurses and other caregivers, was a significant barrier against positive medical and psychosocial interventions, just as it also prevented individuals and families from accessing social support. Children who did not isolate themselves benefitted in increasing a sense of control and self-determination by fostering social support systems. Such children could safely express emotions such as anxiety, anger or a feeling of loss; and their parents could share their experiences, discuss important problems and provide each other with support.

In line with the theoretical framework that informed the study, the participants had insecurities about food and transport provision. This is under the theme of security in Maslow's hierarchy of needs. The participants depended on external sources such as government for social grants, and relatives or spouses for other forms of financial assistance which made them feel that they were not in control of their situations. Because the social grants and the other forms of financial assistance received from relative were not enough to enable them meet all of their needs, some would go without desired nutritious food for some weeks in a month until the next date of payment of the social grants. They wanted their children to feel safe and so the needs of their children often took priority over their own needs. They needed additional support to them as caregivers as well as support groups for the children in order to provide the children with a sense of love and belongingness along with the fulfilment of the need for safety.

Maslow's theory of needs was useful in understanding the needs of caregivers looking after HIV positive children. The theory highlighted deficiencies experienced by caregivers, the need for security, financial security in particular, physiological needs, where food provision was not always available as well as a deficiency in the need for love and belonging where the participants feared rejection should other people (school teachers) learn of the status of the children.

4.2.3 THEME 3: FEAR OF STIGMA

4.2.3.1 Sub-theme 3.1: Stigmatisation of an HIV positive child

The study found that parents of HIV positive children were afraid of stigmatisation of the children by the teachers and family members. A major factor that distinguishes HIV/AIDS from other chronic or terminal illnesses is the stigma (Joshi, Tiwari, Kannan, Dalal & Mathai, 2016). When participants felt that their children might be discriminated against or rejected because of their HIV status, they withheld disclosure. They disclosed when they anticipated that they would be supported by those to whom they disclosed, for example, family members. The sentiments were expressed as follows:

Participant 11 said: Mmmh! What is my understanding? Eish! I understand it very well and we have accepted the fate. If he is infected and he does not know, where will you say he got it from? There is nothing one can change about that. Okay you need to look

into the future. Yes. I contracted it (HIV) without living a promiscuous lifestyle. I got it from his father. Mmmh! Yes.

Participant 6 also added: Parents who do not accept and acknowledge [that their children are HIV positive]; you will find that they have children who are alright and not infected with HIV and only one child who is infected with the virus. I look at other parents with empathy as I am already a grandmother myself.

There's always a temptation to discriminate against children who are HIV positive because you love those who are well as if you blame the HIV positive child that I got infected because of the child. That's how I see it.

Quite often many HIV positive children and their families feel ashamed of associated with HIV/ AIDS. To a greater or lesser degree, discrimination remains a fact of daily life for people living with HIV. Cloete, Strebel, Simbayi, van Wyk, Henda & Nqeketo (2010) reported that reluctance to disclose HIV- positive status, and fears of being rejected and discriminated against are evidence of the persistent nature of AIDS-related stigma in communities and households. They also indicated that stigma in the Western Cape Province of South Africa is such that HIV/AIDS is called "that thing''; it does not only imply that there is no cure, but also suggests that it is a stigmatised illness that cannot be referred to by name. HIV-related stigma had an impact on the study participants although it was not explored extensively.

A study by Avabratha et al. (2011) concluded that social discrimination and stigmatisation persist among both the general public and health care providers. Stigmatisation is an attitude, but discrimination is an act or behaviour. Studies conducted by Shilovskaya, (2014) in Russia indicated that some patients experienced discriminatory behaviour at the hands of healthcare providers. HIV/AIDS is perceived as disgraceful disease in Russia. These findings are consistent with the ones from this study as some participants reported that the experienced rejection and discrimination by other people due to the known condition of HIV; and that this affected the care they were rendering to their HIV positive children. Their neighbours were derogatory to them, which impacted negatively on their responsibilities to render care to their HIV positive children (Achema & Ncama, 2016). Stigmatisation had an effect on the participants' self-esteem, which resulted in a deficiency of this need.

It is not surprising that in the face of such powerfully felt discrimination many families choose not to disclose the HIV status of their children. For most families the decision not to disclose appeared to be based on a desire to protect their children from anticipated stigma and hardships that this knowledge could bring; and on their own concerns about facing questions about death or how they became infected. It is thus important for healthcare workers in HIV care to sensitise the communities towards reduction of stigma and discrimination (Adebimpe, 2013).

4.2.4 THEME 4: CHALLENGES IN ACCESSING SUPPORT

Most of the participants in the study indicated that they were receiving assistance and support from various people and stakeholders that were assisting them with raising their HIV positive children, though the support was not sufficient. Those who provided such assistance and support included family members, spouses, neighbours and friends, the church and the government. Details of these sources of assistance and support are discussed.

4.2.4.1 Sub-theme 4.1: Family support system

The participants in this study primarily described how their family members and significant others offered emotional support and encouraged them to care for themselves and their health. These sentiments were stated as follows:

Participant 6 said: For instance, in our home there is no one who does not know about the child's condition, especially that he has a brother and a sister. We do this so that they can remind him to always take pills. He knows that even if I am not around – I hardly get out of the house but there are times when there is a funeral somewhere and I come back home late. You know that when it is 08h00 others also wait for the time knowing that he needs to take treatment. This is the home support system we have created.

Participant 11 differed: Support? No, I do not need any help. I have support from my family as I was the first to get sick. I have got enough support from my family and they do not discriminate against me. They also do not discriminate against him. Yes. The government supports us with medication, and he also receives a support grant from

government. We use it for transport and food. As a child, he sometimes wants us to buy him things and we just buy him.

For most families the anticipation of having a child is filled with joy, fantasy, and anxiety. Parents of children living with HIV wrestle with the special needs of their children; but they also must face how their own future will be different from their hopes and dreams (Evans, Jones & Prendergast, 2016). Findings by Proudfoot (2017) indicated that upon diagnosis, mothers have to deal with unique challenges. For these mothers, personal needs were secondary to those of their children. On diagnosis of a positive HIV status, the mothers concentrated on the ramifications of the diagnosis for their children. Results of this analysis indicate that social support may be buffering against the negative effects of illness-related stressors on symptomatic depression for mothers of HIV positive children, suggesting that social support is a particularly important coping resource for caregivers experiencing stress related to illness. The participants in this study indicated that they were receiving support from family members, spouses, neighbours, friends, the church and the government.

4.2.4.2 Sub-theme 4.2: Financial support

The study found that the majority of the participants were unemployed and were therefore on the government's social grant programme. Some participants further stated that, although the social grant was very helpful, it was, however, not enough to sustain them. Therefore, they were unable to buy nutritious food that was necessary for children living with HIV. However, one participant indicated that the social grant was sufficient, and she was using it for pay transport costs and also to buy food. They also indicated that they were collecting medication for their HIV positive children from public healthcare facilities because the public healthcare services were free. These sentiments were expressed as follows:

Participant 6 said: The child support grant is insufficient. Sometimes one will be informed of a debit order at the bank and you are struggling because these children also need to eat, and they expect to eat good food. They grew up eating well. All of a sudden, like my kids when they came here in 2012, they do not know morogo as relish, but they only know spinach every day. They know that fish and chips are served as meals on Fridays. At sometimes finances are not sufficient. Nevertheless, I have

trained them that when there are challenges, I would sit down with them to discuss the family's financial challenges.

Participant 7 also said: I also have another one and together they are two and the other one does not have HIV. Mms!!! My only challenge is that I am unemployed. Sometimes I do struggle to find money to come to collect his treatment medication and to bring him here (Hospital). Mms!!!

Participant 10 added: One needs to take care of him by ensuring that he eats when he wakes up; he needs to eat well.

Participants 11 said: Yes. The government supports us with medicine, and he also receives a support grant from government. We use it for transport and food. As a child, he sometimes wants us to buy him things and we just buy him.

Participant 12 concurred: We then brought her to hospital. After taking her to hospital, they gave us some pills. Then this one and the mother started coming here [for treatment] and they found help here at the hospital.

The findings of other studies support the information obtained from the participants in this specific study that most challenges experienced by mothers of HIV positive children are as a result of pre-existing social living circumstances. Some factors related to the pre-existing social disadvantage among the participants in this study were unemployment and lack of funds. In many societies women have lower social and economic status, while also assuming primary care of the family (Wang et al., 2016).

Parents of HIV positive children identified financial strain as a major stressor due to the many needs including the cost of the frequent travel trips for medical check-ups, and also the cost of a balanced diet. The majority of the participants in this study were unemployed and relied on government grants for financial support. These findings suggest that in the context of unemployment, poverty, and lower socioeconomic status, HIV status becomes a secondary concern to mothers of children who are HIV positive.

Individuals living with HIV are faced with numerous issues, including access to medications and food, as well as the struggle to pay for day-to-day expenses, including payment for utilities. In individuals living with HIV/AIDS, food insecurity is linked with

the inability to suppress viral load, which may reduce the effectiveness of treatment (Wang et al., 2016). It is also linked with decreased antiretroviral therapy adherence thus reducing treatment outcome and causing the inability to suppress viral replication. The interaction between HIV infection, undernutrition, and food insecurity can be a significant obstacle to effective HIV care. This study also found that food security is vital for keeping HIV positive people healthy.

4.2.4.3 Sub-theme 4.3: Available support structures for mothers of HIV positive children

Some participants in the study expressed the need for support groups that could meet once a month on weekends where the children could come together and be taught or educated on living with HIV. These sentiments were expressed as follows:

Participant 1 said: I think the support groups for children of this age should be setup so that they continue with the programme because these children could be groomed until they become adults. I do not know if such kind of support programme exists in Polokwane

Participant 8 concurred: So, we have identified a need for help so that if possible, this thing could be organised so that at least once in a month during weekends. Such occasions are ideal for disclosing to them their HIV status because during weekdays they are at school. At such events both parents and children could talk in groups about these things. It should not be just a thing for parents. The children should also be supported.

The findings of this study correspond with those of other studies that found that social support played a key role in the health and well-being of women. Social support is linked with better health and quality of life in people living with HIV (Liamputtong & Haritavorn, 2014). When receiving an HIV diagnosis, a person has to deal with not only a life-threatening disease and issues such as death and HIV-related symptoms, but also with a change in body image, decisions about disclosure, mistrust in relationships, stigma and possible social isolation and rejection. It is likely that people who have social support will be able to seek ways of dealing with the illness.

According to Yates (2016) social support is defined as interactions with family members, peers, and health professionals that communicate information, esteem, aid, and understanding. Some participants expressed the need for support groups that

could meet once a month on weekends where the children could come together and be taught or educated on living with HIV. Mugivhi, (2010) concluded from the findings of a study that the majority of participants were not attending any support group, yet they gave suggestions about the type of support groups they would want and the way in which such groups could help them. The findings of this study also concluded that support in the form of information is needed from people in similar circumstances, counselling services and community awareness needed to prevent discrimination against mothers and children living with HIV.

4.3 CONCLUSION

Altogether the main 4 themes were identified from the collected data. The main themes include disclosure of HIV positive status, taking care of an HIV positive child, fear of stigma and challenges in accessing support. Caring for an HIV positive child has physical, psychosocial and financial implications. Summary, limitations and recommendations will be discussed in chapter 5.

CHAPTER 5

SUMMARY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

This chapter provides a summary of the dissertation as well as the recommendations drawn from the findings of the study. The recommendations are based on the identified themes and limitations of the study are also discussed. The chapter further discusses the limitations of the study, and provides the conclusions.

5.2 SUMMARY OF THE STUDY

Aim of the study

The study aimed at exploring and describing the challenges faced by mothers with HIV positive children in Pietersburg Hospital, Limpopo Province, South Africa.

Research questions

The research questions which guided the study were:

- What are the challenges faced by mothers with HIV positive children in Pietersburg Hospital, Limpopo Province, South Africa?

- What coping strategies can be developed to support mothers with HIV positive children in Pietersburg Hospital, Limpopo Province, South Africa?

Objectives of the study

The objectives of the study were:

- To explore the challenges faced by mothers with HIV positive children at Pietersburg Hospital, Limpopo Province, South Africa.
- To describe the challenges faced by mothers with HIV positive children at Pietersburg Hospital, Limpopo Province, South Africa.
- To develop support strategies for mothers with HIV positive children at Pietersburg hospital.

Research methodology

A qualitative, exploratory, descriptive design was used in the study. Qualitative research involves investigation of a phenomenon, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design (Polit & Beck, 2012). Exploratory research investigates the full nature of the phenomenon, the manner in which it is manifested and the other factors to which it is related. Descriptive designs provide a picture of a situation as it happens. In the study, semi-structured, in-depth interviews were used guided by an interview schedule which contained the main themes to be explored. The data was analysed using open coding, whereby data was reduced, organised, interpreted and given meaning.

Findings of the study

The findings of the study were grouped under the following themes as discussed in the previous chapter:

THEME 1: DISCLOSURE OF HIV STATUS

The participants experienced difficulty disclosing the seropositive status to their children. Parents and caregivers of children living with HIV said that disclosure of the positive HIV status of their children was a necessary process and good for their children, though disclosure rates were low. Fear of HIV- related stigma and related consequences made some participants not to disclose their children's HIV status. Disclosures to friends, family and health-care providers have been associated with marginalisation, isolation and social exclusion. These parents felt that it was important for the children to know their status, and yet they were unable to disclose their own status.

THEME 2: TAKING CARE OF AN HIV POSITIVE CHILD

The participants experienced challenges related to regular visits to the hospital for the monthly check-ups and for the collection of medication for the children. The children had to miss school and some of the participants also indicated that they had to be absent from work because they had to accompany their children to the hospital. Accompanying the children to the hospital for check-ups had financial implications.

Children living with HIV are required to take a nutritious balanced diet and this also has as an added financial burden. Some of the participants were unemployed and they

relied on the government's social grant which was not enough to meet their financial obligations.

Children living with HIV were more susceptible to opportunistic infections than their counterparts who were HIV negative. As a result, symptoms of ordinary illnesses such as coughs were more severe and compounded in HIV positive children than in their HIV negative counterparts.

As the children grew, they would sometimes forget or refuse to take their medication and thereby defaulting on the treatment schedule. Children living with HIV often isolated themselves from other children and appeared lonely and sad.

THEME 3: FEAR OF STIGMA

Most of the parents of children living with HIV were afraid of stigmatisation. They indicated that they were afraid that some teachers might stigmatise their children if they knew that they were HIV positive.

Some of the participants indicated that they had accepted their children's HIV positive status because they realised that this was a reflection of their own positive HIV status. However, some of the participants indicated that it was difficult for them to accept that their own children were HIV positive as doing so would lead to them developing negative attitude and stigma towards their own children.

THEME 4: AVAILABLE SUPPORT

The participants indicated that they received support from family members in the process of raising their HIV infected children. They expressed appreciation for the support they received from their family members, neighbours and friends because they played important roles in the raising of the child.

Some of the participants stated that they were not employed and therefore relied on the government's social grant for financial support. They also indicated that they normally collected medication for their HIV positive children from public healthcare facilities because the public healthcare services were free. Some participants expressed the need for support groups that could meet once a month and provide opportunity for their children to come together and be educated about living with HIV.

5.3 RECOMMENDATIONS

Based on the findings of the study, the following recommendations are put forward.

- Healthcare workers need to intervene and provide ongoing supportive services and counselling services to mothers of HIV positive children within their communities, at clinics and at public hospitals.
- Healthcare workers should advocate for policy changes to ensure that policies that seek to provide social security to the HIV positive mothers and their children's social security are developed and implemented. There is also need for policies that seek to assist mothers of HIV positive children to have their financial needs met.
- A well-coordinated interdepartmental approach, integrating the efforts of departments of health, social development and education in the province needs to be adopted to optimise the impacts of the government's intervention programmes on HIV. It is expected that such a well-coordinated and integrated inter-departmental approach could increase the effectiveness, efficiency and impacts of the intervention programmes because it would entail pooling of resources.

Further research

- It is recommended that research be conducted in different areas within provinces so that there can be sufficient and strong knowledge-base on the challenges faced by mothers with children who are HIV positive.
- It is further recommended that future research should involve the significant others to the mothers, including the family systems, peers, the communities within which the mothers and their HIV positive children live, and schools. It is believed that such extended scope of research could engender more contextual understanding of the challenges that the mothers encounter.

5.4 LIMITATIONS OF THE STUDY

The study was conducted in Pietersburg hospital of the Limpopo Province, where mothers with HIV positive children may have challenges that are less generalisable to

other populations of the province. Therefore, a replication study conducted in other areas of Limpopo may be helpful in coming up with more generalisable findings.

5.5 CONCLUSION

Mothers with HIV positive children are vulnerable because of poverty whose origins lie in the country's history, but which has been exacerbated by the HIV pandemic. The participants in the study strived to cope under these poor conditions. Some participants indicated that they did not have support from families hence they had to face these challenges all on their own. The participants revealed that they faced stigma and discrimination, and little was being done to deal with this stigma and to uplift the women as a marginalised group.

A properly coordinated and integrated interdepartmental approach has the potential to increase the levels of effectiveness, efficiency and impact of the interventions that are currently being rolled out by the departments of health, social development and education in an uncoordinated and unintegrated fashion. Such an approach could result in the significant improvement of the lives of mothers with children who are HIV positive.

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Annexure 1: Interview Guide: ENGLISH

Central Question:

“What are the challenges that you face as a mother of the child who is HIV positive?

Follow up questions:

- Explain your understanding with regard to HIV
- What are your experiences in caring for an HIV positive child?
- What are the challenges of caring for an HIV positive child?
- Describe how you cope with an HIV positive child.
- What kind of support do you need?

Interview Guide: SEPEDI

Potšiso Kgolo:

“Naa ke afe mathata ao o kopanago le ona byale ka mma mabapi le ngwana wa gago wa go ba le twatši ya HIV?

Dipotšišo tsa go latela potšišo kgolo:

- O kwešiša jwang mabapi le twatši ya HIV?
- Maitemogelo a gago ke afe go hlokomela ngwana wa gago?
- Ke afe mathata a o kopanago le ona mabapi le ngwana wa gago wa goba le twatši ya HIV?
- Hlalosa gore o phela jwang le ngwana wa gago goba le twatši ya HIV.
- Ke thekgo efe ka kakaretšo yeo o e hlokago?

ANNEXURE 2: PERMISSION LETTERS

Department of Nursing Science

University of Limpopo

Private Bag x 1106

Sovenga

0727

09.02.2016

The Manager

The Department of Health

Limpopo Province

Private Bag x 9302

Polokwane

0700

REQUEST FOR PERMISSION TO CONDUCT RESEARCH STUDY.

Kindly receive my request to conduct research study at Pietersburg Hospital, Capricorn District. I am a master's degree student in Nursing Science at the University of Limpopo. My research title is: The challenges faced by mothers with children who are HIV positive.

Your positive response will be appreciated.

Yours faithfully

Segoale NO

082 581 3602

Email:naresegoale@gmail.co

Department of Nursing Science

University of Limpopo

Private Bag x 1106

Sovenga

0727

09.02.2016

The Operations Manager

Pietersburg Hospital

Private Bag x 9316

Polokwane

0700

REQUEST TO BE GRANTED PERMISSION TO CONDUCT A STUDY

I, Segoale NO, request to be granted permission to conduct a study at your institution. The study will be about the challenges faced by mothers with children who are HIV positive at your institution. Data will be collected amongst all mothers whose children are HIV positive.

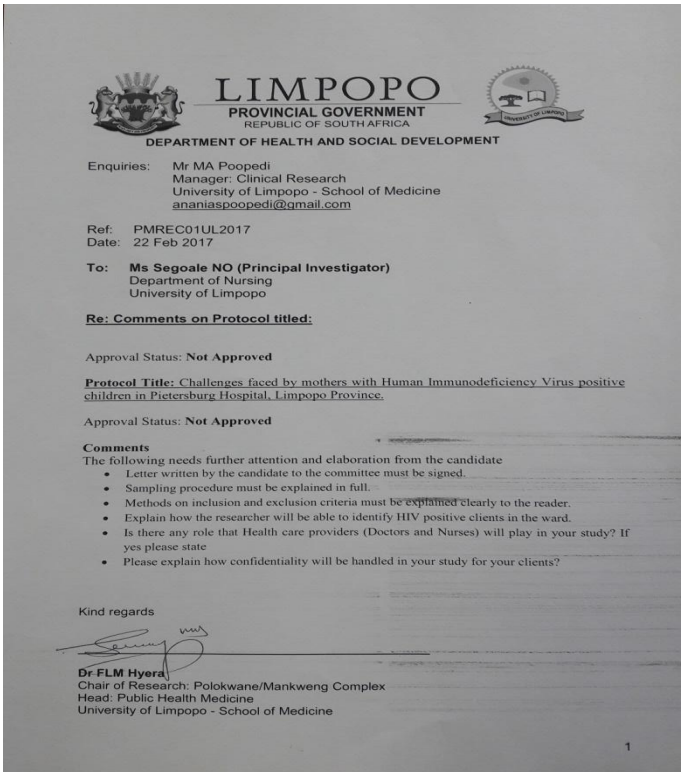
Yours faithfully

Segoale NO

082 581 3602

Email: naresegoale@gmail.com

ANNEXURE 3: PIETERSBURG HOSPITAL LETTERS



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT

Enquiries: Mr MA Poopedi
Manager: Clinical Research
University of Limpopo - School of Medicine
ananiaspoopedi@gmail.com

Ref: PMREC01UL2017
Date: 22 Feb 2017

To: **Ms Segoale NO (Principal Investigator)**
Department of Nursing
University of Limpopo

Re: Comments on Protocol titled:

Approval Status: **Not Approved**

Protocol Title: Challenges faced by mothers with Human Immunodeficiency Virus positive children in Pietersburg Hospital, Limpopo Province.

Approval Status: **Not Approved**

Comments
The following needs further attention and elaboration from the candidate

- Letter written by the candidate to the committee must be signed.
- Sampling procedure must be explained in full.
- Methods on inclusion and exclusion criteria must be explained clearly to the reader.
- Explain how the researcher will be able to identify HIV positive clients in the ward.
- Is there any role that Health care providers (Doctors and Nurses) will play in your study? If yes please state
- Please explain how confidentiality will be handled in your study for your clients?

Kind regards

Dr FLM Hyera
Chair of Research: Polokwane/Mankweng Complex
Head: Public Health Medicine
University of Limpopo - School of Medicine

1

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT

Enquiries: Mr MA Poopedi
Manager: Clinical Research
University of Limpopo - School of Medicine
ananiaspoopedi@gmail.com

Ref: PMREC01UL2017
Date: 29 March 2017

To: Ms Segoale NO (Principal Investigator)
Department of Nursing
University of Limpopo

Candidate: Ms Segoale NO

Title: Challenges faced by mothers with Human Immunodeficiency Virus positive children in Polokwane Hospital, Limpopo province, South Africa

Approval Status: Approved with the following recommendation:

- The candidate has not addressed the queries to the satisfactory of the Mankweng/Polokwane Ethics Committee; hence the candidate has been advised to approached Drs Manzini and Seopa to help with the project and patient identification in the ward.
- The candidate is again asked to clarify the role that will be played by doctors and nurses not social workers and psychologists.

NB: The Clearance Certificate will be given after all comments are addressed.

Kind regards

Dr FLM Hyera
Chair of Research: Polokwane/Mankweng Complex
Head: Public Health Medicine
University of Limpopo - School of Medicine

ANNEXURE 4: CONSENT FORM

Statement concerning participation in a Research Project

Research Topic: Challenges faced by mothers with Human Immunodeficiency Virus positive children in Pietersburg Hospital, Limpopo Province, South Africa.

I have understood the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I know that sound recordings and scientific publications emanating from the study will be electronically available throughout the world. I consent to this provided that my name is not revealed. I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons.

I know that this study has been approved by the Turfloop Research Ethics Committee (TREC), University of Limpopo. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this study.

Name of participant ……..

Signature of participant ……

Witness	Place	Date
……..	……	…….

Statement by the Researcher

I provided verbal and/or written information regarding this study

I agree to answer any future questions concerning the study as best as I am able.

I will adhere to the approved protocol.

Name of Researcher	Signature	Date	Place

ANNEXURE 5: PERMISSION FROM LIMPOPO DEPARTMENT OF HEALTH

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila (015 293 6650) Ref:4/2/2

Segoale NO
University of Limpopo
Private Bag X1106
Sovenga
0727

Greetings,

RE: Challenges faced by mothers with Human Immunodeficiency Virus positive children in Pietersburg Hospital, Limpopo Province , South Africa

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.

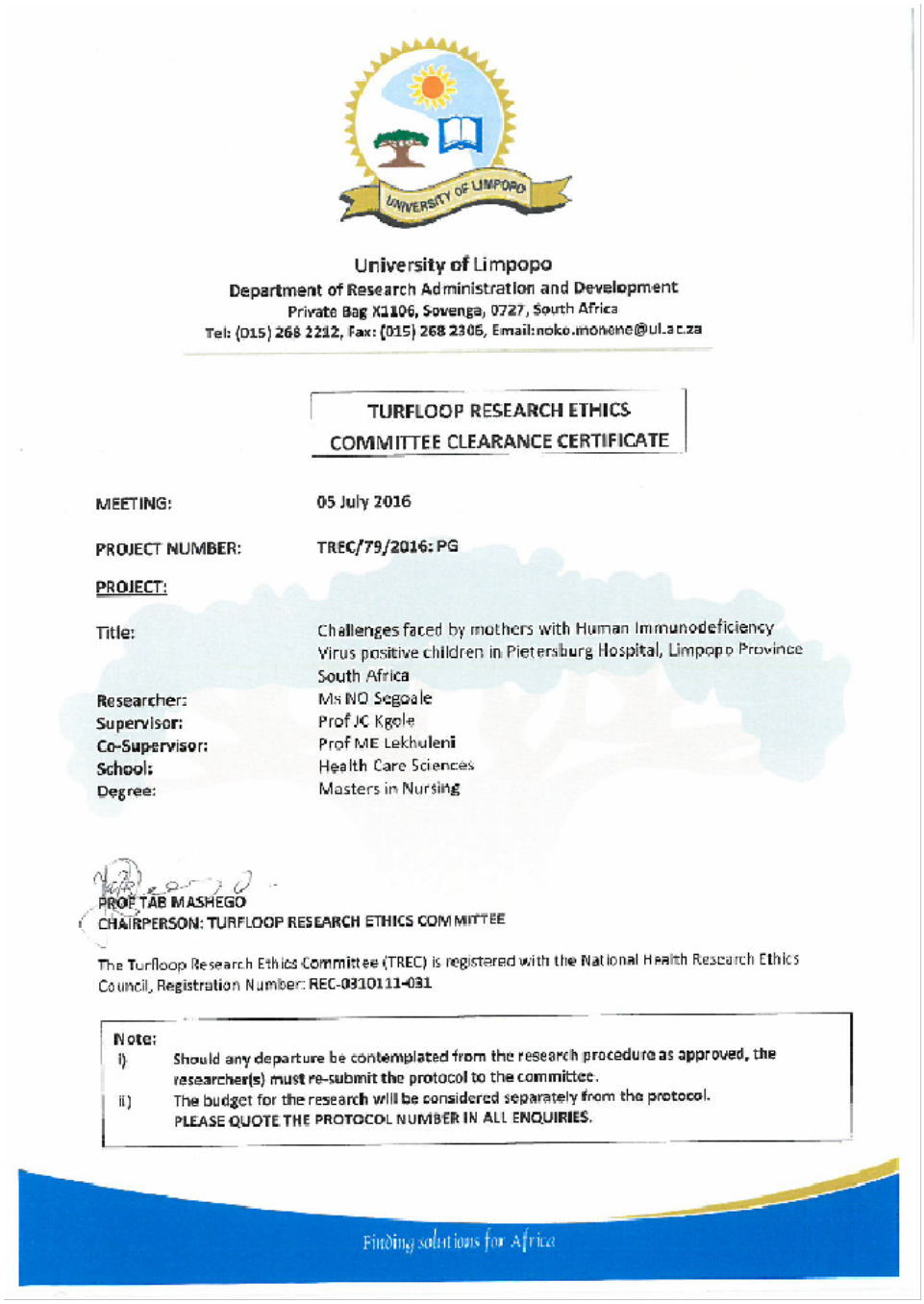
Head of Department

06/10/2016
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 6: CLEARANCE CERTIFICATE FROM TREC



University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2212, Fax: (015) 268 2305, Email:noko.mohone@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING:	05 July 2016
PROJECT NUMBER:	TREC/79/2016: PG
PROJECT:	
Title:	Challenges faced by mothers with Human Immunodeficiency Virus positive children in Pietersburg Hospital, Limpopo Province South Africa
Researcher:	Ms NO Segoale
Supervisor:	Prof JC Kgole
Co-Supervisor:	Prof ME Lekhuleni
School:	Health Care Sciences
Degree:	Masters in Nursing

PROF TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: REC-0310111-031

Note:
i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
ii) The budget for the research will be considered separately from the protocol.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

Finding solutions for Africa

ANNEXURE 7: INTERVIEW TRANSCRIPT

Researcher: Greetings! How are you?

Participant 5: I am fine and how are you?

Researcher: I am fine. My name is Nare Segoale. I am a nurse and also a student at University of Limpopo. I am conducting research on the challenges experienced by mothers raising children living with HIV. The purpose of my study is to determine challenges experienced by mothers raising children living with HIV. In giving a full explanation, we hope to find out exactly what are the challenges experienced by these mothers. The study seeks to recommend ways in which mother raising HIV positive children can find coping mechanisms and be supported to deal with the challenges they are experiencing.

This research has been ethically approved by the University of Limpopo Research Directorate, Limpopo Department of Health and Polokwane Provincial Hospital. It is envisaged that the findings of this study will contribute in providing solutions to challenges experienced by mothers raising HIV positive children. Furthermore, the findings of this research may be disseminated to relevant stakeholders. You are free to ask any questions and participation in this study is voluntary and you may withdraw from participating in this study if you wish to do.

With your permission, we will use the tape recorder and also take notes. I would be writing points to verify the issues arising in this interview. Yes! More importantly, your name will be anonymous in the reporting of the findings of this research. Are you free to participate in the study?

Participant 5: Yes! I am free!

Researcher: Kindly sign this consent form for me. Please write your name here and also append your signature.

Participant 5: Okay!

Thanks! Even if you may have questions in future regarding this study, you are welcome to ask them. Thank you! We can go-ahead with our questions.

Researcher: What are the challenges you encounter as a mother raising a child infected with HIV?

Participant 5 Hei! I just accept and acknowledge that this is the case, mmmh! I take it as God's will for my life.

Researcher: Okay! Did you immediately accept when news broke that the child…, the child has this type of a problem?

Participant 5: Yes! Yes!

Researcher: At what stage did they inform you?

Participant 5: When I was still pregnant.

Researcher: So when you were pregnant, they didn't mention the child, isn't it?

Participant 5: They never referred to the child! They said it was me who is HIV positive.

Researcher: Then what happened?

Participant 5: They conducted blood test which confirmed that I am HIV positive and I started taking medicine. I gave birth through Caesarean and the child was also HIV positive mmmh!

Researcher: Okay! So, what is your understanding of HIV?

Participant 5: HIV is a disease that is prevalent these days. Yes! There are diseases. They are the same. We view it [HIV] as any other disease.

Researcher: For you HIV is like any other disease?

Participant 5: Yes! Yes! So, that's how I consoled myself by accepting and acknowledging that I am infected with HIV, mhhm!

Researcher: So, what are your experiences about raising and taking care of an HIV positive child?

Participant 5: I just look after the child. Yes! I administer medicine to him. What can I say? Mmmh! I am happy when I see him play. There's no problem. Yes! He never had any problem and he doesn't give me any problem.

Researcher: So, which challenges have you ever had with the child? Are you sure that you never experienced any problem with the child?

Participant 5: He was born prematurely at seven months and he spent a long time at the hospital.

Researcher: Was he admitted at Polokwane Provincial Hospital?

Participant 5: Yes! [He was admitted in] this hospital for a long time.

Researcher: By long time, do you mean weeks or months?

Participant 5: He spent months in Intensive Care Unit. I just accepted! What could I say?

Researcher: Did they inform you what the problem was?

Participant 5: They said HIV was the reason he was hospitalised and admitted at ICU. The disease was accompanied by another opportunistic infection relating to too much coughing. He was diagnosed with TB when he was born. mmhh!

Researcher: Do you mean immediately after he was born? So, were you staying with him at the hospital?

Participant 5: Yes! I was staying with him at the hospital.

Researcher: Yes! But he was admitted in the ICU. Okay? And they did eventually discharge him when he got healed?

Participant 5: Mmmh! I then went home and started collecting his treatment medication. They first gave me medicine to treat TB and not for HIV at that stage. Since then, I had been collecting his medicine here until now.

Researcher: Since then he has never had any problem?

Participant 5: No! He was never admitted again in this hospital. No!

Researcher: Could you elaborate on how you live with your child?

Participant 5: I have no challenges thus far.

Researcher: How many children do you have?

Participant 5: They are two but the other one is not sick. The second born is the one that has a problem; he's the one infected with HIV. Mmmh!

Participant 5: Are you treating them the same? No, I actually love this one [HIV positive] more than the other one.

Researcher: So, you mean you treat them the same.

Participant 5: Yes, to me I don't see any difference. I treat them the same regardless of whether one is HIV positive and the other is not. No! I don't want them treated differently. My attention is more on the little one and we will see what the future holds.

Researcher: What kind of support do you need in general?

Participant 5: Eish! I will accept any form of support. I console myself that at least government is assisting us with [Child Support] grants and we are able to bring him for treatment. There's no major problem at all. Now, I just bring him to the treatment when it is due. Mmmh!

Researcher: But beside that, don't you need any other kind of support that need, maybe form the family or government.

Participant 5: Since I stay in my own house with my family, I just told myself that both the father of these children and I know about these circumstances, there's no problem. Mmmh! He's also involved as he sometimes reminds us to drink medicine on time.

Researcher: Are you living together?

Participant 5: Yes! We live together!

Researcher: Okay! Thank you very much, my mother. Do you have any questions you would like to ask me?

Participant 5: No! Thank you.

ANNEXURE 8: INDEPENDENT CODERS DECLARATION

QUALITATIVE DATA ANALYSIS

MASTER OF NURSING SCIENCE

NARE OKNEY SEGOALE

THIS IS TO CERTIFY THAT

Professor Martha Nozizwe Jali has co-coded semi-structured in-depth interviews of mothers with children who are HIV positive

For the study:

CHALLENGES FACED BY MOTHERS WITH CHILDREN WHO ARE HIV POSITIVE IN PIETERSBURG HOSPITAL, LIMPOPO PROVINCE SOUTH AFRICA

I declare that the candidate and I have reached consensus on the major themes reflected by the data during a consensus discussion. I further declare that data saturation was reached as evidenced by repeating themes

MNJali

Prof M.N. Jali

ANNEXURE 9: LETTER FROM THE LANGUAGE EDITOR

P.O. Box 15331
Lynn East
Pretoria
0039
Email: Tamsaidi@yahoo.co.uk

24 June 2019

Prof JC Kgole
Department of Nursing
University of Limpopo
P/Bag X1106
Sovenga
0727

Dear Prof Kgole,

Language Editing of the Master of Nursing Dissertation for Nare Okney Segoale

This serves to confirm that I have edited the Master of Nursing Dissertation of your student, Nare Okney Segoale, titled 'Challenges Faced by Mothers with Children who are HIV Positive in Pietersburg Hospital, Limpopo Province, South Africa'.

I understood my responsibility as that of assisting to make the content of the dissertation clearer and more concise while conforming to the rules of grammar. I was very conscious of the fact that reviewing the science and research methods that informed the content was not part of my brief.

Please do not hesitate to contact me should you have any query regarding the edits I made to the dissertation.

Yours sincerely,

Dr T. A. Saidi