CONTRIBUTORY FACTORS FOR HIV UPSURGE AMONG CHILDREN AGED THREE TO EIGHTEEN MONTHS IN MANGAUNG, FREE STATE PROVINCE

by

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Dedication

In memory of my parents, Mabafula Iris and Kekeletso Malakia Phakisi. They diligently planted the seeds of determination, perseverance, and resilience in me from a very tender age.

I will forever cherish their love, nurture, and support

DECLARATION

Student Number: 42828015

I, Selloane Phakisi, declare hereby that this doctoral thesis entitled:

CONTRIBUTORY FACTORS FOR HIV UPSURGE AMONG CHILDREN AGED THREE TO EIGHTEEN MONTHS IN MANGAUNG, FREE STATE PROVINCE

is my own work, and that to the best of my knowledge, it has not been previously submitted for degree purposes at any institution of higher learning; and that all the sources consulted have been acknowledged accordingly.

July 2018

Selloane Phakisi Date

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HIV UPSURGE AMONG CHILDREN AGED THREE TO EIGHTEEN MONTHS: AN ACCOUNT OF POTENTIAL CONTRIBUTING FACTORS

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ABSTRACT

The purpose of this study was to identify, explore and describe the potential contributing factors of the upsurge of HIV among children aged three to eighteen months in the Mangaung Metropolitan area of the Free State Province in South Africa.

The study was conducted at five primary healthcare facilities and one hospital in the Mangaung metropolitan municipality of the Free State Province with sixty randomly selected mothers of children testing HIV-positive for the first time between the ages of three and eighteen months.

The convergent mixed-methods research design was opted for, according to which both qualitative and quantitative data were collected at the same health facilities selected by means of cluster sampling. The review of medical records, unstructured interviews, and structured questionnaires were used for qualitative and quantitative data collection, while random cluster sampling was used for participant selection. Thematic data analysis was applied for the interpretation of recurrent patterns of qualitative and quantitative data.

The study results revealed that mothers were well-informed about the prevention of mother-to-child-transmission. The main factors that contributed to more children testing HIV positive after the routine tests were conducted at ten weeks included non-adherence factors to PMTCT prescripts mainly by mothers, such as: babies were not brought to the clinics for testing and immunisations at ten weeks, and that mothers acquired HIV infection during the breastfeeding period. Some other potential contributing factors were late antenatal booking which lead to the delay in initiation of antiretroviral treatment, non-adherence to antiretroviral therapy during pregnancy, and mixed feeding. The themes that emerged from the qualitative data were psychological factors, emotional factors, socioeconomic factors, missed opportunities, risky behaviour, as well as women disempowerment; while some mothers were left with unanswered questions. The results

of the qualitative part complemented the quantitative findings as they uncovered the factors that led to the deviation from the PMTCT prescripts by the mothers.

The study's recommendations include PMTCT psychological assessment and counselling; partner and community involvement; women empowerment; and that couple testing at antenatal and postnatal clinics should be a national policy subjected to protracted monitoring and evaluation processes.

Keywords: post-natal; primary health care; upsurge; breastfeeding; PMTCT

ABBREVIATIONS AND ACRONYMS USED IN THE STUDY

AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe Criteria
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CPT	Co-trimoxazole Preventive Therapy
DHIS	District Health Information System
EBF	Exclusive Breast Feeding
EFF	Exclusive Formula Feeding
EPI	Expanded Programme on Immunisations
EMTCT	Elimination of Mother to Child Transmission
FDC	Fixed Dose Combination
FHI	Family Health International
FPC	Free State Provincial Council
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HBM	Health Belief Model
IMB	Information-Motivation-Behaviour Skills Model
IMCI	Integrated Management of Childhood Infections
IPT	Isoniazid Preventive Therapy
MCH	Maternal and Child Health
MDG	Millennium Developmental Goal
MNCH	Maternal New-born and Child Health
MTCT	Mother to Child Transmission
NAAT	Nucleic Acid Amplification Test
NNAAT	Negative Nucleic Acid Amplification Test
NHLS	National Health Laboratory Services
NVP	Nevirapine
PCR	Polymerase Chain Reaction
PHC	Primary Health Care
PICT	Provider Initiated Counselling and Testing
PMTCT	Prevention of Mother to Child Transmission
SAPMTCTE	South African Prevention of Mother to Child Transmission Evaluation
SATS	South African Testing Services

SDG	Sustainable Development Goals
SCA	Supreme Court of Appeals
SDNVP	Single Dose Nevirapine
STI	Sexually Transmitted Infections (STI)
SADC	Southern African Development Community
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Emergency Fund
WHO	World Health Organization

SUMMARY OF THE THESIS

The thesis is organised according to the following six chapters:

Chapter 1: Orientation to the Study

The chapter outlines the introduction and context of PMTCT. It also provides both the South African and global overview of HIV transmission among children. The chapter further outlines the background to the research problem and the purpose and the objectives of the research project. It describes the research design and methods of the study, as well as the significance and scope of the study.

Chapter 2: Literature Review

The chapter provides a context for the protracted search and analysis of the diverse range of sources consulted for the study. In this regard, a brief historical and contemporary outline and background is presented in respect of the South African, international, and World Health Organization's PMTCT guidelines, risk factors for mother-to-child transmission and infant feeding in the context of HIV.

Chapter 3: Theoretical Framework

This is the philosophical orientation of the thesis. The chapter discusses how the theory is constructed, perceived and explored as a research strategy for the study. The chapter then concludes with a justification for the selection and applicability of the theory and its foundational principles.

Chapter 4: Research Design and Method

This chapter presents and discusses the convergent parallel mixed method as the focal point of the research design and method opted for in the study. The chapter also explains the questionnaires and interviews as the preferred data collection methods which were used for quantitative and qualitative data collection purposes respectively. The chapter further discusses cluster and convenience sampling, inclusion and exclusion criteria, as well as the quantitative and qualitative data analysis processes. The chapter also addresses the ethical requirements to which the researcher adhered in the study. The chapter concludes with measures to ensure trustworthiness in the form of validity and reliability. The research site, its geography, HIV profile and HIV services are also discussed in this chapter.

Chapter 5: Data Presentation, Analysis and Interpretation

Chapter five presents the findings from both quantitative and qualitative parts of the study. Quantitative findings are first presented on tables which depicts the frequencies and percentages of the study variables and qualitative findings are in a form of themes, subthemes and categories that emerged from the data followed by narratives obtained from the mothers' interview transcripts. Finding are also compared and substantiated by those from previous studies.

Chapter 6: Main Conclusions, Findings, and Recommendations

This chapter concludes the entire study with the researcher's own evidence-based conclusions, the summary of the study's findings, recommendations and possible limitations of the study.

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CHAPTER 1
ORIENTATION TO THE STUDY

1.1 INTRODUCTION

The purpose of this chapter is to present an overall orientation to the critical units of analysis pertaining to the study, beginning with the prevention of mother-to-child-transmission (PMTCT) of HIV (Human Immunodeficiency Virus) as the pivotal tenet of the research problem. Other pertinent units of analysis discussed in this chapter include the research aims/ purpose and objectives; the research questions and hypothesis; the significance/ justification of the study and definition of key terms/ concepts; the theoretical foundations and scope of the study; as well as the research design and data collection and analysis methods.

1.1.1 The context of mother to child transmission (MTCT)

Mother-to-child-transmission (MTCT) is the main cause of HIV infection in children (The Joint United Nations Programme on HIV/AIDS/ UNAIDS, 2011: 5). Such transmission could occur during pregnancy, labour, birth and the postnatal period through breastfeeding. UNAIDS (2011: 5) asserts that ninety percent (90%) of HIV-infected infants and young children acquire this disease through the mother-to-child mode of transmission. Despite such prevalence rates, there have been significant measures and interventions in place worldwide since 2009 to promote an HIV-free generation and reach the goal of reducing and ultimately eliminating mother-to-child-transmission of HIV (UNAIDS, 2015a: 8).

Despite that breastfeeding is identified as one of the primary modes of mother-to-child-transmission of HIV, it should be noted however, that HIV-positive mothers in developing countries are still encouraged to breastfeed; since the benefits of breastfeeding surpass the risk of HIV transmission through breast milk (World Health Organisation/ WHO, 2010a: 3-4). Safer means have been developed, such as the provision of antiretroviral therapy (ART) to either the mother or the baby, as well as exclusive breastfeeding for the first six months after birth (WHO, 2010a: 3-4). In 2014, there were 36.9 million people living with HIV/AIDS worldwide, and about 2 million of those were newly infected (UNAIDS, 2015b: 3). Between 2009 and 2014, South Africa experienced a 76% reduction in new HIV infections in children (UNAIDS, 2015b: 14).

Success in the reduction of mother-to-child transmission has engendered the realisation that the elimination of paediatric HIV/AIDS is possible. Based on this realisation, a global plan was formulated for the elimination of mother-to-child-transmission (EMTCT) of HIV and keeping mothers alive by 2015 (UNAIDS, 2011: 6). Effectively, the number of new child infections has been reduced by half globally since 2009 (UNAIDS, 2015b: 7). The World Health Organization set the criteria for the

validation of EMTCT of HIV and keeping mothers alive. Indicators were developed for this validation process, which included: less than 50 new paediatric infections per 100 000 live births; a transmission rate of less than 5% in breastfeeding populations; and less than 2% in non-breastfeeding populations (WHO, 2014a: 2).

The prevention-of-mother-to-child-transmission programme in South Africa has shown significant progress towards the broader goal of eliminating mother-to-child-transmission of HIV. Such progress is evidenced by the 2012 South African Prevention of Mother to Child Transmission Evaluation survey (SAPMTCTE), which was conducted on babies aged 4-8 weeks who visited primary health care for the six weeks immunisations (Goga, Dinh & Jackson, 2012: 44). Significant progress with the elimination of mother-to-child- transmission of HIV has been realised in most countries in the sub-Saharan Africa region (UNAIDS, 2015a: 9). In the Free State and other South African provinces, MTCT remains high in children aged 3-18 months, which may impede the realisation of EMTCT. However, the HIV-positive prevalence rate among children aged 3-18 months remains high despite a progressive decline among those below three months of age in Free State Province. The United Nations Children's Emergency Fund (UNICEF) and the World Health Organization formulated an action framework outlining a series of actions to be undertaken in order to reach the goal of eliminating mother-to-child-transmission of HIV by 2015 (UNAIDS, 2011: 3). According to available data, most countries are on track towards attainment of this goal. Cuba was the first country to be announced as having eliminated mother to child transmission of HIV in 2015 (UNAIDS, 2015a: 8, 11).

1.2 THE RESEARCH PROBLEM

In research methodology parlance, the research problem is generally defined as the difficulty posed by a theoretical or practical state of affairs which the researcher has to resolve by means of evidence-based mechanisms (De Vos, Strydom, Fouché & Delport, 2011: 28; Rajasekar, Philominathan & Chinnathambi, 2013: 8; Walliman, 2011: 32-33). The effectiveness with which the research problem has been resolved concomitantly determines the extent of credibility of the evidence-based findings and the recommendations made, as well as the effectiveness or otherwise of the data collection instruments and data analysis processes or approaches (Kumar, 2012: 108; Rajasekar et al., 2013: 8). Furthermore, it is on the basis of the observation, acknowledgement, description, and interpretation of the research problem that a possible resolution of the identified research could be effected (Babbie & Mouton, 2010; 44; de Vos et al., 2011: 28).

By its very nature then, the formulation of an observed research problem is not peripheral to the most pertinent literature concerning the phenomenon being investigated (Kumar, 2011: 46); that is, potential contributing factors to the upsurge of mother-to-child-transmission of HIV among children aged three to eighteen months in the Mangaung Metropolitan Municipality of the Free State Province in South Africa. The research problem further locates and interrogates the association among variables (Grove, Burns & Gray, 2013: 75; Rajasekar, et al., 2013: 13). In the context of the current study, the association exists in the form of factors to the upsurge of mother-to-child-transmission of HIV on the one hand; as well as children aged three to eighteen months in the Mangaung Metropolitan Municipality. In this regard, *children's age* and *mother-to-child-transmission of HIV* are interstitial variables to the research problem.

1.2.1 Background/ Context of the research problem

The Free State Province and South Africa as a whole was succeeding in preventing mother to child transmission of HIV (Barron, Pillay, Doherty, Sherman, Jackson, Bhardwaj, Robinson & Goga, 2013: 72). This measure of success has been attested to by evidence obtained from HIV tests conducted on HIV-exposed infants from birth to ten weeks of age. on HIV exposed babies. However, the tests conducted on infants of this age (birth to ten months) only reflect antenatal and intra-partum transmission respectively (South Africa, 2015a: 24). Further routine tests are conducted six weeks post cessation of breastfeeding and at eighteen months, which mainly reveals the postnatal transmission by means of breastfeeding.

The data from the National Health Laboratory Services indicates that there were more HIV-positive infants after the ten weeks' routine test than before the ten week period (NHLS, 2012-2017). Interaction with colleagues and visits to hospitals as part of the researcher's work-related key performance areas further revealed to the researcher that there were still many HIV/AIDS diagnosed children who are still admitted to hospitals despite the decline in HIV Polymerase Chain Reaction (PCR)-positive children at ten weeks.

1.2.2 Statement of the research problem

Rajasekar et al. (2013: 11) mention that: "The [research] problem must be stated clearly, including any simplifying assumptions. This will require experience and an understanding of the situation in which the problem is embedded". In addition to the literature review (for theoretical perspectives), the source to this research problem was therefore located within the scope of practice and peer interaction (personal and professional knowledge and awareness of the research problem and its milieu) (Grove et al., 2013:75; Rajasekar, 2013: 13). In tandem with the scope of the study, the

research problem is geographically delineated within the Mangaung Metropolitan Municipality in the Free State Province.

The actual research problem is that, *despite the country's achievements in reducing mother-to-child-transmission of HIV at ten weeks after birth, the number of HIV-positive children after the ten weeks test (six weeks before 2015) remains high in the Free State Province. Consequently, the number of young children still admitted in hospitals due to AIDS-related illness in the Free State is growing.*

South Africa is making remarkable strides in preventing mother-to-child-transmission of HIV according to the DNA PCR tests conducted on infants around ten weeks. The country is also making progress towards achieving the target of less than 2% transmission rates as declared in the National Strategic Plan for HIV/AIDS, 2012-2016. The country has also made advances in reaching the UNICEF/WHO target and goal of eliminating mother-to-child-transmission and keeping mothers alive. This is further attested to by the national reduction of mother-to-child-transmission from approximately six weeks at 3.5% in 2010, to approximately 2.6% for the 2012-13 period. In the Free State Province, the transmission rates were reduced from approximately 5.9 % in 2010, to approximately 2.8% for the 2012-13 period (MRC & DoH, 2014: 42). Despite these milestone achievements of reducing mother-to-child-transmission for children at ten weeks from birth, the number of HIV-positive children after the ten weeks from birth (six weeks before 2015) remains high. Correspondingly, the researcher observed that many young children were still admitted in hospitals in the Free State due to AIDS-related illnesses.

Postnatal transmission through breastfeeding also contributes to high MTCT prevalence rates. Especially, for mothers who use mixed feeding during the first six months, those who did not receive any antenatal care, and those whose viral load was high during the breastfeeding period (Wilson, Nizet, Maldonado, Rimington & Klein, 2016: 34). Viral load may be high due to early infection, virological failure and full-blown AIDS (WHO & CDC, 2008: 2, 50). Mixed feeding, the pathological conditions of the breasts, and the infant's mouth also contribute to post-natal transmission of HIV (Okolo, Pam, Idoko & Kankis, 2014: 85). As part of the PMTCT programme in South Africa, all HIV-infected pregnant and breastfeeding women receive antiretroviral treatment (ART) irrespective of their CD4 count (South Africa, 2015a: 44). In addition, Nevirapine syrup is administered daily to all infants of HIV-infected mothers for a minimum period of six weeks, irrespective of the feeding method (South Africa, 2015a: 55).

Some studies have shown that infants to whom ART prophylaxis is administered for PMTCT and those who are breast-fed by mothers who are on ART, could present false negative or indeterminate HIV DNA PCR results (Mazanderani, du Plessis, Thomas, Venter & Avenant, 2014 :574; Burgard, Blanche, Jasseron, Descamps, Allemon, Ciraru-Vigneron, Floch, Heller-Roussin, Lachassinne, Mazy, Warszawsk, & Rouzioux, 2012: 65). These are children who later present with HIV-positive results and increase the positivity rates for older babies. In the Free State and most parts of South Africa, it is not yet known which of these could be the main contributing factors for high HIV positivity rates in the late postnatal period or older infants and children (3-18 months).

The current study may even reveal more factors which have not been mentioned above. Therefore, the question is: *If babies are tested routinely at 10 weeks and most of them are negative, where do these older babies aged three to eighteen months testing HIV-positive in the Free State Province come from?* Rajasekar et al. (2013: 11) assert that a research problem should be simplified on the basis of its own idiosyncratically identified assumptions. Burns and Grove (2013: 40) describe assumptions as those untested taken-for-granted statements by the researcher. Such statements do not necessarily lend themselves to proof, but are embedded in shaping the researcher's interpretation of the study. In this regard, the researcher made ontological assumptions based on the nature of "being" (Van Rensberg, Alpaslan, du Plooy, Gelderblom, van Eeden & Wigston, 2009: 18) or state of affairs regarding the situatedness of the research problem as a factor of two main variables; namely the age of the infants whose ontological state of MTCT is being investigated and factors contributing to the upsurge of MTCT of HIV.

1.2.2.2. Assumptions

Based on the above assertion (paragraph 1.2.2.1) the following ontological assumptions were made concerning the mother-to-child- transmission of HIV for children at from three to eighteen months in the Mangaung Metropolitan Municipality:

- They became infected after the initial test, the post-natal transmission through breastfeeding;
- They were not tested at ten weeks (previously six weeks in 2015), they may have been missed;
- They initially tested HIV-positive, but parents or caretakers did not return for results;
- The ten weeks' test yielded false positive results; and
- They were never tested at birth or at ten weeks after birth, their mothers' HIV status was not established due to incorrect testing technique or sero-converted later. As a result, the babies were not classified as HIV exposed.

Based on the above assumptions, it is then envisaged that the current study will then determine the potential contributing factors or causes of the high HIV-positive rates of prevalence among these identified cohort of babies. Accordingly, the study's focus will not only be on factors that contribute to postnatal transmission, as some babies diagnosed with HIV during this period may have been uninfected during the postnatal period. Table 1.1 below demonstrates the magnitude of the problem by comparing the HIV-positive tests results for children below and above two months of age.

Table 1.1: Comparison of DNA HIV PCR positivity between infants below two months and those above two months in Free State Province

Period	Tests conducted < 2 months	Positive < 2 months	Tests conducted> 2 months	Positive > 2 months
Oct-Dec 2015	4 588	61(1.3%)	2 815	145 (5.1%)
Jan-Mar 2016	2 884	36 (1.2%)	2 607	111(4.2%)

Source: NHLS Report (2015-2016)

Extrapolated from Table 1.1 above, it is evident that the period between October and December 2015 could irrefutably be associate with the upsurge referred to as the critical focus of the study. During this period, 4 588 babies less than two months of age were HIV-tested, and 61 (1.3%) of the cohort HIV-positive; while 5.1% (n=145) of the 2 815 tested two months after birth tested HIV-positive, indicating a 3.8% MTCT increase. The upward surge was noticeable also during the period January to March in 2016, where a 3.0% increase was recorded. Comparing the October-December 2015 and January-March 2016 periods, only a marginal decrease of 0.8% (3.8% minus 3.0%) was recorded. It should be noted that the upsurge still persists to date, and was not only confined to the six-month period cited above. Figure 1.1 below is a statistically derived diagrammatic representation of the same comparative information presented in Table 1.1.

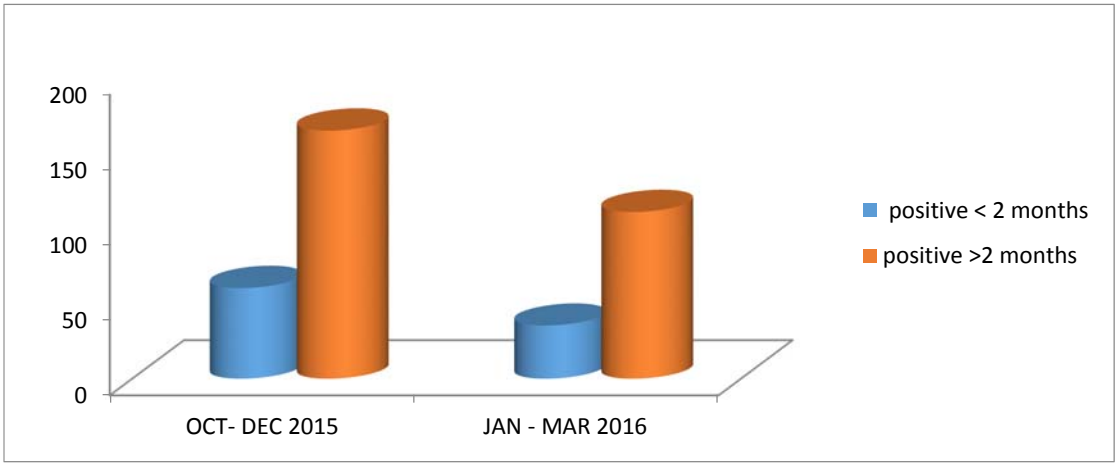


Figure 1.1: Comparisons of HIV-positive babies aged below and above two months in the Free State Province: October 2015-March 2016

1.3 PURPOSE/ AIM AND OBJECTIVES OF THE STUDY

The purpose, aim, or goal of a study refers to the general intentions of the researcher in undertaking the study (Mouton, 2010: 43). The latter author cites further that the purpose, aim or goal of a study is abstract in its conceptualisation, and requires specific and measurable actions to manifest its realisation. The study's objectives are then construed as the specific means or actions undertaken to bring the aim or purpose into tangible or concrete fruition (Babbie, 2010: 563).

1.3.1 Research purpose/ aim/ goal

Most studies conducted on HIV-positive babies after the initial routine six weeks test focused mainly on factors which facilitated postnatal transmission through breastfeeding. Little is known of other potential factors that contribute to higher positivity rates in children aged three to eighteen months. Against this background, the researcher was then interested in establishing other postnatal transmission factors except breastfeeding. Therefore, the aim or purpose of this study is:

- To identify potential factors that contribute to the high rate of HIV positivity in children aged three to eighteen months, and not focusing only on postnatal transmission through breastfeeding.

1.3.2 Research objectives

Rajasekar et al. (2013: 21) illuminate that: Every research problem is undertaken with certain outcomes intended to be reached. In the context of the aim of a study, the research objectives provide the basis and the means for reaching the anticipated outcomes by specifying the activities that reduce the aim of the study to measurable levels. The objectives (specific intentions) of this study are:

- To identify and describe the potential factors that contribute to more children testing HIV-positive between the ages of three and eighteen months in the Free State Province;
- To establish the proportion of children aged three to eighteen months who test HIV positive due to postnatal transmission;
- To make recommendations to the EMTCT programme managers and implementers on plausible measures to curb the challenge of high HIV positivity rate in children aged three to eighteen months in South Africa.

1.3.3 Research questions

A research question refers to a "concise, interrogative statement that is worded in the present tense and includes one or more variables (or concepts)" (Grove et al., 2013: 140) Research questions are posed by the researcher about the nature of real situations, the research problem that led to the study, and further enhance the stated purpose of the study (Given, 2008: 786). As opposed to questions asked in the data collection instrument, the research questions are meant to be 'answered' by the researcher during the entire research process. In such a context, the research questions then serve as guide to remind the researcher on the study's objectives while it is being undertaken. The following research questions were posed to guide the researcher throughout different stages of the study:

- Why does the HIV-positivity rate increase after the initial tests at birth and ten weeks of age in the Free State Province?
- Are all HIV-positive children from the age of three to eighteen months infected during the postnatal period?
- Is the prevention-of-mother-to-child-transmission programme more effective in preventing antenatal and perinatal transmission than the post-natal transmission?
- Which factors contribute more to high HIV positivity in children aged three to eighteen months?

1.3.4 Hypothesis

"A hypothesis is the formal statement of the expected relationships between two or more variables in a selected population". (Grove et al., 2013: 142). It stipulates the researchers' expectations about the relationship between the variables (Polit & Beck, 2017: 56). A research hypothesis further declares the researcher's assumptions concerning the problem being investigated (Rajasekar et al., 2013: 23).

In this study, the researcher makes the assumption that the relationship between non-adherences to PMTCT guidelines (independent variables) and HIV positivity in children aged three to eighteen months (dependent variable) was interrogated and determined. The hypothesis was then established to be: Non adherence to PMTCT guidelines will contribute to increased HIV positivity in children aged three to eighteen months. Figure 1.2 below represents the independent variable and dependent variable relationship.

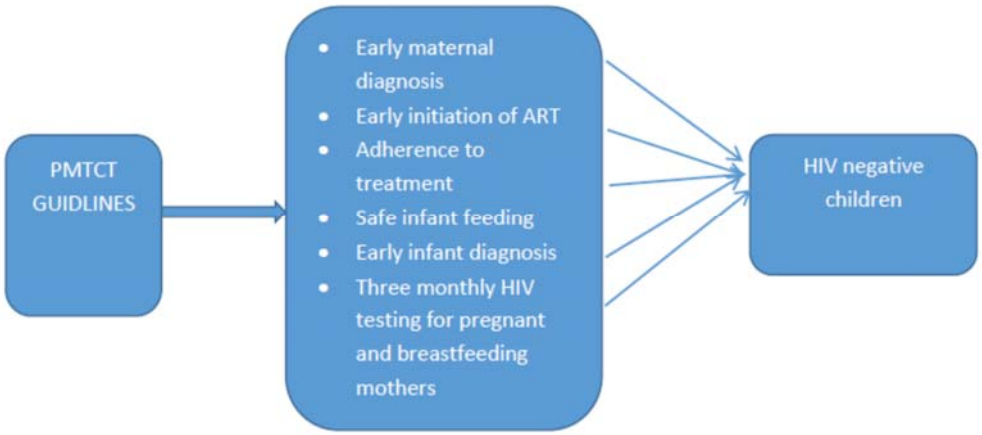


Figure 1.2: Relationship between non-adherences to PMTCT and HIV-positivity in children aged three to eighteen months

1.4 SIGNIFICANCE OF THE STUDY

The significance or value of the study justifies both the reasons (rationale) for its undertaking and the anticipated contribution to the body of knowledge (epistemology) in a specific field in which a phenomenon occurs (Vyncke, 2012: 12). In some fields of knowledge or disciplines, the significance or relevance of a study may translate into socio-economic value or benefit.

In the epistemological context, the study makes its contribution to knowledge generation and dissemination in the specific field of the prevention of mother-to-child-transmission. It is envisaged that this study will contribute towards the attainment of the ambitious target of eliminating mother-to-child-transmission. The targeted elimination of MTCT will in turn facilitate the attainment of the Sustainable Development Goals (SDG's) to "ensure healthy lives and promote well-being for all ages" (United Nations, 2015). The study will assist clinicians and policy makers in the formulation of HIV prevention strategies in children and familiarise them with the potential contributing factors to more babies testing positive after the initial routine HIV test. The study will also contribute towards the evaluation of the current national PMTCT guidelines and progress towards elimination of paediatric HIV. Such knowledge and information will bring to the attention of health authorities that the success attributed to low HIV positivity at 10 weeks does not necessarily translate into the successful curbing of new paediatric HIV infections. Recommendations for curbing new paediatric HIV infections should encourage the development and implementation of new strategies.

1.5 DEFINITION OF KEY TERMS/ CONCEPTS

The key terms or concepts are reflective of the critical mental symbols, cognitive or abstract ideas, or philosophically derived principles which are intended to allocate meaning and significance to specified units of knowledge which are of particular relevance and significance to the phenomenon or phenomena being studied (Brink, van der Walt & van Rensburg, 2012: 24). In their general ontological state, the key terms or concepts in this study have been thematically linked to factors which contribute to HIV transmission in children aged between ten and eighteen months after birth.

The definitions mentioned below are intended to provide factual and contextual clarity, prevent lexical and semantic ambiguity in order to justify their relevance to the research topic and the entire research process (Mouton, 2008:175). The alphabetic order according to which the below-stated terms have been arranged does not necessarily imply the prioritisation of one term over the other; neither does the alphabetic order signify any chronological order of appearance throughout this document.

Adherence: commitment to continue taking medical treatment correctly according to prescriptions under limited or no supervision (Mosby's Medical Dictionary, 2009: 44).In this study it means uninterrupted following of the recommendations or prescripts of the guidelines or health professionals' advice regarding treatment for HIV/AIDS or PMTCT.

AIDS: An acronym for acquired immune deficiency syndrome, a disease which attacks the human immune system and renders the body incapable of warding off opportunistic diseases. It is characterised by a reduction in the number of CD4 bearing T helper cells, thereby causing the individual to be highly susceptible to life threatening diseases (Mosby's Medical Dictionary, 2009: 24). In this study it means when an HIV infected individual's immune system becomes incapable of fighting some opportunistic diseases and some cancers and also increase the susceptibility to MTCT.

Children: Persons of either gender between birth and adolescence (UNICEF[sa]:1). In this study it refers to persons under the age of eighteen years, in particular those under eighteen months and vulnerable to vertical transmission of HIV or MTCT

Infant: A child younger than twelve months (South Africa, 2015a: 7). In this study it means a child under one year whose is at risk of acquiring HIV from his or her mother.

Factors: The elements, circumstances, or influences which contribute to produce a result (The Concise Oxford Dictionary, 2011: 419). In this study the focus is on events that lead to more children testing HIV positive after the ten weeks routine tests

HIV: The human immunodeficiency virus which attacks a person's immune system by destroying the vital cells which fight against diseases (Mosby's Medical Dictionary, 2009: 893).

HIV-exposed infant: Infant who is born of or breastfed by an HIV-infected woman. The infant may test HIV-positive on antibody test, which does not necessarily mean the infant is infected; but at risk of being infected (South Africa, 2015a: 7).

Rate: A measure of the frequency of occurrence of an event in comparison to the number of people at risk (Ehrlich & Joubert, 2014: 23). In this study it means the measure of the frequency of occurrence of HIV positive tests compared to the number of children aged thirteen to eighteen months who are at risk by virtue of being born of, or breastfeed by HIV infected mothers.

Upsurge: A sudden or abrupt increase (The Concise Oxford Dictionary, 2011: 1351). In this study it refers to an unexpected rise, specifically of HIV positivity rate in children aged thirteen to eighteen months.

1.6 THE THEORETICAL GROUNDING OF THE RESEARCH

The theoretical grounding of the study is premised on its foundational or seminal philosophical principles, conceptual ideas, or paradigms which influenced the course of this study' entire investigative processes from its conceptualisation to its actual undertaking (Holloway & Wheeler, 2010: 23-24; Knobloch, 2010: 3). The essence of the theoretical grounding is vested on a theory-driven perspective (paradigm) and main themes uncovered and highlighted by the researcher (Kumar, 2012: 349).

1.6.1 Research paradigm

A research paradigm is defined as "a shared world view that represents the beliefs and values in a discipline and guides how problems are solved" (Schwandt, 2001: 184). Holloway and Wheeler (2010: 24) illuminate that "a paradigm consists of theoretical ideas and technical procedures *[qualitative, quantitative, or mixed-methods]* that a group of scientists adopt and which are rooted in a particular world view with its own *[esoteric]* language and terminology". It is worth noting then, that a research paradigm entails a world view (perspective or approach) in terms of which a particular technically-steeped process is adhered to for purposes of resolving a specific context-specific problematic state of affairs.

Research paradigms, techniques, and research procedures are chosen on the basis of how best they meet the research purpose and provide understanding of the research problem (Creswell, 2014: 10). In this study, the mixed methods (combined qualitative and quantitative) approach (perspective or paradigm) was employed on the basis of the researcher's own pragmatic view of the ontological state of mother-to-

child-transmission of HIV in the Free State Province. Unlike the post-positivistic world view, the pragmatic perspective is grounded on actions, situations and consequences rather than on antecedent conditions (Creswell, 2014: 10). The triangulation of both qualitative and quantitative research orientations was employed in order to attain better understanding of the potential contributing factors concerning the upsurge of HIV positivity in children aged three to eighteen months. Such triangulation laid the foundation for other studies in the same field of the prevention-of-mother-to-child-transmission of HIV. The complexity of the research problem is such that the range of issues addressed could not be addressed by resorting to only a single research paradigm. Creswell (2014: 11) affirms that pragmatism is not committed to any one system of reality or philosophy, but rather draws from both qualitative and quantitative assumptions; hence the researcher's preference of pragmatism for purposes of this study.

1.6.2 Theoretical framework

Kumar (2011: 349) insightfully states that: "The information obtained from different sources needs to be sorted under the main themes and theories, highlighting agreements and disagreements among the authors. *This process of structuring a 'network' of these theories that directly or indirectly has a bearing on your research topic is called the theoretical framework* [researcher's own italicised emphasis]". In the context described by the latter author above, two theories (conceptual models) were interstitially 'networked' as the basis of the theoretical framework pertaining to preventive health care; with key emphasis on compliance to PMTCT interventions and/ or guidelines by both the health care recipients and health care providers. These theory-driven conceptual models are Becker's Health Belief Model (HBM) and the Information-Behavioural-Motivation Model (IBMM), and were chosen on the basis of their well-considered relevance to this study.

1.6.2.1 Becker's health belief model (HBM)

The model above was first developed by Rosestock in 1966, and later modified by Becker and colleagues in the 1970's and 1980's (Raingruber, 2017: 57). The model initially entailed four seminal constructs, namely: perceived susceptibility, perceived severity, perceived barriers, and perceived cost of adhering to interventions. Perceived susceptibility refers to an individual's perception of the health problem's relevance to her/ him, that the diagnosis is correct, and that the severity of the particular health problem is likely to have negative consequences. Compliance/ adherence is influenced by the person's perception of the threat posed by a health problem and the value attached to actions aimed at reducing the threat (Raingruber, 2017: 57; Polit & Beck 2017: 124).

Becker and colleague further developed the model to incorporate people's responses to symptoms of illnesses and their compliance to medical directives. The model was further modified to include illness behaviour, preventative health, and health screening. Factors such health motivation, perceived control, perceived threat, demographic and socio-psychological factors were also later added to the model. The motivation to seek health or adherence to treatment is therefore dependent on perceived susceptibility to illness, perceived seriousness, perceived benefits, and self-efficacy (Raingruber 2017; Polit & Beck 2017: 124).

In the prevention-of-mother-to-child-transmission of HIV, Becker's health belief model could demonstrate women's health-seeking behaviour and motivation to adhere to guidelines and health promotion information. Perceived susceptibility to MTCT informs the mother's decision to accept PMTCT programme interventions such as HIV testing, adherence to antiretroviral treatment, regular clinic visits, administering infant prophylaxis, safe infant feeding practices, abstinence, correct and consistent condom use, and infant testing. The value mothers attach to these interventions and the belief that they would protect their children from contracting the HIV virus is also of paramount importance. The fear of knowing the HIV status, stigma, discrimination and HIV disclosure are some of the identified barriers which mothers should overcome in order to adhere to the PMTCT prescripts (Rael & Hampanda, 2015: 320).

Perceived self-efficacy is demonstrated by the woman's belief and confidence that she will be able to complete the PMTCT interventions. Women would consider themselves susceptible to HIV in the event that they know about it. Its prevalence and incidence in their communities and their susceptibility means their babies would also be at risk. Therefore, their conscious and perceived self-efficacy increase their likelihood to adhere to PMTCT prescripts, and vice versa. The knowledge about the prescripts of PMTCT is gained from advocacy, communication, and social mobilisation provided by health care workers, NGOs and other developmental partners. This information could have noticeable impact and also eliminate the perceived barriers, provided that the mothers accept and act on it. On this basis, health promotion (e.g. social mobilisation and advocacy) also plays a major role.

1.6.2.2 Information-motivation-behavioural skills model

The Information-Motivation-Behaviour (IMB) skills model was first proposed by Fisher and Fisher in 1992 to address HIV/AIDS risk reduction behaviour (Fisher & Fisher, 1992: 455). The model provides an account of the psychological determinants of HIV risk and preventative behaviour which can improve or impair the health status. However, the model could also be applied to other health conditions (Suls & Wallston, 2003: 82-84).

The Information-Motivation-Behaviour (IMB) skills model could be applied to predict, understand, and to promote adherence to ART (Fisher, Amico & Herman, 2006: 463-467). Information, motivation and behaviour skills are also important determinants of health related behaviour. To this effect, Fisher and Fisher (2003: 84) mention that: "Health related information, motivation and behavioural skills are a fundamental determinant of performance of health behaviours. To the extent that individuals are well informed, motivated to act, and possess the requisite behavioural skills for effective action, they will be likely to initiate and maintain health promotion behaviours and experience positive health outcomes". The model has also been used specifically in the analysis of adherence to antiretroviral therapy (Fisher, Fisher, & Herman 2006: 463).

Adherence to antiretroviral therapy is one of the most important aspects of the HIV treatment regime, since it contributes towards the very achievement of viral suppression which is paramount to improving the clinical status of patients. Viral suppression in turn is vital to the PMTCT programme on the basis that the higher the viral load, the more the chances of MTCT during pregnancy, labour and throughout breastfeeding (Remington, Nizet, Maldonado, Rimington & Klein, 2016: 34). Therefore, mothers who adhere to ART and other interventions were unlikely to transmit the virus to their babies. Individuals who are on ART with inconsistent adherence are also at risk of exhausting their treatment options as a result of drug resistance. The inconsistency unavoidably results in treatment failure (Pach, Cerbone & Gerstain 2003; Moatti & Souteyrand, 2000). This also impacts negatively on PMTCT as it limits the treatment options for mothers. As a result of its information-based adherence to treatment, the IMB model is deemed appropriate for application to PMTCT and adherence to all other interventions, in addition to ART adherence.

1.7 THE RESEARCH DESIGN AND METHODS

The research design stipulates the plan for carrying out the study in order to answer the research question, *how* and *what* kind of data will be collected, and in *what* kind of setting the data collection will take place (Polit & Beck, 2017: 56). A convergent mixed methods approach was followed in this study. The qualitative data was collected by means of unstructured face-to-face interviews. Quantitative data, on the other hand, were collected by utilising a researcher-administered structured questionnaire and the review of medical records of both mothers and babies in the PMTCT equation. The data were analysed separately, and both the qualitatively and quantitatively generated results were compared for purposes of complementarity. The entire range of the research design and methods, including the data collection and analysis processes and procedures, is presented and discussed in more detail in Chapter 4.

1.8 SCOPE OF THE STUDY

The scope or delimitation of the study refers to the narrowing or reduction of the study's conceptual boundaries or methodological orientation for purposes of addressing the core variables pertinent to the context of the research topic and the problem being investigated (Singh, 2006: 30; Walliman, 2011: 34). In this study, three symbiotically related factors established a framework of its scope or delimitations.

Firstly, the study was geographically confined to the Mangaung Metropolitan Municipality of the Free State Province of South Africa. Secondly, the study was conducted in public facilities and therefore involved women of low socio-economic status as corroborated by their demographic data in Chapter Five. Mothers from affluent communities were not included in the study since most of them attend private health facilities by virtue of their socio-economic status. Thirdly, mothers who were younger than eighteen years at the time of conducting the study, were excluded from any involvement with the study's empirical data collection stages. (As a factor of the study's limitation, the exclusion of this latter age cohort could have broadened the different stakeholder experiences as part of the triangulated data collection methods.

1.9 CONCLUSION

This chapter presented an overview of the entire study in terms of its conception, the research problem and its background, the aim and objectives of the study, the significance or value of the study, as well as the theoretical foundations and scope of the study. The idea of this study emerged from the clinical observation that the HIV positivity was very low in routine tests conducted on HIV-exposed infants at 10 weeks after birth (previously six weeks) in Free State Province. Despite these very low HIV positivity rates, the hospitals in the area always had more HIV-infected children aged three to eighteen months, than those who tested HIV positive at ten weeks.

The study was grounded on Becker's health belief model (HBM) and the information-motivation-behavioural skill model (IMB). The HBM stipulates that patients' health care seeking behaviour could be influenced or impeded by patients' beliefs concerning susceptibility to, or severity of the illness. On the other hand, the IMB model asserts that well informed individuals with certain behavioural skills were likely to initiate and adhere to health promoting behaviour, which in turn yields positive rewards. It is envisaged that the study will contribute to policy making decisions for clinicians to identify potential contributory factors to more children testing HIV positive after the initial routine tests were conducted at birth and at ten weeks. Such policy orientation would contribute towards the elimination of mother to child transmission by evaluating the effectiveness of the programme beyond three months.

CHAPTER 2
LITERATURE REVIEW

2.1. INTRODUCTION

The review of literature is concerned with the systematic search, consultation, and synthesis of credible sources of information pertaining to the phenomenon or phenomena under investigation (de Vos et al., 2011: 360). To this effect, Kumar (2012: 46) further asserts that: "In the initial stages of research, it helps you [the researcher] to establish the theoretical roots of your study, clarify your ideas and develop your research methodology … ***it is here that the literature review plays an extremely important role*** [researcher's own bold italics for emphasis]". In the context of the afore-cited assertions, it is irrefutable that a protracted search and compilation of literature-based sources of information is of immense benefit to the researcher. Among other factors, the systematic review of available literature enables the researcher to amass sufficient theoretical background and methodological awareness; emerging trends, practices, themes, and contestations in the field or subject/ discipline being researched (e.g. PMTCT); policy implications; any gaps between theory and practice; the contributions of other researchers, experts, professional practitioners and scholars on similar studies; as well as lessons to be learnt from others in other countries (Kumar, 2012: 349; Babbie & Mouton, 2009: 76).

The review of literature focused on the international, continental (African), and local (South African) context of EMTCT, with specific emphasis on factors that contributed to the successes, failures and/ or challenges which impede on the effective implementation of the EMTCT programme. The multi-dimensional context of the elimination of the mother-to-child-transmission of HIV required that relevant data and information be sought from a diverse range of sources, including academic books from reputable academic libraries, published and unpublished university postgraduate theses/ dissertations; medical records and reports; official government policy documents/ reports; search engines, and databases (Gibbs, 2007: 48).

From a research methodological viewpoint, the literature review further provided approaches by means of which all the research questions posed in sub-section 1.3.3 could be responded to. In this regard, the review of literature focused on the prevention and/ or elimination of mother-to-child-transmission of HIV (EMTCT); the evolution of the programme in South Africa; the current guidelines; studies conducted on causes of continued HIV sero-conversion by children older than three months; those that evaluated the programme; as well as initiatives, successes and challenges. Aspects pertaining to children's diagnostic tests in different ages, their reliability, feasibility and challenges with exclusive breastfeeding were also addressed.

2.2. THE DEVELOPMENT OF THE PMTCT PROGRAMME IN SOUTH AFRICA

The PMTCT programme in South Africa was developed from 1998-1999 by the Western Cape Province's Department of Health in its two midwife obstetric units in Cape Town (Barron, Pillay, Doherty, Sherman, Jackson, Bhardwaj, Robinson & Goga, 2013). Prior to this pioneering initiative, there was no national PMTCT policy in the country. In 2001, the National Department of Health (NDH) subsequently endorsed the launch of two PMTCT research sites in each of the nine provinces in South Africa in order to ascertain operational challenges that could occur as a result of ART introduction to prevent mother-to-child-transmission of HIV by pregnant women (Barron et al., 2013). However, this policy was challenged in the courts and the government was ordered to implement a fully-fledged PMTCT programme in December 2001 as well as in 2002.

The PMTCT programme was formally and effectively implemented after the government lost its case challenging the court order (Barron et al., 2013). Prior to the court case in 2002, there were different PMTCT regimens in the country. The programme was pioneered with the administration of a single dose of Nevirapine to HIV-infected women in labour, and also a single dose of Nevirapine syrup to HIV-exposed babies at birth. The single-dose policy changed in 2008 with the introduction of dual prophylaxis of Zidovudine from 28 weeks gestation and Nevirapine during labour, as well as to infants within 72 hours after birth (Barron et al., 2013). In 2010, the policy changed again and Zidovudine was to be administered at 14 weeks gestation for women with CD4 cell count of more than 350 cells/mm³. On the other hand, lifelong antiretroviral therapy (ART) was administered to those with CD4 count of less than 350 cells/mm³, and Nevirapine syrup to HIV-exposed infants daily from birth till six weeks irrespective of feeding choice. NVP prophylaxis was to be continued for the duration of breastfeeding for breastfed infants whose mothers were not on lifelong ART (South Africa ,2010: 30).

There were two feeding options for HIV- infected mothers, namely: exclusive breastfeeding and exclusive formula feeding. Free formula was provided in public facilities for mothers who met the WHO AFASS (Acceptable, Feasible, Affordable, Sustainable and Safe) criteria and opted for replacement feeding after counselling on safe infant feeding (South Africa, 2008: 14). The provision of free formula for HIV-infected mothers was discontinued after the promulgation of the Tshwane Declaration, in which South Africa declared its commitment to the promotion, support and protection of breastfeeding and adoption of the 2010 WHO infant feeding guidelines which recommended breastfeeding by HIV-infected mothers while they receive ART for prevention of transmission. Mothers who still opted for replacement feeding after

intense counselling had to provide for their own formula and still be supported on their choice (South Africa, 2013: 42). In 2013, a fixed-dose combination of Efavirenz, Emtricitabine, and Tenofovir was introduced as a single dose of ART from fourteen weeks gestation to all pregnant and breastfeeding women, irrespective of their CD4 count. In terms of the above-cited fixed-dose combination, women with CD4 count above 350 cells/mm³ discontinued with the treatment one week post cessation of breastfeeding, while women with CD4 count of less than 350 cells/mm³ continued with lifelong ART. Nevirapine syrup was administered to all HIV-exposed infants for six weeks irrespective of feeding choice.

2.2.1 Overview of the current PMTCT programme

The current PMTCT programme in South Africa is cognate from the 2015 guidelines, which are discussed in more detail in sub-section 2.2.2. It is estimated that mother-to-child-transmission of HIV accounts for 90% of children who become HIV infected, mainly during pregnancy, labour, and the postnatal period (FHI, 2004: 1). In the absence of appropriate interventions, MTCT could range from 15%-45%, which is reducible to below 5 % with successful PMTCT strategies (WHO, 2013: 3). The PMTCT programme is a four-pronged strategy which does not only focus on provision of ARV drugs to mothers and safe infant feeding (FHI, 2004: 2; WHO, 2010b: 6).

The first prong is focused on the primary prevention of HIV, and encompasses behaviour modifications, treatment of sexually transmitted diseases (STIs), safe blood transfusions and reducing the vulnerability of women to HIV. The second prong addresses prevention of unplanned pregnancies in women living with HIV by improving access and integrating family planning into routine HIV services. The third prong is premised on the prevention of HIV transmission to children by women who are already infected. The preventive measures cover all PMTCT interventions which are implemented during pregnancy, labour, and breastfeeding. The fourth prong is about care and support that should be provided to HIV-infected mothers, their children, and their families (WHO 2007: 5).

At its General Assembly meeting in July 2011, the United Nations Organisation (UNO) also launched its global EMTCT plan. “This plan provides the foundation for country led movement towards the elimination of new HIV infections among children and keeping their mothers alive” (UNAIDS, 2011: 3). The plan covers all low- and middle-income countries, but focuses mainly on twenty two countries with the highest prevalence of HIV among pregnant women. With the exception of India, all of these countries are in Sub-Saharan Africa and include South Africa (UNAIDS, 2011: 3). These countries had reduced the number of new infections by 48% at the end of 2014, led by South Africa with a 76% reduction rate, followed by Tanzania (72%) and both

Uganda and Mozambique at 69% (UNAIDS 2015: 8). In June 2015, Cuba became the first country to be validated as having eliminated mother to child transmission (UNAIDS, 2015: 11).

2.2.2 South African and World Health Organization PMTCT guidelines

As indicated in section 2.1 above (p. 19), the PMTCT environment is presented in this chapter in both its macrocosmic and microcosmic contexts. Accordingly, the South African and World health organization PMTCT are presented in their summarised versions as illustrated in Figure 2.1 below.

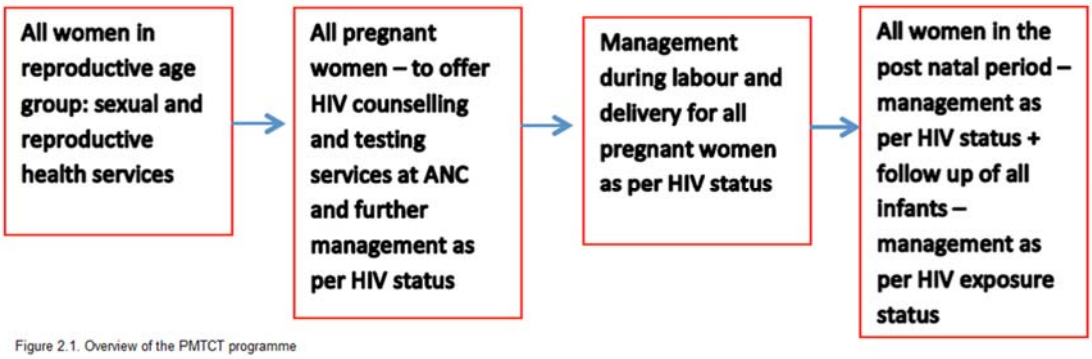


Figure 2.1. Overview of the PMTCT programme

Figure 2.1: South African PMTCT in respect of WHO guidelines (South Africa: 2015; 51; WHO, (2016)

It is noteworthy that the guidelines in Figure 2.1 above also take account of the WHO four-pronged strategy already discussed in sub-section 2.2.1 above. As presented in the figure above, pregnant women are interstitial to all four prongs of the current (2015) South African PMTCT programme, and should start attending antenatal clinics as soon as pregnancy is diagnosed.

2.2.2.1 HIV counselling and testing

HIV testing and counselling (HCT) should be provided to all antenatal clients with unknown HIV status. Repeat tests should be conducted every three months for those who test negative during the antenatal and breastfeeding period. Couple testing should be strongly encouraged (WHO, 2016a: 246). HCT serves an entry point for PMTCT programme and awards opportunity for ARV treatment initiation for the benefits of the mother and the prevention of mother to child transmission. High antenatal testing rates in high burdened countries has contributed significantly to the reduction of MTCT (WHO, 2016a: 43). Repeat tests for those who are HIV negative are conducted to diagnose those who become infected after the initial tests.

2.2.2.2 Antiretroviral therapy

Women who test HIV positive should be immediately initiated on ART with a fixed dose combination of Efavirenz, Emtricitabine, and Tenofovir. Blood sample should be taken for baseline routine tests (serum creatinine and CD4 count), and these samples should

be back after one week for the results and further management if required. In the event that any of these three drugs (Efavirenz, Emtricitabine, and Tenofovir) is contra-indicated, the affected women are to be referred to a high-risk clinic and put on Zidovudine mono therapy while waiting to be attended to at a high-risk clinic (South Africa, 2015a: 45). All women, irrespective of their HIV status, should be screened for tuberculosis (TB). The WHO clinical staging should be conducted on all HIV-infected women on every visit to the healthcare centre. Women who are un-booked or diagnosed with HIV during labour should still be administered with prophylaxis for PMTCT comprising a single dose of Nevirapine and Truvada (Tenofovir and Emtricitabine) and Zidovudine three hourly. Those undergoing emergency Caesarean section should be administered with a single dose of Nevirapine and Truvada. All these women who are un-booked or diagnosed during labour have to be initiated on lifelong ART before leaving the health facility (South Africa, 2015a: 45).

2.2.2.3 Prophylaxis for opportunistic infections

Pregnant HIV-infected women also receive Isoniazid preventive therapy (IPT) and Co-Trimoxazole preventive therapy (CPT) for the prevention of opportunistic infections. IPT is for the prevention of tuberculosis, while CPT is for the prevention of pneumocystis Jirovecii pneumonia, malaria, toxoplasmosis, and other infections. Patients with CD4 count below 100 cells /micro litre are screened for cyptococcal disease. In the event that the reaction is positive with symptoms, treatment is commenced and patients are admitted to hospital, with ART deferred for 4-6 weeks. In the event that the reaction yields positive symptoms and the patients are suspected of having contracted meningitis, the patients are then put on fluconazole. Fluconazole is teratogenic, and pregnant women should be referred to a specialist before commencing ART therapy (South Africa, 2015a: 52).

2.2.2.4 Infant prophylaxis

Nevirapine syrup should be administered to all HIV-exposed babies for six weeks, and this may be extended in the event that the mother has been on ART for less than four weeks prior to delivery, or have not been on ART or HIV-diagnosed during labour. Abandoned babies whose mothers' HIV status is unknown also receive Nevirapine, and the HIV antibody test is conducted to determine the level of exposure. The administration of negative Nevirapine is stopped in the event the HIV antibody test results are negative. If positive, it is continued for six weeks. Babies whose mothers tested HIV-positive during breastfeeding period should be put on Nevirapine and Zidovudine immediately and be tested for HIV using DNA (deoxyribonucleic acid) and PCR (polymerase chain reaction). If the results are negative, the Zidovudine is discontinued and Nevirapine continued for twelve weeks. HIV exposed babies also

receive Co-Trimoxazole preventive therapy (CPT). It is administered from four to six weeks and should be stopped when the baby is PCR-negative for those who are exclusively formula fed. Babies who are breastfed should receive CPT when the HIV, DNA ,and PCR tests are negative at six weeks post cessation of breastfeeding (South Africa, 2015a: 55).

2.2.2.5 Early infant diagnosis

All HIV-exposed babies are tested for HIV using the DNA and PCR tests at birth. According to WHO (2016a: 30), babies who have a positive result at birth are those who became infected during pregnancy, while those infected during labour will not have a detectable virus for several weeks. If the result is negative, the test is repeated at ten weeks, six weeks post cessation of breastfeeding and the final test is conducted at eighteen months using the rapid antibody test. The tests can also be conducted any time when there is a clinical indication. Infants who test PCR positive anytime should be initiated on ART immediately. Babies who are on extended Nevirapine prophylaxis should have a PCR test four weeks after the discontinuation of Nevirapine (South Africa, 2015a: 24). Nevirapine or other antiretroviral drugs taken by the baby for post-natal prophylaxis may lead to false negative or indeterminate results (WHO, 2016a: 13).

Contrary to the South African practice of PMTCT, the WHO recommends that early infant diagnosis should be conducted at 4-6 weeks or earlier. Babies younger than eighteen months should have a virological, rather than an antibody test (WHO, 2016a: 29). The national policy on testing services further stipulates that the following children should be tested for HIV infection:

- Those receiving TB and malnutrition treatment;
- Children of adults and siblings who are receiving HIV services; and
- Those admitted to medical wards (South Africa, 2016: 12).

2.2.2.6 Infant feeding

Counselling on infant feeding is provided to all women, irrespective of their HIV status, and each woman should attend at least four counselling sessions during the antenatal period. The recommended feeding option is exclusive breastfeeding for six months, followed by the introduction of complementary feeding and continued breastfeeding for one year. HIV-infected women could continue breastfeeding for a period of twelve months, while HIV-negative women and those whose infants are already infected could continue breastfeeding for a period of two years and beyond. The risk of mixed feeding, non-adherence to ART, and the need to avoid re infection or acquisition of a new infection during breastfeeding should be emphasised. Women who are on second

or third line ART for less than three months and have a viral load of more than a thousand copies per litre should not breastfeed (South Africa, 2015a: 87). Women who chose not to breastfeed even after intense counselling should also be supported on their choice of feeding. In terms of the stipulations of the Tshwane Declaration, mothers who opted for exclusive formula feeding will no longer receive free infant formula in public health facilities. However, in South Africa breastfeeding is contra-indicated in HIV infected mothers who are on second or third line ART for more than three months and their viral load is still more than 1 000 copies.

2.2.2.7. Safe obstetrical practices

Adaptation or avoidance of some obstetrical practices is required during labour. These are not explicitly stated in the South African guideline, but are highlighted by the Family Health International (2004: 10). The following guidelines were proved to reduce MTCT during labour:

- Elective Caesarean section is known to reduce intra-partum MTCT (FHI, 2004: 10). It should be noted however, that in South Africa, elective caesarean section is not recommended for prevention of mother to child transmission. (South Africa, 2015a: 52). WHO affirms the effect of Caesarean section in PMTCT, but does not recommend it in lowly resourced settings (WHO, 2016a: 104);
- Shortening the time between rupture of membranes and birth;
- Avoidance of invasive procedure including routine episiotomies; and
- Avoidance of oropharyngeal suctioning of the baby unless there is meconium stained liquor, or the baby needs resuscitation.

2.3 RISK FACTORS OF MOTHER TO CHILD TRANSMISSION OF HIV.

Wilson et al. (2016: 34) give the following account of factors which increase the risk of mother-to-child transmission of HIV.

2.3.1 High maternal viral load

High viral load during pregnancy, labour and lactation is associated with an increased risk of mother to child transmission. It is usually present during primary infection and advanced maternal disease or full blown AIDS, and in mothers with no antiretroviral therapy.

2.3.2 Obstetrical factors

Obstetrical factors and interventions that cause exposure of the baby to maternal blood and other secretions also increase the risk of MTCT. These include electronic scalp electrodes for foetal monitoring, episiotomies, vaginal tears instrumental or assisted births, and prolonged rupture of membranes. Other factors include procedures such as amniocentesis and chorionic villus biopsy due to placenta micro transmission.

2.3.3 Maternal co-infection

Maternal co-infections in which there is a high viral load such as malaria pre-dispose the infant to vertical infection. HSV-2 (Herpes Simplex Virus 2) and other Sexually Transmitted Infections expose the foetus to infected blood and other body secretions.

2.3.4 Breastfeeding

Breastfeeding is known to transmit HIV to the infant. However, studies have demonstrated that exclusive breastfeeding with antiretroviral therapy for the mother or infant minimises transmission (WHO, 2016a: 35). Remington et al. (2016: 34) elaborate further on the factors that could increase the risk of transmission through breastfeeding. These factors are: mixed feeding, maternal mastitis, breast abscess, and infant-related factors such as oral thrush and prematurity.

2.4 INFANT FEEDING IN THE CONTEXT OF HIV

MTCT could occur during the postnatal period through breastfeeding, yet it is known as the best way of providing for adequate infant nutrition. Breastfeeding is therefore one of the most effective child survival strategies (WHO, 2016b: 1). The key components of the South African strategic plan on campaign of accelerated reduction of maternal mortality in Africa (CARMMA) include improving child survival by a number of objectives, such as promotion and support of breastfeeding (South Africa, 2012: 12). The Tshwane Declaration was promulgated in 2011, and it stood for the support, promotion, and protection of breastfeeding (South Africa, 2013: 57). Consequently, the supply of free formula for PMTCT was discontinued in public facilities.

South Africa adopted the 2010 WHO PMTCT guidelines which encouraged exclusive breastfeeding by all mothers for the first six months of their babies' birth, irrespective of their HIV status. The country also adopted the introduction of complementary feeding at six months and continued breastfeeding for twelve months by HIV infected women (South Africa, 2013: 9). Exclusive breastfeeding means that "The infant receive only breast milk without any other liquids or solids, not even water, except for oral rehydration solution or drop or syrups of vitamins, minerals or medicines" (WHO, 2016b: iv). According to South Africa (2013: 10), other national and global policies and initiatives which support and promote breastfeeding by all mothers have adopted the following critical aspects:

- Global strategy for infant and young child feeding;
- Mother-baby friendly hospital initiative;
- Innocenti declaration;
- United Nations 2010 joint guidelines on HIV and infant feeding;
- Campaign of Accelerated Reduction of Maternal and Child Mortality in Africa;
- Road map for infant nutrition in South Africa; and

- The strategic plan for maternal, new-born, child and women's health and nutrition in South Africa.

The prevention of mother to child transmission of HIV is mainly through the following: exclusive breastfeeding, provision of ART and adherence support to mothers, regular ART prophylaxis to infants, HIV counselling and testing of breastfeeding mothers and their partners (WHO, 2016b: 33-35). Breastfeeding by HIV infected women is recommended in low socio-economic settings where child mortality is high in non-breastfed children while avoidance of all breastfeeding by HIV infected women is recommend in affluent societies. In this regard, the World Health Organisation (2016a: 125) categorically states: "In countries where diarrhoea, pneumonia and malnutrition remain significant causes of child mortality, recommendations aim to reduce the risk of HIV transmission through breast milk. This is done primarily by providing ART to mothers living with HIV and ARV prophylaxis to their infants, while avoiding malnutrition and the increased risk of serious infections in infants and children through the promotion of breastfeeding. In other settings, avoidance of all breastfeeding is currently recommended".

2.5 STUDIES CONDUCTED ON FACTORS THAT CONTRIBUTE TO MTCT

The fact that children are diagnosed at a later stage may not necessarily mean that they just became infected, hence the fact that these babies might have been infected earlier was considered. Therefore, studies that relate to challenges with early infant diagnosis were incorporated. Maternal sero-conversion in late pregnancy and during breastfeeding, treatment failure and lack of adherence also have a significant impact on mother to child transmission. It is for this reason that studies of the likely verisimilitude with the research topic were also included in the literature review.

The hypothesis of the study is that: *Non adherence to current South African national / WHO PMTCT guidelines will contribute to increased HIV positivity in babies aged three to eighteen months*. Therefore, the ensuing sub-sections (2.5.1 to 2.5.3) focus on a brief overview of the South African (national), the continental (African), and the WHO (international) PMTCT guidelines -with the former (national and continental) posited as the means towards the end (derived from the latter (WHO). In the process, barriers and challenges are also explored and described with regard to adherence to these guidelines.

2.5.1 The international perspective

Early identification and prompt treatment of HIV infected children is known to reduce HIV/AIDS-induced child mortality and morbidity (WHO, 2016a: 28-29). It is conducted routinely to babies enrolled in the PMTCT programme or those of mothers with known HIV positive status. In these mother-infant pairs, vertical transmission rates are very

low. Babies of mothers who have not been identified or diagnosed as HIV infected do not have access to the routine tests and have high transmission rates since they and their mothers do not receive ART (WHO, 2016a: 39). Early infant diagnoses for known HIV exposed babies also emerged as a challenge that could lead to more children being diagnosed late when they have developed AIDS-defining illnesses (Ahmed, Kim, Sungandhi, Phelps, Sabellia, Diallo, Young, Duncan & Kellerman, 2013: 236). Late diagnosis leads to a delay in the initiation of antiretroviral treatment among these children. Early detection could lead to improved outcomes. The researcher believes that these are some of the babies who are diagnosed when already symptomatic and increase the positivity rate of the ten months test.

Chamla, Essajee, Young, Kellerman, Lovich, Sugandhi, Amzel & Lou (2015: 2021) all affirm that despite the success of the PMTCT programme by reducing perinatal and post-natal transmission to babies, the majority of the unidentified children are those who were born to mothers who missed, or lost follow-up on the PMTCT programme; only to be diagnosed at a later stage. This challenge could be mitigated by integrating HIV testing services for children into other programmes, such as the integrated management of childhood infections (IMCI) and immunisations (Davies & Pinto, 2015: 1). Ahmed et al. (2013: 236-237) identified some of the challenges hindering early infant diagnosis and case finding. These hindrances are:

Caregiver challenges: In low-resource settings, less than 20% of HIV-exposed infants are tested early. Reference is also made to the South African prevention of mother to child transmission evaluation (SAPMTCTE), which established that only 35% of HIV infected mothers intended to take their infants for early infant for HIV testing at six weeks (Goga et al., 2012: 43).

Provider challenges: Concerns about confidentiality and disclosure of maternal HIV status, increased workload and lack of understanding in handling paediatric blood specimen. In some instances, providers who have not been sensitised to provider initiated counselling and testing (PICT), would treat the child for repeated opportunistic infections with conducting the HIV test.

Policy level challenges**:** Signed consent is required in most countries for an HIV test, and in some instances care givers are reluctant or not available to give consent for the test. (In the South African context, the South African Testing Services (SATS) policy clearly stipulates that an informed written consent should be signed for an HIV test in order to avoid unintended disclosure of results (South Africa, 2016: 5).

The success of the PMTCT programme lies mostly in the initiation and retention of pregnant and breastfeeding mothers on antiretroviral therapy (WHO). However, failure

to retain women on treatment has emerged as one of the factors that hinder PMTCT. Abram and Strasser (2015: 20296) cite studies who found that high out-of-pocket costs; poor treatment by health workers; self-transfer to other health facilities; and inconvenient clinic hours were some of the individual, structural and health system factors which contributed to the retention of mother infant pairs to treatments. Furthermore, some cultural factors influenced the health-seeking behaviour of women during pregnancy and post-partum periods. In some parts of the world, there is still a low uptake of antenatal care.

Family planning is still one of the important pillars of the four-pronged strategy of PMTCT programme. Providing counselling, support and family planning services to HIV-infected women will reduce the number of HIV-exposed babies (UNAIDS, 2016: 33). Such provision also improves maternal and child health by reducing the number and proper spacing of pregnancies. Eleven of the EMTCT global plan priority countries do not meet the family planning need of more than 20% of married women (UNAIDS, 2016: 33). The United Nations Organization (2014: 1) defines unmet family planning need as the percentage of women of reproductive age, either married or in a union and sexually active, who want to discontinue or delay childbearing but are not using any method of contraception. Despite this unmet family planning challenge, studies have shown that HIV-positive women who know their status are more likely to limit their children through the use of contraceptives (MacQuarrie, 2015: 1). The challenge of the unmet family planning need is also experienced in South Africa. In her study conducted in Mangaung, Phakisi (2014: 55) found that the majority of HIV-infected women who participated in her study had unplanned pregnancies. Another study conducted about missed opportunities in PMTCT programme in the Eastern Cape Province revealed that only 44% of women were counselled about family planning (Rispel et al., 2009: 178).

2.5.2 The continental (African) perspective

A number of studies have been conducted on HIV and infant feeding. Exclusive breastfeeding has been proven to lower the risk of MTCT, as compared to mixed feeding which has been found to increase infant mortality (Piwoz & Tavenga, 2005: 699). Provision of free formula to HIV exposed babies is associated with high infant mortality. In the first quarter of 2006 in Botswana, under-five mortality increased by about twenty times in children under five months who were not breastfed (Luo & Quick 2006). According to the WHO (2016: 3) maternal antiretroviral therapy and exclusive breastfeeding are key to the prevention of postnatal mother to child transmission. However, studies conducted in Sub Saharan Africa have demonstrated that there are challenges with adherence to ART and exclusive breastfeeding (Wojciski, 2017: 2).

The maternal high viral load of HIV during the postnatal period which occurs mainly in newly infected mothers and advanced stages of HIV infection, increases the risk of mother to child transmission through breastfeeding (Remington et al., 2016: 34). A study conducted in Zimbabwe by Humphrey, Peter, Humphrey, Mutasa, Piwoz, Moulton, Chidawanyika, Mahomya and Nathoo (2007: 520) discovered that mother to child transmission through breastfeeding was high in mothers who Seroconvert during the postnatal period. In a randomised double blind, placebo-controlled phase III trials conducted in three African countries, an estimated of 22% of new infections in breastfed babies occurred during the late postnatal period. The main contributory factor associated with this was advanced maternal disease manifested by low CD4 count and high viral load (Chasela, Chen, Fiscus, Hoffman, Young, Valentin, Emel, Taha, Goldenberg & Read, 2008: 5). In high-income countries with low infant mortality, postnatal MTCT is prevented by avoidance of all breastfeeding (Remington et al., 2016: 34).

A non-randomised prospective cohort study conducted by Kilewo, Karlsson, Ngarina, Massawe, Lyamuya, Swai, Lipyoga, Mhalu and Biberfeld (2009: 414) in Tanzania revealed that antiretroviral therapy taken by lactating women reduces the risk of MTCT through breastfeeding. It was on the basis of such developments that the South African and WHO guidelines for PMTCT recommend the provision of ART and adherence counselling for HIV infected breastfeeding women.

A study conducted in Nigeria by Anoje, Aiyenigba, Suzuki, Badru, Akpoigbe, Odo, Odafe Adedokun, Torpey, and Chabikuli (2012: 5), confirmed that lack of PMTCT interventions was a serious affront to MTCT prevention. The study revealed that the HIV positivity rate was 20% at 0 – 6 weeks in babies and mothers who did not receive ART, 4.8% in those who did, and in babies who were mixed-fed. Furthermore, the HIV positivity rate was 25.6% as opposed to 11.8% in those who were exclusively breastfed (Anoje et al., 2012: 5). Although the study was conducted on younger babies, if missed during the earlier tests they could contribute to high positivity in older babies.

Prolonged breastfeeding increases the risk of MTCT. The latter was confirmed by a Malawian study conducted by Taha, Kimwenda, Gibbons, Broadhead, Fiscus, Lama, Liomba, Mkhomo, Miotti and Hoover (2007: 4). The study revealed that late post-natal transmission is associated with continued breastfeeding by HIV infected women beyond six months. Taha et al. also cited other studies which revealed that high maternal viral load and clinical mastitis also contribute substantially. The infection rate in these studies was 1.22% between six weeks and six months, and late postnatal transmission accounted for 85% of all transmission; although it is believed that low

early transmission was due to low breast milk viral load brought about by Nevirapine and sustenance of exclusive breastfeeding during the first months. Postnatal transmission through breastfeeding was associated with some maternal factors such as low CD4 count and high plasma viral load. These are also risk factors for antenatal and intrapartum transmission (Chasela et al., 2008: 5-6). Another study conducted in Malawi demonstrated that ARVs (Nevirapine and Zidovudine) administered to infants of mothers who did not receive antenatal or intrapartum ART, had an effect in preventing vertical transmission (Taha et al., 2003: 1174). The South African PMTCT guidelines therefore make provision for this benefit by stipulating that babies of mothers who have not been on ART prior to giving birth should still receive Nevirapine and both Zidovudine and Nevirapine to those of mothers diagnosed with HIV during breastfeeding for post exposure prophylaxis (South Africa, 2015a: 55).

Moodley et al. (2011: 1233) cite other studies in Africa which demonstrated the effect of acquisition of HIV in pregnancy and lactation on MTCT. These include a study conducted in Rwanda on breastfeeding women. That study found that of women who seroconverted during lactation, 53% of babies became infected. In another study conducted in Zimbabwe, a third of babies whose mothers seroconverted during pregnancy became infected. Concerning another study on the challenges of the PMTCT programme in Northern Ethiopia, Koye and Zeleke (2013: 398) concurred that late HIV follow-up visits exposes babies, adversely affects home deliveries, and renders PMTCT interventions and mixed feeding ineffective.

In their review and exploration of the PMTCT programme in Nigeria and Malawi, Okoli and Lansdown (2014: 2-3) highlight the following challenges:

- Sociocultural factors, which include lack of male participation, stigma, discrimination, and domestic violence;
- Socioeconomic factors, such as; poverty, illiteracy, inadequate knowledge and information, inaccessibility to PMTC programmes, and birth by unskilled health care attendants; and
- Shortcomings and failure of the design of PMTCT programme to cater for women's needs and lack of integration with mother and child services.

2.5.3 The National (South African) perspective

In a study conducted in South Africa by Sherman, Lilian, Bhardwaj, Candy and Barron (2014: 235-236), these authors found that the following factors may increase the number of babies who test HIV positive after the routine ten weeks test:

- There is no unique identifier for each baby's specimen tested for HIV, therefore it is not possible to detect repeat tests which may falsify the number of babies who test positive;
- Mothers who do not adhere to clinic visits schedules or fail to report for early infant diagnosis may also falsify the early infant diagnosis rates and increase the rates of those who test positive at a later stage; and
- Provision of infant and maternal antiretroviral therapy (ART) prophylaxis for longer periods may also yield false negative HIV tests results on infants because of the ART.

The above-cited main findings on maternal ART are further affirmed by the WHO, which alerted clinicians about the possibility of false negative nucleic amplification test (NNAT) on infants thus: "The ability of NAT to detect viruses in the blood may be affected by the ARV taken by the mother or infant for post-natal [sic] prophylaxis resulting in false negative results. This includes a drug that is present in the breast-milk as a result of maternal ART during breastfeeding" (WHO, 2016: 30). This may contribute to the reduction of sensitivity of the six weeks' HIV test and, can also increase the positivity rate at a later stage. However, the WHO (2016: 31) highlights that the quality of evidence is low at this stage, and still recommends infant testing to be conducted at 4-6 weeks for infants who received the ART prophylaxis and those whose mothers are on ARV's, despite the concerns that the test should be delayed. In South Africa, infant testing following the one conducted at birth is now facilitated at 10 weeks -four weeks after discontinuing the infant ART prophylaxis (South Africa, 2015a: 25). The issue of false negative HIV test results in infants on ART was further disputed in another South African study which also found that there was a possibility of false-positive and indeterminate HIV-1PCR tests. However, Mazanderani, du Plessis, Thomas, Venter and Acenant (2014: 576) also caution that further research is needed in the sphere of false negative test result.

HIV counselling and testing (HCT) is one of the strategies for HIV prevention and an entry point for HIV/AIDS treatment. (WHO 2016a: 18, South Africa, 2015a: 11). It is widely available to all in all health facilities in South Africa. Pregnant women who know their HIV status prior to pregnancy have better maternal and child outcomes because of early and prompt initiation of ART. Mnyani and Mcintyre (2013: 64-68) conducted a cross-sectional survey to identify the key aspects of the quality of PMTCT services in Soweto, South Africa. The study revealed that most women (71.5 %) discovered their HIV positive status during the current pregnancy, and only 68% of these women had disclosed their HIV status. Both the delay in HIV diagnosis in women and lack of disclosure have been identified as barriers to the PMTCT programme. Delays in diagnosis lead to late initiation of ART. Perinatal and postnatal mother to child

transmission are lower for women who start ART prior to pregnancy (Ramkissoon & Coovadia, 2014: 18). Mnyani and Mcintyre (2013: 67) also revealed that there were gaps in the knowledge of the PMTCT guidelines by health care providers and some patients received incorrect information about the PMTCT interventions. Such inconsistencies could lead to non-adherence to the PMTCT intervention. In a study conducted in Mangaung, South Africa, Phakisi (2014: 47) also found that some women were receiving incorrect information about the PMTCT interventions from the health care providers

The South African PMTC guidelines also recommend that pregnant and breastfeeding women be tested for HIV every three months (South Africa, 2015a: 23). This is done in order to identify women who become infected during pregnancy and breastfeeding. These guidelines also enhance the identification of women who previously had false negative tests. Kalk, Slogrove, Speert, Bettinger, Cotton and Esser (2013: 90-91) identified women who had been reported to be HIV negative at antenatal clinic. It was later discovered that one had an HIV-exposed infant, while the other infant was symptomatic at two weeks. The above-mentioned Another study by the Medical Research Council on the effectiveness of the PMTCT programme in South Africa reported that 4.1 % of mothers were HIV negative and had HIV exposed babies (Kalk et al., 2013: 91).

Meanwhile, another South African study by Moodly, Esterhuizen, Reddy, Moodley, Singh, Ngaleka and Govender (2011: 1233) also found out that 3.4 % of women seroconverted during pregnancy and lactation; and that the MTCT rate among these women was 20.5%. Seroconversion during pregnancy and lactation predispose to higher risk of vertical transmission (Moodly et al 2011: 1233). In the event that these mothers are not diagnosed or detected, their children do not normally undergo routine tests conducted to HIV exposed children and may present with signs and symptoms at a later stage when they are already infected. Such an eventuality will inevitably have the potential to increasing the transmission rate of older children.

A study conducted in the Eastern Cape by Rispel, Peltzer, Phaswana-Mafuya, Metcalf and Treger (2009: 178), identified some missed opportunities in the provision of PMTCT services. The self-same study revealed the following salient factors:

- Early infant HIV testing was not conducted on most babies;
- Nurses were uncertain about infant feeding in the context of HIV; and
- Pregnant women did not participate in HIV support groups and there were also challenges with monitoring and evaluations.

In her study in the Mangaung Metropolitan Municipality, Phakisi (2014: 47) also found out that health workers were giving incorrect messages about the duration of exclusive breastfeeding.

Failure to follow up has been identified as one of the challenges of the PMTCT programme in South Africa. Not all HIV-exposed babies are taken for early infant diagnoses (Sherman et al., 2014: 236). These are babies who may present later to health facilities with AIDS-defining illness increasing the positivity rate in older babies. Mother to child transmission is also high in mothers with poor health-seeking behaviour because they are unlikely to adhere to treatment and do not bring their infants for immunisation and HIV testing (Sherman et al., 2014: 236)

According to Nuttal (2014: 7), the increased risk of mother-to-child-transmission is associated with a range of maternal factors, such as: unsuppressed maternal viral load greater than 1000cpm from 28 weeks pregnancy; initiation of ART twelve weeks before delivery and defaulted ART for approximately one month during pregnancy; failed 1st and 2nd line ART and new infection in pregnancy from 28 weeks gestation and during breastfeeding; as well as the diagnosis of Tuberculosis, Syphilis and Chorioamnionitis in pregnancy. In babies, MTCT risk factors include preterm birth, low birth weight, and inadequate or no ART prophylaxis (Nuttal, 2014: 7).

The 1994 Clinical Trials Group Protocol 076 argued that the use of antiretroviral drugs for prophylaxis proved to be effective in reducing MTCT (Connor, Sperling, Gelber, Kiselev, Scott, O'Sullivan, M, Van Dyke, Shearer, Jacobson, Jimenez, O'Neill, Bazin, Delfraissy, Culnane, Coombs, Elkins, Moye, Stratton & Balsley, 1994). It was demonstrated that Zidovudine (AZT) administered to mothers during pregnancy and labour and to their infants from birth to six weeks was effective in reducing HIV transmission by two-thirds (Connor et al., 1994). This was a major breakthrough in preventing mother to child transmission of HIV and led to other more effective regimens for PMTCT prophylaxis. Based on these studies and their pioneering findings, the WHO and South Africa recommend antiretroviral therapy during the antenatal period, labour and postnatal period and continued lifelong thereafter (WHO, 2016: 81 (South Africa, 2015a: 14).

2.6 CONCLUSION

This chapter outlined the WHO PMTCT guidelines which are the seminal foundation of the prevention of mother to child HIV transmission globally. The south African guidelines which were derived from these guidelines were also discussed, as well as factors that cause mother to child transmission. The chapter also outlined a number of studies which were conducted with regard to the challenges of the PMTCT

programme globally, continentally and nationally. The review of literature led to the identification of a range of critical concepts. Notwithstanding, the HIV positivity gap of children after the routine tests in infancy, was not adequately addressed and the focus of most studies was around post-natal transmission though breastfeeding.

CHAPTER 3
THEORETICAL FRAMEWORK

3.1 INTRODUCTION

Chapter three addresses the philosophical orientation of the thesis. The chapter describes the two models which were comparatively used to guide this study, namely, the information-motivation and behaviour (IMB) skills model and the health belief model (HBM). In addition, justification for the selection of these models is also outlined. The two models were chosen on the basis that they both emphasise on behaviour change, which is a requirement for successful PMTCT and HIV prevention and treatment in general. The similarities between the two models are further demonstrated in this chapter. It is worth noting that both models have been integrated into a PMTCT theoretical framework conducive for the Free State Province in accordance with the WHO and South African PMTCT guidelines. These guidelines are inextricably linked with other strategic policy initiatives such as the UNAIDS Global Plan towards the elimination of new HIV infections among children by 2015 aimed at keeping their mothers alive; the Strategic Plan for Maternal, Newborn, Child and Women's Health (MNCWH); the Nutrition in South Africa 2012-2016 programme; as well as South Africa's National Strategic Plan for HIV/AIDS, TB and STI's 2017-2022.

3.2 THEORETICAL GROUNDING OF THE STUDY

The theoretical grounding of the study pertains to its theoretical framework. A theoretical framework refers to "the structure that can hold or support a theory of a research study. It introduces and describes the theory that explains why the research problem under study exists" (Swanson, 2013: 1). A theory provides an explanation or prediction of the relationship between concepts and constructs in a specific phenomenon in a given discipline. A theory may appear in a research study as an argument, a discussion or a figure that helps explain or predict a particular phenomenon (Creswell, 2014: 54). Theories consist of concepts and relational statements which explain, describe, predict or control phenomenon being investigated and discussed (Grove et al., 2013: 117). These philosophically founded concepts, principles and shared elements have the inherent characteristic to construct assumptions, explanations and predictions which describe *why* and *how* certain concepts are related. Theories can offer different explanations of the same phenomenon or phenomena. Furthermore, theoretical explanations and predictions are not final, but subject to change. One theory cannot be relied on as the only basis or source of absolute truth pertaining to the reality of a phenomenon or phenomena (du Plooy et al., 2014: 39-41

3.2.1 Conceptual framework

Polit and Beck (2017: 119) draws a distinction between the conceptual and theoretical framework, where theoretical framework is applied in the event that the study is based on a theory; whereas a conceptual framework is used when a study is based on a conceptual model. However, the above-cited authors also infer that the two terms are usually used interchangeably. The United States Department of Health and Human Services and the National Institutes of Health (2005: 4) also explain the reason for the interchangeable usage of theoretical and conceptual frameworks in health behaviour and health promotion theories, stating that: "The health behaviour and health promotion theories draw upon various disciplines, such as psychology, sociology, anthropology, consumer behaviour, and marketing. Many are not highly developed or have not been rigorously tested. Because of this, they often are called *conceptual frameworks* or *theoretical frameworks".*

The theoretical framework outlines the theoretical scope of the study, provides guiding principles and perspective for examining the topic, helps identify key variables to be included in the study, and points the most critical research questions. The main focus of this study was on preventive health care, with some emphasis on compliance by both the health care recipients and health care providers. The relationship between non-adherence to PMTCT guidelines to HIV positivity in children aged three to eighteen months was determined by means of the mixed-methods approach to data collection and analysis. The information-motivation-behaviour skill model (IBM) and the health belief model (HBM) were adopted for this study. The two models together address the theoretical explanations of the levels of individual influence to adhere to treatment as described by the United States Department of Health and human services (2005:12), and focus on behaviour change and/or modification. In this study, these models were applied to describe the factors that influence behaviour change regarding the prevention of mother to child transmission of HIV. Firstly, behaviour is influenced by cognition. *What* people know and think affects *how* they act. Secondly, knowledge is a prerequisite for producing behavioural change, but knowledge by itself is not enough to produce most behaviour change. Lastly, perceptions, motivations, skills and social environment are key determinants of behaviour (Fisher, Amico & Herman, 2006: 463-467).

3.2.2 The information-motivation-behaviour (IMB) skill model

The IBM model was developed to provide an account of psychological determinants of adherence to antiretroviral treatment through the integration of various constructs from health and psychology models. It stipulates the psychological determinants of behaviour which can either improve or impair health status (Suls & Wallston, 2003:

83). Although it originally addressed adherence to ART, the model has been used to address adherence to management of other chronic diseases. In this study, it includes other PMTCT-related behaviour such as early antenatal booking, compliance to exclusive breastfeeding in the first six months, HIV testing, negotiating and maintaining consistent condom use, taking the child for HIV test at stimulated intervals, and adherence to infant PMTCT prophylaxis.

3.2.2.1 Assumptions of the information-motivation-behaviour skill model

Fisher et al. (2006: 463-467) assert that the information-motivation-behaviour skill model is characterised by the following: Individuals who are well informed, motivated and have the necessary behavioural skills are more inclined to adhere to health promotion behaviour. Secondly, individuals who are not informed, not motivated and lack certain behavioural traits are unlikely to engage in health promotion behaviour. Thirdly, personal and social motivation is also a prerequisite for the performance of health related behaviour. Fourthly, a well informed and motivated individual also needs behavioural skills to perform health promotion behaviour. Information should be understandable and applicable to the individual's social ecology and could be in the form of health promotion messages. In the event that the information is incorrect, it could lead to wrong health promotion practices. Motivation relates to attitudes towards personal performance of health behaviour. Another construct of the model is premised on behaviour skills, which uphold that well informed and motivated individuals are able to participate in and maintain health promotion behaviour (Fisher et al., 2006: 467).

3.2.2.2 IMB's relevance to PMTCT

Information is necessary for individuals to initiate and maintain behaviour necessary for PMTCT. According to the South African guidelines for antiretroviral therapy and PMTCT, it is mandatory that all individuals should undergo drug readiness training prior to, or during initiation of ART (South Africa, 2015b: 17). The information provided includes HIV prevention, care, and adherence to treatment. Information in the form of leaflets, posters, health education, radio and television adverts/talk shows is also provided to the population at large. Motivation is influenced by attitudes and beliefs about the susceptibility to MTCT, outcomes of the intervention and the perception of support by the significant others. Behaviour skills would be displayed by perceived ability incorporate PMTCT interventions into social life. Behaviour skill would therefore be demonstrated by early antenatal booking, adherence to ART, safer sex, administration of infant prophylaxis, exclusive breastfeeding in the first six months, infant testing at stipulated intervals, HIV testing every three months during pregnancy and breastfeeding by HIV negative mothers, as well as safer sex practices. Examples of moderating factors include maternal psychological status, socio-economic factors,

risky behaviour, and HIV disclosure and partner support. The outcome of all these would be HIV negative children.

3.2.2.3 A schematic representation of the IMB skills model

Figure 3.1 below is a schematic representation of the IMB skills model and its core elements of: PMTCT/HIV Adherence Information; Moderating Factors Affecting Compliance; Behavioural Skills; Adherence Behaviour; Health Outcomes; and Motivation.

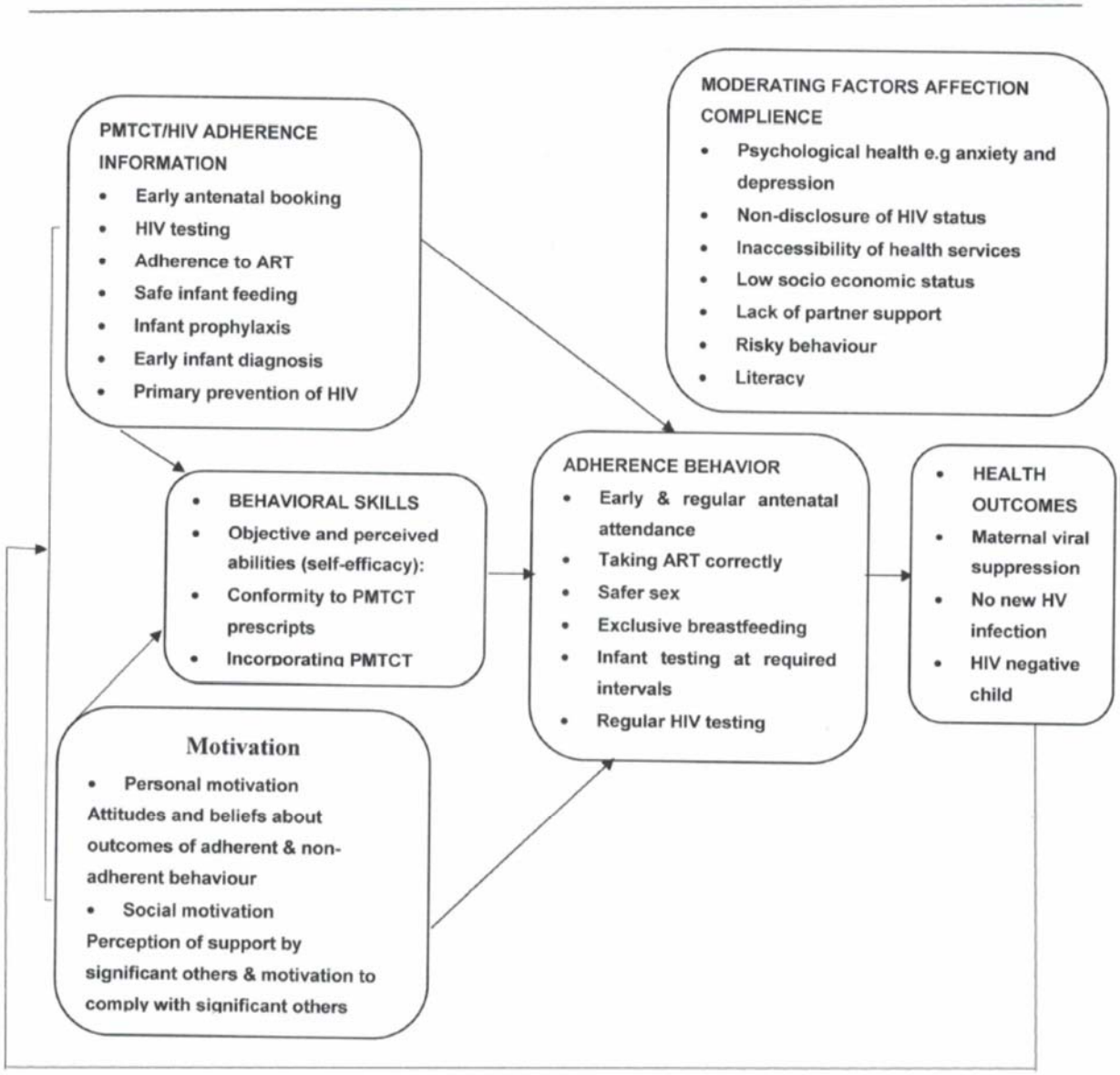


Figure 3.1: IMB model of adherence applied to PMTCT (Adapted from Fisher et al., 2001)

3.2.3 The health belief model (HBM)

The health belief model is a psychological model that tries to explain and predict people's behaviour and attitudes towards health. It is regarded as one of the most influential models in health promotion. It was developed by Rosenstock in 1966

informed by a study on tuberculosis patients' response to X-ray treatment. It was later extended to cover illness behaviour, preventative health, health screening and compliance to medical directives (Raingruber, 2017: 57). It now focuses on patient conformity to prescribed medical regimens and preventive and promotive health care practices.

The basic assumption of the HBM model is that individuals will take health related action in the event that they either feel that the undesirable health condition could be shunned, or have a belief that the undesirable health condition could be prevented by taking treatment and also the belief that the individual could successfully institute preventive action. According to Polit and Beck (2017: 124): "The model postulates that health seeking behaviour is influenced by a person's perception of a threat posed by a health problem and the value associated with actions aimed at reducing the threat". The model addresses the individual's perception of the susceptibility and severity of the health threat and the benefit of avoiding it. It also identifies factors that affect the decision to act such as barriers, cues to action and self-efficacy. (United States Department of Health and Human Services, 2005: 13). This theory has further been developed to include six main constructs, which are: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (United States Department of Health and Human Services, 2005: 13). Perceived susceptibility addresses the person's belief about the possibility of acquiring the particular health condition. Perceived severity is about the seriousness of the condition and its complications. Perceived benefits address the belief that the envisaged action will prevent the adverse consequences. Cues to action are the strategies that are implemented to raise awareness, while self-efficacy is about one's confidence in taking action. (United States Department of Health and Human Services, 2006: 13).

3.2.3.1 Diagrammatic representation of the health belief model (HBM)

Figure 3.2 below is a diagrammatic representation of the health belief model and its six core constructs which are centrally constituted around an individual's perceived threat to diseases.

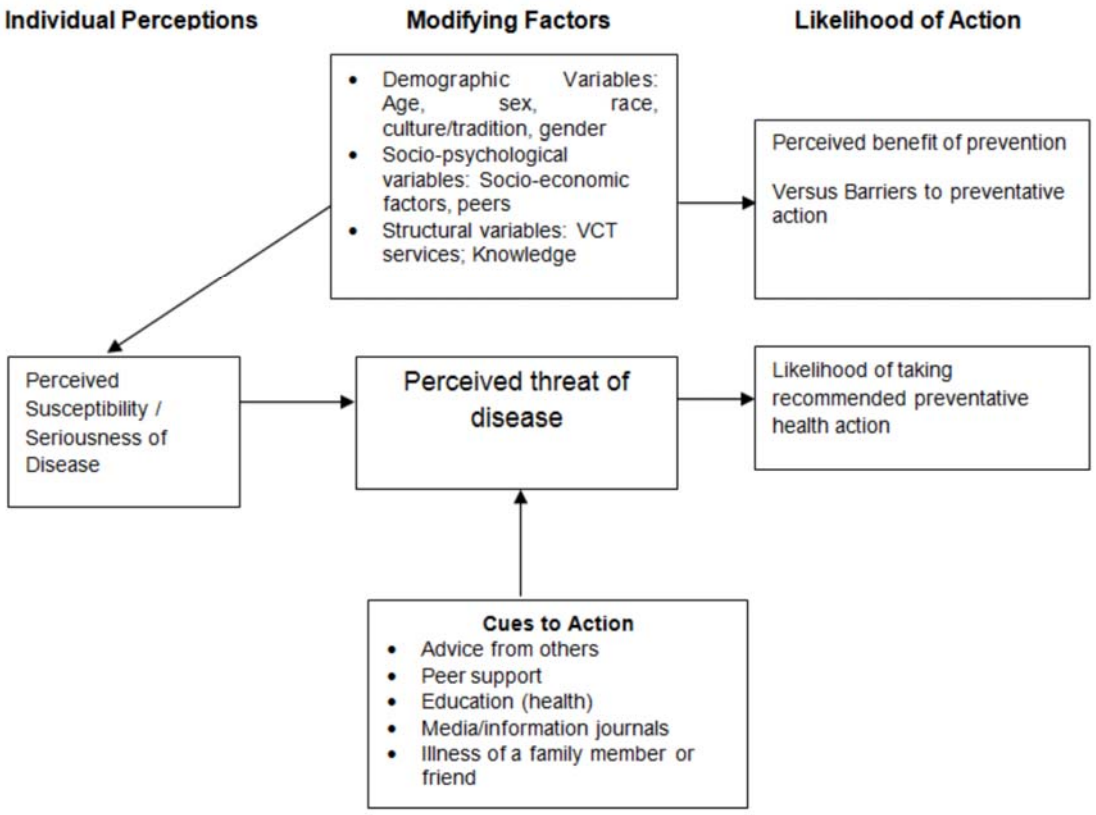


Figure 3.2: Health belief model (Source: Glanz, Rimer & Lewis, 2002: 52)

3.2.3.2 HBM applied to PMTCT

Figure 3.2. above is an illustration of the health belief model. All of its constructs are discussed below in relation to the PMTCT and the adherence to its prescripts as interpreted by the researcher using the model's constructs.

3.2.3.2.1 Perceived susceptibility

Women or couples who believe that they are susceptible to HIV will most likely have an HIV test, book antenatal care early and institute measures to prevent the transmission to their children; whereas those who believe that they are not at risk of HIV infection will not take measures to find out if they are infected or not and will not institute measure to prevent MTCT.

3.2.3.2.2 Perceived severity

This construct relates to the individual's belief about the seriousness of the medical condition and how it may affect his or her life. Individuals who believe that their conditions are serious enough to infect their babies with HIV will most likely comply with the recommended preventive measures such as exclusive breastfeeding for six months.

3.2.3.2.3 Perceived benefits

The main benefit of PMTCT is having HIV negative children. Therefore, mothers who believe in this outcome are most likely to adhere to PMTCT strategies.

3.2.3.2.4 Perceived barriers

Stigma and discrimination, non-disclosure and other psychosocial and socio economic factors may prompt the mothers not to comply with PMTCT measures.

3.2.3.2.5 Cues to action

Parents who are informed about PMTCT are most likely to institute action to protect their children from acquiring HIV. Information, communication and social mobilisation about HIV and PMTCT will prompt them to take preventive action, while parents who are uninformed may not be aware of PMTCT strategies.

3.2.3.2.6 Self efficacy

Positive attitude and confidence by parents that they can carry out measures to prevent MTCT can contribute positively to adherence.

3.2.3.3 Relationship of the HBM and IMB models

Both the health belief model and the information-motivation-behaviour skills model have been selected as the study's conceptual and theoretical frameworks due to their affinity and relevance to PMTCT as the foundational tenet and focus of the research topic. Accordingly, Table 3.1 depicts those interstitial constructs which are similar and apply to both models in respect of Information, Motivation and Behavioural Skills.

Table 3.1: Construct relationship of the HMB and IMB skills model

Health Belief Model (HBM)	Information-Motivation-Behaviour Skills (IMB) Model	Relationship
Perceived susceptibility	**Information**	These three constructs in HBM are made possible by information possessed by mothers or parents. Uninformed individuals will not have these perceptions.
Perceived severity		
Perceived benefits		
Perceived barriers	**Motivation**	Motivation can be negatively affected by the perceived barriers. Absence of barriers may increase of maintain motivation. Cues to action may contribute to motivation and its sustenance.
Cues to action		
Self-efficacy	**Behavioural Skills**	Behavioural skills may be enhanced by perceived self-efficacy

3.3 THE CONCEPTUAL FRAMEWORK RELATED TO PMTCT

Having highlighted the seminal constructs of both the HBM and the IMB skills model, this final aspect of the chapter focuses on the implications of the two models in the PMTCT context of the study. Figure 3.2 below depicts these implications insofar as their applicability to a Free State environment is concerned.

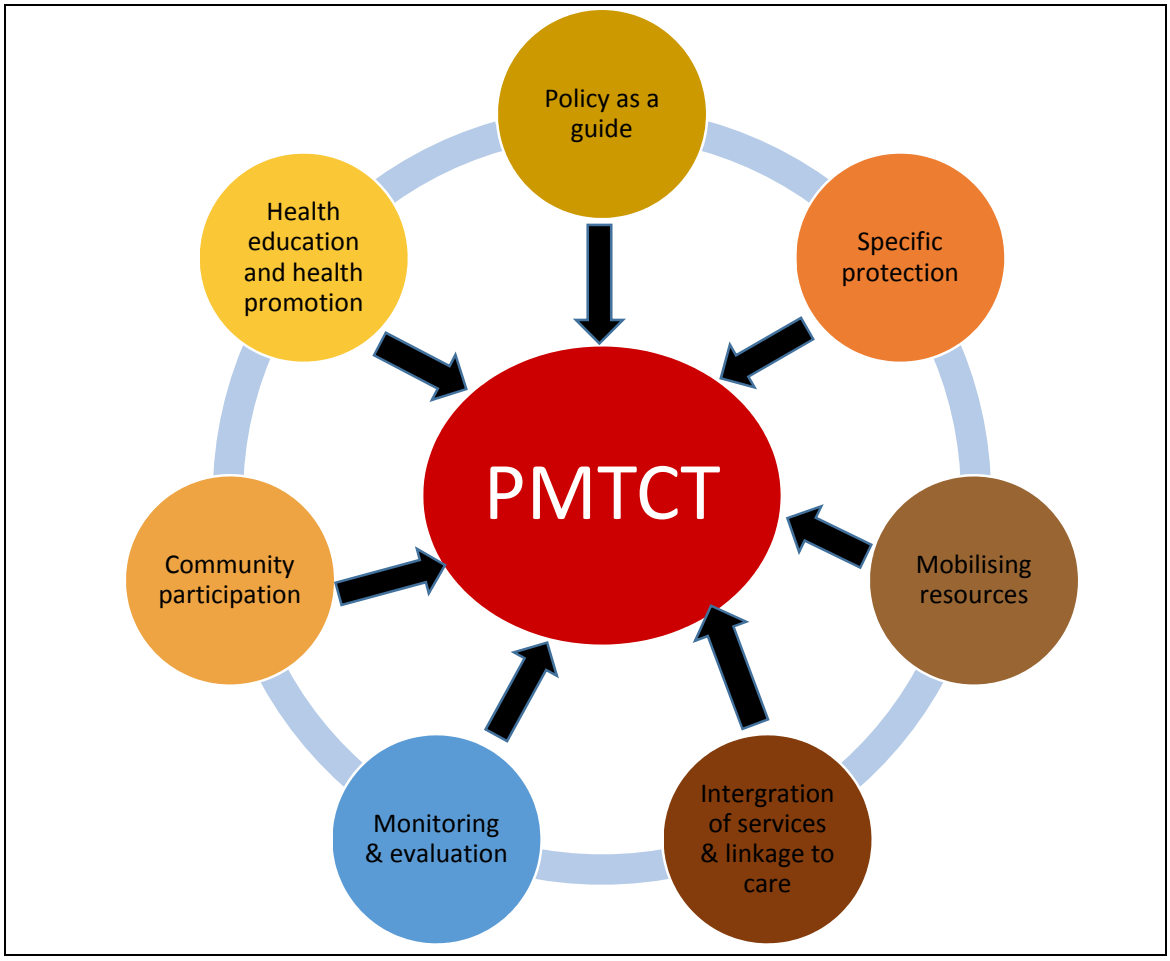


Figure 3.3: Theoretical framework for PMTCT in Free State Province

3.3.1 Policy as a guide

A policy refers to "a law, regulation, procedure, administration action, incentive or voluntary practice of governments and other institutions." (CDC, 2015). In public health, policies cover advancement and implementation of public health laws and regulations which influence individual's behaviour towards the promotion or improvement of health (CDC, 2015). In this study, policy refers to international, national, provincial and institutional prescripts and regulations which directly or indirectly contribute to the prevention and management of HIV/AIDS, including prevention of mother to child transmission. In South Africa, there are policy guidelines which direct clinicians and all health care workers on the management of HIV among adults and children; as well as the prevention of mother to child transmission. There are related policies such as HIV testing services policy of 2016 and the infant and young child feeding policy, all of which are derived from the World Health Organisation's and UNICEF's guidelines. The

national contraception and fertility planning policy and service delivery guidelines of 2012 also addresses the 2nd prong of the PMTCT programme and the prevention of unintended pregnancies in HIV infected women. These policies form the basis for health promotions and health education directed to all citizens to keep them informed about how to prevent mother to child transmission of HIV. There are also provincial and institutional policies which address these issues. The guideline policies also guide the clinicians and health care workers in the formulation and dissemination of information and communications messages to health care recipients during drug readiness training.

3.3.2 Specific protection

The protection of children from the invasion by the HI virus is done through the PMTCT programme as a four pronged strategic framework endorsed by the WHO. According to this framework, the PMTCT programme encompass the primary prevention of HIV; the prevention of unintended pregnancies among HIV infected women; the prevention of transmission of HIV from infected women to their children and the provision of care for HIV infected mothers; as well as their children and families. (WHO, 2007: 5; UNAIDS, 2011: 12). Specific protection can be the ART for PMTCT, consistent and correct use of condoms, adherence to exclusive breastfeeding, early infant diagnosis, regular HIV testing by mothers reported to be HIV negative. Specific protection by health care recipients is influenced by perceived susceptibility or perceived severity and motivation skills of the individuals.

3.3.2.1 Primary prevention of HIV

Prevention of HIV in the general population, especially young women, results in less incidences of HIV in pregnant and breastfeeding women, which in turn reduces or eliminates mother to child transmission. Strategies for primary prevention of HIV include health information and education, behaviour change, safer sex, management of sexually transmitted infection, and couple testing (WHO, 2007: 6).

3.3.2.2 Preventing of unintended pregnancies among HIV infected women

Counselling on family planning should be provided to HIV infected couples in order to assist in decision making, and contraceptive services should be integrated into HIV testing services and the use of condoms with other family planning method should be promoted. (WHO, 2007: 7; FHI, 2004: 2).

3.3.2.3 Prevent transmission of HIV from infected women to their children

Quality antenatal and birthing care should be provided and should cover the following: HIV testing and counselling for all women at first visit and re testing on follow up visits for those who test negative, provision of ART to all HIV infected pregnant and

breastfeeding women, ARV prophylaxis to infants, safer obstetric practices, and counselling and support on infant feeding (South Africa, 2015a: 50).

3.3.2.4 Care for HIV infected mothers and their infants and families

Continued care should be provided to mothers and their families, which should include screening, management and provision of prophylaxis for opportunistic infections, provision of antiretroviral therapy, nutrition counselling, and social support. (WHO, 2007: 7; FHI, 2004: 2).

3.3.3 Mobilising resources

The HIV/AIDS policies and activities in South Africa are mainly funded by the government through the comprehensive HIV/AIDS and TB conditional grant (South Africa, 2017b: 38). The national strategic plan for HIV, TB and STI's prioritises among others, social and structural drivers of the disease. These include programmes to build resilience in youths and children to be undertaken through the provision of community based prevention and early intervention services; as well as strengthening parenting and family psychological and mental health services (South Africa, 2017b: 44). The programme requires the human resources in the form of managers, nurses, doctors, clerks, data capturers, dieticians, and nutritionist. Most of these are not only responsible for the PMTCT programme only, but have other responsibilities within the health facilities.

3.3.4 Integration of services

The PMTCT programme is directly linked to other services which together contribute to its success. Hence, the integration of services is essential for its progress, and the achievement of the ultimate goal of elimination of mother to child transmission. The World Health Organization (2008b: 1) defines integration as "The management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of health system". However, the term can also have multiple meanings for different people and contexts. Six types of usages have been identified as follows (WHO, 2008b: 2): It is used to refer to a package of preventive and curative health interventions to a particular population group according to its stage in its life cycle, for instance, the integrated management of childhood illness. Secondly, it can also mean multi-purpose service delivery points where the services are provided for a specific catchment population at one location under one manager. Thirdly, it can mean achieving continuity of care over time, for instance, the. lifelong care of chronic conditions or a continuum of care between certain stages in a person's life-cycles; for instance, infancy, childhood and adolescence. It also refers to a vertical integration of different levels of services such as health posts, health centres, district hospitals and

regional hospitals. Others use the term to refer to integrated policy making and management which brings together the decisions and support functions across different parts of the health service. Lastly, it refers to working across sectors such as cross sectional funding, regulation and service delivery. The services that are directly related to the PMTCT programme are among others: maternal and child health, family planning, HIV counselling and testing, antiretroviral treatment, TB treatment and screening, and nutrition services.

3.3.5 Community participation

Community participation is defined as "a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change" (WHO, 2002: 10). The phrase is sometimes used interchangeably with other concepts such as; consultation, involvement, community action, empowerment, community capacity building and community development. Community participation may have the following benefits: It can promote the efficient and effective use of resources, increase the uptake of health services, increase the community member's competence and capabilities, enhance ownership, combats irregularity of power and promote creative thinking, and innovative planning and thinking. (WHO, 2002: 11). In the context of PMTCT it can be applied through the use of local non-governmental/ non-profit making organisations. This can enhance participation of all stake holders, not only the mothers involved in the study. Male involvement can result in high uptake of couple testing, the use of condoms which are crucial to PMTCT, but also other HIV and sexual reproductive health services.

3.3.6 Health promotion

Health promotion encompasses other elements such a social mobilisation and advocacy (WHO, 1998: 5). In this study health promotion means activities undertaken by the health sector; health education, advocacy, communication and social mobilisation with the aim of enhancing healthy behaviour and health literacy in the context of HIV/AIDS. WHO (1998: 6) defines health behaviour as "any activity undertaken by an individual regardless of actual or perceived health status, for the purpose of promoting, protecting and maintaining health, whether or not such behaviour is objectively effective towards that end."

According to the Ottawa Charter for health promotion, "health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical mental and social wellbeing, an individual or group must be able to identify and realise aspirations, to satisfy needs, and to change and cope with

the environment" (WHO, 1986: 1). The Ottawa Charter identified five fundamental action strategies for health promotion as follows:

- Building a healthy public policy;
- Creation of physical and social environments supportive of individual change;
- Strengthening community action;
- Development of personal skills such as increased self-efficacy and feelings of empowerment; and
- Reorientation of health services to the population and partnership with patients.

Health promotion could be advanced by avenues such as health literacy, which encompass the cognitive and social abilities that influence the motivation and ability of individuals to gain access, understand and use information in a way which promotes and maintains good health. In this regard, health literacy is not only about reading pamphlets and making appointments (WHO, 1998: 10).

3.4 CONCLUSION

The most critical purpose of this chapter was to provide the conceptual and theoretical parameters of the study in order to provide foundational grounding of the philosophical principles and paradigms which influenced the researcher during the various stages of the research process. In this regard, the chapter outlined the health belief model and the information-motivation-behaviour skills model were opted for to guide the study. These conceptual models were chosen on account of their similarities in addressing behaviour change - a critical element in the PMTCT context. The schematic presentation of the IMB in relation to PMTCT was depicted. The chapter concludes with the illustration of the Free State PMTCT framework as an important aspect of the affinity between theory and practice.

CHAPTER 4
RESEARCH DESIGN AND METHOD

4.1 INTRODUCTION

This chapter delineates the strategies, steps, decisions and processes that were followed in conducting this study. It describes the research design that was opted for, the research methods that were applied, the sampling processes and procedures, the ethical considerations, as well as the measures that were effected for purposes of ensuring the reliability, validity, and the trustworthiness of the study.

In addition to the delineation of strategies, steps, decisions and processes, the essence of this chapter is to provide a context and framework within which the theoretical and/ or conceptual perspectives were integrated against the empirical mould whose practical implications are described and analysed in Chapter 5. Such integration is necessitated by the enhancement and construction of analytic logic, thematic coherence, and evidentiary conclusivity of the research topic and the core phenomenon being investigated (Chesnay, 2015: 1).

4.2 RESEARCH DESIGN

The research describes the study's overall action and management plan in respect of *how*, *where* and *when* data are to be collected and analysed (Wood & Ross-Kerr, 2011: 114). Babbie (2013: 117) propounds further that: "A research design involves a set of decisions regarding what topic is to be studied among what population with what research methods for what purpose". Meanwhile, Polit and Beck (2017: 164) describes research design as strategies which the researcher adopts to develop accurate and interpretable evidence, as well as the methodological decisions justifying such a course of action. It is then beyond dispute that the research design outlines the steps and processes the researcher intends to take, and *how* observations will be made in order to achieve the expected outcomes.

The study employed a mixed-methods research design approach, which incorporates both qualitative and quantitative research methods and elements of convergent parallel mixed approaches. "The core assumption of this form of inquiry [mixed-methods] is that the combination of quantitative and qualitative approaches provide a more complete understanding of the research problem than either approach alone" (Creswell, 2014: 4). The researcher therefore strived to obtain comprehensive data that would provide more understanding of the potential contributing factors of the increase in HIV positivity in children from three to eighteen months, as compared to the initial routine tests conducted at ten weeks. Lohfeldl and Brazil (2002: 46) state the following about the use mixed methods: "Both approaches provide for cross-validation or triangulation – combining two or more theories or sources of data to study the same

phenomena in order to gain a more complete understanding of the phenomenon (interdependence of research method), and they also provide for achievement of complementary results by using the strengths of one method to enhance the other … [researcher's own bold italics for emphasis]".

The convergent parallel mixed approach was used in this study, in terms of which the researcher collects both quantitative and qualitative data, analyses them separately and compares them to determine the complementarity of the results (Creswell, 2014: 219). The fundamental assumption of this kind of inquiry is that the combination of quantitative and qualitative approaches results in a more complete understanding of the research problem than either approach used alone (Creswell, 2014: 4). Accordingly, the researcher utilised comprehensive data collection strategies that would provide more and better understanding on the phenomenon of PMTCT in the context of children aged three to eighteen months. Creswell (2014: 217-218) explains further that the integrated-ness of mixed method research involves the concurrence of data collection and analysis of both quantitative and qualitative data. Such a process is a contemporary methodology which originated in the late 1980s and early 1990s from the works of scholars in the field of Management, Sociology, Education and Health Sciences. Figure 4.1 below is a diagrammatic representation of the mixed-methods' inter-connectedness.

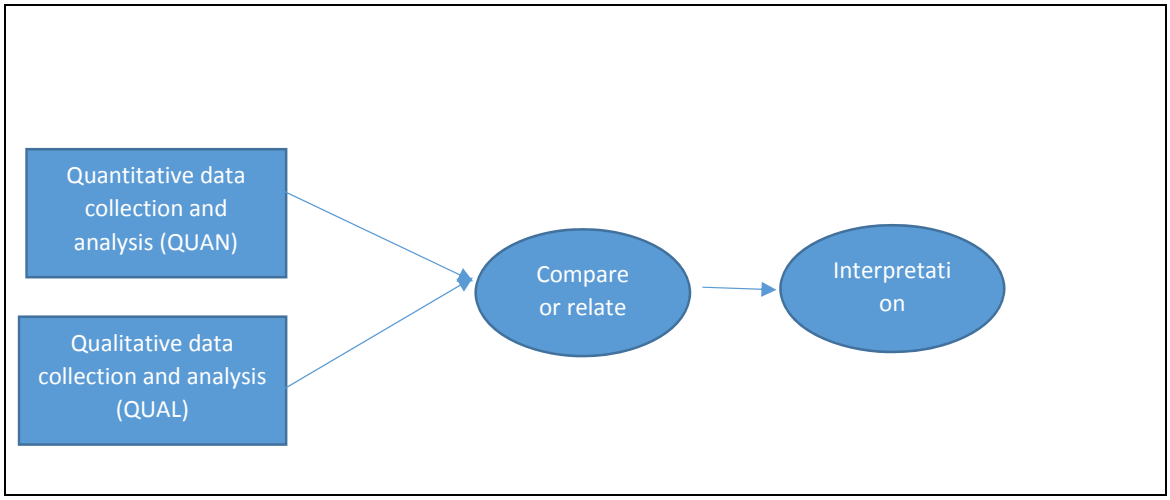


Figure 4.1: Convergent parallel mixed method (Creswell, 2014: 220)

The mixed-methods research design was opted for, on the basis of the following factors, consonant with the articulation by Polit and Beck (2017: 578):

- **Complementarity:** The two methods complement each other by engaging narratives and numbers and therefore avoid the limitations of a single approach;
- **Practicality:** There is flexibility in addressing the research problem and answering the research questions, not only adherence to a particular approach;

- **Incrementality:** Progress on the research topic becomes incremental with one method building on the other. Qualitative findings could be used to generate hypothesis that can be verified or tested quantitatively;
- **Enhanced validity:** Triangulation of methods awards an opportunity for testing alternative interpretations of the data and in turn improves validity of the findings; and
- **Collaboration:** There could be teamwork between qualitative and quantitative researcher working on similar problem.

The qualitative and descriptive aspect was undertaken to determine the experiences of mothers throughout the stages of pregnancy, labour and puerperium whose babies tested positive for the first time between the ages of three and eighteen months. Their experiences focused on issues pertaining to the prevention of mother to child transmission of HIV. Qualitative research investigates phenomena in an in-depth holistic manner through the collection of narrative data (Polit & Beck, 2017: 741). Individual interviews were conducted with the selected mothers of HIV-infected children aged three to eighteen months. A grand tour question was asked, followed by probing questions to obtain more and better understanding of their PMTCT experiences, perspectives, and knowledge.

Quantitative research is “a formal, objective, systematic process implemented to obtain numerical data for understanding aspects of the world and among others identify problems with current practice” (Grove et al., 2013: 215). Descriptive studies focus on people characteristics and events in real-life situations, and the frequency at which a particular phenomenon occur (Grove et al., 2013: 692; Polit & Beck, 2017: 726). The quantitative and descriptive-exploratory aspect was employed in order to identify the factors that contribute to high HIV positivity in children aged three to eighteen months in Free State Province. In this study, the frequency of deviation from PMTCT guidelines or prescripts and certain characteristics of the individuals are presented, followed by the identification of challenges which led to the problem of not adhering to guidelines.

4.3. RESEARCH METHOD

In the context of the various definitions and descriptions ascribed to ‘research design’ in section 4.2 (pp. 35-37) above (which emphasise processes), the nuance, ‘research method’ here refers to the nature and type of the specific research instrumentation utilised by the researcher to actualise the research design itself (Creswell, 2009: 15). Since the research design opted for in this study is method-triangulated (mixed-methods), the research methods are also both qualitative-quantitative. Accordingly, the research instrumentation used conforms to both the qualitative and quantitative

data collection mould. Concomitantly, the data analysis approach is also a combination of both the qualitative and qualitative approaches.

4.4 DATA COLLECTION

Data collection refers to the systematic gathering of information and data relevant to the study's purpose and objectives in order to respond cogently to the research questions (Grove et al., 2013:691). The review of literature facilitated the researcher's methodological awareness and theoretical perspectives pertaining to the approach, the development, and the processes associated with the satisfactory development of appropriate data collection instruments as demanded by a study of this nature (Babbie & Mouton, 2009: 173). Holloway and Wheeler (2010: 176) contend that data collection and data analysis are two concurrent processes, although the collection of data logically preceded its analysis. Ultimately, the most fundamental purpose of data collection was to obtain an empirical perspective of the research participants (mothers) regarding the prevention of mother to child transmission of HIV in children aged three to eighteen months.

4.4.1 Data collection approach

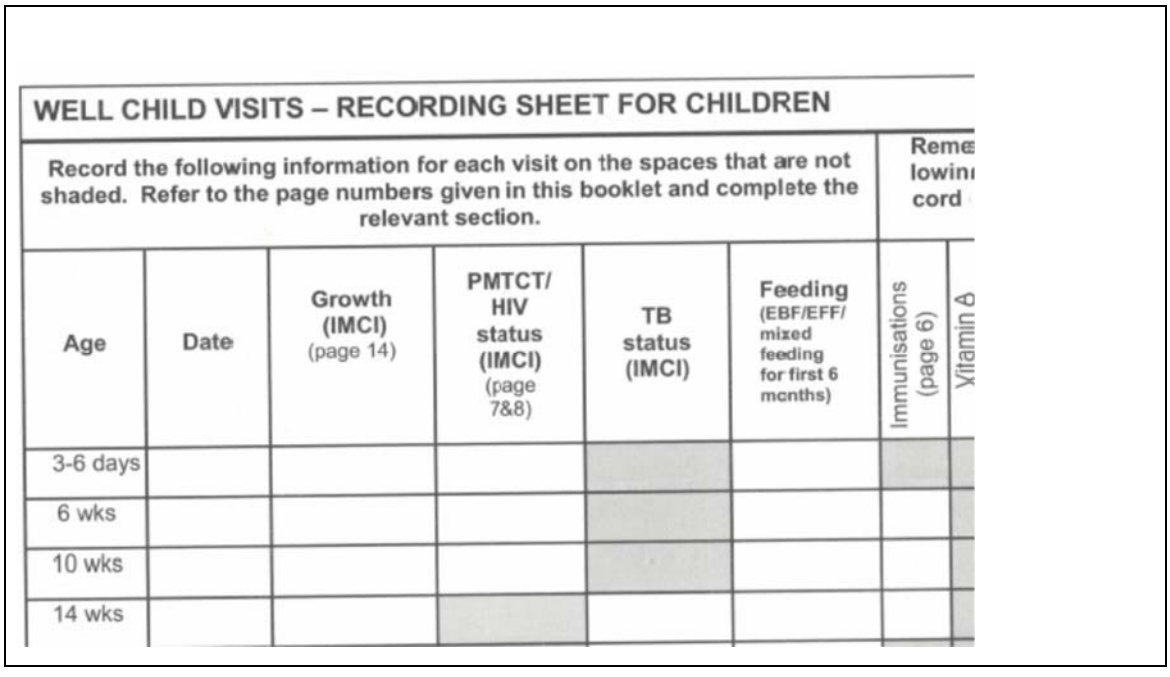
The preferred research design was that of convergent parallel mixed methods, therefore the researcher collected both qualitative and quantitative data in the natural setting or surroundings of the selected participants. A natural setting is a real-life physical situation with which the participants are familiar. The researcher interacts within the specific natural setting or habitat of the participants without any manipulation of the environment (Grove et al., 2013: 373).

The individual interviews were conducted at the clinics where mothers attend the maternal and child services and at the hospital for those whose children were admitted and were done in private rooms away from other cubicles and waiting areas to insure privacy. The qualitative data was collected through in-depth unstructured interviews which were guided by this grand tour questions: "Tell me about your journey through the PMTCT programme". This was followed by probing questions which were prompted by the selected research participants' responses. The maximum duration for the interviews was thirty minutes. Saturation was reached after interviewing ten mothers.

Quantitative data was collected through interviewer-administered structured questionnaires and the review of medical records of mothers of children who tested HIV positive for the first time between their 13th week and 18th month after birth. This was also done in private rooms away from waiting rooms and other cubicles. The choice of the interviewer-administered over the self-administered questionnaire was based on the advantages of the former. Saunders, Lewis and Thornhill (2009: 361)

emphasise that the choice between self-administered and interviewer administered questionnaire is influenced by characteristics of the respondents; avoidance of contamination or distortions of respondent's answers; as well as the types and number of questions. The questionnaire was administered by the researcher to ensure that mothers understood the questions and to ensure that the responses are from the correct and targeted respondents, and that they understood the complex questions which needed explanation and clarification and also to verify the information with the mothers and the child's medical records.

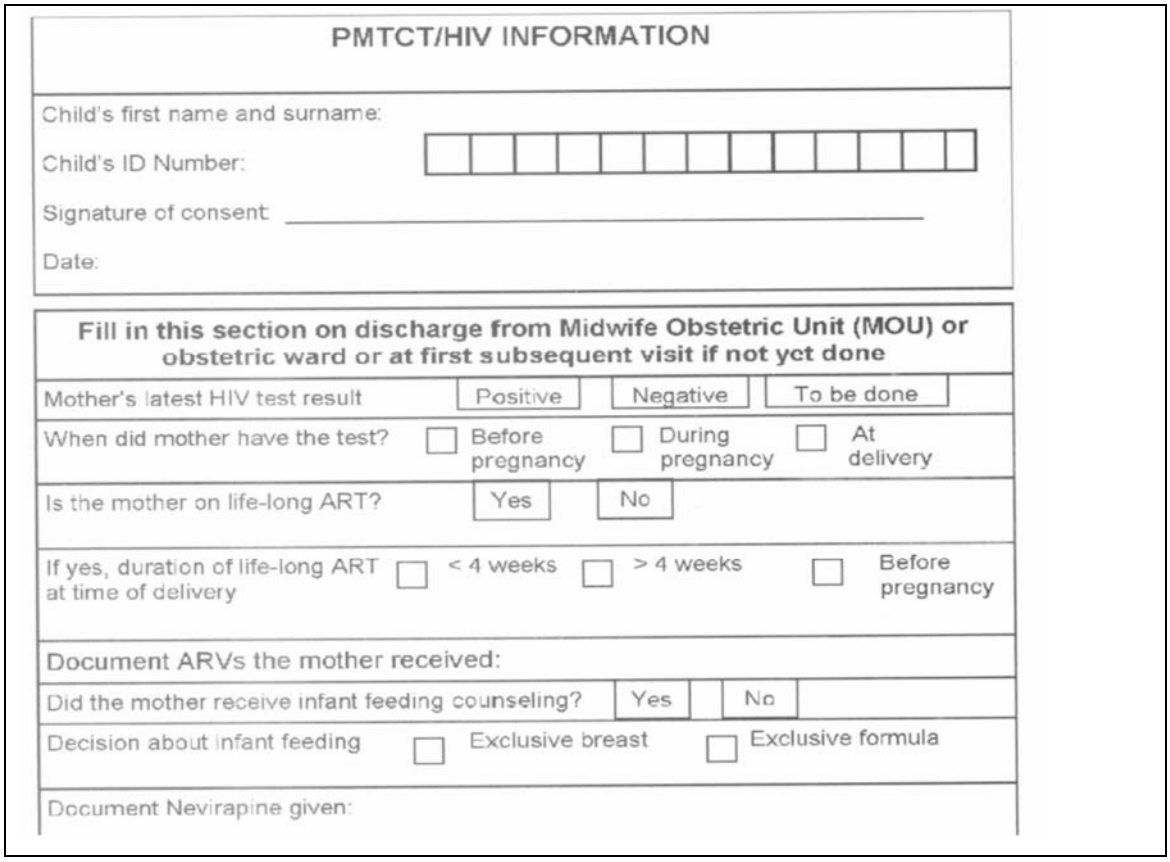
The questionnaires were administered to mothers on their children's visits to the health facilities or when admitted to hospital. As a rule, mothers should always have their children's 'Road to Health' booklets whenever they visit a health facility. This booklet contains a lot of information regarding the history of the child's health. It was this historical record which was used for data collection purposes. The information was used to verify some of the questionnaire responses provided by the mother. The booklet provided information on a range of issues, including on whether or not the mother was HIV-positive at confinement; whether Nevirapine prophylaxis was administered to the baby, and the duration thereof; the method of feeding in the first six months; the duration of breastfeeding; whether or not the baby was tested at ten weeks; as well as the age at which the baby tested positive for the first time. Figures 4.2 to 4.4 below depict various aspects of the child's medical record as contained in the 'Road to Health' booklet.



WELL CHILD VISITS – RECORDING SHEET FOR CHILDREN

Record the following information for each visit on the spaces that are not shaded. Refer to the page numbers given in this booklet and complete the relevant section.						Reme lowin cord	
Age	Date	Growth (IMCI) (page 14)	PMTCT/ HIV status (IMCI) (page 7&8)	TB status (IMCI)	Feeding (EBF/EFF/ mixed feeding for first 6 months)	Immunisations (page 6)	Vitamin A
3-6 days							
6 wks							
10 wks							
14 wks							

Figure 4.2: Well child record in road to health booklet



PMTCT/HIV INFORMATION

Child's first name and surname:

Child's ID Number:

Signature of consent: _____

Date:

Fill in this section on discharge from Midwife Obstetric Unit (MOU) or obstetric ward or at first subsequent visit if not yet done

Mother's latest HIV test result: Positive | Negative | To be done

When did mother have the test? ☐ Before pregnancy ☐ During pregnancy ☐ At delivery

Is the mother on life-long ART? Yes | No

If yes, duration of life-long ART at time of delivery ☐ < 4 weeks ☐ > 4 weeks ☐ Before pregnancy

Document ARVs the mother received:

Did the mother receive infant feeding counseling? Yes | No

Decision about infant feeding ☐ Exclusive breast ☐ Exclusive formula

Document Nevirapine given:

Figure 4.3: PMTCT discharge record in road to health booklet

10 week visit, or earlier if ill

PCR result: Positive | Negative

Post test counseling done? Yes | No

Referred for ART? Yes | No

Stop Nevirapine if PCR is positive

Cotrimoxazole given? Yes | No

Has child received Nevirapine? Yes | No

If yes: Stop now | Continue

Encourage a mother whose baby is HIV positive to continue breastfeeding

Retest HIV negative children 6 weeks after cessation of breastfeeding, or if clinical suspicion.
An HIV exposed child should be retested with a rapid HIV Antibody test at 18 months

Repeat PCR test ☐ Positive ☐ Negative
Date:

HIV antibody test ☐ Positive ☐ Negative
Date:

Figure 4.4: PCR testing information in road to health booklet

The questions of time of commencement of ART by the mother and whether she ever defaulted treatment was verified by the information from the tier.net system -which is a system in which ART information is captured and stored in public clinics and can be retrieved whenever necessary.

4.4.1.1 Data collection process

Data was collected by the researcher at all sampled facilities through a two-pronged process. Firstly, the files of babies under three years who are on antiretroviral therapy were drawn by the data capturers employed by the Department of Health at each primary health facility. The researcher would then check the date for the next visit for those who met the eligibility criteria so that she could come for interviews or for the administration of the questionnaire with their mothers. In some facilities, there were books containing HIV PCR results with the names of all HIV-tested children. The researcher would then check those who met the eligibility criteria and their return dates to the clinic. The process was simplified by the fact that most facilities had specific days for children and babies who were on HIV treatment.

The researcher also visited the hospital twice a week to check whether there were any admitted HIV-infected children who were with their mothers. In the event that the mothers were present, the researcher then conducted the interviews and administering of the questionnaires for those who met the criteria. Secondly, the researcher requested the professional nurses responsible to call her whenever there was a child between the age of three and eighteen months who had positive HIV PCR results, and she would in turn establish whether the mother met the eligibility criteria. The informed consent would first be sought from the mothers before their voluntary participation in the study. The questionnaire was administered to sixty mother from the five facilities. Saturation for the qualitative data was reached after interviewing ten mothers. Saturation is considered to have occurred when interviews do not yield new information (Grove et al., 2013: 371). Data was collected over a period of six months.

4.4.2 Development and testing of data collection instrument

The questionnaire was developed by the researcher for the quantitative component of the study, and the questions were based on the information from the South African PMTCT guidelines. The final questionnaire was first piloted on ten subjects prior to its use on the main study. Modification was conducted which led to exclusion of some questions because data could not be obtained either from the mothers or the health records of their children's records

4.4.2.1 Characteristics of the data collection instrument

The first part of the questionnaire encompassed questions directly formulated to include elements of the South African and PMTCT guidelines which were derived from WHO guidelines. The second part focused on the demographic data of the selected respondents. The questions were based on guidelines and were on statistically generated nominal measurements. In nominal measurement, the numbers that are assigned to responses do not have any quantitative meaning (Polit & Beck, 2017:357).

4.4.3 Pilot testing

A pilot study was conducted for the quantitative phase of this inquiry. Pilot studies are small scale versions of the full study to test the feasibility and refine the protocols, methods and procedures in the main study (Thabane, Ma, Chu, Cheng, Ismaila, Rios, Robson, Giangregorios & Godsmith, 2010: 2; Polit & Beck, 2017: 177). The research topic addresses a sensitive and controversial issue of HIV/AIDS. Therefore, the researcher sought to establish the feasibility of the study, especially the reliability and validity of the envisaged design and modification if need arose. The developed data collection instrument also had to be tested in order to establish the extent to which it would yield cogent answers to the research questions.

The sample and the sampling procedure also posed an uncertainty and the researcher also wanted to check whether the chosen sampling method was appropriate for this study. Thabane et al. (2010: 2-3) highlight that pilot studies could be conducted in order to assess the feasibility of important processes; the time and resource problems that could occur during the mains study; as well as the possible human resources and data management problems.

The pilot testing was therefore conducted on the sample of ten subjects, using the initially chosen stratified random sampling. The eligibility criteria embraced mothers of babies who were diagnosed with HIV when aged three months to eighteen months. Furthermore, the mothers had to be eighteen years old and above. The study was to be conducted in all districts of the Free State province. The questionnaire used for collection of data was designed by the researcher and included the results of the viral load and CD 4 Cell count during pregnancy and the postnatal period.

4.4.3.1 Pilot testing results and challenges identified

Since pilot testing entails a degree of pre-investigative feasibility and application of the questionnaire, it was anticipated that its outcomes would either be completely relevant, or expose shortcomings which the researcher may not have foreseen. In this regard, the outcomes of the pilot testing yielded some pertinent results pertaining to sampling and the nature of the research instrument itself.

4.4.3.1.1 Sampling

The sampling frame could not be developed because the number of children who were diagnosed with HIV between the ages of three and eighteen months in the Free State Province could not be obtained. Such data is not collected on district health information systems and hospital information systems. It was also found out that the study would be very costly and time consuming in the event that the sample was drawn from all facilities of the Free State Province. Consequently, stratified random sampling was not feasible. In addition, the chosen sampling method would not work because of the

limited number of subjects. Cluster sampling was then chosen as a result which ended up limiting the sample to health facilities in Mangaung metropolitan municipality.

4.4.3.1.2 Data collection instrument

The questionnaire had to be modified after the pilot study. The questions on viral load and CD4 cell counts had to be removed as it was not easy to obtain the results and mothers could not recall at which gestation they had such tests conducted. A question on the type of syrup administered to babies for prophylaxis was also removed as the mothers only knew that the baby had prophylaxis; but not the name, and almost all HIV-exposed babies had Nevirapine. Therefore, infant prophylaxis would mean administration of Nevirapine syrup.

4.4.4 Ethical issues related to data collection

Ethical clearance was granted by the University of South Africa (UNISA). Permission to conduct the study in public facilities of the Free State Department of Health was obtained from the head of the Free State Health. The district health manager of Mangaung Metropolitan Municipality was informed, and the chief executive officer of the hospital also gave permission for the study and stipulated the conditions under which the data could be collected. T

4.4.5 Sampling processes and procedures

Kumar (2011: 116) illuminates that: “Sampling … is the process of selecting a few (a sample) from a bigger group (the sampling population) to become the basis for estimating or predicting the prevalence of an unknown piece of information, situation or outcome regarding the bigger group. A sample is a sub-group of the population you are interested in”. Additionally, sampling is necessitated by the fact that it is both logistically and financially not feasible to include the entire group in the study. The sampling processes and procedures of the study entail a range of issues, such as the research site; the study population and sample size; the sampling technique or strategy and sampling criteria.

4.4.5.1 The research site

A research site or research setting refers to the actual *place* (physical or geographical location) at which the study was conducted, taking cognisance of the milieu (context or characteristics of the environment) (De Vos et al., 2011: 334). The study was to be conducted in all districts of the Free State province. The characteristics or context of the research environment take into consideration important elements such as the *timing* (era) of the study, the *people* involved, as well as the *profile* of the phenomenon being studied.

The timing of the study is premised on the period from October to December 2015, and January to March 2016 , a period during which there was a conspicuous upsurge of MTCT in the Mangaung Metropolitan Municipality of the Free State Province. The situation still prevails, according to NHLS data and researchers observation. The people involved in the study were the sixty sampled research participants and respondents selected according to the researcher's inclusion criteria for involvement in both the preferred qualitative (interview-based) and quantitative (structured questionnaire-based) data collection methods of the study. The profile of the PMTCT phenomenon was obtained by means of the information obtained from the medical records of both the mother and their babies at the 1 (one) hospital and the five primary health care facilities in the Mangaung Metropolitan Municipality.

4.4.5.1.1 Geography of the research milieu

Figure 4.5: Map of the Free State Province and its municipalities

Free State Province is geographically located in the middle of South Africa, and shares its south-eastern borders with the Kingdom of Lesotho. The province is surrounded by six other South African provinces, namely: Eastern Cape, Northern Cape, North-West, KwaZulu-Natal, Mpumalanga, and Gauteng provinces. Five major South African national roads intersect through the Free State province, which is also accessible by rail and air (Free State Development Corporation, 2017: 1). According to the 2017 midyear estimates, the population of Free State was estimated at 2,866,700, which is 5.1.% of the total population of South Africa (Statistics South Africa, 2017: 2).

Mangaung Metropolitan Municipality is one of the five municipal districts of the Free State province, and is situated towards the south-eastern part of the province. The Mangaung Metropolitan Municipality is composed of seven towns, namely:

Bloemfontein, Botshabelo, Thaba-Nchu, Wepener, Dewetsdorp, Soutpan, and Van Stadensrus. Bloemfontein is the sixth largest city in South Africa, the capital town of the Free State Province, and is the seat of the Supreme Court of Appeals (SCA) of South Africa.

Mangaung is bordered by three other Free State districts and the kingdom of Lesotho, with two border posts between the two. In 2016, the population of Mangaung was estimated to 789 929 (Municipalities of South Africa, 2016: 1; Mangaung Metro, 2017: 40-41). There are forty seven (47) primary health care facilities, three (3) district hospitals, one (1) tertiary hospital and one (1) academic hospital in Mangaung. The academic and tertiary hospitals receive referrals from all the other five (5) districts of Free state, as well as from Northern Cape, Eastern Cape and Lesotho.

4.4.5.1.2 HIV profile

According to the Free State Provincial Council (2017: 17), the overall prevalence of HIV in the Free State was 12.9%. The prevalence rate among males aged 15-24 was 3.9%, and 13.3% among their female counterparts. Among the 15-49 age cohort, the HIV incidence was 0.85% against the overall 12 113 new infections in the province. In 2015, the overall HIV prevalence rate of occurrence among antenatal clients was 29.8% in the entire province, with Mangaung accounting for 31.7% of the prevalence (South Africa, 2017: 23).

Figure 4.6: HIV epidemic curve among antenatal women, Free State 1990 - 2015
(South Africa 2017:29)

Figure 4.6 above illustrates an upward spiral of the HIV epidemic among antenatal women between 1990 and 2014. It was only in 2015 that the upsurge began to indicate a period of decline. In addition to Figure 1.4 above, Table 1.2 below illustrates the HIV

prevalence rates of occurrence among pregnant women by district in the entire Free State Province for the period 2010-2015.

Table 4.1: HIV prevalence among pregnant women by district: 2011-2015

District	2010		2011		2012		2013		2014		2015	
	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI
Fezile Dabi	32.9	28.0 - 38.3	35.6	31.2 - 40.3	32.9	29.3 - 41.1	26.0	21.6 - 30.8	31.4	25.6 - 37.8	26.5	19.4 - 35.1
Lejweleputswa	30.0	26.1 - 34.2	34.2	30.3 - 38.3	30.6	26.8 - 34.7	32.3	27.9 - 37.2	38.4	33.9 - 43.1	27.3	23.0 - 32.1
Mangaung	32.1	27.2 - 37.4	29.9	26.0 - 34.2	30.3	24.1 - 37.4	30.4	25.5 - 35.8	31.9	26.1 - 38.3	31.7	28.5 - 35.0
Thabo M.	30.7	26.0 - 35.8	31.9	27.9 - 36.2	33.5	30.1 - 37.1	30.1	26.4 - 34.1	34.9	30.6 - 39.5	31.0	27.5 - 34.8
Xhariep	17.0	10.4 - 26.5	26.1	17.8 - 36.6	29.3	22.8 - 36.7	25.8	18.6 - 34.6	32.2	22.3 - 44.2	35.1	22.7 - 49.8
Free State Province	30.6	28.3 - 33.0	32.5	30.5 - 34.5	32.0	29.8 - 34.3	29.8	27.6 - 32.0	34.3	31.8 - 36.9	29.8	27.5 - 32.3

Source: South Africa (2017: 30)

4.4.5.1.3 HIV services

In 2016, there were about 7.1 million people living with HIV in South Africa, accounting for 19% of the global number of people living with HIV globally (UNAIDS, 2017: 12). Approximately, 56% were on antiretroviral treatment (ART), and about 95% of pregnant women were on treatment or prophylaxis for PMTCT. Twelve thousand children were newly infected through mother to child transmission, while 40% of HIV-infected people had viral suppression, and there were 11 % HIV-related death (UNAIDS 2017:40). The prevalence of HIV among pregnant women was 30.6% in 2015. The Fezile Dabi health district had a 32.9% prevalence rate, followed by Mangaung Metropolitan Municipality at 32.1% (table 4.1). All primary health care facilities and hospitals in the Free State Province provide HIV/AIDS prevention and treatment services such as: HIV counselling and testing, antiretroviral treatment, condom distribution, and PMTCT. In addition, there are facilities which also provide medical male circumcision and post exposure prophylaxis (Free State Department of Health, 2012: 45-46).

4.4.5.2 Study population and sample size

The study population refers to the entire group in which the researcher has interest. It is not only confined to humans, but may also include varied inanimate object such as hospital records and laboratory specimen (Polit & Beck, 2017: 249). In this study, the target population was mothers of babies younger than three years whose children tested HIV positive for the first time when aged between three and eighteen months, and visited health public facilities in Mangaung, Free State Province.

A sample size relates to the number of representative cases selected from members of the larger study population (Polit & Beck, 2017: 249). The sample size also possesses a greater degree of homogeneous (similar) characteristics, qualities, or traits with the

population from which they were selected (Babbie & Mouton, 2009: 107). This study's sample size consisted of 60 mothers selected from one hospital and five PHC facilities.

4.4.5.3 Sampling techniques/ Strategy and sampling criteria

A sampling technique or strategy defines the researcher's method of objectively selecting the representative group of participants in the study (Polit & Beck, 2017: 249). In this study, probability randomised cluster sampling was chosen to select the sixty respondents and participants from the five (out 47) PHC facilities and one (out of four) hospitals in the Mangaung Metropolitan Municipality area.

In random sampling, every element has an above-zero chances of being selected and therefore, the samples obtained are more likely to be representative of the population (Grove et al., 2013: 357). In this form of sampling, a sampling frame is developed for all institutions, organisations or cities in which elements of the population of interest are linked and all the elements who fit the criteria for the study may all be included or could further be randomly selected. (Grove et al., 2013: 360; Maree, 2007: 176, Joubert & Ehrlich, 2007: 99). This method of sampling is also useful when the population is wide-spread to minimise the costs of travelling to reach all elements of the sample (Grove et al., 2013: 361; Maree, 2007: 176). Creswell (2014: 158) further affirms that this method is useful when it is not feasible to obtain a list of all the elements comprising the population.

Data on babies who are tested and those who test HIV positive after the routine birth and ten weeks tests (between ten weeks and eighteen months) is not collected on district health information system (DHIS). It was therefore not possible to obtain the total number of children who tested HIV positive for the first time after the ten weeks tests at any given period. It should be noted however that despite the absence of this data element on DHIS. Children are tested any time when the history or clinical picture is suggestive of HIV infection, six weeks post cessation of breastfeeding, when a parent requests a test and in children considered for adoption or fostering (South Africa, 2015a: 25). The total population could therefore not be established; hence probability random cluster sampling was preferred.

4.4.5.3.1 Inclusion criteria

The inclusion criteria is concerned with the objective and systematic selection of research participants and/ or respondents on account of their pre-determined representative/ homogeneous characteristics or attributes (Holloway & Wheeler, 2010: 47). It is only on account of such qualities that respondents and/ or participants are considered to be eligible for involvement with the empirical phase of the study in a direct manner, and at the level of participation as 'prescribed' in the informed consent

and further oral explanations by the researcher prior and during the actual execution of the study. The following criteria were applicable in this study:

- A list of public primary health facilities in the Mangaung Metropolitan area was drawn and a random selection of five primary health facilities out of the total of forty seven was conducted and one hospital out of four and all mothers who met the eligibility criteria in those six sampled health facilities were all included;
- The mothers had to be eighteen years old and above and their babies had to be between three months and three years but should have tested HIV positive for the first time when aged three to eighteen months. This means there were babies older than eighteen months but who were diagnosed with HIV before or when they were eighteen months; and
- Only those whose medical records of the mother-baby pair were reviewed. For the babies, the records comprised mainly the 'Road to Health' booklets for outpatient babies. for admitted babies, the in-hospital records as well. The review of records was conducted firstly to validate the mothers' self-reports from both interviews and questionnaires. For instance, the age at which the child tested positive would be confirmed by checking the child's' Road to Health' booklet. It was presumed by the researcher that some mothers could withhold information about defaulting treatment therefore this was also obtained from the mothers' records. Secondly to obtain additional information some of which the mothers could not understand.

4.4.5.3.2 Exclusion criteria

Sampling is a process of selecting subjects, events, behaviours or elements which will be included in the study (Grove et al., 2013: 37. Posited against this background, sampling criteria then establishes a range of propositions against which exclusion from participating in the study is justified and validated (Holloway & Wheeler, 2010: 47). The following factors and considerations justified exclusion or ineligibility to the study:

- Adoptive and foster mothers, and mothers of children who were younger than eighteen years of age, and whose children were older than three years;
- Mothers of children who tested positive before three months and of babies who were having a second HIV positive test as a confirmation of the first test conducted. In South Africa a positive DNA PCR test is confirmable by another repeated test of the same type (South Africa, 2015a: 26); and
- Adoptive parents and caretakers were excluded, and the use of interview administered questionnaires also eliminated them from the study, which increased the reliability of the data.

4.4.6 Ethical considerations related to sampling

The following sampling-related ethical principles were upheld, as described by de Vos et al. (2011: 115) and Grove et al. (2013: 162-165):

- *Voluntary participation:* participants were not coerced into participating in the inquiry. An informed consent was sought from all participants before taking part in the study;
- *Confidentiality/ privacy/ anonymity:* The participants were recruited by the professional nurses who usually treats them at the health facilities and when they agreed to participate they were introduced to the researcher. No information about the subjects was be disclosed and their true names are not used in reports;
- *Deception of subjects:* True and correct information was provided to subjects and no information was withheld from them about the study;
- *Beneficence:* which obliges that the researcher should do only good and avoid harm. The participants were therefore not exposed to any physical, psychological or social harm or discomfort;
- *Justice:* stipulates that human subjects should be treated with fairness. There was therefore no unfair treatment of subjects in this study; and
- *Protection of human rights:* which encompass right to self-determination, privacy, autonomy, confidentiality.

The study involved HIV infected children and their medical records were reviewed. The rights of children were protected as stipulated by UNICEF in the convention on the rights of a child (UNICEF,2005). See annexure H. All forms of discrimination against children were avoid and the study was done in best interest of children, mainly PMTCT and to make recommendation to all stake hold with regard to EMTCT.

4.5 DATA MANAGEMENT AND ANALYSIS

Data management relates to the manner in which the collected raw data was treated and processed or 'handled' prior to its analysis into intelligible categories of evidence (Marshall & Rossman, 2011: 13). On the other hand, data analysis is concerned with the classification or categorisation of data from its content into themes. The above-cited two authors indicate further that data management and data analysis are connected into a sequence, but data management precedes data analysis (Marshall & Rossman, 2011: 13). Since the study entails the mixed-methods approach, both qualitative and quantitative data analysis perspectives were made use of. The researcher employed the side by side comparison data analysis approach as described by Creswell (2014:222). Each data set was analysed separately and the two merged though the use of table (see figure 4.1 page 46 and table 5.16 on page 91). Statistical analysis was done, followed by qualitative findings. the findings of both data sets were compared to check if they if they confirm or disconfirm.

4.5.1 Quantitative data analysis

Numerical data was collected by means of questionnaires and entered into an excel spread sheet for purposes of generating frequency tables which included the percentages. The percentages were then visually presented in the form of graphs and other diagrams. The final result was presented on the basis of the majority of percentages for each questionnaire variable.

4.5.2 Qualitative data analysis

The audio-recorded interviews were transcribed verbatim, and the transcripts were read in conjunction with the fields notes. The transcripts were read several times in order to gain understanding of the mothers' experiences. The researcher collected the data and was therefore familiar with the transcripts, and had also documented the observations made on each mother during the interviews as well as the field notes.

The next step after transcription and reading was coding of data. Saldana (2013: 4) describes a code in qualitative research as "a researcher-generated construct that symbolises and thus attributes interpreted meaning to each individual datum for later purposes of pattern detection, categorization, theory building, and other analytic processes." Coding is therefore a preliminary stage of intensive data analysis in which meaning is attached to each unit of data. A code could be in the form of a word, a phrase or a symbol (Grove et al., 2013: 281).

Codes are developed from emerging information collected from participants. Iin some instances, researchers make use of predetermined codes, which are usually applied in studies when there is a theory that is being examined (Creswell, 2014: 199). In this study, no predetermined codes were used. Different units of data were assigned different codes. Similarly, coded data or topics that related to each other were organized and grouped together into categories or themes. The researcher used her own reasoning and intuition to determine thematically connected data (Saldana, 2013: 9; Creswell, 2014: 198). Subsequently, themes were developed. Saldana (2013: 14) defines a theme as "an outcome of coding, categorization, or analytic reflection …". The themes then become the items portrayed as headings in the major findings supported by either paraphrased analysis/ interpretation or quotations and specific evidence (Creswell, 2014: 200). Themes that reflected the participants' perspectives were then generated from the data and quotations from which they were derived or cited.

4.6 QUALITATIVE MEASURES TO ADVANCE TRUSTWORTHINESS

Trustworthiness determines the extent of the study's scientific worth as established by the quality and efficacy of its preferred measuring instruments (Holloway & Wheeler,

2010: 61). Researchers should always strive to produce truthful and unbiased results, on whose weight rests the high quality of the self-same results' reliability and validity. Reliability and validity are the two criteria which are used in quantitative research to assess rigor or scientific merit of the studies (Polit & Beck, 2017: 160). The quality of the qualitative aspect of the study was established by means of the criteria of credibility, transferability, dependability, conformability and authenticity (Polit & Beck, 2017: 559-560).

4.6.1 Reliability

Reliability refers to accuracy and consistency of the information gained in the study, the extent to which it would yield the same results if repeated (Polit & Beck, 2017: 160). In this study reliability was ensured by the use of interviewer administered as opposed to self-administered questionnaire. The latter increases reliability as the researcher can always be sure that the right respondents were reached and eliminates, contamination of respondents' answers. With self-administered questionnaires respondents can discuss their answers with others and therefore yield biased results or deliberately guess the answers due to lack of knowledge (Saunders, Lewis & Thornhill, 2009: 363).

4.6.2 Validity

Validity refers the soundness of the study's evidence, establishment of whether the findings are unbiased and well-grounded and is crucial for evaluating methods used to measure variables (Polit & Beck, 2017: 161). It is the extent to which the measurement reflects the real meaning of the phenomenon under investigation. It incorporates truth, strength, value, integrity and quality (Grove et al., 2013: 393; Mouton, 2013: 189). Validity in this study was ensured by firstly extensive literature review and subjecting the data collection instrument to clinical experts for scrutiny. The researcher having been a PMTCT trainer and provincial coordinator for more than a decade, also has a strong background knowledge and experience of the WHO and South African PMTCT guidelines; all of which increased the content validity of the research instrument. Secondly, a pilot study was conducted and followed by modification of the questionnaire by eliminating ambiguous and confusing questions; and those questions which required the data that could not be obtained, such as the results of viral load testing. Thirdly, by triangulation of data sources using multiple sources of data, the questionnaires administered to mothers and the review of medical records.

4.7 QUANTITATIVE MEASURES TO ADVANCE TRUSTWORTHINESS

It is worth stating that the qualitative trustworthiness measures of validity and reliability have the equal measure of the quantitative corollaries. The listing of both qualitative

and quantitative measures is not necessarily a semantic or conceptual differentiation. Rather, the emphasis is on the effect of the research processes and extent of efficacy (or a lack thereof) of the type and nature (quality) of the respective research instruments.

4.7.1 Credibility

Credibility refers to "confidence in the truth of the data and its interpretation" (Polit & Beck, 2017: 559). It includes activities that increase the probability that the findings will be reliable. This was ensured by prolonging the time with subjects and gathering more information. On-going member checking was also carried out during data collection. This was made possible by the fact that data was collected over six months and mothers come to clinics monthly and this provided sufficient time for the researcher to interact with mothers. In member checking the participants are provided with feedback on the emerging interpretations to establish whether they would recognise the experiences captured as their own (Polit & Beck, 2017: 564).

4.7.2 Transferability

Transferability refers to whether the findings of the research can be generalised or be applicable to other situations or other target populations or be applicable in other settings or groups (Polit & Beck, 2017: 560; De Vos et al., 2011: 420). In this study, this criterion was ensured by providing a detailed description of the findings that would enable other researchers to determine whether or not they could be transferred to other situations or be generalised. The findings and their methodological processes were also subjected to review by professionals and practitioners in both research methodology and the field of PMTCT.

4.7.3 Dependability

Dependability refers to the extent to which the study would yield the same results In the event that it is replicated. To meet this criterion, the researcher provided adequate and relevant methodological information to enable others to replicate the study as demonstrated by Given (2008: 209). This was also enhanced by thorough systematic documentation that provides an audit trail to other researchers that would like to establish trustworthiness of this study.

4.7.4 Confirmability

The goal of confirmability is to establish whether the data represents the participants' experiences and views and that the information is not invented or distorted by the inquirer (Polit & Beck, 2017: 559). The provision of audit trails and triangulation of data sources also enhanced this criterion.

4.7.5 Authenticity

Authenticity refers to the extent to which the study reflects the researcher's fair and honest range of realities displaying real feelings and experiences of participants (Polit & Beck 2017: 360). Audio-recording and verbatim transcription of interviews, persistent observation and prolonged engagement with participants contributed to the attainment of this criterion.

4.7.6 Method triangulation

Method triangulation in research is defined as the use of more than one research strategies in the same research investigation (Streubert & Carpenter, 2011: 351). There are various forms of triangulation that are used by researchers, namely: data, time, space, theory, investigator and method triangulation (Streubert & Carpenter, 2011: 351; Polit & Beck, 2017: 563). The benefits of triangulation in research are associated with revealing unique findings, increasing the validity of the study, innovative ways of understanding a phenomenon, and provision of a clearer way of understanding the problem (Thurmond, 2001: 253-254).

In this study, the triangulation of research methods and data collection methods was used. Qualitative and quantitative research methodologies were employed and data were collected by means of unstructured interviews and structured questionnaires. The questionnaires responses were further verified by the review of medical records. The review of records was also undertaken in order to verify the information obtained from the interviews and the questionnaires, all of which contributed to the validity and reliability for the study and its attendant theoretical and empirical parameters (Streubert & Carpenter, 2011: 351).

4.8 CONCLUSION

This chapter presented the research design and methods used in this study, namely, the convergent parallel mixed methods which employed both qualitative and quantitative approaches. The sampling domain of the study provided the context of *where* the study was conducted (i.e. the research setting); *who* were the people participating (i.e. study population and sample size); and *how* they were selected (i.e. sampling strategy or technique and sampling criteria). Both the data collection and analysis aspects of the study were also presented and discussed. Ethical issues pertaining to the data collection and analysis aspects were also presented. The salient aspect of trustworthiness, together with its qualitative and quantitative control and quality measures, was prominently discussed. The following chapter (Chapter 5) focuses on the presentation and discussion of the qualitatively and quantitatively obtained data in order to translate it into meaningful and practical understanding.

CHAPTER 5
DATA ANALYSIS AND INTERPRETATION

5.1 INTRODUCTION

The current chapter focuses on the data analysis, presentation and interpretation of research findings from the quantitative and qualitative data. The quantitative data is presented first, with tables and graphs depicting the statistical information which is analysed and interpreted below each table and graph. Quantitative data was obtained by means of questionnaires which consisted of questions derived from factors which have been found to increase the rate of mother to child transmission according to previous studies and which are the foundation of the WHO and South African PMTCT guidelines. Therefore, these factors are discussed after each visually illustrated data presentation.

Qualitative data is presented in the form of narratives which were obtained through the interviews (Walliman, 2012: 173). Verbatim transcripts were reduced to small manageable units followed by coding which involved the identification of themes. The narrative statements which are related to the identified themes were quoted, followed by discussions of similar findings from previous studies. The following table (Table 5.1) illustrates a summary of all the 60 respondents' demographic information, after which each demographic variable is presented and discussed individually.

Table 5.1: Summary of respondents' demographic data

Demographic Information of Respondents		Respondents (n=60)	
Age of Participants	18 -25	21	35%
	26- 35	32	53%
	36-45	7	12%
	>45	0	0
Total		**60**	**100%**
Employment Status	Employed	23	38%
	Unemployed	37	62%
Total		**60**	**100%**
Highest Qualification	Primary school	9	15%
	Secondary without grade 12	41	68%
	Grade 12	10	17%
	Tertiary education	0	0
Total		**60**	**100%**
Number of Children	One	18	30%
	Two	20	33%
	Three	13	22%
	Four	5	8%
	>four	4	7%
Citizenship	South Africa	56	93%
	Lesotho	4	7%
Total		**60**	**100%**

5.2 QUANTITATIVE DATA PRESENTATION AND ANALYSIS

A total of sixty questionnaires were administered to the selected respondents. However, only twenty mothers acquired the HIV infection after giving birth. Therefore, some variables were not applicable to them and their children. In such instances, the totals are out of forty.

5.2.1 Respondents' demographic data

As indicated in Table 5.1 above, the demographic variables of the respondents focus particularly on their ages, employment status, highest qualifications, number of children, and citizenship (country of origin or birth).

5.2.1.1 Respondents' age distribution

Figure 5.1 below illustrates the age distribution of all the sixty respondents who responded to the various structured questionnaire items.

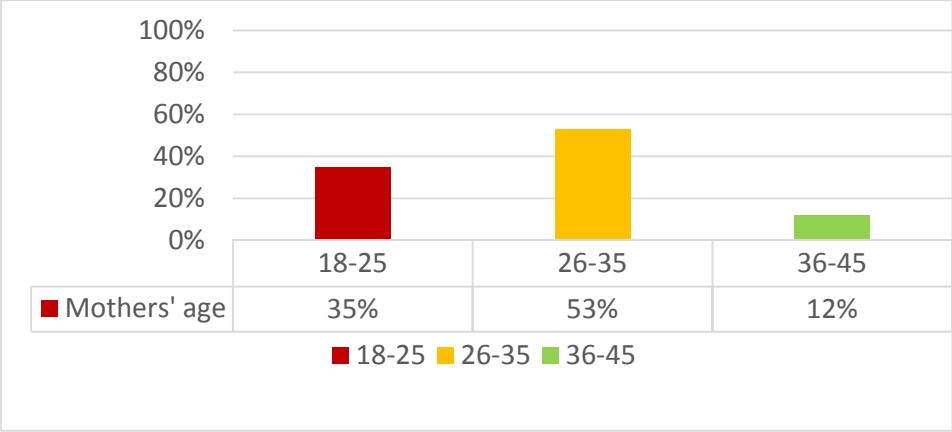


Figure 5.1: Respondents' age distribution

In terms of Figure 5.1 above, 21 mothers (35%) were aged 18-25; 32 (53%) were aged 26-35 years; and 7 (12%) were aged 36-45 years. It is apparent that the majority of the mothers (53%, n=32) were in the median age of 26-35. The mothers aged 36-45 years constituted 12% (n=7), which is reminiscent of a similar trend observed in the 2015 antenatal HIV survey, where about 11.3 % of mother were aged 35-44; and only 0.2% were 45-49 (South Africa, 2017: 20).

There were no mothers older than 45 years in this study. More than half of the mothers were aged 25-35 years, representing the average child-bearing age of women. It is revealing that the 18-25 years' age group is the second category, which attenuates the perception that MTCT is mainly among younger women those below 18 years of age). These figures show that age may not necessarily be a factor of MTCT, as the percentages above show that it is among the relatively older and more mature age cohort that MTCT was found at its highest prevalence rate.

5.2.1.2 Respondents' employment status

The essence of the employment variable is premised on the researcher's interest to find whether a correlation existed between employment status and individual and collective MTCT prevalence among the respondents. Figure 5.2 below represents the employment status of all the sixty respondents.

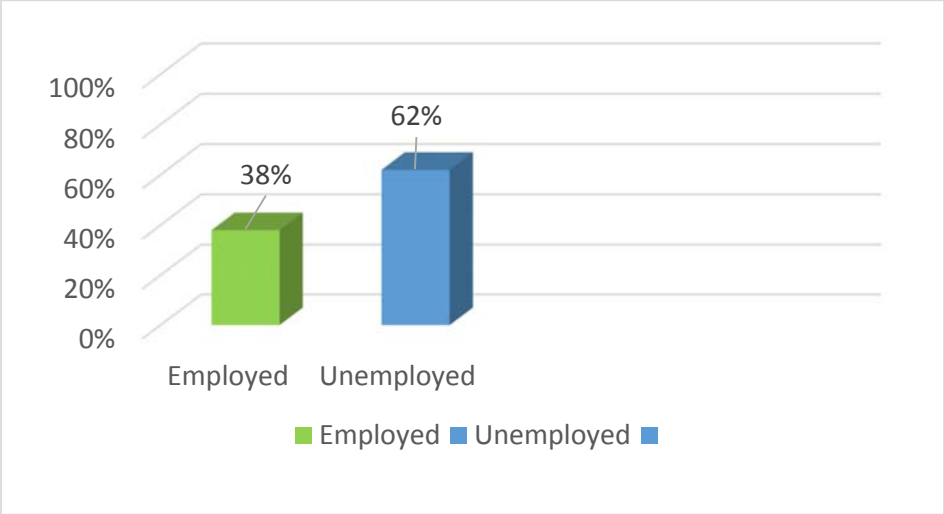


Figure 5.2: Respondents' employment status

Figure 5.2 above shows that the majority of the participating mothers (62%, n=37) were unemployed; and only the minority (38%, n=23) were employed. Other than reflecting the current high unemployment rate in the country (25.4%), the impression above, when compared with the result of Figure 5.1 (in which the majority of 53% (n=32), implies that some degree of correlation may be drawn between employment status and age. Based on this truism, it could then be concluded that strategies of mother to child prevention of HIV necessitate radical implementation mostly among the unemployed women of child-bearing age.

5.2.1.3 Respondents' educational levels

Formal learning plays a critical role in HIV/AIDS awareness. Traditionally held stereotyping and stigmatisation tends to increase with little knowledge and information. HIV/AIDS is a school subject in most formal learning institutions. Therefore, little, or non-attendance of formal schooling renders more people vulnerable to useful formal knowledge on this disease. Figure 5.3 below shows the educational levels of the respondents.

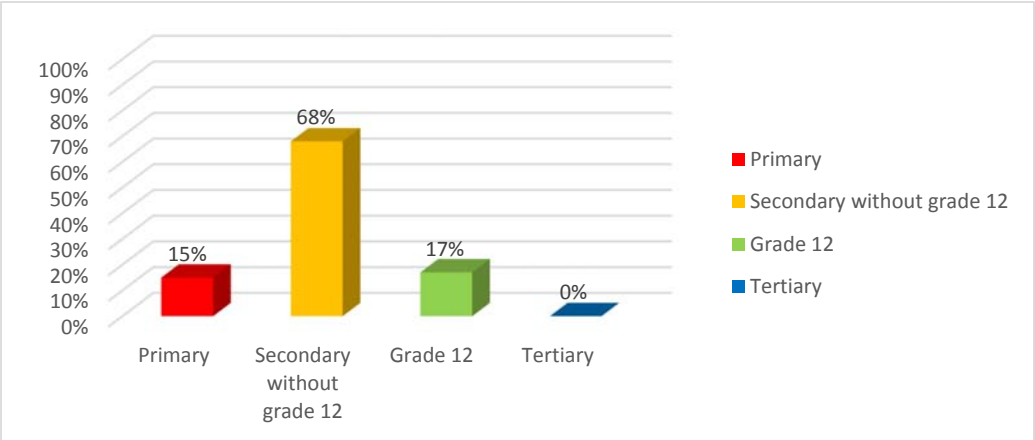


Figure 5.3: Respondents' educational levels

Extrapolated from Figure 5.3 above is that 9 of the respondents (15%) only had primary school education, 41 (68%) had secondary education without grade 12, while 10 (17%) had grade 12; and none of the mothers had tertiary education. That the majority (68%, n=41) had less than twelve years of formal education was a serious risk factor, which could be linked to unemployment. This risk factor was identified as a risk factor for MTCT in a study conducted in South Africa (Mnyani et al., 2014: 4).

5.2.1.4 Respondents' number of children

Similar to age, employment status, and educational level, the researcher was interested in finding out whether or not a relationship existed between the number of children the respondents had and the prevalence of MTCT. Figure 5.4 below represents the number of respondents' children as a group.

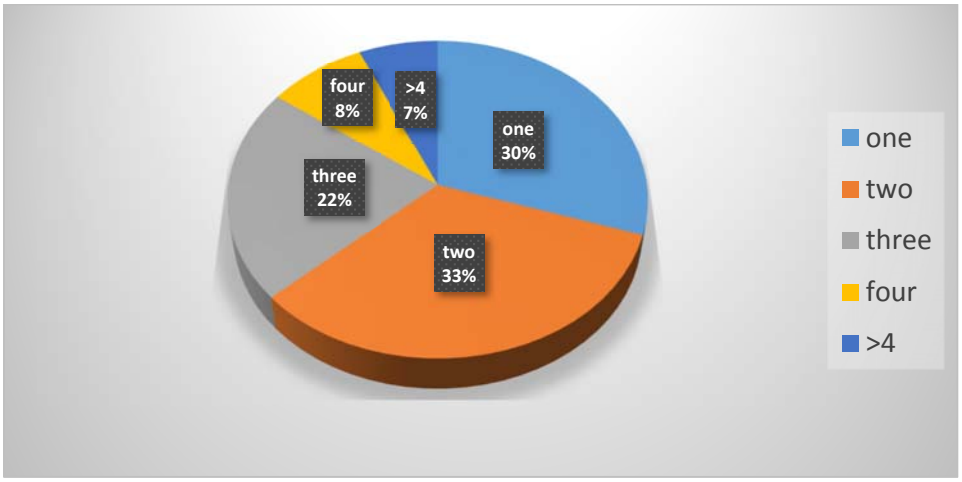


Figure 5.4: Respondents' number of children

Figure 5.4 indicates that the majority (33%, n=20) of the respondents had 2 children; followed by 30% (n=18) had only 1 child. Twenty-two percent (22%, n=13) had 3 children, and 8% (n=8) had 4 children; while 7% (n=4) had more than 4 children.

Interestingly, those who had the most number of children (more than four) constituted the least number (4 =7%) of respondents; while those with the least number of children (1) constituted the second majority (30%, n=18) of the group.

5.2.1.5 Citizenship status of the respondents

As an HIV variant, MTCT is not a uniquely South African burden of disease. Lesotho and South Africa are both members of the Southern Africa Development Community (SADC) and all members are in the sub-Sahara region which is mostly affected by HIV/AIDS. As a demographic variable, citizenship was necessitated by the fact South Africa's relatively developed socio-economic infrastructure and opportunities are the most attractive in Africa and the SADC region. For this reason, there are millions of expatriates from various parts of the African continent and the world. Figure 5.5 below

depicts the citizenships of respondents. Worth mentioning is that naturalised and permanent citizens were notably absent from the sampled respondents.

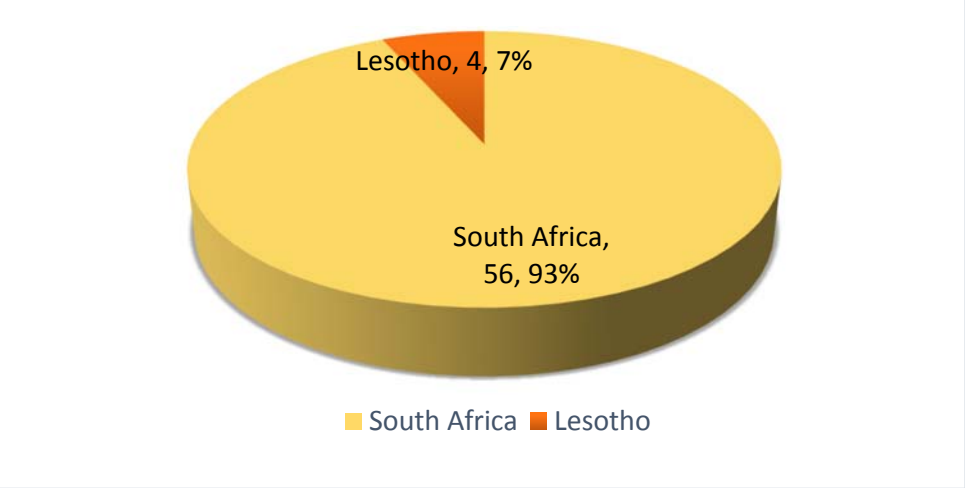


Figure 5.5: Citizenship status of the respondents

From the figure above, 56 respondents (93%) were South African, while 4 (7%) were Lesotho citizens. The presence of Lesotho nationals in the study is that Lesotho is the nearest country to the south east of Mangaung Metropolitan Municipality, the research site. The Lesotho nationals did not adhere to most of the guidelines because they did not have the necessary documents to be in South Africa and did not attend health facilities regularly for fear of repatriation. They had exceeded the maximum time allowed to stay in South Africa and one did not even have a passport.

5.2.2 PMTCT RELATED INFORMATION

The previous sub-section (5.2.1) focused entirely on the demographic characteristics of the sixty respondents selected for the questionnaire-based quantitative aspect of the research. The demographic representation was intended to broaden the stakeholder perspectives as much as possible and prevent a skewed perspective of the lived experiences of the people most familiar with the real-life situation (Walliman, 2011: 116). The current sub-section (5.2.2) is less focused on the personal characteristics of the respondents, but more on the extent to which they relate to various aspects of the core PMTCT phenomenon.

5.2.2.1 Respondents' source of PMTCT knowledge

In Figure 5.3 (p. 67), the emerging picture reflects that the majority of participants (68%, n=41) have not acquired grade 12 formal learning. Despite that the researcher could not have predicted their levels of education prior to the commencement of the study, it was still of particular interest for the researcher to determine *where* and *how* they acquired any HIV/AIDS-related knowledge in general and MTCT in particular. Both Table 5.2 and Figure 5.6

Table 5.2: Source of respondents' PMTCT knowledge

Source of PMTCT Knowledge	Frequency	Percentage
Health workers	56	94%
Media	2	3%
Community	2	3%
Did not know about it	0	0%
Total	**60**	**100%**

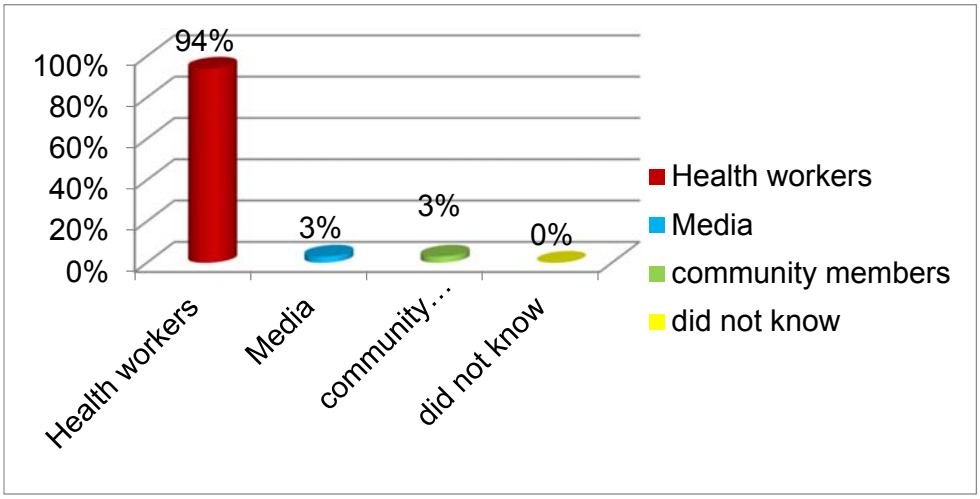


Figure 5.6: Source of respondents' PMTCT knowledge

Emanating from both Table 5.2 and Figure 5.6 above, all the sixty mothers indicated that they knew about prevention of mother to child transmission of HIV. Fifty six (94%) of them reported that they acquired the information from the health care workers; 2 (3%) from the media, while another (3%) reported to have obtained the information from other community members. According to the South African national PMTCT and management of HIV guidelines, it is mandatory to provide pregnant women with PMTCT information during all visits to health care facilities (South Africa, 2015a: 38), which explains the reason for the majority citing health workers as the primary source of their information and knowledge concerning PMTCT HIV messages and information leaflets are also widely available in the health facilities, from the media, the billboards and some government and private vehicles are branded with HIV messages. Some studies have identified lack of knowledge about the PMTCT as a contributing factors to non-adherence to PMTCT interventions (Mnyani & Mcintyre, 2013: 68; Baek & Rutenberg, 2007: 303).

5.2.2.2 Antenatal booking gestation

In South Africa, women are encouraged to book for antenatal care as soon as they discover or suspect that they are pregnant (South Africa, 2015a: 22). Antenatal booking after twenty weeks was also found to be one of the impediments of PMTCT in South Africa (Mnyani, Simango, Murphy, Chersich & Mcintyre, 2014: 4). Both Table 5.3 and Figure 5.7 below reflect the respondents' booking gestation.

Table 5.3 Antenatal booking gestation

Period	Frequency	Percentage
<20 weeks	21	35%
>20 weeks	38	63%
Unbooked	1	2%
Total	**60**	**100%**

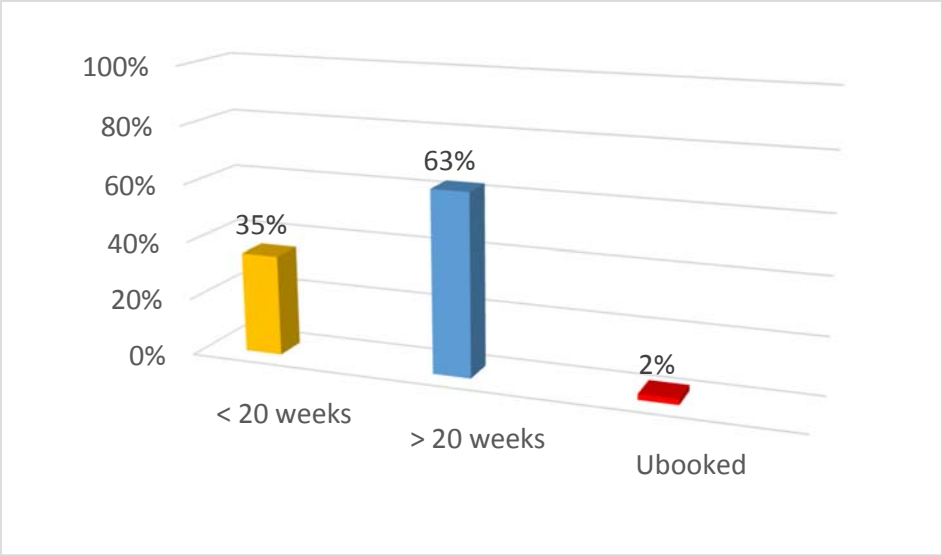


Figure 5.7: Antenatal booking gestation

Some studies have found that late antenatal booking is generally a problem in Africa (Ndidi & Oseremen, 2010: 50). Early antenatal booking affords mothers an opportunity for HIV testing and timeous initiation of ART in the event that they test HIV-positive. Each additional week of treatment confers cumulative reduction of risk of MTCT (Chibwesha, Giganti, Putta, Chintu, Mulindwa, Dorton, Stringer & Stringer ,2011: 226). This is also affirmed by Myer, Zulliger, Bekker and Abrams (2012: 6).

Table 5.3 and Figure 5.7 above show that the majority of respondents (63%, n=38) booked for antenatal clinic from 20 weeks, followed by 35% of the respondents (n=21) who booked prior to 20 weeks; while the minority of 2% (n=1) did not attend at all. On the whole, the fact that a total of 98% (n=59) respondents generally did book for antenatal clinic demonstrates that the Mangaung Metropolitan area was an aberration to the trend depicted by Ndidi and Oseremen (2010: 50) above.

5.2.2.3 Period of maternal HIV diagnosis

The period at which mothers tested HIV-positive for the first time was of interest to the researcher, and logically links with the gestation period above, as it indicates the level of HIV/AIDS awareness in particular and MTCT in particular. The 2015 antenatal HIV and syphilis survey found that HIV prevalence among antenatal clients in public facilities was 30.8% nationally, and 29.8% in Free State Province (South Africa, 2017: 23). In some mother–infant pairs, the baby tested positive before the mother, and in

these instances the babies were tested because they were presented illness symptoms (Myani, et al., 2014: 4). Table 5.4 and Figure 5.8 below illustrate the respondents' period of maternal HIV diagnosis.

Table 5.4: Period of maternal HIV diagnosis

Period	Frequency	Percentage
Before pregnancy	13	22%
During pregnancy	23	38%
During labour	4	7%
Post birth	20	33%
Total	**60**	**100%**

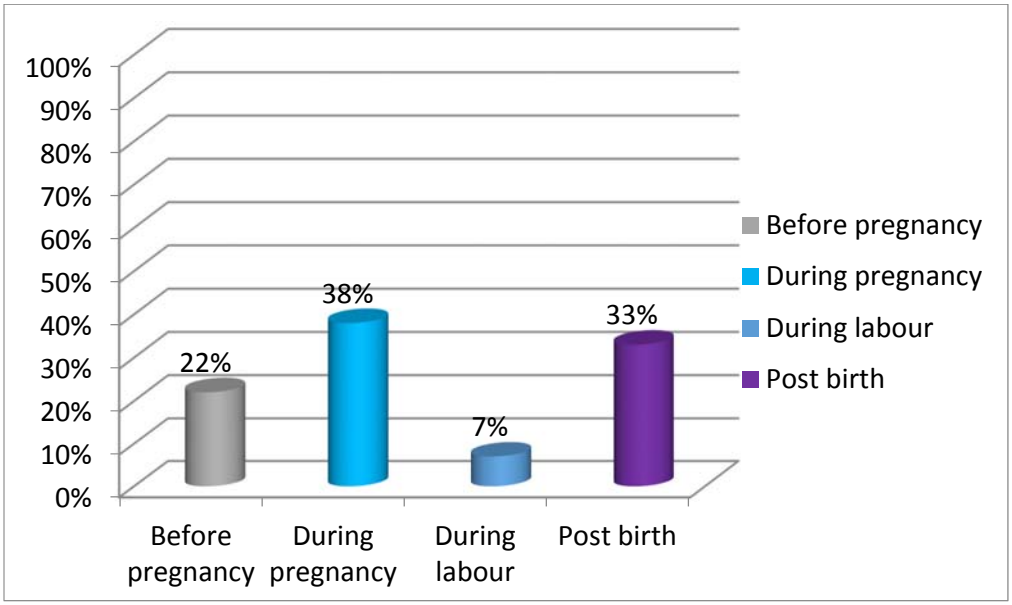


Figure 5.8: Period of maternal HIV diagnosis

The information above depicts that 13 respondents (22%) tested positive for the first time before pregnancy, and they reported to the antenatal clinics already knowing their HIV+ status Twenty three mothers (38%) tested HIV positive during pregnancy, and the majority of them on the first antenatal clinic visit; and four mothers (7%) tested positive for the first time during labour. Twenty mothers (33%) tested positive for the first time after they had given birth. Based on the 38% majority (n=23), the general view is that the respondents generally conducted antenatal testing during the pregnancy stage itself, and not before. The implication could be that there is a greater need for MTCT education and awareness. With regard to the data above, the time of infection of the twenty three mothers (38%) who tested positive for the first time during antenatal period could not be established. The chances of mother to child transmission are higher in the event that the mother becomes infected during pregnancy due to high viral load during seroconversion (Ochoga, Okolo, Pam, Okolo, Idoko & Kanki 2014: 85).

Women with unknown HIV status before pregnancy are at an increased risk of MTCT. The twenty mothers (33%) who tested HIV positive for the first after delivery, and the four (7%) during labour reported to have had negative results during antenatal period; were unbooked. Therefore, the time of infection was not known. These findings concur with those of the South African PMTCT evaluation survey. These findings revealed that 5.4% of mothers in the Free State, and 4.1% in the rest of South Africa reported HIV-negative during antenatal period, had HIV-exposed babies at six weeks (Goga, Dinh & Jackson, 2012: 18 (Humphrey et al., 2010: 7).

5.2.2.4 Time of maternal initiation of antiretroviral therapy

Initiation of ART during or before the first trimester was found to reduce MTCT to less than 2% (Goga, Jackson, Lombard, Puren, Sherman, Ramokolo, Woldesenber, Doherty, Noveve, Magasana , Singh, Ramaraj, Bhardwaj & Pillay, 2016: 8). A study conducted in Johannesburg found out that MTCT rate is low in mothers who start ART prior to pregnancy (Hoffman, Black, Technau, van der Merwe, Coovadia & Chersich, 2010: 39). Table 5.5 and Figure 5.9 depict the respondents' time of maternal ART initiation.

Table 5.5: Time of maternal initiation of antiretroviral therapy

Period	Frequency	Percentage
Before pregnancy	13	22%
During pregnancy	23	38%
After birth	24	40%
Total	**60**	**100%**

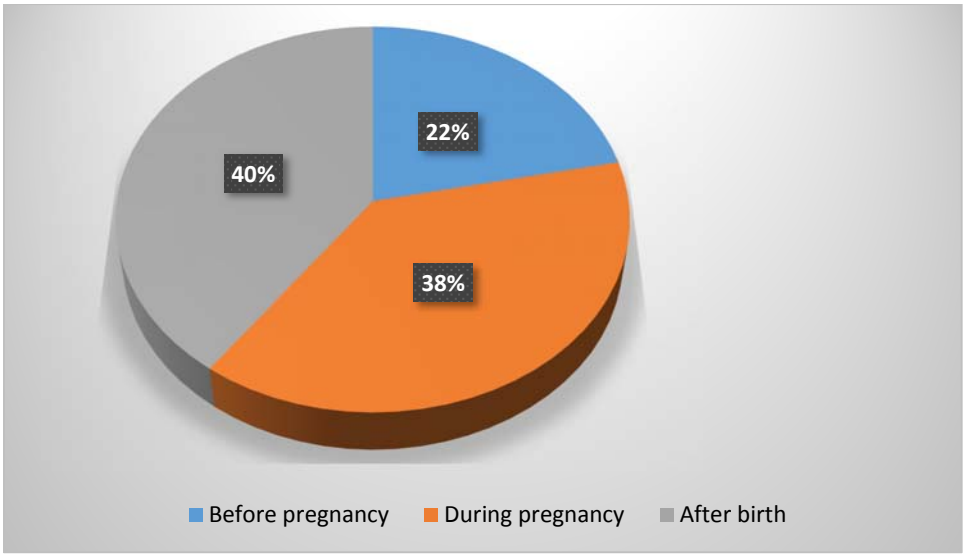


Figure 5.9: Time of maternal initiation of antiretroviral therapy

The data above indicates that 13 respondents (22%) started ART before pregnancy, 23 (38%) during pregnancy; and 24 (40%) after birth. The 13 (22%) who reported to antenatal knowing their HIV positive status were already on antiretroviral treatment on first antenatal visit. The 23 (38%) were initiated on antiretroviral treatment during the

antenatal period, while 24 were initiated after birth. Twenty four (40%) of the mothers who were initiated on ART after birth are those who tested positive for the first time during labour. Pre conception ART presents the lowest risk of MTCT. Women who initiate ART before pregnancy are more likely to be virally suppressed during labour and breastfeeding. (Drake, Wanger, Richardson, & John-Stewart , 2014: 7; Mnyani et al., 2014: 7).

5.2.2.5 Period of ART defaulting

The period of the respondents' ART defaulting during both the pregnancy and breastfeeding stages was of particular importance to the researcher for purposes of determining adherence to PMTCT guidelines. Table 5.6 and Figure 5.10 below are a reflection in this regard. Twenty mothers who tested HIV positive for the first time post birth were not included on this variable because their babies were already infected when they commenced ART; therefore, defaulting treatment would not contribute to MTCT in their situation. Four mothers who tested HIV positive for the first time during labour were included.

Table 5.6: Period of ART default

Period	Frequency	Percentage
Never	21	52%
Defaulted	19	48%
Total	**40**	**100%**

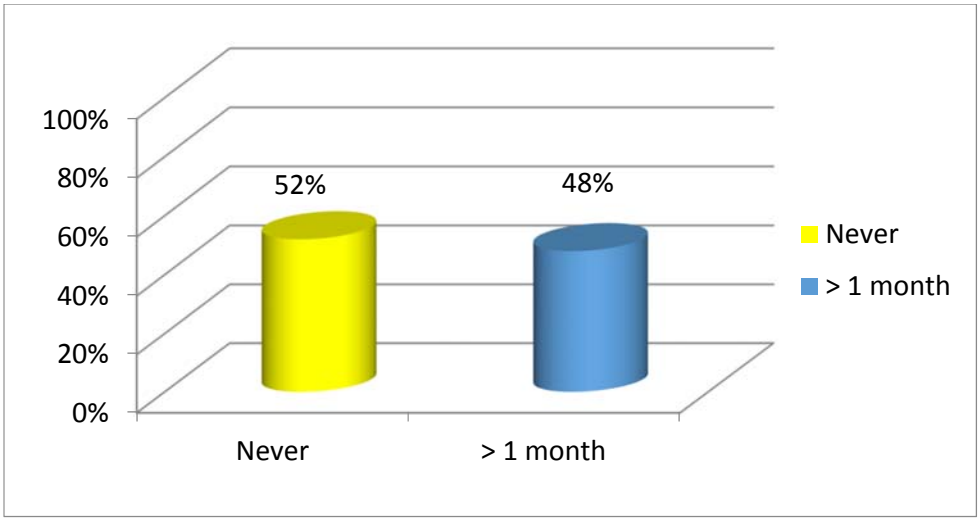


Figure 5.10: Period of ART defaulting

The majority of the respondents (52%, n=21)) of those who initiated ART before pregnancy, during pregnancy and during labour reported to have never defaulted on ART while 19 (48%) reported and were found to have defaulted on ART for more than a month with some going beyond three months during pregnancy and breastfeeding.

Nachega, Uthman, Aderson,Peltzer, Wampold, Cotton, Mills, Ho, Stringer & Mcintre (2012: 2032) In a meta-analysis of ART adherence during and after pregnancy, it was

revealed that optimum adherence was still a challenge during these periods -when it is essential for viral suppression and good clinical outcomes. Other studies have identified lack of psychosocial support, stigma and low treatment literacy as some of the challenges of retaining women on ART (Phiri, Tweya, van Lettow, Rosenberg, Trapence, Kapito-Tambo, Kaunda-Khangamwa, Kesende, Cataldo, Stanly, Gugsa, Sampathkumar, Schouten, Chiwaual & Hosseinipour 2017: 141). Morning sickness - which is common in the first trimester – and heartburn - which is common in late pregnancy is also associated with non-adherence to ART in pregnancy -have also been identified as contributors to non-adherence during early pregnancy (American College of Obstetrics and Gynaecology, 2004: 803; Nachega et al., 2012: 2033).

5.2.2.6 Infant nevirapine prophylaxis in the first six weeks

The purpose of Table 5.7 and Figure 5.11 below is to determine whether the respondents' infants have ever been without Nevirapine prophylaxis in the first week six weeks after birth. Twenty infants (33%) were not classified as HIV exposed at birth; therefore, they did not qualify to receive prophylaxis in the first six weeks.

According to the Department of Health, all HIV exposed babies should receive Nevirapine prophylaxis as soon as possible after birth and daily up to a minimum of six weeks (South Africa, 2015a: 55). Meanwhile, Mnyani et al. (2014: 5) also found the uptake of Nevirapine to be high (94.7%) compared to other PMTCT indicators.

Table 5.7: Infant nevirapine prophylaxis in the first six weeks

Period	Frequency	Percentage
No	35	87%
Yes	5	13%
Total	**40**	**100%**

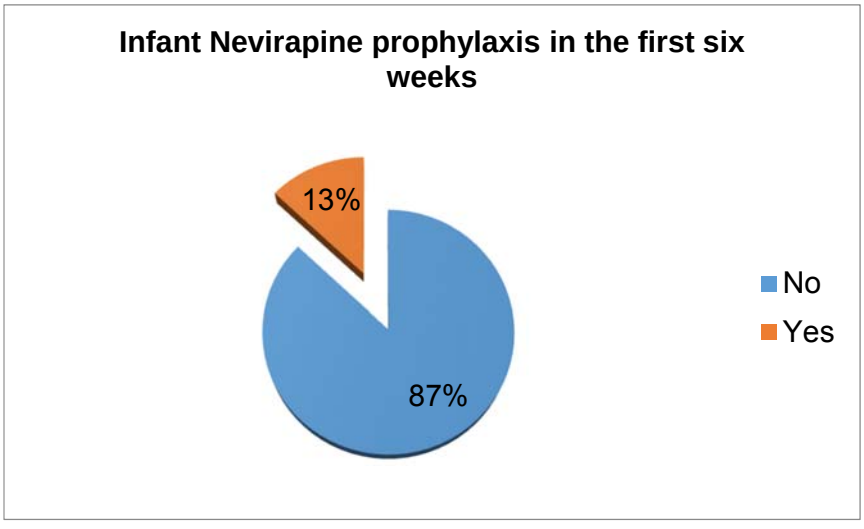


Figure 5.11: Infant nevirapine prophylaxis in the first six weeks

.Forty infants were supposed to receive Nevirapine prophylaxis for a minimum duration of six weeks. Thirty five mothers (87%) of the forty HIV-exposed babies reported that

their infants were never without prophylaxis in the first six weeks; while five mothers (33%) reported that there were times when their infants did not receive the prophylaxis.

5.2.2.7 Infant feeding method during the first six months

For developing countries, the World Health Organization recommends exclusive breastfeeding for the first six months by all mothers, including those who are HIV-infected. This was also endorsed by the Tshwane Declaration, which supported breastfeeding in South Africa 2011. As opposed to exclusive breastfeeding, mixed feeding is known to be a risk factor for MTCT (WHO & CDC, 2008: 2). Table 5.8 and Figure 5.12 below shows the respondents' infant feeding methods during the first six months after birth.

Table 5.8: Infant feeding method during the first six months

Period	Frequency	Percentage
Exclusive formula feeding	2	3%
Exclusive breastfeeding	31	52%
Exclusive breastfeeding and exclusive formula (Changed to formula before six months)	9	15%
Mixed feeding	18	30%
Total	**60**	**100%**

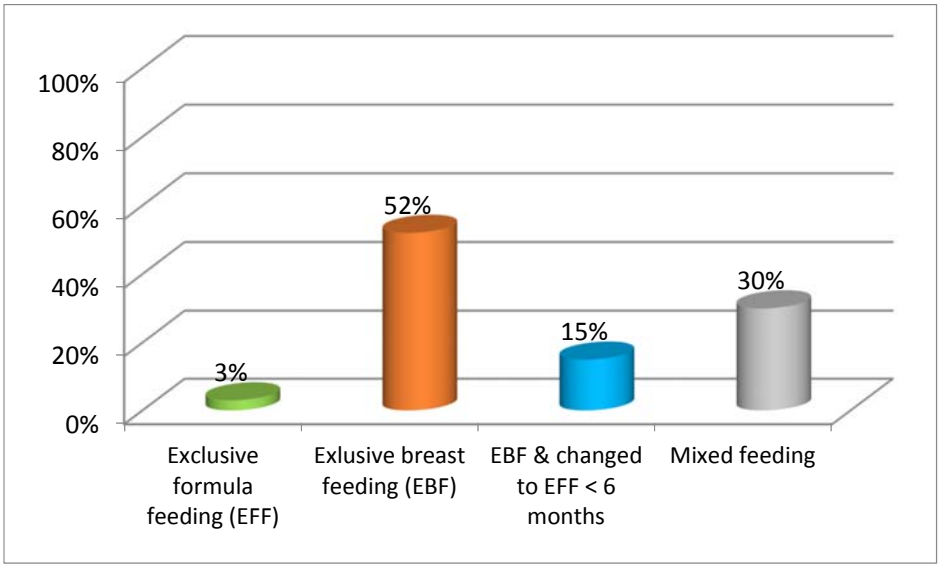


Figure 5.12: Infant feeding method during the first six months

Extrapolated from the information above is that 2 respondents (3%) exclusively formula-fed their babies, 31 (52%) reported to have practiced exclusive breastfeeding for six months; while 9 (15%) initially mainly breastfed, but discontinued and started exclusive formula feeding before six months. Eighteen respondents (30%) reported that they mixed-fed their babies in the first six months. It is evident from the data that exclusive breastfeeding was the predominant mode of feeding the infants during the first six months of their birth, as supported by 52% (n=31) of the respondents. The

latter is in discord with the findings of the South African PMTCT evaluation study by Goga et al. (2012: 39), which found that only 20.4% of mothers were exclusively breastfeeding; while 61.52% were not giving any breast milk, and 18.1% were mix-feeding between six and eight weeks of their infants' lives.

Another study by Mnyani et al (2014: 5) in Johannesburg reported that only 11.7% of mothers were breastfeeding, and 68% were formula feeding. The study conducted in the Western Cape Province concluded that none (0%) of the respondents were exclusively breastfeeding at six months (Cotton & Esser, 2016: 398). Although mixed feeding also refers to giving breast milk and formula besides solids, a cohort study conducted in KwaZulu-Natal revealed that giving breast milk and solids carries a greater risk for MTCT than giving breast milk and formula (Coovadia, Rollins, Bland, Little, Coutsoundis & Newel, 2007: 1113).

5.2.2.8 Duration of breastfeeding

Whereas Table 5.8 and Figure 5.12 above focused on the specific method of baby feeding, Table 5.9 and Figure 5.13 below reflects the different periods of the duration of the different feeding methods. The rationale and logic of these two variables (method and duration of feeding) is to determine the extent (if any) to which one has any effect or influence on the other. In adherence to the stipulations of the World Health Organization, the South African PMTCT guidelines recommend that infants be exclusively breastfed at least for the first six months of their lives. It is in this specific regard that the researcher was interested to find out whether or not this minimum requirement was complied with; and if so, to what extent?

Table 5.9: Duration of breastfeeding

Duration	Frequency	Percentage
Never	2	3%
Still on breast	6	10%
≤ 1 year	30	50%
>1 year	22	37 %
Total	**60**	**100%**

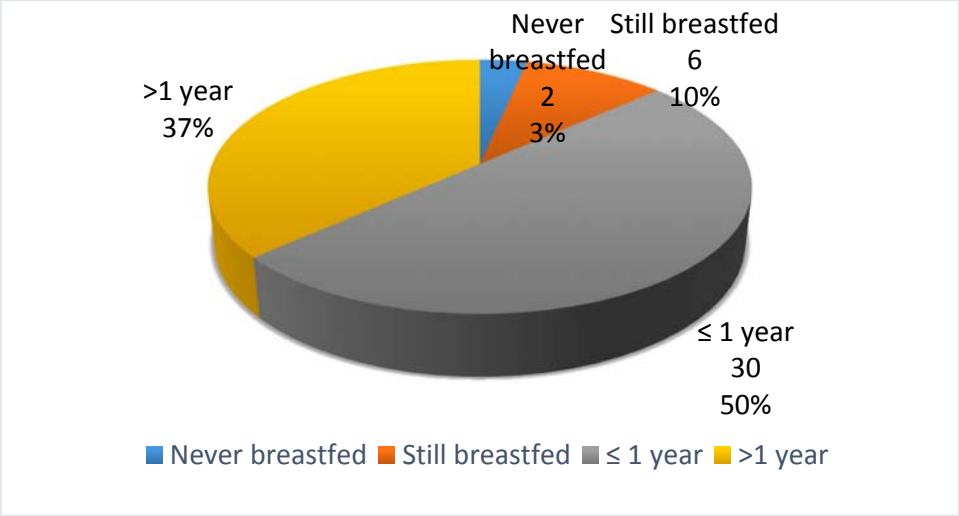


Figure 5.13: Duration of breastfeeding

Two respondents (3%) never breastfed their infants, six (10%) were still breastfeeding at the time of data collection, 30 respondents (50%) breastfeed for less than a year; while 22 respondents (37%) were already doing so for more than a year. Eleven of the 22 respondents who breastfed for more than a year are those who tested HIV-positive for the first time after they gave birth. Breastfeeding by HIV infected mothers for more than a year carries more risk for MTCT than stopping at one year. From the information above, it is apparent that the majority (50%, n=30), who have been breastfeeding for less than one year, constitute the dominant breastfeeding period. That is, less than one year of breastfeeding is the most dominant duration of breastfeeding among the respondents.

Table 5.10: Mothers who breastfed for more than a year

Category	Frequency	Percentage
Mother who tested HIV-positive for the first time before delivery	11	50%
Mothers who tested positive post delivery	11	50%
Total	**22**	**100%**

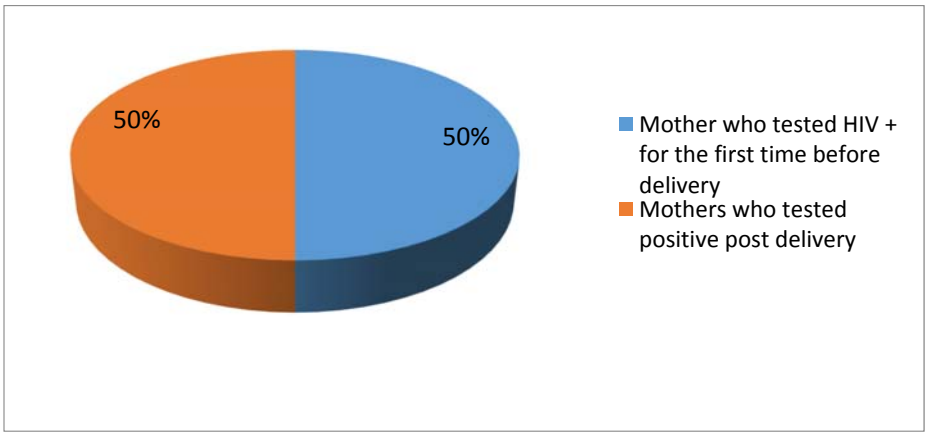


Figure 5.14: Mothers who breastfed for more than a year

Eleven respondents (50%) who tested HIV-positive prior to giving birth were breastfeeding their babies for less than a year; and 11 (50%) breastfed for more than a year. According to this statistical information, there is virtually no difference between those who breastfed for more than 12 months and those who breastfed for less than the 12 months. Breastfeeding for more than 12 months is contrary to the South African guidelines for PMTCT. These guidelines categorically state that HIV infected women should breastfeed for at least 12 months (South Africa, 2015a: 87).

5.2.2.9 Infant testing at ten weeks

Early infant diagnosis (EID) of HIV is critical for minimising early child mortality. For this reason, the WHO recommends testing of HIV exposed infants between four and six weeks of life for diagnosis of intrapartum transmission (WHO, 2016: 32). Twenty babies (40%) did not qualify for the test because their mothers did not have HIV-positive results during antenatal and perinatal period. Table 5.11 and Figure 5.15 below show the status of infant HIV testing at ten weeks.

Table 5.11: Infant testing at ten weeks

Infant Test Status for HIV at 10 Weeks	Frequency	Percentage
Tested	18	45%
Not tested.	22	55%
Total	**40**	**100%**

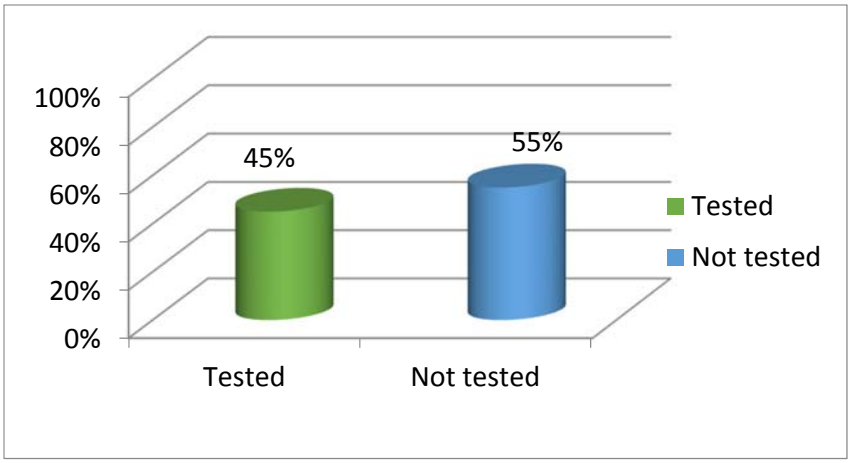


Figure 5.15: Infant testing at ten weeks

From the information derived in Table 5.11 and Figure 5.15 above, 18 babies (45%) of the 40 who met the HIV-exposed classification at birth were tested for HIV at 10 weeks, and were HIV-negative. They later tested positive, implying postnatal transmission through breastfeeding. Twenty-two (55%) were not tested, the majority of whom were not brought for the ten weeks EPI testing. Only 1 (one) of the babies not tested at ten weeks was HIV- negative on the first test, but became HIV-positive later; also implying postnatal transmission. The remainder of the babies (52%, n=21) tested HIV-positive on the first test. Therefore, it could not be established whether they

became infected through breastfeeding, or whether they were already infected at ten weeks.

The dominant trend from this is that the majority (55%, n=22) of the babies were not subjected to early childhood diagnosis at ten weeks, despite that in the Free State, the HIV PCR testing is available in all primary health care facilities. The dominant majority findings above (of the 55% non-testing for EID) is in contrast with a meta-analysis and systematic review of studies conducted in 15 Sub-Saharan countries between 2002 and 2012; which found that two thirds of HIV-exposed babies were brought for EID during the stipulated ten-week period (Wettstein, Mugglin, Egger, Blaser, Salazar, Estill, Bender, Davies, Wandeler & Keiser, 2012: 2366).

5.2.2.10 Age of baby's first HIV diagnosis

The age of a baby's first HIV diagnosis is of particular importance for a number of reasons. One such reason is that it establishes the extent of the mother's PMTCT awareness. Table 5.12 and Figure 5.16 below are indicative of the age at which the different infants were first subjected to the HIV diagnosis.

Table 5.12: Age of baby's first HIV diagnosis

Age at baby's' first HIV + diagnosis	Frequency	Percentage
13 weeks – 14 weeks	15	25%
>14 weeks – 6 months	10	17%
6-12 months	15	25%
12- 18 months	20	33%
Total	**60**	**100%**

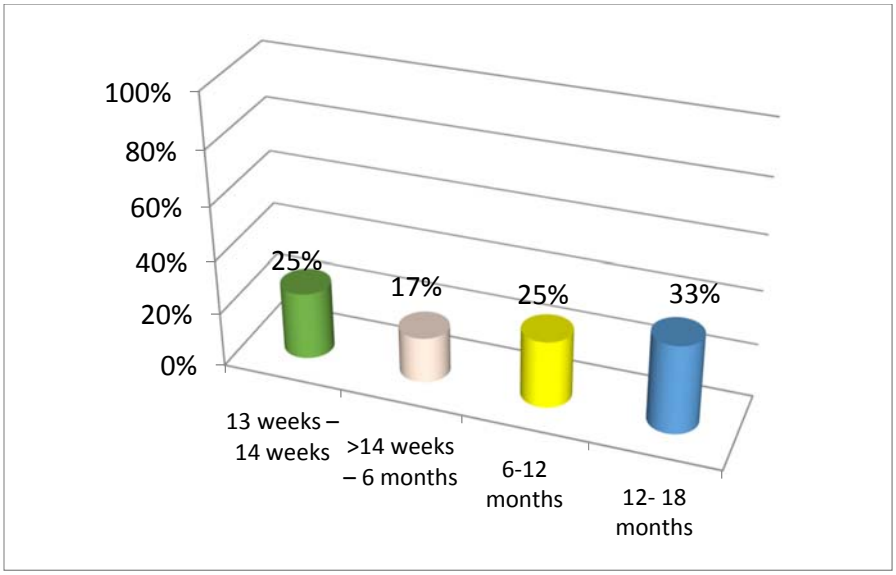


Figure 5.16: Age of baby's first HIV diagnosis

The information above indicates that 15 (25%) of the babies tested HIV-positive for the first time at 13-14 weeks, 10 (17%) between fourteen weeks and six months; another 15 (25%) 6-12 months, and 20 (33%) between 12 and 18 months. Twenty-

two of the forty babies who were eligible for the test at 10 weeks were missed. This suggests that some of the babies who were diagnosed positive after 10 weeks could have been infected earlier. The overall outcome is that the majority of the babies (33%, n=20) were first tested between 12-18 months.

5.2.2.11 Breast diseases

Breast diseases during breastfeeding have been identified as one of the risk factors for MTCT during breastfeeding (Ekpine, Wiktor, Sattern, 1997: 1057; Remington et al., 2016: 34; King, Ellington & Kourtis, 2013: 15). The researcher was interested in determining the extent to which breast diseases became an MTCT cause in this study. Table 5.13 and Figure 5.13 below address this specific issue of possible breast diseases which have a direct link with the spread of HIV to the infant.

Table 5.13: Breast diseases

Breast Diseases During the Breastfeeding Period	Frequency	Percentage
No	53	88%
Yes	7	12%
Total	**60**	**100%**

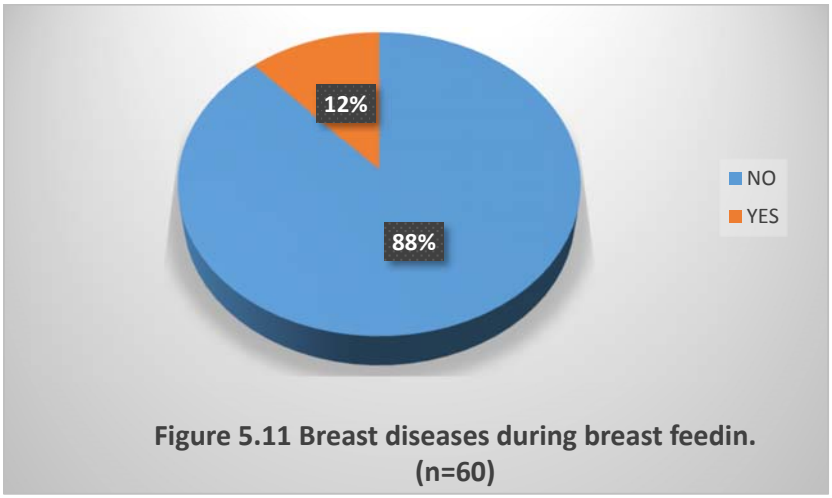


Figure 5.17: Breast diseases

Fifty three respondents (88%) did not have breast-related diseases during breastfeeding, while 7 (12%) presented one form or the other of such diseases. That the majority of 88% did not present any breast-related disease during breastfeeding is in stark contrast with the findings in other studies. Accordingly, in the context of this study, breast diseases did not contribute much to MTCT.

5.3 QUALITATIVE (INTERVIEW-BASED) DATA ANALYSIS

Saturation was reached after interviewing a total of 10 (ten) mothers. These were part of the sixty mothers of children who tested HIV positive for the first time at the age of 3 (three) to 18 months who participated in the quantitative part of the study. The interviews were conducted at 5 (five) primary health facilities and 1 (one) hospital.

Some of the information obtained from the mothers was still verified by the review of medical records, mainly the 'Road to Health' booklet of the Free State Province Department of Health.

5.3.1 Demographic Information of the research participants

Table 5.14 below presents the demographic variables of the ten respondents who were interviewed. These demographic variables include their age, employment status, educational level, marital status, number of children, as well as their citizenship. While these demographic variables are informative as well, it is the PMTCT-related information that is of more serious concern to the study.

Table 5.14: Demographic information of participants

Demographic Information		Respondents (N=10)	
		Number	Percentage
Age	18-25	2	20%
	26-35	5	50%
	36-45	3	30
Total		**10**	**100%**
Employment status	Employed	4	40%
	Unemployed	6	60%
Total		**10**	**100%**
Educational level	Primary school	2	20%
	Secondary school without grade 12	5	50%
	Grade 12	3	30%
	Tertiary education	0	0%
Total		**10**	**100%**
Marital status	Single	6	60%
	Married	3	30%
	Cohabiting	1	10%
Total		**10**	**100%**
Number of children	One	2	20%
	Two	3	30%
	Three	3	30%
	≥Four	2	20%
Total		**10**	**100%**
Citizenship	South African	9	90%
	Lesotho	1	10%
Total		**10**	**100%**

From Table 5.14 above, it is clear that the majority of the participants (50%, n=5) were in the 26-35 years' age cohort, followed by 30% (n=3) who were in the 36-45 years' age cohort; while 2 (20%) were in the 10-25 years' age group. Four of the ten respondents. The impression is that the majority were in the child-bearing age. The majority (60%, n=6) were employed, while the minority (40%, n-4) were not, a reflection of the general current unemployment situation in the country. The majority (50%, n=5) did not complete their high school education, followed by 3 (30%) who completed their high school education; and 2 (20%) who had only primary school education. That only 3 (30%) completed their high school education does not augur well for PMTCT knowledge and awareness, thus placing dissemination of HIV/AIDS

knowledge and education more on as a responsibility of health care workers and practitioners.

Mnyani et al. (2014: 4) identified less than twelve years of schooling as one of the risk factors of MTCT. A study conducted in Ethiopia revealed that some demographic variables such as marriage, education level, religion and occupation had a bearing on the women's knowledge of PMTCT. Education level above primary school, being married and a formal occupation increased the mother's chances of knowing about PMTCT (Luba, Fengi, Gebremedhins, Erena, Nassen, & Tangi, 2017: 5). In this study majority of women were single and unemployed. However, more of them had above primary school education. A systematic review of seven Sub-Saharan African studies found that there was an association between maternal lower education and adherence to ART, while nine studies found no association. In three studies, married women or those living with partners were not eager to take prophylaxis for PMTCT, while in other studies there were no associations (Gourlay, Birdthistle, Mburu, Iorpenda & Wringe, 2013: 4).

5.3.2 Themes, Sub-themes and Categories

The qualitative review of information derived from the interviews involved their reduction or classification into themes, sub-themes, and associated categories. Table 5.15 below reflects these aspects.

Table 5.15: Themes, subthemes and categories

Themes	Sub-themes	Categories
Psychological factors	Positive feelings	Commitment to treatment Acceptance Well informed
	Negative feelings	Denial Fear of stigma Overwhelmed Regret
Emotional factors		Disappointment
		Gullibility
		Unclosed life chapters
Socio economic factors		Migrant labour Financial constraints
Missed opportunities		Non accessibility of health services Lack of resources in health facilities Poor communication
Risky behaviour		Inconsistent or no condom use Drinking Non adherence to PMTCT prescripts Poor health seeking habits
Women disempowerment	Over dominance	Fear of rejection Lack of partner support Submissiveness

Six themes emerged from the classification of the qualitatively obtained data, namely: psychological factors, emotional factors, socioeconomic factors missed opportunities, risky behaviour and women disempowerment; all of which demonstrate the participants' experiences within the PMTCT programmes from pregnancy until their children were first diagnosed HIV positive.

5.3.2.1 Psychological factors

Mothers reported an array of psychological factors which were classified as either positive or negative.

5.3.2.1.1 Positive feelings

- Commitment to treatment

One mother who was diagnosed HIV-positive before pregnancy expressed how she did everything possible to prevent her baby from contracting the HIV virus. She booked antenatal clinic early, adhered to ART, gave the baby nevirapine prophylaxis and breastfeed exclusively for six weeks, also taking the baby to the clinic at required intervals.

"I started the antenatal clinic when I was three months pregnant. At the clinic they told me about how important it is that I continue taking my treatment well so that my baby could not be infected and I took it as instructed because I did not want my baby to be infected."

- Acceptance

A mother who tested negative throughout pregnancy and breastfeeding but became ill at the same time with her baby and both tested positive, said:

"Now there is nothing that can be done, we are already infected, I still have hope that we are going to live a normal life as long as we continue taking treatment. I am healthy and my baby is healthy as well I believe it's because we are taking treatment well."

- Well informed

Nine (90%) of the ten mothers knew about HIV and PMTCT prior to pregnancy and also received some information about it during antenatal visits and drug readiness training.

"I even attended the class where that nurse told us everything about HIV. I should give the baby only breast milk for the first six months to prevent infection, I should take my medications every day, that nurse really taught us some important things".

"They explained to me that it's important to test regularly so that if positive I just get treatment that prevents transmission to the baby therefore I tested at every visit"

"The nurse at the clinic did her job and educated me but I do not know what was wrong with me".

Although the mothers reported knowledge of PMTCT, they did not adhere to the guidelines. A descriptive cross sectional study conducted in Ghana found that knowledge of PMTCT did not contribute to the utilisation of the service (Boateng, Dokuaa, Kwapong & Agyei-Baffout (2013: 4). Contrarily, earlier studies had indicated that knowledge of PMTCT and HIV are good predictors of utilisation of the services (Addo, 2005: 32; Falnes, Tylleskar, Paoli, Manongi & Engebretsen, 2010).

5.3.2.1.2. Negative feelings

- Denial

One thirty-year old mother of three who tested HIV positive on the first antenatal visit mentioned that she did not believe she was HIV infected until her husband died of AIDS. She did not take the antiretroviral treatment during pregnancy and breastfeeding.

"But to me this HIV thing was not real. I heard all what that nurse said, but to me it was not real. So I told her I was not going to take treatment because I did not believe the story. I did not take treatment throughout pregnancy and breastfeeding."

- Overwhelmed Inability to cope

Another mother aged twenty four and a primipara who also tested HIV positive on first antenatal visit expressed that she was not ready to start treatment because she was unable to cope with the new diagnosis

"I started attending the clinic at three months and got the medication each time I went to the clinic. But I did not drink them. I just fetched them because I did not want the nurses to scold me. This new diagnosis was too heavy on me, I suffered a lot of stress … I did not have the strength to take the medications. I used to fetch them but threw them away on the way home from the clinic…. Whenever I came to the clinic I would lie about taking medication and they gave me more."

- Fear of stigma

The twenty year old mother also expressed that one of the reasons why she did not take her treatment was because of fear of stigma although she reported to have been aware of the implications.

"Telling people about my status and facing rejection would add to the burden."

Another mother who did not adhere to antiretroviral treatment because she did not always have money for transport to the clinic said this when asked why she did not walk to the clinic which is one kilometre away for her treatment;

"I do not get treatment from a nearby clinic because most of the people who go there know me".

- Regret

The mother who had not taken her antiretroviral treatment blamed herself and regretted her decision when the baby tested HIV positive.

"Now I feel if I had taken this seriously and taken the treatment and told my husband about it my baby would not be infected …. And for some time I had a lot of stress because of this."

In their quantitative exploratory study conducted in South Africa, Mbokane, Ehlers & Roos (2016: 13) found that women had a variety of emotional and psychological reactions when they were first informed of their HIV-positive status. The reactions excluded surprise, anxiety, confusion, anger, hopelessness and resentment. Psychological factors such as denial, shock and depression were also found to be barriers to PMTCT (Gourlay et al., 2013: 6). In other studies, fear of stigma has been associated with non-adherence to ARV treatment in (Mukumbang, Mwale & van Wyk, 2017: 2; Rael & Hampanda, 2016: 323; Okoli & Lansdown, 2014.

5.3.2.2 Emotional factors

The mothers of HIV-infected children reported various emotional factors associated with their experiences arising from their children's status. These emotional factors included disappointment, unclosed life chapters, and a sense of gullibility.

5.3.2.2.1 Disappointment

A mother who tested HIV negative during pregnancy and twice while breastfeeding expressed her disappointment thus:

"I don't know what to say, but I wish it could not have happed and as I said I wonder why it was negative all along. I am very disappointed because I could have taken treatment that prevents the baby from being infected if it had not hidden itself."

5.3.2.2.2 Unclosed life chapters

Two mothers could not reach closure as a result of their children's HIV diagnosis, because they did not understand how and when they became infected.

The same mother who tested HIV negative during pregnancy and twice while breastfeeding could not understand why her baby became infected because she never had any sexual relationship since pregnancy when the father to the baby left her.

"What I don't understand is why they could not detect it the four times that I tested and suddenly I hear it when the baby is sick, and I never had a boyfriend since I broke up with the father of this baby during pregnancy."

Another mother knew her HIV positive status prior to her pregnancy, and was already on antiretroviral treatment. She breastfed her baby for six weeks and changed to formula feeding. Her baby tested HIV negative at birth, at fourteen weeks and at six months. At nine months, the baby was diagnosed with pulmonary tuberculosis and tested HIV positive. The three negative PCR tests were recorded in the 'Road to Health' booklet, and that she was formula feeding from six weeks.

"Nobody is able to explain to me why my baby became infected I hope you will be able to tell me. I started giving the baby formula and stopped breast feeding when he was six weeks … why is it that my baby is now positive. It would make sense if the baby was positive at 14 weeks and now it's too late look at how sick he is? "

5.3.2.2.3 Gullibility

A mother who was HIV negative throughout pregnancy and during part of the breastfeeding period, and whose baby tested HIV positive first (before the parents) said this:

"I was not scared of testing because I believed I was not at risk of contracting the disease I am married to a faithful husband…… There was absolutely nothing that could make me suspect that he could cheat on me……. It meant the three of us are all infected."

Concerning her reason for not using condoms, another mother mentioned:

"We did not use condoms because I trusted my boyfriend, he had told me that I was his only girlfriend and he would not cheat on me. I do not know if he was already infected when we met and I knew I was not positive."

5.3.2.3 Socio-economic factors

The socio-economic factors include migrant labour and financial constraints.

5.3.2.3.1 Migrant labour

A twenty-six year old mother who also resided at a farm left her baby with her mother while she went to look for a job in Johannesburg. Her mother never took the child to the clinic until the child was admitted to hospital due to ill health at six months. The baby subsequently tested HIV positive while he was admitted at the hospital.

5.3.2.3.2 Financial constraints

Some mothers cited lack of money for non-adherence to PMTCT guidelines.

"I went to the clinic late because I did not have money for transport. We mostly rely on the transport offered by the farmer when he comes to town."

Studies conducted in Malawi and Nigeria found that both socio-economic and socio-cultural factors also emerged as barriers to PMTCT. In this regard, the main

contributory factors were poverty and stigmatisation (Okoli & Lansdown, 2014: 3). Another study conducted in Ethiopia also found out that lack of funds and transport contributed negatively to PMTCT utilisation (Deressa, Seme, Asafa, Teshome & Enqusellassie, 2014: 9).

5.3.2.4 Missed opportunities

Inaccessibility of health services and the concomitant poor communication accounted for the missed opportunities factor.

5.3.2.4.1 Inaccessibility of health services

One mother reported that her child was not tested at ten weeks on the routine visit because the health facility did not have PCR test kits.

"*At 10 weeks, I took the baby again for injections and the HIV test. The HIV test was not conducted because they did not have the testing equipment, so the baby was tested at 14 weeks."*

The baby of the twenty-six year old mother referred to in sub-section 5.3.2.3.1 was never taken to the clinic until the age of six months because the mobile clinic which served their farm had not visited the place for four months.

5.3.2.3.2 Poor communication

One mother was diagnosed HIV before pregnancy and was already on ART. However, it was not indicated that her baby was HIV exposed in the 'Road to Health' booklet. The baby was not tested for HIV at birth and at ten weeks, but was tested for the first time at 10 months and not given the date to come back for results.

"*He (the nurse) did not tell me when to come for results so I did not come until a nurse (community care giver) came to my home after two months to ask me to come to the clinic."*

In previous studies, the shortage of resources and poor record keeping were also found to be some of the barriers to PMTCT (Gourlay et al., 2013: 8).

5.3.2.5 Risky behaviour

The risky behaviour also emerged from the data, namely: inconsistent or no condom use, drinking, non-adherence to PMTCT prescripts despite the health education provided, and poor health seeking habits. Five mothers reported not using condoms while another five reported inconsistent condom use. One mother reported drinking home brewed beer every day. Eight mothers did not adhere to PMTCT prescripts – (e.g. adherence to ART), exclusive breastfeeding, early antenatal booking and early infant diagnosis. These mothers did not adhere because of some psychological, emotional and socioeconomic factors already mentioned above.

5.3.2.5.1 Inconsistent or no condom use
"I did not use condoms. Men do not like condoms".

"We did not use condoms because I trusted my boyfriend, he had told me that I was his only girlfriend and he would not cheat on me. I do not know if he was already infected when we met and I knew I was not positive."

5.3.2.5.2 Drinking of alcohol
One mother who did not adhere to treatment, citing lack of transport money said:

"Yes I drink but other people buy the beer for me because I don't have money. I take my treatment if available even when I am drunk, I don't forget."

5.3.2.5.3 Poor health seeking habits
"I don't always take my ARV's. I go to the clinic only when I have money for transport."

In studies conducted in Zambia, excessive drinking has also been found to affect retention in care and adherence to treatment (Mukumbang, Mwale & van Wyk, 2017: 2).

5.3.2.6 Women disempowerment
Some women in the study were not able to make decisions in their sexual relationships. They could not initiate or insist on condom use, and could not ask their partners' HIV status. These women also expressed fear of violence and rejection by their partners.

5.3.2.6.1 Lack of partner support
Another mother who did not know her boyfriend's HIV status had this to say:

"My boyfriend who is the father of the baby left us when the baby was six months and I haven't seen him again ... I believe he is the one who infected me. He does not know yet because he left us for another girlfriend. It's obvious he was cheating on me because I was negative throughout pregnancy and even immediately after delivery. I feel betrayed".

One mother said this when asked if she knew her partner's HIV status.

"I do not know because he has changed since I told I told him about the pregnancy and I didn't even border to know if he is, because I know he will put the blame on me and harass me so I will just take treatment and give it to my baby as well."

5.3.2.6.2 Fear of rejection
Fear of rejection was identified as one of the interpersonal factors that influence retention to care by HIV patients (Gourlay et al., 2013: 8). When asked about condom use, one mother said:

"I did not use condoms. Men do not like condoms and I was scared that he would leave me if I insisted on condom use."

5.3.2.6.3 Submissiveness

Lack of partner support has been identified as a hindrance to PMTCT in a number of studies conducted in Africa (Deressa et al., 2014: 9; Gourlay et al., 2013: 17; Dionne-Odom, Welty, Westfall, Chi, Ekouevi, Kasaro, Tih & Tita, 2016: 5). One of the participants in this study had all three of her children HIV infected through MTCT and on second line ART because of drug resistance. She said:

"My boyfriend who is not the father of the first two children is also HIV positive but does not want to go to the clinic for treatment and also refuses to use the condoms, he says what the use is because we are both infected". I do not know the status of the father of the first two".

Knowledge of a partner's HIV status contributes to the utilisation of health services and adherence to treatment (Farquhar, Kiarie, Richardson, Kabur, John & Nduati, 2004: 1622; Kinuthia, Kohler, Okanda, Otieno, Odhjambo & John-Stewart, 2015: 6; Mpembeni, Killewo, Leshabari, Massawe, Jahn & Mushi, 2007: 29; Okoli & Lansdown, 2014: 3). Male involvement in PMTCT also proved to be a factor in the reduction of the risk of vertical transmission in a study conducted in Nairobi, Kenya (Aluisio, Richardson, Bosereg, John-Stewwart, Mbori-Ngachah & Farquhar, 2011: 5). The South African HIV Counselling and Testing policy guideline promotes couple testing (South Africa, 2015b). The benefits of couple testing include that there is immediate mutual disclosure; counsellors are present to deal which tension and ease the blame; there are more chances of adherence to treatment should HIV results be positive; couples can make informed decisions about fertility planning; sero-discordant couples can be identified and counselled on how to prevent infection to the uninfected partner; and couple testing has also proven to increase the PMTCT uptake and outcomes.

5.4 DISCUSSION OF BOTH QUALITATIVE AND QUANTITATIVE FINDINGS.

The two data sets (quantitative and qualitative) demonstrate that the factors leading to the upsurge of HIV in babies aged thirteen to eighteen months are interrelated. Quantitative data revealed that mothers did not adhere to PMTCT guidelines and qualitative data revealed that the mothers' experiences also contributed to deviation from the PMTCT guidelines. The two data sets also revealed that mothers were well informed about PMTCT, and that HIV and demographic variable did have an influence. Qualitative and quantitative data findings were merged and compared through the use of a table which indicated potential factors that contributed to MTCT and the narratives from qualitative interview transcripts finding which could have led to those factors.

Table 5.16 below demonstrates how the two data sets were merged and conclusions drawn on factors that contribute to the upsurge

Table 5.16 Comparison and convergence of findings from data sets used in convergent parallel mixed methods design

Quantitative data	Qualitative data
Knowledge of PMTCT	**Informed** *"I even attended the class where that nurse told us everything about HIV. I should give the baby only breast milk for the first six months to prevent infection, I should take my medications every day, that nurse really taught us some important things".*
Late antenatal booking	**Socio economic factors** *"I went to the clinic late because I did not have money for transport. We mostly rely on the transport offered by the farmer when he comes to town."*
Diagnosis of HIV during post-natal period (breastfeeding)	**Unclosed life chapter** *"What I don't understand is why they could not detect it the four times that I tested and suddenly I hear it when the baby is sick, and I never had a boyfriend since I broke up with the father of this baby during pregnancy."*
Non Adherence to ART	**Socio economic factors** *"I don't always take my ARV's. I go to the clinic only when I have money for transport."*
Mixed feeding method	**Non-disclosure of HIV status** *I stayed with my mother in law who gave my baby some formula and water before he was one month old. I did not tell anyone about the positive HIV test*
Time of initiation of maternal ART	**Denial** *"But to me this HIV thing was not real. I heard all what that nurse said, but to me it was not real. So I told her I was not going to take treatment because I did not believe the story. I did not take treatment throughout pregnancy and breastfeeding."* **Overwhelmed** *"I started attending the clinic at three months and got the medication each time I went to the clinic. But I did not drink them.*
late infant HIV diagnosis	**Missed opportunities** "*At 10 weeks, I took the baby again for injections and the HIV test. The HIV test was not conducted because they did not have the testing equipment, so the baby was tested at 14 weeks."*
Citizenship	*I did not attend antenatal clinic because I come from Lesotho and I was afraid that they would ask for the identity document*

The findings justify the two models that were used to guide this study, namely the health belief model and information motivation and behavioural skills model (IMB).

From the health belief model; mothers were eager to engage in PMTCT intervention in order to prevent HIV transmission to their babies. Perceived susceptibly was

indicated by the mothers' willingness to test for HIV. All mothers, except for those who were already known to be HIV positive, underwent an HIV test on the first antenatal visit, as well as subsequent visits and during the breastfeeding period. A mother who did not test during breastfeeding indicated that she believed she was not susceptible to HIV. Perceived severity and perceived benefits resulted in mothers engaging in PMTCT interventions to protect their babies from contracting HIV. However, some of them did not adhere as a results of some perceived barriers.

Perceived cost did not have much influence because primary health care and maternity services are free in South Africa. Notwithstanding, a few mothers did not comply, citing lack of money for transport to the clinics. Perceived and real barriers were revealed by the qualitative data. Some mothers did not adhere to PMTCT interventions because of some factors/barriers that were identified from the qualitative data, such as psychological and socioeconomic factors. Cues to action were brought about the extensive advertising of PMTCT, HIV and maternal and child health services at national, provincial and district level. Information education and communication material are widely available in health facilities.

The IMB model upholds that adherence information, motivation and behavioural skills influence the individual's adherence to ART. It is mandatory for all HIV positive individuals to attend the drug readiness programme in South Africa prior to initiation of ART in addition to adverts and information provided through other media. Therefore, all mothers were informed about HIV and PMTCT. Adherence motivation may also be guided by personal beliefs and attitudes. Lack of motivation was found to be engendered by the psychological and socioeconomic factors. Therefore, it contributed to non- adherence to PMTCT prescripts. Behavioural skills, which are some of the constructs of the IBM, determine whether well informed and motivated individuals will adhere to treatment. It involved the person's objective abilities and self-efficacy to acquire and access treatment in the form of PMTCT services.

5.5 CONCLUSION

The analysis, interpretation and discussion of both quantitative and qualitative data was presented in this chapter. Quantitative data was obtained from the selected mothers' questionnaire responses substantiated by information obtained from the review of medical records. Qualitative data was presented in the form of themes and categories that were identified from these selected mother's interview transcripts. Some of the information was verified by the review of medical records. Narratives from each theme were quoted and findings were compared to those of previous studies to identify connections and contradictions. The chapter concludes by outlining the finding from both qualitative and quantitative components of the study.

CHAPTER 6

MAIN CONCLUSION AND RECOMMENDATIONS, AND FURTHER STUDY

6.1. INTRODUCTION

This chapter presents the conclusions and recommendations which are based on the findings of this study, contributions and limitation of the study and the concluding remarks. The findings are derived from both the qualitative and quantitative data analysis and comparisons and relationships between the two are made in conjunction with the two models which guided the study. The recommendations are grounded on the theoretical framework which was discussed in chapter 3. It also evaluated whether the objectives of the study were achieved.

6.1.1 Research objectives and their attainment

This sub-section articulates the extent to which the study's undertaking is justifiable on the basis of achieving or attaining all its pre-determined objectives. The overall intention of this study was to identify potential factors that contributed to the high rate of HIV positivity in children aged three to eighteen months in the Mangaung Metropolitan Municipality. In this regard, the focus was not only on the postnatal transmission through breastfeeding. The following objectives formed the core of the study's intentions:

- ***Objective 1:*** *To identify and describe the potential factors that contribute to more children testing HIV-positive between the ages of three and eighteen months in the Free State Province.*

This objective was achieved by means of identifying and describing the contributory factors to the increase in HIV positivity in children aged three to eighteen months in the Mangaung Metropolitan Municipality. Quantitative data revealed that by identifying the failure of children to be tested at ten weeks, HIV diagnosis in mothers during the breast feeding period, and non-adherence to ART. The findings from the qualitative study uncovered some of the factors that lead to the deviation of PMTCT prescripts by mothers. Some of the reasons for mothers' deviation from the PMTCT prescripts included lack of partner support, the fear of stigma and rejection, migrant labour causing mothers to leave children with their grandparents, and inaccessibility of health services (for instance, some mothers failed to visit clinics at the stipulated times, and in some cases even mobile clinics were not visited).

- ***Objective 2:*** *To establish the proportion of children aged three to eighteen months who test HIV positive due to postnatal transmission.*

This objective was achieved by means of identifying that not all babies who tested positive were infected in the postnatal period through breast feeding. More than half

(55%) of children classified as HIV-exposed children were not tested at ten weeks as stipulated in the South African PMTCT guideline. Therefore, the period of MTCT infection could not be attributed to breastfeeding alone. The infection could also indicate intrapartum transmission. The findings of this study also reveal that 45% of babies classified as HIV-exposed tested negative at ten weeks, implying transmission through breastfeeding because the exposure to the virus after birth was only through breast milk.

- ***Objective 3:*** *To make recommendations to the EMTCT programme managers and implementers on plausible measures to curb the challenge of high HIV positivity rate in children aged three to eighteen months in South Africa.*

This objective was achieved by the study's finding that early infant diagnosis is still a challenge in some parts of the country. This challenge is one of the leading factors contributing to the increase of HIV positivity in children between thirteen and eighteen months of age. Concomitant recommendations were made to curb this challenge (see sub-section 6.3.1 below). Other recommendations address the challenge of diagnosis of HIV in mothers during the breastfeeding. Such recommendations include: making couple testing a national policy and advocating for partner and community involvement in PMTCT and reproduction health issues; inter-departmental collaboration in improving adherence to PMTCT prescripts; as well as improvement in monitoring and evaluation, health promotion and health education.

6.2 CONCLUSIONS

The three main factors that contribute to the upsurge of HIV in children aged thirteen to eighteen months in the Free State Province were: the deficit in early infant diagnosis which is mainly patient related; sero-conversion of mothers during the postnatal period, which increases the risk of MTCT through breastfeeding; as well as non-adherence to PMTCT prescripts mainly by mothers. That is, the upsurge persists, despite the mothers' being well informed on factors which contribute to MTCT. Psychological factors, emotional factors, socio economic factors, risky behaviour and women disempowerment all play a role in the non-adherence to healthy practices. Mothers who were HIV negative during their pregnancy did not consider themselves susceptible to MTCT. This was manifested by their reaction to the diagnosis of HIV in their children.

6.2.1 Non adherence to PMTCT guidelines

Mothers did not adhere to PMTCT prescripts despite being well informed. This was influenced by other factors such as denial, fear of stigma, shock, and lack of resources, non-accessibility of health services, lack of support, gullibility and fear of rejection by

partner. These above-cited factors contributed to late antenatal booking, non-adherence to ART, mixed feeding, and missing clinic appointments. It was also revealed that self-reported adherence to treatment is not a reliable PMTCT indicator.

6.2.1.1 Lack of early infant diagnosis

Failure to test babies at ten weeks as recommend in the South African PMTCT guideline was mainly because mothers did not attend the ten weeks immunisation visits. These babies tested positive later when they were already ill. It is not known how many of these babies die before they are tested. The low HIV positivity rate around ten weeks in the province affords the false assurance that the PMTCT programme is very successful.

6.2.1.2 Diagnosis of HIV infection in mothers during breastfeeding

Thirty-three percent of mothers tested positive for the first time during the breastfeeding period. They had tested HIV negative on previous tests. It is presumed that they also became infected during this period. The possibility of false negative HIV results with previous tests cannot be dismissed. This can result from, among factors, faulty test kits or incorrect testing technique; such as interpreting the results before the stipulated time. However, the majority of these mothers had more than one negative HIV test prior to the positive one, which can rule out the possibility of the false negative tests. This can also be disputed by the fact that they might have been tested at the same facility by the same health care workers. The HIV diagnosis of mothers during breastfeeding jeopardises the main PMTCT strategies which mostly address prevention from mothers who are already known to be positive. It should be noted that the searcher uses the phrase “HIV diagnosis during breastfeeding” because it is not clear as to when these mothers became HIV infected. What is known is that they were diagnosed during breastfeeding and previous tests were negative.

6.2.1.3 Late antenatal booking

The PMTCT guidelines stipulate that pregnant mothers should book and be offered antenatal care as soon as pregnancy is diagnosed. Early antenatal booking is monitored on the district health information systems (DHIS), but the data elements are stated as antenatal booking before twenty weeks and antenatal booking after twenty weeks. Sixty percent of the mothers of the HIV-infected babies booked after twenty weeks, which is a deviation from the guideline.

6.2.1.4 HIV diagnosis during pregnancy

Knowledge of HIV status prior to pregnancy is a good predictor of PMTCT. However, in this study only twenty two percent of mothers were diagnosed HIV positive prior to pregnancy.

6.2.1.5 Time of initiation of antiretroviral therapy

Initiation of antiretroviral therapy before pregnancy, or in early pregnancy, results in viral suppression during birth and breastfeeding; which in turn accommodates PMTCT.

6.2.1.6 Defaulting antiretroviral treatment

Adherence to treatment is paramount to the control of most diseases. Hundred percent of adherence is required for satisfactory PMTCT and HIV outcomes. In this study, 48% of mothers defaulted on their antiretroviral treatment, which predisposed them to treatment failure. The Department of Health and some developmental partners – such as *Right to Care* - are already implementing strategies that address the challenge of non-adherence to ART to all who are HIV infected.

6.2.1.7 Infant prophylaxis

The PMTCT guidelines stipulate that all HIV exposed babies should receive an antiretroviral prophylaxis for at least six week, and it may be extended according to the time of maternal HIV diagnosis. Only thirteen percent of mothers reported that their infants went without Nevirapine syrup in the first six weeks. This variable therefore had positive outcomes. However, the babies were still infected, because the Nevirapine syrup is not the only MTCT determinant.

6.2.1.8 Infant feeding in the first six months

Exclusive breastfeeding in the first six months is recommended for all mothers in developing countries, where avoidance of all breastfeeding is a common practice. The majority of mothers adhered to this feeding method. However, this indicator is also dependent on adherence to other prescripts. It alone cannot assure prevention of the vertical transmission of HIV.

6.2.1.9 Duration of breastfeeding

The South African PMTCT guidelines recommend that HIV infected mothers should breastfeed for at least one year. Most mothers breastfed for more than a year. However, it should be borne in mind that 33% of mothers were diagnosed HIV positive during breastfeeding, some after one year.

6.2.1.10 HIV testing of pregnant and breastfeeding mothers every three months

In this study, the issue of the testing of pregnant and breastfeeding mothers for HIV every three months was adhered to. However, the period in which they were infected could not be established. Some mothers were diagnosed with HIV during this routine tests. Their babies were subsequently tested and found to be already infected. The positive aspect of this testing in this instance was that babies were diagnosed and initiated on treatment before they fell sick and therefore had good outcomes. In some instances, the babies tested positive before the mothers and majority of these were babies who were diagnosed after cessation of breastfeeding.

6.3 RECOMMENDATIONS

Recommendations are basically propositions made by the researcher for both the sustainability and significance (justification) of the study as objectively derived from the study's findings (Walliman, 2011: 186). In this study, the recommendations are presented in the context of their implications to health care education and policy, health care practice, as well as health care research, particularly in developing countries. For purposes of this study, Figure 6.1 below is a depiction of the framework or context of the recommendations. The core variables of the framework of recommendations are: early infant diagnosis; community participation; health promotion and health education; psychological support; as well as the management of the PMTCT programme.

6.3.1 Early infant diagnosis

Recommendations for early infant diagnosis are framed in the context of inter-departmental collaboration between the Departments of Health and of Social Development; routine HIV testing for babies irrespective of their HIV exposure; as well as the testing breastfeeding mothers and their babies.

6.3.1.1 Inter-departmental collaboration between the Departments of Health and of Social Development

Registration for social grants should be conducted at postnatal and well-baby clinics, and the qualifying criteria should be attendance of immunisation clinics. Alternatively, parents should present their babies' 'Road to Health' booklets periodically at the Department of Social Development premises for confirmation that their immunisations are up to date for continued provision of social grants. This will address the issue of mothers not bringing their children for immunisations and early infant testing. A similar model was used in the kingdom of Lesotho where donated food parcels were only distributed during EPI (Expanded Programme on Immunisation) visits in the nineteen seventies and eighties. This improved immunisation coverage as mothers were keen to take their babies for immunisation in order to receive food parcels. This can be conducted in collaboration with the department of social development. Strategies have been implemented to improve infant follow up but the challenge remains and babies are diagnosed HIV when it's already too late.

6.3.1.2 Routine HIV testing should be conducted for babies irrespective of HIV exposure

It is evident that some babies of mothers who are infected during breastfeeding are missed due to the practice of testing HIV exposed babies only. The cost-effective HIV antibody test which is more preferable to the PCR test, and can be conducted on all babies during immunisation visits to determine exposure as it is conducted during

SAPMTCTE surveys. The antibody tests are simple, and can be conducted by non-health professionals because of the shortage of personnel at the public health care facilities. This can reduce the expenses of diagnosing and treating babies when they are already sick, and also reduce child mobility and mortality due HIV and AIDS. The cost of each test will not be more than that of late diagnosis and treatment of babies, which is conducted in the hospitals when the child is already very ill.

6.3.1.3 Testing breast feeding mothers and their babies

The South African and WHO PMTCT and HIV guidelines recommend testing of pregnant and breast feeding mothers who are reported to be HIV negative every three months. In this study, some mothers were diagnosed with HIV during the routine tests. Their babies were subsequently tested and found to be already infected. The positive aspect of this testing in this instance was that babies were diagnosed and initiated on treatment before they fell sick and therefore had good outcomes. In some instances, the babies tested positive before the mothers, and majority of these were babies who were diagnosed after cessation of breastfeeding. The PMTCT guidelines recommend that babies should be tested six weeks post cessation of breast feeding. Some of these babies were indeed tested and were negative, but later tested positive when already sick. The recommendation is therefore that the HIV exposed babies should not only be tested once post cessation of breastfeeding, but should at least have two HIV PCR tests if still below eighteen months, and antibody test if above eighteen months.

6.3.2 Community participation

Community participation which should start within house hold should be encourage and supported. This should start with the partners who are fathers to these children. Thirty three percent of mothers were diagnosed with HIV during breastfeeding. This implies that they were infected by their partners. The participation of fathers in PMTCT and MCWH issues will reinforce how critical behaviour modification is. Partners should be aware that risky sexual behaviour does not only affect the other partners but their children as well.

6.3.2.1 Couple testing

Couple testing is already one of the recommendations of the World Health Organisation and the South African Department of Health. This should be made a national policy for antenatal care, and targets should be set and it should be monitored and be classified as one of the most important PMTCT indicators. Currently, there is no rule that awards opportunity for fathers to get a day off from work to accompany their wives or partners to antenatal clinics which will in turn facilitate couple testing. Couple testing will insure prompt diagnosis of HIV in fathers while their partners are in the incubation period. It will also help identify non-complying couples and measures

can be taken to prevent infection to the other partner. In this case, it will be the mother and in turn the baby.

6.3.3 Health promotion and health education

This is already promoted in South Africa and throughout the world. The communities are informed about HIV/AIDS in general. As one of the modes of transmission of HIV, MTCT should receive even more attention. This should not be provided only in health care facilities, but to schools and the community at large. There is some PMTCT media coverage, but it is evident that it is not enough. The success of the programme is measured by tests conducted at six to ten weeks and eighteen months. This gives a false assurance that PMTCT programme is very successful. It is evident that some babies become infected and even die between these testing periods.

6.3.4 Management of foreign nationals

Health services are free for all in PHC facilities in South Africa, including for foreign nationals from the South African Development Community (SADC) countries. Notwithstanding, non-South Africans from this region still perceive the passport requirement as a discriminatory criterion, unaware that it is for identification purposes. There should be a clear policy that address the treatment of foreign nationals at health facilities in the form of IEC (Information Education and Communication) material stipulating that the requirement of passports at the health facilities is not for law enforcement or discrimination purposes; but for identification purposes. Failure to treat foreign nationals impacts negatively on the health services as it increases the burden of disease for the country.

6.3.5 Psychological support

Mothers do not only need drug readiness training for adherence, but also need continuous in-depth psychological assessment and counselling. Therefore, psychological services and support should be provided for all pregnant mothers until their children are at least six months of age or older.

6.3.6. Monitoring and evaluation of the PMTCT programme

The district information system (DHIS) which monitors health indicators in all public health facilities should have the capacity to monitor HIV positivity in children between the ages of nineteen weeks (five months) and eighteen months. Currently, the test conducted at ten weeks is monitored and it can accommodate those who are tested up to eighteen weeks for various reasons. Thirty-seven of the sixty children in this study tested positive for the first time between the ages of twenty weeks and eighteen months.

The information on those who tested positive after eighteen weeks is not captured anywhere in the DHIS because there is insufficient data capturing capacity. Consequently, important information on HIV positivity status of children to eighteen weeks is lost and not known to authorities. The researcher also believes that some even die during this period because most were diagnosed when they were very sick. The eighteen months' test is also monitored on DHIS and it is of paramount importance to monitor what happens between eighteen weeks and eighteen months to give a true reflection of the effects and outcomes of the PMTCT programme. This new indicator will cater for all those who test between the ages of nineteen weeks and eighteen months. The SAPMTCTE survey, which is one of the most important tool for measuring the programme, focuses on infants below ten weeks. It is evident from this study that some children become infected after this age. The survey should therefore expand to older babies in order to give a true reflection of the success or otherwise of the PMTCT programme.

6.4 POSSIBLE STUDY LIMITATIONS

The possible limitations of the study pertain to the specific research variables which have the potential to either reduce the generalisability of the study, expose the non-realisation of the objectives, or highlight on the methodological deficiencies (Grove et al., 2013: 598). Accordingly, the study limitations are as follows:

The researcher was affected by the time and financial implications involved in undertaking the study. The quantitative and qualitative phases of the study, the characteristics of the participants and respondents, coupled with the multiple research sites, required the study to cover a large geographical area during data collection. Nonetheless, the researcher mitigated these possible limitations by requesting the assistance of on-duty health care workers at the respective sites to administer the informed consent form on her behalf whenever there was an admission or visit by the mothers fitting the inclusion criteria. Thereafter, the researcher came to collect the completed questionnaires herself at the scheduled times.

The unavailability of sufficient information pertaining to the DHIS (District Health Information System) could pose a constraint for data accuracy. However, the researcher mitigated this possible limitation by resorting to the mothers' and infants' medical records in order to complement the questionnaire- and interview-generated data.

6.4.1 Further study

From the researcher's perspective, it is evident that more research in the field of PMTCT is still needed, especially continued sero-conversion of babies after the routine tests in terms of those who are classified as HIV exposed and those who are not. Community based surveys - as opposed to facility based ones - will greatly assist in identifying the magnitude of the challenge, and also assist in identifying infected babies before they become sick or even die. The study could also be conducted in other parts of the country. The researcher does not believe that the challenge is confined to the Mangaung Metropolitan Municipality or Free state Province only.

6.5 CONCLUSION

The significance of the study was justified by the extent to which it achieved its objectives, as measured and articulated in sub-section 6.1.1 (p. 93) above.. The thematic approach to the analysis and interpretation of data enabled the researcher to distinguish the various categories associated with each main theme. It was on the basis of the thematically organised evidence that objective recommendations were made in order to account for the scientific worth of the study, whose significance is to be determined by its contribution to PMTCT policy development in the Free State.

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Annexure A: UNISA Ethics Clearance

UNISA university of south africa

RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES
REC-012714-039 (NHERC)

1 February 2017

HSHDC/599/2017
MS S Phakisi
Student: 4282-801-5

Supervisor: Prof ON Makhubela-Nkondo
Qualification: Doctorate Harvard Universityl
Joint Supervisor: -

Dear MS S Phakisi

Decision: Ethics Approval

Name: MS S Phakisi

Proposal: Factors that contribute to high HIV positivity in children aged three to eighteen months.

Qualification: DPCHS04

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted for the duration of the research period as indicated in your application.

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 1 February 2017.

The proposed research may now commence with the proviso that:

1) *The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*

2) *Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*

Open Rubric

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

3) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

4) *[Stipulate any reporting requirements if applicable].*

Note:
The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.

Kind regards,

Prof L Roets
CHAIRPERSON
roetsl@unisa.ac.za

Prof MM Moleki
ACADEMIC CHAIRPERSON
molekmm@unisa.ac.za

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Annexure B: Letter of Request for Permission to the Department of Health Free State Province

P.O. Box 6840

Bloemfontein

9323

2nd January 2017

Head of Department

Free State Department of Health

REQUEST FOR PERMISSION TO CONDUCT RESEARCH WITHIN THE FACILITIES OF THE FREE STATE DEPARTMENT OF HEALTH

I am a Master's post-graduate student at the University of South Africa (UNISA). One of the requirements of my study is that I conduct a health related study. I therefore request permission to conduct this research within and with participants recruited from public health facilities in the Free State Province.

Researcher	Ms Selloane Phakisi
Title	Factors that contribute to high HIV positivity in children aged three to eighteen months in Free State.
Participating facilities	PHC facilities and hospitals
Target population	Mothers of babies who tested HIV positive for the first time at the age of three to eighteen months

The information gained from this study will be shared with policy makers and clinicians in order to identify challenges relating to the elimination of mother to child transmission of HIV and to accelerate the attainment of this goal.

Participation is voluntary and participants will not be remunerated. There will be no financial implications for the Department of Health in this study. I guarantee confidentiality and anonymity of all participants and the data collected will not be made known to any unauthorised persons.

Signature of the researcher

Contact details of the researcher

Cell number: 0837851126

Tel (work): 051 4039793

E mail address: phakisis@fshealth.gov.za

Annexure C: Letter of Approval: Free State Department of Health

health
Department of Health
FREE STATE PROVINCE

08 March 2017

Ms. S Phakisi
P.O Box 6840
Bloemfontein
9300

Dear Ms. S Phakisi

Subject: Factors that contribute to high HIV positivity in children aged three to eighteen months in Free State.

- Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participants must be obtained
- Serious adverse events to be reported and/or termination of the study.
- Ascertain that your data collection exercise neither interferes with the day to day running of facilities nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and please do not obtain information regarding the identity of the participants.
- Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of South Africa and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of the University of South Africa and to Free State Department of Health.
- **Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to** sebeelats@fshealth.gov.za **before you commence with the study**
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution managers/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day
- Future research will only be granted permission if correct procedures are followed see http://nhrd.hst.org.za

Trust you find the above in order.

Kind Regards

Dr D Motau
HEAD: HEALTH
Date: 8/3/17

Head : Health
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www.fs.gov.za

Annexure D: Research Questionnaire

SECTION A: PMTCT RELATED INFORMATION

Circle the number next to the relevant answer.

1. Where did you learn about PMTCT?	1. At the health facility
	2. In the media
	3. From friends and family
	4. Did not know about it
2. At what gestation did you start antenatal clinic (ANC)?	1. <20 Weeks
	2. <20 weeks
	3. Never been to ANC
3. When did you learn about your HIV positive status?	1. Before pregnancy
	2. On first ANC visit
	3. During labour
	4. During breast feeding
4. When did you start antiretroviral treatment?	1. Before pregnancy
	2. During pregnancy
	3. After delivery
5. Did you ever default on your antiretroviral treatment during pregnancy or breastfeeding?	1. Yes
	2. No
	3. Not on ART (Started post birth)
6. Did your baby ever been without nevirapine syrup/ ARV prophylaxis in the first six weeks	1. N0
	2. Yes
	3. Not applicable (baby not exposed at birth)
7. What did you feed to the baby during the first six months?	1. Exclusive formula
	2. Exclusive breast feeding
	3. Breast and some other food. (formula, solids or water
8. For how long did you breastfeed the baby?	1. never
	2. ≤ one year
	3. >One year
9. Was the baby tested for HIV at 10 weeks of birth?	1. Yes
	2. No
	3. Not HIV exposed at birth
10. At what age did your baby test HIV **positive** for the first time?	1. At birth
	2. After 10 weeks
	3. After 13 weeks
11. For how long did you breastfeed the baby?	1. never
	2. ≤ one year
	3. >One year
12. To whom have you disclosed your HIV status?	1. Talk freely to everyone about it

	2. House hold members only
	3. My partner

SECTION B: DEMOGRAPHIC INFORMATION

1. Age(mother)	1. 18-25 2. 25-35 3. 35-45 4. Above 45
2. Age of the child	3-6 months 6-9 months 9-12 months 12-18 months Above 18 months
3. Marital status	1. Single 2. Married 3. Divorced 4. widowed 5. Cohabiting
4. Employment status	1. Employed 2. Self employed 3. unemployed
5. Mothers education	1. none 2. Primary school education 3. Secondary school without grade 12 4. Grade 12 5. Tertiary education
6. Number of children	1. One 2. Two 3. Three 4. Four 5. More than four
7. Citizenship of mother	1. South African 2. Lesotho 3. Zimbabwe 4. Somalia 5. Other

Annexure E: Informed Consent Form

Informed Consent

I am a post graduate student at the University of South Africa (UNISA). As part of my studies I will be conducting a research whose purpose is to find out about the factors that contribute to high HIV positivity in children aged three to eighteen months.

You are therefore requested to participate because you meet the criteria for this study. You will be requested to fill the questionnaire with the help of the researcher and/ or also have some interviews. The interviews will be audio recorded without using your name or that of your baby and will last about 30 minutes. Participation is voluntary and you can withdraw at any time you want to and there is no penalty for unwillingness to participate.

There are no anticipated risks, compensation or other direct benefits for you as a participant in this study. Your identity will not be revealed to anyone. The information gained from you will be assigned a code and you name will not be used in the reports. When the study is completed and the data has been analysed the information and the audio tapes will be destroyed.

I (name) …….. hereby agree to participate in this research. I understand that my participation is voluntary and I am free to withdraw anytime I want to without any penalty, and that my personal information will be kept confidential.

_____	_____	_____
Participant initials and surname	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Kopo ya Tumello

Ke moithuti wa University of South Africa. Ele karolo ya dithuto tsa ka ke tshwanela ho etsa dipatlisiso (research) e batlisisang mabaka a ka etsang hore sekgahla sa tshwaetso ya HIV se be hodimo baneng ba dikgwedi tse tharo ho isa hot se leshome le metso e robedi.

O kopuwa ke hona ho nka karolo dipatlisisong tsena. O kopuwa ho araba dipostso tse ngotsweng ka thuso ya mofuputso le h oba le dipuisano (interviews). Ke tla buisana le wena metsotso e 30 -45, ho utlwa maikutlo a hao ka taba eena. Puisano ya rona e tla hatiswa ka tape recorder mme ha re na ho sebelisa lebitso la hao kapa la ngwana hao la nnete. Ha o qobellwe ho nka karolo mme ha ho kotlo eo o tla e fuwa ha u ikgula dipatlisisong tsena.

Ha ho kotsi e tla o hlahela ka ho nka karolo, lebitso la hao kapa ditaba tse ka amahangwang le wena ha di na ho phatlalatswa e tla ba lekunutu. . Ditaba tse hatisitsweng ka tape di tla hlakolwa kaofela ha di report di ngotswe. Ha hona tefo bakeng sa ho nka karolo.

Nna……ke dumela ho nka karolo dipatlisisong tsena mme ke etsa hona ka boithaopo kea utloisisa hore nka nna ka tlohela neng kapa neng ha ke batla ho se kotlo le hore ditaba tsena e tla ba lekunutu.

_____ _____ _____

Lebitso le fane Mosaeno Letsatsi

_____ _____ _____

Researcher ……. Signature ……. Date

ANNEXURE F

INTERVIEW GUIDE FOR QUALITATIVE DATA

Grand tour question:

Kindly tell me about your journey through the PMTCT programme?

1. Can you tell me about the information you had about mother-to-child transmission of HIV and where you acquired it?
2. During which period (before conception, antenatal or post-natal) did you learn about your HIV positive status.
3. Can you tell me how you felt after being told about your HIV status?
4. During which period did you default your antiretroviral treatment and what were the reasons?
5. What were your reasons for deviating from the PMTCT and HIV/AIDS prevention advice that you got from the health professionals e.g taking the baby for tests at ten weeks, exclusive breast feeding, late antenatal booking, not using condoms etc.?
6. What support did you receive thorough this journey and from who?
7. What kind of support did you get from your partner.?
8. What could have been done better to make sure your child is not infected?

ANNEXURE G

EDITORS LETTER

EDITOR'S LETTER

This letter is proof of editing services provided to **Ms Selloane Phakisi** (Student Number: 42828015) in respect of her Doctoral research with the University of South Africa, as supervised by Prof ON Makhubela-Nkondo. This service was provided for purposes of enhancing both the academic integrity and scientific rigour of her study entitled:

Contributory Factors for HIV Upsurge Among Children Aged Three to Eighteen Months in Mangaung, Free State Province

As an independent academic editor, I further confirm that Ms S Phakisi's study was subjected to comprehensive (substantive) academic editing and review, language control, and technical compliance in accordance with the rigorous intensity expected in postgraduate research studies.

Ms Phakisi's preliminary research report and final drafts were subjected to the editor's manual Internet-based plagiarism check, and yielded no significant ethical impropriety concerns.

I further provided editorial support in respect of her academic supervisor's suggested corrections and recommendations in compliance with acceptable practices in research methodology.

In compliance with conventional ethical principles of research, I have undertaken to keep all aspects of **Ms Phakisi's** study confidential, and as her own individual initiative.

Sincerely.

All enquiries: TJ Mkhonto
BA Ed: North-West University, Mahikeng Campus (1985)
M Ed: University of Massachusetts-at-Boston, USA, Harbor Campus (1987)
PhD: University of Johannesburg, Aucklandpark Campus (2008)

Email: mkhonto9039@gmail.com
Cell: 076 035 2929

Signed: _____ **Date:** 09 October 2018

Dr TJ Mkhonto dd/mm/yyyy

ANNEXURE H

THE CONVENTION ON THE RIGHTS OF THE CHILD

Guiding principles: general requirements for all rights

Definition of the child (Article 1): The Convention defines a 'child' as a person below the age of 18, unless the laws of a particular country set the legal age for adulthood younger. The Committee on the Rights of the Child, the monitoring body for the Convention, has encouraged States to review the age of majority if it is set below 18 and to increase the level of protection for all children under 18.

Non-discrimination (Article 2): The Convention applies to all children, whatever their race, religion or abilities; whatever they think or say, whatever type of family they come from. It doesn't matter where children live, what language they speak, what their parents do, whether they are boys or girls, what their culture is, whether they have a disability or whether they are rich or poor. No child should be treated unfairly on any basis.

Best interests of the child (Article 3): The best interests of children must be the primary concern in making decisions that may affect them. All adults should do what is best for children. When adults make decisions, they should think about how their decisions will affect children. This particularly applies to budget, policy and law makers.

Right to life, survival and development (Article 6): Children have the right to live. Governments should ensure that children survive and develop healthily.

Respect for the views of the child (Article 12): When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account. This does not mean that children can now tell their parents what to do. This Convention encourages adults to listen to the opinions of children and involve them in decision-making -- not give children authority over adults. Article 12 does not interfere with parents' right and responsibility to express their views on matters affecting their children. Moreover, the Convention recognizes that the level of a child's participation in decisions must be appropriate to the child's level of maturity. Children's ability to form and express their opinions develops with age and most adults will naturally give the views of teenagers greater weight than those of a pre-schooler, whether in family, legal or administrative decisions.