

**BARRIERS INFLUENCING THE USE OF PREVENTION OF MOTHER-TO-CHILD
TRANSMISSION OF HUMAN IMMUNODEFICIENCY VIRUS FOLLOW-UP
SERVICES AT MANKWENG CLINICS**

BY

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DECLARATION

I, Refilwe Ramoshaba, declare that this dissertation: **Barriers influencing the use of Prevention of Mother-to-Child Transmission follow-up services at Mankweng clinics** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

Declaration by: Refilwe Ramoshaba

Signature:

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ABSTRACT

The pandemic of Human Immunodeficiency Virus (HIV) is the most severe health challenge affecting children across the world (WHO, 2010; UNAIDS, 2016a). Poor uptake of Prevention of Mother-to-Child Transmission (PMTCT) follow-up services by HIV positive mothers and their babies is a major setback in PMTCT programmes (Kalembo & Zgambo, 2012).

A qualitative approach and a cross-sectional design was applied in the study. The sample size of the study was 26 participants. Purposive sampling was used to select HIV infected mothers enrolled for PMTCT follow-up services and health care providers responsible for the implementation of the PMTCT programmes. In-depth interviews were conducted with fifteen (15) HIV infected mothers at two health facilities. Two Focus Group Discussions (FGDs) were conducted with eleven (11) health workers at the two health facilities. Focus groups comprised of six (6) participants from Mankweng Clinic and five (5) respondents from Mankweng Gateway Clinic.

The findings from the study reveal that the majority of the respondents were aware of Mother-to Child Transmission (MTCT), but lacked knowledge and understanding about how a mother can transmit HIV to her child during pregnancy, labour and breastfeeding. The findings also show that the participants had insufficient knowledge about feeding practices advised to them by health care workers at health facilities. The majority of the participants were breastfeeding and understood the nutritional benefits of breastfeeding and treatment adherence. However, participants fail to adhere to exclusive breastfeeding, most of the participants were not aware of the required duration for a mother to exclusively breastfeed her child. The majority of the participants showed little understanding of the danger of continued breastfeeding, and lacked awareness of the risks involved in replacement feeding.

The majority of the respondents pointed out that people living with HIV are treated badly in the community. However, the majority of the participants did not personally experience stigma or discrimination. Cultural beliefs about postnatal PMTCT follow-up practices hinder the success of the PMTCT programmes. The majority of the participants believe that their culture does not allow mothers to follow exclusive breastfeeding and exclusive formula feeding.

Furthermore, the findings show that the majority of the respondents were able to disclose their HIV status to their partners and their families and that it was easier for most of the participants to negotiate for safer sex practices. The findings further show that most participants were not well supported in terms of information about feeding practices at health facilities. Most of the participants described the information that they received from health workers about PMTCT practices as insufficient. The findings also showed that there are shortages of staff and space at health facilities.

Educational and awareness programmes need to be developed or strengthened on health risks. Further health education need to be conducted for mothers, and they should be counselled individually during clinic visits about the importance of exclusive breastfeeding and exclusive formula feeding in the first six months of their children's lives. The researcher also recommends that more staff should be appointed in order to alleviate shortages of health workers.

ACRONYMS

| | |
|--------|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ANC | Antenatal Care |
| ART | Antiretroviral therapy |
| ARV | Antiretroviral |
| AZT | Zidovudine |
| FGD | Focus Group Discussions |
| HAART | Highly Active Antiretroviral Therapy |
| HIV | Human Immunodeficiency Virus |
| MDG | Millennium Development Goal |
| MTCT | Mother to Child Transmission |
| NVP | Nevirapine |
| OHCHR | Office of the United Nations High Commissioner for Human Rights |
| PCR | Polymerase Chain Reaction |
| PMTCT | Prevention of Mother to Child Transmission |
| SANAC | South African National Aids Council |
| TB | Tuberculosis |
| UNAIDS | United Nations Programme HIV/AIDS |
| UNICEF | United Nations Children's Fund |
| VCT | Voluntary counselling and testing |
| WHO | World Health Organization |

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CHAPTER ONE: ORIENTATION TO THE STUDY

1. 1. Introduction

The pandemic of Human Immunodeficiency Virus (HIV) is the most severe health challenge affecting children across the world (Department of Health, 2013b; WHO, 2010; UNAIDS, 2016a). The devastating source of HIV infection in children occurs through Mother-to-Child Transmission (MTCT). MTCT results in more than 90% of all HIV infection in children around the world (UNAIDS, 2012; UNAIDS, 2016a). It is estimated that 3.2 million children were living with HIV worldwide in 2013, and 360 000 of these children were from South Africa (UNAIDS, 2014). Global scale up of interventions to prevent MTCT has reduced new infections by 70% between the year 2009 and 2015. In 2015, approximately 1.8 million children were living with HIV worldwide (UNAIDS, 2016b). Despite the global scale up of interventions, paediatric infections of HIV still remain high.

The implementation of PMTCT programmes has become one of the most important areas of intervention that prevents the spread of HIV (Department of Health, 2013b; PMTCT interventions help prevent HIV infections from a mother living with HIV to her child during pregnancy, labour or delivery and breastfeeding (UNAIDS, 2012). In South Africa, the Department of Health introduced the PMTCT programmes in 2001, where a single dose of nevirapine was administered as an antiretroviral (ARV) prophylaxis during labour. In 2008 the procedure was updated to a dual therapy protocol that added Zidovudine (AZT) to the treatment regimen (Department of Health, 2008). Infant feeding guidelines were also revised during that period.

The aim of PMTCT programmes is to reduce the spread of HIV from mothers to their babies, but the identification and elimination of barriers that influence the use of PMTCT postnatal follow-up service has proven to be a challenge for programme planners and healthcare workers in implementing successful PMTCT programmes (Department of Health, 2013a; WHO, 2015). In the PMTCT programme, postnatal follow-up services are provided for mothers and their babies, where they undergo Polymerase Chain Reaction (PCR) HIV testing to determine whether the babies are HIV exposed or not (Department of Health, 2010). The poor uptake of PMTCT follow-up services will continue to be a problem unless the barriers are identified and

eliminated. This study, therefore, identifies barriers influencing the use of PMTCT follow-up services in Mankweng Clinics, Limpopo Province, South Africa.

1.2. Statement of the problem

The implementation of the PMTCT programmes is less efficient in many hospitals and clinics across the country (Goga, Dinh & Jackson, 2012). The poor uptake of PMTCT follow-up services by HIV positive mothers and their babies is a major challenge to PMTCT programmes (Kalembo & Zgambo, 2012). PMTCT programmes are widely implemented in the country, and the availability and coverage of their services is improving (UNICEF, 2010). However, the poor uptake of these services by mothers and their babies remain high, with close to 40% lost to follow-up within one year of starting Antiretroviral Therapy (ART) (Kalembo & Zgambo, 2012). In South Africa, 91% of women attended antenatal clinics in 2015, and only 54% attended their first visit before 20 weeks (Hall, Sambu, Berry, Giese, Almeleh and Rosa, 2016).

A mother's ability to seek PMTCT follow-up services is influenced by barriers that diminish service use, and this highlights many of the missed opportunities to PMTCT programmes (Frizelle, Solomon & Rau, 2009). Lack of awareness and knowledge is one of the individual factors that impact negatively on the up-take of PMTCT follow-up services. PMTCT programmes around the country are hugely affected by the level of awareness and knowledge of HIV and Acquired Immune Deficiency Syndrome (AIDS) as well as MTCT, which consequently increases HIV prevalence among children (Kalembo & Zgambo, 2012).

Postnatal follow-up services in PMTCT programmes provide treatment for HIV infected mothers and their babies through the provisions of continuous post-test counselling and support for exclusive breastfeeding, where infants are required to be fed only with breast milk, with no exception of any other liquids or solids foods. Without these interventions, infants who are not able to benefit from these services will likely be infected with HIV, and probably die before the age of two years (Kalembo & Zgambo, 2012; Hazemba, Ncama & Sithole, 2016).

Furthermore, healthcare infrastructure and shortages of staff impact on the general service delivery of PMTCT programmes. Many PMTCT programmes have weak healthcare systems that include poor infrastructure and shortage of health workers in

South Africa (UNICEF, 2009). The standard of care and capacity of health facilities is affected and even more problematic when there is insufficient supply of PMTCT drugs or testing kits (Kalembo & Zgambo, 2012).

A study conducted in the Eastern Cape showed that the shortage of PMTCT staff and space for counselling were some of the reasons leading to the loss of clients in the PMTCT programmes (Peltzer, Mosala, Shisana, Nqeketo & Mngqundaniso, 2007). Working conditions and lack of space for confidential counselling impact on PMTCT programming because the lack of privacy during delivery prevents women from disclosing their HIV status (UNICEF, 2009). The low uptake of PMTCT will continue to be a problem as long as these conditions are avoided.

Research throughout the years have demonstrated more effective ways of preventing new paediatric infections in an effort to achieve the Millennium Development Goals (MDGs) (UNAIDS, 2012). However, two goals, number 5 and 6 of the MDGs which focus on reducing maternal mortality by three-quarters and mortality of children aged under-five by two-thirds, respectively were not achieved in sub-Saharan Africa. Sustainable Development Goals (SDGs) will be placed in action to tackle these challenges when they replace the MDGs, which expired in 2015 (United Nations, 2016).

This study is guided by goal 3 of the SDGs, which pinpoints the importance of combating HIV and other PMTCT challenges in HIV affected countries around the world, more especially in Sub-Sahara Africa. The following indicators are focal points for monitoring the progression of goal 3 of SDGs: Reduce the global maternal mortality ratio to less than 70 per 100,000 live births by 2030; End preventable deaths of new born and under-five children by 2030; and End the epidemics of AIDS by 2030 (Bose & Hawkes, 2015). PMTCT goals are committed to developing norms and standards for the effective interventions, and for supporting countries in order to scale up the quality of PMTCT services (WHO, 2010). Hence, the study intends to identify barriers that influence the use of PMTCT follow-up services in Mankweng Clinics.

1.3. Aim of the study

The aim of the study is to explore barriers influencing the use of PMTCT follow-up services in Mankweng Clinics.

1.3.1. Objectives of the study

The following are objectives of the study:

- To identify the severity of predisposing factors (stigma, knowledge and awareness) on the use of PMTCT follow-up.
- To determine the effect of enabling factors (socio-economic status, social support) on the use of PMTCT follow-up services.
- To establish the influence of need factors (perception towards illness and health service) on the use of PMTCT follow-up services.
- To ascertain the effect of the healthcare system (infrastructure, shortage of staff) on the provisions of PMTCT follow-up services.

1.4. Operational definitions

Barrier: A structure or object that prevents access or progress, or impedes free movements (Oxford Dictionary of Sociology, 2014).

Follow-up: Follow-ups are services provided for mothers to bring their infants to the health facility/clinic for postnatal check-ups, where they will undergo PCR HIV testing (Department of Health, 2013b).

Mother-to-Child HIV Transmission (MTCT): This is a process where HIV is spread from a mother to her child through the placenta during pregnancy or through blood contamination during childbirth or through breast-feeding after birth.

Prevention of Mother-to-Child HIV Transmission (PMTCT): This is a programme that includes activities that prevent women from being infected by the HIV virus, preventing unwanted pregnancy in mothers, preventing the transmission of the virus to the baby during pregnancy, labour and delivery or breastfeeding and the provision of care and support.

Use: The act or practice of employing something (Oxford Dictionary of Sociology, 2014).

1.5. Significance of the study

The significance of this study is to add knowledge regarding social barriers contributing to loss of follow up to the PMTCT programme. The study provides an understanding of these barriers and how they hinder the success of the PMTCT programme. The study will inspire management to find means to eliminate these barriers at clinics. The findings will assist programme planners and health care providers in terms of providing help for mothers during and after Antenatal Care (ANC). The study findings will also provide insight for the Department of Health, policy makers and programme planners to achieve the goal of providing effective PMTCT services through the training of health workers and ensuring that women benefit from these interventions.

1.6 Chapter outline

This dissertation consists of six (6) chapters. The study captures the implementation of PMTCT follow-up services by looking at the lived experiences of HIV positive mothers and health care providers in Mankweng Clinics, Limpopo Province.

Chapter 1: The chapter focuses on the introduction, research problems, purpose and the significance of the study.

Chapter 2: This chapter focuses on the literature review which includes a general overview of HIV and PMTCT follow-up services and barriers influencing the use of these services.

Chapter 3: The chapter presents the research methodology, problem statement, research design and methods, sampling techniques, data collection methods, ethical considerations, data analysis and trustworthiness of the study.

Chapter 4: This chapter discusses data analysis and findings from in-depth interviews.

Chapter 5: This chapter discusses data analysis and findings from focus group discussions.

Chapter 6: In this chapter, summary, conclusion and recommendations based on the findings are presented.

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction to HIV

In South Africa HIV is a prominent health concern, and continues to have a significant impact on women and children (Department of Health, 2010, UNICEF, 2012). The virus weakens the human immune system by destroying the cells which play a significant role in coordinating both antibody-mediated and cell-mediated immune response. If the functions of these cells are impaired or destroyed, the immune system weakens and AIDS and other diseases occur (WHO, 2010).

2.2. HIV prevalence in South Africa

South Africa has more people living with HIV than any other country in the world (Department of Health, 2012; SANAC, 2016; UNAIDS, 2016b). In 2009, South Africa was reported as having the largest population of HIV infected people in the world, with a total of 5.6 million (Department of Health, 2010). It was estimated that 12.2% of the population (6.4 million people) were HIV positive in 2012, which is approximately 1.2 million more people living with HIV than in 2008 (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios & Onoya, 2014). In 2015, 6.19 million people in South Africa were living with HIV (Statistic South Africa, 2015; UNAIDS, 2016a).

The prevalence of HIV in South Africa varies by provinces, with rates reaching higher proportions in KwaZulu-Natal, Mpumalanga, Free State, and the North West. Limpopo (22.3%) is one of the provinces which recorded the lowest HIV prevalence rates, along with Western Cape (16.9%) and Northern Cape (17.8%) in 2013 (Shisana *et al*, 2014). However, there is still work to be done to reduce new infections among women and children.

2.3. Limpopo provincial antenatal HIV prevalence

In 2013, the Limpopo provincial HIV prevalence amongst antenatal women was estimated at 22.3%. The overall provincial HIV prevalence in Limpopo has increased slightly from 21.9% in 2010 to 22.1% in 2011 and 22.3% in 2012. Meanwhile, HIV prevalence has shown significant change for most of the districts. Changes in HIV prevalence rates were seen in Vhembe District, which has consistently recorded the lowest HIV prevalence, from 17.0% in 2010 to 14.6% in 2011 and 17.7% in 2012 (Department of Health, 2013b).

Sekhukhune had similar trends from 20.2% in 2010 to 18.9% in 2011 and 23.0% in 2012. Waterberg District on the other hand, continues to record the highest HIV prevalence in the province, although a remarkable decrease of 3% from 30.3% to 27.3 % was noted in 2012. Capricorn District carries the heaviest HIV burden among 15 to 49 years old pregnant women, with an HIV prevalence estimate of 23.8% (Department of Health, 2013b).

2.4. The Prevention of Mother-to-child transmission programme

PMTCT programmes are provided in hospitals and public clinics to prevent HIV from a mother to her child (UNAIDS, 2012). The programmes include prevention activities that help prevent women from being infected with HIV, prevention of unwanted pregnancy and the provision of care and support for all mothers and their children (UNAIDS, 2012). Children around the world are infected by HIV through their mothers, and this accounts for more than 10% of new HIV infections and for over 90% of new infection worldwide (UNAIDS, 2012). In the absence of any intervention, about 20% to 45% of infants may be infected with HIV, which may result in mortality (WHO & UNICEF, 2007).

The process of MTCT occurs when HIV is transmitted from a mother, who is infected, to her baby, through the placenta during pregnancy, or through blood contamination during childbirth, or through breast-feeding after birth (UNAIDS, 2012). The risk of MTCT ranges from 20% to 45% (WHO & UNICEF, 2007). During pregnancy the risk ranges from 5-10%, 10-20% during labour and delivery, and 10-20% through mixed infant feeding (WHO & UNICEF, 2007). With specific interventions, the risk of MTCT can be reduced to less than 2%, and to 5% or less in breastfeeding populations.

The PMTCT programme reduces MTCT by improving access to PMTCT services that include uptake of HIV testing and counselling and ensuring the use of ART as prophylaxis to those mothers who are infected by HIV (Department of Health, 2013a; WHO & UNICEF, 2007). In the antenatal period, PMTCT includes counselling and testing for HIV, and the supply of ARV prophylaxis for sero-positive women. During delivery, elective caesarean section and other obstetrical interventions aimed at the minimisation of the infant's contact with maternal blood and cervical-vaginal secretions reduce the risk of transmission. In the postnatal period, the PMTCT

programme includes continued follow-up services and treatment for HIV positive mothers and their children, especially for the first 18 months of the child's life. Treatment includes ARV prophylaxis to the infant and complete avoidance of breastfeeding (Department of Health, 2010).

2.4.1. PMTCT postnatal follow-up services

The PMTCT programmes identify HIV positive mothers and their infants and register them for follow-up post-natal visits within 3 days. Mothers will bring their infants to health facilities to undergo PCR HIV testing, in order to determine whether or not they have been infected. Infants should undergo weekly visits to the health facilities during their first month of life. Thereafter, the infants will undergo monthly visits until the age of twelve months, and three monthly visits between the ages of 12 months and two years. They will go through tests and if found to be HIV positive, he or she will urgently be referred for early use of ART (Department of Health, 2010).

HIV exposed infants will be given vaccinations against HIV at six, ten and 14 weeks of age and at nine and 18 months. At six weeks of age, HIV exposed infants are required to start with 2.5 ml of co-trimoxazole daily and test for HIV. If the PCR test for the infant is negative, co-trimoxazole is stopped for the infant who is fed with formula milk (Department of Health 2010; WHO, 2010). For seven days, a single dose of Nevirapine (NVP) and AZT is given to infants whose mothers had started taking AZT for prophylaxis at 28 weeks gestational age, had received a single dose of NVP during labour or AZT for 28 days, and demonstrates the following indications:

- Mother received less than four weeks of AZT during pregnancy;
- Mother received less than four weeks of Highly Active Antiretroviral Therapy (HAART) during pregnancy; and
- Mother received only a single dose NVP.

Infants whose PCR test results are positive are quickly referred for ART and are further investigated for any changes. Children who are breast fed and whose mothers are on lifelong ART are only given NVP for the first six weeks of life and co-trimoxazole from six weeks until breastfeeding is stopped and when the child has tested HIV negative. Children who are formula fed, on the other hand, only receive NVP for the first six weeks of life and co-trimoxazole from six weeks (Department of Health, 2010).

Mixed feeding in the first six months of life is discouraged since it is associated with a high rate of transmission (WHO, 2010; UNAIDS 2012). Therefore, HIV-positive mothers will be given a choice to either exclusively breastfeed for six months or exclusively formula feed. Mothers who cannot afford to practise replacement feeding are advised to exclusively breastfeed their children in the first six months of life, then introduce complementary foods thereafter, and continue breastfeeding for the first 12 months of life (Department of Health, 2010). However, to be able to successfully implement these policies, HIV positive mothers need to bring their infants for follow-up appointments at their Primary health care centres/clinics. They will be informed about recommended feeding practices and alternative feeding options (WHO, 2010; UNAIDS, 2012; UNICEF, 2012).

2.4.2. The importance of PMTCT follow-up services

Since the HIV prevalence among pregnant women in 2009 was 29.3%, almost 360,000 babies born are exposed to HIV every year (Department of Health, 2013b). It is important for HIV infected mothers to bring their infants to health facilities for follow-up visits (WHO, 2010; Department of Health, 2010). Testing for HIV during follow-up visits determines whether their babies have been infected with the virus or not. Once HIV exposed infants are identified, they can receive the appropriate care, feeding options and other related services during PMTCT follow-up visits (Department of Health, 2010). HIV-exposed infants whose mothers do not access the PMTCT programme experience a delay in diagnosis and are often only identified when they experience severe morbidity or death (Woldesenbet, Goga & Jackson, 2010).

The increasing loss of follow-up is a major set-back in sub-Saharan Africa (WHO, 2010; Department of Health, 2013b). Estimated between 20-28% loss of follow-up during ANC, up to 70% of mothers are lost to follow-up four months after delivery and close to 81% at six months after delivery (UNAIDS, 2010; WHO, 2011). A study done in Nigeria by Rawizza, Meloni and Oyeboade (2012) has revealed that 10 078 (52%) clients from 19,303 women entering PMTCT care during the antenatal period completed the entire cascade of services. However, in prenatal care, only one infant's follow-up visit was made.

Another study of 3030 participants in Malawi shows 472 (16%) participants who were breastfeeding, of which, 577 (20%) missed a scheduled clinic appointment. In the same study, 229 (40%) of those lost to follow-up were successfully traced, of whom 10 (4%) had died. Of the 219 women found alive, 118 (54%) had stopped taking ARV drugs, 67 (30%) had self-transferred to another ART clinic, 13 (6%) had collected drugs from other sources, 9 (4%) had treatment interruptions and 12 (5%) had other outcomes (Tenthani, Haas, Tweya, Jahn, Van Oosterhout, Chimbwadira, Chirwa, Ng`ambi, Bakali, Phiri, Myer, Valeri, Zwahlem, Wandeler & Keiser, 2014).

In the current South African context, reports indicate that continuity of PMTCT care is compromised because of ineffective recording systems in hospitals and clinics (Department of Health, 2013b). In other cases, mothers do not report their status to healthcare workers; they do not enquire about their status and that of their infants (Woldesenbet *et al*, 2010).

Infants exposed to HIV in South Africa had increased between 2008 and 2011(Barron, Pillay, Doherty, Sherman, Jackson, Bhardwaj, Robinson & Goga, 2013). However, there was an improvement in PCR testing coverage and PCR positivity rates for early infant HIV diagnosis in 2011 (see table 2.1 below).

| Year | No. of HIV exposed infants | No. (%) of HIV-exposed Infants tested with PCR | No. (%) of Infants with Positive PCR Results |
|------|----------------------------|--|--|
| 2008 | 240 739 | 88 006 (36.6) | 8 405 (9.6) |
| 2009 | 232 227 | 120 354 (51.8) | 7 481 (6.2) |
| 2010 | 241 645 | 144 501 (59.8) | 6 293 (4.4) |
| 2011 | 241 645 | 170 030 (70.4) | 4 770 (2.8) |

(Barron *et al*, 2013)

Table 2.1 Infants exposed to HIV in South Africa

The above table demonstrates the burden of under-five HIV exposure and the need for early infant diagnostic services. This propose that there is a need for follow-up services to reduce infant HIV-exposure and child mortality in South Africa. Follow-up services are important for mothers and their HIV exposed babies to prevent transmission and optimises maternal and infant outcome (UNAIDS, 2010; WHO,

2011). More than one-third of infants never return for follow-up in South Africa, and more than 70% are lost to follow-up by 4 months of age (UNAIDS, 2012).

In the Limpopo Province, infants exposed to HIV had shown a significant improvement between 2009 and 2010, with 42.1% PCR testing coverage in 2009 and 50% PCR testing coverage in 2010, and 8% PCR positivity rates in 2009 and a PCR positivity rates of 5,5% in 2010. However, despite these changes, the province still lacks consistency in optimising follow-up care for mothers and their babies (Woldesenbet et al, 2010). Lack of child care management to identify HIV exposed infants is one of the many challenges in providing PMTCT follow-up care (Woldesenbet et al, 2010; UNAIDS, 2010; WHO, 2011).

Compliance to medications and clinic follow-up is very important in preventing postpartum HIV transmission by improving the overall health outcomes of both the mother and the infant (UNICEF, 2009; UNAIDS, 2016b). Follow-up services identify early diagnosis of HIV infections and initialise ARVs medications for infected children. Failure to comply with ARV medications and prophylaxis as well as follow-up to clinic visits for medication re-supply and other PMTCT services disrupt the interventions in the course to eliminating paediatric HIV infections (Department of Health, 2010).

2.5. Prevention of Mother-to- Child Transmission policies and guidelines

2.5.1. The South African Antiretroviral Treatment Guideline 2013

According to the Department of Health (2013a), the national PMTCT Policy and guidelines aims at providing guidance towards a reduction in vertical transmission of HIV. The PMTCT policy recognises four elements of PMTCT to prevent HIV among women and children. These include: primary prevention of HIV, especially among women of childbearing age; preventing unintended pregnancies among women living with HIV; preventing HIV transmission from a woman living with HIV to her infant, and providing appropriate treatment, care and support to women living with HIV and their children and families. The National PMTCT programme aims to ensure:

- Primary prevention of HIV, especially among women of child-bearing age;
- Integration of PMTCT interventions with basic ANC, sexual and reproductive health, child and adolescent health and Tuberculosis (TB) services;

- Strengthening postnatal care for the mother-baby pair; and
- Provision of an expanded package of PMTCT services.

These services include routine offer of HIV counselling and testing for all pregnant women attending ANC if symptom screen is positive; the provision of provider-initiated counselling and testing services in the context of PMTCT, in facilities offering routine ANC; involvement of the partner and the family in order to ensure a comprehensive approach; the provision of other appropriate treatments such as those for opportunistic infections management and nutritional support; and the provision of psychosocial support to HIV-positive pregnant women (Department of Health, 2013a).

Furthermore, the services include the provision of quality, objective, and individualized counselling on safe infants; feeding practices for HIV-positive women in health facilities offering routine ANC, through trained lay counsellors and health care professionals; strengthened obstetric practices which reduce MTCT; the provision of antiretroviral prophylaxis to infants, initiated soon after birth and continued for 6 weeks; integrated follow-up of infants born to HIV-positive women through routine child health services and the Integrated Management of Childhood Illness Strategy; early infant HIV testing at 6 weeks of age for all infants born to HIV-positive women irrespective of feeding option; testing of all HIV-exposed infants at any age from birth if symptomatic of HIV, including all premature and low birth weight infants who are expected to have a higher incidence of transmission; and strengthening of community-based household and door-to-door activities to educate and enhance the utilisation rates and effectiveness of health programs. The 2013 guidelines recommend that countries follow option B+, where triple-drug antiretroviral regimen should be taken throughout pregnancy, delivery and breastfeeding, continuing for life, regardless of clinical stage (Department of Health, 2013a).

2.6. Literature identifies the following barriers influencing the use of PMTCT follow-up services

2.6.1. Level of knowledge and awareness of MTCT and the PMTCT programme

The PMTCT programmes around the world are hugely affected by the level of awareness and knowledge, which consequently increases the prevalence of HIV infections in children (Asefa & Beyene, 2013; WHO, 2015; Abteu, Awoke & Asrat, 2016). Lack of awareness and knowledge about HIV, MTCT and PMTCT programmes impact negatively on the use of PMTCT follow-up services (Asefa & Beyene, 2013; Department of Health, 2013b; UNAIDS, 2016a). This is because awareness and knowledge of PMTCT programmes and its activities play a significant role in providing relevant information for mothers about the importance of PMTCT follow-up services, for them to be well informed about the risk of MTCT and other reproductive health issues (Department of Health, 2010).

Knowledge about HIV transmission is important in preventing the spread of HIV, especially from mothers to their children (Department of Health, 2013b). An increased knowledge and awareness about PMTCT practices, MTCT and HIV can have a positive influence on the use of PMTCT follow-up services (Department of Health, 2013b; Kalembo & Zgambo, 2012; UNAIDS, 2016a). However, most HIV infected mothers lack sufficient knowledge of PMTCT practices and continuously overlooks the importance of bringing their babies for follow-up visits (Woldesenbet *et al*, 2010).

Although basic knowledge about HIV and AIDS seems to be increasing in most communities, there is insufficient knowledge about MTCT among mothers enrolled for PMTCT follow-up services (Department of Health, 2013b, UNAIDS, 2016). A study of 202 women participants identified at least 94% of the participants who have knowledge about HIV and AIDS. The study shows 48% of participants who were not aware of any means to prevent MTCT (Rogers, Meundi, Amma, Rao, Shetty, Antony, Sebastian & Shetty, 2006). A similar study by Asefa and Beyene (2013) discovered that all interviewed participants were aware of HIV transmission, but only 60.7% were aware of the risk of MTCT. The study shows that the proportion of women who were fully knowledgeable on timing of MTCT was 11.5%.

Another study conducted by Peltzer, Masala, Dana and Fomundam (2008) identified 36.7% of participants who believed that a baby born to an HIV-positive mother will also be infected. This was further supported by Bajunirwe and Muzoora (2005), revealing that 12% of the participants lacked knowledge about the possibility of the virus being passed on to an unborn baby, and at least 8% of the participants did not know how the virus can pass from a mother to a child. However, a study by Peltzer *et al* (2007) has shown significant improvement in knowledge about MTCT, revealing that 81% of pregnant women, mothers or mother-in-law (74%) and partners or husbands (74%) knew that HIV can be transmitted to an unborn child from their mothers.

Knowledge and awareness about PMTCT follow-up services and its practices is vital to ensure the success of the PMTCT programme (Kalembo & Zgambo, 2012). Knowledge and awareness about feeding practices play a significant role in reducing the spread of HIV from a mother to a child especially during breastfeeding. It is important for mothers to know about feeding methods after giving birth (WHO, 2015). Most mothers lack the knowledge about exclusive breastfeeding. They lack awareness of the risks involved in replacement feeding (Department of Health, 2013b).

Mothers have high level of knowledge about HIV transmission and MTCT, but they are unable to correctly explain exclusive breastfeeding or mixed feeding (Hazemba *et al*, 2016). This proves that though many women have some general knowledge about HIV, they tend to have very limited knowledge about MTCT and PMTCT strategies, and this limits the success of PMTCT programmes. A study carried out in Lagos, Nigeria indicates that the majority of women (89.9%) had good knowledge of the mode of HIV transmission, however specific aspects of PMTCT was poor. Close to half of the study participants (41.7%) were not aware of the association between breast milk and HIV transmission (Ekanem & Gbadegesin, 2004).

HIV positive mothers need adequate information in order to make the right decision about their health and that of their babies. This information can be obtained from, among others, health workers in the PMTCT programme and from other affiliations like mother-to-mother programmes (Department of Health, 2008). Most women are aware of PMTCT practices through mass media and friends. A study conducted in

Polokwane by Maputle and Jali (2008), found that mothers have knowledge about MTCT through breastfeeding from the hospital and from lay referral.

However, patients still lack sufficient and adequate information regarding MTCT even with the support from the PMTCT and m2m programmes. Even when mothers are counselled, they still lack adequate knowledge about MTCT and fail to understand the importance of attending PMTCT follow-up services or bringing their babies for follow-up visits. A study of 2930 participants in Malawi (Tenthani *et al*, 2014) shows 10% of participants who claim that the reason for stopping taking ART is because of a lack of understanding about the initial ARV education session. Patients had inadequate information of PMTCT services, given that they could not recall the information communicated to them during counselling. Clients only made use of counselling services once during their first visit and not on successive visits, suggesting limited relationship between providers and clients (Frizelle *et al*, 2009). Findings by Moth, Ayayo and Kaseje (2005) in Kenya indicated that 68% of the participants received less than 5 minutes of post-tests counselling, 21% had 5–10 minutes, and only 10.7% had more than 10 minutes of post-tests counselling. In the study, poor monitoring of PMTCT services by health workers was blamed for poor follow-up services in PMTCT programmes because health facilities did not have registered information on HIV positive mothers who enrolled in PMTCT but failed to return for follow-up care.

Lack of adequate information about PMTCT follow-up services contribute to a lack of understanding of the importance of the therapy, which leads to non-adherence to treatment instructions (Kalembo & Zgambo, 2012). A study conducted in Mpumalanga by Peltzer, Phaswane-Mafuya, Ladzani, Davids, Mlambo, Phaweni, Dana and Ndabula (2009) found maternal NVP consumption and administration of NVP to the baby were associated with a mother's knowledge about HIV and PMTCT. Furthermore, a study conducted by Peltzer *et al* (2009) revealed that 74.2% of the participants knew that HIV can be transmitted to the child during delivery, while 77.9% knew that it can also be transmitted through breastfeeding. The study found that 7.7% of the mothers did not know that Azidothymidine (AZT) and NVP reduced the chances of the child contracting HIV, and they did not even know how and when to take the medication.

A study in Addis Ababa, Ethiopia on prophylactic treatment uptake and compliance with recommended follow-up among HIV-exposed infants (Shargie, Eek and Abaychew (2011) found 42.2% adherence among children whose mothers had primary education; 41.0% among children whose mothers had secondary education, and 6.0% among children whose mothers were unable to read and write. However, several studies demonstrate high level of knowledge about MTCT and PMTCT among women with no formal education (Abiodun, Ijaiya, and Aboyeji, 2007; Abteu *et al*, 2016). A study conducted by Abiodun *et al* (2007) indicated that 74% of respondents with no formal education were aware of MTCT of HIV.

Moreover, to close the gap in knowledge about HIV and MTCT, health personnel who are responsible for conducting and implementing the PMTCT programme should emphasize the importance of MTCT during counselling to empower mothers with the relevant information. The use of media and awareness campaigns will help promote health education about MTCT for all women who are enrolled in PMTCT follow-up services (Chama, Udo & Omotora, 2010).

Lack of knowledge and awareness promote issues such as stigma and discrimination, and plays an unexpected role that allows stigma to continue (Frizelle *et al*, 2009). Most people do not understand the difference between HIV and AIDS, how the disease progresses, and life expectancy of people living with HIV. This is because they fear death and therefore stigmatise or discriminate individuals suspected to have HIV, even though they know that HIV is not transmitted through casual contact (UNAIDS, 2012).

2.6.2. Stigma and discrimination

Stigma of HIV refers to unfavourable attitudes directed towards people living with HIV. Discrimination is the treatment of an individual or group with prejudice (SANAC, 2015; UNAIDS, 2015). Stigmatisation emphasises attitude, while discrimination emphasises an act or behaviour. It is an expression, either purposively or unintentionally (OHCHR & UNAIDS, 2007). Stigma and discrimination are socially constructed and reinforces prejudice behaviours in the society. Fear of stigma and discrimination was found to be the most significant barrier to the use of PMTCT follow-up services among HIV positive mothers (Department of Health, 2013b; Kalembo & Zgambo, 2012; UNAIDS, 2015). Fear of stigma and negative reaction or

conditions influence mothers from utilising PMTCT services (Frizelle *et al*, 2009; SANAC, 2015; UNAIDS, 2015).

Fear of stigma and discrimination from the community, family, and health workers is the most occurring barriers to the use of PMTCT follow-up services. This finding has evidence in multiple reports and studies (Department of Health, 2013b; Kalembo & Zgambo, 2012; SANAC, 2015 UNAIDS, 2015). Stigma and discrimination of people living with HIV and AIDS serves as a strong obstacle to people seeking HIV-related care (Department of Health, 2013b; UNAIDS, 2015). Lack of knowledge and unawareness has been found to often play a major role in spreading stigma in South African communities. In 2005 the national HIV/AIDS household survey in South Africa found that 29% of South Africans stated that they would not buy food from a person who has HIV and 20% stated that HIV-positive children should be kept separate from other children to prevent infection (Shisana *et al*, 2005). This significantly outlines the level of knowledge and awareness about how HIV is transmitted.

Stigma and discrimination have consequences that people fear and therefore keep them from seeking HIV information, adopting preventive behaviour, getting tested, disclosing their status and adhering to treatment (Department of Health, 2011; SANAC, 2015). Most mothers have difficulties when it comes to disclosing their HIV status or utilising PMTCT follow-up services because they fear that somehow their status will be exposed (Kalembo & Zgambo, 2012; Adedimeji, Abboud, Merdekios and Shiferaw, 2012).

There is a clear relationship between fear of stigma and disclosure of HIV status and loss of follow-up in the PMTCT (Department of Health, 2013b; Kalembo & Zgambo, 2012; Mitiku, Arefayne, Mesfin & Gizaw, 2016). Women fear the reactions of a partner or husband if they disclose their HIV status. They fear losing their husbands and the response of other family members, believing that they will be ignored, isolated, financially excluded or openly disgraced and blamed (Frizelle *et al*, 2009). This is supported by a study of 199 participants in Soweto, South Africa that women do not disclose to their partners because they fear rejection from both their partners and their families. Among 31 experiences of disclosure by females in Johannesburg (South Africa), 93.5% of the participants had voluntarily disclosed their status to at

least one person (Varga, Sherman & Jones, 2006). There are different types of stigma that result into poor uptake of PMTCT follow-up services, namely, internal and external stigma (UNAIDS, 2015).

Internal or self-stigma occurs when individuals or HIV-positive mothers decide not to seek HIV care and treatment because they feel responsible or blame themselves by internalizing negative perceptions about people living with HIV (SANAC, 2015). HIV and AIDS make people feel less about themselves, and blame themselves for acquiring the virus (Department of Health, 2013b; UNAIDS, 2015). A mother avoids seeking PMTCT follow-up services and fears HIV testing because she believes it might happen that she may be HIV positive (Department of Health, 2013b).

External stigma occurs when an HIV-positive mother decides not to seek HIV care and treatment because she fear negative perceptions from the family or partner, and the community (SANAC, 2015). HIV-positive mothers avoid PMTCT follow-up services and HIV treatment because they believe women living with HIV in their community experience stigma and discrimination when they use HIV-related services (Kalembo & Zgambo, 2012). Women are unwilling to test because they fear negative reactions from family; more especially their partners, and fear being discriminated against by their community (Adedimeji *et al*, 2012; SANAC, 2015). When they disclose their HIV-positive status, most women are physically or verbally abused or socially isolated (Kalembo & Zgambo, 2012; Mitiku *et al*, 2016).

There is a visible relationship between gender and stigma (SANAC, 2015). Women experience stigma more than men. They are perceived as carriers of the illness in other cultures and AIDS is perceived as a woman's disease. They are often blamed by their partners, families or communities for not properly raising their HIV-positive sons and daughters (Frizelle *et al*, 2009). Women and children are more disadvantaged than men to abandonment and violence as a result of their HIV status. Most children experience stigma because they live in an AIDS-affected households (Department of Health, 2013b; Frizelle *et al*, 2009; Kalembo & Zgambo, 2012).

2.6.3. Gender inequality and male involvement

The PMTCT programmes in South Africa are some of the key efforts that promote gender equity (Department of Health, 2013a; SANC, 2016). Gender inequalities

make it difficult for women to access and adhere to HIV prevention, care and treatment. Women in South Africa confront a number of gender-based issues when they use PMTCT follow-up services (Frizelle *et al*, 2009; Kalembo & Zgambo, 2012). HIV is the leading cause of death and disease in low and middle-income countries worldwide, and sub-Saharan Africa is reported to have about 60% of women living with HIV (UNAIDS, 2012, WHO, 2015).

Women are more disadvantaged than men in terms of HIV infections (Department of Health, 2013b). In many developing countries, women do not make independent choices about their own health or that of their babies. For example, if a male partner disagrees with his female partner's decision to test for HIV then she is unlikely to undergo HIV testing (Frizelle *et al*, 2009).

A study conducted by Falnes *et al* (2011) confirms that women are unable to negotiate sex or safe sexual practices with an HIV positive partner. They refuse to ask their partners to use a condom despite the knowledge that they receive from clinics about condoms, claiming to fear reaction from their partners. They practise unprotected sex and continue breastfeeding their infants to avoid exposing their HIV status when they use formula milk to feed their infants. They are concerned about the treatment, inequity and the tension that may result in the relationships with their partners.

In most cases, mothers who are enrolled for PMTCT follow-up services are likely to go against instructions they receive from health professionals (Department of Health, 2013b). Adherence to infant feeding practices affected since infant feeding is often done in public settings where it is evident to neighbours and family members. Mothers risk disclosing their HIV status if they decide to follow the instructions from doctors or nurses. In this case, they are forced to breast feed their infants to avoid disclosure of their status (Falnes *et al*, 2011).

Most mothers are unable to access PMTCT follow-up services because their partners control the household finances or transportation resources (Frizelle *et al*, 2009). It is almost impossible for mothers to access PMTCT follow-up services without disclosing their HIV status to their partners/husbands (Frizelle *et al*, 2009; Mitiku *et al*, 2016). A mother's decision not to disclose her HIV-positive status to her partner/husband is mostly influenced by fear. They fear discrimination,

abandonment, rejection, divorce and physical violence from their partner. Therefore, avoid PMTCT follow-up services spouses (Kalembo & Zgambo, 2012).

Involving men to participate in PMTCT activities is important to the PMTCT programme. This influences women to use PMTCT follow-up services. If both partners are involved, they can both get tested and know their status to ensure and improve their baby's chance of a healthy survival (UNAIDS, 2012). Male involvement is when men choose to go to the clinic with their female partners to support them by getting involved in activities such counselling and testing with their partner (Frizelle *et al*).

Most women do not feel empowered to ask their partners to undergo an HIV test because they fear the risk of disclosing their HIV status to their partners. Women feel burdened by clinics' request that their partners be tested. The need for mother to discuss with their partner whether to undergo HIV testing or not is also a factor that leads to rejection of HIV testing (Falnes *et al*, 2011).

Up-take of Voluntary counselling and testing (VCT) is relatively good among women, but not among their male partners/husbands. If a male does not know his HIV status or about PMTCT, his female partner is less likely to adhere to PMTCT strategies or to engage in PMTCT programmes. HIV-positive women whose partners attend VCT are more likely to use treatment and more likely to adhere to infant-feeding method that they have selected (Department of Health, 2010; Frizelle *et al*, 2009).

South African men do not involve themselves actively in reproductive healthcare with their partners and are not typically involved in consulting with their partners around family planning or antenatal issues (Frizelle *et al*, 2009). Men's involvement can influence the mothers to seeking HIV treatment, adhere to medications and clinical appointments, and remaining in care both during the pregnancy and after delivery (Department of Health, 2010).

Men's involvement plays a role in HIV prevention by employing communication among couples on HIV infections and related topics (Frizelle *et al*, 2009). However, most men are not encouraged to participate from the initial stages in the PMTCT programme, which makes it difficult for them to participate as the process continues (Morfaw, Mbuagbaw, Lehana Thabane, Rodrigues, Wunderlich, Nana and Kunda,

2013). Men's positive perceptions about the benefits of PMTCT and participation in antenatal HIV testing and counselling is very low (Frizelle *et al*, 2009). Falnes *et al* (2011) found a lower male testing rate at the antenatal clinic, at 3%, in the United Republic of Tanzania.

Knowledge about HIV, stigma and discrimination and other social, community and individual factors play a significant role in men's participation in PMTCT follow-up services (Falnes *et al*, 2011). Male participation is affected by social background, culture or religion and societal roles (Frizelle *et al*, 2009). Most men usually do not accompany their wives to antenatal clinics because they fear being mocked by their peers (Falnes *et al*, 2011).

2.6.4. Cultural and religious beliefs

HIV as an infectious virus has been deeply stigmatised and surrounded by cultural myths and misunderstandings (Frizelle *et al*, 2009). The use of PMTCT follow-up services is hugely affected by a widespread of cultural beliefs about HIV (Laar & Governder, 2011; Frizelle *et al*, 2009). Most people in South Africa use traditional practitioners as their only choice of health care for HIV treatment. Beliefs about HIV treatment can be dangerous when patients continue to access only the traditional healthcare system and ignore other alternatives (Frizelle *et al*, 2009). A survey conducted in South Africa by Peltzer *et al* (2008) found that 36% rural adults who reported to have had sexually transmitted diseases in the past 12 months consult traditional healers for treatment. The following are some of the reasons for the utilisation of such medications: they believe that traditional medicine is safer than ARVs as it does not have side effects (12%); they believe that traditional healers are able to cure diseases western doctors cannot.

According to Doherty (2009), health beliefs related to pregnancy care, delivery and breastfeeding interact with advice received from health workers, therefore affecting the programme. Traditional beliefs concerning the uptake of services hinder the success of the PMTCT programme and these beliefs can destroy relationships especially when traditional remedies fail to produce the desired effect. These beliefs can also lead to conflicts through witchcraft accusations (Frizelle *et al*, 2009; Varga & Brooks, 2008).

Most women believe that HIV results from bewitchment or spiritual forces and alternative treatments may be recommended because of their prevailing norms and traditional views (Varga & Brooks, 2008). People differ in terms of beliefs about HIV infections: People think they are infected because they are cursed or because of demons and evil spirits around their place are angry, that is why they are infected (Frizelle *et al*, 2009). There are church leaders who believe that they can cure HIV through prayers. Religious beliefs influence HIV-related stigma, which is strongly associated with religious beliefs such as the belief that HIV is a punishment from God (Zou, Yamanaka, John, Watt, Ostermann and Thielman, 2009).

Culturally accepted practices about infant feeding may make it very difficult for a mother to adhere to PMTCT related feeding practices (Frizelle *et al*, 2009; Laar & Governder, 2011). The issue of culture on breastfeeding could be a serious factor hindering the use of PMTCT services. Breast feeding doubles the transmission of HIV. Culturally, a mother is expected to breastfeed immediately after delivery (Laar & Governder, 2011). Failure to do so may result in her in-laws pressurising her where she may fear to reveal her status. This is because these women may mix feed, and if they continue breastfeeding without following instructions from health workers, their babies stands a higher risk of infection. Without the required knowledge, like the fact that breastfed infants are more likely to become infected than non-breastfed infants, these mothers are bound to infect their infants (WHO, 2016; WHO & UNICEF, 2016).

2.6.5. Socio-economic factors

Socio-economic status in HIV related health care entails a person's inability to access HIV treatment because of his or her socioeconomic standing, which may increase his or her likelihood of contracting HIV and developing AIDS (Hiarlaithe, Grede, De Pee & Bloem, 2014; Yacobson, Malkin & Lebetkin, 2016). Most people in South Africa experience socio-economic difficulties when it comes to utilising health care services (Department of Health, 2013b). Unemployed citizens are the most affected by the HIV epidemic. Lack of socioeconomic resources can lead to earlier practices of sexual activity and less use of condoms (Department of Health, 2013b).

Poor environmental conditions and lack of resources necessary to maintain good health status are major barriers that influence the use of PMTCT follow-up services (Yacobson *et al*, 2016). People in low socio-economic standings often delay

treatment because of the financial burden of accessing PMTCT follow-up services (Kalembo & Zgambo, 2012; Yacobson *et al*, 2016).

In South Africa, mothers may not have the finances to continue purchasing formula feed for six months, and consequently mix feed their babies (Department of Health, 2008). Most women are struggling to follow instructions given to them by their doctors because they are under financial constraints to purchase relevant resources to perform the instructions given to them (Hiarlaithe *et al*, 2014). Financial constraints often hamper a woman's ability to rapidly stop breastfeeding, either because she will not have the money to purchase formula feed to replace breast milk (Department of Health, 2008).

A study conducted in Kenya, Moth *et al* (2005) found that pregnant women experience financial problems when accessing PMTCT services. The study reports that the reasons mothers are lost for follow-up visits in the PMTCT programme was failure to pay for the service. Furthermore, a study of 2930 participants in Malawi (Tenthani *et al*, 2014) shows 16% of participants claiming transport money as the reason for stopping ART.

The PMTCT programme is ineffective due to inadequate cost of accessing services and low-socioeconomic status of women (Yacobson *et al*, 2016). A qualitative study by Adedimeji *et al* (2012) reports that focus group participants and key informants reported that access to PMTCT services is severely restricted for many women who travel long distances to reach health facilities. In the study, one of the participants was reported as saying;

“The women who come here are poor and many find it difficult to pay the fees before they are treated. Many patients do not show up for follow-up services because of transportation or medication costs. Most of these women stay distances away from health care facilities and need means of transport or they will have to walk to these facilities if they do not have money”

The up-take of services is affected by poor transportation in most communities since people are unable to get to relevant treatment sites. Money is an important component to acquire health services. Poor access to government grants is one of the barriers that denies women in resource-poor contexts the means to access

PMTCT follow-up services (Frizelle *et al*, 2009; Yacobson *et al*, 2016). Distance to facilities and the cost of transportation affect testing, the collection of results and health-seeking behaviours (WHO, 2008). Some women have to visit multiple departments in a single day with long waiting times, and have to visit the hospital on several different days.

2.6.6. Social Support

Social support is the perception that entails a sense of caring or assistance from other people. It involves relationships within social networks such as parents, children, extended family members, co-workers, mentors, social workers or other professionals (Lifson, Workneh, Hailemichael, Demissie, Slater & Shenie, 2015; Taylor, 2011). Supportive resources can be emotional, financial assistance or informational (Taylor, 2011). Support is important to any human being to provide confidence and a sense of freedom through services which can provide advice and referrals for individuals needing immediate assistance (Holt-Lunstad, Smith & Layton, 2010; Taylor, 2011).

Studies around the world have proven that social support is very important for the progression of PMTCT programmes (Frizelle *et al*, 2009; Peltzer & Mlambo, 2010; Shroufi, Mafara, François Saint-Sauveur, Taziwa, Viñoles, 2013). Social support plays a significant role for mothers to use PMTCT follow-up services. Social support in the PMTCT programme helps patients cope and enhances quality of life (Frizelle *et al*, 2009; Shroufi *et al*, 2013). Mothers can be able to respond adequately to the stress of being infected if they receive adequate support (Shroufi *et al*, 2013).

Community based support is one of the most important barriers for the progression of the PMTCT programme, as poor support from the community can reduce the use of services (Frizelle *et al*, 2009). Pregnant women and mothers trying to decide whether or not to be tested for HIV are influenced by negative community attitudes and stigma towards individuals suspected of having AIDS. A community that tends to blame women for the spread of HIV makes women more reluctant to take the test (Arrey, Bilsen, Lacor, Deschepper, 2015).

A study by Okonkwo, Reich, Alabi, Umeike, and Nachman (2007) found that 69.2% of the respondents believe that they would be discriminated against by the community if they utilize HIV related care. Women who perceived a positive attitude

from their community were significantly more likely to participate in PMTCT follow-up activities (Frizelle *et al*, 2009). A woman may choose to carry on breastfeeding even if she is in a position to stop. This behaviour is influenced by fear of negative reaction from members of her community (Laar & Governdor). According to Busza, Walker, Hairston, Gable, Lee, Katirayi, Simiyu and Mpofu (2012), pressure from the community and family members discourages HIV-positive women from abandoning the traditional breastfeeding and weaning patterns.

Support from health workers to provide quality service is also an issue affecting the PMTCT programme (Frizelle *et al*, 2009; Chopra & Rollins, 2008). Information that is not up-to-date impacts on the service quality due to poor advice and quality counselling by health workers on important programme practices like breastfeeding, but most health workers report that they do not have enough training or guidelines to share with their patients in terms of giving information about breastfeeding and other practices in the programme (Chopra & Rollins, 2008).

Initiatives such as 'mothers2mothers' (m2m) programme are a source of support most women receive in the PMTCT programme. The m2m programme is there to provide services through mentorship from experienced mothers to provide education and psychological support to pregnant women and new mothers receiving PMTCT services. These initiatives teach pregnant women and new mothers about reducing the risk of transmitting HIV through information on the programme and feeding choices (Department of Health, 2013b; Frizelle *et al*, 2009).

2.6.7. Health care system factors

Shortages of resources in South Africa impacts negatively on the use of PMTCT follow-up services, which leads to the drop-out of patients (Department of Health, 2008). Shortages of staff and medical supplies delay HIV testing for mothers and their infants, and therefore, affect the quality of services delivery. Shortage of PMTCT staff, space and interrupted supplies of materials are some of the reasons leading to loss of clients in the PMTCT programme. This can lead to long waiting periods for post-tests counselling (Mute, Akondé & Doumbia, 2011). A lack of trained lay counsellors prevents mothers from receiving quality services like VCT. In other hospitals, nurses provided all counselling and related HIV services, with a single nurse per facility running the PMTCT programme and offering all HIV counselling

(Frizelle *et al*, 2009; Mute *et al*, 2011). Inadequate spaces for confidential counselling and private disclosure also influence uptake of PMTCT follow-up services. Findings by Raburu (2004) in Kenya found that 92% of respondents lacked privacy in counselling rooms, as indicated by the presence of more than two people in the room.

PMTCT related policies are important for the smooth implementation and operation of the programmes to achieve positive results. Therefore, poor policies may affect the programme negatively, resulting in an increasing number of loss of follow-up in the PMTCT programme. It is very important for policy makers and programme planners to develop good relationships in order to successfully implement quality programmes, and achieve positive results. However, the success and scaling-up of PMTCT follow-up services have been compromised in various facilities due to poor communications between the government, PMTCT service providers and other parties involved (WHO & UNICEF, 2007). Poor communication has proven to be a challenge to health workers in terms of quality service delivery. A lack of up-to-date information results in health workers giving poor advice and poor-quality counselling on important PMTCT practices (WHO & UNICEF, 2007; Adedimeji *et al*, 2012).

2.6.3. Accessibility

According to WHO (2012), travelling to clinics is one of the setbacks that limit the accessibility of PMTCT follow-up services. A study of 111 participants conducted in Malawi found that the reasons for loss to follow up of women were travelled away (38%) and transport costs (16%) (Tweya, Gugsa, Hosseinipour, Speight, Ng`ambi, Bokosi, Chikonda, Chauma, Sampathkumar, Mtande, Khomani, & Phiri, 2014). A study of 2930 participants in Malawi by Tenthani *et al*. (2014) shows 38% of the participants claimed travelling as the reason for stopping taking ART. Many women live far away from health facilities and might not have access to transportation in their areas. HIV-positive mothers are encouraged to bring their babies for follow-up services at clinics, but due to the issue of transport and the distance between their homes and the clinic, they dropout from the programme instead (Kalembo & Zgambo, 2012; Yacobson *et al*, 2016).

Distance to facilities and cost of transportation affect testing, collection of results and health-seeking behaviours. Some women have to visit multiple departments in a

single day with long waiting times and have to visit the hospital on several different days. Infant follow-up is often a challenge because maternal and paediatric care is provided at distinct centres (Rawizza *et al*, 2012).

Mothers who live in rural areas have limited access to PMTCT follow-up services (Frizelle *et al*, 2009; Rawizza *et al*, 2012). Lack of telephones in rural areas impacts on referrals and general PMTCT delivery. Lack of telecommunications means that healthcare workers and patients will not be able to communicate with each other directly (Frizelle *et al*, 2009). A situation analysis of PMTCT services in the Eastern Cape Province (South Africa) found that in rural underdeveloped areas, there may be only one main road, while secondary roads are gravel or dirt, which are difficult to cross during rainy seasons. Under such circumstances, reaching a clinic may be difficult or impossible (Kalembo & Zgambo, 2012).

2.7 Conceptual Model

2.7.1. The Andersen Behavioural Model

In this study, one theoretical framework will be used. The Andersen Behavioural Model is a kind of conceptual framework which has been widely used to explain factors that influence service utilisation and will be adopted as a framework. The Andersen Behavioural Model was developed in 1968 to study factors that influence health care utilisation. The model has been used in many studies as a theoretical or analytical framework to explain factors that influence service utilisation by people such as those with HIV and AIDS. The original model suggests that people's use of health services is a function of their predisposition to use services and factors which enable or hinder use (Andersen, 1995).

2.7.2. Scope and Core Assumptions

The original model, which is phase one, was an attempt to study reasons why individuals use health services. The model implies that there are three characteristics that relate to an individual's ability to utilise health services. These characteristics are: predisposing, enabling and needs factors. Predisposing factors include the following dimensions: demographic characteristic such as age, gender, marital status, social structure characteristic such as formal education, race and occupation, and health beliefs such as religion, beliefs, knowledge about health issues and attitudes towards medical professions (Phillips, Morrison, Andersen &

Away, 1998). Women may not access PMTCT services because their partners control the household financial or transportation resources, or because they cannot take time off work, or because they cannot leave their dependents to travel to clinics or hospitals (Frizelle *et al.* 2009)

Enabling factors include availability of services, socio-economic status, social class, and social support networks (Andersen, 1995). The issue of socio-economic status affects the utilisation of PMTCT services. Lack of money in low-income areas prevents follow-up visits. For example, people may not have money to pay transportation to reach healthcare sites. Lastly, the needs factors include the need for care, perception of illness, values and attitudes towards health services (Andersen, 1995). HIV positive mothers do not feel the need for PMTCT follow-up services because they have their own interpretation of illness and health services. Most positive mothers thought that PMTCT follow-up services had no benefit for them since ART was seen as not part of the PMTCT programme (Kalembo & Zgambo, 2012).

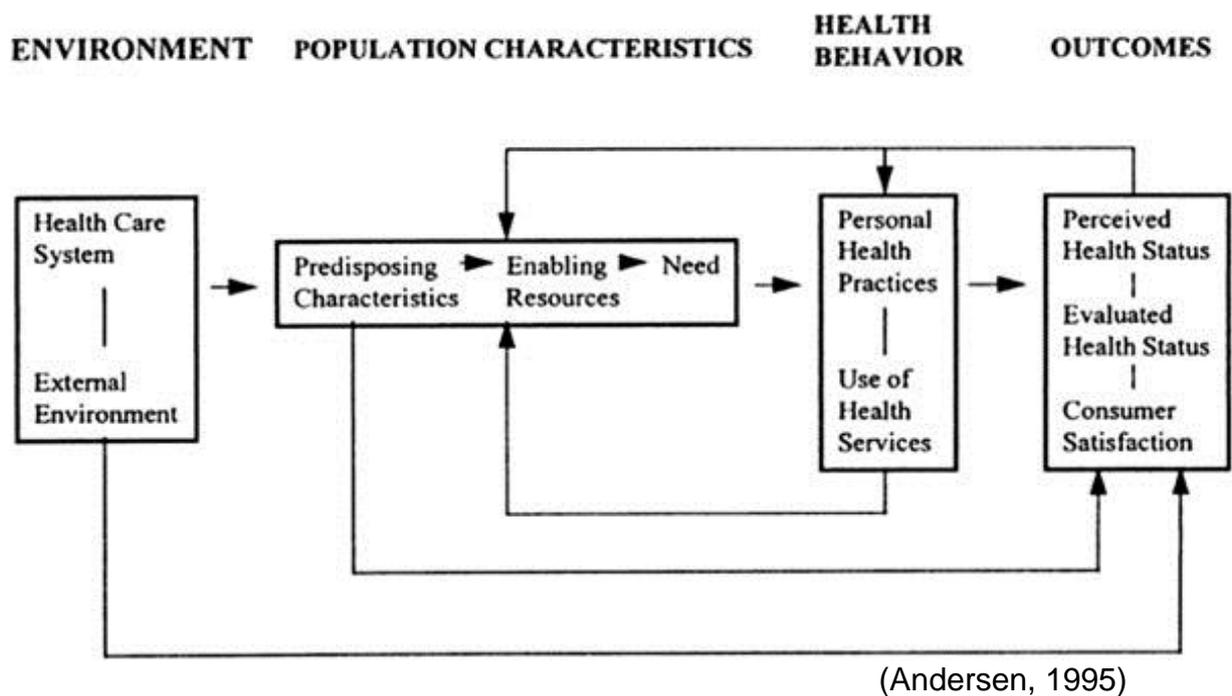


Figure 2.1 Flowchart of the Andersen's health care utilisation behavioural model

Furthermore, the model recognises the importance of health care services and point out the responsibility of the health care system in terms of improving and maintaining

the health status of the population (see figure 2.1). The model also acknowledges the external environment as an important input for understanding health use. These external environments include physical, social, political and economic components (Andersen, 1995). These factors hinder women from accessing PMTCT services as they reflect on the level of stress and violence, politics, prevailing norms in the society and relative wealth. The level of service utilisation is determined by characteristics such as services delivery, availability of drug supply or availability of resources, attitude of health personnel towards patients and clients, health policies and availability of health providers. These contextual factors are determinants of service utilisation and helps researchers to understand behaviours of patients in terms of accessing and utilising PMTCT services.

The sociology of health and illness explores factors such as education, religion, beliefs about illness and treatment, gender roles and power relations, beliefs on illness as source of punishment, stigma, and shape how health is promoted. The model is essential to this study as its assumptions highlight the tendency of individuals in healthcare use. Practices such as polygamy are common in many South African societies and may be a problem in communication and relationships of couples, especially about sensitive issues such as disclosure of HIV test results or encouraging male partners to go for HIV testing (Chinkonde, Sundby & Martinson, 2009). The model incorporates phenomena that influence how women encounter challenges in terms of utilising PMTCT follow-up services (Kalembo & Zgambo, 2012). Therefore, it will provide insight and direction to the study as it encompasses all major factors that influence the use of PMTCT follow-up services and attitudes towards health services (Andersen, 1995).

2.8. Summary

The state of the HIV epidemic in Africa was presented in this chapter. South Africa has many people living with HIV. In South Africa HIV prevalence varies according to provinces, with KwaZulu-Natal remaining one with the highest prevalence and Limpopo categorised with one of the provinces with the low HIV prevalence. An overview of the PMTCT programme was outlined, the importance of PMTCT follow-up services also presented. This chapter discussed the literature review on barriers influencing the use of PMTCT follow-up service, both national and worldwide. The literature review identified barriers associated with the use of PMTCT postnatal

follow-up services, which included knowledge and awareness; stigma and discrimination; gender inequality, socio-economic factors, cultural factors, healthcare factors, accessibility factors and social support. The Anderson behavioural model was also presented and linked with the literature. The next chapter presents the research methodology.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1. Introduction

This chapter presents the research design, study setting and population of the study, sample size and sampling procedure, data collection, data analysis and ethical considerations. This study investigated barriers that influence the use of PMTCT follow-up services. Mother-to-Child Transmission is the most severe health challenge affecting children across the world with more than 90% of all HIV infections world (UNAIDS, 2012). Poor uptake of PMTCT follow-up services by HIV positive mothers and their babies is a major challenge to the success of the PMTCT programmes (Kalembo & Zgambo, 2012).

3.2 Study settings

The study setting refers to the physical location in which data collection takes place in a study (Burns & Grove 2005). This study was conducted at two health facilities at Mankweng Township in Limpopo Province. Mankweng is a township located in the Capricorn District Municipality, Limpopo Province, South Africa. Mankweng Gateway and Mankweng Clinics were two of the facilities selected for this study and both clinics provide PMTCT service. HIV infected mothers are referred to the clinics for follow-up services after giving birth in hospitals.

3.3. Research methodology

Research methodology refers to the entire strategy of the study from the identification of the problem to the final plans for data collection (Burns & Grove, 2005). Research methodology consists of aims, objectives, definition of terms, study type and design, study population, sampling, data collection tools, data analysis as well as ethical considerations (Neuman, 2011).

In this study, a qualitative approach was employed. Qualitative research involves the collection of a variety of empirical methods to describe routine and problematic moments and meanings of an individual's life. This method includes case study, personal experiences, introspective life story, interview, artefacts, cultural text and productions, observational, historical, interactional and visual texts (Burns and Grove, 2005). Qualitative research is used to gain insight, behaviour, motivation, lifestyle and concern on individuals (Christensen, 2004).

3.4. Research design

Burns and Grove (2005) define the research design as an overall plan for conducting a research, a blue print to guide the planning and implementation of a study to address the objectives and answer the research questions so as to achieve the intended goals. The research design of choice for this study was cross-sectional in nature. The design provides a snapshot of the attributes included in the study at one particular point in time. In this design, the researcher explored the association between the exposure and the outcome attributes (Neuman, 2011).

3.5. Study Population

Population is the entire element that meets certain criteria for inclusion in a given universe (Burns & Groves, 2005). The target population of this study were nurses, lay counsellors, and HIV-positive mothers who were enrolled for PMTCT follow up services in Mankweng Clinics, and who met the eligibility criteria for inclusion in the study. To meet the eligibility criteria:

- Mothers must be HIV-positive and enrolled into the PMTCT follow up programme for treatment.
- Nurses and lay counsellors must be trained and have at least two years or more experience in implementing the PMTCT programme.

3.6. Sampling

A sample is a subset of the population that is selected for a particular study (Burns & Grove, 2005). A non-probability sampling technique was used to select the participants of the study. For the purpose of this study, purposive sampling was used. Participants of the study were selected with a specific purpose in mind (Neuman, 2011). Respondents were approached through clinic managers. The following procedures were used to select the sample:

- The clinic administrator checked patients who entered for the day, and patients who reported for PMTCT follow-up services were referred to the researcher's temporary office in the facility;
- The researcher was introduced to the patients, and after checking their records, patients who met the criteria were selected;

- The purpose of the study was explained to each respondent in their home language after which they were asked if they were willing to participate in the research; and
- The interview was then conducted after the patients agree to participate and sign consent form.

In the focus group discussions, the facility managers were informed by the researcher about the study, and appointments were scheduled with health workers (nurse and lay counsellors) for focus group interviews which were conducted at the clinics. The researcher approached the participants in a meeting to discuss with them the research procedures to be followed. Those willing to participate were included in the group. The researcher outlined the purpose of the study and the objectives and then participants were given informed consent forms.

3.6.1. Sampling size

Sample size refers to the number of elements that are included in the sample (Burns & Grove, 2005). The sample size of the study was 26 participants. Two (2) health facilities in the Capricorn District were sampled using purposive sample. For inclusion in the study, the health facilities met the following criteria: (1) the facilities have HIV and AIDS counsellors or lay counsellors and nurses responsible for the implementation of the PMTCT programme; and (2) the facilities provide postnatal PMTCT follow-up services.

The participants scheduled for in-depth interviews consisted of fifteen (15) HIV positive mothers enrolled for PMTCT postnatal follow-up services. The participants scheduled for focus group discussions consisted of eleven (11) health workers (nurses and lay counsellors) who were working in the PMTCT programme. Since fewer than five participants tend to result in inadequate discussions, it was critical to recruit the appropriate number of participants for each of the focus group (Burns & Grove, 2005). In the focus group discussion, the respondents must have been male or female health care providers who worked at the clinic for over one year. Respondents were approached through their clinic managers. The sample size was suitable for the study as it is more manageable, required less time and was cost efficient. The primary consideration in this sample is participants who can provide the best information to achieve the objectives of the study.

3.7. Data collection

Data collection is the precise, systematic gathering of information relevant to the research purpose or specific objectives (Burns & Grove, 2005). Primary data was gathered once by the researcher between the months of June and July 2016. Data refers to pieces of information that are collected during a study (Burns & Grove, 2005). The researcher met with the study respondents and collected qualitative data on barriers influencing the use of PMTCT follow-up services. Triangulation methods of in-depth interviews and focus group discussions were conducted in the study. Voice recording tapes and direct note taking tools were used to collect data.

3.7.1. In-depth interviews

Interviews of the selected participants were held at the clinics, and due to the number of questions and follow up questions, interviews lasted approximately 45 minutes for each respondent to allow the researcher to gather more data and to ensure accuracy of information from the respondents. Interviewees were encouraged to talk freely about events, behaviour and beliefs related to PMTCT follow-up service utilisation. The interviews were conducted with fifteen (15) HIV-positive mothers who are enrolled into the PMTCT follow-up services.

3.7.2. Focus Group Discussion (FGD)

Two focus group discussions were conducted. Each group discussion comprised six (6) and five (5) participants (lay counsellors and nurses) responsible for the implementation of the PMTCT programme. The aim was to get more in-depth information on perceptions, insights, attitudes, experiences, or beliefs from key participants (Neuman, 2011). Data was collected on the participants' perceptions about loss of follow-up by mothers and their babies to the PMTCT programme and how this affects the programme. The researcher facilitated group discussions to keep the group focused on the topics of interest. The focus group discussions lasted at least forty five (45) minutes each.

3.8. Data analysis

Data analysis means search for patterns in data. Data analysis was conducted to reduce, organise and give meaning to data (Burns & Groves, 2005). The researcher applied the thematic data analysis method. In the first stage, the researcher listened to the audio, and read and re-read transcripts in order to become familiar with what

the data entails. In stage two (2), the researcher generated the initial codes by documenting where and how patterns occur. Data was labelled in order to create categories for more efficient analysis. Categorisation helped to overview the data and to enhance its understanding.

In stage three (3), the researcher combined codes into main themes that represent the data. Themes were identified, where data was grouped under different themes in accordance with the categories under which data was collected. In stage four (4), the researcher looked at how the themes supported the data, and where the analysis seemed incomplete, the researcher went back to find what was missing. In stage five (5), the researcher defined each theme, the aspects of data that were captured, and the interesting aspects of the themes. The researcher decided on the themes that make meaningful contributions to the study. The researcher conducted "member check" where he went back to the sample at hand to see if their description is an accurate representation.

3.9. Methods to ensure Trustworthiness

Trustworthiness refers to the quality value of the final results and conclusions reached in a qualitative research (Neuman, 2011). The criteria of credibility, transferability, dependability, and confirmability according to which trustworthiness is evaluated were applied to ensure the quality of the data in this research, as described below:

3.9.1. Credibility

Credibility refers to confidence in the truth of the data, its integrity and interpretation (Neuman, 2011). In this study credibility was ensured by applying the member checking method. Member checking entails giving the research participants an opportunity to determine whether the initial findings and interpretations are consistent with their views and experiences which they share with the researcher. The researcher went back to the respondents of the focus groups to ask the participants more questions about barriers that influence the use of PMTCT follow-up services.

3.9.2. Transferability

Transferability refers to the extent to which the findings of a study can be transferred to another context or with other participants (Neuman, 2011). In this study transferability was enhanced through triangulation where multiple informants and data-gathering methods were used to increase the value of the study for other settings. Different data sources (health workers and mothers) and different methods of data collection (individual interviews and FGD's) were used for purposes of triangulation.

3.9.3. Confirmability

Written field notes and the use of a tape recorder supported interviews and FGDs as a point of reference. The scientific methods and procedures employed in this study were described in detail. Information gathered from individuals and focus group discussions and field notes were verified through literature control to determine whether similar findings were identified in other studies.

3.9.4. Dependability

The concept of dependability refers to the consistency of research findings in a qualitative study (Neuman, 2011). Dependability in this study was ensured by a detailed description of the research methods, reviews and tracking of the research process.

3.10. Bias

In research, bias is an error that can occur at any phase of the research, including study design or data collection, as well as in the process of data analysis and publication (Neuman, 2011). To avoid selection bias, the sample which meets the eligibility criteria for inclusion was clearly identified. To minimize no-response bias, the researcher made the project easy for the participants to contribute and not to take too much time during interviews and to express the importance of the study. The participants were able to relate with the study since the research questions had a Sepedi language version, which they understand better. The researcher used triangulation methods of both in-depth interviews and FGD during data collection in order to minimize bias.

3.11. Ethical considerations

The proposal served before the Turfloop Research Ethics committee to obtain ethical clearance for the study.

3.11.1. Informed consent

The use of informed consent is meant to give study participants a choice whether to participate in the study or not (Neuman, 2011). The principle of the consent form states that the participants have the right to know what the research is about and how it will affect them, the risks and benefits of participating and that they have the right to decline from participating at any time. The participants were asked to sign the consent form if they agree to participate in the study.

3.11.2. Confidentiality and anonymity

In this study, the participants were not mentioned by their names. The researcher used the coding system to identify the participants' data and to ensure that information obtained from the participants is used for scientific use only.

3.11.3. No harm to respondents

Social research can harm participants in several ways namely: physical harm, psychological harm, legal harm and harm to a person's career (Neuman, 2011). In the case of this study, the researcher assured the participants that they would not be subjected to any kind of harm. The researcher achieved this by assuring the participants that their involvement would be confidential and anonymous, and that the interviews and focus group discussions would take place in remote and safe areas.

3.11.4. Debriefing

The research could place participants in stressful and anxiety-producing situations since the study dealt with a sensitive topic (Neuman, 2011). The researcher took responsibility to minimize any negative feelings that the participants could have as a result of participating in the study. During data collection, the participants were informed about the purpose of the study, and those who experienced discomfort were referred to psychologists or social workers for counselling at the hospital.

3.12. Summary

This chapter presented the research methods and research design. The study setting was described, including the target population, sample, sampling, data collection, data-collection tools, data analysis and ethical considerations of the study. The next chapter presents the data analysis and interpretation the finding from in-depth interviews.

CHAPTER FOUR: ANALYSIS, PRESENTATION AND INTERPRETATION OF THE FINDINGS FROM IN-DEPTH INTERVIEWS

4.1. Introduction

This chapter analyses the data and interpret the findings. The researcher used qualitative methods and a cross-sectional research design. In-depth interviews were used to gather information from HIV-positive mothers in two selected health facilities in order to identify barriers that influence the use of PMTCT follow-up services. The study was conducted with fifteen (15) HIV-positive mothers who were enrolled for PMTCT follow-up services. A total number of 15 participants (n=15) were interviewed, eight (8) from Mankweng Gateway Clinic and seven (7) from Mankweng Clinic in the Capricorn District, Limpopo Province. The aim of the proposed study was to explore barriers influencing the use of PMTCT follow-up services at Mankweng.

The following were the objectives of the study:

- To identify the severity of predisposing factors (stigma, knowledge and awareness) on the use of PMTCT follow-up services.
- To determine the effect of enabling factors (socio-economic status, social support) on the use of PMTCT follow-up services.
- To establish the influence of need factors (perception towards illness and health service) on the use of PMTCT follow-up services.
- To ascertain the effect of the healthcare system (infrastructure, shortage of staff) on the provisions of PMTCT follow-up services.

In the study, the researcher applied the thematic analysis method. The data obtained during in-depth interviews was transcribed and divided into categories and then coded. Demographic data were analysed and interpreted using tables and graphs. Themes and sub-themes were identified and discussed with reference to the literature review and are clearly outlined. The study was based on the Anderson Behavioural Model (ABM), which guided the construction of the in-depth interview schedule.

4.2. Demographic data presentation

The demographic data covered the respondents' age, marital status, educational level, employment status and medical aids.

4.2.1. Respondents' age distribution

The respondents were asked to indicate their age (see figure 4.1).

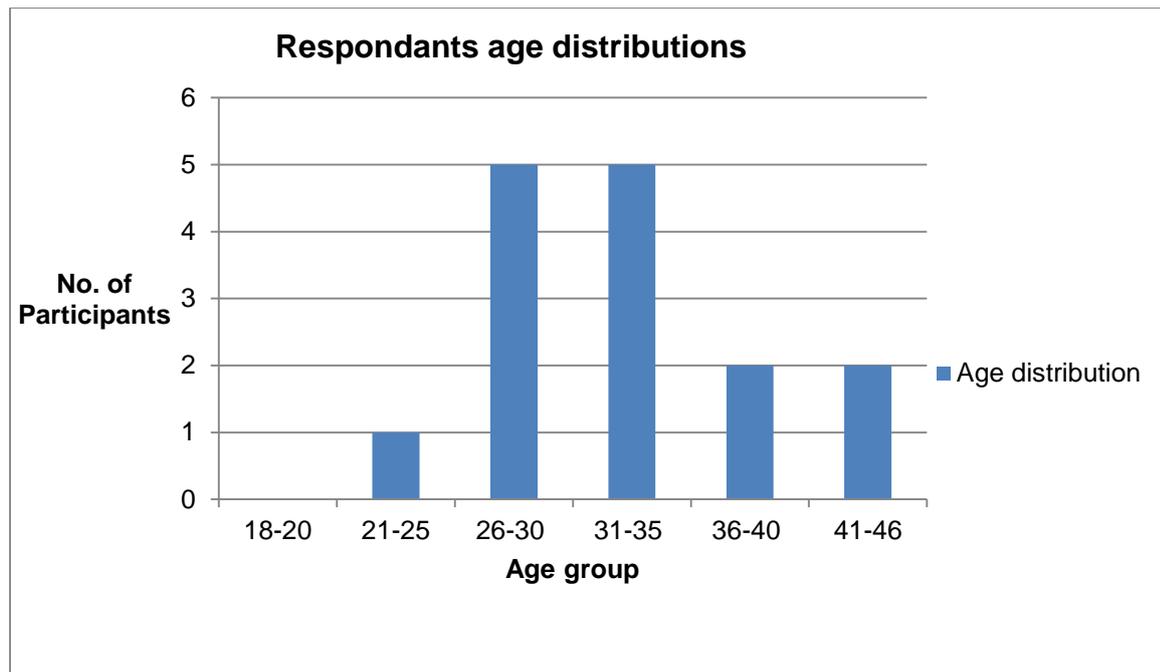


Figure 4.1 Respondents' age distribution (N=15)

All the respondents were above the age of 18, and agreed to take part in the study (see figure 4.1). There were no respondents in the age group of 18-20. Respondents between the age group of 26-30 and those between the age group of 31-35 were the most represented, registering five (5) respondents each. The second highest groups were respondents between the age of 36-40, and those between 41-45, each group registered two (2) respondents. The lowest group was respondents between the age of 21-25, registering only one (1) respondent. The findings show that participants below the age of 26 and above the age of 45 are likely to not use PMTCT follow up services.

A study conducted in Ethiopia by Mitiku *et al* (2016) found that women who were 18 to 24 years at ART initiation were more likely to be lost for follow-ups than older women. In 2005, a national survey in South Africa on HIV prevalence found that

there is a knowledge barrier amongst young people between the ages of 12 and 14 and adults over the age of 50 that affects the use of service. In the survey, 31.9% of 12–14-year-olds and 23.5% of individuals 50 years of age or older answered ‘no’ or ‘do not know’ when asked if HIV could be transmitted from a mother to a child (Shisana *et al.* 2014).

4.2.2. Respondents’ marital status

The respondents were asked to indicate their marital status (see Table 4.1).

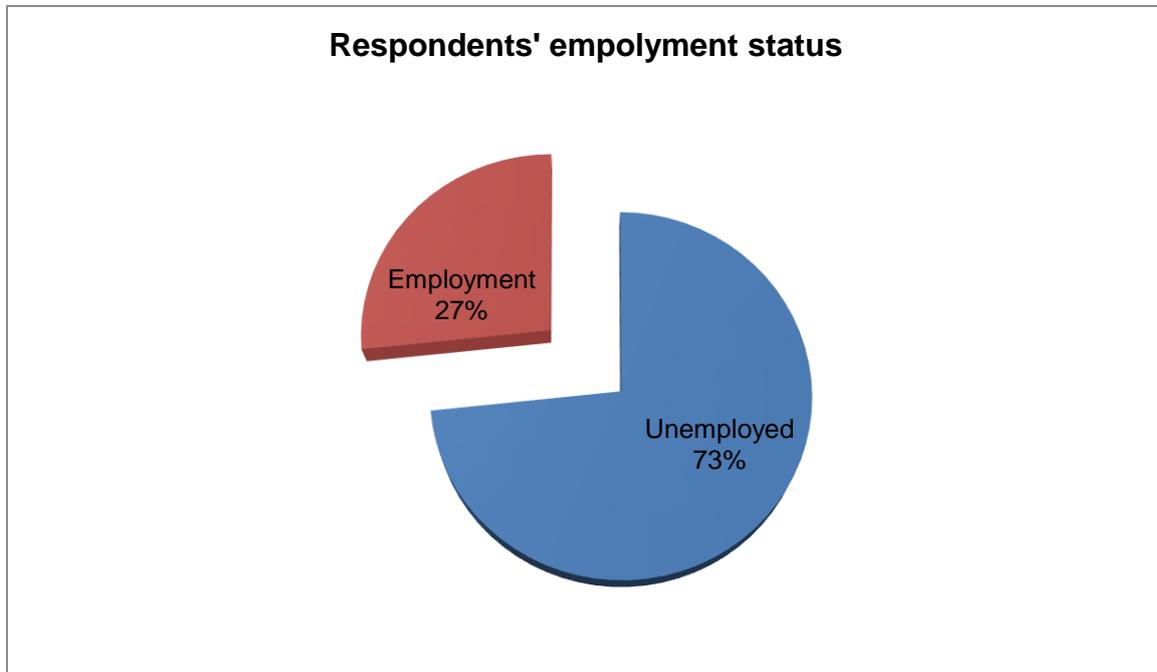
| Marital status | Frequency | % |
|----------------|-----------|----|
| Single | 6 | 40 |
| Married | 4 | 27 |
| Separated | 0 | 0 |
| Cohabiting | 5 | 33 |

Table 4 1: Respondents’ marital status (N=15)

Marital status can influence the decision of mothers to use PMTCT follow-up services if they are tested HIV-positive. The findings of this study show that the majority of the respondents were single. Therefore, they were likely to use follow-up services because they can make decisions on their own without consulting their partners. The findings also show that the majority of the participants were living with their partners (both married and cohabiting). They are likely not to use services because they may fear reactions of their partners, or because their partners may decide for them not to use the services. This is supported by several African studies which found that married or cohabiting women were less likely to use PMTCT ARVs or other HIV services due to perceived negative reactions from partners (Muchedzi, Chandisarewa, Keatinge, 2010).

4.2.3. Respondents' employment status

The respondents were asked to indicate their employment status (see Pie chart 4.1).

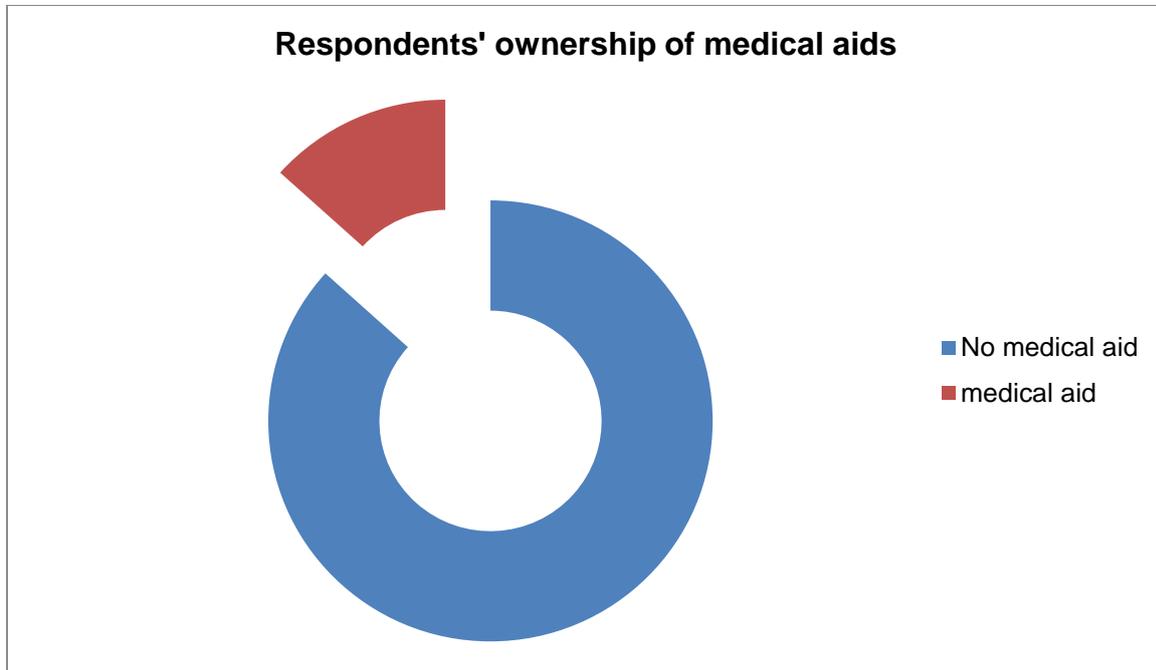


Pie Chart 4.1 Respondents employment status (N=15)

Of the fifteen (15) respondents, 73% (n=11) were not employed and 27% (n=4) were employed. The findings show that the majority of the respondents in this study were unemployed. This implies that 73% (11 out of 15) of the respondents might have encountered financial difficulties if they needed to access PMTCT follow-up services. South Africa has a very high rate of unemployment and as a result, many families experience financial constraints. Employed individuals are able to access resources such as transportation to attend follow-up visits at clinics or be able to afford formula milk for their babies (Kalembo & Zgambo, 2012; Anígilájé, Ageda & Nweke, 2016). Lack of financial resources like money prevents follow-up visits. For example, in contexts where transportation is needed to reach healthcare sites, people may not have the money to pay for transportation (Anígilájé *et al*, 2016).

4.2.4. Respondents' of medical aids status

The respondents were asked to indicate if they have medical aids (see Doughnut 4.1).



Doughnut 4.1 Respondents medical aids (N=15)

The percentage of the participants with no medical aid was high (90%) (N=13) in this study. Only 10% (2) had medical aid. Anthony, Gardner, Marks, Anderson-Mahoney, Metsch, Valverde, Del Rio and Loughlin (2007) found that participants with medical insurance were likely to use services than those without any medical insurance. Participants who did not have medical aid were asked a follow-up question to provide reasons for not having medical aids and all mentioned unemployment and lack of money as their reasons. Unemployed citizens are the most affected by the HIV epidemic. The disease is more severe where health care is much needed. HIV infected mothers who access PMTCT follow-up services find it hard to follow PMTCT activities because of financial constraints (Kalembo & Zgambo, 2012). Mothers who choose exclusive formula feeding may struggle to maintain the practice because of financial constraints and may end up mix feeding (Frizelle *et al*, 2009; Kalembo & Zgambo, 2012).

4.2.5. Educational level of the respondents

The respondents were asked to indicate educational level (see table 4.2).

| Educational Level | Frequency | % |
|----------------------|-----------|-----|
| Never went to school | 0 | 0 |
| Primary level | 2 | 13 |
| Secondary level | 8 | 53 |
| Tertiary level | 5 | 34 |
| Total | 15 | 100 |

Table 4.2 Respondents' Educational Level (N=15)

In this study, all the respondents could read and write. Women with at least a primary or secondary education are in a better position to understand the requirements of the PMTCT programme. A study by Shargie, Eek and Abaychew (2011) in Addis Ababa, Ethiopia on prophylactic treatment uptake and compliance with recommended follow-up visits among HIV-exposed infants found 42.2% adherence among children whose mothers had primary education; 41.0% among children whose mothers had secondary education, and 6.0% among children whose mothers were unable to read and write.

4.2.6. Religious affiliation of respondents

The respondents were asked to indicate their religious affiliation (see table 4.3).

| Religion | Frequency | % |
|-------------------|-----------|-----|
| Christianity | 15 | 100 |
| African tradition | 0 | 0 |
| Islam | 0 | 0 |
| Buddhism | 0 | 0 |

Table 4.3 Respondents' religious affiliation (N=15)

All the respondents (100%; N=15) selected Christianity as their religious affiliation (see table 4.3). Mankweng is predominantly a Christian community. There are many different churches in the country, and one of the biggest churches, the Zion Christian Church (ZCC), is located next to Mankweng Township. The findings show that the participants are likely to be influenced by their respective churches to use follow-up services. Mothers are lost for follow-up services because of beliefs that HIV and MTCT can be cured through prayer feeding (Frizelle *et al.*, 2009). Church leaders are getting involved in campaigns against HIV infection around world. However, there are church leaders who believe that they can cure HIV through prayers. Religious beliefs influence HIV-related stigma, which is strongly associated with religious beliefs such as the belief that HIV is a punishment from God (Zou *et al.*, 2009).

4.3. Qualitative Data Analysis Framework

In this section, themes and categories emerged after the researcher analysed the data. In the process, the researcher listened to audio, read and re-read the transcripts to familiarize himself with the data. The researcher then generated the initial codes by documenting where and how patterns occur. Data was labelled in order to create categories for more efficient analysis. Categorising helped to overview data and to enhance its understanding. Themes were identified, where data was grouped under different themes in accordance with the categories under which data was collected. Nine themes and 30 sub-themes emerged from the analysed data. Relevant quotations from individual participants were used to support the themes. The quotes were discussed and incorporated with literature to confirm the findings of the study. The discussions of the findings were related to the statement problem and the objective of the study. The following themes were identified:

- Knowledge about awareness
- Stigma and discrimination
- Cultural factors
- Accessibility
- Social support
- Genders inequality and male involvement

- Socio-economic factors
- The Need for health services
- Health care system factors

4.4. Knowledge and awareness of MTCT and the PMTCT programme

| Themes | Sub-themes |
|----------------------------------|--|
| Knowledge about awareness | <ul style="list-style-type: none"> • Knowledge and awareness of Mother-to-Child Transmission (MTCT) after birth • Knowledge about the stages of Mother-to-Child Transmission (MTCT) • Infection of HIV from an HIV positive mother to her baby • Knowledge and awareness of the PMTCT programme • Knowledge about the use of HIV treatment • The importance of breastfeeding • The duration for exclusive breastfeeding |

4.4.1. Knowledge and awareness of Mother-to-Child Transmission (MTCT) after birth

This section of the in-depth interview schedule examined the respondents' knowledge of HIV and MTCT. All the respondents were aware that an HIV-positive mother can transmit HIV to her baby. However, the majority of the respondents lack knowledge and understanding of how a mother can transmit HIV to her child after birth. For example, one respondent had this to say:

"I don't know, I don't know how a mother transmit the virus to her baby after birth".

Another participant, when responding to the same question about MTCT after birth said:

"The mother infects the child through blood from the mother, if there is cut".

Similar response was provided by another respondent, saying:

“If I am hurt, I can transmit the virus through my blood”

Other participants at the clinics, however, reflected knowledge about MTCT of HIV infection. For example, one respondent had this to say:

“It can be transmitted to the baby through breastfeeding if the mother is HIV positive and if the mother is not on treatment”

The findings show that the participants were aware that an HIV-positive mother can transmit HIV to her baby. However, the majority of the participants lacked knowledge of how a mother can transmit HIV to her child after birth. The majority of the participants did not understand the risk of MTCT after birth and failed to mention breastfeeding as a mode of transmission. This is similar to a study carried out in Lagos, Nigeria which indicates that the majority of women (89.9%) had good knowledge of the mode of HIV transmission; however, specific aspects of PMTCT were poor. Close to half of the study participants (41.7%) were not aware of the association between breast milk and HIV transmission (Ekanem & Gbadegesin, 2004).

PMTCT programmes around the world are hugely affected by the level of awareness and knowledge which consequently increases the prevalence of HIV infections in children (Asefa & Beyene, 2013; Abteu *et al*, 2016). PMTCT counselling on MTCT and postnatal follow-up practices are provided at health facilities to help mothers prevent HIV transmission after birth, especially during breastfeeding. Mothers who lack knowledge and awareness of MTCT may ignore PMTCT follow-up services, and miss out on HIV treatment for both their health and that of their babies (Department of Health, 2013). A study by Peltzer *et al* (2007) conducted in the Eastern Cape confirmed that knowledge levels about PMTCT were low among mothers enrolled for PMTCT follow-up services, and this affects the uptake of services.

4.4.2. Knowledge of stages of Mother-to-Child Transmission (MTCT)

Mother-to-Child Transmission (MTCT) occurs when HIV is transmitted from a mother who is infected to her baby through the placenta during pregnancy, or through blood contamination during childbirth, or through breast-feeding after birth (UNAIDS, 2012). In this study, the respondents were aware of the stages where an HIV

positive mother can transmit the virus to her baby. However, the majority of the respondents lack knowledge of how MTCT of HIV occurs in these stages. For example, one respondent reflected on lack of knowledge about MTCT during pregnancy by saying:

“I know that a mother can transmit the virus to her child when she is pregnant, but I don’t know how”

When asked about how a mother transmits the virus during breastfeeding, another respondent who also lacked knowledge said: “I don’t know “

One respondent did not believe that a mother can transmit the virus through breastfeeding. This is what she said:

“If I’m not on medication for a long time I can infect the child, not through breastfeeding, breast milk is healthy, they say it protect against diseases, maybe through a cut”

The study findings also reflected a level of doubt, as some of the respondents were not sure about how MTCT occurs. One of the participants had this to say:

“I heard but don’t know what happened. I read somewhere that is when there is cut during operation”

Another respondent changed her response and did not agree that an HIV positive mother can transmit the virus to her child during pregnancy. This is what she said:

“I doubt that a mother can infect her child during pregnancy, but if the people with HIV have sex without protection infection can occur. I don’t know the process but if there is unprotected sex”

The findings showed that participants lacked knowledge of how a mother can transmit HIV to her child. Although basic knowledge of HIV and AIDS seems to be increasing in most communities, there is insufficient knowledge of MTCT among mothers enrolled for PMTCT follow-up services (Frizelle *et al*, 2009; Kalembo & Zgambo, 2012). A study conducted by Bajunirwe and Muzoora (2005) revealed that 12% of the participants lacked knowledge about the possibility of the virus being passed on to an unborn baby, and at least 8% of the participants did not know how

the virus can pass from a mother to a child. This is supported by a study conducted by Peltzer et al. (2009), which revealed that 74.2% of the participants knew that HIV can be transmitted to the child during delivery, while 77.9% knew that it can also be transmitted through breastfeeding.

4.4.3. Infection of HIV from a mother who is HIV positive to her baby

The respondents were asked if all babies born to HIV positive mothers always become infected with HIV. The majority of the respondents agreed that all babies born to HIV-positive mothers cannot always become infected. Only one participant reflected lack of knowledge, and this is what she said: *“I don’t know”*

The findings showed that most of the participants were aware that MTCT can be prevented. This was evidenced by the response of the participant, who said:

“It depends on whether the mother was on treatment. It is possible for the child to be negative if the mother was on treatment”

A similar response was expressed by another participant. This is what she said: *“because if the mother is on treatment, she protect the baby from infection”*. Another participant responded by saying: *“No, other people don’t get infected, because HIV treatment”*.

The respondents are aware of the importance of treatment adherence as a prevention measure to avoid MTCT. During the postnatal period, the PMTCT programme includes continued follow-up services and treatment for HIV positive mothers and their children, especially for the first 18 months of the child’s life. Treatment includes ARV prophylaxis to the infant and complete avoidance of breastfeeding (Department of Health, 2010). A study conducted in Mpumalanga by Peltzer *et al* (2009) reported that only 7.7% of the mothers did not know that AZT and NVP reduced the chances of the child contracting HIV. Compliance to medications and clinic follow-ups is very important in preventing HIV transmission, by improving the overall health outcomes of both the mother and their babies (UNICEF, 2009).

4.4.4. Knowledge and awareness of the PMTCT programme

The majority of the respondents were aware of interventions that help women to prevent the MTCT of HIV. This was demonstrated by a response from one of the participants, who said:

“I am aware of the PMTCT programme; I heard about it from the radio, it talks about ARV and safe sex”

Another respondent gave a similar response. This is what she said:

“I know about the PMTCT programme, read about it from books. It helps children not to get infected”

Other participants did not know what the PMTCT programme is when they were asked to identify programmes that help prevent MTCT. However, the respondents knew that HIV drugs are given to mothers to reduce HIV transmission. These are responses from the participants:

“The one that provide ARV and condom”

“Provide education about HIV; provide the treatment before and after birth”

Other participants were able to identify the programme but could not explain what it entailed. This was demonstrated by a response from one of the participants, who said:

“I know the PMTCT programme I heard about it from the street but I don't know what it does”

The findings showed that most of the participants were aware of interventions that help women to prevent MTCT. Most respondents could not identify the programme; they could however identify activities that are provided in the programme. This supported by a study of 202 women participants found that at least 94% of the participants have knowledge of HIV and AIDS. However, 48% of the participants were not aware of any means to prevent MTCT (Rogers *et al*, 2006).

4.4.5. Knowledge of the use of HIV treatment

All the respondents agreed that the use of anti HIV drugs helps in preventing MTCT of HIV. They were aware of the use of anti HIV drugs as one of the interventions provided to prevent MTCT of HIV. One of the participants had this to say:

“ARV prevents mother-to-child transmission, if not taking the medication is likely that the child will be infected”

Another respondent gave a similar response, and this is what she said: *“The virus will not affect the child if I am on medication”*

Other respondents provided information from what they observed from other people’s experiences. One of the participants had this to say:

“They work, my sister is HIV positive and got pregnant, by using ARV she end up having a child who is HIV negative”

A similar response was provided by another participant, and this is what she said:

“My friend took her medication in time and now her child is negative”

The findings showed that the participants were aware that anti HIV drugs are helpful in preventing MTCT. The respondents could identify the importance of using HIV drugs, and most of them were aware that the use of these drugs can prevent children from being infected by their HIV infected mothers. A study conducted in Mpumalanga by Peltzer *et al* (2009) found that the consumption of maternal nevirapine (NVP) and administration of NVP to the baby were associated with the mother’s knowledge of HIV and PMTCT. A study by Boateng, Kwabong and Agyei-Baffour (2013) found that most of the respondents had good knowledge on PMTCT and ARVs. Most of the women in the study stated that, the drugs makes the virus weak and unable to attack their immune system. The study show that 88% knew that vertical transmission was preventable whiles only 7.2% did not know that MTCT was preventable.

4.4.6. The importance of breastfeeding

In this study the majority of the respondents were breastfeeding, and believe that HIV positive mothers should breastfeed their babies. They believe that it is safe to breastfeed as long as the mother is on treatment. They also highlighted the

importance of breast milk as a healthy option for the baby. This was evidenced by one of the participants, who said:

“Breastfeeding is good for the baby; however mothers should take treatment to prevent infection”

Another respondent had this to say:

“Breast milk is important for the child growth. It won't be a problem if the mother is on treatment”

One respondent agreed that HIV positive mothers should breastfeed their babies. However, she did not trust the information provided to her from the clinic and opted to avoid breastfeeding.

“There is no problem with breastfeeding, according the clinic it is healthy but I refused”

One of the respondents did not agree that HIV positive mothers should breastfeed their babies. This is what she said:

“It is not right for the child. It is a risk of infection”

The findings show that most of the participants were aware that mothers can breastfeed their babies as long as they are on treatment. The respondents identified the importance of breastfeeding and adherence to treatment. HIV infected mothers are advised to breastfeed their babies at health facilities (Department of Health, 2013b). According to a guideline by UNICEF & WHO (2016), breastfeeding is one of the foundations of child health, development and survival, especially where diarrhoea, pneumonia and under nutrition to prevent mortality among children. Long-term breastfeeding benefits both the mother and her child, health outcomes including child development and prevention of non-communicable diseases.

However, mothers are recommended to exclusively breastfeed for the first six months of life, followed by continued breastfeeding with appropriate complementary foods for up to two years or beyond, while on treatment. If mothers show little understanding of the danger of breastfeeding without treatment, and lack awareness of the risks that involved, they risk exposing HIV to their children. Mothers can

protect their children from HIV infections if they have knowledge of HIV transmission and MTCT during breastfeeding and the importance of adhering to treatment (Hazemba *et al*, 2016; UNICEF & WHO, 2016).

4.4.7. The duration for exclusive breastfeeding

The respondents were asked about how long it takes for HIV positive mothers to exclusively breastfeed their babies, and to provide reasons for their answers. Most of the respondents were mix feeding and did not know the required duration set for HIV positive mothers to exclusively breastfeed their babies. The majority of the participants were certain that it is safe to breastfeed until the child no longer wants to breastfeed; they highlighted the importance breastfeeding. This was evidenced by one of the participants, who said:

“I don`t know, the baby need breast milk because they don`t want to eat food. I will breastfeed my child for two years if she does not refuse to eat”

This is what other participants said:

“I will breastfeed for one year, the clinic told me I can breastfeed the child until the child grow teeth”

“As long as you want. It doesn`t matter how long, three years or more, there shouldn`t be any restriction because the longer the better”

Other participants who knew the duration that mothers should exclusively breastfeed their babies did not know the reason why a mother should breastfeed for six months. One of the participants have this to say: *“6 months but I am not sure why”*.

Another participant had this to say:

“For six month because there are no implications after six month”

“For six month because after six month the child grow teeth therefore will bite the mother`s breast”

Furthermore, the findings show that majority of the participants were not exclusively breastfeeding their babies. The participants showed little understanding about the danger of breastfeeding, and lack awareness of the risks involved in replacement feeding. This was evidenced by one of the participants, who said:

“My mother says I should not only breastfed my child, when the child is crying she say I should give it water”

The findings show that the participants lacked knowledge and understanding of feeding practices that help mothers prevent infections to their babies. The majority of the participants were not aware of the required duration for a mother to exclusively breastfeed her child. The participants did not have knowledge about the purpose of exclusive breastfeeding nor were they aware of the danger of mix feeding. Mothers are unable to correctly explain exclusive breastfeeding or mixed feeding.

Lack of knowledge and understanding of the PMTCT follow-up practices is a significant barrier that is marked from poor uptake of PMTCT services (WHO, 2015). Knowledge and awareness of feeding practices play a significant role in reducing the spread of HIV from a mother to a child especially during breastfeeding. It is important for mothers to know about different feeding methods after giving birth (WHO, 2015). Although mothers receive information about PMTCT activities and practices in hospitals and clinics, they still fail to bring their babies for follow-up service. Mothers who fail to attend follow-up services miss out on important information on the risk of breastfeeding and mixed feeding (Department of Health, 2013b).

4.5. Stigma and discrimination

| Themes | Sub-themes |
|----------------------------------|---|
| Stigma and discrimination | <ul style="list-style-type: none"> • People living with HIV treatment in communities • Experience of stigmatisation because of HIV status • Experience of discrimination because of HIV status |

4.5.1. Treatment of people living with HIV in communities

In this study most of the respondents pointed out that people living with HIV are treated badly in their community. One of the participants had this to say:

“They are disgusted by people living with HIV. I witnessed this happening to a person who was believed to be HIV positive, people wouldn’t share food or drinks with him. He was given separate plate to eat alone and after his death

people were disgusted and did not want to touch his body or be close to him, they used a stick to touch him”

Fear of stigma and discrimination from the community is the most occurring barriers to the use of PMTCT follow-up services. HIV-positive mothers avoid PMTCT follow-up services and HIV treatment because they believe women living with HIV experience stigma and discrimination in their communities when they use HIV-related services (Kalembo & Zgambo, 2012). Other participants had this to say:

“They are called name and disgusted, they don` t compare you with them, they don` t take you as one of their own”

“They are discriminated. My aunt say she won` t eat food that is prepared by a person who is infected”

The findings show that stigma still exist in the community. The majority of the participants pointed out that people living with HIV are treated badly in their communities. A study conducted by Shisana *et al* (2005) in South Africa found that 29% of participants would not buy food from a person who has HIV, and 20% stated that HIV-positive children should be kept separate from other children to prevent infection. Mothers are unlikely to use PMTCT follow-up services if they are stigmatised in their communities. Women who receive positive attitude from their community participate in PMTCT counselling than women who receive negative reaction (Frizelle *et al*, 2009; Kalembo & Zgambo, 2012).

4.5.2. Experience of stigmatisation because of HIV status

HIV-related stigma refers to unfavourable attitudes and beliefs directed toward people living with HIV or those perceived to be infected. Majority of the respondents pointed out that they had never experienced stigma or discrimination. In the study only one participant indicated that she had experienced stigma. This is what she said:

“They say that they don` t want me close, they don` t want to share water because they fear infection”

This is how the participant dealt with the discrimination:

“I was hurt, I just pretended like I didn’t hear them. I couldn’t show them that I was angry because maybe they don’t know for sure”

According to UNAIDS (2015) stigma is socially constructed and reinforces prejudiced behaviours in society. In this study, the findings show that the majority of the participants were never stigmatised. However, most of the participants indicated that stigma still exists in their community. Stigma has consequences that people fear and therefore keeps them from seeking HIV information, adopting preventive behaviour, getting tested, disclosing their status, and accessing treatment (Department of Health, 2013b; Frizelle *et al*, 2009; Kalembo & Zgambo, 2012).

Fear of stigma and discrimination from the community, family, and health workers is the most occurring barriers to the use of PMTCT follow-up services. This finding has evidence in multiple reports and studies (Department of Health, 2013b; Kalembo & Zgambo, 2012; SANAC, 2015 UNAIDS, 2015). Stigma and discrimination of people living with HIV and AIDS serves as a strong obstacle to people seeking HIV-related care (Department of Health, 2013b; UNAIDS, 2015). Lack of knowledge and unawareness has been found to often play a major role in spreading stigma (Frizelle *et al*, 2009).

4.5.3. Experience of discrimination because of HIV status

In this study, only one participant experienced discrimination. Most of the respondents indicated that they had never experienced discrimination. This is what she said:

“A security guard where I was working in Gauteng just looked at me and start treating me different because I’m too skinny, showing expressions that she does not want me near her. Sometime they laugh when I pass by the gate”

A study by Shisana *et al* (2005) found that 20% of the participants believe that HIV-positive children should be kept separate from other children to prevent infection. People react differently to similar situations, and likewise, the respondents in this instance dealt with discrimination in various ways. This is how a participant dealt with the discrimination: *“I just accept and move on with my life”*

The findings show that the majority of the participants were not discriminated against. Mothers experienced the most damaging and difficult discrimination from

their family and partners. However, some of the participants did not disclose their status. If a woman's HIV status is known, discrimination may occur and the main concern for the individual is fear of negative attitudes or discrimination from their peers.

4.6. Gender inequality and male involvement

| Theme | Sub-themes |
|----------------------------------|--|
| Gender and marital status | <ul style="list-style-type: none"> • Partners testing for HIV • Negotiating for safer sex practices • Disclosing of HIV status • The effect of HIV on marriage or relationship • Following PMTCT feeding instructions |

4.6.1. Partners testing for HIV

All the respondents agree that partners of all HIV-positive mothers should get tested for HIV. They emphasized the importance of testing for HIV and that their partners need to get tested and know their status. This was evidenced by one of the participants, who said:

“They need to get tested because they have to know their status”.

The findings show that the participants are aware of the importance of testing for HIV. They also acknowledged the importance of their partner's involvement in HIV testing. If a male does not know his HIV status or about PMTCT, his female partner is less likely to adhere to PMTCT strategies or to engage in PMTCT programmes. Involving men to participate in PMTCT activities is important to the PMTCT programme. This influences women to use PMTCT follow-up services. If both partners are involved, they can both get tested and know their status to ensure and improve their baby's chance of a healthy survival (UNAIDS, 2012). Male involvement is when men choose to go to the clinic with their female partners to support them by getting involved in activities such counselling and testing with their partner (Frizelle *et al*, 2009).

Most women do not feel empowered to ask their partners to undergo an HIV test because they fear the risk of disclosing their HIV status to their partners. Women feel

burdened by clinics' request that their partners be tested. The need for mother to discuss with their partner whether to undergo HIV testing or not is also a factor that leads to rejection of HIV testing (Falnes *et al*, 2011). HIV-positive women whose partners attended VCT are more likely to use treatment and more likely to adhere to the infant-feeding methods that they select. If both partners are involved, they can both get tested and know their status to ensure and improve their baby's chance of a healthy survival (UNAIDS, 2012).

4.6.2. Negotiating for safer sex practices

Most respondents find it easier to negotiate for safer sex practices. They understand the importance of safe sex practice like using condoms to avoid infection. They are able to negotiate for safer sex practices because their partners are supportive and understanding of the risk involved. Three participants from the study could not negotiate for safer sex practices with their partners. They found it hard to negotiate this with their partners. This was evidenced by one of the participants, who said:

“He refuses to use condom and he doesn't have a valid reason, he will think I'm cheating if I say no”

Another participant had this to say:

“He says because he is the father of the child why should he use a condom. I tell him to use a condom but he refuses”

This was supported by a study conducted by Falnes *et al*. (2011), which confirms that women are unable to negotiate safe sex or safe sexual practices with an HIV positive partner. They refused to ask their partners to use a condom despite the knowledge received from clinics about condoms. They claimed to fear negative reactions from their partners. However, the findings show that the majority of the participants were able to negotiate for safer sex practices because their partners are supportive and understanding of the risk involved.

4.6.3. Disclosure of HIV status

The majority of the respondents were able to disclose their HIV positive status to their partners and family. They believe it is important for their partners to know their status. One of the participants had this to say:

“He should know so that he can use protection if he go around sleeping with other women”

Another participant had this to say:

“So that he can know his status because he is the one who infected me”

The findings show that the participants acknowledge the importance of disclosing their status to their partners so that they can practise safe sex. Women who have not disclosed their HIV status fear the reactions of partners or husbands. They feared losing their husbands and the response of other family members, believing that they will be ignored, isolated, openly disgraced and blamed (Frizelle *et al*, 2009; Mitiku *et al*, 2016). This was supported by a study of 199 participants in Soweto, South Africa that women failed to disclose to their partners because they feared rejection from both their partners and their families. Among 31 experiences of disclosure by females in Johannesburg (South Africa), 93.5% of the participants voluntarily told their status to at least one person (Varga *et al*, 2006).

4.6.4. The effect of HIV on marriage or relationship

The respondent provided their opinions and experiences on whether their marriages or relationships were affected by HIV. The majority of the participants agreed that their status does not affect their relationships. They emphasised the importance of communication by disclosing their status to their partners so that they can both know their status. Two participants experienced problems in their relationships. One of the participants had this to say:

“We fought before, he used to disagree and refused to go for testing but he ended up going, so now we fine”

Another participant has this to say:

“Our relationship will be affected because my husband may cheat on me. He may meet another woman without the virus, so I think he would rather be with someone without HIV”

The findings show that disclosing HIV status does not affect relationships. The majority of the participants agreed that their status does not affect their relationships. Mothers whose relationship is affected because of their HIV status may stop

attending follow-up visits because of tension in their relationships. Disclosing HIV status leads to tension and rejection, and mothers are sometime isolated, openly disgraced and blamed for having HIV (Frizelle *et al.*, 2009; Varga *et al.*, 2006).

4.6.5. Following PMTCT feeding instructions

The participants were asked if they are following instructions provided to them by health workers at health facilities. These instructions are provided by nurses or lay counsellors in hospitals or clinics. The findings from this study demonstrated that most of the respondents did not follow instructions to either breastfeed their children exclusively for 6 months or not breastfeed at all. One of the participants had this to say:

“The hospital told me to breastfeed but they did not tell me for how long”

One of the participants who was breastfeeding expressed her feelings that she experienced problems at home from her family when trying to follow instructions from the clinic. This is what she said:

“My family say I should not only breastfed my child, when the child is crying my mother says the child is dehydrating and I should give it water”

Several participants decided not to take the risk of breastfeeding their babies. This is what they said:

“Because of my status I decided to avoid breastfeeding my child”

The respondents were asked a follow-up question about how their partners feel about the feeding instructions from the clinics. Most respondents received support from their partners. One participant complained about her family for lack of support. This is what she said:

“My partner doesn` t have a problem, my family were angry asking why I am not breastfeeding, saying the child need breast milk”

In many developing countries, women do not make independent choices about their own health or that of their babies. Therefore, a mother’s decision regarding her pregnancy and other health issues are deeply influenced by her partners (UNAIDS, 2011). For example, if a male partner disagrees with his female partner’s decision to

exclusively breastfeed or exclusively formula feed then she is unlikely to undergo follow the instructions from health workers (Frizelle *et al*, 2009). However, in this study most of the respondents were supported by their partners and family. The findings further show that participants lacked knowledge about PMTCT feeding practices. Most of the respondents did not follow instructions to either breastfeed their children exclusively for 6 months or not breastfeed at all. A study by Chopra and Rollins (2008) found that poor support and quality counselling by health workers on important PMTCT practices like exclusive breastfeeding and exclusive formula feeding are the reasons why mothers are not follow PMTCT practices. Most health workers report that they do not have enough training or guidelines to share with their patients in terms of giving information about breastfeeding and other practices in the programme.

Initiatives such as ‘mothers2mothers’ (m2m) programme are a source of support most women receive in the PMTCT programme. The m2m programme is there to provide services through mentorship from experienced mothers to provide education and psychological support to pregnant women and new mothers receiving prevention of MTCT services. These initiatives teach pregnant women and new mothers about reducing the risk of transmitting HIV through information on the programme and feeding choices (Department of Health, 2013b; Frizelle *et al*, 2009).

4.7. Cultural and religious beliefs

| Theme | Sub-themes |
|-------------------------|--|
| Cultural factors | <ul style="list-style-type: none"> • The influence of religious beliefs on PMTCT services use • The use of traditional medicines and western HIV medicines (ARV) • The influence of cultural beliefs on PMTCT feeding practices |

4.7.1. The influence of religious beliefs on PMTCT services use

The respondents were asked if their religion allowed them to use PMTCT services. The majority of the participants agreed that their religion allowed them to access PMTCT services. Their religions do not have any problem with the PMTCT

programme, and support the importance of using PMTCT services. This was evidenced by one of the participants, who said:

“They are supportive and understand about HIV”

However, a few participants expressed different views about their religion, that their religion does not allow them to use services against HIV. This was evidenced by one of the participants, who said:

“The church believes that they can help, they can pray for you. I heard them telling one person that they can deal with the virus”

The findings show that religious beliefs did not influence the use of services. All the participants were Christians. The majority of the respondents were supported by their respective churches to use PMTCT services. Church leaders are getting involved in campaigns against HIV infection around world. Beliefs concerning the uptake of services hinder the success of the PMTCT programme. The belief that a new-born infant cannot be taken out of the home until the umbilical cord had fallen off leads to the refusal of the mother in taking the child for postnatal care in the first days following birth because they follow their tradition. Mothers are lost for follow-up services because of beliefs that HIV and MTCT can be cured through prayer feeding (Frizelle *et al*, 2009). There are church leaders who believe that they can cure HIV through prayers (Zou *et al*, 2009).

4.7.2. The use traditional medicines and western HIV medicines (ARVs)

The respondents were asked if it is safer to use traditional medicines than western medicines. All the participants were Christians. They all provided responses that it is not safe to use traditional medicines; instead, they highlighted the importance of western medicines. This was evidenced by one of the participants, who said: *“ARVs are better, you live longer”*.

Another participant had this to say:

“Traditional medicine are not meant for people who are HIV positive, if a patients is using western medicine he or she must not use traditional medicine, no mixing”

Traditional medicines are perceived as unhygienic practices. This was supported by two other participants, who said:

“Traditional healers have herbs with germs and bacteria. Some sangoma can help but not all of them, I heard that one patient was taking her medication and then decided to stop and go use traditional medicine, she got worse”

This was supported by another participant, who said:

“They don’t have dosage; you end up having kidney problems. I saw a person who started drinking herbs, believing that he has been bewitched and did not take treatment”

The findings further show that the participants did not find traditional medicines effective in terms of preventing MTCT. Most of the participants described the importance of western medicines in the PMTCT services. They emphasised the need for western health services as important in reducing the spread of HIV. The participants believed that it is not safe and healthy to use traditional medication for HIV/AIDS prevention. They believed that traditional healers have no knowledge; they are inexperienced and their medications are ineffective in dealing with HIV/AIDS.

A South African survey conducted in 2003 found that 36% of rural adults of those who reported to have had sexually transmitted diseases in the past 12 months had consulted traditional healers for treatment. The following are some of the reasons for the utilisation of such medications: the belief that traditional medicine is safer than ARVs as it does not have side effects (12%), the belief that traditional healers are able to cure diseases that western doctors cannot. However, in most parts of South Africa, traditional health practitioners are more accessible geographically and provide culturally accepted treatment. They often provide education about diseases and illnesses, and when they feel that they are unable to help their patients with traditional medicine, they make referrals to western doctors (Peltzer et al, 2008).

4.7.3. The influence of cultural beliefs on PMTCT feeding practices

Most respondents believed that their culture does not allow mothers to follow PMTCT feeding options which highlight that a mother should exclusively breastfeed their babies for six (6) months or not breastfeed at all. This was evidenced by one of the participants, who said:

“My culture does not support that a child should not be breastfed, I’m referring to how I was raised, and I was breastfed and received food myself”

Another participant had this to say:

“According to our culture a child is supposed to be breastfed until the child grows”

This was supported by three other participants, who said:

“Culture says a baby should be provided with food and water, they say breast milk is different from artificial milk”

“They say a child must be breastfed for long, the duration for breastfeeding is a year”

“In my culture a child should be breastfed for more than 6 months, until the child is right”

The findings show that the participants were not supported by their culture to follow PMTCT feeding practices. The majority of the respondents believe that their culture does not allow mothers to follow PMTCT feeding options, which highlights that a mother should exclusively breastfeed their babies for six (6) months or not breastfeed at all because there are practices that specify how a child should be fed.

According to Doherty (2009), health beliefs related to pregnancy care, delivery and breastfeeding interact with advice received from health workers, affecting the programme. Culturally accepted practices about infant feeding may make it very difficult for a woman to adhere to PMTCT related feeding options. Pressure from male partners/husbands, family members, and the wider community can dominate an HIV-positive woman’s decision not to have a child or utilise PMTCT services (Frizelle *et al*, 2009).

The issue of culture on breastfeeding could be a serious factor hindering the use of PMTCT services, because the service is associated with HIV positive status. Breast feeding doubles the transmission of HIV. Culturally, after delivery a mother is expected to breastfeed immediately. Failure to do so may lead to her in-laws to pressurize her but she may be afraid to reveal her status. This is because these

women may mix feed their infants when they are HIV positive. If their status is hidden and they continue mix feeding, the child stands a higher risk of infection. Without the required knowledge, like the fact that breastfed infants are more likely to become infected than non-breastfed or exclusively breastfed infants, these mothers are bound to infect their infants (UNAIDS, 2015).

4.8. Socio-economic factors

| Theme | Sub-themes |
|-------------------------------|---|
| Socio-economic factors | <ul style="list-style-type: none"> The influence of financial status on the use of PMTCT follow-up service |

4.8.1. The influence of financial status on the use of PMTCT follow-up service

The respondents were asked if they were struggling to access PMTCT follow-up services because of financial reasons. Most of the respondents did not have financial problems when utilising PMTCT follow-up services. Since these respondents lived closer to the clinic, they did not have to spend money for transportation. This was evidenced by one of the participants, who said:

“For me the service is closer, I don’t have to travel”

Four participants experienced financial difficulties when utilising PMTCT services. This is what one of the participants said:

“I need money I have to ask for money I struggle to get money from my partner”

Other participants describe the cost of transportation as an obstacle for accessing PMTCT follow-up services. This was evidenced by one of the participants, who said:

“The distance is a problem I need money for transport. The time for follow-up visits money is not available”

The findings show that not all participants had financial problems in the utilisation of PMTCT follow-up services. Most of the respondents stay closer to the clinic, so they did not spend money for transportation. A qualitative study by Adedimeji *et al* (2012) stated that focus group participants and key informants reported that access to PMTCT services was severely restricted for many low-income women who live on the outskirts and have to travel long distances to reach health facilities. This is

supported by a study of 2930 participants in Malawi (Tenthani *et al.*, 2014) that shows that only 16% of participants claimed that transport money is the reason for stopping taking ART.

4.9 Social Support

| Theme | Sub-themes |
|-----------------------|---|
| Social Support | <ul style="list-style-type: none"> • Support from family • Partner support • Support in terms of feeding options • Support from the community |

4.9.1 Support from family

The respondents were asked if their family support them when they use PMTCT follow-up services. Three participants did not disclose their HIV status to their family, and this what they said:

“I did not tell them yet, my sister talk to too much, and she will tell everyone”

Another participant had this to say:

“I didn’t tell my family because I’m staying with my husband, I am married so there`s no need to tell them and beside my parent are very old”

The majority of the respondents were supported by their family. This was evidenced by one of the participants, who said:

“They don`t discriminate, they also provide me with money for transport”

The findings show that the participants were supported by their families to use PMTCT services. Social support is the perception that entails a sense of caring or assistance from other people. It involves relationships within social networks such as parents, children, extended family members, co-workers, mentors, social workers or other professionals (Lifson *et al*, 2015). Supportive resources can be emotional, financial assistance or informational (Taylor, 2011). Support is important to any human being to provide confidence and a sense of freedom through services which can provide advice and referrals for individuals needing immediate assistance (Holt-Lunstad *et al*, 2010).

Studies around the world have proven that social support is very important for the progression of PMTCT programmes (Frizelle *et al*, 2009; Peltzer & Mlambo, 2010; Shroufi *et al*, 2013). Social support plays a significant role for mothers to use PMTCT follow-up services. In the PMTCT programme, it helps patients cope and enhances quality of life (Frizelle *et al.*, 2009). Mothers can be able to respond adequately to the stress of being infected if they receive adequate support, therefore access PMTCT services for treatment (Shroufi *et al*, 2013).

4.9.2. Support in terms feeding options

The respondents were asked if they were supported with their feeding choices instructed to them by health workers at the clinic. Most of the participants were breastfeeding their babies at the time of the interview, and only a few of the participants were formula feeding their babies. Most of the participants were not supported with feeding options. A mother is supposed to either breastfeed her child exclusively for 6 months or not breastfeed at all. Participants experienced challenges with exclusive breastfeeding. This was evidenced by one of the participants, who said:

“My mother use to enforce that the baby need to eat”

One of the respondents complained about insufficient information from health workers at the hospital, and this what she said:

“The hospital was not supportive about relevant information; they just said I must breastfeed and did not tell for how long”

One of the participants who was not breastfeeding experienced poor support from her family with a feeding option. This is what she said:

“At first my mother was forcing me to breastfeed; my family disagree with my option”

The findings show that the participants were not well supported by their families and the healthcare system. In this study, the majority of the participants were unemployed and without medical aids. Although most participants were breastfeeding, some of the participants were formula feeding. According to nurses at

the clinics, the government no longer provides free formula milk for mothers; therefore mothers have to rely on their families or partners for support.

The findings indicate that the participants were not provided with enough support in terms of their PMTCT feeding choices. A mother may decide to stop following PMTCT practices if she is afraid of reactions by her family or the community (Kalembo & Zgambo, 2012). Research in rural Burkina Faso demonstrated that women who receive positive attitudes from their communities participate in PMTCT practices than women who receive negative. Support from health workers to provide quality service is also an issue affecting the PMTCT programme. Information that is not up-to-date impacts on the service quality due to poor advice and quality counselling by health workers on important programme practices like breastfeeding (Chopra & Rollins, 2008).

4.9.3. Partner support

The respondents were asked if their partner support them when they use PMTCT follow-up services. Two participants did not disclose their HIV status to their partners. This is what she said:

“I didn’t tell him, we are no longer together”

Involving men to participate in PMTCT activities is important in the PMTCT programme. Support from a partner can influence mothers to use PMTCT follow-up services. In this study, the majority of the participants were living with their partner through cohabitation or marriage. The majority of the participants were supported by their partners when accessing PMTCT services.

“He is cooperative an understanding and sometimes he come with me to the clinic”

In addition, the findings show that the participants were supported by their partners to use PMTCT services. Partner support is important in the PMTCT programme as it can influence women to use PMTCT follow-up services. A study of 1325 women found that 721 (54.4%) of women declared very good support from their current male partners during antenatal care follow up. Poor support and no support at all were declared by 37 (2.8%) and 90 (6.8%) of women, respectively (Asefa & Beyene, 2013).

A mother may choose not to use follow-up services because she has to rely on her partner for support. Men who are involved in PMTCT can influence their partners' social environment, which is more encouraging to seeking treatment, being adherent to medications and clinical appointments and remaining in care both during the pregnancy and after delivery. South African men do not involve themselves actively in reproductive healthcare with their partners, and are not typically involved in consulting with their partners around family planning or antenatal issues. Loss of follow up by mothers can decrease if a partner is involved in PMTCT activities (Van Lettow, Bedell & Landes, 2011; Kalembo & Zgambo, 2012).

4.9.4. Support from the community

The respondents were asked if their communities were supportive of their feeding choices instructed by the health workers at the clinic. Community based support is one of the most important form of support for the progression of the PMTCT programme, as poor support from the community can reduce the use of services (Frizelle *et al.*, 2009). Most participants believe that their community is not supportive of the feeding options instructed by the health workers at the clinic. This was evidenced by one of the participants, who said:

“They say you must breastfeed because breast milk is better than formula milk”

Another participant had this to say:

“They say a child needs to eat when hungry, breastfeeding alone is not enough”

The findings show that the participants were not well supported by their community in terms of feeding options advised by health workers at the clinic. Most of the participants believe that their community is not supportive. A woman may choose to carry on breastfeeding even if she is in a position to stop. This behaviour may be influenced by fear of negative reaction from members of her community. According to Busza *et al* (2012), pressure from the community and family members discourages HIV-positive women from abandoning their traditional breastfeeding and weaning patterns.

4.10 Accessibility

| Theme | Sub-themes |
|---------------|---|
| Accessibility | <ul style="list-style-type: none">The influence of geographic location on the use of PMTCT follow-up services |

4.10.1. The influence of geographic location on the use of PMTCT follow-up services

Most respondents were not affected by distance when accessing PMTCT follow-up services. Most of them stay closer to the clinic, so they do not have to spend money for transportation. This was evidenced by one of the participants, who said:

“For me the service is closer, I don’t have to travel”

The findings show that the distance to the health facilities did not affect the use of PMTCT follow-up services. Most respondents stay closer to clinics, so they do not have to spend money for transportation. According to WHO (2012), travelling to clinics is one of the setbacks that limit accessibility of PMTCT follow-up services. Distance to facilities affect HIV testing, the collection of results and other health-seeking behaviours (WHO, 2008). The up-take of services can also be affected by poor transportation in most communities since people are unable to get to relevant treatment sites (Frizelle *et al*, 2009).

A study of 2930 participants in Malawi Tenthani *et al*. (2014) shows that 38% of participants claim travelling as the reason for stopping using ART. Many women live far away from health facilities and might not have access to transportation in their areas. HIV-positive mothers are encouraged to bring their babies for follow-up services at clinics but due to the issue of transport and the distance between their homes and the clinic, they dropout from the programme instead (Kalembo & Zgambo, 2012).

4.11. The Need for health services

| Themes | Sub-themes |
|------------------------------|---|
| The Need for health services | <ul style="list-style-type: none">• Perceptions towards illness |

4.11.1. Perceptions towards illness

The respondents were asked if they need to use PMTCT services. Most participants describe the service as important to them as it provides treatment, and helps prevent MTCT. This was evidenced by one of the participants, who said.

“Helpful in-terms of knowledge from doctors better than the knowledge we get from the street”

Another participant had this to say:

“Help to prevent mother-to-child transmission”

This was supported by another participant, who said:

“Because it help the baby from been infected”

Another participant had this to say:

“Need it for my health and my baby`s health”

One of the participants claimed that she does not need PMTCT interventions. This is what she said:

“I feel fine I do not need to take medication, I feel healthy”

The participants' perceptions towards HIV and MTCT were not found to affect service use. Although the majority of the participants described PMTCT follow-up services as important interventions against the spread of HIV, one participant was not taking medication, claiming that she does not need treatment. A mother might decide not to use follow-up services if she thinks the intervention is not useful. HIV-exposed infants whose mothers do not perceive PMTCT programmes as important experience a delay in diagnosis and are often only identified when they experience severe morbidity or death (Woldesenbet *et al.*, 2010). This is supported by a study of 3030 participants in Malawi (Tenthani *et al.*, 2014), which shows that 229 (40%) participants who were lost to follow-ups were successfully traced, of whom, 10 (4%)

had died. Of the 219 women found alive, 118 (54%) had stopped taking ARV drugs, 67 (30%) and 9 (4%) had treatment interruptions.

4.12. Health Care System Factors

| Themes | Sub-themes |
|-----------------------------------|---|
| Health Care System Factors | <ul style="list-style-type: none"> • Health workers attitude towards patients • Information about PMTCT follow-up activities at the health facilities • PMTCT guidelines and policies • The government`s contribution in the PMTCT programme • Resources to provide PMTCT services |

4.12.1. Health workers attitude towards patients

Respondents were asked to describe how the service was provided to them. Most participants described the service as good and that health personnel were supportive and sympathetic. This was evidenced by one of the participants, who said:

“I was well treated, the clinic is clean and they treat people well”

Another participant had this to say:

“Counselling is good they are always here, they do their service good”

However, one participant complained about the long waiting hours. This is what she said:

“Waiting period are too long, there is no communication”

“Results are been delayed”

The majority of the participants described the service as good and that they were well treated. Although most of the participants received good treatment from health workers, a few participants complained about lack of communication. Patients who are fearful of health care workers are not likely to return for follow-up sessions (Frizelle *et al*, 2009). A study conducted in Ivory Coast discovered that mothers complain that health workers did not attend to them when they had come for follow-up visits. Mothers were afraid of being yelled at by these health workers (Kalembo &

Zgambo, 2012). Quality of PMTCT service could be enhanced by improving communication and other skills of health workers, providing them with greater support and enhancing their motivation (Department of Health, 2010).

4.12.2. Information about PMTCT follow-up activities at the health facilities

The respondents were asked if they were well informed of MTCT and PMTCT activities. Most participants described the information not enough. Knowledge of health personnel about MTCT is good and that health personnel provide support and education. This was evidenced by one of the participants, who said:

Another participant had this to say:

“They didn’t inform me. They didn’t offer me information”

The participants complained about information provided to them by health workers about feeding practices. This was evidenced by one of the participants, who said:

“Was not provided with information about feeding choices”

This was supported by another participant, who said:

“But the information is not complete, because they do not elaborate more about breastfeeding”

“Not well informed about exclusive breastfeeding”

Some of the participants were satisfied about the information provided to them by health workers about feeding practices. This was evidenced by one of the participants, who said:

“Was well informed, they told me to come after 6 weeks for testing they did not inform me about feeding options”

The findings show that the participants were not well informed by health workers at the facilities. Most participants lacked knowledge about feeding practices, especially exclusive breastfeeding. A lack of up-to-date information results in health workers giving poor advice and poor quality counselling on important PMTCT practices like exclusive breastfeeding. A study in South Africa found that clients that enrolled for PMTCT services could not recall the information communicated to them during

counselling. The study found that most of the clients only made use of counselling services once during their first visit and not on successive visits, suggesting limited rapport between providers and clients (Kalembo & Zgambo, 2012).

HIV positive mothers need adequate information to make the right decisions about their health and that of their babies (Kalembo & Zgambo, 2012; Department of Health, 2013). This information can be obtained from, among others, health workers in the PMTCT programme and from other affiliations like mother-to-mother (m2m) programmes (Department of Health, 2008).

However, patients still lack sufficient and adequate information regarding MTCT even with the support from PMTCT programmes. Even when mothers are counselled, they still lacked adequate knowledge about MTCT and fail to understand the importance of attending PMTCT follow-up services or bringing their babies for follow-up visits. A study of 2930 participants in Malawi by Tenthani *et al.* (2014) shows that 10% of the participants who claim that the reason for stopping taking ART is that they lacked understanding of the initial ARV education session.

4.12.3. PMTCT guidelines and policies

The respondents were asked if current the PMTCT guidelines and policies were effective. Most participants described PMTCT guidelines and policies as effective and educational. This was evidenced by one of the participant, who said:

“The guidelines and policies are effective, that why we adhere to treatment, they are educational”

Another participant had this to say:

“They guidelines are working because they are able to prevent Mother-to-Child Transmission, now children can grow without the virus”

The data show that the participants were supportive of current PMTCT guidelines and policies. The majority of the participants had knowledge about current PMTCT guidelines and policies and understood the importance of adhering to treatment. PMTCT related policies are important for the implementation and operation of the PMTCT programmes in order to achieve positive results. Poor PMTCT policies and guidelines may have a negative on the use of follow-up services. It is very important

for policy makers and programme planners to develop good relationships and successfully implement quality programmes that will lead to the achievement of positive results (Chopra & Rollins, 2008).

4.12.4. The government`s contribution to the PMTCT programme

The respondents were asked if the government contributions in providing PMTCT follow-up services for mothers and their babies are effective or satisfactory. The majority of the participants describes the government`s contribution to the PMTCT programme as visible and satisfactory. They highlighted the provision of free treatment as one of the government strongest points. This was evidenced by one of the participants, who said: *“They supply medication for free”*. Another participant had this to say: *“Treatment is free, service is accessible”*.

Other participants described the government`s contribution to the PMTCT programme as not enough. This was evidenced by one of the participants, who said:

“They not doing enough because there are risk of infection”

This was supported by another participant, who said:

“They provide information and with medication but sometimes is not enough”

The findings show that the participants were supportive of the government`s contribution in providing PMTCT follow-up services for mothers and their babies. The majority of the participants underlined the provision of free treatment as an indication that the government is contributing in providing PMTCT follow-up services for mothers and their babies. Although the majority of the participants support the government`s contribution to PMTCT, a few participants were not satisfied. A study in South Africa found that clients complained about inadequate information on PMTCT services, and that they could not recall the information communicated to them during counselling. Access to free healthcare and government social grants can influence women from resource-poor contexts to access PMTCT follow-up services. Poor access to government grants denies women in many resource poor contexts the resources to attend clinic follow-up sessions (Frizelle *et al*, 2009).

4.12.5. Resources to provide PMTCT services

The participants were asked if health care facilities have relevant resources to provide PMTCT services. The majority of the participants claim that health workers do not have enough resources to provide quality services. Although most of the participants were happy with the way health workers treated them at the facilities, most of the participants complained about poor service delivery, and mentioned the following challenges in the use of PMTCT services: shortages of staff, shortages of space and sometimes shortages of medication. This was evidenced by one of the participants, who said:

“Sometimes they don’t have medication; the hospital did not provide me with nevirapine (NVP)”

Another participant had this to say:

“There is lack of staff, you find it only two or one nurse is working and also there is no space, we have to sit outside and use service through the cold.”

This was supported by another participant, who said:

“No space, we stay outside, it is a problem when it rain, we feel cold outside and there is no enough staff”

Other participants had this to add:

“There is shortage of staff and no space, there many people, and we take long sitting here”

“Lack of staff, lack medication, for two moth they keep delaying, there is also no space, waiting room is small”

The findings show that the health care facilities lack relevant resources to provide PMTCT services. Most participants claim that health workers do not have enough resources such staff, space and medications. Shortages of appropriately trained and skilled health workers impacts on the use PMTCT follow-up services (Department of Health, 2008). Shortage of staff and supplies delay HIV testing for mothers and their infants. It affects the quality of service delivery, leading to the drop-out of patients. Shortage of space for counselling and long waiting periods for post-test counselling

results in women leaving without test results; therefore, discouraged from returning (Mute *et al*, 2011). Inadequate spaces for confidential counselling and private disclosure have been found to prevent the uptake of PMTCT follow-up services (Frizelle *et al*, 2009; Mute *et al*, 2011).

4.13. Summary

This chapter discussed the data analysis and interpretation of the findings from in-depth interviews with HIV infected mothers enrolled for PMTCT follow-up services. The demographic data of the participants was outlined. Themes and sub-themes emerged and were discussed, with reference to the literature review. The next chapter, chapter 5, present the data analysis and interpretation of the findings from FGDs with Health workers.

CHAPTER FIVE: ANALYSIS, PRESENTATION AND INTERPRETATION OF THE FINDINGS FROM FOCUS GROUP DISCUSSIONS (FGDS)

5.1. Introduction

This chapter focuses on the findings from FGDs. Two FGDs were conducted at Mankweng Clinic and Mankweng Gateway Clinic. Each focus group consisted of 6 and 5 participants, respectively. Eleven (11) healthcare workers (nurses and lay counsellors) participated in the FGDs. The respondents were approached through clinic managers. Health facility managers were informed by the researcher about the study, and appointments were scheduled with participants (nurse and lay counsellors) for the focus group interviews.

The researcher was introduced to the staff by the clinic manager during the meeting. The researcher approached the participants to discuss the research procedures to be followed. The purpose of the study was explained to each respondent after which they were asked if they were willing to participate in the research. The interview was then conducted after the patients had agreed to participate. To be included in the study the respondents had to be male or female health care providers who had been working in the PMTCT programme for over a year.

5.2. Demographic information

Table 5.1 below shows demographic characteristics of FGDs of the study participants. A total of 11 nurses and lay counsellors from two health facilities participated in the FGDs. The table shows that there were more female participants than their male counterparts. The highest proportions of the participants were above the age of 36, which highlights the level of their maturity and experience in implementing PMTCT follow-up services. Most participants had tertiary education and, therefore, could provide valuable input. The proportion of lay counsellors was very low compared to nurses, which suggests shortages of lay counsellors in both health facilities.

| Demographic information | Frequency | N |
|-------------------------|-------------------------|----|
| Age | Age group of 22-25 | 1 |
| | Age group 26-30 | 1 |
| | Age group 31-35 | 1 |
| | Age group 36-40 | 2 |
| | Age group 46-50 | 3 |
| | Above the age of 50 | 2 |
| Gender | Females | 10 |
| | Male | 1 |
| Marital status | Married | 6 |
| | Single | 5 |
| Occupation | Lay counsellors | 3 |
| | Nurses | 8 |
| Qualification | Matric | 1 |
| | FET/Collage Certificate | 3 |
| | Diploma | 6 |
| | Degree | 1 |

Table 5.1 Demographic information of FGDs

5.3. Qualitative Data Analysis Framework

Themes and categories emerged after the researcher analysed the data from the focus group discussions. During the process, the researcher read and re-read field notes that were taken during the discussions. In order to familiarize himself with the data, the researcher listened to audio recordings taken during the FGDs and compared them with the field notes for more efficient analysis. The researcher then generated the initial codes.

Themes were identified and data was grouped under different themes in accordance with the categories under which it was collected. Eight (8) themes and 17 categories emerged from the analysed data. Relevant quotations from individual participants were used to support the themes. The quotes were discussed and incorporated with literature to support the research findings. The discussion of the findings related to

the problem statement and the objectives of the study. The following are themes identified during the FGDs:

- Knowledge about MTCT of HIV
- Stigma and discrimination
- Cultural factors
- Accessibility
- Social support
- Socio-economic factors
- The need for health services
- Health care system factors

5.4. Knowledge and awareness

| Themes | Sub-themes |
|--------------------------------|--|
| Knowledge and awareness | <ul style="list-style-type: none"> • Knowledge and awareness of MTCT of HIV • Client knowledge of MTCT • Intake of ARVs |

5.4.1. Knowledge and awareness of Mother-to-Child Transmission (MTCT) of HIV

The participants were asked to discuss the possibilities of HIV transmission from an HIV infected mother to her baby. The participants provided adequate knowledge of MTCT of HIV. HIV-positive mothers can transmit HIV to their babies during pregnancy; the foetus is infected by HIV when it crosses the placenta. This was evidenced by one of the participants, who said:

“If there is depression during pregnancy and ruptured of the membrane, transmission can occur through the placenta”

Another participant had this to say:

“If a mother is pregnant and positive and not using treatment”

An HIV-positive mother can transmit HIV to her baby during labour, through the mother's cervical secretions or through blood. This was evidenced by one of the participants, who said: *“During delivery if there is cut, blood can enter to the child”*

Similar responses were provided by another participant, who said:

“An HIV-positive mother can transmit HIV to her baby if there is cut, blood can enter to the child if the mother have a cut”

The transmission of the HIV virus from an HIV infected mother to her baby can also occur during breastfeeding where the baby is infected through the mother's breast milk (or through blood if there is a cut). This was evidenced by one of the participants, who said:

“Breastfeeding and not taking treatment, if the mother is not on long-life treatment”

Another participant had this to say:

“During breastfeeding more especially from six month old babies where they are introduced solid food they develop teeth so they bite the mother, that`s where transmission can occur, from the cut”

The findings show that the participants have knowledge and understanding of MTCT. A study by Balogun and Odeyemi (2010) found that 98.1% of health workers who participated in the study correctly knew HIV to be an infection. When asked to mention modes of transmission of HIV, only 20.4% of spontaneously mentioned transmission from an infected mother to child, however, when probed with a closed question, the proportions that were aware of MTCT increased to 90.7% and breastfeeding was most often mentioned as a possible period of MTCT.

HIV-positive mothers need adequate information in order to make the right decision about their health and that of their babies. This information can be obtained from, among others, health workers. This question was asked to assess knowledge from health care workers regarding MTCT. Providing quality service is an issue affecting the PMTCT programmes. Information that is not up-to-date impacts on service quality due to poor advice and quality counselling by health workers on important programme practices like breastfeeding can affect service use (Chopra & Rollins, 2008).

5.4.2. Clients` knowledge of Mother-to-Child Transmission

The respondents were asked if they think HIV-positive mothers understand the possibility that they can transmit the HIV virus to their babies. The following responses were given:

“Yes but not 100%”

“Some have this belief that they go somewhere and be cured, that a priest pray for them”

Another participant had this to say:

“Clients do not disclose their status to their family at home, hence they are forced to give their babies medication. So they find it hard to give the child medication in front of family members because they haven’t disclosed their status, so to avoid disclosure of their HIV status they stop treatment”

By contrast, other respondents believe that their clients have knowledge about the methods of PMTCT. Clients are provided with education in health facilities. This was evidenced by one of the participants, who said:

“They have that knowledge, through education at the facility”

The findings further show that clients have knowledge and understanding of MTCT. Most participants emphasized the importance of educating clients at the health facilities. This is supported by a study conducted in Polokwane by Maputle and Jali (2008) which found that mothers have knowledge about MTCT from hospitals and from lay referral.

5.4.3. Intake of medication

This study revealed that participants were aware that the implementation of ARVs plays a significant role as a strategy utilised to prevent HIV transmission from HIV infected mothers to their babies. This was evidenced by one of the participants, who said:

“Immediately when the clients come to clinic, and get tested, and then find that she is positive, she is provided with treatment”

Another participant had this to say:

“Intake of ARVs is a lifelong treatment”

ART (ART) is the use of HIV medicines to treat HIV infection. ART is recommended for everyone infected with HIV. ART helps people with HIV to live longer, healthier lives. HIV medicines reduce the amount of HIV in the body. Having less HIV in the body reduces a woman's risk of passing HIV to her child during pregnancy and childbirth (Department of Health, 2013). The participants agreed that their clients are taking treatment. This was evidenced by one of the participants, who said:

“In the past clients were not following treatment but now because of education they follow treatment”

The findings show that the participants have knowledge about the importance of ARVs intake as a basic strategy that helps mothers from transmitting HIV to their babies. Participants also emphasize the importance of educating their clients to ensure that they prevent MTCT by adhering to treatment. Follow-up services help identify HIV infected babies and initialize ARVs medications for infected children (Kalembo & Zgambo, 2012). Failure to comply with ARV's medications and prophylaxis as well as follow-up to clinic visits for medication re-supply and other PMTCT services disrupt the interventions in the course to eliminating paediatric HIV infections (Department of Health, 2013b; Kalembo & Zgambo, 2012).

5.5 Stigma and discrimination

| Themes | Sub-themes |
|----------------------------------|--|
| Stigma and discrimination | <ul style="list-style-type: none">• Treatment of patients at the health facilities• Stigma at home or communities |

5.5.1. Treatment of patients at the health facilities

The participants were asked how patients are treated in the facilities. People living with HIV are supposed to be provided with high-quality care, treated with respect and compassion at health facilities. The respondents were asked to describe how they provide equal services for their clients at the facilities, and the following responses were given: *“They are all provided with treatment, we don't discriminate”*

Another participant had this to say:

“We use the supermarket approach, any day any time we provide treatment”

HIV stigma refers to beliefs and attitudes that deeply discredit a person or group of people because of association with HIV or AIDS. HIV related discrimination is the unfair treatment of an individual based on his or her HIV status. Participants were asked a follow-up question on whether clients experience stigmatisation at the facilities and the following responses were provided:

“They don’t experience stigma”

Another participant had this to say:

“People nowadays have accepted”

Stigma and discrimination against people living with HIV can be seen as obstacles in the way to the effective response to HIV. People who have are associated with HIV often experience negative attitudes and harmful actions from other patients at healthcare facilities, and this can discourage them from accessing services and adhering to treatment (Kalembo & Zgambo, 2012). The findings show that clients are treated well at health facilities. The data also emphasize that clients do not experience stigma or discrimination from other patients.

5.5.2. Stigma at home or communities

The respondents were asked if they think mothers experience stigma at home or community, and the following response was given:

“Some experience stigma at home and even in the communities”

Most respondents were not sure whether their clients experienced stigma at home or their communities. Most participants emphasised that clients do not experience stigma or discrimination from other patients. HIV-positive mothers avoid PMTCT follow-up services and HIV treatment because they believe women living with HIV in their community experience stigma and discrimination when they use HIV-related services (Kalembo & Zgambo, 2012). Women are unwilling to test for HIV because they fear negative reactions from the families, more especially from their partners. They are also afraid of being discriminated against by their community.

5.6. Cultural and religious beliefs

| Themes | Sub-themes |
|-------------------------|---|
| Cultural factors | <ul style="list-style-type: none">• Religious beliefs and the use PMTCT services• Beliefs about who can manage HIV better• Client`s reaction to feeding practices |

5.6.1. Religious beliefs and the use PMTCT services

The respondents were asked if religious beliefs of clients enrolled in the PMTCT programme affect the use of services at their facilities, and the following responses were given:

“They are those religious beliefs that are stopping clients from getting treatments, we don`t usually ask them which church a person will just say my pastor will pray for me”

Another participant had this to say:

“Last week I have spoken to client on Thursday, like he came carrying a letter from another clinic and he is from Hammanskraal so he came to me with his girlfriend and said he is here to take treatment, so while we were talking I checked which treatment he was taking, so this person has been taking treatment for so long, and said he was also using another treatment in a form of water for three days and then collapsed”

The use of PMTCT follow-up services is hugely affected in most African counties by widespread cultural beliefs about HIV. There is a belief that HIV results from bewitchment or spiritual forces and alternative treatments may be recommended because of their prevailing norms and traditional views (Varga & Brooks, 2008). The findings show that there is evidence of religious beliefs from patients that influence the use of services. However, most participants indicated that they do not find religious beliefs as a challenge to the use of PMTCT follow-up services at the facilities. They emphasise the importance of educating clients on adhering to western medicine at the facilities.

5.6.2. Beliefs about who can manage HIV better

The respondents were asked to describe who they think clients believe can manage HIV better (whether is western medicine doctors, traditional healers or priests) and the following responses were given:

“Some clients end up understanding that health workers are the one who can manage HIV better”

Another participant had this say:

“Clients now understand that health workers are more informed to treat HIV”

In this study, the findings show that the majority of the participants believe that their clients support healthcare workers in the fight against HIV and MTCT. A survey conducted in South Africa by Peltzer *et al* (2008) found that 36% of rural adults of those who reported to have had sexually transmitted diseases in the past 12 months have consulted traditional healers for treatment. They believe that traditional medicine is safer than ARVs as it does not have side effects (12%); they believe that traditional healers are able to cure diseases that western doctors cannot.

5.6.3. Client`s reaction to feeding practices

In the PMTCT, a mother is supposed to either breastfeed the child exclusively for only 6 months or not breastfeed at all. The informants were asked to describe how clients reacted to the feeding instructions provided by health workers at the clinics, and the following responses were given:

“Some you find they have fear of disclosing at home”

Other participant had this to say:

“It depends, if the client disclose in the family, they family complain that the child is crying get him or her food, so they end up giving the child food and then breastfeed, so if not breastfeeding they will ask why not breastfeeding”

“They create excuses if they not ready to disclose and provide good explanations”

Findings show that there is clients experience challenge in terms of feeding practices. Participants highlighted the issue of disclosure as a challenge faced by mother in terms of feeding practices. PMTCT practices are vital to ensure the success of the PMTCT programme (Kalembo & Zgambo, 2012). Feeding practices play a significant role in reducing the spread of HIV from a mother to a child especially during breastfeeding. It is important for mothers to know about feeding methods after giving birth (WHO, 2015). Culturally accepted practices about infant feeding may make it very difficult for a woman to adhere to PMTCT related feeding options. Pressure from male partners/husbands, family members, and the wider community can dominate an HIV-positive woman’s decision not to follow PMTCT practices (Frizelle *et al*, 2009).

5.7. Accessibility

| Themes | Sub-themes |
|---------------|---|
| Accessibility | <ul style="list-style-type: none"> The effect of distance on service use |

5.7.1. The effect of distance on service use

Geographical location health care facilities can have contributed to access to and utilisation of health services in this population. Respondents were asked if the distance between the clinics and clients affect service use and the following responses were given:

“Clients reside close to the clinic and hospital”

A few participants complained that they face challenges with patients who do not use their local clinics. This is what she said:

“Clients that are local do not pose a problem, the problem is clients who stay far and don’t want to go to their local clinic so they decide to come to other clinics, the problem is transport”

Another participant had this to say:

“There are those patients who don’t want to use the clinics at their communities so they come here at our clinic, they are the one who are affected”

“we experience challenges of loss to follow-up of patients, especially clients who are not local, like for example, University students, when they pass their degrees they leave and never come back”

The majority of the participants agreed that the distance between the clinic and the client`s residence is not a challenge since most participants reside closer to the health facilities. However, the findings also show that access to health care facilities affects patients who travel distances from their community clinics to use services at other communities. A study by Leach-Lemens (2016) found that patients seeking care at other facilities elevate loss to follow-up. The study found that, 50% successfully traced patients who were loss to follow-up continued care at a new facility. Of these, close to three quarters were often suspending care for extended periods of time.

Patients who travel distances from their community clinics to use services at other communities are influenced by a number of factors. A study by Masango-Mthakgobela, Govender and Ndimande (2013) found that eighty per cent (281) of the patients had visited their nearest clinic previously and 54 of these (19.2%) said they would not return. The reasons for this were: long waiting time (88; 25.1%); long queues (84; 24%); rude staff (60; 17%); and lack of medication (39; 11.1%).

Distance to facilities and the cost of transportation affect testing, the collection of results and health-seeking behaviours (WHO, 2008). Some women have to visit multiple departments in a single day with long waiting times, and have to visit the hospital on several different days. A situation analysis of PMTCT services in the Eastern Cape Province (South Africa) found that in rural underdeveloped areas, there may be only one main road, while secondary roads are gravel, making it difficult to cross during rainy seasons. Under such circumstances, reaching a clinic may be difficult or impossible (Kalembo & Zgambo, 2012).

5.8. Social support

| Themes | Sub-themes |
|-----------------------|---|
| Social support | <ul style="list-style-type: none">• Challenges faced by the programme in terms of feeding choices for mothers• Support for mothers in terms of feeding options |

5.8.1. Challenges faced by the programme in terms of feeding choices for mothers

Usually in PMTCT, a mother is supposed to either breastfeed the child exclusively for only 6 months or not breastfeed at all. The respondents were asked if clients are supported in terms of their feeding options. The following responses were given:

“The challenges that they face now are that of exclusive formula feed because you may find that the mother is poor financially, and end up giving the child diluted milk”

Another participant had this to say:

“You find that maybe the mother want to breastfeed but because of her viral load is not possible, we don’t encourage breastfeeding if the virus is not suppressed”

Only few participants agreed that clients were experiencing challenges in-terms of their feeding options. The findings show that most clients were not experiencing challenges in terms of feeding choices. One of the participants mentioned that exclusive formula feeding is one of the challenges due to financial constraints of clients. Patients are struggling to follow instructions given to them by their doctors because they are under financial constraints to purchase relevant resources to perform the instruction given to them. For example, a woman’s ability to rapidly stop breastfeeding is either because she will not have the money to purchase formula feed to replace breast milk, or because the clinic has run out of formula feed (Department of Health, 2008).

5.8.2. Support for mothers in terms of feeding options

The respondents were asked if mothers were supported with their feeding choices. Most participants claim that clients are well supported with feeding options. A mother is supposed to either breastfeed her child exclusively for 6 months or not breastfeed at all. One of the participants claimed that other clients experienced challenges with exclusive breastfeeding. This is what she said:

“Not really because some clients will be asked to give their babies water, add soft porridge or something like that at home because they don’t understand the importance of exclusive breastfeeding”

Clients were encouraged to breastfeed because the government no longer provides free formula milk for mothers; therefore mothers have to rely on their families or partners for support: One of the participants had this to say:

“They get support from partner; the government is no longer providing milk”

The findings show that most mothers were supported with feeding choices. Support from health workers to provide quality service is also an issue affecting the PMTCT programme. Financial constraints often hamper a woman’s ability to rapidly stop breastfeeding, either because she will not have the money to purchase formula feed to replace breast milk, or because a clinic has run out of formula feed. In South Africa, mothers may not have the finances to continue purchasing formula feed after six months, when the government stops providing free formula (Department of Health, 2008).

5.9. Socio-economic factors

| Themes | Sub-themes |
|-------------------------------|--|
| Socio-economic factors | <ul style="list-style-type: none">• Financial status of clients and the use PMTCT follow-up services |

5.9.1. Financial status of clients and the use PMTCT follow-up services

The respondents were asked if the financial status of clients affect the use PMTCT follow-up services, and the following responses were given:

“No, most our clients stay closer to the facilities, so they spend much for transportation”

Another participant had this to say:

“Our clients are local, some travel by foot to access service”

One of the participants pointed out that clients who experience challenges with transportation costs are those clients who choose not to use their local clinics and travel far to use the service. This is what she said:

“Those that are staying locally there is no problem the problem is that of those that are stay far and they don` t want to go to their local clinic so they decide to come to other clinics, the problem is transport”

It was found that socioeconomic factors have influence on service use. The majority of the participants agreed that clients were not affected by financial problems. Patients fail to attend follow-up appointments due to transportation and costs. Primary health care services in most South African health care facilities are free. Socioeconomic factors such as poverty and geographical relocation influence a mother`s decision to comply with the PMTCT follow-up activities (Kalembo & Zgambo, 2012).

5.10. The need for health services

| Themes | Sub-themes |
|-------------------------------------|--|
| The need for health services | <ul style="list-style-type: none">• Clients` perception toward illness |

5.10.1. Clients` perception toward illness

The respondents were asked if they think clients believe PMTCT follow-up services are important in reducing the spread of HIV, and one of the responses was:

“Yes they believe in that because after 10 weeks they will be eager to test their children to find out if they are really negative or not”

One participant stated that one of her clients has negative perceptions of PMTCT interventions. This is what she said:

“One participant refuses to take treatment, she was counselled several time by multiple nurses and then she came after three days and told us that her child has died, she was not taking treatment, she did not adhere to the

instructions and claim that her man doesn't have the virus so she doesn't have it too"

The findings show that perceptions toward illness were found not to have influence on service use. Most participants agreed that clients were well informed about the importance of PMTCT services and adhering to treatment. It is important for HIV infected mothers to bring their infants to health facilities for follow-up visits (WHO, 2010; Department of Health 2010). HIV testing during follow-up visits determines whether their babies have been infected with the virus or not. Follow-up services are important for mothers and their HIV exposed babies to prevent the transmission and to optimize maternal and infant outcome (UNAIDS, 2010, WHO, 2011).

5.11. Health Care System Factors

| Themes | Sub-themes |
|-----------------------------------|--|
| Health Care System Factors | <ul style="list-style-type: none"> • Challenges that participants face when providing services • Encountering difficult patients • PMTCT guidelines and policies • Resources to provide PMTCT services |

5.11.1. Challenges that participants face when providing the PMTCT follow-up services

The respondents were asked if they experience challenges when they provide PMTCT services, and the following response was given:

"Challenges is loss to follow-up, those clients who are not local, like students when they pass they leave and never come back"

The findings show that most participants agreed that they did not face challenges when providing PMTCT service use. They mentioned loss of follow-ups from students, especially from the university at one of the facilities. The increasing loss of follow-up is a major set-back in sub-Saharan Africa (WHO, 2010; Department of Health, 2013b). Estimated between 20-28% loss of follow-up during ANC, up to 70% of the mothers are loss of follow-up four months after delivery, and close to 81% at six months after delivery (UNAIDS, 2010; WHO, 2011). A study done in Nigeria by Rawizza *et al* (2012) has revealed that 10 078 (52%) clients from 19,303 women

entering PMTCT care during the antenatal period completed the entire cascade of services. However, in prenatal care, only one infant follow-up visit was registered.

5.11.2. Encountering difficult clients

The respondents were asked if they experience challenges when they provide PMTCT services, and this is one of the responses:

“Some patient decide to take treatment and then not use it or hide it at home because they did not disclose at home and not take treatment”

Another participant had this to say: *“One participant refuses to take treatment, she was counselled several time by multiple nurses and then she came after three days and told us that her child has died, she was not taking treatment, she did not adhere to the instructions and claim that her man doesn` t have the virus so she doesn` t have it too”*

Most participants agreed that they never encountered difficult patients when they were providing PMTCT services. The findings show that most participants were able to listen to healthcare workers and followed instructions provided to them. It is important that HIV infected mothers adhere to instructions provided to them by health care workers and to bring their babies for follow-up visits. HIV-exposed infants whose mothers do not access the PMTCT programme experience a delay in diagnosis and are often only identified when they experience severe morbidity or death (Woldesenbet *et al*, 2010).

5.11.3. PMTCT guidelines and policies

The respondents were asked if PMTCT guidelines and policies are effective, and this is one of the responses:

“Yes, the PMTCT guidelines and policies are effective”.

All the participants agreed that they are satisfied and well informed about PMTCT policies and guidelines. PMTCT related policies are important for the smooth implementation and operation of the programmes to achieve positive results. Therefore, poor policies may affect the programme negatively, resulting in an increasing number of losses to follow-up in the PMTCT programme (Chopra & Rollins, 2008). It is very important for policy makers and programme planners to

develop good relationships and to successfully implement quality programmes in order to achieve positive results. However, the success and scaling-up of PMTCT follow-up services has been compromised in various facilities due to poor communications between the government, PMTCT service providers and other parties involved (WHO & UNICEF, 2007).

5.11.4. Resources to provide PMTCT services

The respondents were asked if they experience challenges when they provide PMTCT services, and this is one of the responses given:

“We have shortage of staff”

The shortage of appropriately trained and skilled health workers impacts on the use of PMTCT follow-up services (Department of Health, 2008). The shortage of staff and supplies delay HIV testing for mothers and their infants, thereby affecting the quality of service delivery, which leads to the drop-out of patients. Another participant had this say: “Shortage of space, we need a new clinic”

Most participants agreed that they experience shortage of staff and space at the facilities. The findings show that participants could have experienced challenges when providing services. Studies conducted in Uganda and Kenya revealed that shortage of PMTCT staff and shortage of space for counselling are some of the reasons leading to loss of clients in PMTCT programmes (Mute *et al*, 2011). Lack of trained lay counsellors has been found to prevent a number of people who receive services like VCT. In other hospitals, nurses provide all counselling and related HIV services, with a single nurse per facility running the PMTCT programme and offering all HIV counselling.

5.12. Summary

This chapter discussed the data analysis and interpretation of the findings from Focus Group Discussions with Health workers who are responsible for the implementation PMTCT programme. The demographic data of the participants was outlined. Themes and sub-themes emerged and were discussed, with reference to the literature review. The next chapter presents the summary, conclusions, limitations of the study, and makes recommendations for the study and for further research.

CHAPTER SIX: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter presents summary of the research findings, the conclusions of the findings and recommendations for improving PMTCT follow-up services, including recommendations for future studies.

6.2 Summary of the study

This study investigated barriers that influence the use of PMTCT follow-up services. Poor uptake of Prevention of Mother-to-Child Transmission (PMTCT) follow-up services by HIV positive mothers and their babies is a major challenge in the success of the PMTCT programmes (Kalembo & Zgambo, 2012). The aim of the proposed study was to explore barriers influencing the use of PMTCT follow-up services at Mankweng Clinics. The following were the objectives of the study:

- To identify the severity of predisposing factors (stigma, knowledge and awareness) on the use of PMTCT follow-up services.
- To determine the effect of enabling factors (socio-economic status, social support) on the use of PMTCT follow-up services.
- To establish the influence of need factors (perception towards illness and health service) on the use of PMTCT follow-up services.
- To ascertain the effect of the healthcare system (infrastructure, shortage of staff) on the provisions of PMTCT follow-up services.

6.2.1 Research methods and design

A qualitative approach and a cross-sectional research design were used. A total number of 26 participants (n=26) were interviewed. In-depth interviews were conducted with fifteen (15) HIV-positive mothers who were enrolled for PMTCT follow-up services and eleven (11) health workers (nurses and lay counsellors) in both Mankweng Gateway Clinic and Mankweng Clinic in the Capricorn District, Limpopo Province. A thematic analysis method was employed. The study was based on the Anderson Behavioural Model (ABM), which guided the construction of both the in-depth interview schedule and the focus group discussions.

6.2.2 Demographic characteristics

Demographic variables such as age, marital status, religious affiliation and level of education have an influence on the use of PMTCT follow-up services. The findings from in-depth interviews with HIV infected mothers show that majority of the participants were between the ages of 26 to 35, and 40% were single, 33% were cohabiting and 27 % were married. Of these respondents, 54% achieved secondary and tertiary education 13% had and tertiary education, and 73% were unemployed. A total of 11 nurses and lay counsellors from two health facilities participated in the focus group discussions (FGDs). There were more females compared to males. The highest proportions of the participants were above the age of 36, and most of the participants had tertiary education.

6.2.3 Findings of the study

This section summarises the extent to which the objectives of the study were achieved in alignment with the research findings. Each objective will be listed, and conclusions will be made in relation to the objective.

6.2.3.1 The severity of predisposing factors on the use of PMTCT follow-up services

The first objective of this study was to identify the severity of predisposing factors (knowledge and awareness, stigma, cultural beliefs, gender and marital status) on the use of PMTCT follow-up services. On the basis of the Anderson Behavioural Model (ABM), predisposing factors have an influence on the use of healthcare services. Knowledge and awareness of how a mother can transmit HIV to her baby was significantly low among key participants. Although the participants were aware that an HIV-positive mother can transmit HIV to her baby, the majority of the participants had no knowledge of how an HIV infected mother can transmit HIV to her child during pregnancy, labour and breastfeeding.

The findings of the study suggest that the respondents were aware of interventions that help mothers to prevent MTCT of HIV. However, the majority of the participants had insufficient knowledge about feeding practices. The majority of the participants were breastfeeding and understood the benefits of breastfeeding and treatment adherence. However, participants fail to adhere to exclusive breastfeeding, most of the participants were not aware of the required duration for a mother to exclusively

breastfeed her child. The participants showed little understanding about the danger of continued breastfeeding, and lack awareness of the risks involved in replacement feeding.

Stigma and discrimination still exist in the community and this can cause delays for mothers to access health care services. Although most respondents pointed out that people living with HIV are treated badly in their communities, the majority of the participants did not personally experience stigma or discrimination. Fear of stigma and discrimination from the community is a significant barrier in the use of PMTCT follow-up services. More awareness activities are needed in communities to control stigma and discrimination.

Cultural beliefs can delay the use of postnatal PMTCT follow-up services. All key participants were Christians and agreed that their churches support them to use PMTCT services. The majority of the participants believed that it is not safe to use traditional medication for HIV/AIDS. They believed that traditional healers are not well trained, have no knowledge, are inexperienced and their medications are unhygienic and ineffective in the war against HIV and MTCT. Furthermore, the participants were convinced that their community is not supportive of their feeding practices instructed by the health workers at the clinics. They stated that their culture does not allow a mother to follow PMTCT feeding options. Education and awareness activities are required in the community to control cultural beliefs that are against PMTCT follow-up activities.

Gender and marital status can influence mothers' decisions to access PMTCT follow-up services. In this study, the majority of the respondents were able to disclose their HIV status to their partners and their families. It was easier for most participants to negotiate for safer sex practices. The participants understood and were aware of the prominence of safe sex practices like using condoms in order to avoid infection. The respondents also supported their partners to undergo HIV testing, and that it is important for partners to know their status. Most respondents were supported by their partners and agreed that their status does not affect their relationships. They also emphasized the importance of communication in their relationships.

6.2.3.2 The effect of enabling factors on the use of PMTCT follow-up services

Social support was provided for most of the respondents by their partners and families. There were only few participants who did not disclose their HIV status to their partners and families. The majority of the participants were not well supported with relevant information regarding various feeding options. The participants experienced challenges of insufficient information concerning exclusive breastfeeding. The findings emphasise that participants were not well supported in terms of information about feeding practices at the health facilities.

The findings show that most participants were unemployed, and therefore could not afford formula feeding, and have to rely on their partners or families for financial support. These socio-economic factors can delay the use of PMTCT follow-up services. Formula feeding practices are expensive and require mothers to be financially stable; support from the government to provide free formula milk for mothers has been cancelled. In terms of geographical location of health facilities, the majority of the respondents reside closer to the clinics; therefore spend less money for transportation. Although accessibility to health care facilities was not a problem for most participants, there are challenges with respect to patients who did not use their local clinics and who travel distances to access follow-up services at the facilities.

6.2.3.3 The influence of need factors on the use of PMTCT follow-up services

Mothers who understand the nature of HIV and its outcomes are able to bring their infants to health facilities for follow-up visits. One of the objectives of this study was to establish the influence of need factors (perceptions towards illness and health service) in the uptake of PMTCT follow-up services. The findings show that the majority of the participants perceived PMTCT follow-up services as important to them, and that PMTCT initiatives are crucial against the spread of HIV. The participants assert that they were well informed about the need for PMTCT follow-up services and adherence of treatment.

6.2.3.4 The effect of the healthcare system factors on the provisions of PMTCT follow-up services

The government's contribution to the PMTCT programme was viewed as visible and satisfactory by most participants. The provision of free treatment was highlighted as one of the government's strongest point. The findings show that the participants were well treated by health workers; and that healthcare workers were caring and sympathetic. However, the participants complained about insufficient information from health workers. The majority of the participants described information relating to important PMTCT practices like exclusive breastfeeding as insufficient. Shortage of staff and space were the most occurring themes in the study. These Healthcare system factors can influence the use of postnatal on PMTCT follow-up services.

6.3. Recommendations

Based on the findings of the study, the following recommendations are made to promote the use of PMTCT follow-up services.

- Educational and awareness programmes need to be made or strengthened on the health risks.
- There is a need to conduct further health education for mothers and to counsel them individually at all clinic visits about the importance of exclusive breastfeeding and exclusive formula feeding in the first six months of children's lives. During health education, the dangers of mixed feeding should be strongly emphasised.
- More campaigns should be arranged and organised to raise community PMTCT awareness. Health education on HIV and PMTCT to all people utilising the clinics and the community help reduce the level of stigma and discrimination.
- Mass campaign media should be organised to provide information on the importance of PMTCT activities. For example, through the use of community radio stations, TV, newsletters, bill boards etc. People need to know more about PMTCT activities.
- Staff training and re-training. The researcher recommends that more staff should be appointed in order to alleviate shortages. The Department of Health should recruit more counsellors and nurses. This will reduce waiting time.

6.4. Recommendations for further research

The findings of this study suggest that future researchers could investigate the following:

- A duplicate study on barriers influencing the use of PMTCT follow-up services in other districts and provinces.
- Studies could investigate the knowledge level of HIV infected mothers in the PMTCT programme.
- Explore social behaviour issues that influence HIV infected mothers to mix feed their infants.
- Investigate experiences of HIV infected mothers in utilising PMTCT services.
- To identify challenges of treatment adherence by mothers enrolled in the PMTCT programme.
- Further research on reasons for breast-feeding.
- More research on the effect of non-disclosure of HIV status to partners and families.
- Investigating the influence of unemployment on health seeking behaviours for HIV infected mothers.

6.5. Limitations of the study

The study was limited to Mankweng Complex in Limpopo Province and the findings could not be generalised to all public clinics. Key respondents were HIV infected mothers and the subject matter was sensitive. Hence, the participants could have provided less detailed information. The study was supposed to conduct FGDs with seven participants in each of the two groups. However, due to staff shortages, the researcher was able to conduct the discussions with six and five participants in the two respective groups. At the time of the first FDGs, one participant was not available for participation as she was on leave.

6.6. Concluding remarks

This study and other studies from other countries in Africa and the world have demonstrated barriers influencing the use of PMTCT follow-up services, which consequently results in lost to follow-up of HIV infected mothers and their babies. Experiences of stigma and discrimination in the study were very minimal, but serious. Stigmatisation and discrimination are found to be vital barriers to the

ineffectiveness of PMTCT programmes. This includes several other barriers that were analysed in the study such as; knowledge and awareness of MTCT and PMTCT feeding practices, socio-economic factors, social support, cultural factors and accessibility, and Health care factors such as; shortage of staff and space and insufficient information from health workers. Poor support from health care providers in terms of sufficient information about MTCT and PMTCT feeding practices may have resulted in the low knowledge and awareness amongst mothers in the programme. Therefore, the importance of utilising PMTCT follow-up services, people need to be well educated to prevent and eliminate HIV transmission from HIV infected mothers to their babies. This benefit is not for the children alone, but also for mothers and the community at large, in the quest to achieve goal 3 of the SDGs. The fight against HIV transmission from a mother to her child is progressing in the right direction. But there is still more to be done to eliminate new infections.

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APPENDIX A

FACE-TO-FACE INDIVIDUAL IN-DEPTH INTERVIEWS

(Key participants/Mothers)

INTRODUCTION

Thank you for agreeing to participate in this study. My name is Refilwe Ramoshaba. I am a Master of Arts (MA) student in Sociology at the University of Limpopo. I am conducting a study on **Barriers influencing the use of Prevention of Mother-to-Child Transmission (PMTCT) follow-up services at Mankweng clinic**. The information you provide will be treated with the utmost confidentiality and will only be used for the purposes of this study. Some of the questions will be very personal and sensitive. To assure your anonymity, your name will not appear on this form, and the information you provide will not be used against you. The interview will take approximately 45 minutes

Section 1: Demographic information

1. Age

| | |
|------------------|---|
| 18-21 | 1 |
| 22-25 | 2 |
| 26-30 | 3 |
| 31-35 | 4 |
| 36-40 | 5 |
| 41-45 | 6 |
| 46-50 | 7 |
| Others (specify) | 8 |

2. Marital status

| | |
|------------------|---|
| Never Married | 1 |
| Married | 2 |
| Divorced | 3 |
| Separated | 4 |
| Co-habiting | 5 |
| Others (specify) | 6 |

3. Are you employed?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

4. Please specify below, which category you belong

| | |
|------------------|---|
| Teacher | 1 |
| Bank teller | 2 |
| police | 3 |
| nurse | 4 |
| Others (specify) | 5 |

5. How much do you earn every month?

| | |
|-------------|---|
| R100-R1000 | 1 |
| R1001-R2000 | 2 |
| R1501-R2000 | 3 |
| R2001-R3000 | 4 |
| R3001-R4000 | 5 |
| R4001-R5000 | 6 |
| R5001-R6000 | 7 |
| R6001-R7000 | 8 |

| | |
|------------------|----|
| R7001-R8000 | 9 |
| R8001-R9000 | 10 |
| Others (specify) | 12 |

6. Educational Level

| | |
|----------------------|---|
| Never went to school | 1 |
| Primary level | 2 |
| Secondary level | 3 |
| Tertiary level | 4 |
| Others (specify) | 5 |

7. What is your Religion?

| | |
|---------------------|---|
| Christianity | 1 |
| African traditional | 2 |
| Islam | 3 |
| Buddhism | 4 |
| Others (specify) | 5 |

8. Do you have a medical aid?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

9. If no, please explain

.....

Section B: Barriers influencing the use of Prevention of Mother-to- Child Transmission (PMTCT) follow-up services

Predisposing factors

Knowledge and attitude towards the PMTCT programme

10. Can an HIV-positive mother transmit HIV to her baby?

| | |
|--------------|---|
| Yes | 1 |
| No | 2 |
| I don't know | 3 |

11. If yes, how can a mother transmit HIV to her child after birth?

.....

.....

.....

12. At what stage could a mother transmit HIV to her child?

| | | |
|---------------------------|-----|---|
| During pregnancy | Yes | 1 |
| | No | 2 |
| During delivery or labour | Yes | 3 |
| | No | 4 |
| During breastfeeding | Yes | 5 |
| | No | 6 |

13. Do all babies born to HIV positive mothers always become infected with HIV?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

14. Support your answer

.....

.....

.....

.....

15. How can Mother-to-Child Transmission of HIV be prevented?

.....

.....

.....

.....

16. Are you aware of any intervention that helps women to prevent mother-to-child transmission of HIV?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

17. If yes, please identify and explain what the programme entails?

.....

.....

.....

.....

18. Does the use of anti HIV drugs prevent mother-to-child transmission of HIV?

| | |
|--------------|---|
| Yes | 1 |
| No | 2 |
| I don't know | 3 |

19. If yes, please explain?

.....
.....
.....
.....

20. Do you think HIV positive women should breastfeed their babies?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

21. Please support your answer

.....
.....
.....
.....

22. If yes, how long can a mother breastfeed her baby and why?

.....
.....
.....
.....

Stigma and discrimination

23. How are people living with HIV treated in your community?

.....
.....
.....

24. Have you ever experienced stigmatisation because of your HIV status?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

25. If yes, please explain what happened

.....
.....

26. How did you deal with the stigma?

.....
.....

27. Have you ever experienced discrimination because of your HIV status?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

28. If yes, please explain what happened

.....
.....

29. How do you deal with the discrimination?

.....
.....
.....

Gender and Marital status

30. What role does a partner play in the PMTCT programme?

.....
.....

31. Should partners of all HIV-positive mothers be tested for HIV?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

32. Please support your answer

.....
.....
.....

33. Do you find it easy to negotiate for safer sex practices?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

34. If no, please explain why?

.....
.....

35. Will you disclose your HIV positive status to your partner?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

36. Please support your answer

.....
.....
.....

37. Do you think being HIV positive will affect your marriage?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

38. Please support your answer

.....
.....
.....

39. Usually in PMTCT a mother is supposed to either breastfeed the child exclusively for only 6 months or not breastfeed at all. Did you or are you currently following these instructions?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

40. Please support your answer

.....
.....
.....

41. If yes, how does your partner feel about it?

.....
.....
.....

Cultural factors

42. Does your religion allow you to use PMTCT services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

43. Please support you answer

.....
.....
.....

44. Is it safer to use traditional medicines than western HIV medicines (ARV)?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

45. Please support you answer

.....
.....

46. Who do you believe can manage HIV better?

| | |
|--------------------|---|
| Traditional healer | 1 |
| Medical doctor | 2 |
| Priest | 3 |
| Other (specify) | 4 |

47. Please support you answer, what is the reason for your choice?

.....
.....
.....

48. In the PMTCT programme, a mother is supposed to either breastfeed the child exclusively for only 6 mouths or not breastfeed at all. Does your culture allow these practices?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

49. Please support your answer

.....
.....

Enabling factors

Socio-economic factors

50. Are you struggling to access PMTCT follow-up services because of financially reasons?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

51. Please support your answer

.....
.....
.....

52. Can you describe the cost of transportation as an obstacle to accessing PMTCT follow-up services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

53. Please support your answer

.....
.....
.....

Social Support

54. Does your family support you to use PMTCT follow-up services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

55. Please support your answer

.....
.....
.....

56. Does your partner support you to use PMTCT follow-up services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

57. Please support your answer

.....
.....
.....

58. Usually in PMTCT a mother is supposed to either breastfeed the child exclusively for only 6 months or not breastfeed at all, what sort of challenges do you face in terms of feeding choices?

.....
.....
.....

59. Are you supported in terms feeding options?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

60. Please support your answer

.....
.....
.....

61. Do you think the community support mothers with their feeding options advised by your facility?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

62. Please support your answer

.....
.....

Accessibility

63. Would you use the prevention of mother-to-child transmission follow-up services if it is near your home?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

64. Please support your answer

.....
.....

65. Does the distance of the clinic affect your ability to access PMTCT follow-up services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

66. If yes, please explain

.....
.....

Need factors

Need for health services

67. How would you describe the service provided to you in the PMTCT programme?

| | |
|----------|---|
| Good | 1 |
| Bad | 2 |
| Moderate | 3 |

68. Please support your answer

.....
.....

69. Is there a need for you to use PMTCT follow-up services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

70. Please support your answer

.....
.....
.....

71. Do you think PMTCT follow-up services are important in reducing the spread of HIV?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

72. Please support your answer

.....
.....
.....

73. Will you recommend anyone to use PMTCT follow-up services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

74. Please support your answer

.....

.....

.....

Health Care System Factors

75. Do you think PMTCT service providers know how to deal with loss to follow-up of babies?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

76. Please support your answer

.....

.....

.....

77. Do you think current PMTCT guidelines and policies are effective?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

78. Please support your answer

.....

.....

.....

79. Specify any strategies to improve PMTCT follow-up services for the future.

.....
.....

80. Is the government doing enough to promote the use of PMTCT follow-up services by mothers?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

81. Please support your answer

.....
.....
.....

82. Did you receive quality PMTCT services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

83. Please support your answer

.....
.....
.....

84. Were you well informed about PMTCT follow-up services at the health facility?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

85. Please support your answer

.....
.....
.....

86. In your opinion do you think health care personnel know enough about PMTCT follow- up activities?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

87. Please support your answer

.....
.....
.....

88. Do you think the healthcare system has relevant resources to provide PMTCT services?

| | |
|-----|---|
| Yes | 1 |
| No | 2 |

89. Please support your answer

.....
.....
.....

THANK YOU FOR YOUR TIME AND PARTICIPATION

APPENDIX B

FOCUS GROUP DISCUSSION (Nurses and lay counselling)

INTRODUCTIUON

My name is Refilwe Ramoshaba. I am a Master of Arts (MA) Sociology student at the University of Limpopo. I am conducting a study on **Barriers influencing the use of Prevention of Mother-to-Child Transmission (PMTCT) follow-up services at Mankweng Clinic**. I want you to share your thoughts and experiences when implementing the Prevention of Mother-to-Child Transmission (PMTCT) programme. I will be a facilitator to guide the group throughout the discussion and keep the group focused on the topics for discussion. There will be a note taker who will not interact with the group. Everyone should participate openly to enable us to benefit from this focus group discussion. The information you provide will be treated with the utmost confidentiality and will only be used for the purposes of this study. To assure you anonymity, your name will not appear on this form, and the information you will provide will not be used against you. A tape recorder will be used to capture all the issues that we are going to discuss. The focus group discussion will take approximately 60 minutes.

Section A: Demographic information

1. Gender

| | |
|--------|---|
| Male | 1 |
| Female | 2 |

2. Age

| | |
|-------|---|
| 15=17 | 1 |
| 18-21 | 2 |
| 22-25 | 3 |
| 26-30 | 4 |
| 31-35 | 5 |
| 36-40 | 6 |

| | |
|------------------|---|
| 41-45 | 7 |
| 46-50 | 8 |
| Others (specify) | 9 |

3. Marital statuses

| | |
|------------------|---|
| Never Married | 1 |
| Married | 2 |
| Divorced | 3 |
| Separated | 4 |
| Co-habiting | 5 |
| Others (specify) | 6 |

4. What is your occupation?

| | |
|----------------|---|
| Nurse | 1 |
| Lay counsellor | 2 |

5. What is your highest level of qualification?

| | |
|-----------------|---|
| Metric | 1 |
| Certificate | 2 |
| Diploma | 3 |
| Degree | 4 |
| Other (specify) | 5 |

Section B: Implementation of the Prevention of Mother-to-Child Transmission of HIV programme

Predisposing factors

Knowledge about Mother-to-Child Transmission (MTCT) of HIV.....

6. How is it possible for HIV-positive mothers to transmit the HIV virus to their baby?
7. In your experience with clients, do you think mothers understand the possibility that HIV-positive mothers can transmit the virus to their baby?
8. How can a baby be protected from getting the HIV virus from an infected mother?
9. When should clients take ARVs, and for how long?

Stigma and discrimination

10. How do you provide equality for all clients enrolled into the PMTCT programme?
11. Explain how clients are treated at your facility?
12. How do clients experience stigmatization at your facility?
13. In your work experience, do you think mothers experience stigma at home or community?
14. How did you deal with the issue of discriminated and stigmatized clients?
15. How did you deal with the discrimination from other health worker to their clients?

Cultural factors

16. How do religious beliefs affect the use PMTCT services?
17. Who do you think clients believe can manage HIV better?
18. In the PMTCT, a mother is supposed to either breastfeed the child exclusively for only 6 months or not breastfeed at all. What is the client's reaction to these practices?

Enabling factors

Accessibility

19. For a mother to join the PMTCT programme she has to have an HIV test and if positive gets registered into the programme. Who makes a decision for a mother to join the PMTCT programme?

20. Who do you think is supposed to make a decision for a mother to join the PMTCT programme?

Social support

21. What is the role and responsibilities of a spouse (husband) in PMTCT?

22. Usually in PMTCT a mother is supposed to either breastfeed the child exclusively for only 6 months or not breastfeed at all. What are challenges faced by the programme in terms of feeding choices for mothers?

23. Who provide support for mothers in terms feeding options?

24. Do you think the community support mothers with their feeding options advised by your facility?

Socio-economic factors

25. How does the financial status of clients affect the use PMTCT follow-up services?

26. Can you describe Socio-economic challenges faced by clients in accessing PMTCT follow-up services?

Need factors

Need for health services

27. How do clients describe the service provided to them in the PMTCT programme?

28. Do they see the need to use PMTCT follow-up services?

29. Do you think they believe PMTCT follow-up services are important in reducing the spread of HIV?

Health Care System Factors

30. What sort of challenges do you face when providing the services?
31. How is your relationship with clients enrolled into the PMTCT programme?
32. In your line of work, have you ever encountered difficult patients?
33. How do other Health care providers in the programme deal with difficult patients at your clinic?
34. In your experience with the programme, what are the challenges or problems faced by mothers registered for PMTCT follow-up services?
35. How does your clinic deal with the challenges or problems faced by mothers registered for PMTCT follow-up services?
36. Do you think current PMTCT guidelines and policies are effective?
37. Do you think the healthcare system has relevant resources to provide PMTCT services?
38. How do you provide quality PMTCT services?
39. How does the community look at the quality of PMTCT services at your health facility?
40. How do PMTCT clients look at the quality of PMTCT services at your clinic?

THANK YOU FOR YOUR TIME AND PARTICIPATION

APPENDIX C: CONSENT FORM

I.....hereby voluntary consent to participate in the following project: **Barriers influencing the use of Prevention of Mother-to-Child Transmission of Human Immunodeficiency Virus (HIV) follow-up services in Mankweng Clinic**. I have been fully informed of the project; the procedures to be followed for taking part in the project have been explained to me. I understand that there are conditions to be met for me to participate in the study. I will be required to answer questions relating to barriers influencing the use of Prevention of Mother-to-Child Transmission of HIV follow-up services. I am aware that I do not have to take part in the project and may voluntary withdraw at any stage. Under these conditions I am willing to participate in the project.

Signature of participant.....Date.....

Signature of witness.....Date.....

Signature of project leader.....Date.....

APPENDIX D: UNIVERSITY OF LIMPOPO TURFLOOP ETHICAL CLEARANCE CERTIFICATE



University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2212, Fax: (015) 268 2306, Email:noko.monene@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING: 03 March 2016

PROJECT NUMBER: TREC/17/2016: PG

PROJECT:

Title: Barriers influencing the use of prevention of mother-to-child Transmission of Human Immunodeficiency Virus follow-up Services at Mankweng Clinic

Researcher: Mr R Ramoshaba

Supervisor: Prof SL Sithole

Co-Supervisor: N/A

Department: Sociology and Anthropology

School: Social Sciences

Degree: Masters in Sociology


PROF. TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

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

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

APPENDIX E: DEPARTMENT OF HEALTH LIMPOPO PROVINCIAL ETHICAL CLEARANCE



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila

Ref:4/2/2

Ramoshaba R
University of Limpopo
Private Bag X1106
Sovenga
0727

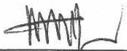
Greetings,

RE: Barriers influencing the use of prevention of Mother – to – Child Transmission of Human Immunodeficiency Virus follow-up Services at Mankweng Clinic

The above matter refers.

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

Your cooperation will be highly appreciated.


Head of Department

05/04/2016
Date

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

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**APPENDIX F: PERMISSION TO CONDUCT RESEARCH AT MANKWENG CLINIC
FROM DEPARTMENT OF HEALTH CAPRICORN DISTRICT**



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH- CAPRICORN DISTRICT

Ref: 4/2/2
Enq: Mokgohloa K.A
Tel: 015 290 9154
Date: 30 May 2016

From: HRD and Training

To: Director PHC
Assistant Director PHC
Polokwane Sub-district
Mankweng Clinic

**RE: BARRIERS INFLUENCING THE USE OF PREVENTION OF
MOTHER –TO-CHILD TRANSMISSION OF HUMAN
IMMUNODEFICIENCY VIRUS FOLLOW-UP SERVICE AT
MANKWENG CLINIC**

The above matter refers

This letter serves to inform you that the Head of Department has approved the research project in partial completion of the Masters of Art in Sociology of Mr Ramoshaba R.

He will be there in your clinic to collect data, conducting interviews and focus group discussion for a period of three years. Please give him a necessary support.

Hope you will find this in order

M.M. Polokwane

District Executive Manager

30.05.16

Date

Private Bag x9530, Polokwane, 0700, 34 Hans Van Resenberg ST, Polokwane 0700
Tel: (015) 290 9000, Fax: (015) 291 3260/1568 Website: <http://www.limpopo.gov.za>

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

APPENDIX G: PERMISSION TO CONDUCT RESEARCH AT MANKWENG GATEWAY CLINIC FROM DEPARTMENT OF HEALTH CAPRICORN DISTRICT



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH- CAPRICORN DISTRICT

Ref: 4/2/2
Enq: Mokgohloa K.A
Tel: 015 290 9154
Date: 15 June 2016

From: HRD and Training

To: Director PHC
Assistant Director PHC
Polokwane Sub-district
Mankweng Gateway Clinic

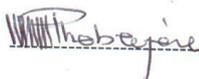
RE: BARRIERS INFLUENCING THE USE OF PREVENTION OF MOTHER –TO-CHILD TRANSMISSION OF HUMAN IMMUNODEFICIENCY VIRUS FOLLOW-UP SERVICE AT MANKWENG GATEWAY CLINIC

The above matter refers

This letter serves to inform you that the Head of Department has approved the research project in partial completion of the Masters of Art in Sociology of Mr Ramoshaba R.

He will be there in your clinic to collect data, conducting interviews and focus group discussion for a period of three years. Please give him a necessary support.

Hope you will find this in order



District Executive Manager

15/06/16

Date

Private Bag x9530, Polokwane, 0700, 34 Hans Van Rasnberg ST, Polokwane 0700
Tel: (015) 290 9000, Fax: (015) 291 3260/1568 Website: <http://www.limpopo.gov.za>

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