THE PREVENTION OF MOTHER TO CHILD TRANSMISSION PROGRAMME (PMTCT): EXPERIENCES OF HIV POSITIVE MOTHERS AT TONGA HOSPITAL IN NKOMAZI EAST

BY

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Declaration

I, the undersigned, Aluwani Nemutudi hereby declare that this is my original work and that it has not been submitted previously in its entirety or in part to any other university for a degree.

Signed: ---------- Date: ----------

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ABSTRACT

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DEGREE: MSW (Social Health Care)

Mother To Child Transmission (MTCT) of HIV is a major challenge in Sub-Saharan Africa due to a variety of socio-economic and political factors. In South Africa, for example, there was element of denialism by government on the fact that treatment could assist in reducing the likelihood of transmitting the virus to the baby. It was only in 2001 after the Treatment Action Campaign took the South African government to court that they were ordered to develop a programme to prevent the transmission of HIV from mother to child. The South African government established a PMTCT programme that aligned itself with the United Nations' Millennium Goal of ensuring that all HIV positive pregnant women receive treatment in an effort to eliminate babies born with HIV.

This study, therefore, explored the experiences of HIV positive mothers who enrolled on PMTCT programme at Tonga hospital. The researcher explored the participants' understanding of the programme prior to enrolment, the extent to which they experienced the programme, the nature of support and services they received while on the programme as well as challenges they faced. All this was done with the intention

and commitment to strengthening the intervention strategies for the HIV pregnant women, thereby ensuring that they receive top quality services from a group of multi skilled professionals.

To achieve this, the study applied a collective case study within a qualitative approach. The population for the study was HIV positive mothers who enrolled on the PMTCT programme between June 2011 and July 2012. The sample consisted of 12 HIV positive mothers who took part in the PMTCT programme at Tonga hospital. For data collection purposes, the researcher applied semi-structured interview.

Informed by the findings, the study concluded that there is lack of knowledge and understanding of the programme in the community. It further established that the clinic is situated under the ward where HIV positive patients are treated and that psycho social services are not offered to the HIV positive pregnant women. It also concluded that the women's husbands or partners are not encouraged to be part of the programme.

Consistent with the above, the study recommended that the PMTCT programme should be provided in a holistic and well integrated manner, where all health care disciplines contribute as required to make the participants' experiences on the programme more comfortable both socially and emotionally. There should be a way to get the male counterparts of the participants more involved in the programme so as to afford them the opportunity to get first-hand information about pregnancy and what is expected of them as partners. Each health worker's role should be clearly defined and a referral system be developed so that all services are easily accessible.

KEY CONCEPTS:

- Experience
- HIV
- PMTCT
- Programme

ACRONYMS

- ANC Antenatal Care
- ARV Antiretroviral
- HIV Human Immunodeficiency Virus
- HAART Highly Active Antiretroviral Therapy
- MTCT Mother-to-Child Transmission of HIV
- NSP National Strategic Plan
- PMTCT Prevention of Mother-to-Child Transmission of HIV
- S2S South to South
- UNAIDS United Nations Programme on HIV/AIDS
- UNICEF United Nations Children's Fund
- VCT Voluntary Counselling and Testing
- WHO World Health Organisation

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CHAPTER 1

INTRODUCTION AND HISTORICAL BACKGROUND OF PMTCT

1.1. Introduction

The Prevention of Mother to Child Transmission (PMTCT) programme was one of the programmes designed in South Africa to prevent the transmission of HIV from mother to child. The PMTCT programme was aimed at preventing the transmission of HIV from a pregnant mother to her unborn baby during pregnancy, labour or delivery and after birth. A comprehensive package of a PMTC programme was introduced in 2001. Initially, the programme was introduced as a pilot project and, thereafter, (in response to a constitutional ruling) as a full scale national programme. Policy guidelines for the standards of care were also developed (S.A., 2008:21).

In South Africa, the PMTCT programme did not come without difficulties. The South African government, for instance, consistently denied the efficacy of the drug nevirapine in preventing the transmission of HIV from mother to child. The government was later taken to court in order to provide antiretroviral nevirapine (NVP)—the drug that minimized the likelihood of transmitting HIV to a baby during birth. In 2001, the court ruled for the treatment action campaign (TAC) and the government was ordered to develop PMTCT programme and used NVP for PMTCT (Nicola, 2005:1).

This study claimed that although the government later established a comprehensive programme to prevent the transmission of HIV from mothers to children, the recipients of the services, to a certain extent, were affected both emotionally and psychologically. The sensitivity of the HIV question as well as the stigma associated with it made the infected mothers who received the services go through different experiences.

The study, furthermore, argued that the way pregnant women experienced the whole process had a bearing on the duration of their stay on the program. The study also claimed that women's experiences varied considerably, and were influenced by, amongst other things, the Health Department processes and procedures, relationships with health workers as well as other personal issues.

In addition, the study also confirmed that an HIV diagnosis in the context of pregnancy and childbirth could greatly affect not only the experience of childbearing, but also the desire and ability to access HIV/AIDS healthcare services. However, important questions remained unanswered around such issues as the women's perceptions of illness, healthcare and giving birth in light of the knowledge of their HIV status and the prospects of accessing PMTCT and highly active antiretroviral therapy (HAART) services (Preventing mother to child transmission, 2010:3).

Mtshali (2010), a professional nurse at the PMTCT clinic at Tonga Hospital in the Mpumalanga Province, indicates that most pregnant women expressed feelings of shock, fear, and uncertainty about relationships with their partners after an HIV positive result. It is important to note that the extent to which these feelings were addressed remains unknown as both the professional nurses and counsellors were not adequately skilled to deal with them. This was also due to the fact that no follow-up counselling was provided for the infected pregnant women, and no efforts were made to involve the male partner in the whole process. This situation put strains on relationships between couples and, most importantly, disclosure of a positive result by infected women proved difficult.

Against the above background, the study was aimed at exploring the experiences of HIV positive mothers in the PMTCT programme. The study contended that HIV positive women tended to go through the programme despite the fact that they were psychosocially and emotionally not prepared to deal with the situation in which they find themselves.

With regard to the administration of the programme, Mtshali (2010) indicates that PMTCT services were provided at the wellness clinic. A separate clinic was also established in September 2009 and PMTCT services were integrated into other antenatal care services. In spite of this effort, there was no formal and consistent referral system to the social worker for counselling services in order to address the emotional and psychosocial needs of these women. Tonga hospital had 14 satellite clinics and the clinics had their own PMTCT units for their own patients. All clinics did not have social workers to attend to the patients' psychological and emotional needs of the patients.

Teasdale and Besser (2008:60-61) argue that the efficacy of the PMTCT programmes depended on the capacity of the health care system to deliver services, and the willingness of women to accept HIV testing as well as their abilities to follow through with PMTCT interventions. They also point out that essential elements of PMTCT programmes included testing all pregnant women for HIV CD4 tests to identify those eligible for highly active anti-retroviral therapy (HAART), and ensuring that all women had the necessary drugs for PMTCT, including those who delivered at home.

Teasdale and Besser (2008:60) further emphasize that after delivery, PMTCT services must include sustained education and support for safer infant feeding options, namely: C trimoxazole prophylaxis for HIV–positive or exposed new-borns, HIV testing for infants, family planning, counselling and, in addition, referral to HIV care and treatment programmes where necessary. Frizzelle, Solomon & Rau (2009:07) also indicate that the National Department of Health's policy on PMTCT, in line with the international standards, recognized the need for a comprehensive, four-pronged response, as mentioned below, to reduce MTCT of HIV:

- Primary prevention of HIV, especially amongst women of childbearing age;
- Prevention of unintended pregnancies amongst HIV positive women;
- Prevention of HIV transmission from an HIV positive woman to her infant;
- Provision of appropriate treatment, care and support to women with HIV, their children and families.

Frizzelle *et al.* (2009:08) further reveal that the strategic plan for 2009/10-2010/2011 of the National Department of Health was aimed at accelerating the implementation of the HIV-AIDS national strategic plan and to strengthen the implementation of the national PMTCT programme. They explain that in line with the Millennium Development Goal No. 4, the Department of Health would ensure:

- an increase in the number of those HIV-exposed infants who receive dual-therapy for PMTCT;
- an increase in the proportion of pregnant women who tested for HIV;

- an increase in the number of pregnant women who are placed on dual therapy; and
- an increase in the number of eligible pregnant women who are placed on HAART.

Consistent with the above, Minister Dr Aaron Motsoaledi in his June 2009 budget speech pledged:

> "We will work with provinces to ensure that 80% of HIV exposed infants receive ARVs for PMTCT (based on dual therapy). This figure will increase to 95% over two years of the medium term expenditure framework (2010/11-2011/12). The proportion of pregnant women who are tested for HIV will be increased from 80% in 2009/10, to 95% in 2010/11 and 2011/12".

To strengthen the prevention of mother-to-child transmission of HIV, 80% of pregnant women who were eligible were placed on ARV prophylaxis based on dual therapy in 2009/10. This figure was increased to 95% in the outer two years of the MTEF period: 30% of eligible women were placed on HAART in 2009/10. This service was expanded to cover 50% and 75% of pregnant women in 2010/11 and 2011/12, respectively. In order to achieve all these set goals, the National Department of Health ensured that the experience of accessing PMTCT services was not frustrating to HIV positive pregnant women. Instead, it should be seen as an emotionally comfortable experience, and this was achieved by addressing adequately the psychosocial needs of the women. These psychosocial needs included, for example, fear to disclose HIV positive status to spouses and family members and cultural pressure to breastfeed the baby after delivery.

A study conducted by Towie & Lende (2008:219-228) in rural Lesotho regarding the cultural and structural difficulties surrounding effective prevention of PMTCT concluded that interventions should move beyond a myopic biomedical best practices approach to address the social groups and contextual determinants affecting vertical HIV transmission. The study contended that the attitude and mental state of those providing

PMTCT services also contributed to the way HIV positive mothers experienced the program.

Also, a research project conducted in Ekurhuleni Region B on the experiences of midwives counselling HIV positive pregnant women concluded that midwives were stressed, overworked and understaffed, and there was also poor emotional and supervisory from coordinators. Subsequently, all this resulted in job dissatisfaction, unhappiness, frustration, helplessness, reduced productivity and ultimately sub-standard care to HIV positive pregnant women (Marumolo, 2004:1).

At the time of this study, the researcher was employed as a trainer and mentor. The researcher trained and mentored counsellors and other health care workers on counselling skills and promotion of adherence on people who were on ARVs at Tonga Hospital and its feeder clinics. However, he did not have any direct contact with the participants and no conflict of interest was envisaged.

Driven by its purpose as highlighted in the introductory part of this chapter, the study sought to enrich the social work discipline with scientific evidence on how PMTCT enrolled HIV positive women experienced the programme and how their individual feelings and needs were addressed. The study hoped to provide useful information that would assist the discipline in designing its intervention strategies so as to make participation in the programme a beneficial and pleasant experience for the HIV positive pregnant women.

1.2. Problem formulation

A report compiled by Evidence 4 Action (n.d.:03) in Kenya shows that no studies that presented an in-depth qualitative data on this topic were ever conducted. While it was important, on the one hand, to note that the number of pregnant women attending public antenatal clinics in South Africa increased markedly since the launch of the programme, it was worth mentioning, on the other, that little was known about how they felt and experienced the programme.

Statistics show that there had been continuous increase of women who tested HIV positive during pregnancy across the provinces. The table below depicts statistics of

women who attended public antenatal clinics in South Africa and who received HIV testing, by year and Province.

Province	2001/2	20002/3	2003	2004	2005/6	2006/7	2007/8
Eastern Cape	1,7	6,7	*	*	*	75,3	88,3
Free State	4,6	15,8	31,1	33,7	40,0	66,9	80,1
Gauteng	*	20,0	17,6	39,0	47,4	60,6	73,3
Kwazulu-Natal	7,2	13,6	*	*	43,8	58,5	70,7
Limpopo	1,0	8,4	26,0	37,6	46,5	77,5	90,1
Mpumalanga	0,6	0,0	10,9	12,9	31,4	58,2	74,6
North West	2,2	30,7	*	34,7	47,9	74,3	85,6
Northern Cape	5,0	4,6	18,2	16,4	59,1	81,5	88,5
Western Cape	*	43,9	*	*	*	93,7	95,7
South Africa	**6,9**	**15,6**	**25,3**	**37,3**	**49,1**	**69,2**	**81,0**

Adapted from: *Children's institute, University of Cape Town* (Johnson, 2009:01)

Frizzelle *et al.* (2009:45) recommend that studies should be conducted on the experiences of HIV-positive women who disclosed to their partners, and on the views and experiences of those accessing various PMTCT services.

Consistent with Frizzelle ***et al.***'s recommendations, this study focused on how HIV positive mothers experienced the PMTCT program from enrolment until giving birth. It explored the nature of the mothers' psychosocial needs and as well as the extent to which such needs were addressed. Furthermore, the study examined the type of support needed for the infected mothers from service providers in the programme.

At the time of this study, the nursing sisters and lay counsellors provided counselling to pregnant women on the PMTCT programme and had limited understanding on how to address their feelings and perceptions. These feelings and perceptions were either left unattended to or were ineffectively addressed. The study argued that social workers as trained therapists were in a better position to adequately address the psychological and emotional needs of these women.

The nursing sisters tended to refer the infected mothers after trying to help without success. The referral procedure was clear—all patients should see the social worker for psycho-social assessment. Although PMTCT forms part of the Comprehensive Care Management and Treatment (CCMT) programme, the same procedure was not applied and hence the lack of referral. The study therefore hoped to provide an in-depth insight on how HIV positive women on PMTCT programme view their involvement in the programme and how they feel their needs could be efficiently and effectively addressed.

In summary, the focus of the study was the experiences as encountered by HIV infected mothers as a group. These experiences included how the participants personally felt about counselling and support services received and the impact thereof. This involved making a distinction of whether the experience was good or bad, pleasant or unpleasant, comforting or discomforting and the reasons thereof.

1.3. Goal and objectives of the study

1.3.1. Goal of the study

The goal of this study was to explore how HIV positive mothers experience the PMTCT programme at Tonga Hospital in Nkomazi Municipality

1.3.2. The objectives of the study were to:

- determine the understanding of HIV positive mothers regarding the PMTCT programme at Tonga Hospital in Nkomazi Municipality;
- ascertain services received from the PMTCT programme;
- identify the strength and shortfalls of the PMTCT programme; and
- determine the support received from social workers.

Based on the research findings and conclusions, recommendations were made to address the needs of HIV positive mothers on the PMTCT programme.

1.4. Research question

A research question was employed because this study was qualitative in nature and focused on the nature of a real situation. In qualitative studies, research problems are phrased as research statements or questions, and not as hypotheses (Macmillan & Schumaker in Maree, 2009:26, Wellman, Kruger & Mitchell 2005:26). The research question for this study was:

What are the experiences of HIV positive mothers of the PMTCT programme at Tonga Hospital in Nkomazi East?

1.5. Research approach

The qualitative research approach was applied in this study. This paradigm was suitable for this study in that it focused on the experiences and perceptions of the participants. This study was aimed mainly at understanding social life and the meaning that people attach to their everyday life. In addition, this approach elicited participants' accounts of meaning, experiences or perceptions. Furthermore, the study was concerned with understanding rather than explaining the subjective exploration of reality from the perspective of an insider as opposed to the outsider perspective (McRoy in Fouché and Delport, 2009:74).

This study focused on describing and understanding the PMTCT programme within its naturally occurring context, with the intention of developing an understanding of the meanings imparted by the respondents—a "seeing through the eyes of the participants" so that the phenomenon can be described in terms of the meaning that they have for the actors or participants (Maree, 2009:26).

As such, the researcher opted for this approach because the study required participants to give an account of their own personal feelings and experiences regarding the PMTCT program. The researcher also sought to understand rather than to explain how HIV positive mothers on the PMTCT programme experience the enrolment on the

programme and this provided the basis upon which to establish scientific evidence-based intervention strategies for the social work discipline.

1.6. Type of research

This research was classified as applied in nature and the primary purpose of applied research is to solve social problems or make a contribution to real-life issues. The study intended to find solutions experienced in the PMTCT programme. It therefore established knowledge that strengthened the PMTCT programme. This knowledge contributed to addressing of the psycho–social needs of HIV positive pregnant women attending the PMTCT programme. The issue of PMTCT of HIV was an existing social problem in South Africa and hence called for an applied research project (Mouton, 2009:105).

1.7. Research design and methods

1.7.1. Research design

The study used a collective case study research design. The design was appropriate for this study as it sought to explore the experiences of a group of cases of the PMTCT programme. A case study is a process, activity, event, programme, individual or multiple individuals. In the context of this study, the PMTCT programme was the case to be studied and mothers who participated in the programme helped the researcher to better understand their views about it (Fouché, 2009:272).

1.7.2. Research population, sample and sampling method

In this study, the population was 12 all-added HIV positive women who received PMTCT services during pregnancy. The unit of analysis was the HIV positive status during pregnancy and participation in the PMTCT programme. In this context, the population is the total sum of all the cases that meet our definition of the unit of analysis (Mouton, 2009:52).

The study used probability sampling method for the purposes of data collection. In the probability sampling method, the odds of selecting a particular individual are known and

can be calculated (Forzano & Gavetter in Strydom, 2009:198). This method was used in this study because there was a list of women on the PMTCT programme at the hospital, thus the population was known.

For the purposes of this study, systematic sampling method was applied. The first case was selected randomly from a list of names. The researcher, with the help of a professional nurse in charge of the PMTCT clinic, compiled a list of names of HIV positive mothers who received PMTCT services during pregnancy between July 2011 and July 2012. A two-digit number was assigned to the entire population; the numbers ranged from 01 to 40 (Hoinville *et al.* as cited in Strydom, 2005:200).

In the sampling process, the first name was selected randomly and thereafter an interval of two was used, thereby selecting every second name on the list until the required number was reached. The size of the sample for this study was 12 participants. The researcher requested a list of PMTCT clients with their contact numbers and told them about the research and found out if they were willing to be participants in the study. Those willing, an appointment was made for an interview in the comfort of their own homes.

1.7.3. Data collection

The researcher wanted to learn more about participants' ideas, beliefs and views of the PMTCT programme. Given the nature and the sensitivity of the phenomenon to be studied, the researcher applied semi-structured, one-to-one interview to collect data. Semi-structured interviews were used in order to gain a detailed understanding of participants' beliefs about, and perceptions or accounts of, the PMTCT programme. The researcher followed-up particular interesting avenues that emerged in the interview, and the participant gave a fuller picture.

In addition, semi-structured interviews were suitable because the researcher was particularly interested in the PMTCT programme because it was a controversial or personal issue. The researcher had a set of predetermined questions on an interview schedule (Greef, 2009:296).

1.7.4. Data analysis

Terre Blanche, Durheim & Kelly's (2006:32) pattern of analysing data was applied. The following steps were taken to analyse data: familiarisation and immersion where the researcher started working with the text than lived reality. The researcher read the material many times over, made notes, drew diagrams and brainstormed. In the second step which involved inducing themes, the researcher looked at the material and tried to work out the organizing principles that naturally underlie the material.

Thirdly, the researcher coded phrases, lines, sentences or paragraphs, thereby identifying textual bits by virtue of their containing material that pertained to the themes under consideration. After coding, the elaboration step followed and the researcher explored the themes more closely in order to capture the finer nuances of meaning not captured by the original, possibly quite crude, coding system. Interpretation was the final step where the researcher puts together interpretations. This was the written account of the phenomenon that was studied using thematic categories from the analysis as sub-headings.

1.8. Feasibility of the study

The researcher interviewed participants who attended the PMTCT program at Tonga hospital in the Mpumalanga province. The researcher, at the time of the study, was working at Tonga hospital as a Skills Trainer and Counsellor Mentor.

The researcher discussed with the professional nurse managing the PMTCT clinic on how to access the prospective respondents for this study. The intention to conduct this study was also discussed with the matron who manages the Comprehensive Care unit, Management and Treatment programme and she expressed her willingness to offer her support. A written permission to conduct the study was also granted by the Department of Health and written consents were obtained from potential participants.

1.9. Delimitation of the study

The collection of data was not conducted at the participants' homes as initially planned. The researcher struggled to locate the homes of the respondents as most of them indicated that they lived in the surrounding areas of the hospital while in actual fact they

were from other areas away from the hospital. In other words, some of these participants only used local addresses in order to receive medical services from the hospital. After consultation with PMTCT clinic manager regarding the difficulties in tracing these participants, it was agreed that participants would be tracked down for the purposes of interviews when they come back for medical review and check-ups with their babies. Eventually, interviews were conducted in the hospital premises than was initially planned and, as a result, this could have influenced, to a certain extent, the responses given by participants.

1.10. Ethical aspects

The following ethical aspects were relevant to this study:

1.10.1. Voluntary participation

For the purposes of this study, no participants were coerced or forced to take part against their wish. Each participant was given a letter of informed consent, explaining the details of the research. Those who agreed to participate voluntarily signed a letter of consent (Babbie, 2001:438).

1.10.2. Informed consent

In this study all respondents were informed about the procedures and goals of the study and that there was no remuneration for taking part in this project as participation was voluntary. Informed consent letters were developed and used in order to address the issue effectively and consistently (Neuman in Strydom, 2009:59; Wellman *et al.* 2009:201). The participants were informed individually about the purpose of the study and also requested to complete a consent form. In instances where a participant was illiterate, the consent form was read to her and, thereafter, she was requested to give consent by using a cross in the presence of an independent witness who also signed the form.

1.10.3. No harm to the participants

Although the researcher did not anticipate any physical harm to the participants given the nature of the study, psychological discomfort could not be ruled out due to the sensitiveness of the phenomenon under investigation (PMTCT). The researcher conducted a debriefing session after data was collected. In instances where further counselling was needed, contingency plans were put in place. These included referrals to Ms Mbatha, a social worker who worked in the hospital, when the need arose (Strydom, 2009:58).

1.10.4. Anonymity and confidentiality

No names of the participants were recorded during the data gathering process in this study. Instead, pseudonyms were used to ensure anonymity and confidentiality of the participants (Babbie & Mouton 2008:523).

1.10.5. Deception of respondents

In this study, no respondent was given misleading information in order to participate. All respondents were provided with adequate information about the goals and procedure of the study through the informed consent letter (Wellman *et al*. 2009:118).

1.10.6. Debriefing

For the purposes of this study, the researcher conducted a debriefing session with each participant after the data collection process. Due to the sensitivity of the phenomenon under investigation, a debriefing session was necessary and where further counselling was needed arrangements were made with Mrs Mbatha, the social worker who worked at the hospital, to provide counselling (Salkind in Strydom, 2006:66).

1.10.7. Actions and competence of the researcher

For the completion of this project, the researcher was guided by the code of ethics of the social work profession as well as the knowledge of research methodology module completed at the university. The researcher also ensured that his belief system and value judgment did not interfere with the study. The researcher was competent enough

in that he consulted the relevant literature and also had a supervisor to guide him throughout the study process (Strydom, 2009:63).

1.10.8. Release or publication of the study

The researcher informed all participants that the findings would be released in the form of a mini-dissertation that was to be made available to the public via the University of Pretoria's library. With the help of the supervisor, the researcher also ensured that all ethical aspects in conducting research were observed and adhered to. A manuscript for possible publication, with the supervisor as co-author will be submitted, for publication in an accredited scientific journal.

1.11. Key concepts

1.11.1. Experience

The Oxford dictionary (2005:513) defined experience as things that have happened to a person and influenced the way that person thinks and behaves. Within the context of this study, experience referred to how HIV positive mothers perceived, or felt while pregnant on the PMTCT programme.

1.11.2. HIV

While Van Dyk (2009:492) defines HIV as the human immunodeficiency virus—the virus that causes AIDS, the *HIV 911 Mpumalanga*: HIV-related services directory manual (2009:10), defines HIV as the virus that causes Acquired Immunodeficiency Syndrome. According to this study, HIV is the virus that causes the immune system to become weak, thereby making the body more susceptible to attacks by diseases.

1.11.3. PMTCT

The *HIV 911 Mpumalanga:* HIV-related services manual (2009:10) defines PMTCT as the prevention of infection of HIV from an HIV-positive mother to her child during pregnancy, labour, delivery or breastfeeding. In the context of this study, PMTCT is a programme established by the South African government to prevent the infection of

children with HIV from their mothers during pregnancy, labour, delivery and breastfeeding.

1.11.4. Programme

According to the oxford dictionary (2005:1163), a programme is a plan of things that will be done or included in the development of something. In the context of this research project, the term programme is used to refer to the plan designed by the South African government to fight the transmission of HIV from infected mothers to their children.

1.12. Contents of the research report

Chapter 1 of this research project presents the general introduction and orientation to the study, the research methodology, goal and objectives and the key concepts relevant to this study.

Chapter 2 offers a historical background of Prevention of Mother to Child Transmission (PMTCT) of HIV programme, factors that are barriers to accessing the programme and the theoretical framework of the programme in the context of South Africa.

Chapter 3 presents the methodological procedures used in this study and, in the process, offers a discussion on the empirical results and findings of this study.

Chapter 4 gives the conclusions, recommendations and provides a summary on how the goal and objectives of the study were achieved.

CHAPTER 2

LITERATURE REVIEW: HISTORICAL BACKGROUND AND THEORETICAL FRAMEWORK OF PMTCT

2.1. Introduction

The World Health Organization (WHO) (2003:12) explains that mother-to-child transmission (MTCT) of HIV, also known as vertical transmission and perinatal transmission, is responsible for about 1500 new HIV infections in infants daily. The WHO argues that transmission mainly occurs during the time of delivery, rarely during early pregnancy, with breastfeeding contributing substantially to the overall risk. The other risk factors for transmission include high maternal immune deficiency, prolonged rupture of membranes and vaginal delivery.

The PMTCT program is designed and aimed at reducing the likelihood of transmitting HIV from a pregnant mother to the unborn baby during pregnancy, delivery and breastfeeding. It is an ambitious programme which seeks to reduce MTCT by 80% by 2015. At the 19th Board Meeting of the Global Fund in May 2009, the UNAIDS Executive Director called for the virtual elimination of mother to child HIV transmission by 2015 (UNAIDS, 2009:18).

WHO (2003:04) explains that considerable advances have been made in discovering new and varied types of short-course antiretroviral therapies (ART) and other medical interventions that have considerably reduced the transmission of HIV from mother to child. Voluntary HIV counselling and testing (VCT) plays a vital role in preventing MTCT. The primary focus of VCT is on knowledge development and risk assessment in order to promote HIV testing. If a person tests positive for HIV, for example, then counselling focuses on behavioural change and supportive adherence counselling with therapeutic regimens.

Although VCT is vital in preventing MTCT, the psychosocial and emotional needs of women and families who test HIV positive cannot be ignored. There is considerable evidence to suggest that people can only absorb and understand important health information through effective interpersonal communication. This communication goes

beyond the simple provision of information; it addresses the emotional, psychological, social and legal needs of the person being counselled. Issues of family violence, abuse, legal inequity, discrimination, stigma, poverty and other social ills lead to the vulnerability and oppression of HIV-infected women and their families (WHO, 2003:04).

2.2. People's experiences of HIV/AIDS in developed and developing world

The World Health Organization (2003:8) indicates that the main modes of transmission in developed countries are from male to female unprotected sexual intercourse and sharing HIV-contaminated needles and syringes. However, the incidence of AIDS in these countries is increasing steadily through heterosexual exposure from male partners. Most people in living in developed countries have access to affordable or free health care, including various ARTs and treatments for opportunistic infections.

Contrary to the above, 40% of women in the developing countries lack access to adequate antenatal care. In sub-Saharan Africa, less than half of all births are attended to by a professional health care provider, with even lower levels being reported from individual African countries and some parts of Asia. Reports from studies in Africa and the developed world indicate that even before the introduction of ART, the rates of MTCT in the European Collaborative study were lower than those of cohort studies in Africa (WHO, 2003:08).

In less developed countries antenatal care (ANC) is limited; testing programmes for HIV are almost non-existent; effective interventions for PMTCT remain unimplemented and prevention of postnatal transmission of HIV through breast milk, without compromising infant nutrition, is a major dilemma (WHO, 2003:08). Meanwhile, the Centre for Disease Control and Prevention reports that in the USA, HIV/AIDS accounted for the largest proportion of death of women between the ages of 25-34 (CDC: 2008:2). Clearly, these are women who are still in the child bearing age.

2.2.1. PMTCT in European countries

WHO: (2004:05) indicated that the HIV epidemic in Western Europe initially resulted in large numbers of paediatric infections until interventions became available to avoid mother-to-child transmission of HIV. The year 1994 was a turning point, the results of

the ACTG 076 trial demonstrated for the first time the efficacy of antiretroviral drugs in preventing mother-to-child transmission of HIV. The demonstrated risk of the transmission of HIV through breastfeeding ensured that HIV positive infected mothers were strongly advised to refrain from breastfeeding.

In addition, it was shown that elective caesarean section could substantially reduce mother-to-child transmission, even in women undergoing effective antiretroviral therapy. The standard approach to reducing mother-to-child transmission of HIV in Western Europe and the United States thus became a combination of antiretroviral drug use (ACTG 076 prophylactic regimen or antiretroviral therapy for the mother), elective caesarean section and avoidance of breastfeeding. As a result, the rate of mother-to-child transmission of HIV decreased in these countries from 15%-20% to 2% or less. (WHO, 2004:05)

This success was due, first and foremost, to the fact that national programmes to prevent HIV infection had already gathered a large amount of information on HIV in general and amongst pregnant women prior to the introduction of specific interventions to prevent mother-to-child transmission of HIV. Moreover, prevention programmes targeting injecting drug users and other vulnerable populations were already in place. Voluntary HIV testing and counselling was widely available, and was accepted as a standard procedure in antenatal care for all pregnant women. A well-endowed clinical infrastructure with few resources constrains, a network of clinical experts on mother-to-child transmission of HIV, and a well-trained cadre of midwives and obstetricians allowed these interventions to be rapidly and easily integrated into existing services.

In Eastern Europe, most countries adopted policies of mandatory HIV testing during pregnancy in the late 1980s primarily for surveillance purposes. United Nations agencies strongly advocated replacing these policies with a surveillance strategy based on sentinel surveillance sites, and many countries have abandoned mandatory testing. Some countries, however, continue to test all pregnant women routinely, either nationwide or in areas with high levels of HIV prevalence.

Soon after the release of the ACTG076 study results, a number of central and eastern European countries adopted policies to provide the antiretroviral prophylactic regimen to

HIV-infected pregnant women and nationwide programmes. Other countries are still at an early stage of planning interventions or were undertaking some pilot activities. Access to comprehensive services to prevent HIV infection in infants remained limited for many HIV infected women and, in particular, highly vulnerable women such as injecting drug users (WHO, 2004:05).

2.2.2. Prevention of Mother-to-Child Transmission of HIV-1 in Sub-Saharan Africa

The World Health Organization estimated that approximately 40 million people live with HIV/AIDS worldwide and that 28 million of these reside in sub-Saharan Africa. While 55% of infected adults in sub-Saharan Africa were women, 90% of them were in their reproductive years. Given the situation above, it follows that hetero-sexual transmission was the major route of HIV transmission in sub-Saharan Africa. HIV sero-prevalence in sub-Saharan Africa was about 8.4% compared to 0.6% in North America. Out of the total 5 million new infections in the world in 2001, 3.4 million occurred in sub-Saharan Africa.

Of these figures, women and girls made up a growing proportion of those infected by HIV/AIDS. This was confirmed at the end of 2004 when UNAIDS reported that women made up almost half of the 37.2 million adults (aged 15 to 49) living with HIV/AIDS worldwide. The hardest-hit regions were areas where heterosexual contact was the primary mode of transmission. This was most evident in sub-Saharan Africa, where close to 60% of adults living with HIV/AIDS ere women. Informed by this, the United Nations estimated that every day 6,000 young people aged 15 to 24 become infected with HIV. A staggering two-thirds of these new cases were adolescent women (Prevention of mother-to-child transmission, n.d.).

2.2.3. Prevention of Mother-to-child Transmission of HIV

A four-fold strategy is needed to prevent babies from acquiring HIV from their infected mothers (Prevention of mother-to-child transmission, n.d). One of such strategies is the prevention of HIV amongst prospective parents. In this case, the main thrust should be to prevent HIV infection among women of reproductive age. This can be done through

economic empowerment of women, educating the girl child, premarital HIV counselling and testing (VCT), creating awareness through health education programmes.

Even more important in the fight against MTCT is the prevention of unwanted pregnancies amongst HIV-positive women. While voluntary counselling and testing (VCT) services may enable women to know their HIV status before becoming pregnant, family planning services are needed to prevent unwanted pregnancies in HIV seropositive women. Unfortunately, women in sub-Saharan Africa majority do not have access to VCT and family planning (FP) services. Such services tend to be concentrated in the urban communities thus leaving out those women in rural areas.

In contrast to the above, western countries managed to virtually eliminated due to, amongst other things, the effectiveness of voluntary testing and counselling, access to antiretroviral therapy, safe delivery practices and the widespread availability and safe use of breast-milk substitutes. If these interventions were used worldwide, they could save the lives of approximately 300,000 children each year.

Pursuant to the above background, the risk of MTCT of HIV in developed countries dropped to as low as 2% amongst the limited number of HIV infected women. In developing nations, however, particularly sub-Saharan African countries where the vast majority of HIV-infected women of child bearing age live, MTCT remains high. Such high rates persist due to lack of access to existing prevention interventions, including VCT, replacement feeding, elective caesarean section and antiretroviral drugs.

To clarify, the UNICEF pilot programmes, a combined data from 9 African countries, showed that while 43% of ANC attendees accepted VCT, 19% and 39% of pregnant women tested HIV positive and received ARV therapy, respectively. Furthermore, a combined data from call for action (CTA) programme reveals that amongst 110,000 women who tested at ANC, 90% of them were counselled. In addition, out of 80% of those who were tested, 17% were found to be HIV positive. Out of 58% of women who tested positive, only 30% of their new-borns received antiretroviral therapy.

In a Kenyan programme, while 73% of women who attended ANC were offered VCT, 89% of them accepted testing for HIV, and only 6% were found to be HIV positive.

Amongst the women who test positive, 64% accepted treatment. In Botswana, 56% of ANC attendees accepted counselling, 52% of them were tested. Amongst the tested women, 52% of those who were found to be HIV positive received ARV therapy, and only 1/3 of them completed the course of therapy. Based on these findings, it is clear that certainly there is poor uptake of MTCT services amongst those few "lucky" HIV positive women who have access to care. The challenge of PMTCT in sub-Saharan Africa is still prevalent.

2.2.4. Factors associated with Mother-to-Child Transmission of HIV

There are several factors that influence the risk of infection HIV from mothers to their unborn babies. These factors include the viral load of the mother at birth. The viral load of the mother at birth is directly proportional to risk of infection on the part of the child. As such, it is important that ARV therapy is administered to pregnant mothers in order to reduce their viral load and thus reduce the chances of MTCT of HIV.

Vaginal delivery is found to be associated with increased chances of HIV transmission from mother to the child. However, elective caesarean sections proved effective in the fight against MTCT of HIV. Other than this, poor obstetric practices such as early rapture membranes, frequent vaginal examinations are also thought to increase the chances of MTCT of HIV.

Breastfeeding is associated with 10% to 20% chance of transmission of HIV from the mother to the infant. Under current socio-economic trends in sub-Saharan Africa, most HIV positive mothers are left with breast feeding as the only "safe" and affordable option. A number of studies show that the preventative effect of the various drug regimens diminish when babies continue to be exposed to HIV transmission during breastfeeding, and this can erode greatly the short-term benefit of drugs to prevent MTCT of HIV (Prevention of mother-to-child transmission, n.d.).

2.3. The South African PMTCT Policy guideline

On the 11th of February 2008, the South African National Department of Health published the Policy and Guidelines for the implementation of the PMTCT programme. This was an update of the national PMTCT policy and guidelines conceptualized in

2000 and implemented at pilot sites in 2001, and nationally in 2002. The policy sought to provide continued guidance towards successful reduction of mother-to-child transmission (SA, 2008:12).

The principles guiding this policy included the imperatives of the Constitution, Batho Pele, those outlined in the Comprehensive Care Management and Treatment plan (CCMT) and those guiding the implementation of the National Strategic Plan (NSP) 2007- 2011, which are:

- Supportive leadership;
- Effective communication;
- Effective partnership;
- Tackling inequality and poverty;
- Using scientific evidence;
- Strengthening service delivery and integrating services;
- A human rights paradigm and life-course approach;
- Rights of women, pregnant women and mothers to information, treatment, management and care;
- Protecting and respecting children; and
- Duty and responsibility of all health care personnel (SA, 2008:24-25).

The objective of this policy guideline is to optimize maternal and child health survival by preventing HIV infection in infants and managing HIV positive women through effective and comprehensive evidence-based set of interventions provided at all levels. This policy guideline is premised on the integration of relevant components and services in the health care and social development system as part of a continuum of care (SA, 2008:26)

2.3.1. Enrolment of pregnant women into the PMTCT programme

In order for pregnant women to be enrolled into the PMTCT programme, the following procedures should be followed:

- The pregnant women should receive routine antenatal care, including micronutrient supplementation;
- They should be offered information on the availability of PMTCT interventions during any health care consultation;
- They should be counselled on safer sex and provided with condoms; and
- They should be counselled on safe infant feeding options and advised on making an appropriate feeding choice.

In addition to the above, all pregnant women who are HIV-positive should:

- Have a CD4 cell count taken on the same day that the HIV positive status is established and, preferably at the first ANC visit, be assessed for clinical stage according to WHO staging;
- Be screened for TB in line with the Basic Antenatal Care; and
- Receive ARV regimens prescribed by a registered health professional for PMTCT short course or HAART.

To ensure efficiency on, and control over, the administration of prevention measures put in place for the purposes of preventing MTCT, the following also proved necessary:

- Women who start HAART in their pregnancy should be monitored and managed, where possible, by the same provider, and should be followed-up by the antenatal healthcare worker until at least six weeks postpartum before being referred to CCMT service point;
- Women who test HIV-negative should receive post-test counselling and counselling on risk reduction interventions, focusing mainly on how to maintain their HIV-negative status and should continue to receive routine antenatal care;
- Women who test HIV-negative should be offered a repeat HIV test at or around 34 weeks to detect late sero conversion;
- Women who choose not to be tested should be offered voluntary HIV testing at every subsequent visit during the antenatal period or shortly after childbirth if testing at onset of labour was not possible;

- 'Unbooked' women reporting in labour: should be offered voluntary counselling and testing for HIV during the first stage of labour and offered a PMTCT intervention if positive; and
- For continuity of care and management, information on HIV status, infant feeding choice, PMTCT/HAART regimen and CD4 cell count should when necessary be shared between health care personnel at all levels of the health service.

2.3.2. Voluntary counselling and testing

All women attending antenatal care (first attendees and women attending follow-up visits) should be given routine information about voluntary HIV testing and the PMTCT programme**.** The initial information on HIV and its transmission should be given in a "Group Information Session." Subsequently, all women who have not previously been tested or those who require repeat testing should go to a counsellor for a one-on-one "Individual Information Session."

At the Individual Information Session, each woman should be informed of the routine voluntary HIV procedure and the option of not accepting for whatever reason. Also, each woman should be given the opportunity to ask further questions. Each woman should then be offered an HIV test and asked to provide verbal and written consent to the testing. For woman who may refuse an HIV test, routine voluntary HIV testing should be offered on every subsequent clinic visit.

All women who test HIV-positive on the screening rapid test should have their HIV status confirmed using a second rapid finger prick with a different kit. Post-test counselling should be offered to both HIV-positive and negative women. HIV-positive women should only be counselled after the second rapid HIV test has been performed, and confirmed a positive HIV status (SA, 2008:28).

2.3.3. Nutritional support

Micronutrient supplementation for HIV-positive women is the same as that routinely provided during pregnancy for all women. Supplementation includes multivitamins, iron and foliate. However in the case of advanced HIV disease where malnutrition or wasting or poor weight gain is evident, nutritional support in the form of vitamin and mineral

fortified porridge should be provided. These women should also have an opportunistic infection such as tuberculosis excluded and be followed up closely (SA, 2008:39).

2.3.4. Antiretroviral (ARV) interventions

Antiretroviral therapy provides an opportunity to significantly reduce the maternal HIV viral load and MTCT to the infant. A reduction in HIV transmission rate is achievable using regimens containing single, dual- or triple–drug combinations. Decisions around supporting women's choices of infant feeding to avoid mixed feeding and reducing MTCT need to be made during pregnancy (SA, 2008:39).

2.4. Factors that are barriers to PMTCT

Barriers to PMTCT could also have a major impact on how the PMTCT services are experienced. Frizzelle, Solomon & Rau (2009:14) explain that there is evidence that suggests that while many women may enrol in a PMTCT programme, a number of factors result in a high drop-out rate. Statistical data of healthcare coverage in South Africa shows that while 94% of women who attended ANC at least once, only 73% attended four or more times, and only 27% attended ANC by the time their infant was 20 weeks old. This shows a cascade of diminishing service use and highlights that there are many missed opportunities for PMTCT, especially through follow-up services.

Frizzelle *et al*. (2009:14-24) identify four barriers that contribute towards PMTCT enrolment: individual barriers, social network barriers, community barriers and societal barriers. All these barriers will be discussed below:

2.4.1. Societal barriers

2.4.1.1. Individual barriers

2.4.1.1.1. Lack of awareness and knowledge

Frizzelle *et al.* (2009:14) indicated that lack of awareness and knowledge about HIV/AIDS and MTCT in the general population is an on-going concern. Research in the Eastern Cape indicates that knowledge levels about PMTCT are low not only amongst women and mothers, but also amongst mothers' in-law and male partners or husbands.

2.4.1.1.2. Confusion about infant-feeding options

The review of the literature highlighted a level of confusion around infant feeding, and breastfeeding in particular. The general published discussion confirmed that programme managers, counsellors, and pregnant women continued to be confused. Such confusion also occurred at the level of scientific debate where polarisation continued to exist between those practitioners who supported the avoidance of all breastfeeding amongst HIV infected women and others who acknowledged the importance of the counselling approach to help women who choose the feeding options as the most appropriate to them.

2.4.1.1.3. PMTCT practices perceived of as discriminatory

An HIV testing is a practice that is generally associated with groups at higher risk of exposure to HIV. An active, “opt-in” counselling and testing is likely to be avoided by pregnant women who may not identify with so-called high-risk groups or who may fear being associated with one of these groups. Exclusive breastfeeding practices for the first six months of an infant’s life may not be in line with general breastfeeding practices nor with cultural norms; complying with this practice, therefore, often makes it impossible for women to hide their HIV status—a major concern for women living in a highly stigmatised context.

2.4.1.1.4. Psychological barriers

Fears of death, HIV testing, HIV-test results, and reactions to an HIV-positive status are reported as psychological barriers to particular PMTCT services such as VCT and disclosure of status. Denial of one’s HIV status and a sense of hopelessness are additional psychological barriers. Shame is also reported as a reason for not returning for follow-up visits.

2.4.2. Community barriers

If social support from the general community is perceived as low, this may have a negative impact on the up-take of PMTCT services and adherence to ARV treatment regimens. For example, a woman who fears a negative reaction from members of her

community if she suddenly ceases exclusive breastfeeding at six months, may instead choose to carry on breastfeeding even if she is in the position to cease breastfeeding.

2.4.3. Social network barriers

2.4.3.1. Stigma

Women may not access PMTCT services due to a fear of stigmatisation as actively participating in a PMTCT programme or following specific recommendations can make public a woman's HIV status. In contexts where HIV is unjustly associated with promiscuous behaviour, as it is the case in many Sub-Saharan African countries, women may be reluctant to test because their partners may question their faithfulness. This is so because some women fear negative reactions and rejection from their partners or discrimination from the wider community. Research in Soweto found that stigma did not diminish as women failed to disclose their positive HIV status to their partners because they feared rejection from their partner and family members (Frizzelle *et al*., 2009:18)

In her study, Chitambala (2003:45-46) states that the focus group members indicated that some families do not allow HIV positive persons to cook for them as they are afraid that such persons may transmit the virus to other members in the family. It was also stated that in some households, the bath and toilet rooms are immediately disinfect after the HIV positive persons used the facility. Furthermore, the study shows that some HIV positive persons are given their own kitchen utensils for eating purposes for fear of transmitting the HIV virus to other members of their families. It is this level of stigma that makes some women appears reluctant to test for HIV infection.

2.4.3.2. Gender-related issues and male partners

Women in many African countries reported fear of discrimination, rejection, divorce and physical harm as reasons for not wanting to disclose to the male partner or husband. In many developing countries, women are often not in the position to make independent choices about their own health or that of their babies. Therefore, it is often impossible for women to access PMTCT services without disclosing their HIV status to their partners. In Botswana, for instance, research found that while a lack of male support

prevented women from participating in PMTCT programmes, women who believed their partners would accompany them to an antenatal clinic and who expressed confidence in the fact that they would disclose their HIV status to their partners were significantly more likely to want to get tested.

Jackson *et al. (*in Sibanda 2008:35) observe that even if a woman endorsed the benefits of the prevention of MTCT programme, her lack of decision-making powers would ensure that all decisions about her reproductive healthcare are deferred to her husband, in-laws and sometimes other members of the extended family. In cases where women stop breastfeeding, Mate (in Sibanda 2008:35) claims that there could be "traditional explanations", which may include mental illness, being possessed with evil spirits, and one having lied about the baby's paternity or general ill health.

2.4.4. Social barriers

2.4.4.1. Healthcare infrastructure and shortage of staff

Frizzelle *et al*. (2009:11) argued that shortage of appropriately trained and skilled health care workers impacts on general service delivery. Research conducted in the rural Eastern Cape Province, reports that after PMTCT services were integrated into the clinic, no additional staff were allocated to the clinic and, as a result, the nurses reported that they did not have the capacity to provide quality services. In relation to this, it is clear that healthcare workers who offer family-planning services are seldom trained in HIV/AIDS care, which in turn points to the lack of an integrated approach to healthcare provision.

A lack of trained lay counsellors is found to inhibit a number of people who receive services such as VCT. In South Africa, research indicates that the North-West and Eastern Cape provinces still struggle to integrate lay counsellors into their VCT programmes. In resource-poor contexts, poor working conditions for healthcare workers lead to low retention of staff. Also, inadequate spaces for confidential counselling and private disclosure as well as insufficient number of sites in widely dispersed populations proved to inhibit the uptake of PMTCT services. In other contexts, although PMTCT programmes could be integrated into antenatal services, various HIV-related services

are housed in different buildings. This makes HIV positive women who attend certain PMTCT services vulnerable to stigmatisation.

2.4.4.2. Healthcare worker's poor attitudes and interactions with clients

The South African healthcare system is characterised by highly coercive relationship between programme providers and service users, particularly between nurses and their clients. Clients who are fearful of healthcare workers are not likely to return for follow-up sessions. Nurses are primarily schooled in a medical discourse, where value is attached to compliance to evidence-based medical interventions rather than to individual rights. In faith based organisations, limited extensive family-planning counselling might not be offered due to religious perspectives on sexuality. Research in a resource-poor setting in the Eastern Cape Province found that clients feared a lack of confidentiality among counsellors.

In relation to the above, Sibanda (2008:29) refers to the study conducted by Feldman & Maphoshere (2003), in which women complained that nurses scolded at them especially when they were pregnant after they were advised not to have children any further due to their HIV status. In many instances, their rude attitude towards pregnant mothers who were HIV positive took a form of verbal abuse, undermining comments, calling names and telling pregnant mothers that their unborn infants would not survive.

2.4.4.3. Poor quality counselling and information

The uptake of testing and PMTCT services is low in sites where counselling is of poor quality. Such poor-quality of counselling often results in the transmission of incomplete knowledge, which impedes the effectiveness of PMTCT programmes. Research in South Africa, for example, found that while the communication skills of counsellors were often good, the mother's knowledge remained low after counselling. Also, observations of counselling sessions revealed that inaccurate beliefs were corrected by counsellors in only 32% of the sessions offered. Additionally, the counsellors did not determine which infant feeding practice would be most appropriate for the client who attended their counselling sessions.

2.4.4.4. Inadequate family planning services and counselling

Research South Africa suggested that family planning policies may not be adequately sensitive to gender-related issues and that attention to individual women, as opposed to men and couples, may be comparatively overemphasised. It also reported inadequate male involvement in family planning. Studies also reveal that men are more likely to feel intimidated by the large number of women attending regular family-planning sites as there is a lack of male friendly family-planning sites and programmes. In addition, research in a number of developing countries found that in settings with low level of contraceptive use and HIV prevalence, the family-planning needs of HIV-positive women are typically dealt with by parallel family-planning services, but these services are often not tailored to meet the needs of HIV-positive women.

2.4.4.5. Inadequate integration of services

In developing countries, PMTCT services such VCT are not routinely offered and integrated as part of maternal, newborn and child health (MNCH) services. In cases where they are integrated, it does not guarantee that family planning will take place. In South Africa, for instance, it was found that while the majority of facilities provided routine MNCH services, additional follow-up care, including HIV-testing for infants and AIDS care, were not integrated into PHC services.

Research findings in South Africa showed that PMTCT programmes were often integrated into healthcare systems that were already understaffed and over-pressured. Consequently, there were delays in aspects of implementation and the training process.

2.4.4.6. Poor referral link

The issue of poor referrals within the healthcare system and between clinics impacts negatively on follow-up visits and on the continuity of care between the different facilities. In many rural areas, there is a shortage of telephones. Hence, healthcare workers often resort to communication by sending letters through public transport, which is unreliable. Moreover, poor communication between clinics impedes responses to emergency situations, complicates on-going management, and limits important exchanges of information and referrals between sites.

2.4.4.7. Poverty and infrastructure

In low-income areas where transportation is needed to reach healthcare sites, people may not have the money to pay for transport. More often than not, clients across Sub-Saharan Africa may have to walk considerable distances due to a lack of money for transportation to cover long distances between sites. Thus, financial constraints often hamper a woman's ability to rapidly cease 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 the formula feed. Also important to mention is that poor access to government grants denies women in many resource-poor contexts the means to attend follow-up sessions at clinics.

2.4.4.8. Cultural factors

The concept of PMTCT is suggestive of the fact that it is the primary of women responsibility to protect their infants from HIV infection. This implied meaning tends to undermine efforts to increase male involvement in PMTCT. Research conducted in South Africa research shows that in some cultures it is considered inappropriate for women to disclose their pregnancy to their mother-in-law until pregnancy shows. Similarly, a study conducted in Lesotho reveals a general taboo around public acknowledgement of pregnancy.

The Issue of cultural taboos (including talking about sex) impacts negatively on the uptake of certain PMTCT services which may include family planning or discussions about safer-sex. Apart from this, culturally accepted practices about infant feeding may also make it difficult for a woman to adhere to PMTCT related feeding options. In some cultures in South Africa, a young mother is highly likely to be pressurised by family regarding her infant-feeding choices.

Also important to note is that social expectations regarding a woman's childbearing role influence decisions about childbearing. Pressure from male partners or husbands, family members, and the wider community can override an HIV-positive woman's

decision not to have a child. Research conducted in Botswana and South Africa, revealed that gender power imbalances have an effect on women's ability to negotiate the use of condom with their partners during sexual intercourse.

2.5. Efficiency of PMTCT

Averting HIV and AIDS (nd:04-11) indicates that improving efficiency of PMTCT services means taking a closer look at nine main issues as presented below:

- accessibility,
- clinic resources,
- testing methods,
- fear and distrust,
- disclosure and discrimination,
- drug effectiveness,
- treatment for mothers,
- feasibility of replacement feeding, and
- male visits to antenatal clinic.

These issues might have a direct bearing on individuals' experiences and perceptions regarding their participation on the programme.

2.5.1. Accessibility

Women form poverty stricken families in the developing countries tend to have mare responsibilities in comparison with those who are from well-to-do families. For example, besides caring for their children, poor women are expected to work hard preparing food, fetching water or tending crops. While some of them live in places far away from health facility and have little access to transport, many others visit clinics only once during pregnancy. In fact, nearly two-thirds give birth unattended by a skilled health worker. These unfortunate circumstances reduce greatly the number that could be reached by PMTCT programmes. This situation becomes worse when women have to make follow-up visits to receive counselling, drugs or other services. It is therefore hardly surprising that a third of the world's pregnant women do not attend antenatal clinics.

To increase attendance, clinics should be made more accessible to community members. One way to achieve this is make provisions for travel services and changing opening hours. For example, one programme in rural India increased attendance by setting up a Saturday clinic. Also, women who are HIV positive should be encouraged to give birth at a clinic. To attain high coverage, PMTCT programmes need to reach those who deliver at home. The programmes can also increase acceptance of self-administered drugs by working with traditional birth attendants, who attend the majority of home deliveries.

2.5.2. Clinic resources

Shortages of HIV test kits, preventive drugs and other supplies can limit the efficiency of PMTCT programmes. It is therefore important to have reliable supply chains that are integrated into systems serving maternal and child health clinics. Staff shortages and motivational issues are also important especially when it comes to counselling, which takes a long time to do well. Ultimately, the best solution is to recruit more health workers. In the shorter term, better training, greater support and motivation can improve the efficiency of existing staff. Boost to morale may include psychosocial support, improved availability of supplies, and training on precautions and post-exposure prophylaxis, which helps to prevent health workers from becoming infected with HIV.

2.5.3. Testing methods

The conventional form of testing for HIV in antenatal clinics is called voluntary counselling and testing (VCT). According to the VCT approach, women are offered an HIV test and need to decide whether they think it is worth accepting or not. An alternative model is routine testing. In this model, women are told that HIV testing is a standard part of antenatal care, but they can opt out if they want to.

PMTCT interventions can still be effective in the third trimester of pregnancy, during labour and even after delivery. These programmes should therefore seize every opportunity to offer testing to women of unknown HIV status. They should also consider retesting women who were previously negative to confirm their negative status. By integrating HIV counselling and testing into all parts of the maternal and child health

systems, including family planning clinics, labour and delivery services, postpartum care and even immunisation clinics, PMTCT programmes can, to a considerable extent, reach more women.

2.5.4. Fear and distrust

While some women refuse to test for HIV because they are afraid that they may have a life-threatening disease whose resultant worries and stress may quicken death, others refuse because they perceive few benefits of testing, either to their unborn babies or to themselves. In relation to this, a study in Cote d'voire found that a significant number of pregnant women who had been diagnosed with HIV were unwilling to take part in follow-up visits because they had had bad experiences dealing with health workers. Their problems included distrust of staff and their medicines, dissatisfaction with counselling, disbelief of test results, fear of hostile staff.

To allay concerns, while clinic staff should be approachable and supportive, programmes should seek to raise community awareness of PMTCT services and their benefits. Such promotion may take such forms as videos, talks, brochures, radio programmes or songs. Also, working with community leaders, perhaps by setting up advisory boards promotes the idea of collective ownership and helps to raise acceptance of PMTCT services.

2.5.5. Disclosure and discrimination

Many women are concerned that, if found to be HIV positive, their diagnosis will not remain secret. Their concern relate to stigma and discrimination and can lead to social isolation and even loss of family support. Fear of such prejudice can make some of the women refuse HIV testing, or decide not to return for their test results. Often the greatest worry is the reaction of a male partner. Among pregnant women who do take a test and are found to be HIV positive, a high proportion chooses not to tell their partners. One common reason for such a decision is fear of violence or abandonment.

An HIV positive, pregnant woman who did not disclose her diagnosis to her partner, family or friends is generally less likely to accept preventive drugs and to practice unconventional methods of infant feeding. This is so because she might not want to

reveal her HIV status. In cases such as this, PMTCT programmes should be geared towards making disclosure less difficult for their clients, thereby running support groups or anti-stigma campaigns. They should also me aimed at identifying and assisting those who wish to avoid or defer disclosure.

One good idea is to involve male partners in the PMTCT programme. If couples are counselled and tested together then there is less potential for blame and recrimination. Counsellors can emphasize the man's responsibility for protecting the health of his partner and family, and can promote the use of PMTCT and other services—thus resulting in much higher take–up rates. Other possible ways to increase male participation include hand delivered invitations and routine testing for men who accompany their partners. Unfortunately, it is usually far from easy to persuade men to attend what they regard as women's clinics dealing with women's issues.

2.5.6. Drug effectiveness and adherence

Studies show the Nevirapine, given in one dose each to mother and child, is by far the easiest type of drug for PMTCT programmes to administer. However, it is important to highlight that Nevirapine only reduces the risk of transmission by around 50%, but can encourage HIV to develop drug resistance. This means that if a woman begins taking antiretroviral treatment within a few months of taking single dose-nevirapine, she might not receive any benefit.

Rather, longer courses of drugs involving daily doses for several weeks are more effective at preventing HIV transmission and less likely to cause drug resistance. The problem is that the obstacles that prevent women from receiving Nevirapine are even greater in the case of longer regimens. In particular:

- More money and resources are required to supply the extra drugs;
- Women may need to make additional clinic visits to collect their medication;
- The drugs can cause side-effects including anaemia;
- Women who are taking pills every day and storing them at home are much less able to avoid disclosing their HIV status to their partners, friends or relatives; and

- Some women may have difficulty adhering to daily treatment.

Common problems with regard to drug adherence are often the result of poor patient education. This is due to the fact that antenatal clinics usually do not have the time and expertise required to educate women about the drugs they are given. Such expertise and education are necessary in communicating the importance of taking every dose at the right time as well as explaining the need to provide follow-up visits.

Faced with such challenges, many PMTCT programmes are unable to switch from nevirapine to longer regimens. Some experts suggest that it is important to focus on attaining a good level of access to the single-dose drug before considering anything more ambitious. Yet the unfortunate truth is that as long as programmes supply a drug that is only 50% effective many babies will continue to become infected.

2.5.7. Treatment for mothers

Ideally, pregnant women in the advanced stages of HIV disease should be offered antiretroviral treatment to protect their own health and to further reduce the risk of mother-to-child transmission. This type of treatment will prevent children from becoming orphans by keeping their mothers alive for longer. It can therefore mentioned that this type of treatment a powerful incentive for women taking part in PMTCT programmes.

Of all drug interventions, however, long-term treatment are not without challenges—they are the most difficult to administer. In most cases, PMTCT services are provided at antenatal clinics, while treatment is provided at treatment clinics. Even if they are located in the same building, the two programmes tend to have different working methods and separate medical records. Treatment clinics often have little experience of dealing with the extra complications associated with treating pregnant women. Usually patients are put on a waiting list for weeks or even for months and are expected to undergo “lengthy literacy” lessons. In the case of pregnant women, any delay increases the risk of mother-to-child transmission. In the worst case, a woman may end up receiving no preventive drugs at all before giving birth.

Antenatal clinic staff rarely have expertise to establish which women need antiretroviral treatment. To provide this service, they require special training and extra resources

including expensive CD4 testing equipment. They must have time available to carry out the assessments and referrals in addition to their daily duties. Having overcome difficulties to attend an antenatal clinic, a pregnant woman may have little enthusiasm for joining another queue at her local treatment facility, especially if, despite her illness, she does not feel particularly sick. If at all she does attend, there is less chance that she will be able to keep her status secret. Although there are no easy answers to these problems, a possible step is to improve communication between the different medical services. Beyond that, substantial investment in training and resources is required.

2.5.8. Feasibility of replacement feeding

Given the fact that HIV can be transmitted through breast milk, a mother's method of infant feeding has a strong influence on the likelihood that her baby will be infected. To avoid transmission, HIV positive mothers need to abstain from breastfeeding and provide replacement food. Although is a safe option, many impoverished mothers are best advised to breastfeed even if they are HIV positive. In this case, mixed feeding is strongly discouraged as it carries greatest risk of HIV transmission. With regard to replacement of feeding, it is worth mentioning that unless mothers have access to a reliable supply of safe water as well as the ingredients for the food itself, it may still prove unsafe, expensive and time consuming.

While it may seem obvious that PMTCT programmes should assist HIV positive mothers by offering free supplies of infant formula, there are some drawbacks to this approach. The most worrying is that by distributing formula, clinics may inadvertently encourage mothers to give up breastfeeding even if they are HIV negative. In addition, mothers who have the resources to practise safe replacement feeding are least likely to need free formula. Therefore, some experts argue, supplying free formula is not an effective use of money.

2.5.9. Male visits to antenatal clinics

A study from Kenya revealed that where women are supported and accompanied by their male partners, they are more likely to consistently visit antenatal clinics. Few men usually accompany their wives on visits to antenatal clinics for fear of being ridiculed by

peers. However, it has been shown that when male partners are involved, both partners can get tested for HIV and, once they get to know their positive status, they will improve the baby's chances of a healthy survival. According to the study, HIV positive pregnant women who did not disclose their status to their partners would not return to the clinic—thus putting the baby's life in jeopardy. These findings indicate that promotion aimed at increasing male attendance in antenatal care could function to reduce the risk of vertical transmission and infant mortality.

2.6. Reported experience of Voluntary Counselling and Testing

Much of the literature reviewed for the sake of this report regarding the experiences of VCT providers addressed the following issues: uptake of testing; reasons that make people refuse HIV test as well the reasons that make people not to return for test results. There reviewed literature also dealt with issues regarding whether VCT should be conducted individually or in groups; and whether VCT for PMTCT should be integrated into existing services or be considered as a new, specialised service (WHO, 2003: 21-23).

2.6.1. Uptake for testing

Recent studies on vertical transmission of HIV showed that the majority of women are not willing to be tested. Amongst the many factors responsible for women's refusal to do HIV test, fear of knowing the outcome of the test was cited in a study conducted in Cote d'Ivoire (Sherr in WHO, 2003:21). It was also found that women who did not endorse testing were more anxious than those who agreed to be tested. A study conducted in Cote d'Ivoire and Burkina Faso (Cartoux, *et al.* in WHO 2003:21), found that although there was a high uptake of testing, several factors, including wanting more time to consider whether to be tested or not, accounted for unwillingness by many mothers.

Other factors leading to test refusal included high educational level and last trimester gestation. In this study, refusal for testing increased with age and almost doubled for women over 35 years of age. Ignorance about sexual HIV transmission and condom use was another factor for test refusal. In addition, women who perceived themselves to be at risk of infection were better able to analyse potential adverse consequences of

testing and, as such, were more likely to decline HIV test. Finally, this study revealed that some counsellors appeared to have a negative impact on women's willingness to accept counselling, possibly due to their limited professional skills and empathy.

2.6.2. Failure to return for tests results

The rapid HIV tests can give final results within a few minutes. Thus, women can wait for their HIV test result at one visit. However, these women will not be afforded the time to consider whether they want to know their test results or not. In other words, during rapid HIV test pregnant women may neither have the opportunity to get appropriate counselling nor be given enough time to reflect on the advantages and disadvantages of knowing their status in order to make an informed decision.

The WHO Clinical guides for the management of pregnant women with HIV infection series emphasizes the importance of providing women with the choice of whether they receive their results immediately or at a subsequent antenatal visit. In cases where the woman does not choose to wait for her test result, it is important to give her a date on which she can return for the results. In contrast to the simple/rapid HIV tests, the slower tests can take up to two weeks for the results to be known. In this case, women can fully consider the impact of an HIV test result, and might choose not to be informed.

In many VCT sites in developing countries, up to 50% of people do not collect their results. In a study in Western Africa (Cartoux *et al.* as cited in WHO,2003:22), it was found that women were three times less likely to return for test results than uninfected women, and that return rates were independent of the pre-test technique. In an international study, fear of disclosure of HIV status and the risk associated with unfaithful regular partner caused women to fail to return for their test results. The type of test requiring a two-week waiting period for results negatively affected women's return rates. Women who had to travel long distances or delivered in the meantime or those who had second thoughts about knowing their test results failed to return to the clinic. Therefore, the type of test used can have a significant bearing on whether the woman accesses her test results or not.

2.6.3. Group pre-test versus individual counselling

Several studies suggested that group pre-test counselling is effective for test uptake. Cartoux *et al*. in WHO (2003:22) reported that, on the whole, knowledge about HIV/AIDS was better after group than after individual counselling. In addition, the report stated that individual counselling accounted for a higher uptake of testing, but both group and individual counselling accounted for a high degree of test acceptability.

2.6.4. Separate or integrated VCT services

Access to women who may benefit from VCT for PMTCT is most likely to be found in antenatal clinics. In the developing world where 95% of MTCT occurs, many pregnant women know little about HIV/AIDS and would consider themselves at low or no risk for infection. In addition, where there is a high degree of awareness about HIV/AIDS, the risk of vertical transmission is not as known or understood. As such, successful VCT and PMTCT services would most likely be found as an extension of ANC. However, the costs of recruiting and training new, committed staff and the added strain on already busy antenatal clinics must be taken into account. Furthermore, special projects and initiatives to prevent MTCT might require additional space and funding.

An integrated PMTCT service within ANC also helps prevent stigma and discrimination about woman's HIV status. It is often the case that the wider community holds misconceptions about HIV resulting in stigma and denial. These attitudes may affect women's willingness to participate in PMTCT. In a study in Botswana and Zambia, it was found that the men and elders had a considerable influence on the decisions women made about participating in PMTCT and/or on the difficulties women experienced during their participation. Taking these issues into account, UNAIDS suggests that strengthening reproductive health services is essential so that they can integrate HIV into regular activities.

It is also noted that specialised services for VCT and PMTCT are also effective. The specialized services that have HIV/AIDS prevention and care as their mandate can provide more focused care. In these programmes, counsellors can be trained and supported in VCT and PMTCT practices. Referral services can be coordinated and the

specialised treatment for PMTCT can be monitored and evaluated. Moreover, most ANC services are not considered to be inviting or supportive to men. This is problematic when women are encouraged to bring their partners along for testing. Cartoux *et al.* in WHO (2003:23)found that more than half of the women in their study stated that they wished to receive their test result in the presence of another person, and the regular partner was the first choice.

2.7. Psychosocial support

WHO (2003:24) indicates that a person diagnosed as HIV-infected undergoes considerable psychological stress. The main concerns for those who test seropositive include the need for social, peer and psychological support, access to medical care and treatment, disclosure and planning for the future, and access to PMTCT and family planning services. Other common initial reactions to an HIV-positive result include anger, fear, depression and denial. In addition to this, women who are tested during the antenatal period usually have more profound psychological distress. Generally, this is due to the fact that they probably did not considered the possibility that they may be HIV-infected until they consent to testing as part of VCT in ANC.

WHO (2003:24) further argues that not only do these women have to adjust to being pregnant, they also have worries about the pregnancy, and often have to make decisions about whether to terminate it, or to agree to interventions such as ART and replacement infant feeding. Added to these stressors is the knowledge that the woman is diagnosed with a disease that carries stigma, fear and discrimination. In countries where breastfeeding is the norm, this will lead to an added strain as decisions have to be made about whether to breastfeed or artificially feed her infant. All this stressors are combined with the desire of women to have children, and the strong social pressures for them to do so.

Temmerman *et al.* in (WHO 2003:24) consider the aim of counselling HIV-Infected women as being to help them cope with the disease and prepare for the future, reduce the sexual risk behaviours, and enable them to make informed choices about reproductive health. WHO (2003:25) also indicated that the diagnosis of HIV infection for women contemplating pregnancy, or presenting at the antenatal clinic already

pregnant, is associated with considerable psychosocial distress. WHO (2003) points out that emotions such as worry, anxiety and despair, shame, fear, grief, worry, and depression, distress, anger, guilt, self-pity, confusion, fear of death, loneliness and worrying about health are the most common challenges facing HIV positive mothers.

2.8. The strengths and weaknesses of the PMTCT programme

A study commissioned by SADC (2008:07) on the development of harmonized minimum standards for guidance on HIV testing and counselling and PMTCT of HIV in the SADC region reported its findings using the SWOT analysis. Such findings showed the following:

Strengths

- PMTCT policy drafted in 2001;
- New PMTCT guidelines published February 2008;
- PLWHA and disability sector involved in social mobilization plan for PMTCT; and
- Wide consultation on policies and plans.

Weaknesses

- PMTCT protocol does not (fully) match international best practice norms;
- Men are not sufficiently involved (however, programmes such as 'Men as partners' are designed to address this);
- Adolescent mothers are not included in PMTCT planning;
- Inadequate human resources;
- Poor quality counselling;
- Infant formula supply problems; and
- Inaccurate M&E.

Opportunities

- Recent renewed political commitment;
- Accelerated PMTCT roll out launch (Mar/Apr 2009);
- Change to PITC in ANC and maternity settings; and
- PNC register piloted and ready to be printed

The report concluded that the quality of counselling to pregnant mothers was one of the weaknesses that impacted on the effectiveness of PMTCT (SADC 2008:8).

2.9. The family centred approach to PMTCT of HIV

Betancourt, Abrahams, McBain, & Smith (2010:02) argue that the family centred PMTCT model include all family members in the care paradigm and addresses the comprehensive health needs of all of family members, particularly the mother and the child. The family centred approach to PMTCT has the potential to enhance health outcomes for both mother and child as well as other members within the household. A central issue is that HIV-affected families are at risk for a broad range of negative health outcomes, which have cascading effects on the health of all family members. For example, by offering HIV testing and treatment to other family members, pregnant women may be more likely to accept HIV testing and collect their results, adhere to PMTCT regimens, and disclose their HIV positive status to their partners (Betancourt *et al*., 2010: 02).

Betancourt *et al.* (2010: 02) explain that the family-centred care is defined in a number of ways. A useful definition comes from the American Academy of Paediatrics (APP), which states that, “In paediatrics, family-centred care is based on the understanding that the family is the child’s primary source of strength and support.” In this model a number of core principles of family-centred care are outlined. These include such elements as: (a) respect for each child, (b) recognizing and building on family strengths and (c) providing and/or ensuring formal and informal support for the child and parents or guardians during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood.

Betancourt *et al.* (2010:02) acknowledge that the rubric outlined by the APP does not perfectly translate to the context of PMTCT in resource limited settings. They further indicate that one might think of these principles as a more general recognition of the need to assume a family-centred approach to the treatment and maintenance of child health and wellbeing, and could be including within the frame work of PMTCT. This need has increasingly been acknowledged by international organizations such the WHO, which recently outlined its PMTCT Strategic Vision 2010-2015 that “priority will be given to strengthening linkages between PMTCT and HIV care and treatment

services for women, their children and other family members in order to support an effective continuum of care.

A number of barriers to developing a family-centred PMTCT in low-resourced countries have been identified. These include, amongst many, limited access to antenatal care and obstetric services, lack of (opt-out) and rapid HIV testing, poor access to CD4 monitoring, limited access to ART, limited access to multi-drug prophylactic regimens for PMTCT, limited testing of partners, low access to paediatric testing and treatment for HIV, poor adherence as well as retention in care after delivery (Betancourt *et al.*, 2010:07).

2.10. The role of the social worker in PMTCT

The National Association of Social Workers in Zastrow (2004:40) defined social workers as “Graduates of schools of social work (with either a bachelor’s or master’s degrees), who use their knowledge and skills to provide social services for clients (who may be individuals, families, groups, communities, organisations or society in general). Social workers help people increase their capacities for problem solving and coping and help them obtain needed resources, facilitate interactions between individuals and between people and their environments, make organisations responsible to people, and influence social policies.

Surface (2007:20) indicates that social workers are one of the strongest sources of social support associated with high levels of medication compliance in patients with HIV/AIDS. He further argues that in the battle against HIV/AIDS, social workers help clients cope with HIV/AIDS in a variety of settings, including home health agencies, hospitals, infectious disease clinics, and AIDS service organisations. While the doctor’s relationship with the patient seldom extends beyond the clinic or hospital doors, the social worker’s concern reaches into every area of the client’s daily life, confronting the challenges the client faces every day.

The role of the social worker at a PMTCT clinic is determined by psychosocial support needs of HIV positive pregnant and postpartum women. The South to South psychosocial and adherence support training manual (2010:86) identifies common

psychosocial support needs of this type of clientele. As part of psychosocial assessment and counselling, the following support needs should be discussed:

- Feelings and concerns about their HIV status and the effect it has on their own and their family's lives;
- Fears of passing HIV to the baby;
- Empathy and acceptance from partner and family members;
- Support in understanding and coming to terms with their HIV status;
- Support to have a safe pregnancy and delivery;
- Support to safely feed the baby;
- Support to bring the baby for follow-up and care, testing, and treatment;
- Peer support from other pregnant women and mothers;
- Strategies to disclose their HIV status to their partner and other family members and children living with HIV;
- Strategies to encourage their partner and family members to test and, if appropriate, enrol into care and treatment programmes;
- Strategies and support for positive living;
- Strategies and support for positive prevention, including in discordant couples;
- Access to community based organisations and support groups;
- Access to nutrition support for self and family;
- Access to social grants and in-come generating projects;
- Spiritual support and referral to spiritual counselling;
- Knowledge about their legal issues and rights;
- Support about their legal issues and rights;
- Support for mental health, including anxiety and depression; and
- Substance abuse management

The S2S manual (2010:88) further indicates key topics to address during a psychosocial assessment with a PMTCT client which are the client's coping, the client's support system, disclosure, actual or potential risk of stigma, discrimination, and /or violence at home and in the community, sources of income and other material support, plans for the client's own care, plans for the baby's care, partner testing and, if necessary, enrolment

in care and treatment and referrals to other clinical, as well as community and home based services.

2.11. Summary

The experiences of women enrolled on PMTCT programme are influenced by a variety of factors. However, agreeing to do an HIV test is the first step towards receiving treatment for both the unborn baby and the pregnant woman. In Sub-Saharan Africa, cultural factors are found to play a major role in influencing the enrolment of pregnant women on PMTCT programmes. Although education about HIV/AIDS is widespread, stigma is one of the biggest challenges HIV positive pregnant women still face. None involvement of partners in the whole process puts strains on women. This also stifles efforts to make a disclosure of an HIV positive test result. An integrated approach to providing PMTCT services is ideal where services will be more accessible, stronger support system for women is mobilised and the involvement of the family is prioritised.

CHAPTER 3

RESEARCH METHODOLOGY, EMPIRICAL STUDY AND RESEARCH FINDINGS

3.1. INTRODUCTION

This chapter outlines the research methodology of the study. The chapter also offers a discussion on the ethical issues relevant to this study. The research findings are later presented and discussed. As highlighted in the introductory section of this report, the goal of the study is to explore how HIV positive others experience the PMTCT programme at Tonga Hospital in Nkomazi Municipality. Its objectives are to:

- determine the understanding of HIV positive mothers regarding the PMTCT programme at Tonga Hospital;
- ascertain the services received from the PMTCT programme;
- identify the strength and shortfalls of the programme; and
- determine the support received from social workers and other health care professionals.

To achieve these objective, this study was guided by the following question.

What are the experiences of HIV positive mothers with the PMTCT programme?

3.2. RESEARCH METHODOLOGY

The following form part of the research methodology: the research approach, the type of research, the research design and methods, the feasibility of the study and ethical aspects.

3.2.1 Research approach

The qualitative research approach was applied in this study. This paradigm was suitable for this study in that it focused on the experiences and perceptions of the participants. The study was aimed at understanding social life and meaning that people attach to their everyday life. In addition, this approach elicited participants' accounts of meaning, experiences or perceptions. Furthermore, the study was concerned with understanding

rather than explaining the subjective exploration of reality from the perspective of an insider as opposed (McRoy in Fouché & Delport, 2009:74).

This study focused on describing and understanding the PMTCT programme within its naturally occurring context. Its intention was to develop an understanding of the meanings imparted by the respondents—a "seeing through the eyes of the participants"—so that the phenomenon could be described in terms of the meaning that they had for the actors or participants (Maree, 2009:26).

As such, the researcher opted for this approach because the study required participants to give an account of their own personal feelings and experiences regarding the PMTCT programme. The researcher also sought to understand rather than to explain how HIV positive mothers on the PMTCT programme experienced the enrolment on the programme. This was done to provide a strong base to establish scientific based evidence and strategies for the social work discipline.

3.2.2. Type of research

This study was located within the confines of applied research. The primary purpose of applied research is to solve a social problem or to make a contribution to real-life issues. This study, therefore, was intended to find solutions to challenges experienced on the PMTCT programme. Thus, the study would establish knowledge that would strengthen the PMTCT programme. This would also contribute to addressing the psycho–social needs of HIV positive, pregnant women attending the PMTCT programme. The issue of prevention of mother-to-child is an existing social problem that calls for a project of this nature (Mouton, 2009:105).

The study explored the experiences of HIV positive mothers while on the PMTCT programme. Their experiences gave insight on how they felt about the services they received as attempts to addressing their psychosocial needs.

3.2.3. Research design and methods

3.2.3.1. Research design

The study used collective case study research design. A case study can be understood as referring to a process, activity, event, programme, individual or multiple individuals. In the context of this study, individual or multiple individuals and the PMTCT were the cases to be studied. As such, a collective case study research design was appropriate for this study as it sought to explore the experiences of a group of cases relating to the PMTCT programme (Fouché, 2009:272).

3.2.3.2. Research population, sample and sampling method

The concept of population in research is understood as referring to the total sum of all the cases that meet our definition of the unit of analysis (Mouton, 2009:52).Thus, the population for this study was HIV positive women who received PMTCT services during pregnancy. The unit of analysis was the HIV status during pregnancy and participation in the PMTCT programme. To study the population for this project, probability sampling method was applied. In the probability sampling method, the odds of selecting a particular individual are known and can be calculated (Forzano & Gavetter in Strydom, 2009:198). In the context of this study, a list of women who participated in the PMTCT programme at the hospital was provided.

For the purposes of this study, systematic sampling method was also applied. To do this, the first name was selected randomly from a list of names. The researcher, with the help of the professional nurse in charge of the PMTCT programme, compiled a list of names of HIV positive mothers who received PMTCT services during pregnancy between July 2011 and July 2012. A two-digit number was assigned to the entire population; the numbers ranged from 01 to 40 (Hoinville *et al*., as cited in Strydom, 2005:200).

Once the first name was selected, an interval of two was used—selecting every second name on the list until the required number was reached. The size of the population for this study was 12 participants. The researcher requested a list of PMTCT clients with their contact numbers to inform them about the research and, in the process, establish

their willingness to take part in the study. Thereafter, appointments with the willing participants were made and interviews were conducted in the comfort of their own homes

3.2.4. Data collection

The researcher hoped to learn more about participant's ideas, beliefs and views of the PMTCT programme. Due to the sensitivity of the phenomenon under investigation, the researcher applied semi-structured, one-on-one interview to collect data. This was done in order to gain a detailed picture of participant's beliefs, perceptions or accounts the PMTCT programme. In addition, semi-structured interview was suitable because the researcher was particularly interested in the PMTCT programme as it deals with the personal aspects of the participants' lives. In order to solicit relevant responses from the participants, the researcher prepared a set of predetermined questions on an interview schedule (Greef, 2009:296). Subsequently, the researcher followed-up interesting avenues that emerged during the interview process. This ensured that the participants provide a detailed account of their individual experiences.

3.2.5. Data analysis

Terre Blanche, Durheim & Kelly's (2006:32) pattern of data analysis was applied. To achieve this, the following steps were taken: familiarization and immersion where the researcher started to work with the text than lived reality. The researcher read the material many times over, making notes, drawing diagrams and brainstorming. The second step involved inducing themes, the researcher looked at the material to work out what could be the organizing principles that naturally underlie the material.

The third step was to be followed was coding. In this context, the researcher coded phrases, lines, sentences or paragraphs, thereby identifying textual bits by virtue of their containing material that pertained to the themes under consideration. After coding, elaboration performed and the researcher explored the themes more closely in order to capture the finer nuances of meaning not captured by the original, possibly quite crude, coding system. Finally, interpretation of data was made and the researcher put together

interpretations which were the written account of the phenomenon being studied. This was done using thematic categories from the analysis as sub-headings.

Planning for recording

The researcher explained to the participants the reasons for using the tape recorder. The respondents used numbers for the sake of anonymity when recording.

Familiarization and immersion

The researcher read the memos may times, making notes, drawings, diagrams and brainstorming.

Inducing themes

The researcher identified recurring themes and patterns that emerged from the data, and from the themes he was able to identify sub-themes.

Coding data

Themes and sub-themes were coded using markers.

Interpretation

The data was analysed through emerging information using themes and responses from participants.

Trustworthiness

The researcher ensured trustworthiness by giving each participants the opportunities to refuse to participate in the study, to ensure that data collection sessions involved only those who were genuinely willing to take part and prepared to offer data freely. It was also made clear to the participants that they had the right to withdraw from the study at any point, and they would not be required to provide any explanation to the investigator thereafter (Shenton, 2004:66-67).

Credibility

Member checking was applied in this study to gain credibility. The researcher summarised information provided by each participant at the end of each interview to determine accuracy. Where participants disagreed with the information, it was immediately corrected so as to reflect their feelings, perceptions and views (Cresswell, 2007; Lincoln & Guba, 1985 in Harper & Cole, 2012:511).

3.2.6. Pilot study

A pilot study was conducted with two participants who were not part of the actual study.

3.3. Empirical Research Findings

Research findings will be presented and discussed in this section. The first section will present the biographical data of the respondents and offer discussions on the themes and sub-themes as they emerged from the data. Where applicable, the research findings will be substantiated by literature. At least 12 HIV positive mothers were interviewed.

3.3.1. Biographical data

The study focused on HIV positive mothers who enrolled on the PMTCT programme. As represented in the figure 1 below, seven mothers were unmarried, two were married and three were in co-habitation. Those in co-habitation felt that they were not married because the partners had not paid lobola as it is required by their custom in the Swazi culture.

Biographical data in this section included the following factors: age of the respondents, race profile of the participants, marital status, number of children and educational level.

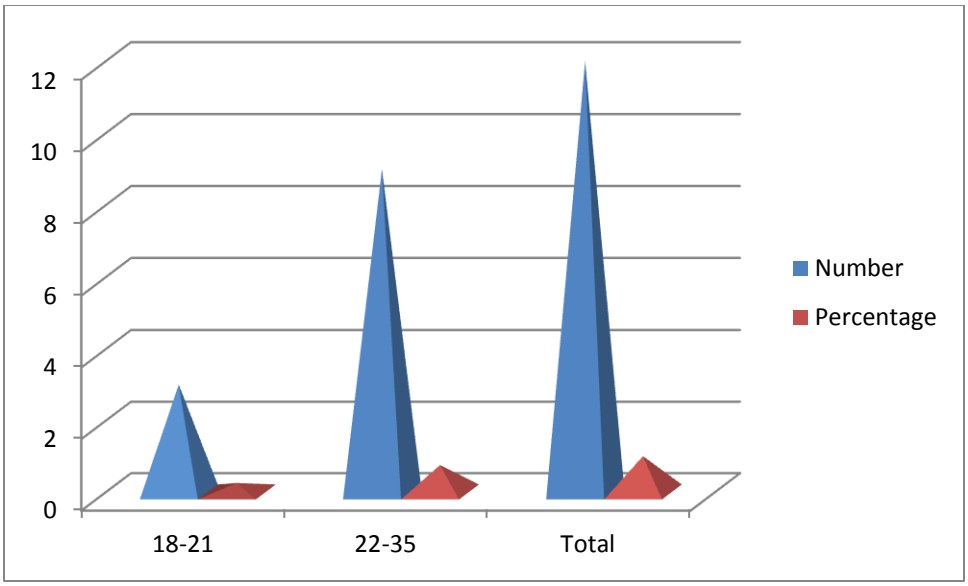

Figure 1: Age distribution of participants

In this study, the majority of participants fell within the age group of 22-35 years. The other group fell within the age group of 18-21. The findings in this study correlate with the findings in a number of studies on the age distribution. The Centre for Disease Control and Prevention reported that in the USA HIV/AIDS accounted for the largest proportion of death of women between the ages of 25-34 (CDC: 2008:2). These are women who are still in the child bearing age.

Table 1. Educational level of participants

Grade	Number	Percentage
1-3	-	-
4-6	-	-
7-9	02	17%
10-12	08	67%
N1-N3	01	8%
N4-N6	-	-
Abet Level 1-3	01	8%
Abet Level 4-6	-	-
Certificate/Diploma/Degree	-	-
Others, please specify	-	-
Total	12	100%

Table 1 above reflects that the highest level of education successfully completed by participants. It is interesting to note that the majority (67%) of participants had grade 10-12 level of education. It is also important to mention that while 17% had grade 7-9 level of education, and 8% had N1-N3 college level of education, the other 8% had Abet level 1-3 education. None of the participants achieved university education. This is also confirmed by study conducted in South Africa on the effectiveness of PMTCT programme six weeks postpartum found that in Eastern Cape, the majority of participants' educational level was grade 8-12 (Goga, Dihn and Jackson, 2010:20).

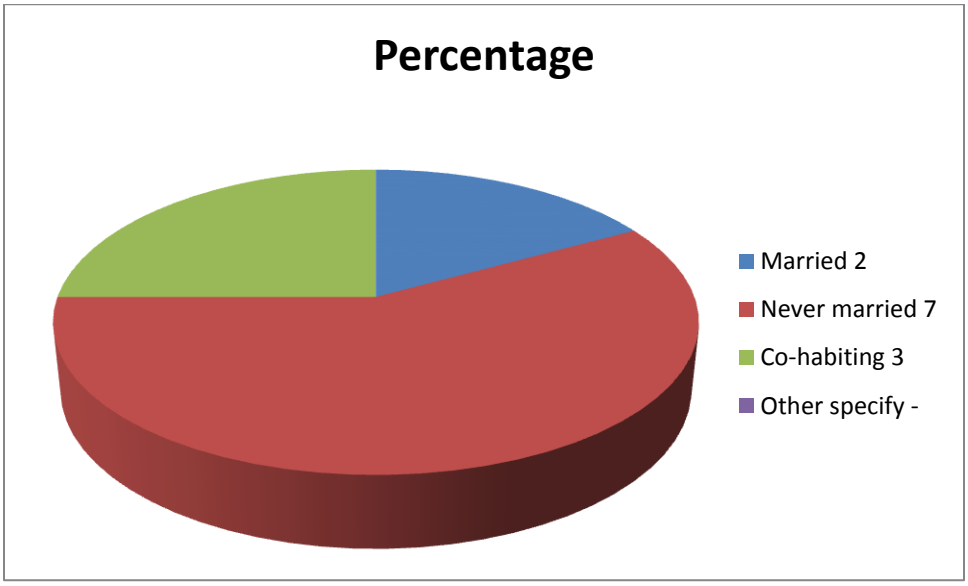

FIGURE 2. The marital status of respondents

Figure 2 indicates that out of seven participants, only two participants were married. Three participants indicated they were in co-habitation because their partners did not pay the lobola, according to their Swazi culture. This is similar to the study conducted in the Free State province on the effectiveness of PMTCT programme measured at six weeks postpartum, where the majority (67%) of participants were unmarried (Goga *et al* 2010:22).

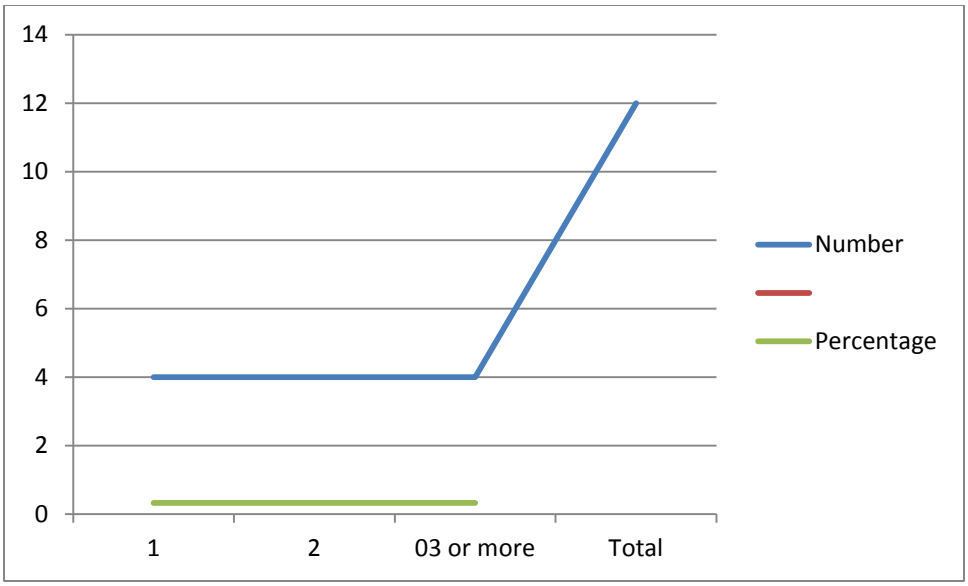

FIGURE 3. Number of children

Figure 3 indicates that four participants had one child, the other four had two children while the last four participants had three and more children.

All participants spoke isiSwati and did not understand English well. As the questions were written in English, a translator was used to make the questions accessible to the participants. Answers were also given in isiSwati and the researcher together with the translator translated the conversation into English.

3.4. SECTION 2: RESEARCH FINDINGS

In the data analysis phase, there were recurring themes and sub-themes that emerged from the data. The following are the themes and sub-themes:

Number	Theme	Sub-theme
3.4.1.	Understanding of PMTCT	Experience of the PMTCT programme
3.4.2.	Services received in PMTCT	Counselling
		Social work services
		Quality of counselling
		Other services
3.4.3	Support system	Pillar of support
		Professional support

		Men's involvement
3.4.4.	Challenges experienced by HIV positive mothers	Attitudes from family members
		Attitudes from health care workers
3.4.5.	Culture	The impact of culture
3.4.6.	Plan for the future	Benefits of being on the PMTCT programme

3.4.1. Theme 1: Understanding of PMTCT programme

The findings of this study showed that most of the participants did not have knowledge about the programme. For example, six participants confirmed that they only heard about PMTCT when they visited the hospital, and they had not received any information about it prior to their visit to the hospital. Their lack of knowledge was expressed through the following statement:

> *"I did not know anything about the programme, I learnt so much about it at the hospital"*

Lack of knowledge about HIV and MTCT in the general population is an on-going concern. Research in the Eastern Cape, for instance, indicated that knowledge levels about PMTCT are low not only among women and mothers, but also among mothers-in-law and male partners. Another research in the Western Cape found that participants had a high level of knowledge about HIV transmission and correctly knew that MTCT was preventable. However, only 11% of these participants were able to correctly explain exclusive breastfeeding or mixed feeding (Frizzelle *et al.,* 2009:22-23).

3.4.1.1. Sub-theme 1: Experience of the programme

All participants described their experiences about being on the PMTCT programme as pleasant. Most of them indicated that the quality of relationship they had with health care workers made it their experiences about the programme more comfortable. The following quotations illustrate the experiences of the participants:

"*I was treated well when I was sick at the hospital, I was welcomed and when I needed treatment, it was given to me. It was comfortable and the health care workers made it easy for me"*

"I enjoyed being on the programme, the health care workers taught us a lot, so I learned a lot"

"It was an enjoyable experience, the health care workers taught us not to take children to traditional healers"

This is in contrast to what Sibanda (2008:29) indicates that women enrolled on the PMTCT programme complained that nurses scolded at them especially when they were pregnant after they were advised not to have children any further due to their HIV status. In many instances rude attitudes towards pregnant mothers who were HIV positive took a form of verbal abuse, undermining comments, calling names and telling pregnant mothers that their unborn infants would not survive.

3.4.2. Theme 2: Services received on the programme

Counselling plays a vital role in ensuring the effectiveness of the PMTCT programme. In the context of this study, all participants indicated that they received counselling immediately when they enrolled into the programme and, thereafter, once a month until delivery. While one indicated that she received counselling from a counsellor, others claimed that they received counselling from professional nurses. The participants also indicated that they received educational sessions on diet while others who met the requirements were initiated on HAART.

3.4.2.1. Theme 2.1: Counselling

The majority of participants indicated that they received counselling monthly from professional nurses when they visited the facility for follow-up on their pregnancy. The content of the counselling focused on healthy eating, how to use treatment to prevent transmission of HIV to the baby, feeding options and the use of condoms. In relation to this, Frizzelle *et al*. (2009:16) point out that poor counselling often results in the

transmission of incomplete knowledge that can impede the effectiveness of PMTCT programme.

Issues relating to feelings and emotions were expressed identified as areas on which counselling was focused. It appears that the focus of the counselling sessions was on educating the women than helping them deal with their feelings and emotions where the social worker's intervention was needed. Their feelings, worries, concerns and emotions were therefore left unresolved. In relation to this, participants expressed the following:

> *"If you are using AZT you should it take at the same time, we should eat healthy and use protection all the time"*
>
> *"To protect ourselves, we should eat fruits. To protect the child from infection after birth, we should use protection all the time and give the baby nevirapine"*
>
> *"They talked about how I can protect myself, eating well and not to use traditional medicine"*
>
> *"They talked about healthy food, not to eat soil, not to smoke and to have sex without protection and that I should always have medication with me"*
>
> *"How to take care of the baby, how to breastfeed, diet, and not to use traditional medicine"*

The issue of regarding the use of medication to prevent transmission of HIV to the baby was cited by eleven participants as one of the focus of the counselling received. Only two participants cited feeding options as one of the focus of the counselling sessions. One participant cited both healthy eating and using protection when having sex as the focus of the counselling sessions. This is in contrast to the findings of research conducted in South Africa, which found that while the communication skills of counsellors were good, the mother's knowledge remained low post-counselling (Frizzelle et al., 2009:16).

3.4.2.2. Sub-theme 2.2: Social work services

All participants indicated that they were not referred for or received any social work services while they were on the PMTCT programme. The majority did not have clear understanding of what social workers do. Those who had some knowledge about the role of social workers mentioned that because social workers help with problems and social grants, they should be part of the PMTCT programme. Participants expressed the following with regards to social work services:

> "*I did not see a social worker and I do not know well what social workers do, but I wanted to be assisted with the application of a grant".*
>
> *"I did not receive any social work services and I think they should be involved in PMTCT so that they can advise me on what to do".*
>
> *"I did not see a social worker but I think it is necessary to be referred to them because they help people with problems"*
>
> *"I was not referred to a social worker but it is necessary because now my husband does not want to use a condom or protection"*

The role of the social worker at the PMTCT clinic is determined by psychosocial support needs of HIV positive pregnant and postpartum women as it tends to differ in its role compared to other contexts. The South to South (S2S) psychosocial and adherence support training manual identifies psychosocial support needs for this type of clientele. Such include, amongst others, helping with disclosure to the partner and family members, support about legal issues and rights, access to social grants and nutrition support for self and family, and strategies and support for positive living (S2S, 2010:86).

3.4.2.3. Sub-theme 2.3: Quality of counselling

The majority of participants indicated that the counselling they received was excellent. Only two participants said the counselling was simply good. The participants presented different views and reasons although they had the same answer. The following quotations indicate how participants experienced the counselling provided:

"The counsellor comforted me"

"What they taught us is very important"

"The way I was treated was good and I followed all that they taught me"

"I was satisfied"

"I was able to understand myself and even to counsel others"

"I had lost hope but I was made to see life differently"

"I was scared but after the counselling I was alright"

"I learnt a lot and the nursing sisters were very open and friendly"

These experiences are considered to some of the aims of counselling. Temmerman *et al*. (in WHO, 2003:24) consider the aim of counselling HIV-infected women as being to offer them support and help them cope with the disease. This, furthermore, include preparing them for the future, thereby helping them in terms reducing sexual risk behaviours and enable them and possibly their partners to make informed choices.

3.4.2.4. Other services received

The majority of participants indicated that after the discovery of their status, they received nutritional education from the dietician, and those who had a CD4 count less than 350 were referred to the wellness clinic for initiation on HAART. This shows that other disciplines were involved in helping the pregnant women on PMTCT. In relation to this, the participants had this to share:

"I was educated on how to eat healthy"

"I was educated on which food to eat"

"I am now on ARVs because I enrolled on PMTCT"

The South African PMTCT guidelines advocate for micronutrient supplementation for HIV-positive women, which is the same as the one that is routinely provided during pregnancy for all women. Supplementation should include multivitamins, iron and

foliate. However, in the case of advanced HIV disease where malnutrition or wasting or poor weight gain is evident, nutritional support in the form of vitamin and mineral fortified porridge should be provided (SA, 2008:39).

3.4.3. Theme 3: Support system

While the majority of the participants received support from their partners, few others were supported by their parents. One participant was supported by her own daughters after her partner dumped her while pregnant due to her HIV positive status. Those who did not disclose to their partners relied on other family members whom they trusted. One participant relied on her cousin (who was also HIV positive herself) for emotional support. Informed by this, one can deduce that participants received their support from different members of the family. Such support differed from material support to emotional ones. To clarify this, the respondents reveal that:

> *"The child's father supported me and he provided all the things I needed during pregnancy"*
>
> *"It was my mother who supported me, she knows about my status and said people live with HIV, so I must accept"*
>
> *"My husband used to accompany me to the hospital"*

WHO (2003:24) states that women who are tested during antenatal period usually have more profound psychosocial distress. This could be due to the fact that these women probably did not consider the possibility that they may be HIV-infected until they agreed to be tested as part of VCT ANC. As such, not only do they have to adjust to being pregnant, they also have worries about pregnancy, and often have to make decisions about whether to terminate it, or to agree to interventions such as ART and replacement infant feeding. In this study participants received support from those they disclosed to, but the support varied in terms of whether it was emotional, financial or professional.

According to Lesyna (2010:9), being infected by HIV affects many aspects of people's lives, and the goal of psychosocial support is to focus on the physical, psychological,

social and spiritual well-being of the patient. Psychosocial support is needed to enable both those infected and their care givers to be able to cope with their status.

3.4.3.1. Sub-theme 3.1: Pillar of support

Of the many participants who took part in the study, four participants cited their partners as their pillars of support during their difficult time. Others also pointed out that partners provided the much needed support:

> *"The support from my partner was emotional because I could talk to him when I was down"*
>
> *"He encouraged me to continue with my treatment, he would check if I had taken the treatment"*
>
> *"The father of my baby provided financial support and was also concerned about my emotional well-being"*
>
> *"My partner provided for the things I needed during pregnancy"*

Three participants said that their mothers were their pillars of support during pregnancy while they were on the PMTCT programme. Where partners where not providing support, respondents relied on their mothers (parents) as evidenced by the following statements:

> *"My mother said people live with HIV and I should accept it"*
>
> *"My mother assisted me with the things I needed such as food, fruits and vegetables"*
>
> "*She encouraged me to protect myself and to take treatment*"

Two of the participants claimed they received support from their sisters. While two respondents claimed to have received support from relatives, one indicated that she has full support from children. Frizzelle *et al*. (2009:22) argue that women who believe their partners would accompany them to an antenatal clinic and who expressed confidence in the fact that they would disclose their HIV status to their partners were significantly

more likely to want to get tested. In Botswana, research found that a lack of male support prevented women from participating in PMTCT programmes.

3.4.3.2. Sub-theme 3.2: Professional support

From the findings of this study, it appears that all the participants received professional support specifically from professional nurses in the antenatal clinic and dieticians. Although the services of a social worker were readily available, no participant received support from social workers. However, participants expressed satisfaction from the support they received from professional nurses throughout their enrolment on the PMTCT programme. For example, asked about their experiences about the programme, respondents claimed:

> *"The sisters helped me very well, the counselling they provided made me comfortable with myself"*
>
> *"I received support because when I had problems, I would go to the sisters"*
>
> *"The sisters provided support, they were open to me and I was also open to them"*
>
> *"They always asked if you were experiencing problems or side effects from medication"*
>
> *"I received a lot of help. Dietician provided education on eating, I never thought the issue of exercising was important"*
>
> *"The assistance was good because when I started in the clinic I was in pain, but after counselling I accepted my status and decided to take medication"*
>
> *"I received the right assistance because this time my baby is alive. I lost the first one because I did not follow treatment instructions"*

It is obvious from the statements expressed by the participants that support is important as it enables HIV positive women to cope better during pregnancy. WHO (2003:27) states that following the stages and states that a person might experience after diagnosis, considerable care, psychosocial support and counselling are more required

than just the information sharing and support for decision making, behavioural change or adherence to treatment.

3.4.3.3. Sub-theme 3.3: Men's involvement

Ten participants agreed that men should be part of the PMTCT programme. Only two of the participants pointed out that they were accompanied to the antenatal clinic by their partners although this was not a regular practice. Their partners, however, did not take part in the educational discussions around issues of pregnancy despite the HIV positive status of their female partners. Those who agreed for their men's involvement cited different reasons for the need to have them participate. Below are some of those reasons:

> *"Men should be involved because the baby needs love from both of us"*
>
> *"I wish men could be involved so that they can offer support"*
>
> *"It will enable men to open up to their partners, like on issues surrounding the use of condom, if involved they will be able to learn the necessity of using it and taking treatment"*
>
> *"Men should be involved a lot because if I was with him, things could have turned-out differently. My partner could have received information about HIV directly from the hospital, unlike me having to tell him"*
>
> *"In most of the times, men do not understand the things we have to do at home. It would be better if they could have received some education from the clinic"*
>
> *"He must come to the clinic so that he can get information himself"*
>
> *"Men should be involved so that they are educated on how to treat their partners*"

In the study conducted in Kenya, it was revealed that where women are supported and accompanied by their male partners, women are more likely to visit the antenatal clinic consistently. It was also shown that when male partners are involved, both partners can get tested for HIV, know their status, and therefore improve the baby's chances of a healthy living. These findings indicate that promotion of programmes aimed at

increasing male attendance in antenatal care could function in reducing the risk of vertical transmission and infant mortality (Averting HIV and …, 2010:10)

Although the approach of establishing programmes for men may be helpful, the South African migrant labour system may pose some challenges to it. This is because for most of the participants (whether married or living together as partners), do not stay with their husbands on a daily basis as they are in big cities where they work or are looking for jobs In support, (Frizzelle *et al*., 2009:27) indicate that women are more likely to adhere to PMTCT strategies when they have the support of their partners or husbands.

3.4.4. Theme 4: Challenges experienced by HIV positive mothers

Stigma and discrimination are some of the biggest factors that affect people who test HIV positive. The majority of the participants said they did not experience any form of stigma or discrimination from those who knew their status. Most of them, however, disclosed to their partners and some close relatives. Three of the participants disclosed to their partners only and no other person apart from the health workers knew the status. This indicates that participants are afraid of being stigmatized and discriminated against because of their newly acquired health status.

3.4.4.1. Sub-theme 4.1: Attitudes from family members

Alonzo & Reynolds (in WHO, 2003:9) contend that stigma represents a construction of deviation from some ideal expectations. Stigma is a powerfully discrediting and tainting social label that radically changes the way individuals view themselves, or how they are viewed by others. When individuals fail to meet societal expectations they become discredited and rejected, which isolates them from themselves and others. One participant experienced some form of discrimination from their relatives who knew their status. Below is how the only participant who went through some form of discrimination expressed her experience:

> *“My friend and aunt do not love me the way they used to do, they do not want to eat with me or share the same clothes with me as before”*

WHO (2003:9) indicates that the consequences of stigma and discrimination for HIV-infected are profound. It is further indicated that it is common for stigmatized people to repress their anger at being discriminated against, which often manifests itself as self-hatred and shame.

3.4.4.2. Sub-theme 4.2: Attitudes from health care workers.

Research suggests that South African health care system is characterized by highly coercive relationships between programme providers and users, particularly between nurses and their clients. Research findings revealed that HIV positive woman who decided to have a child runs the risk of being judged by the health care worker (Frizzelle *et al*., 2009: 15).

Contrary to the above findings, the majority of the participants in this study pointed out that they were happy with the treatment they received from the health care workers who assisted them, and this is all they have to share:

> *"The health workers did not discriminate against me, I was treated fairly and I am happy about it"*
>
> *"They were very open and it helped me to be open as well. They were very friendly and I took them as my friends because I was able to talk about anything"*
>
> *"They made me feel welcomed, were open and empathized with me"*
>
> *"They did not have a problem, they treated us well. When you asked questions they always answered them. They also gave us their cell phone numbers to contact them anytime"*
>
> *"They treated us very well. We ended up feeling the same way as those who were HIV negative. We even had their cell phone numbers"*
>
> *"The treatment was very good, they treated us very well. They educated and took care of us"*
>
> *"They never shouted at us, they spoke to us in the right way"*

"They treated us well and taught us very well. With the first child that I lost, I did not receive the kind of counselling I received this time"

"There is nothing that was bad that I can pick up. They treated me very well"

The responses above suggest that participants found the experience of being on the PMTCT program at Tonga hospital quite comfortable and rewarding. Frizzelle *et al*. (2009:15) state that clients who are fearful of health care workers are not likely to return for follow up sessions. Sibanda, (2008:29) indicates that a study conducted by Feldman & Maphoshere (2003) reported that women who participated complained that nurses scolded at them, especially when they were advised not fall pregnant anymore due to their health status. Sometimes their rudeness took a form of verbal abuse and undermining comments or calling HIV pregnant women names.

3.4.5. Theme 5: Culture

The issue of culture is cited as one of the factors that could serve as a barrier to successful PMTCT program. Frizzelle *et al*. (2009:20) indicate that culturally accepted practices about infant feeding may make it difficult for a woman to adhere to PMTCT related feeding options. They further indicated that social expectations regarding a woman's child bearing role influence decisions about child bearing.

3.4.5.1. Sub-theme 5.1: The impact of culture

The majority of participants indicated that they do not see anything culturally positive that could be considered for inclusion in the PMTCT programme. However, some participants expressed the need for older women such as their mothers or mothers-in-law to be educated about PMTCT so that they do not put unnecessary pressure for the baby to be taken care of in ways that could often contradict the recommended practices from the antenatal clinic. The suggestion made above shows that women are put under pressure to perform some cultural rites for the baby, which they believe could compromise the baby's health. In case, it is clear that an undisclosed status will prove difficult to bear.

"Old ladies will need to be educated because they may want to give the baby traditional medicine and might also need to start giving the baby soft porridge earlier than the recommended period"

Jackson *et al.* in Sibanda (2008:35) observe that while women may endorse the benefits of the PMTCT programme, their lack of decision-making powers may mean that decisions about their reproductive healthcare deferred to their husbands, in-law and other members of the extended family. Mate (in Sibanda 2008:35) argues that there could be "traditional explanations" for women who do not breastfeed their babies. Such may include mental illness, being possessed with evil spirits, and one having lied about the baby's paternity or general ill health.

3.4.6. Theme 6: Plan for the future

All participants indicated that enrolling on the PMTCT programme equipped them with the knowledge and skills to live positively with the HIV status. Temmerman *et al*. in WHO (2003:24) understand the aim of counselling HIV infected women as to help them cope with the disease and prepare for the future. The majority of participants expressed satisfaction in the counselling provided as preparation to live positively with the virus. Below are their expressions:

"The assistance was good because when I started at the clinic, I was in pain but after the counselling I accepted and decided to take treatment"

"The sisters helped me very well, the counselling they provided made me feel comfortable with myself"

The assistance was good, they gave me full support, made me feel I am not the only one and have to take care of myself"

"Since I tested, I receive my treatment and have accepted the status. I use protection when having sex and do not use traditional medicine"

3.4.6.1. Sub-theme 6.1: Benefits of enrolling on PMTCT programme

Some participants claimed that PMTCT programme prepared them to live positively with HIV, but acknowledged that living with the positive HIV status proved difficult.

> *"I now know my status and how to take care of myself because I enrolled on the programme"*
>
> *"I am on ARVs because I enrolled on the programme"*
>
> *"I benefited knowledge and what is expected of me as a mother"*
>
> *"I learned a lot on how to take treatment. If I take the treatment correctly I will live longer"*

PMTCT (2010:6) indicates that some women refuse HIV testing because they are afraid of learning that they have a life-threatening disease whose resultant worries and stress will quicken death. All the participants agreed that although testing HIV positive invoked feelings and emotions such as fear, anger and pain, the process of going through the PMTCT programme for nearly nine months prepared them to live positively after exiting the programme.

3.5. Summary

This chapter was guided by the research methodology as discussed in this chapter. From the collected data, six themes emerged: understanding of the PMTCT programme, services received in the PMTCT programme, support, challenges experienced by HIV positive mothers, culture and plan for the future. The findings of this study were complemented and supplemented by the respondents' narrative recounts presented in the form of direct quotations, and by the reviewed literature for the purposes of this project. Conclusions and recommendations of the study will be presented in the next chapter.

CHAPTER 4

CONCLUSIONS AND RECOMMENDATIONS

4.1. INTRODUCTION

This chapter seeks to explain how the researcher achieved the goal and objectives of this study. The chapter will also highlight the main findings of the study. It will, furthermore, draw conclusions and make recommendations based on the key findings of this study.

4.2. GOAL AND OBJECTIVES OF THE STUDY

While the central goal of this study was to explore the experiences of HIV positive women who enrolled on the PMTCT program at Tonga Hospital in Nkomazi East, its main objectives were to:

- determine the understanding of HIV positive mothers regarding the PMTCT programme at Tonga Hospital;
- ascertain services received from the PMTCT programme;
- identify the strength and shortfalls of the PMTCT programme; and
- determine the support received from the family, social workers and other health care professionals.

The research question that directed the study was as follows:

What are the experiences of HIV positive mothers on the PMTCT programme at Tonga Hospital in Nkomazi East?

4.3. CONCLUSIONS

Based on the empirical findings, the following conclusions with regard to experiences of HIV positive mothers were arrived at:

Understanding of PMTCT programme

The majority of the HIV positive women did not have knowledge of PMTCT programme and its goals. This therefore suggests there is insufficient knowledge and understanding

about the PMTCT in the community until one enrols on the programme. The participants in this study revealed that that it was only after they visited the hospital that the programme was introduced to them and had to be tested for the sake of the unborn babies. They also claimed that they got to understand the programme better as they continued with educational sessions offered by professional nurses. Although there was lack of knowledge about the programme, the pregnant mothers remained determined to stay on the programme to save their unborn babies from getting infected with the virus. To do this, they showed commitment to attending to all the appointments and adhering to the advices professional nurses gave to do them.

The experience of being on the programme and services received

The experience of PMTCT programme at Tonga was good and comfortable for all the women who participated in this study. They expressed that their relationship with the health care staff was good. They indicated that they received counselling (including one- on-one counselling sessions to women whose weight showed no improvement) from the nursing sisters, while dieticians provided them with nutritional education. Food supplements were also provided to these women by the dietician. In cases where some of them showed signs for pregnancy complications, referrals were made to physicians for assessment and treatment. In addition, for those women who qualified for HAART, referrals were made for initiation at the wellness clinic.

While there were no social work services provided to these pregnant women, it is difficult to ascertain to extent to which their expressed feelings and emotions. The non-provision of social work services does not do well for the programme, for nursing sisters cannot provide counselling that can impact on the deepest levels of feelings and emotions. In the group counselling sessions, the pregnant women should be made aware of the availability of and social work services, and be encouraged to use such services. In other words, social work services should be marketed to both the antenatal nurses and the HIV positive pregnant women.

Strengths and shortfalls of the programme

One of the strengths of the PMTCT programme at Tonga Hospital is that the programme is headed by a nursing sister with advanced knowledge on pregnancy and child birth. She is a professional nurse and has received a certificate on PMTCT integrated with infant feeding. The clinic does not only cater for HIV positive women but also assist HIV negative persons. This assists in minimizing stigma and discrimination at the hospital.

Some of the shortfalls of the programme are that it falls under the wellness clinic wherein HIV positive patients are attended to, where they are screened and initiated on ARVs and visit for follow up sessions. The clinic is situated at a ward whose HIV/AIDS specialization is known by both health care workers and other patients. This further compounds the problem of stigma and discrimination.

Another shortfall is that, although the participants in this study expressed their wish to see men or their partners involved on the programme, there are no attempts or policy requirement to get the men on board. Those who accompanied their partners out of their own wish were left outside during PMTCT educational sessions.

There is also no referral procedure or system in place at Tonga hospital to make sure that pregnant women receive all the necessary services from all the disciplines available. The professional nurses use their own discretion to decide whether a client should be referred for certain services such as dietary or social work.

Support received

All participants received some form of support during their enrolment on the programme. The participants were mostly happy with the support they received from health care professionals more especially the nursing sisters who worked at the PMTCT clinic. More support was also received from partners and their family members. The support ranged from emotional, financial and material backing.

4.4. RECOMMENDATIONS

The following recommendations from the study are made:

- PMTCT program should adopt a holistic and well-integrated approach that will allow for a multi-disciplinary team system where the pregnant women will receive services from other disciplines available in the institution. Counselling pregnant women should not be confined to antenatal professional nurses only. Rather, counsellors, nurses, dieticians, medical officers and, lastly, social workers should also do their part. Team members need to know where other disciplines should intervene to avoid duplication of services. A referral system to allow for a smooth flow of clients from one discipline to another should be established.
- Considering the fact that social workers did not make any intervention in the HIV positive pregnant women who were part of this study, the social worker should therefore market his/her services to all multi-disciplinary team members. Once this is done, team members should pass on the information to all pregnant women who visit the antenatal clinic. The social worker's role, amongst other things, should include helping with disclosure and providing support through home visits as the family centred approach advocate.

In conclusion, additional research should be conducted on the following themes:

- Men's involvement in the PMTCT programme: women who participated in this study overwhelmingly felt that men should be part of the programme. Research is needed to explore possible ways to ensure that antenatal clinic are men-friendly. In this context, such a project could also investigate the perceptions of men regarding their participation in the programme.
- Research is also needed to explore the impact of culture as different African cultures in South Africa, for example, have particular influences that may affect a woman's preferred method for both child birth and child rearing. Also, African cultures have religious rites that are performed on the arrival of a baby. Therefore, more research is needed to investigate the extent to which such rites may impact on the PMTCT programme.

4.5. Achievement of the goal and objectives of the study

The goal of this study was to explore how HIV positive mothers experience the PMTCT programme at Tonga Hospital in Nkomazi Municipality.

Table 4.5.1. Summary of the achievement of objectives

Nr	Objective	Objective achieved
1.	To determine understanding of HIV positive mothers regarding the PMTCT programme at Tonga Hospital.	Participants were requested to give their understanding of the programme prior to, and after, the enrolment. Participants had poor understanding of the programme but improved as they continued with educational sessions of the programme.
2.	To ascertain services received by participants while on the programme.	Participants were asked to give an account of services they received while on the programme. Participants received medical services from doctors and nurses, nutritional education from dieticians and counselling from nurses.
3.	The strength and shortfall of the programme.	The strength and shortfalls were assessed based on the ones outlined using SWOT analysis in the SADC report for South Africa. Strength: the PMTCT programme in the clinic was headed by a highly skilled nurse. PMTCT services were integrated into other antenatal services. Weaknesses: there was no formal referral system of patients from one professional to another. Men were still excluded in the whole process. Psychosocial needs of the patients were not addressed.

4.6. Summary

The findings of this study indicate that social work's contribution on the PMTCT programme is non-existent at Tonga Hospital. Although there was a need for social workers to help in various capacities as expressed by the participants of this project, no referrals to social workers were made. While it is evident that participants went through different emotions and feelings when they were on the programme, there is a need for multi-disciplinary intervention strategies from a social worker's perspective to help with the emotional aspects of the patients. Such a multi-disciplinary approach will help other members to see the need to include social workers in the PTMCT programme in order to effectively address the psychosocial needs of their patients.

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ANNEXURE A:

SEMI-STRUCTURED INTERVIEW SCHEDULE

SEMI-STRUCTURED INTERVIEW SCHEDULE

Experiences of HIV positive mothers who enrolled on the PMTCT

Research topic

The prevention of Mother to Child Transmission programme (PMTCT): Experiences of HIV positive mothers at Tonga Hospital in Nkomazi East.

The goal of the study is to explore how HIV positive mothers experience the PMTCT programme at Tonga Hospital.

BIOGRAPHICAL DATA

1. Age

18-21	22-35

2. Ethnicity

African	White	Coloured	Others, please specify

3. Marital status

Never married	
Married	
Co-habiting	

4. Number of children

1	
2	
3 and more	

5. Formal education

Grade 1-Grade 3	
Grade 4- Grade 6	
Grade 7- Grade 9	
Grade 10- Grade 12	
N1- N3	
N4- N6	
ABET LEVEL 1-3	

ABET LEVEL 4-6	
Certificate/Diploma/Degree	
Others, please specify	

THE EXPERIENCE OF BEING ENROLLED ON THE PMTCT PROGRAMME

- What was your understanding of the PMTCT programme?
- How long did it take you to disclose to your partner and what was his response?
- What were your feelings regarding your unborn baby?

COUNSELLING DURING ENROLMENT ON THE PROGRAMME

- Who provided counselling to you while on the programme?
- What was the main focus of the counselling sessions?
- How often did you receive counselling?
- What services did you receive from the social worker?
- Do you think social workers have a role to play on PMTCT programme? Please explain your answer.
- How would you rate the quality of counselling you received at the hospital in a scale of 1-5?
    1. Very poor
    2. Poor
    3. Fair
    4. Good
    5. Excellent

SUPPORT AND STIGMA

- What or who do you regard as your support system and why?
- Do you think you received the necessary support from the health care workers?, give reasons for your answer
- What kind of support did you receive from your partner?
- How were the attitudes of family members who knew about your status?
- How did you cope with the HIV positive status until you gave birth?
- Do you think man should be involved in the programme? Please give reasons for your answer.
- How would you describe attitudes of health care workers who helped you while on the programme?

CULTURAL INFLUENCE

- Are there cultural aspects that you think should be considered when enrolling on the programme? Please explain.

GENERAL

- How would you describe the assistance you received at the hospital and how it prepared you for the future, to live positively with the HIV positive status?

ANNEXURE B:

CONSENT: MPUMALANGA PROVONCIAL DEPARTMENT OF HEALTH

MPUMALANGA PROVINCIAL GOVERNMENT

Building No.3
No. 7 Government Boulevard
Riverside Park Extension 2
Nelspruit
1200
Republic of South Africa

Private Bag X 11285
Nelspruit, 1200
Tel: 013 766 3429
int: +27 13 766 3429
Fax: 013 766 3458
int: +27 13 766 3458

Department of Health

Litiko Letemphilo | Umnyango WezaMaphilo | Departement van Gesondheid

Enquiries: Themba Mulungo (013) 766 3511

18 September 2013

Mr. A. Nemutundi
P.O. BOX 1468
KWALUGEDLANE
1341

South Africa

Dear Mr. A. Nemutundi

APPLICATION FOR RESEARCH & ETHICS APPROVAL: HIV POSITIVE MOTHERS EXPERIENCES OF THE PMTCT PROGRAMME AT TONGA HOSPITAL

The Provincial Research and Ethics Committee has approved your research proposal in the latest format that you sent.

Kindly ensure that you provide us with the soft and hard copies of the report once your research project has been completed.

Kind regards

Mr. Molefe Machaba
Research and Epidemiology

18/09/2013
Date

We care. Do you?
Siyanakekela

MPUMALANGA
A Pioneering Spirit

ANNEXURE C:

CONSENT: ETHICS COMMITTEE OF THE FACULTIES OF HUMANITIES, UNIVERSITY OF PRETORIA

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities
Research Ethics Committee

2012-06-01

Dear Prof Lombard

Project:	**The Prevention of Mother to Child Transmission Programme (PMTCT): Experiences of HIV positive mothers at Tonga Hospital in Nkomazi East**
Researcher:	**A Nemutudi**
Supervisor:	**Ms A Bila**
Department:	**Social Work and Criminology**
Reference numbers:	**28440529**

I am pleased to be able to tell you that the above application was **approved** by the **Research Ethics Committee** on 31 May 2012 after receipt of the information as requested in letter dated 02 March 2012. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof John Sharp
Chair: Postgraduate Committee &
Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

ANNEXURER D:

PARTICIPANTS' INFORMED CONSENT

12/09/2011

Our Ref: Ms NJ Bila

Tel number: 012- 420 -2599

Fax: 012 – 420-2093

Email: Nontembeko.Bila@up.ac.za

INFORMED CONSENT FORM

1. **Title of the study:** The prevention of Mother to Child Transmission Programme (PMTCT): Experiences of HIV positive Mothers at Tonga Hospital in Nkomazi East.

2. **Goal of the study:** To explore how HIV positive mothers experience the PMTCT programme at Tonga Hospital in Nkomazi East**.**

3. **Procedures:** As a participant I will be requested to partake in a 30 – 40 minutes interview to express my individual experience regarding to PMTCT programme in Tonga Hospital.

4. **Risks and Discomfort:** There are no known risks or discomforts associated with this study. Should it happen that risks and discomfort are encountered, referral to the Social Worker will be made for counselling.

5. **Benefits:** I understand that there are no direct benefits for me in participating in the study. However, the results of the study may provide feedback and recommendations that will improve the PMTCT programme.

6. **Participant's Rights:** Participation is voluntary and I may withdraw from participation in the study at any time and without negative consequences.

7. **Confidentiality and anonymity:** I will remain anonymous as the participant and the information shared with the researcher will be treated confidentially. I am aware that the tape recorder may be used to capture data for analysis. Should I withdraw from the study; the data provided will be destroyed. Only the researcher

and the research supervisor will have access to the collected data before publication. I am fully aware that the results of this study may be published in the researcher's final research document, professional journals or presented at professional conferences, but my records will not be revealed unless required by law.

8. **Data storage:** I am aware that the collected data will be stored for 15 years at the Department of Social work and Criminology according to the policy of the University of Pretoria and when necessary may be used for future research.

Researcher contact details:

Department of Social Work & Criminology
University of Pretoria

PRETORIA 0002
Republic of South Africa

Tel: Number 2325/2030
Fax: Number 2093

00 27 12 420
00 27 12 420

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Mr Aluwani Nemutudi

PO Box 1468

Kwalugedlane

1341

Cell: 0763324959

MRS NJ BILA

SUPERVISOR

Declaration

I, ……understand my rights as a research participant, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being conducted.

----------	----------	----------
Date	Place	Participant's signature
----------	----------	----------
Date	Place	Researcher's signature
----------	----------	----------
Date	Place	Supervisor's signature