

**PROBLEMS EXPERIENCED BY MOTHERS WHO OPTED FOR
REPLACEMENT INFANT FEEDING IN A PREVENTION OF MOTHER-TO-
CHILD TRANSMISSION PROGRAMME IN MAKHADO MUNICIPALITY,
LIMPOPO PROVINCE, SOUTH AFRICA**

by

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DEDICATION

In memory of my late mother, Silomo Margaret Khuzwayo “Celo”, whose energy and love for life inspire me even today; she always wished me success, but unfortunately passed away during the course of this study on 18 May 2010. Also in remembrance of all the mothers that HIV/AIDS has taken from us at Makhado Municipality.

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DECLARATION

Student number: **3375-414-4**

I declare that “**Problems experienced by mothers who opted for replacement infant feeding in a prevention of mother-to-child transmission programme in Makhado Municipality, Limpopo Province, South Africa**” is my own work and that all the resources that I have used or quoted have been indicated and acknowledged by means of complete references.

SIGNATURE_____

(Mrs MR Mugivhi)

DATE_____

ABSTRACT

The recommended infant feeding method for mothers living with HIV is either exclusive breastfeeding for six months or replacement infant feeding (RIF), while a mixed feeding method carries the greatest health risks for infants. This study focused on identifying the challenges faced by mothers who opted for RIF and the coping strategies they employ. A theoretical framework, based on gender and power, was developed. The study used a qualitative design, with semi-structured in-depth interviews. Using purposive sampling, data was collected at three clinics from 22 participants.

The participants reported experiencing challenges related to RIF such as intermittent availability of formula milk at the clinics. Socio-cultural challenges include power inequalities between health care workers and mothers, pressure from family members to breastfeed, stigmatization and discrimination from community members. Coping strategies such as withdrawal from the community and trying to hide RIF from others were not sufficient to meet the challenges experienced.

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LIST OF ABBREVIATIONS AND ACRONYMS

AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ARV	Antiretroviral
DOH	Department of Health
EBF	Exclusive breastfeeding
EFF	Exclusive formula feeding
GBV	Gender-Based Violence
HAART	Highly Active Antiretroviral Therapy
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
INFACT	Infant Formula Action Coalition
MTCT	Mother-To-Child Transmission
NASCOP	National AIDS/STDs Control Programme
PCBs	Polychlorinated Biphenyls
PLWH	People Living With HIV
PMTCT	Prevention of Mother- to-Child Transmission
RIF	Replacement Infant Feeding
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNISA	University of South Africa
UNPA	United Nations Population Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Background

Across the world, 2.2 million women living with HIV and AIDS are giving birth each year (WHO 2005:1). Globally, 2.1 million children under 15 years of age were living with HIV in 2008, while an estimated 430 000 children were newly infected with HIV. Most of these new infections are believed to stem from transmission in utero, during delivery or post-partum as a result of breastfeeding (Joint United Nations Programmes on HIV/AIDS & World Health Organization 2009:6). In 2008, 280 000 children under the age of 15 years died worldwide of AIDS-related illnesses, while in sub-Saharan Africa the estimated number of HIV-infected children was 390 000 (UNAIDS & WHO 2009:35). In South Africa an estimated number of 420 000 adults and children died of AIDS in 2007 (WHO, UNAIDS & UNICEF 2008:5). The national overall HIV prevalence among 15-to-49-year-old antenatal women served in the public health clinics was estimated at 29% in 2008, although there is no significant evidence of an increase in HIV prevalence among pregnant women compared to previous years – 29.1% in 2006 and 29.4% in 2007 (Department of Health 2008a:6).

The transmission of HIV by mothers living with HIV to their children during pregnancy, labour and delivery is called mother-to-child transmission (MTCT) (WHO 2008:1). MTCT of HIV through breast milk is well documented, accounting for between one quarter and one half of all pregnancy-related transmissions (Reproductive Health Matters 2006:197). The Joint United Nations Programmes on HIV/AIDS/World Health Organization (UNAIDS/WHO) has recommended that HIV-positive women avoid all breast-feeding where replacement infant feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), so as to prevent post-natal MTCT (Doherty, Chopra, Nkonki, Jackson & Peterson 2006b:2421; Bland, Rollins, Coovadia, Coutsource & Newell 2007:289). In South Africa a comprehensive for the prevention of mother-to-child transmission (PMTCT) of HIV was introduced in 2001, initially as a pilot study to explore the impact of the nevirapine drug, but later as a response to a constitutional court ruling as a full-scale national programme

(Department of Health 2008b:3). The South African national PMTCT of HIV programme offers among others, voluntary counselling and HIV testing (VCT), provision of antiretroviral (ARV) prophylaxis to the pregnant HIV-positive woman and her newborn infant, and counselling on safe infant feeding practices, including provision of free formula milk for mothers who choose not to breastfeed. The primary goal of the PMTCT of HIV programme is to reduce infection by improving access to HIV testing and counselling in antenatal clinics (Treger 2007:99). The South African President announced on the World AIDS Day in 2009 that pregnant women were going to start Highly Active Antiretroviral Therapy (HAART) as from 14 weeks of gestation, and the revised PMTCT policy guideline began operating from the first of April 2010 (Department of Health 2010:1). The new policy guideline outlines the aims of the national PMTCT programme. Among those is the provision of an expanded package of PMTCT services which also includes provision of quality, objective and individualised counselling of safe infant feeding practices for HIV-positive women in health facilities, offering routine antenatal care services through a trained lay counsellor and health care professionals (Department of Health 2010:8). The objectives of the National Strategic Plan and the Millennium Development include aiming to reduce child mortality by two-thirds between 1990 and 2015, improving maternal health by reducing the maternal mortality rate by three quarters, having the spread of HIV/AIDS halted by 2015, and beginning to reverse the spread of the disease (WHO 2003:1 ; Department of Health 2006:2).

Avoidance of breastfeeding while giving formula milk is thus important, since breastfeeding increases the risk of post-natal transmission (Doherty *et al.* 2006b:2425). For this same reason, formula feeding is free to mothers who are on the PMTCT programme and who opted for replacement infant feeding in South Africa, since it is unaffordable for most HIV-infected women in sub-Saharan Africa (Nduati, Richardson & John 2000:1174). Despite this knowledge and lofty ideals, the mother's socio-economic circumstances, including her health status, her access to health counselling and the support she is likely to receive, should be considered when infant feeding options are considered. Guidance on infant feeding for women known to be HIV-infected requires personal attention to the individual women (UNICEF, UNAIDS, WHO & UNPF 2004:4). Taking into consideration the socio-economic circumstances of the majority of HIV-infected mothers in sub-Sahara, there are two

recommended infant feeding options to mothers who are infected with HIV in South Africa, namely to either introduce the infant to commercial infant formulas which is RIF or to exclusively breastfeed with early cessation until the end of the first 6 months (UNICEF, UNAIDS, WHO & UNPFA 2004:4). Exclusive breastfeeding is defined as feeding no other food besides breast milk for the first 4 to 6 months of life, and exclusive formula feeding is defined as feeding no other food besides properly prepared infant formula for the first 4 to 6 months of life (UNICEF, UNAIDS, WHO & UNPF 2004:2). To help HIV-positive mothers make the best choice, they should receive counselling that includes information about both the risks and the benefits of various infant feeding options, based on local assessment and guidance in selecting the option that best suits their circumstances, and they should have access to follow-up care and support (UNICEF, UNAIDS, WHO & UNPFA 2004:4). It is universally agreed that mixed feeding confers the highest risk of MTCT in the post-partum period (Coutsautis, Goga, Rollins & Coovadia 2002:1). Mixed feeding is a common and culturally accepted practice in many parts of sub-Saharan Africa, including South Africa, and involves feeding an infant a mix of breast milk, other liquids and solids from a few days after birth. The introduction of solids and liquids (other than breast milk) increases the risk for gut tissue irritation in newborns and very young infants (Varga & Brookes 2008:176). Both breastfeeding for a period of more than six months and the early introduction of complementary food by an HIV-positive mother increase the risk of HIV transmission to an infant. It is hypothesised that babies who are mixed-fed are more vulnerable to the HIV because feeds other than breast milk may disturb the lining of the gastrointestinal tract which facilitates the entry of the HIV into the baby's system (Van Dyk 2008:44). However, for various reasons, the choice of and adherence to one method of infant feeding is challenging for HIV-positive women.

Post-natal HIV transmission occurs mainly through breast milk when a mother lactates her infant; therefore the rate of HIV infections in breastfeeding infants has been increasing over the past few years, and also increases as the period of breastfeeding continues. However, recent evidence suggests that exclusive breastfeeding has a lower risk of mother-to-child transmission of HIV than mixed feeding (Doherty, Chopra, Nkonki, Jackson & Greiner 2006a:90). One of the beneficial attributes of breast milk is that it protects the infant against common

childhood infections such as diarrhoea, pneumonia, neonatal sepsis and acute otitis media.

Although most infant feeding strategies render women the bearers of the responsibility for feeding their children, practices are rarely the sole decision of the mother (Sibeko, Coutsooudis, Nzuza & Gray-Donald 2009:1887). There are socio-cultural factors that interact with replacement infant feeding options and adherence, making it a dilemma and challenge to mothers living with HIV. The challenges and difficulties faced by mothers living with HIV could have implications for the effectiveness of PMTCT programmes in resource-constrained settings (Doherty *et al.* 2006a:95). Although infant formula feeding is the recommended feeding option for HIV-positive mothers in developed countries, the socio-cultural problems and challenges also need to be taken into consideration, for example, women in sexist patriarchal communities are regarded as adult minors who are dependent on men (Buskens, Jaffe & Mkhathswa 2007:1107). For these reasons, gender and power are theoretical orientation constructs in this study.

In the current HIV/AIDS pandemic, children who have contracted HIV did so through mother-to-child transmission of HIV/AIDS, which is a significant contributor to infant mortality in Africa (Kapelman & Van Niekerk 2005:183). The proportion of antenatal clients tested for HIV in Limpopo Province was 59% and nevirapine coverage for both (infected) mothers and babies was 100% in 2006 (Department of Health 2007:30). If a woman discovers during pregnancy that she is HIV-positive, she has a relatively short period of time before the birth of her child to cope with her diagnosis. Hiding her diagnosis may put her child at risk of HIV infection if, fearing exposure, she does not take her antiretroviral prophylaxis or choose a safe method to feed her baby (Makin, Forsyth, Visser, Sikkema, Neufeld & Jeffrey 2008:907).

The national health PMTCT programme to prevent mother-to-child transmission of HIV offers voluntary counselling and testing which enables mothers to know their HIV status and to make decisions about infant feeding methods. However, the HIV epidemic has significantly altered the context within which women make decisions about how they will feed their infants (Doherty *et al.* 2006a:91). HIV-infected mothers are encouraged to select options that best suit their cultural, economic and

physical environment (Wachira, Otieno-Nyunya, Ballindawa & Braitsein 2009:120). The decision whether or not to breastfeed is regarded as a very difficult and complicated choice for women living with HIV (De Paoli, Manongi & Klepp 2004:612). In some communities a woman's authority to make infant feeding decisions is undermined by prevailing social and cultural attitudes and perceptions. The choice involves not only the beliefs of the woman, but also those of her partner, extended family and community.

The power differential in a patriarchal society between the dependent or disempowered mother and the provider in the family prohibit easy or complete disclosure, and the same power differentials contribute to the relative/provider's influence over all matters in their homestead including infant feeding (Buskens *et al.* 2007:1107). If a sero-positive mother wishes to breastfeed, she grapples with her fear of infecting her infant; conversely, were she to choose to formula feed she runs the risk of arousing suspicion regarding her HIV status (Sibeko *et al.* 2009:1986).

1.2 Research problem

The research problem of this study is focused on the challenges and coping strategies of mothers living with HIV when opted for replacement infant feeding. The following two research questions summarise the research problem:

- What challenges do mothers living with HIV face when choosing replacement infant feeding in the rural settings of Makhado Municipality, Vhembe district?
- What are the coping strategies of mothers living with HIV who opted for replacement infant feeding?

1.3 Rationale for the study

Sub-Saharan African countries, including South Africa, are severely affected by the HIV/AIDS pandemic and both prevention and treatment efforts are considered as critical components in fighting HIV/AIDS. Women of childbearing age are particularly affected by the pandemic, resulting in large numbers of children being

affected and infected by the transmission of HIV during pregnancy, delivery and also post-partum. The recommended infant feeding practices for HIV-positive mothers are affected by socio-cultural challenges that hinder the effectiveness of the PMTCT programme in South Africa. The HIV epidemic has changed the context in which women make choices about feeding their infants (Doherty *et al.* 2006a:93). Breastfeeding is a norm in most sub-Saharan countries. Women who opted for formula feeding experienced community, family and spousal pressure to breastfeed and were sometimes concerned about maintaining the confidentiality of their HIV status (Nduati *et al.* 2000:1173; Doherty *et al.* 2006a:93). Doherty *et al.* (2006b:2421) argue that there is an increasing amount of literature on the determinants of successful exclusive breastfeeding, but very little in the context of HIV. Furthermore, there are some studies that looked at experiences of mothers who opted for replacement infant feeding, but most focused on exclusive breastfeeding in urban areas, and very few covered mothers in resource-constrained areas. The effectiveness of a PMTCT programme could improved child survival therefore the programme could be seriously compromised if there are few studies that focus on replacement infant feeding in rural areas. The challenges experienced by HIV-infected mothers who choose RIF method needed to be studied.

As a health care worker, I have experienced on several occasions that mothers who were on a PMTCT programme and opted for replacement infant feeding were not using this method openly, since they experienced a variety of challenges. I have been working as a health care worker since 2000 and started working directly with these PMTCT programmes since 2004, and I soon realised how pregnant women and mothers who are on a PMTCT programme meet challenges, for instance long queues at the clinics that result in mothers waiting for long hours to receive their infant milk and not getting the full attention of health care workers when presenting with different problems. In addition, I witnessed pregnant women and mothers who were on a PMTCT programme suffering stigmatisation and discrimination from health care workers, family and community members. The kind of stigmatisation includes unprofessional sharing of confidential information for the purpose of gossip, being denied care and being forced to undergo sterilisation and formula feeding because of their HIV-positive status. My professional background and experience motivated me to do a study that could give a voice to the experiences of these marginalised women.

1.4 Purpose and objectives of the study

This study aims to identify challenges experienced and coping strategies used by mothers who opted for replacement infant feeding in a resource-constrained area, namely the rural area of Makhado Municipality. The results of this study could give insight in problems and may help to improve intervention strategies for effective PMTCT programmes in rural areas. Recommendations will be submitted with the report to the Department of Health and the findings will be presented in a PMTCT committee for decision-making.

1.5 Overview of research methodology

A detailed discussion of the methodology will be given in Chapter 3, but a brief overview of the main aspects and ethical considerations are provided here.

1.5.1 Research design

Since the study aims to understand the challenges faced and the coping mechanisms used by mothers living with HIV regarding feeding practices, a qualitative research design was deemed relevant since it could provide the in-depth knowledge needed. Neuman (2006:157) argues that qualitative researchers look at social life from multiple points of view and explain how people construct identities.

In the study, semi-structured, in-depth interviews were used by employing an interview schedule which contained the main themes to be explored. Twenty two (22) mothers living with HIV were purposively sampled and interviewed at Mbokota, Ekurhuleni and Waterval clinics, all falling under the Makhado Municipality. The data was analysed using open coding, which is a process whereby certain segments of text are attached to certain meaningful key labels or codes (Babbie & Mouton 2002:493).

According to Lietz, Langer & Furman (2006:444), reflexivity is another strategy that qualitative researchers must engage in, in order to describe their research findings in a way that authentically represents the meanings as described by the participants; therefore reflexivity also forms part of this study.

1.5.2 Ethical considerations

Both the University of South Africa's Ethics Committee (see Appendix 4) and the Limpopo Department of Health and Social Development approved the study (Appendix 5). The following ethical aspects were important:

The research participants participated in this study on a voluntary basis, and a consent form was drawn up and signed by all the participants (see Appendix 3). In cases of illiterate participants, verbal consent was given and recorded on audiotape.

Confidentiality and anonymity were maintained as the researcher was the only person who could access the data and pseudonyms were used in the dissertation to protect the identity of participants. The interviews took place either at the participant's house or at the clinic to ensure a confidential environment –in each case the participant chose the venue.

The research carried minimum risk to the participants. Adequate information was given to the participants before the study by discussing the study and what it entails with potential participants beforehand. This information is formalised in the information letter (see Appendix 2).

1.6 The layout of the dissertation

Chapter 2 gives an overview of the relevant literature and theoretical constructs used in the study. The study used theoretical constructs related to Gender and Power to understand the challenges faced by mothers who are living with HIV when opting for replacement infant feeding, and also their coping strategies.

In Chapter 3, the focus is on the research methodology, describing the research design, the method of data collection and analysis as well as the ethical issues considered for this study.

Chapter 4 outlines the findings of this study by discussing and interpreting the results.

Chapter 5 consists of conclusions and recommendations drawn from the findings of this study.

The final part of this report consists of five Appendices of which Appendix 1 is an interview schedule, Appendix 2 an information letter (also available in Tshivenda, Xitsonga and Sepedi), Appendix 3 contains the informed consent document given to research participants (also available in Tshivenda, Xitsonga and Sepedi), Appendix 4 is the approval letter from the University of South Africa Research Ethics Committee, and lastly Appendix 5, which is a letter from the Limpopo Department of Health giving approval to conduct this study.

1.7 Conceptual and operational definitions of key terms

Cohabiting: living with a partner without a customary or civil marriage having taken place

Educational level: the highest level (grade) that was obtained at school

Exclusive breastfeeding: infant receives only breast milk and no other liquids, not even water, but may receive vitamin and mineral supplements and medication from the doctor

Exclusive formula feeding: infant receives no breast milk but instead suitable commercial formula milk during the first six months of its life that provides adequate nutrients

Household: number of people living with a research participant – both family (members are related) and non-family (members are not related) households are identified

Marital status: type of relationship that the mother has (or does not have) with partner, e.g. single, married (according to customary or civil law) and cohabiting

Mixed feeding: feeding of breast milk complemented with other food or liquids

Mothers: women who recently gave birth and are in their post-partum period (from six weeks to six months after the birth of the child) at the time of the study

Parity: the number of living children the women has during the time of the study

PMTCT programme: the programme that offers HIV counselling and testing, and also infant feeding, antiretroviral therapy and free formula milk for HIV-positive mothers with the aim of preventing HIV transmission from the mother to the baby

Replacement infant feeding: feeding an infant who is receiving no breast milk with other food or liquids that provides all the necessary nutrients

Sharing of HIV-positive status: to tell someone at home, e.g. husband, partner or any family member or community member about one's HIV-positive status

Socio-cultural challenges: problems and dilemmas that mothers come across after having opted for replacement infant feeding and that affect/hinder the PMTCT programme

Support system: an available network of people that includes professional and lay people at the health care facility, home and community levels that provide support, information, counselling and encouragement to the mother

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

In this chapter, a conceptual framework of the socio-cultural factors will be established. The study looked at the concepts of motherhood, breastfeeding and replacement infant feeding to understand the realities, expectations, advantages and disadvantages of different feeding practices. The study also used the theoretical constructs *gender* and *power* to enhance an understanding of the position of women, the empowerment of women through activism and agency. These constructs are discussed to illuminate the socio-cultural challenges faced by mothers living with HIV and their coping strategies. In addition, the relevant literature was reviewed, particularly several studies that looked specifically at the choice and adherence of replacement infant feeding practices, socio-cultural factors, disclosing of an HIV status and support systems.

2.2 Conceptual framework

This study used the theoretical constructs *gender* and *power* to analyse the position of women in a specific socio-historical milieu, focusing on motherhood and different feeding methods. Such an analysis deepens the understanding of the socio-cultural factors that contribute to the challenges experienced by mothers who are living with HIV. The concept of breastfeeding, including its advantages, and replacement infant feeding, including its positive and negative aspects, are also focused on.

2.2.1 Motherhood

Giving birth and motherhood play a significant role in the social status and self-image of women in various cultures. Women alone have the capacity to bear children, and in most cultures they bear most of the responsibility for caring for those children (Gelb & Palley 2009:143).

According to Matlin (2004:333), there are stereotypes that exist in the perception of motherhood. Motherhood elicits a rich variety of pleasant emotions such as warmth, strength, protectiveness, nurturance and self-sacrifice. In certain cultures it is believed that a woman achieves her ultimate fulfilment by becoming a mother. Motherhood stereotypes may include that mothers require only a few moments of adjustment to the new baby and she will feel perfectly competent as her “natural” mothering skills take over. She is completely devoted to her family and she shows little concern for her own personal needs. Many mothers feel guilty when they cannot live up to these standards of “perfect mothering”. In addition, their mistakes are readily identified: mothers are sometimes portrayed as being overly concerned or domineering, mothers’ faults are exaggerated, and their positive attributes ignored. Matlin (2004:334) further outlines the reality of motherhood by looking at both negative and positive factors.

2.2.1.1 Positive factors

Matlin (2004:337) states that some women discover that one of the positive consequences of motherhood is a sense of their own strength; after all, they have successfully brought a new life into this world. Matlin (2004:338) argues that the major benefits for most mothers are the interactions with their children. Mothers explained how children developed an important part of their personalities and many women point out that having children helped them to identify and develop their ability to nurture. Unger (2001:170) examined motherhood as a defining aspect of women 's adult female identity and mothering, the role mothers plays in ensuring that children become well adjusted and competent members of society. Motherhood’s role understood as women 's identities as mothers, their practices and impact on their children.

2.2.1.2 Negative factors

In some cultures, fathers are expected to help mothers in child rearing but they usually help much less with child rearing than mothers had expected (Matlin 2004:334). Childcare is physically exhausting; fatigue is almost universal in the first weeks after childbirth and sleep deprivation is common. Because caring for an infant takes so much time, new mothers often feel that they can accomplish very little other than

taking care of the infant. New mothers seldom have training for the tasks of motherhood and they often report feeling incompetent. Because mothering is done at home, mothers of newborns have little contact with other adults, friends or extended family and the much needed support they may provide. This kind of isolation adds to the invisibility of women. Because the woman's attention has shifted to the newborn, her romantic partner may feel neglected, which can lead to fighting between partners – a situation that is exacerbated if the father spends little time taking care of the child. Women feel disappointed in themselves because they do not match the standards of “ideal motherhood” – the completely unselfish and perfect women. In reality these are cultural stereotypes of motherhood which no one can ever live up to (Matlin 2004:334-335). These cultural motherhood stereotypes are mostly applicable to married or cohabiting mothers with husbands/partners and other immediate family members at hand, whereas in the case of a single mother it could be a different situation.

Women become mothers and bring up children in a wide range of contexts or settings. Some of these are designated as “good” and appropriate and others as “bad” and inappropriate based on factors such as women 's age, their sexuality able-bodiedness, whether they are single or partnered, their race, ethnicity, social class/economic position and employment status (Unger 2001:171). Unger urged that the concentrating on the mother-child dyads has failed to address the wider social, economic and cultural context of mothering including women 's relations and other children, fathers and relations outside their families. In most societies, women are expected to become mothers and motherhood is constructed as “normal” and “natural” because motherhood is expected and taken for granted, it is often only when women do not become mothers, or when they experience fertility problems that they have to explain or account for themselves. The taken for granted nature of motherhood also means that women 's choices and decisions are not so much about whether or not to become mothers, but about when or in what situations to become mothers. Ideas and expectations about mothering derive a variety of Psychological theories and research. Maternal practice currently considered as optimal includes listening to children, being warm and responsive but also setting high standard and monitoring children 's activities. These ideas and expectations about motherhood and mothering skills provide context in which mothers and others make sense of what it means to be a

mother and evaluate their mothering skills. Mothering is presented as essential that is applicable to all women regardless of the settings in which they become mothers and bring up children. Although women share many of these ideas they resist and challenge ideal and expectations about motherhood in the light of their situations and experiences (Unger 2004:171). Motherhood and the production of children who are competent, well-adjusted and effective citizens are publicictly valued and give women a sense of being effective, powerful and in control. Women consider motherhood as a source of satisfaction, enjoyment and pleasure but they also experience it as costly in terms of time and energy and because they are expected to subordinate their needs and identities to those of their children.

Hooks (2000:133) identified that, during the early stages of contemporary women 's liberation movement, feminist analyses of motherhood reflected the race and class biases of participants. Motherhood was regarded as a serious obstacle to women 's liberation, a trap confining women to the home, keeping them tied to cleaning, cooking and child care by White middle-class and college educated women. Others simply identified motherhood and child rearing as the locus of women 's oppression, while black women voiced their views as a serious obstacle to their freedom as women which are lack of jobs, lack of skills or education, and a number of other issues but not motherhood. The findings pertaining to motherhood from 56 reports of qualitative studies conducted with HIV-positive women motherhood in the context of maternal HIV infection entailed work directed the illness itself and the social consequences of having HIV infection. The two primary goals were to protect their children from HIV infection and HIV-related stigma and the preservation of a positive maternal identity (Sandelowski & Barrosa 2003:470-482).

The stereotypes and negative factors of motherhood place pressure on the practice of mothering. It is even worse for HIV-positive mothers to cope with those major life changes and expectations. Sleep deprivation and fatigue could deteriorate the health of the mother. The social withdrawal from other adults could increase the stigma of not breastfeeding if the mother chose RIF. Matlin (2004:339) found that a poor relationship between the mother and the husband/partner might lead to negative consequences such as extra-marital affairs and abuse. The high expectations of motherhood might leave mothers living with HIV in a confused state if they cannot

meet the expectations and might even introduce self-doubt about being competent and complete mothers.

2.2.2 Feeding methods

According to WHO guidelines (UNICEF, UNAIDS, WHO & UNPFA 2004:4), there are two recommended infant feeding methods for mothers living with HIV, as indicated in Chapter 1 (section 2), namely exclusive breastfeeding for six months, or replacement infant feeding for a minimum period of one year. Mixed feeding, which refers to breastfeeding and RIF, is not recommended for mothers who are HIV-positive, but often mothers use both methods due to different constraints that could arise during infant feeding.

2.2.2.1 Breastfeeding

The study looked at the concept of breastfeeding which is the norm in most African countries and therefore adds to the challenges faced by HIV-positive mothers who opted for replacement infant feeding. Gelb & Palley (2009:129) describe breastfeeding as human females engaging in the biological production of milk to nourish their infants. Babies have a suckling instinct and breastfeeding is a basic human capability. There are still confusing issues about breastfeeding by HIV-positive mothers, regardless of recommended WHO guidelines. This is exaggerated by the type of information and the attitude of role players, i.e. health care workers, and family and community members. Mothers end up with no clear direction for weighing the benefits of breastfeeding and mostly just avoid it altogether.

2.2.2.2 Importance of breastfeeding

According to Gelb & Palley (2009:129-130), breastfeeding has health benefits for both mother and child. Breast milk lowers the risk of developing a wide variety of ailments including asthma, allergies, eczema, inner ear infections, intestinal infection, diarrhoea, respiratory tract infections, diabetes, Crohn's disease and even certain forms of cancer. Breastfed babies are considered less likely to develop severe

illnesses. Matlin (2004:342) also documents that breast milk protects against allergies, diarrhoea, infections and other diseases.

The health benefits of breastfeeding for the mother include a faster return to her pre-pregnancy weight and suppressing ovulation, which in turn prevents a pregnancy before the body has had time to regain its strength, a decreased risk of developing ovarian cancer, osteoporosis or pre-menopausal breast cancer (Gelb & Palley 2009:129-130).

Gelb and Palley (2009:130) state that breastfeeding creates a close bond between mothers and infants, contributing to their psychological well-being. Mothers who breastfeed are also likely to believe that breastfeeding establishes a close bond between the mother and baby. They are also pleased that they can satisfy their infants' nutritional needs. Mothers describe nursing as a pleasant experience of warmth, sharing and openness (Matlin 2004:342). Because breast milk is readily available, and can be life saving where the supply of water is scarce. As it is, commercial formula is very expensive. This is an important consideration, especially if one keeps in mind that diarrhoea is the main cause of infant mortality in developing countries and is exacerbated by the preparation of milk using polluted water (Gelb & Palley 2009:130).

However, breastfeeding could also be affected by other social and environmental factors that can introduce harm to the infant. Environmental pollutants contaminate mothers' breast milk and can be passed along to their children, and most of these pollutants, including polychlorinated biphenyls (PCBs) and polybrominated biphenyl ethers, are industrial chemicals that are stored in human fatty tissue (Gelb & Palley 2009:136). HIV-infected mothers can also pass the virus to the baby. Research accepted by the mainstream medical community indicates that HIV-infected mothers who breastfeed, double the risk of infecting their children with the virus.

The figures in the following table show the risk rate of MTCT:

TABLE 2.1: HIV TRANSMISSION ESTIMATES

Timing	Transmission rate
During pregnancy	5-10%
During labour and delivery	10-15%
During breastfeeding	5-20%
Overall without breastfeeding	15-25%
Overall with breastfeeding for six months	20-35%
Overall with breastfeeding longer than 18 months	30-45%

SOURCE: UNICEF, UNAIDS, WHO & UNFPA 2003:5

Gelb & Palley (2009:130) also view factors such as social and economic changes as accounting for the decline in breast feeding rates. Hospital practices that include feeding of formulas, distribution of formula samples by hospital personnel and lack of support by health workers of breast feeding remain a difficulty. Although health professionals should encourage breastfeeding, they should at the same time not make mothers feel inadequate or guilty if they choose to bottle-feed their babies. The hierarchy of power that exists between health care workers and mothers leaves mothers with little choice, resulting in them obeying the rules or preferences of health care workers. Matlin (2004:342) further argues that women are more likely to nurse successfully if their friends and the hospital staff members are supportive and encouraging.

2.2.3 Replacement infant feeding

Mothers who bottle-feed their babies are more likely to emphasise that bottle-feeding is convenient and trouble-free (Matlin 2004:342). As discussed above, mothers who are HIV-positive could prevent the transmission of the virus to the baby by giving replacement infant feeding as recommended by WHO guidelines. The replacement infant feeding method is a successful strategy to improve child survival – but only if the milk preparation is done correctly, which includes the use of electricity or another form of heat, clean utensils, sterilising liquid, the fresh preparation of feeds and the correct estimate of volume to be given to a child at each feed. Coutsaotis *et al.*

(2002:159) argue that many people in sub-Saharan countries are too poor to meet these conditions and in some cases, people are not educated on these aspects which are vital for safe replacement infant feeding.

2.2.3.1 Historical overview

The history of replacement infant feeding is fully recounted by Gelb & Palley (2009:131-132). The first commercially manufactured infant formula was produced in 1867 by Henri Nestlé, the founder of the Swiss-based Nestlé Corporation. He claimed this food saved the life of a neighbour's child, but medical professionals have long observed that infants who are fed on formula milk have a higher mortality rate than those who are breastfed. As early as 1900, a Chicago public health campaign encouraged mothers to breastfeed, using the slogan: "Do not kill your baby." However, the dangers posed by artificial baby foods diminished over the years, especially in some developed countries where formula milk was associated with fashion and high status. These advances provided bacteria-free milk and a plentiful supply of safer clean water that could be used to mix formulas. Experts note that in some regions of the world, women associate bottle-feeding with "modern" or scientific parenting practices (Gelb & Palley 2009:130).

Gelb & Palley (2009:131) further explain that by 1970 these developments had led to a worldwide drop in breastfeeding rates. After another seven years, in 1977, physicians working in the developing world alerted the United Nations about rising rates of infant death and malnutrition among infants who were on formula milk. In response to the growing international concern, the United States-based Infant Formula Action Coalition (INFACT) initiated a boycott against the Nestlé Corporation "baby milk Action n.d". INFACT charged that Nestlé's aggressive marketing practices in the developing countries led women to use infant formula rather than breastfeeding their babies. These marketing practices included extensive use of "milk nurses" who were hired to sell formula on commission and visited mothers in hospital maternity wards wearing a nurse's uniform that was meant to convey the medical and scientific validity of formula. The boycott received a boost in 1978 when United Nations Senator Edward Kennedy held a senate hearing on the marketing practices used by Nestlé and other infant formula manufacturers in the developing world.

In 1981, the WHO adopted the international code of marketing of breast milk substitutes with a final vote of 118 against one, with three abstentions. The code includes several recommendations and restrictions, including resolutions to instruct health care workers to promote breastfeeding and clearly state the hazards associated with the use of formula, to ban the distribution of free formula milk samples to new mothers, to ban the use of aggressive marketing practices, to prohibit the use of milk nurses, and to forbid formula company salespersons from providing instructions of infant care to new mothers. Several countries acted immediately to implement the provisions of the code, and formula companies came under significant pressure to conform to these international standards (Gelb & Palley 2009:132). Looking at the history of replacement infant feeding, it is clear that it was even previously not uniformly accepted due to its potential hazards and risks to the infant's health. Currently RIF is an alternative or recommended method in the fight against HIV transmission. However, within the context of a high level of stigmatisation of people with HIV, many mothers – especially those accessing free formula milk – may rather hide the tins of formula milk than face the ridicule and scorn (Doherty *et al.* 2006a:93).

2.2.3.2 Guidelines for replacement infant feeding

According to the WHO (2003:13) guidelines, the various requirements for successful replacement infant feeding (AFASS) are defined as follows:

a. Acceptable

The mother perceives no barriers to replacement infant feeding. The barriers may include those of cultural or social reasons, including RIF being culturally unacceptable and the fear of stigmatisation and discrimination. The mother should be under no cultural or social pressure against using RIF and she should be supported by family and community in opting for this method of feeding. If RIF is chosen despite these barriers, the mother should be able to cope with the pressure from family and friends to breastfeed her baby and she should be able to deal with possible stigmatisation.

b. Feasible

The mother or another family member has adequate time, knowledge, skills and other resources to prepare the replacement infant feeding and to feed the baby up to 12 times in 24 hours. The mother has to understand and follow the instructions for preparing the infant formula, and with the support from the family can prepare enough replacement infant feeds correctly every day or at night without disruption to the preparation of the family's food or other work.

c. Affordable

The mother and the family, community members or health system if necessary, should be able to pay the cost of purchasing or producing, preparing and using replacement infant feeding, including all the ingredients (fuel, clean water, soap and the equipment needed), without compromising the health and nutrition of the family members. It also includes access to medical care if necessary for diarrhoea and the cost of such care.

d. Sustainable

This refers to the availability of a continuous and uninterrupted supply and dependable distribution of all the ingredients and products needed for safe replacement infant feeding, for as long as the baby needs it, up to one year of age or longer. There should be little risk that formula milk will ever be unavailable or inaccessible, and another person should be available to feed the child in the mother's absence.

e. Safe

Replacement infant feeding should be correctly and hygienically prepared and stored, and feeds should be in nutritionally adequate quantities, using clean hands and utensils, preferably by cup. This means the mother should be able to

- prepare the feeds that are nutritionally sound and free of pathogens;
- wash hands and utensils with soap and clean water, and regularly boil the utensils to sterilise them;
- boil water for preparing each of the baby's feeds;
- store unprepared feeds in clean, covered containers and protect them from insects or animals (UNICEF *et al.* 2004:13).

2.2.4 Mixed feeding

Mixed feeding refers to the feeding of both breast milk and other foods or liquids and giving the baby breast milk and other drinks such as formula, glucose, water or traditional medicines. Mixed feeding is common in many countries and the risk of HIV transmission through breast milk are increased in this practice (UNICEF *et al.* 2004:1). According to Healthlink Worldwide (2000:16) and Van Dyk (2009:44), giving the baby anything except breast milk, such as food, formula or something else to drink, can damage the lining of the intestines and stomach, and once the intestine lining has been damaged, the natural protection against all infections including HIV is lost. Thus mixed feeding make it easier for HIV transmission through breast milk to the baby. Mixed feeding is a common practice in most African countries to supplement “insufficient breast milk”.

Both breastfeeding and replacement infant feeding have advantages and disadvantages. Breastfeeding is the preferred option if the birth mother is healthy, but in the case of mothers who are HIV-positive, the preferred feeding option is more complicated. Mixed feeding is even more dangerous to the baby’s health and is not recommended. This will be further discussed in the review of the literature below (section 2.3.1), but first the constructs *gender* and *power* are now focused on.

2.2.5 Gender and power

The interplay between gender and power can illuminate the experiences of HIV-positive mothers who opted for replacement infant feeding and the socio-cultural challenges they experienced. Gelb & Palley (2009:3-5) explore a sex/gender system by stating that gender is best understood not as a simple category but as three interrelated elements that must be explored to understand the system as a whole. Firstly, gender as a fundamental category through which meaning is ascribed to everything; secondly, as a way of organising social relations and the structure of personal identity; thirdly, gender is described as a learned or imposed behaviour that nonetheless can determine both the consciousness of and opportunities afforded to particular individuals. Traditional views of women and men have emphasized differences historically attributed to biological sex, stereotypical belief about women

's biological features, for example women are believed to be at the root of discriminatory in employment practices and the homogenization of women's abilities and roles (Hooks 2000:156).

Gelb & Palley (2009:6) define a social group as a collective of persons differentiated from at least one other group by cultural norms, practices or a way of life. Social groups may encounter a variety of different forms of oppression that shape their perceptions of themselves as a group. The five types of oppression identified are exploitation, marginalisation, powerlessness, cultural imperialism and violence (Gelb & Palley 2009:6).

Based on the above definition, the authors regard women as a social group since social norms, values, ideas and practices shape the formation and identity of women. The variations in understanding the body indicate there is nothing natural about the assumptions made about sexual difference, but they indicate that women's bodies are a primary source of their oppression and justify the differential treatment of those in women's bodies. Historically it appears that the female body is the subject of so much interest in part because women are seen as more closely tied to their bodies "by bodily functions such as menstruation and reproduction", rather than to intellectual or spiritual capacity. The bodies of women are often seen as both weaker than those of men and as a source of societal disruption. The societal disruption could be behaviour that goes against the societal norms and culture. The equation about the female body also has a significant impact on women's self-understanding and daily practices. Philosophical reflections on the nature of the mind and the body have material manifestations in the everyday lives and experiences of women that are significant in constructing sexual differences. The association of women and their bodies is not merely philosophical; it is not a matter of theoretical concept, but it also informs women's experiences of themselves, and their behaviour as they attempt to conform to the expectations of others. Women's role in the family and their primary definition as mothers and wives "in the private sphere" have often rendered them invisible and their work being ignored in the public sphere (Gelb & Palley 2009:7-10). In sexual relationships of any kind "in or out of wedlock" women and girls often lack the power to abstain from sex or to insist on condom usage. Marriage has been noted as a risk factor for women with regard to HIV/AIDS because married couples are likely to

engage in unprotected sex, especially if children are desired (Gelb & Palley 2009:120).

DiClemente, Crosby & Kegler (2002:314-321) explain the dynamics between gender and power by referring to different social levels that form the base of the inequality of power between the genders.

There are three major structures that form the base of gender relationships, namely the sexual division of labour, the sexual division of power and the structure of cathexis (which was later modified by Wingood and DiClemente and called affective and social exposure, to emphasise the importance of social factors that compromise this structure). These three structures may overlap but they are distinct structures that serve to explain the culturally bound gender roles that men and women assume. The three structures exist at two different levels, namely societal and institutional. The societal level, which is regarded as the higher level, is explained as the place where the three structures are rooted in society through numerous historical and socio-political forces that consistently segregate power and introduce norms, based on gender-determined roles. As society slowly evolves, these structures remain largely intact at the societal level over a long period of time (DiClemente *et al.* 2002:315). Below is a proposed model conceptualising the influence of gender and power on health issues:

Table 2.2: Gender, power and health

Societal level	Institutional level	The social mechanism
Sexual division of labour	Work site School Family	Manifested as unequal pay which produces economic inequities for men and women
Sexual division of power	Relationship Medical system Media	Manifested in control, which produce inequalities
Structure of Cathexis: Social norms and affective attachments	Relationships Family Church	Manifested as constraints in expectations, produce disparities in norms for women

(SOURCE: DiClemente *et al.* 2002:316)

The presence of the three structures within the institutions and other social mechanisms constrains women's daily lifestyle practices by producing gender-based

inequities in women's economic potential, control of resources and gender-based expectations of women in society. Institutional changes occur more rapidly than societal changes, but changes at the institutional level are also gradual (DiClemente *et al.* 2002:320). According to DiClemente *et al.* (2002), power can be defined as having the ability to “act change” or exercise influence over others – where acting change means changing behaviour. At the institutional level, the sexual division of power is maintained by social mechanisms such as the abuse of authority and control in relationships. Women in power-imbalanced relationships tend to depend on their male partner because men usually bring more financial assets (money and status) to the relationship. The sexual division of power is also maintained at the institutional level by social mechanisms such as media and cultural practices which may disempower women through sexually degrading images.

The inequities resulting from a sexual division of power are manifested in physical exposure and behavioural risk factors. As the power inequity between men and women constrain women's sexual choices and behaviour, it increases their risk of contracting HIV (DiClemente *et al.* 2002:317).

According to DiClemente *et al.* (2002:318), the “Structure of Cathexis” refers to attachments and social norms. At the societal level, this structure dictates “appropriate” sexual behaviour for women and is characterised by the emotional and sexual attachments that women have with men. This structure constrains the expectations that society has about women with regard to their sexuality, and as a consequence it shapes women's perceptions of themselves and others and limits their experiences of reality. This structure also describes how women's sexuality is attached to other social concerns, such as those related to impurity and immorality (DiClemente *et al.* 2002:319).

The institutional level contains the structure of social norms and affective attachments, like relationships in families, that are maintained by social mechanisms such as the expected norms that include biases and expectations people have regarding how women and men should express their sexuality and reproductive lives. Those expectations and biases produced by cultural norms, the enforcement of strict gender roles and stereotypical beliefs such as women should have sex only for

procreation, create taboos regarding female sexuality “e.g. being labelled as a bad girl for having pre-marital sex”. It is restraining women’s sexuality (being monogamous as opposed to having multiple partners, the latter being an accepted norm for men but not for women) and believing that women should refrain from touching their own body (DiClemente *et al.* 2002:321). The inequalities resulting from the social mechanisms occurring within the structure of social norms and affective attachments also manifest in the field of public health, where women are at risk of contracting HIV which often introduces stigmatisation and discrimination.

According to the structure of social norms and affective attachments, women who are exposed to more social and personal risk factors will be more burdened by the structure of social norms and affective attachments, compared to women not having these exposures and risk factors, and subsequently they will experience poorer health outcomes. Social risk factors include women who have older partners, an interest or a partner’s interest in conceiving children, family influences that are not supportive of HIV prevention, a mistrust of the medical system, conservative cultural and gender norms, and a religious affiliation that forbids the use of contraception (DiClemente *et al.* 2002:322). Family norms for women and men has different views of normative development and how society should prepare women and men for their adult roles in future. The family roles if are more equitable before improve health, well being and personal happiness on women in addition to enhance economic independence (Hooks 2000:169).

Family life often expresses patterns of male domination and female subordination. Johnson (2008:447) mentions that the differences in power and the resulting benefits that marriage provides to men as opposed to women, lead to the distinction that Jessie Bernard identified as **HIS** marriage versus **HER** marriage. Johnson (2008:448) further argues that on the micro-level, focusing on the socialisation process of the family and interpersonal relations among the women and men in maintaining traditional gender roles from the beginning of their lives, sons and daughters are rewarded in their families for behaving in accordance with appropriate gender roles. Thus, they learn to view such patterns as natural and incorporate them into their self-concept. Among adults, male domination and female submission are manifested in interpersonal encounters as men’s views and interpretations usually seem to be given

more weight, often by women as well as men. The result is that women's behaviour often reflects a high level of compliance with traditional gender roles, partly because of the social approval and other rewards they receive in exchange. This micro-level subordination is reinforced by the macro-level and the unequal distribution of power, as explained above. These power differences enable men to impose their definitions on the roles and relations between men and women in all aspects of life, both micro and macro (Johnson 2008:448). The male dominance pattern resulted in some women with no power and some men being prone to violence.

Violence against women takes on a number of forms including rape, wife battering, incest, stalking, trafficking in women, female genital mutilation, sexual harassment and psychological harassment (Gelb & Palley 2009:159). Gelb & Palley (2009:159-161) describe women abuse as follows: All of these types of violence are abuses that women rather than men tend to suffer. Women are victimised in these ways at least partially because they are women. Men and women tend to be victims and perpetrators of different kinds of violence under different circumstances. Men are more likely to be assaulted by strangers usually men, whereas women are more likely to be assaulted by intimates or people they know also usually men. This is because violence against women is largely a result of women's economic and social dependence on men. Matlin's (2004:442-443) view on the abuse of women includes the kind of aggression that women experience from husbands or partners. The abuse of women includes intentional acts that injure women. These acts may be physical abuse such as hitting, kicking, burning, pushing, choking and use of a weapon. Emotional abuse can include humiliation, intimidation, name-calling, degradation, extreme jealousy and refusal to speak. Another form of emotional abuse focuses on finances, for example when a man withholds money or takes money away from his wife.

Gelb & Palley (2009:159) feel that "patriarchal terrorism" is motivated by a desire to control and dominate one's partner and is accompanied by an ideology of patriarchal control whereby women are expected to sexually serve men, cook their food – and if they do not, men have the right to physically punish them. Patriarchal or intimate terrorism is the type of domestic violence that is most likely to result in injury or death. The latter type of violence is what most feminists are talking about when they

use the term “domestic violence against women” – intimate violence that is driven by a traditional gender ideology and happens to women simply because they are women (Gelb & Palley 2009:161).

When describing women abuse, Gelb & Palley (2009) and Matlin (2004) both focus on physical and emotional harm or hurting of a woman by a man. The women abuse that is relevant for this study encompasses physical abuse in the form of wife battering, and emotional abuse in the form of name-calling, humiliation, intimidation, degradation, extreme jealousy, refusal to speak and withholding of money by husband or partner. Women abuse may result in physical problems, such as chronic diseases and permanent injuries, and emotional problems, such as mental illness, low self-esteem, mistrust and even attempting suicide.

The physical side-effects such as medical conditions, injuries, mental and emotional problems, which may result from women abuse, could complicate the situation for mothers living with HIV because the issue of mistrust could lead to non-disclosure of their HIV status to a husband or partner. Non-disclosure could in turn result in a poor quality of life, which may in turn lead to social withdrawal or even suicide.

Mothers thus encounter many socio-cultural challenges and difficulties that put them at a disadvantage. However, a theoretical orientation of women and empowerment provides another perspective on how mothers can become equipped with support, knowledge and skills to deal with the socio-cultural challenges of their daily lives.

2.2.5.1 Women and empowerment

The Beijing Platform of Action of the Fourth World Conference on Women explains that “the human rights of women include their right to take control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence” (Beijing Declaration 1995:4). In the Sida Studies (2001:18) it is explained that “disempowered” refers to the process by which those who have been denied the ability to make choices, acquire such ability. It is generally agreed that women were previously disadvantaged by being prevented from making life decisions due to male

dominance. People who exercise a great deal of choice in their lives may be very powerful but they are not empowered in the sense that they were never disempowered in the first place. Empowerment thus refers to the expansion in people's ability to make strategic life choices in a context where they have previously been denied this ability (Sida Studies 2001:19).

Empowerment entails different aspects such as knowledge or know-how, which refers to the ability to translate one's knowledge into actions and resources e.g. how to prevent illness or how to analyse a problem. A second aspect is will "internal power", which refers to the power within, psychological strength or spiritual power that includes one's values and fears, self-confidence and self-perception. It is the ability to make one's own choices for the future, the awareness of one's own life plan as well as the challenges facing one's community. A third aspect is capacity "internal power or power within", which means having the opportunity to make decisions, take on responsibility, be free to act as one pleases and use resources "assets, knowledge and will" (Commission on Women and Development 2007:912).

2.2.5.2 Empowerment through activism

Parker (2005:78) explains the concept of power as imbalances in the subordination of women "as first articulated in the early twentieth century by Charlotte Parkins Gilman". The violence against women prevented them from full participation in society, violates them and impairs their enjoyment of human rights and fundamental freedom, and lowers the status of women in the family, community and society. The author further emphasises that acquiring voice is important and crucial for women's political development of a sense of self and creates a platform from which to act. This action may be within the confines of the community or the society at large. Training activities that increase participants' awareness of the societal factors that contribute to domestic violence and also increased activism and participation therefore decrease the violence. Gender inequalities related to the sharing of status, power and control of household income hinder women's full participation in genuine development.

Inequitable social, cultural, economic and political structures are the root cause of crimes against women, and hinder women's full potential in the empowerment

process. The transfer of power to a previously disempowered or excluded group is a process. Empowerment is a process of critically understanding that power is constructed and developed, which leads to the subordination of women. Empowerment is not only about opening up access to decision-making, but must also include a process that leads people to perceive themselves as being able and entitled to occupy that decision-making space (Parker 2005:79).

Empowerment is demonstrated by the quality of people's participation in the decision-making processes affecting their lives. Participation is at the heart of the empowerment process, as individuals come together with equally valid but different perspectives, sharing problems and exploring answers. Through education, people gain the ability to analyse their situation critically, to recognise their options and to make choices of their own reality. Education makes people aware of the effect of their personal choices on society and on the world and allows them to choose wisely. It is one of the important means of achieving self-determination, particularly for women, providing the chance to develop fully one's dignity and potential. Education needs to be participatory, as this creates a relationship of communication between people. Part of the solution to developmental issues is for women to acquire knowledge, which gives them the opportunity to be an actor and not just an object in the process (Parker 2005:79).

2.2.5.3 Agency

The Sida Studies (2001:21) argue that the second dimension of power relates to agency, the ability to define one's goals and act upon them. Agency is about more than observable action; it also encompasses the meaning, motivation and purpose which individuals bring to their activity, their sense of agency or the power within. Agency is often understood as "individual decision-making". Particularly in the dimension of health it encompasses a much wider range of purposive actions, including bargaining, negotiation, deception, manipulation, subversion, resistance and protest, as well as the more intangible cognitive process of reflection and analysis. Agency also encompasses collective as well as individual reflection and action.

Agency has both positive and negative meaning in relation to power. In the positive sense of "having the power to" it refers to people's capacity to define their own life

choices and to pursue their own goals, even in the face of opposition from others. Agency can also be exercised in the more negative sense of “power over” in other words, the capacity of an actor or category of actors to override the agency of others, for instance through the use of violence, coercion and threat. The norms and rules governing social behaviour tend to ensure that certain outcomes are reproduced without any apparent exercise of agency (Sida Studies 2001:21-23).

Women’s acceptance of their secondary claims on household resources, their acquiescence to violence at the hands of their husbands or partners, their willingness to bear children to the detriment of their own health and survival to satisfy their own or their husband’s preference of sons, are all examples of behaviour by women which undermine their own well-being. Women’s adherence to social norms and practices, such as the promotion of the practice of female circumcision, shows the active construction of a less powerful position in society by women themselves. The oppressive exercise of authority by mothers-in-law over their daughters-in-law, a problem often identified in the South Asian context, are examples of behaviour in which women’s internalisation of their own lesser status in society lead them to discriminate against other females in that society (Sida Studies 2001:24).

A related concept to agency and gender empowerment is gender mainstreaming. Gender mainstreaming implies that attention to equality between women and men should pervade all development policies, strategies and interrelations. Gender mainstreaming does not simply mean ensuring that women participate in a development agenda that has already been decided upon, it aims to ensure that women as well as men are involved in setting goals and in planning so that development meet the priorities and needs of both women and men (Sida Studies 2001:76).

Hooks (2000:92) argued that women need to know that they can reject the powerful definition of their reality- that they can do so even if they are poor, exploited or trapped in oppressive circumstances. They need to know that the exercise of this personal is an act of resistance and strength. Many poor and exploited women, would have been unable to develop positive self-concept if they had not exercised their power to reject the powerful definition of their reality (Hooks 2000:92).

Hooks (2000:92) indicated that even though women organizing and participating in feminist movement were in no way passive, unassertive or unable to make decisions, they perpetuated the idea that these characteristics were typical female traits, a perspective that mirrored male supremacist interpretations of women 's reality. They did not distinguish between passive role many women assume in relation to male peers and/or male authority figures and the assertiveness even domineering role they assume in relation to one another, to children or to those individuals, female or male who have lower social status whom they see as inferiors (Hooks 2000:93).

The idealised expectations of motherhood indicate how mothers living with HIV experience challenges if they do not meet those expectations. In discussing the different feeding methods, it was explained how breastfeeding is culturally accepted as part of motherhood, while replacement infant feeding is not. The theoretical concepts of gender and power illuminated gender inequality, and this explains how women's choices are not based on individuals, but their life decisions are shaped by norms and culture. Gender inequalities put women at a disadvantaged position which makes them vulnerable to HIV transmission and in some cases even domestic violence. The gender and power theory as explained by DiClemente *et al.* (2002) shows how women can be shaped by male dominance in every sphere of life. Empowerment of women and agency could be the most effective approaches to make women's voices to be heard.

2.3 Infant feeding practices among mothers living with HIV

In this section specific studies dealing with mothers living with HIV are discussed by focusing on the various feeding practices that these mothers resort to.

2.3.1 Infant feeding: choices, practices and adherence

First a few studies in African countries, other than South Africa, focusing on the choices, practices and adherence to replacement infant feeding are considered before focusing on the findings of South African studies on this topic in different parts of the country.

De Paoli *et al.* (2004:611-619) investigated pregnant women's views on the infant feeding options recommended to HIV-infected women in Tanzania. It was found that infant feeding was regarded as too costly, but if recommended by health workers and distributed free of charge, the majority of the women (82%) were confident that they would then choose this option. The more affluent women were the more confident regarding their ability to practise replacement infant feeding, which involves monetary costs and dealing with the social problems of not breastfeeding. The challenges that HIV-positive mothers faced were financial (buying formula milk) and dealing with the pressure to breastfeed according to the norms of the community. The conclusions were that future research on infant feeding options should include the broader cultural context and the psychological stress that HIV-infected women face when choosing an infant feeding method.

A study was done in Kenya by Kaai, Geibel, Mcodida, Benson, Muthumbi, N'katha-Matiko & Rustenburg (2005:1-5) to test several community-based strategies to reduce the mother-to-child transmission of HIV in urban slums of Nairobi. Sixty (60) HIV-positive women with infants 10 weeks or younger were interviewed using first structured interviews and then in-depth interviews to further explore issues raised in the quantitative section of the study. Infant feeding guidelines on the prevention of mother-to-child HIV transmission (PMTCT) in Kenya include that HIV-infected mothers are counselled about the risks of breast milk transmission of HIV and be given three options for feeding, namely a) exclusive breastfeeding for 6 months and abrupt cessation, b) replacement infant feeding with commercial infant formulas, and c) replacement / home-modified formula like cow, goat, camel milk or soy protein (NASCOP 2002). The above guidelines correspond with those of the WHO, although the latter issue is contentious since the safety of home-modified formula cannot be guaranteed. The modifying of animal milk for feeding infants below the age of six months raises difficult technical challenges (World Health Organization 2006:6). The findings were that infant feeding practices among most HIV-positive women reflect adherence to the National Kenyan infant feeding guidelines as compared to HIV-negative women and women of unknown status who do not adhere to the guidelines as closely as HIV-positive women.

In a rural area of Cameroon, a study was undertaken to ascertain the proportion of mothers choosing different methods of feeding, to determine the various factors influencing their choices, and to ascertain the relationships of these factors to their respective choices. Questionnaires were completed by 108 HIV-positive mothers who had had babies and who were administered nevirapine at least three months prior to the study. A focus group discussion with mothers took place and it was found that some of the factors against artificial feeding were cost (69%), stigma (64%), family pressure (44%), inconvenience in preparation/administration (38%), prior education from health care workers (23%), and loss of special attention from family (8%) (Muko, Tchangwe, Ngwa & Nyoya 2004:134).

Nlend, Penda, Ekobo, Tene and Tsague (2007:15) undertook a study to identify risk factors associated with infant feeding choices among HIV-positive mothers in urban areas of Cameroon. The study used a cross-sectional sample of 47 HIV-positive mothers at six months post-partum. In this sample, 87.5% of mothers opted for artificial feeding since birth, and 12.5% opted for breastfeeding. The choice practices during the first six months were 10% in breastfeeding and 84% in artificial feeding, and 6% chose mixed feeding. More mothers opted for artificial feeding rather than breastfeeding and the adherence rate was higher for women who opted for artificial infant feeding than those who opted for breastfeeding. This study confirmed that mothers who opted for replacement infant feeding are more likely to adhere to the method than those who opted for breastfeeding at the birth of their babies. The conclusion was that adequate infant feeding counselling could lead to post-natal prevention of HIV through consistent breastfeeding “as opposed to mixed feeding” and must be promoted even after delivery.

Another study, which aimed to provide empirically grounded knowledge on the relevance of the proposed feeding methods, was conducted in northern Tanzania. In this study, 20 HIV-positive women were interviewed three times, that is, during the last part of their pregnancy, at delivery, and during the first six months after birth. Cases describing the challenges linked to exclusive breastfeeding, cow’s milk and formula feeding demonstrated the gap between intentions and practice in a context where the social expectations of breastfeeding are high and where kin and neighbours are part of the decision-making team on an infant’s feeding. It highlighted the tension

between the medical and the social risks involved in the choice of infant feeding methods, and documented that feeding options may be difficult to adhere to, whether the mother chose exclusive breast feeding or replacement infant feeding (Leshabari, Blystad & Moland 2007:544-555).

In Zambia, a study was done in 2000 to examine the actual infant feeding practices of HIV-infected women in Lusaka. Out of 140 mothers with infants aged 2-12 months, 121 (86.4%) knew their HIV sero status, 55 mothers were infected, 65 mothers were not infected and 19 mothers were waiting for their HIV results. The mothers were interviewed using structured questionnaires. Data collected includes socio-demographic information, maternal knowledge and attitude to breast milk substitutes and complementary food. It was found that infant feeding practices of HIV-infected mothers differed significantly from those of uninfected mothers. Mothers with HIV infection receiving advice on infant feeding appeared aware of the increased risk of HIV infection through breastfeeding, but they did not stop breastfeeding although they introduced complementary feeds earlier than mothers who were not HIV-infected. It is regarded as a potential cause for poor infant growth when mothers change their feeding practices, and it puts their infants at greater risk of both HIV transmission and non-related morbidity (Omari, Luo, Kankasa, Bhat & Bunn, 2003:156-162).

In a study done in South Africa, Doherty *et al.* (2006a:90-95) explored how the HIV epidemic has affected the infant feeding experiences of HIV-positive mothers in South Africa. In order to assess the effectiveness of the national PMTCT programme, 650 HIV-positive mothers with babies were questioned using in-depth interviews. The main reason for mothers opting for artificial infant feeding practices was to try to protect their children from HIV transmission by avoiding breastfeeding. Mothers had a constant struggle to access formula supplies because of their dependency on health workers to obtain milk for their infants. This relationship between health care workers and clients suggest power dynamics and was identified as a challenge by HIV-positive mothers in this study. The study on the effect of the HIV epidemic on infant feeding by Doherty *et al.* (2006a:93) also found that most mothers were only able to maintain feeding practices for a short period because of various community and health system constraints. Furthermore, during the initial post-partum period, inadequate support

from health workers can lead to a change from their initially intended feeding option. Omari *et al.* (2003) also in a study found low rate of adherence to chosen feeding practices by HIV-positive mothers, which contributed to constraints mothers encountered by community and health care system.

Doherty *et al.* (2006b:2421-2425) further highlighted the role of the health care worker on feeding practices in a longitudinal qualitative study. In this study, a purposive sample of 27 respondents was used to examine the challenges that HIV-positive women face at different stages of early infant feeding in South Africa. This study also found that health workers seemed to have the greatest influence on the mothers' initial infant feeding choices and that the relationship between health workers and clients is often based on power and hierarchy. Moreover, due to a lack of knowledge on infant feeding practices by health workers, contradicting messages were often given to mothers. Mothers even reported being forced to use a formula because of their HIV-positive status.

The studies discussed above (Doherty *et al.* 2006a; Doherty *et al.* 2006b; Muko *et al.* 2004; Leshabari *et al.* 2007) all used qualitative study designs, although De Paoli *et al.* (2004) used both qualitative and quantitative approaches to investigate the choice of infant feeding. Doherty *et al.* (2006a) highlighted the role of the health care worker that places the mother at the bottom end of a power hierarchy. The findings underlined that there was a problem of not meeting AFASS criteria, i.e. lack of supply of milk, and Doherty *et al.* (2006b) also highlighted that there was a problem of accessing free formula milk. Doherty *et al.* (2006b) found that health care workers sent different messages due to a lack of sufficient knowledge about infant feeding and mothers were forced to use formula milk because of their HIV status, while Muko *et al.* (2004) and Leshabari *et al.* (2007) both found that the medical and cultural (including familial) aspects affected mothers' choice of infant feeding. It can be concluded that living with HIV impacts on the choice of infant feeding, especially when mothers want to protect their HIV-positive status from becoming known. The other studies discussed above, namely Nlend *et al.* (2007) and Kaai *et al.* (2005), confirmed a high rate of adherence by HIV-positive mothers who are on replacement infant feeding. Kaai *et al.* (2005) found that in Kenya mothers experienced good

counselling by health care workers, while Nlend *et al.* (2007) found inadequate infant feeding counselling behaviour by health care workers.

2.3.2 Socio-cultural factors

The following studies focused on socio-cultural factors that played a role in the choice of and adherence to replacement infant feeding. The first three studies are all from Tanzania, another three are from Kenya and one is from South Africa. In all the studies the influence of family and/or community members on mothers' choices of feeding practices for their infants are apparent. The stigma associated with being HIV-positive is a recurring theme in all these studies.

In the north-eastern part of Tanzania, a study was undertaken to investigate how socio-cultural factors influence women when making choices regarding feeding practices. In this part of Tanzania the rate among pregnant women attending antenatal clinics was 20%. The method that was used was participant observation and in-depth interviews with 20 HIV-positive women during ANC classes, labour and post-natal periods in the zones of the hospital and also during home visits in the first six months of the baby's life. The aim of the study was to explore views on potential dilemmas around implementing infant feeding options among HIV-positive women, using case studies. In this study the women's choice of infant feeding methods, including exclusive breastfeeding or cow's milk or formula feeding, was analysed and discussed with an emphasis on the context of the choice and the situational concerns of each women. It was found that women who choose replacement infant feeding, end up breastfeeding – despite their knowledge of the risk of HIV transmission through breast milk. The cost of not breastfeeding includes shame and rejection by close kin and neighbours, which seems an even greater burden to carry. The study suggests that HIV-related stigma and fear of rejection are major factors when HIV-positive mothers decide how to feed their infants. The socio-cultural factors play a vital role in the choice of and adherence to a method of infant feeding (Leshabari 2004).

Another study in Tanzania aimed to further the understanding of barriers to PMTCT programmes (Ntabaye & Lusiola 2004). Qualitative data was collected on the health infrastructure, and focus group discussions were held to understand PMTCT

opportunities and barriers to HIV testing and disclosure. This study found that community members perceived HIV as a serious disease affecting young people. Women reported that any mother who did not breastfeed her child was discriminated against by community members and faced the threat of domestic violence.

Similar findings were reported in a case study from Kilimanjaro, Tanzania. Leshabari (2004) explored the experiences and concerns of childbearing HIV-positive women who opted for exclusively breastfeeding or replacement infant feeding, with the aim to understand the dynamics in the choosing of a feeding method. The focus was on how HIV-positive women coped with suggested options of infant feeding in the African social context and the cultural determinants of such feeding choices. The findings were that HIV-related stigma and fear were major factors when HIV-positive mothers decided how to feed their babies, since the mothers experienced a great burden when not breastfeeding due to shame and rejection by close kin and neighbours. The rejection of HIV-positive mothers who opted not to breastfeed by family members and community members often lead to inappropriate practices that could put the baby at risk of contracting HIV/AIDS.

In Kenya, a study was done to assess cultural factors that influenced infant feeding among 659 HIV-positive mothers in a PMTCT programme between December 2002 and December 2003. There were 269 (41%) mothers who opted for breastfeeding their babies, while only 64 (10%) of them opted for replacement infant feeding. Again, the findings confirmed that the decisions made by mothers on their infant feeding practices were to a large extent affected by the socio-cultural norms of the Kenyan society (Ngeno, Sawe, Foglia, Birx & Robb 2004).

Another study in Kenya by Leshabari *et al.* (2007) confirmed the importance of culture in opting for and adhering to replacement infant feeding. Mothers who opted for replacement infant feeding without disclosing their HIV-positive status to their families are in a difficult position since family members will suspect an HIV-positive status if it is noticed that she uses formula milk and is not breastfeeding the baby. The community members are associating formula milk with an HIV-positive status. Not disclosing an HIV-positive status thus interferes with healthy infant feeding while the disclosing of a positive HIV status puts a mother at risk of divorce, abuse, violence or

discrimination. HIV-positive mothers were experiencing stigmatisation and discrimination if not breastfeeding, which often lead to inappropriate feeding i.e. mixed feeding.

A cross sectional cross-sectional study that was conducted in 2003-2004 in Kenya assessed knowledge, attitudes and practices with regard to infant feeding in the context of HIV (Wachira, Otieno-Nyunya, Ballindawa & Braitstein 2009:123-125). The study's target population was people between the ages of 18 to 45 years. Structured questionnaires were used to collect data and 385 individuals participated in the survey, of which 50% were women. Breastfeeding was found to be the norm. Most women (94.2%) reported that they breastfed their infants from birth. According to the traditional birth attendant, the only time when breastfeeding is not allowed is when the mother is either ill and on medication or does not have adequate breast milk or is pregnant, when she has to preserve milk for the baby she is expecting. The stigma associated with not breastfeeding was apparent and HIV-positive mothers were reported to make use of mixed feeding practices. Women are normally pressured to give reasons for not breastfeeding. Other studies also reported socio-cultural factors such as stigma, discrimination and lack of male involvement as challenges faced by non-breastfeeding mothers (Cooper, Morroni, Orner, Moodley, Harries, Cullingworth & Hoffman 2004:79; Oladokun, Brown & Osinusi 2010:6; Peltzer, Mosala, Shisana, Nqueko & Mngqundamiso 2007: 57-66 ; Kebaabetswe 2007:358).

In South Africa, a qualitative study on HIV and child nutrition used mothers' narratives on infant feeding practices. Titus (2004) found that infant feeding practices remain one of the most serious challenges facing childcare and development, particularly in areas with high HIV and AIDS prevalence. Although health care providers promote exclusive infant feeding practices, in developing countries mixed feeding commonly occurs.

The studies discussed above showed how socio-cultural factors play a vital role in the choice of and adherence to infant feeding. Ngeno *et al.* (2004) indicated how the choice of replacement infant feeding was affected by socio-cultural norms, while Leshabari *et al.* (2007) and Wachira *et al.* (2009) confirmed the stigmatisation and discrimination experienced by HIV-positive mothers who opted not to breastfeed their

babies. Because of the pressure by family and community members, non-breastfeeding mothers try to hide the fact that they do not breastfeed, which results in mixed feeding practices, as confirmed by Titus (2004). This is the least desirable of all the feeding options.

It should also be noted that the guidelines on infant feeding for HIV-infected mothers are not following WHO recommendations in some countries. Ntabaye & Lesiola (2004) and Ngeno *et al.* (2004) also found that socio-cultural norms play a role in opting for and adhering to an infant feeding method. The impact of introducing the WHO guidelines of safe infant feeding on mothers' actual feeding practices has not previously been examined (Omari *et al.* 2003:156). Some of the studies discussed above highlighted how socio-cultural factors play a vital role in the choice of and adherence to replacement infant feeding. Despite the knowledge of HIV transmission by mothers to their babies through breast milk, they have to face community expectations and family pressure. The stigma, shame and rejection that are associated with non-breastfeeding make it difficult for women to consistently adhere to replacement infant feeding practices, and then mixed feeding occurs. Spire, de Zoysa and Himmich (2008:1763) proposed a therapy against stigma and discrimination called "Triple Therapy". It is believed to be an effective approach to fight the stigmatisation and discrimination that people living with HIV/AIDS (PLWHA) are currently facing. The elements of the Triple Therapy are firstly, fighting for a greater acceptance of PLWHA. Secondly, to improve relevant laws and policies, and lastly to involve prevention strategies that will help people living with HIV rather than for people, and this could avoid passive recipients.

2.3.3 Disclosing an HIV-positive status

Disclosure is one of the important aspects that play a vital role in a PMTCT programme, since it was found that failure to disclose a positive HIV status to a sexual partner decreases the effectiveness of PMTCT programmes. Varga *et al.* (2006:952) argue that disclosure is classified into different forms, namely voluntary and involuntary. Voluntary disclosure is the act of divulging one's HIV status through a decision made and is undertaken without coercion, while involuntary disclosure occurs when an HIV status is revealed without the individual's permission

or intent. In relation to PMTCT programmes, non-disclosure should be considered as a behavioural risk factor for vertical transmission of the HIV virus (Varga *et al.* 2006:959). To be able to adhere to the chosen infant feeding practice, one needs support from a partner or family member. The lack of disclosure makes adherence to drug regimes and infant-feeding guidelines difficult (Doherty *et al.* 2006a:93). However, mothers who opted for replacement infant feeding face socio-cultural pressure for fear of stigmatisation and discrimination, and this results in non-disclosure, which in turn could lead to the introduction of breast milk into the feeding programme. The following studies done in other African countries and South Africa on the issue of disclosure are discussed:

An in-depth qualitative study was done at 11 different sites in Namibia, Swaziland and South Africa on pregnant women and mothers with infants one year old or younger. The study used participant observation, observation, formal and informal interviews and focus groups totalling 155 mothers and pregnant women, 31 relatives, 92 health workers and seven traditional healers. The study focused on experiences and perspectives of mothers to understand how they made infant feeding decisions, counselling encounters, the influence of the health context and gender dynamics. The findings were that mothers who participated in the programme often hid their status from partners and relatives, stating fear of rejection, physical abuse and of losing financial or social support as reasons (Buskens *et al.* 2007:1105).

A study done in Tshwane, South Africa found that among 293 HIV-positive women during pregnancy and 3 months post-delivery, 59% had disclosed their HIV-positive status to at least one person other than health care providers, while 41% had not done so. Those who had disclosed had primarily told their partners (80%), and those who had not told their partners, had told a parent (20.2%) and/or another family member (23%); a few respondents had disclosed their status to others outside their family circle (14.6%). The reasons for not disclosing included not feeling ready to disclose to their partners (27.8%), since they felt that they first had to deal with the disease emotionally and/or wait for the development of symptoms, and would then discuss the results with the partner or wait for the partner to test for HIV. A large number of the women in this study felt fearful of abandonment (31.8%), of being blamed (7.3%), of

violence (6.6%) and of emotional abuse (6%) (Visser, Neufeld, De Villiers, Makin & Forsyth 2008:1139-1140).

Skunodom, Linkins, Culnane, Prymanee, Kannasoot, Suwannapha *et al.* (2006:692-720) found that not living with a partner every day was independently associated with non-disclosure until post-delivery. The rates of disclosure continued to decrease over time. There may be a group of women who do not disclose regardless of the amount of time passed since learning their HIV status, as this could depend on a person's personality. Skunodom *et al.* (2006:697) also looked at the partner's knowledge of status and the length of time knowing the status. Non-disclosure was found to be associated with a few demographic and behavioural factors such as having more than two sexual partners, not having a partner tested for HIV or not knowing whether the partner was ever tested for HIV, learning about post-test results during labour or in the immediate post-partum period, not taking AZT during pregnancy for PMTCT, and lack of the communication and negotiation skills needed for open discussion on sensitive sex topics like sex history. The attitudes and skills of health professionals contribute to non-disclosure behaviour. Not living with a partner every day was independently associated with non-disclosure by four months post-partum by those women who had not disclosed by immediate post-partum.

Makin *et al.* (2008:907) found in their research that 59% of their research participants had disclosed to their partners and 42% to others. The increased level of stigmatisation decreased the likelihood of disclosure to a partner. Women who had disclosed their status to their partners, had had higher household incomes and were more likely to be married. Their partners were more likely to have a tertiary level of education and a regular income and, more of these couples had discussed the test prior to being tested. Women who had experienced two or more types of violence in the past were significantly less likely to have disclosed to their partners. The study found that a woman's decision to disclose her HIV status to her partner early after being told her diagnosis was primarily impacted by issues that relate to the couple's relationship (Makin *et al.* 2008:990).

In Brou, Djohan, Becguet, Allou, Ekouevi, Viho *et al.* 's (2007:346) study in Abidjan, almost half of the participants were not living with their partners, and disclosure to other members of the family were 33.9%. It is deduced that such disclosure patterns

were done for support rather than protection and care services. The tendency of disclosing to anyone who is not a family member was low (about 1.7%) – to a fellow church member or co-worker. HIV-infected women declared that disclosing their status to their partners seemed essential to them, so the women could benefit from comfort and support to make important decisions for their infant and for them as a couple. The non-disclosure behaviour was being supported by different reasons, such as fear of gossip (24.3%), not feeling ready (24.3%), fear of being chased/left alone (21.6%), fear of being blamed (8.1%) and other reasons (13.5%) such as lack of trust. The negative reactions that HIV-infected women might encounter inhibit the process of disclosure. There are a number of potential risks from disclosure, especially for HIV-infected women. This includes loss of economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationships. Antelman, Fawzi, Kaaya, Mbwambo, Msamanga, Hunter and Fawzi 2001:1870) in their study found that women were less likely to disclose to their partners if they were married or cohabiting for less than two years, had low-wage employment and reported ever using a modern contraceptive method. However, women reporting fewer than six lifetime sexual partners or knowing someone with HIV/AIDS were more likely to disclose to their partner. The duration of the relationship played a role, with long-term relationships guaranteeing trust and encouraging disclosure, but short-term relationships introduced uncertainties, mistrust and fear of divorce and resulted in non-disclosure of a positive HIV status. Economic instability also contributed to not disclosing a positive HIV status. In studies from some developing countries, disclosure of a positive HIV status to a sexual partner was associated with positive outcomes including increased social support, acceptance, kindness, decreased anxiety and depression and strengthening of the relationship. Until recently, women were not recognised as being economically active, despite the fact that on a micro-level they constitute the African continent's food producers (Seidel 1993:171).

The studies discussed above indicated low levels of disclosure by HIV-positive mothers to their partners and relatives. Visser *et al.* (2008), Buskens *et al.* (2007) and Makin *et al.* (2008) indicated the low level of disclosure, and Skunodom *et al.* (2006) found that the rates were decreasing. Specific studies found that disclosure was mostly towards partners, parents or family members for support purposes and seldom was towards others outside the family circle, e.g. co-workers or fellow church

members (Brou *et al.* 2007 ; Visser *et al.* 2008). Makin *et al.* (2008) found certain demographic factors to be associated with disclosure, e.g. high household incomes, marriage (as opposed to cohabitation) and husband's level of education. Skunodom *et al.* (2006) found that behavioural factors associated with non-disclosure were having more than two life sexual partners, not knowing the partners' HIV status, not taking PMTCT prophylaxis, lack of communication and negotiation skills between partners, attitude and skills of health care workers, not living with a partner and knowing about his HIV-positive status during labour and immediate post-partum period. Antelman *et al.* (2001) found a short duration of the relationship, the use of modern contraceptives and low-wage employment were associated with non-disclosure, while knowing someone with HIV and fewer life sexual partners were associated with disclosure. Buskens *et al.* (2007), Brou *et al.* (2007) Visser *et al.* (2008) and Makin *et al.* (2008) found that non-disclosure was associated with fear of rejection, blame, physical, emotional and verbal abuse, loss of financial and social support, marital problems, hatred, stigmatisation and discrimination. To summarise – disclosure was aimed at finding support from partners and other family members, with demographic and behavioural factors that contributed towards disclosure, while non-disclosure was associated with fear of various negative consequences.

2.3.4 Support systems

When receiving an HIV diagnosis, a person has to deal with not only a life-threatening disease and issues such as death and HIV-related symptoms, but also with a change in life expectancy, change in body image, decisions about disclosure, mistrust in relationships, choice of infant feeding, stigma and possible social isolation and rejection (Skinner & Mfecane 2004:157-161). As already stated, breast-feeding is a norm in many African countries and is embedded as a motherhood practice. Mothers who are unable to breastfeed are therefore not meeting the community's, and often the family's, expectations regarding motherhood. These expectations already place pressure on mothers and may add to their psychological distress.

In a descriptive survey on two groups of pregnant women and non-pregnant women living with HIV in KwaZulu-Natal, South Africa, the relationship between social support and health behaviour of rural and urban areas was explored. It was found that

belonging to a support group constituted 12% (n = 262) among participating women. The social support as well as membership of a support group was higher in the rural group than in the urban group. Good social support was associated with condom use, support group attendance and taking vitamins. However, receiving counselling as well as membership of a support group showed stronger association with positive health behaviour than social support on its own (Gaede, Majeke, Modeste, Naidoo, Titus & Uys 2006:363-366). Similarly, in a study done in Cape Town, South Africa, which looked at barriers to participating in PMTCT programmes, it was found that emotional support increased participation in PMTCT programmes (Peltzer *et al.* 2007:57-66).

2.3.5 Conclusion

This chapter gave an overview of the reality of motherhood by focusing on the concepts of breastfeeding and replacement infant feeding. Gender and power inequalities, as well as empowerment, were discussed by emphasising the socio-cultural norms that are experienced by mothers. Finally, the issue of agency was highlighted to show how women should be equipped with knowledge and skills to meet the challenging environment.

PMTCT programmes need to be effective to prevent mother-to-child transmission of HIV, although replacement infant feeding is recommended for mothers living with HIV. However, there are challenges that are faced with these. The concept of motherhood including the stereotypes, realities and expectations embedded in the process even complicate the situation. Therefore, the situation leaves mothers as expected to breastfeed their babies. Replacement infant feeding is associated with stigmatisation and discrimination, and is culturally not accepted. Mothers often resort to mixed feeding practices to meet the criteria and expectations of motherhood.

The discussion on gender and power indicated how women are disadvantaged by male dominance, gender roles and cultural norms. It was also indicated how women are prone to be victims of abuse. The concepts *empowerment* and *agency* were identified as important in making life decisions and rectifying aspects associated with gender and power inequalities. It was indicated in the literature consulted that socio-cultural

factors play a role in choices, practices and adherence to replacement infant feeding. There is also an identified power hierarchy between a health care worker and mothers, and accessibility of resources was difficult.

The literature consulted indicated that HIV-positive mothers experienced problems in opting for a particular infant feeding method and adhering to the chosen method. The majority of women choose and adhere to replacement infant feeding to protect their babies, as they understand that breastfeeding is a major route of transmission of HIV from the mother to the baby. In addition, the relationship that a health worker has with a client and counselling both play a role in her choosing and adhering to infant feeding. However, mothers who are HIV-positive are facing socio-cultural challenges in various African countries in choosing and adhering to replacement infant feeding. Socio-cultural factors play an important role in making decisions about infant feeding. Low disclosure rates of an HIV-positive status are problematic since disclosure leads to positive behavioural patterns that help to prevent HIV transmission to the baby and helps the mother to live openly with an HIV-positive status. Yet, the disclosure of an HIV-positive status may have negative side effects which could leave mothers confused and even at risk of abuse from their partners. Not disclosing an HIV-positive status could introduce the problem of mixed feeding, which puts the baby at risk of post-partum HIV transmission. Mothers are being stigmatised and discriminated against if they do not breastfeed their babies, as breastfeeding is regarded as the norm in many countries. Support system plays a major role in comforting mothers living with HIV but there is still the challenge of stigmatisation and discrimination. An HIV-positive diagnosis is stressful and is further exaggerated by the pressure from relatives and community members with their expectations that all mothers should breastfeed. The above studies indicated that counselling and support groups contribute to positive health behaviour of HIV-positive mothers. Being diagnosed as HIV-positive constitutes a serious life crisis that requires considerable coping resources – and even more so when one has a baby. The research methodology used in the study is going to be discussed.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

In this chapter, the methodology used to conduct the research on problems experienced by mothers who opted for replacement infant feeding in a PMTCT programme are discussed. The focus is on the research setting, the research design, non-probability sampling, the methods of data collection and analysis and the relevant ethical considerations.

3.2 Research setting

The study was conducted in Limpopo Province, which is located in the north-eastern part of South Africa. It has the fourth largest population in South Africa, almost 6 million in 2005/200 and is considered a poor province with approximately 87% of its people living in rural areas (Baron, Day & Monticelli 2007:173). The Limpopo Province, as the most northern Province of South Africa, is situated in the great curve of the Limpopo river and borders on the countries of Botswana to the west, Zimbabwe to the north and Mozambique to the east (Limpopo Provincial Government 2009:1). The language distribution in the province is 52.1% Sepedi, 22.4% Xitsonga and 15.9% Tshivenda, Afrikaans 2.6% and English half a percent. The Limpopo Province consists of five districts, including Vhembe, which borders with Zimbabwe. Vhembe district has close to 1.3 million inhabitants and falls into the lowest socio-economic quintile (Baron, Day, Monticelli, Vermaak, Okarafor, Moodley & Doherty 2006:150).

Figure 1: Map representing four sub-districts in Vhembe District



Makhado Municipality is one of the four sub-districts of Vhembe and is divided into seven local areas (Department of Health 2007:12). It includes 290 villages with a total population of approximately 600 000 in 2007, and there are five main languages: Venda, Tsonga, Northern Sotho, English and Afrikaans (Makhado Municipality 2007:4). In 2009, Makhado Municipality had 3 district hospitals, 4 community health centres, 43 fixed clinics and 10 mobile clinics (Department of Health 2007:16).

3.3 Research design

The study used a qualitative approach with semi-structured, face-to-face interviews as research method. Vos & Strydom (2002:298) argue that, at the root of unstructured interviewing is interest in understanding the experiences of other people and the meaning they make of those experiences. HIV-positive mothers experience various problems and a qualitative methodology offers the opportunity to seek depth in the understanding of complex experiences rather than seeking the breadth of findings that a quantitative design offers (Lietz *et al.* 2006:445). The qualitative approach involves direct learning about experiences that are lived. Patton (2002:21) states that a qualitative design is naturalistic to the extent that the research takes place in a real-life setting and the researcher does not attempt to manipulate the phenomenon of interest.

3.4 Sampling design

The study was conducted at three of the clinics in the Makhado Municipality. The clinics were randomly selected from seven clinics.

Non-probability sampling in the form of purposive sampling was used in this study. Patton describes purposeful sampling (2002:46) as cases for study that are selected because they are “information rich” and illuminate the phenomenon of interest. Neuman (2006:222) states that purposive sampling may be used to select members of a difficult-to-reach, specialised population and is appropriate to select unique cases that are especially informative. Such sampling is aimed at insight about the phenomenon and not at empirical generalisation from a sample to a population. Moreover, the logic and power of purposeful sampling derive from the emphasis on in-depth understanding and information-rich cases, cases from which one can learn a great deal about the issues of central importance related to the purpose of the research.

Since the purpose of the study was to identify problems experienced by mothers who opted for RIF, mothers who are giving their babies formula and not breast milk are information-rich cases from whom we can learn more about problems they experience. Stigmatisation and discrimination are experienced by people living with HIV, and lead to mothers living with HIV belonging to a “hidden population”. They are not free and are afraid to be identified by community members due to stigmatisation and discrimination. The purposive sampling technique is often used to access such “hidden populations” and therefore it was considered the most appropriate (Salganik & Heckathorn 2004:223).

As orientation to the sampling criteria, the PMTCT programme has to be explained. It is a programme at an antenatal clinic with the aim of preventing HIV transmission from mother to child. Mothers who are tested HIV-positive chose to breastfeed their babies for six months or use replacement infant feeding from birth. The 6-to-14-weeks, post-partum period (that is from one month and two weeks up to four months post-delivery) is a crucial period for the choice of and adherence to infant feeding by HIV-positive mothers. The criteria used for inclusion in this study are: an HIV-positive mother who is on a PMTCT Programme within the borders of the Makhado

Municipality, had opted for replacement infant feeding, and is 18 years or older in order to give informed consent. Those who opted for replacement infant feeding but did not know their status, were not willing to participate. Non-permanent residents, women who came to deliver in the clinic but are not residing in the area and are from different places such as urban areas or from outside South Africa, were excluded from participating. The reason for their exclusion is simply that they are difficult to reach.

The sample consisted of 22 participants resulted after saturation in the data from mothers available and willing to participate, and which was sufficient to identify problems faced by HIV-infected mothers, but still manageable for one researcher to collect in-depth information in a limited time. Appointments were made after participants agreed to be interviewed and time frame was ranging from two weeks to a month. Data was collected from November 2009 to April 2010. Participants were interviewed until saturation of information was reached – seeing or discovering nothing new in sampled units/interviews (Sandelowski 1995:180).

3.5 Investigating instrument

The interview schedule (see Appendix 1) for this study was developed based on the literature review, which was discussed in the previous chapter. The questions on the interview schedule focused firstly on demographic characteristics such as home language, location, place of birth, living arrangements, and include details on other household members and educational level, the highest standard passed at school. Apart from such demographic characteristics, detail on pregnancies and parity were obtained (the latter referring to the number of pregnancies and births a woman has had). The remainder of the interview schedule focused on the participant's reasons for choosing replacement infant feeding, consistence in the use of replacement infant feeding, socio-cultural challenges, sharing of HIV-positive status and support systems available to her.

A pilot study was done with three mothers who spoke different languages, namely Venda, Tsonga and Northern Sotho, were older than 18 years and were involved in a PMTCT programme at Nkhensani Clinic. Certain questions that were not well understood in specific languages were revised after this pilot study.

3.6 Data collection

The researcher, who is able to speak the different languages that are used in the community and who have worked in the community for 10 years as a clinical nurse practitioner, collected the data using different languages and understanding of different local cultural practices. Face-to-face, semi-structured interviews were conducted using the interview schedule (see also translated interview schedules in Appendix 1), and audiotapes were made of the interviews. This was a valuable tool to accommodate illiterate participants. The researcher introduced herself and stated the purpose of the study, explaining that the participant may ask questions at any time during the interview and reiterating the voluntary nature of participation in the study on the audiotape. Mothers who meet the criteria outlined above were asked to participate in the study by the researcher, who is employed by the Department of Health and specifically involved in PMTCT and HIV counselling during “Baby well clinic”. The “Baby well clinic” involves visits by mothers with babies between the ages of six and fourteen weeks. During the visits mothers may also collect formula milk and attend counselling sessions. In addition, during “Baby well clinic” mothers bring their babies to the clinic for immunisations, with a “Road to Health” chart for growth monitoring as part of the PMTCT programme.

The information letter and informed consent form (see Appendices 2 and 3) were given to eligible participants by the researcher during such a clinic day, after having explained the study. During the next appointment, participants who were willing to take part in the research returned the signed informed consent letter, and an appointment for an interview was made. An appointment for the interview was only done if the mother was willing to take part in the research and she then chose the venue for the interview, which was either at the clinic or at her home and any day that suit the participants even weekends. Eighteen (18) of the interviews took place in the same clinic where mothers attend the continuous PMTCT programme counselling sessions, and four took place at the homes of research participants as preferred by them. The duration of the interviews ranged from 15 to 30 minutes, depending on the participant’s openness. Non-verbal communication and emotional responses were observed and noted. The researcher dealt with sensitive issues and tried to create a

relationship of trust for open discussions. The study was conducted over a period of six months in 2009 to 2010.

3.7 Data management and analysis

The interviews were audio-taped and transcripts of the tape recordings were made. Both the audiotapes and transcripts were locked in a cupboard to which only the researcher had access. Open coding was used to sort and structure the data, which entailed that themes were first identified and different colours were used to highlight similarities and differences in the responses of the research participants. Based on these identified themes, the development of categories followed, which illuminated the challenges experienced by mothers living with HIV. Various themes and sub-themes emerged. Thereafter a card index was used to arrive at the conclusions and evaluations, which are presented in Chapters 4 and 5 below.

Patton (2002:40) states that the qualitative analyst owns and is reflective about her or his own voice and perspective; a credible voice conveys authenticity and trustworthiness, complete objectivity is impossible and pure subjectivity undermines credibility, but the researcher's focus must aim to be balanced. It is important to bear in mind that the researcher is part of the instrument of data collection and analysis and that the truthfulness and accuracy of the interview data is based on the interpretation of the researcher. A brief look now at trustworthiness, authenticity and reflexivity.

3.7.1 Trustworthiness and authenticity

The real voice of rural, marginalised women needs to be heard through the honesty of the researcher, which includes commitment and devotion. Trustworthiness and authenticity are analogous to validity and reliability which are characteristics of quantitative research. It ensures that the study has been conducted with academic vigour, is representative of what is being studied, and that the research is worthy of being read by other scholars. According to Rolfe (2006:305), trustworthiness is divided into credibility, which corresponds roughly with the positivist concept of internal validity, and transferability, which is a form of external validity and

conformability, and is largely an issue of presentation. Credibility is enhanced when researchers describe and interpret their experience as researchers (Koch 2006:92), hence the following section on self-reflexivity. Authenticity refers to truthfulness of origin, attribution, commitments, sincerity, devotion and intentions (Mauther & Doucet 2003:420). In presenting the data in Chapter 4, the voice of the participants are thus presented by way of quotations and care has been taken to identify the relevant data and to present it in a comprehensive manner to demonstrate the authenticity of the origin of the data.

3.7.2 Reflexivity

According to Lietz *et al.* (2006:444), reflexivity is a strategy that qualitative researchers must engage in, in order to describe research findings in a way that authentically represent the meanings described by the participants. In order to successfully “speak for the mothers”, it is important to reflect upon myself, my culture, belief system, values, personal and professional experiences, strengths and weaknesses. Horsburg (2003:308) argues that reflexivity is an active acknowledgement by a researcher that his/her own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation. Reflexivity also involves deconstructing who we are and the ways in which our beliefs, experiences and identity intersect with those of the participants (Lietz *et al.* 2006:447).

Reflexivity is an important part of qualitative enquiry because it is through this that qualitative researchers can ponder the ways in which they may both assist and hinder the process of co-constructing meaning, as Lietz *et al.* (2006:447) emphasise. Reflexivity involve considering the multiple identities and perspectives of the researcher, which could both support the process of data analysis and also acknowledge the potentials for reactivity and bias (Guillemin & Gillam 2004).

Mauther & Doucet (2003:422) state that the choices we make in our research with regard to ontological and epistemological positioning, methodological and theoretical perspectives, and the adoption of particular research methods are bound to our

personal or academic biographies and not only motivated by intellectual concerns. Qualitative inquiry offers opportunities not only to learn about the experiences that the enquirer brings to the enquiry, experiences that will, to some extent, affect what is studied and help to shape for better or worse what is discovered (Patton 2002:27).

In line with the above guidelines, the relevant aspects of my position in relation to this research is as follows: I have started to work as a health care practitioner rendering VCT and PMTCT programmes whereby I was testing and counselling mothers – including on their infant feeding choices. I was also issuing ARV prophylaxis to pregnant women and free formula milk to non-breastfeeding mothers, doing follow-ups to infected and affected babies and their mothers, and giving debriefing sessions to lay counsellors at various clinics in the Gauteng Province in 2004.

I am currently involved in Primary Health Care Services at the clinic but I asked to be placed at the VCT and PMTCT room where those services are being done on a full-time basis. I then started to work full-time at the VCT and PMTCT room for three months, during which time I could start collecting data. This was done to gain experience, make entries in my journal and to gain trust from the participants. Due to the stigmatisation and discrimination attached to HIV, PLWH are usually not free to talk to anyone especially about their condition, especially a stranger they mostly feel uncomfortable when seeing a new person. PLWH may even request to be helped by only one particular lay counsellor or health care worker, which is not always possible due to shared confidentiality, encouraging them to disclose to health care workers, and the unavailability of a particular health care worker.

Confidentiality may be divided into different forms, namely shared confidentiality and group confidentiality. According to Van Dyk (2009:260), shared confidentiality means sharing the information (on a confidential basis) with family, loved ones, caregivers and trusted friends who are willing to give support, while group confidentiality is when a health practitioner (nurse/doctor) performs an HIV test while a counsellor is doing pre- and post-counselling. This could also include other health professionals who might have to be informed about the status since it impacts on treatment, e.g. when a client starts antiretroviral therapy it involves a multidisciplinary team – nurses, doctors, pharmacist, social workers etc. Information about a person's

HIV status may not be disclosed to anyone without that person's fully informed consent, except in group confidentiality (Van Dyk 2009:430).

I would like to refer to the few journal entries that demonstrate the stigmatisation and discrimination encountered by HIV-positive mothers.

One entry in my journal was made when I witnessed a junior health worker shouting, "Thank God your child PCR results are back and they are negative." This took place in the corridor where many people were waiting and they just stared at that woman. She stood up and left.

One day, one of the mothers who are on a PMTCT programme, came to collect milk and was told there is no one who is working in that room. Fortunately I was just coming from another consulting room and the mother could be helped.

I used to be biased against women living with HIV when they decided to hide their status from their partner, because I believed it was due to the fact that they had been unfaithful to their partners. One of my journal entries indicates a change in my biased view when a man who came with his mother asked a supervisor to see a lay counsellor and me. The man and his mother were concerned about knowing the pregnant women's status and the mother even pronounced her son to be pure and HIV-free.

I analysed those experiences and my emotional responses towards the different entries. I sometimes became sympathetic to the mothers and the experiences they were going through and offered my professional duties to them beyond my paid duties. The moment I started working there full-time, I applied professional values such as empathy. As a mother, I only gave my baby breast milk for a month because I was still in training and had to leave the baby with my mother. When I took the baby to the clinic other health workers were asking why I used formula feeding. My in-laws were also not happy about the decision; even my neighbours were unhappy about this. I thus share this experience of not being able to breastfeed the baby and other people's responses to that.

Overall, I believe that these shared experiences of not being able to breastfeed in a community that values breastfeeding so highly, enhanced an empathetic relationship with the research participants, which in turn contributed to the rich data obtained in this study.

3.8 Ethical considerations

Ethical consideration is another paramount aspect when conducting research. The proposal for this study served before the University of South Africa Ethics Committee, where it was approved, and the Limpopo Department of Health also gave me permission to conduct the study (see Appendices 4 and 5).

The study of human behaviour, especially issues related to sexuality, concerns ethical considerations because of its personal nature that intrudes in areas that are considered private by most people. Furthermore, it holds potentially negative effects such as psychological, emotional and social impacts that might even change the roles of an individual or the situation. Babbie & Mouton (2002:470) argue that most definitions of ethics are typically associated with morality and deal with matters of right and wrong, but explain that morality and ethics in day-to-day life is a matter of agreement among members of a group.

Respect for the research participants' rights to privacy and dignity were adhered to by focusing on confidentiality, anonymity, informed consent, openness and debriefing:

Confidentiality – the data was treated as absolutely confidential and only the researcher had access to the audio tape, and the transcripts were locked in a cupboard.

Anonymity – the dissertation does not include information that may identify any of the participants, as the participants' real names are not being used.

Informed consent – informed consent means that respondents must base their voluntary participation in research projects on a full understanding of the possible risk involved. Mothers who were identified as eligible by the researcher in a PMTCT

programme were orally informed of the study, then received the information letter and were asked to give informed consent to the study. The participants participated voluntarily without being forced or compromising their health care at the clinic. The participation in this study was absolutely voluntary; no participant was under any obligation to participate. Research participants had the right to stop at any time and their withdrawal would not affect their treatment in any way. The consent was also emphasised before the interview could take place. The participants' permission to be audio-taped was obtained before starting with the interviews. There was no victimisation of those who withdrew from the study. The researcher asked permission to continue with the study on the audio tape and gave participants a chance for questions.

Openness – the information letter (see Appendix 2) includes information on the purpose of the study, the procedure, risks and benefits of the study, the rights of participants, ethical approval and confidentiality and the contact number and name of the researcher for additional information. Therefore, the participants knew the researcher and no form of deception was used.

Debriefing –debriefing counselling was provided, and additional information was given to participants to minimise any possible harm. Furthermore, contact details were made available should additional information or debriefing counselling be needed. Four participants had continuous counselling after the study according to their needs.

3.9 Conclusion

This chapter outlined the qualitative approach of this study on problems experienced by mothers who opted for replacement infant feeding. Face-to-face, semi-structured interviews were used with the help of an interview schedule. Purposeful sampling was employed in the Limpopo Province by accessing women who were attending PMTCT programmes. The data collection and analysis procedure were discussed, and the process of reflexivity to enhance trustworthiness and authenticity was touched upon. Finally, the ethical considerations specific to this study were highlighted. The study findings and interpretations are going to be elaborated.

CHAPTER 4

THE STUDY FINDINGS

4.1 Introduction

In this chapter, the results of the study are presented and interpreted. Firstly, the demographic characteristics of the research participants are outlined. Thereafter the results are organised thematically according to the research questions of this study: What challenges do mothers living with HIV face when choosing replacement infant feeding in the rural area setting of Makhado Municipality, Vhembe district? What are the coping strategies employed by mothers living with HIV who opted for replacement infant feeding? Three major themes raised by this study are going to be discussed here, i.e. feeding, role players and emotions.

4.2 Demographic characteristics of participants

The demographic characteristics of the 22 research participants are outlined in Table 1 and then discussed.

Table 4.1: Demographic characteristics

Name*	Age	Marital status	Home language	Highest level of education	Household members	Parity	Age of youngest
1 Mahlatse	31	Married	Xitsonga	STD 9 (Grade 11)	Husband, children and mother-in-law	P3	3 m [#]
2 Thanyi	28	Co-habiting	Tshivenda	SUB B (Grade 2)	Partner and children	P2	3 m
3 Leloko	21	Co-habiting	Sepedi	STD 10 (Grade 12)	Partner and his mother	P2	2 m
4 Khasa	29	Co-habiting	Sepedi	STD 10 (Grade 12)	Partner and child	P1	4 m
5 Tsakane	39	Married	Xitsonga	STD 8 (Grade 10)	Husband and children	P4	3 m
6 Nkhensi	37	Married	Xitsonga	STD 7 (Grade 9)	Husband and children	P6	2 m
7 Ravu	21	Single	Tshivenda	STD 5 (Grade 7)	Mother, father, mother's younger sister, siblings and	P1	2 m

					child		
8 Ngeli	33	Single	Xitsonga	None	Mother, brother's son, father and three children	P3	3 m
9 Marusa	29	Single	Xitsonga	STD 10 (Grade 12)	Mother, siblings and baby	P1	6 w
10 Grama	30	Married	Tshivenda	STD 2 (Grade 2)	Husband and five children	P5	7 w
11 Kharikani	18	Co-habiting	Tshivenda	STD 9 (Grade 11)	Partner, his mother and baby	P1	3 m
12 Masindi	27	Single	Tshivenda	STD 10 (Grade 12)	Two children, mother (intermittently)	P2	7 w
13 Tshina	20	Co-habiting	Tshivenda	STD 6 (Grade 8)	Partner and two children	P2	3 m
14 Muvhale	29	Co-habiting	Tshivenda	STD 8 (Grade 10)	Partner, his mother and sisters	P3	3 m
15 Hlamala	28	Co-habiting	Xitsonga	STD 6 (Grade 8)	Partner and children	P3	2 m
16 Rubani	22	Single	Xitsonga	STD 10 (Grade 12)	Grandmother, siblings and father	P1	2 m
17 Thembi	26	Single	Xitsonga	Tertiary	Two siblings, two children, mother (occasionally)	P2	4 m
18 Maliphu	25	Co-habiting	Tshivenda	STD 9 (Grade 11)	Partner's mother, sister, brother and baby (partner works in Pretoria)	P1	3 m
19 Vutshilo	27	Married	Tshivenda	STD 9 (Grade 11)	Husband and two children	P2	3 m
20 Bonie	22	Co-habiting	Xitsonga	STD 9 (Grade 11)	Partner, his mother, siblings and her two children	P2	6 w
21 Tinyiko	29	Single	Xitsonga	STD 9 (Grade 11)	Mother, siblings and four children	P4	2 m
22 Thuli	27	Co-habiting	IsiZulu	STD 4 (Grade 6)	Partner's mother and siblings	P1	2 m

					(partner works in Witbank)		
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*Pseudonyms have been used to protect the identity of the participants.

m = months; w = weeks

All the research participants were in their twenties and thirties except for the youngest, Kharikani, who was 18 years old and still at school (grade 11) at the time of the interview. The oldest participant was Tsakane, who was 39 years old at the time of the study.

The marital status of the participants were varied, with seven being single, ten cohabiting i.e living together with the partner without a customary or civil marriage having taken place, and the remaining five were married according to either civil or customary law. Kharikani was amongst those who were cohabiting with a partner who was unemployed, and was staying with her partner's mother, who was a retired teacher and the only income earner in the household. Among the research participants the following were married: Mahlatse, Tsakane, Nkhensi, Grama and Vutshilo, while Tsakane and Nkhensi's husbands were working as farm workers at nearby farms and sleeping at home. There were six participants who were staying with their mothers-in-law: Mahlatse, Bonie, Maliphu, Thuli, Muvhale and Kharikani. All the participants who were married or cohabiting were staying with their husbands/partners, except Thuli and Maliphu. They mentioned that they were staying with the relatives of their partners, as Maliphu's partner was working in Gauteng at the mines and Thuli's partner was working in Witbank, Mpumalanga Province as a truck driver and came home at the end of each month.

The home languages of the participants were Tshivenda, Xitsonga, and Sepedi, with only Thuli speaking isiZulu. The educational levels of the participants ranged from no formal education to tertiary education. Amongst those with low or no educational levels, Ngeli had no education, Thanyi had completed Sub B (Grade 2), Grama Standard 2 (Grade 4), Ravu Standard 5 (Grade 7), and Thuli Standard 4 (Grade 6). There were only five participants who had completed secondary school. The remaining 11 participants left school before completing Grade 12. The only

participant who completed a tertiary qualification was Thembi, although she was still looking for employment.

Parity refers to the obstetric history and the number of living children the mothers had at the time of the study. Seven participants gave birth for the first time, seven participants gave birth for the second time, and four participants had a third pregnancy. The highest number of children was Nkhensi with six children, Grama with five children, and Tsakane and Tinyiko with four children each. The age of the youngest child was included above to determine the duration of infant feeding. Eighteen (18) participants had babies whose ages ranged from seven weeks to three months, while Khasa and Thembi's babies were four months old, and Marusa and Bonie's babies were six weeks old during the time of the study.

One of the objectives of this study was to identify challenges experienced by mothers who opted for replacement infant feeding. Three major themes emerged in response to the participants' experiences, namely feeding patterns/practices, role players in choosing of infant feeding and emotions. These are discussed next.

4.3 The feeding patterns/practices

Feeding practices form a cornerstone of this study, and the following sub-themes emerged from the research interviews: protection of the baby's health, consistency of replacement infant feeding, quality and preparation of milk, the stigma associated with free formula milk tins, meeting AFASS criteria, the availability of milk and protecting the mother's HIV-positive status. These sub-themes will be discussed by giving voice to the participants of this study.

4.3.1 Protection of the baby's health

After receiving an HIV-positive test result during pregnancy, through Voluntary Counselling and Testing (VCT) – a routine procedure at antenatal clinics – participants were concerned about protecting the health of their babies by preventing the transmission of HIV through breast milk. The only participants who knew about their positive HIV status before pregnancy were Nkhensani, Marusa and Tinyiko; all

the other participants found out while being pregnant with the youngest babies in the group. Although there are reported clashes of interest in protecting the baby's health and hiding one's HIV-positive status by giving breast milk (refer to Chapter 2), most women opted to protect their baby's health by avoiding breast milk so as to lower the risk of HIV infection, and therefore opted for replacement infant feeding:

Beauty: *I thought after testing HIV-positive, if I give breast milk he will be infected and I wanted to protect him.*

Leloko: *I felt as if my breasts are still positive, that is why I choose to give my baby replacement infant feeding (tearful and wanted to cry).*

Khasa: *I was checked and found that I am HIV-positive. I decided to give my baby replacement infant feeding. I wanted to protect my baby from transmitting the HIV disease through breastfeeding.*

The majority of the participants mentioned that they wanted to protect their babies from HIV transmission since they knew their HIV-positive status. The goal and objective of the PMTCT programme is to prevent mother-to-child transmission of HIV. The participants' reports were clearly in line with those of the programme.

Doherty *et al.* (2006a:95) also found that the main reason motivating mothers to opt for artificial infant feeding practices was to try and protect their children from HIV transmission by avoiding breastfeeding. The mothers believed that breast milk was carrying the HIV virus and they did not want to infect their babies. Although most mothers voiced this proudly and with confidence, Leloko looked depressed, tearful and crying when she talked about this. She mentioned that she was blaming herself for not being able to give her baby breast milk, and that she hates the fact that she is living with HIV and does not want it anywhere near her baby.

4.3.2 Consistency of replacement infant feeding

Adherence to the chosen infant feeding method remains a challenge to participants, because they tend to shift from one practice to the other. The 12 participants who opted for replacement infant feeding from the birth of the baby, i.e. Mahlatse, Leloko, Tsakane, Nkhensi, Ravu, Ngeli, Grama, Masindi, Rubani, Bonie, Tinyiko and Thuli, implemented this method without changing their feeding methods. The other remaining 10 participants opted for breastfeeding at birth of their babies. The

following participants reported how they changed from breast milk at birth to replacement infant feeding later on:

Maliphu: *I breastfed for three months, then changed to replacement infant feeding because I was afraid that my baby could get this virus if I breastfeed him for a long time, so I wanted to protect my baby and I was advised by a nurse.*

Thembi: *I was tested when I was pregnant and found that I was HIV-negative. I then decided to breastfeed my baby. When I took my baby for the three months check-up, I decided to test again, but unfortunately, I was HIV-positive. I immediately stopped the breastfeeding and started replacement infant feeding to protect my baby.*

The reason for Maliphu to change from breastfeeding, which she chose at the birth of the baby, to replacement infant feeding, was a health professional's recommendation, while for Thembi it was a different experience: she only discovered her status after the birth of her baby. She was tested HIV-negative while she was pregnant, which could have been caused by her being still in the "window period", i.e. she was newly infected and had not yet developed antibodies against the HIV virus.

The tension between the competing concerns of the medical and the social risks involved in the choice of infant feeding method includes the fact that both feeding options may be difficult to adhere to, regardless of whether mothers chose exclusive breast feeding or replacement infant feeding (Leshabari *et al.* 2007:544-555). Nlend *et al.* (2007:15) found that most mothers opted for artificial feeding rather than breastfeeding, and the adherence rate is higher for women who opted for artificial infant feeding than those who opted for breastfeeding. The conclusions were that adequate infant feeding counselling can lead to post-natal prevention of HIV through breastfeeding and must be promoted, even after delivery.

4.3.3 Quality and preparation of milk

Participants complained about the type of milk that they received at clinics as being different from the milk bought from the shops. The type of milk was also making mothers doubt whether the milk was healthy for their babies. Some participants voiced their concerns about the free milk as follows:

Thembi: *The milk separates from fats and water and the baby loses weight fast as he has diarrhoea or is sick with any disease when he is on this milk. There is a difference*

between a baby on formula and one on breast milk, especially when the baby has flu or diarrhoea. The baby usually refuses to suck a bottle when he is sick.

Tsakane: *The problem is that the milk that we receive is not the usual one; fats separate from water and is different from the one you buy from shops.*

Nkhensani: *The problem is that that milk we receive from the clinic contains many fats; after preparing it, the milk goes up and the water goes down.*

Vutshilo: *The preparation of a milk bottle must be finished when the baby wakes up. If he finds not yet prepared, he will cry a lot and people will be surprised.*

Participants expressed concern about the quality of the milk received from clinics when compared to those from shops. This resulted in them doubting whether the milk was of a good quality and healthy to their babies. Certain participants also mentioned that the baby lost weight easily compared to a baby on breast milk. The milk was seen to be full of fats which separates from the water after preparation. Their lack of trust in the milk was shown by the above quotes. It is surprising that in the literature review no studies were found that mentioned the mothers' concerns about the quality of the milk received from clinics, since it was a recurring theme in this study. The counsellor/health worker is expected to reassure the mother during infant feeding counselling that it is a best quality and nutritious milk.

4.3.4 Stigmatisation associated with free formula milk tins

The free formula milk was associated with stigmatisation by family members and community members. If you give your baby that "particular milk", it was automatically known that you were "HIV-positive".

Tsakane: *If you give your baby a bottle in front of people, you will be asked what type of milk you are giving your baby. You are always identifiable when you prepare in front of people; even if there is a visitor at home you are afraid to take out that tin of milk because it has a government stamp on it. We hide it, unlike Nan from the shop which you can take out freely. You cannot even visit places unless there will be someone who will look after your baby for you while you are away.*

Nkhensani: *At the clinic, you do not want to meet people that you know seeing you taking formula milk. Even at home, you do not want people to know that you are receiving milk for what reasons. People are pointing fingers at you when walking on the street and say, you are sick, you are even HIV-positive. You do not feel good. We take milk but it is emotionally painful. You do not live nice, when you are at home, you want people to know that you bought the milk. This milk is having a stamp, which*

people identify you easily with and knows that is from government and not like the one in the shops.

Grama: *“Low voice” At home there is no problem, I have not yet received other milk since I gave birth. I will come and fetch it next time but I have a problem, when I will be going to collect the milk I will be accompanied by other ladies from my village as we usually do so, and I do not know what would I tell them.*

Vutshilo: *I have no problem except the people are talking a lot and pressurising us, they really hurt us. When you come out from a clinic with a big bag of milk people are looking at you and tomorrow will be telling other people about you. People talk a lot. You even want to give a bottle to your baby when people are not seeing you because it is problematic. People are looking at you if you are not breastfeeding your baby. If you give formula milk they say you are sick. Even the milk... many people know it. You do not even know where to throw an empty tin because people will see it in the dustbin and they know that tin and conclude that you are sick, but if you use any other milk it is better because they know this clinic milk. The problem now is that my mother-in-law knows the clinic milk.*

Tshina: *My partner is not working. We are only depending on a grant. I have a problem when I come to collect milk at the clinic with friends seeing me with that milk. They gossip about me, saying we saw her with that clinic milk, which means her status is HIV-positive, and I usually tell them that I bought milk for my baby. I always make sure that I have that big black plastic bag “for refuse” to hide this milk in my big bag when I collect it at the clinic.*

Participants explained that the milk tin was not the same as the one from the shops, which makes those mothers who are not breastfeeding and reliant on milk from the clinic, easily identifiable. The tin also has a government stamp on it, which indicates the free milk from the clinic. They were even hiding the milk when receiving relatives, neighbours and community members because they were aware of the free milk for HIV-positive mothers. The milk and the containers were thus clearly associated with an HIV-positive status.

Similarly, other studies also indicated the stigma associated with this free milk. The climate of HIV stigma and discrimination at times contributed to some mothers being fearful of exposure when they picked up their supply of formula from public spaces such as a clinic. In the same manner within the home, a mother feeding formula might hide the infant feeding bottle from specific individuals, giving instead the impression that she was breast-feeding (Sibeko *et al.* 2009:1986).

Matji *et al.* (2009:21-22) also witnessed that there was a stigma related to formula feeding, which was shown by the high proportion of women (61 of 69) stating that they made up “excuses” to explain why they were not breastfeeding. The formula feeding was related to the stigma persisting in this community and has been documented in other PMTCT sites in South Africa, where women have reported feeling the discrimination.

4.3.5 Meeting AFASS criteria and availability of milk

Some participants indicated the problems of utensils needed for replacement infant feeding e.g. bottles and sterilising equipment, because they have to buy these as they do not receive it at the clinic like formula milk. In addition, the occasional shortages of milk supplies at the clinics leave them worried and insecure. This is how certain participants expressed their frustrations:

Thanyi: *When I boil these bottles, the teats are not strong and I have no money to replace them.*

Thembi: *Sometimes there was no milk at the clinic and I was scared that milk from the supermarkets would be different from the ones we receive from the clinics. I usually give my baby solid food for him not to lose weight...*

Bonie: *I have a problem because of my situation – I cannot afford to buy a flask to keep water for milk when the baby wakes up at night. I have to wake up and prepare milk, during the middle of the night using firewood outside, because the situation does not allow me to have a flask and electric kettle. There is electricity in the household but if you did not buy an electricity card you are not allowed to use the kettle. My partner is working but is not prepared to buy electricity for me.*

Hlamalani: *Nothing, I have no problem. Only the milk gets finished at the clinic.*

Tshina: *I used to come to the clinic and then found that there is no milk. I was forced to borrow money from people to buy milk. I also use the grant of my other child to buy milk.*

The milk is not always available to the participants, which leaves them frustrated and forced to look for alternatives which may even include a premature introduction of solids into the diet. Participants voiced their concern about the lack of resources to prepare the milk, for instance electricity, flask and electric kettle. Others mentioned the irregular supply of milk at the clinic, which forces them to buy milk. In addition, different milk formulas make certain participants uneasy. The situation of Bonie

whereby she could not afford to buy an electric kettle and flask to keep warm water is pitiful and frustrating. She has to wake up in the middle of the night and boil water using firewood outside the house, because she does not have any alternative. This situation further puts her at risk, as her health could deteriorate by this lack of rest.

Although infant formula is the recommended feeding option for mothers living with HIV in developed countries, this is rarely a feasible or a preferred choice for women living in resource-poor communities due to the prohibitive cost of utensils to prepare the formula, the lack of safe water, the lack of infrastructure to ensure a consistent supply of formula, and the socio-cultural values and stigma associated with formula feeding (Sibeko *et al.* 2009:1983-1984). Another study also documented that most women in the largely rural population do not have the resources to prepare replacement feeds in an acceptable, feasible, affordable, sustainable and safe manner (Bland *et al.* 2007:292).

Alternatives for many HIV-infected mothers remain limited. Formula feed may not be available, or clean water and the appropriate skills to reconstitute them may be lacking, or formula feeding may be associated with the stigma of HIV, causing many mothers to reject this option (Reproductive Health Matters 2006:197). Mothers faced the problems of shortage of supply and needed to borrow money to buy milk for the baby, which is a frustrating situation to be in. This situation also puts the baby's health at risk because if the mother does not have money she can end up with mixed feeding practices or too early introduction of solid foods.

4.3.6 Protecting HIV-positive status

Some participants started by breastfeeding their babies at birth and then moved on to replacement infant feeding. Thanyi, for example, was protecting her status since she knew that, when giving formula milk it will be obvious to her partner's relatives that she is HIV-positive, but later she thought of protecting the baby against the virus:

Thanyi: *I gave my baby breast milk at birth for a period of one week, because I was afraid of what my relatives and my partner's relatives would say when seeing me not breastfeeding immediately after delivery. I thought of my baby's health and then changed to replacement infant feeding.*

Kharikani: *He first sucked my breast for one week and I have changed to bottle-feeding, but now I am mixing both breastfeeding and bottle-feeding to protect my status.*

Vutshilo: *I wanted to protect my baby. When I breastfed him, I was afraid what will people say when I'm not breastfeeding. I breastfed my baby for a week but I was not free, my heart was always painful when I give him my breast thinking of infecting him. I then changed to replacement infant feeding.*

Kharikani was using both methods of infant feeding i.e. formula milk and breast-feeding (mixed feeding), which was not recommended to mothers living with HIV due to the high risk of infection. She risked her baby's health because if she gave formula alone, it would be obvious to her family and community members that she was HIV-positive; she could not give breastfeeding alone since she was still a pupil. She even avoided receiving milk from the clinic to avoid the stigma, and relied on her partner's mother, a retired teacher, to buy formula milk at the shops – an act that could also be regarded as suspicious.

Sometimes when a mother living with HIV wishes to give her baby breast milk, but fears to transmit the HIV virus to her baby, she gives formula milk, which introduces the fear of being suspected by community members as being HIV-positive (Sibeko *et al.* 2009:1886). For women using formula milk, the fear of stigmatisation can lead to the continued offering of breast milk, and erratic clinic supplies can lead to the early introduction of weaning food (Doherty *et al.* 2006b:2424).

4.4 The role players in choosing of infant feeding

There were socio-cultural factors that played a role in mothers' choosing of infant feeding and added to the negative experiences of participants. The health care sector and the family in particular emerged as important.

4.4.1 Health care sector

The health care sector e.g. hospitals and clinics provide information on infant feeding through counselling and education sessions. Participants indicated that there were health care workers who played a vital role in their opting for replacement infant feeding. It emerged that in certain cases participants were advised or recommended by

a health care worker to choose replacement infant feeding, but others stated that they felt forced by the health care workers.

Hlamalani: *The sister at the clinic sat down with me and talked about the danger of breastfeeding and the importance of replacement infant feeding to protect my baby. The way the clinic sister advised me I could not give breast milk anymore, even if I had enough milk. I then decided to change to replacement infant feeding.*

Muvhaleni: *I chose replacement infant feeding because I talked with my cousin and my health care worker. The nurse said if you are breastfeeding, you could transmit a virus to the baby, and it is as if you do not value your baby.*

Ngeli: *I was at the clinic when a nurse saw me breastfeeding and asked me why you are breastfeeding while you really know about your status. I was in a long queue of many people and I felt embarrassed. I answered her, "I thought they said if you can breastfeed your baby for six months it is still fine and safe."*

Nurse "You are gambling and risking your baby's health dear, do you know that!" I then decided to start using Replacement Infant Feeding from that day.

Bonie: *I told the hospital sister that my status is like this, can I give my baby breastfeeding. They did not give me a clear answer but they just said, "Milk is available at the clinic, especially for HIV-positive women like you." They did not even mention anything about possibilities of breastfeeding. When someone starts talking, I always sit alone and start to ask myself many questions.*

The wording in the above quotes suggests that replacement infant feeding was not a first choice for these mothers, but health care workers' advice and recommendations made them opt for replacement infant feeding. The participants indicated that health care workers preferred the replacement infant feeding and did not encourage them to breastfeed their babies. Participants understood, trusted and believed that replacement infant feeding is the safest infant feeding method, regardless of whether it met AFASS criteria i.e. being accessible and feasible. Besides advice and recommendations, certain participants stated that they were almost forced to use replacement infant feeding since it was not their choice to use the method. This confirmed the power hierarchy that exists between the participants and the health care workers.

Doherty *et al.* (2006b:2425) also found that health workers seemed to have the greatest influence on the mother's initial infant feeding choices, and that the relationship between health workers and clients is often based on a power hierarchy. Due to health workers' lack of knowledge of infant feeding practices, different messages were given to mothers, which led to an increase in health workers' authority over the infant feeding choice. Participants even reported being forced to use formula

milk because of their HIV-positive status. Nurses often present HIV transmission through breast milk as a certainty instead of as a probability (Buskens *et al.* 2007:1103).

Most counsellors tried to persuade mothers towards the PMTCT outcome to “save the baby” by promoting the feeding choice most preferred by their unit or clinic (Buskens & Jaffe 2008:342). This could be due to lack of appropriate information concerning counselling on infant feeding and the attitude of health care workers towards people living with HIV/AIDS. The stigma associated with the HIV diagnosis and the disease itself encourage the health care workers to associate it with replacement infant feeding. Some mothers even had a constant struggle to access formula supplies because of their dependency on health care workers to obtain milk for their infants. This relationship between health care workers and clients suggest power dynamics and was identified as a challenge by HIV-positive mothers in this study. Instead of having their feeding choice recorded and respected, mothers are persuaded to opt for replacement infant feeding. Buskens & Jaffe (2008:342-343) also found that mothers complained about receiving confusing information and mixed messages from different clinics and even different subsections of the same facility. There appears to be a mismatch between what is needed in terms of counselling behaviour and what counsellors are currently equipped to provide.

During the initial post-partum period, inadequate support from health workers can lead women to change from their intended feeding option. For women using formula milk, the fear of stigmatisation can lead to irregular introduction of breast milk, and erratic clinic supplies can lead to the early introduction of weaning foods (Doherty *et al.* 2006b:2424).

The WHO recommended that the counselling on infant feeding should involve all the information concerning feeding methods. In this study, only Tshina reported that she was given enough information for her to opt for an appropriate method:

Tshina: *I was checked at the clinic and found that I am HIV-positive, and they explained to me the different infant feeding methods. Then I opted for replacement infant feeding.*

Tshina clearly indicated that the proper information was given to her through infant feeding counselling and she assessed all possible methods and concluded by opting for replacement infant feeding. In contrast to the above cases, she opted for this method after sufficient information was given to her. She was one of the fortunate clients who happened to have appropriate counselling by a skilled and knowledgeable health care worker.

According to the Population Report (2008:19), every HIV-positive mother's decision whether to breastfeed or use replacement infant feeding is her own individual decision, but health care providers should take responsibility for making sure that the mother has adequate, accurate information to make that decision and they should provide support for the decision that she makes. In particular, they can help women weigh the risks of breastfeeding and replacement infant feeding. Bland *et al.* (2007:294) found that infant feeding counselling is often of poor quality or unavailable for many women – as certain responses in this study also suggest.

4.4.2 The family and community members

Family relations and interaction with community members played a role in the mother's deciding on the infant feeding options and in the challenges faced by participants. In this regard, stigmatisation and discrimination, pressure from family members, gender-based violence and the complexities embedded in the disclosure of a positive HIV diagnosis emerged as key aspects.

4.4.2.1 Stigmatisation and discrimination

Most participants highlighted to experience stigmatisation and discrimination because of not breastfeeding their babies. A common belief amongst community and family members is that anyone who is not giving her baby breast milk is HIV-positive. Here are the voices of mothers who were experiencing stigmatisation and were being discriminated against for being non-breastfeeders:

Beauty: *Community members are gossiping about me because I am not breastfeeding my baby. They are asking why am I giving replacement infant feeding? It means I have a disease.*

Leloko: *People asked why I'm not breastfeeding and mentioned that these days if you are not breastfeeding it means you are HIV-positive.*

Khasa: *When the baby was crying people were expecting me to give breastfeeding, but seeing me taking out the bottle they were asking why. Even at home they were asking many questions about why I am not breastfeeding. I had problems about people's questions of why I am giving replacement infant feeding. I am also having a problem about this virus I have. I always ask myself that why me, how and where did I get this deadly virus. I am really worried about these people's questions. You're always being asked many questions, especially in gatherings like church etc. and people are talking bad about HIV-positive people. Community members are making this issue worse because they always gossip badly about HIV-positive people.*

Bonie: *People talk a lot, saying these days when you give formula milk we know that you are HIV-positive. It looks like you are also falling under such people because you are also giving your baby a bottle. Why was your first baby breastfed and this one gets formula milk?*

Marusa: *People talk a lot – why give formula milk while even not working.*

Rubani: *People talk a lot about me not breastfeeding. I do not care what they say about me because I am prepared to give my baby formula milk and they will just guess why I am not breastfeeding.*

Gramma: *Another girl from next-door one day asked me why a young baby like this is sucking a bottle and not my breast. I explained that all my children were sucking only one breast so at the hospital they decided that I must stop giving breast because my breasts are having a problem, that is why you see this baby sucking a bottle. When the people who are asking left my home my heart become painful and I asked myself why these people are asking me so many questions. It means they will think that I am sick. Nobody knows about my status except my husband.*

Masindi: *People at home and community members ask me why am I not breastfeeding my baby but at the hospital, no one asked me. Another woman came to my home and asked me that she heard from other people that I was not breastfeeding and why was I giving my baby a bottle. I lied to her that my breasts are having a disease and therefore the milk is dirty. She was not convinced by my explanation; she just said we do not know, only God knows the truth, and she left. I was afraid that she would gossip about me if she could know about my status but she was suspicious since my elder child was given breast milk.*

The participants experienced the stigmatisation associated with not breastfeeding from family and community members. They mentioned that they were asked questions about why they were not breastfeeding, because breastfeeding is expected

from every new mother and is a norm in African culture. Community members were suspicious of a mother who was not giving breast milk, and mothers had to lie about the condition of their breasts, because they did not want to disclose their HIV-positive status for fear of gossip, which is a form of stigmatisation that can easily lead to discrimination.

Muko *et al.* (2004:136-137) highlighted the connection between artificial feeding and stigmatisation since many people are now aware that breastfeeding is not recommended for HIV-positive mothers. Similar to this study, they also found that if a mother was using artificial feeding, relatives and neighbours suspect the reason is HIV-related. Furthermore, breastfeeding mothers enjoyed a prominent status in the society, so that they were given special food “sweet palm wine, which is erroneously thought to replace artificial milk” and a special diet that included eggs. Mothers giving their children artificial milk automatically lost this status.

Buskens *et al.* (2007:1106) also documented that exclusive breastfeeding or formula feeding where mixed breastfeeding is the norm, makes relatives and neighbours suspicious. In the face of non-disclosure or limited, gradual disclosure, HIV-positive mothers are also confronted and questioned both by relatives and neighbours who wonder why water, solids or breast milk are strictly prohibited (Buskens *et al.* 2007:1106). The history of replacement infant feeding also highlighted the discrimination in this method of feeding in Chapter 2.

The cost of not breastfeeding includes shame and rejection by close kin and neighbours, which seems an even greater burden to carry. The study suggests that HIV-related stigmatisation and fear of rejection are major factors when HIV-positive mothers decide how to feed their infants. Ntabaye and Lusiola (2004) found that community members perceived HIV as a serious disease affecting young people. In their study women reported that any mother who did not breastfeed her child was discriminated against by the community members and faced the threat of domestic violence. The findings of another study also indicated that one of the major challenges faced by non-breastfeeding mothers was stigmatization (Oladokun *et al.* 2010:6).

4.4.2.2 Pressure from family members

Participants reported experiencing pressure from family members who interfered with the choice of replacement infant feeding, concern about the HIV status of both the mother and the baby, and questions about their not breastfeeding. This is how participants verbalised the pressure they experienced from their relatives, and in particular their mothers-in-law:

Thanyi: *But myself I am currently not feeling well. I had a problem, with family members, I told my husband's aunt and she was so interested to know about my baby's HIV status, but I lied to her that my baby tested HIV-negative, while she had actually tested HIV-positive. What will my partner's family say when I give my baby replacement infant feeding? I do not care about community members because I do not even visit them.*

Leloko: *My partner's mother said I do not give breastfeeding because I wanted to run after my partner and I feel very bad about it "tearful and looked depressed". I feel sad and keep quiet because I cannot tell her about my status.*

Thuli: *I have a problem with my partner's mother. She wants to know why I am giving the baby a bottle. She even took my partner and went to the clinic behind my back to ask the health care workers why I am not breastfeeding. She even mentioned that there are some nurses who are my friends who gave me ill advice not to breastfeed my baby. The supervisors at the clinic told them that infant feeding is the choice done by the mother of the baby, and the work of the health care worker is just to give information. My partner's mother came back home and accused me of dying of HIV and AIDS, and said I mentioned that I wanted to kill her son. They "my partner and his mother" even hid the milk, kettle and the flask that I am usually using for milk preparations, and they forced me to give my baby breast milk.*

Gramma: *My elder sister's daughter visited me one day and saw me giving my baby bottle milk and she told her mother "my sister". She quickly called me and asked why am I giving such a new baby formula milk and she is not happy that I am not breastfeeding. I explained to her that my breasts are having a problem. She replied, "You are lying" and I just could not hold myself and dropped the phone in her ear, but my heart was so full of pain to lie to my relatives about my breasts. My mother-in-law was also concerned, asking my husband and me why it is that I am not breastfeeding.*

Tsakane: *Even my mother-in-law does not know my status, she came and influenced my husband that I must breastfeed because she also breastfed my husband, but my husband told her that we decided that the baby should get formula milk. She was not happy and she even stopped visiting me.*

Kharikani: *My partner's mother suggested that we should give the baby a bottle because he is not getting full and I was supposed to go back to school. He first sucked*

my breast for one week and I have changed to bottle-feeding, but now I am mixing both breastfeeding and bottle-feeding to protect my status.

The participants indicated that relatives, especially mothers-in-laws, were placing pressure on them by asking questions about why they were not breastfeeding and even forcing them to give breast milk. Grama was very upset when her sister was quite rightly accusing her of lying about her reasons for not breastfeeding. As an elder sister, she felt that she had to guide her younger sister about infant feeding. The power differential contributes to the relative or provider's influence over all matters in their homestead, including infant feeding. Relatives feel they have authority over infant feeding or the right to interfere with infant feeding or the introduction of solids or other foods (Buskens *et al.* 2007:1107). It was explained in Chapter 2 (Sida Studies 2008:24) that the oppressive exercise of authority by a mother-in-law over her daughter-in-law was found in the South Asian culture as a result of internalising of their own lower status in the society, and thus resulted in discrimination.

Tshina: *Firstly at the clinic they told me that I must give my baby a bottle because of my HIV-positive status, and I will collect milk at the clinic, and when I was discharged from the hospital I was given 6 tins of milk, and when I arrived at home the father of this baby did not accept his baby to drink formula milk. My partner was not accepting formula milk; he was very difficult and not understanding, mentioning that he was also breastfed for him to be a strong man. He then took that milk and threw it in a toilet pit outside the house saying his child should be given breasts, not a bottle. I was forced to give my baby breast milk because there was nothing I could do then. I came to the clinic to explain my problem to the nurses, because I had a problem with giving my baby breast milk. At the clinic, they advised me to go and see the social worker. I went to the social worker. They wrote a letter to my partner asking to see him. They explained everything to him, and then he accepted the formula milk.*

The study documented results similar to Buskens *et al.* (2007:1105). The grandmothers very often feel that they have the right to have a say in what their grandchildren are fed and how they should be cared for. In all the cases, only the paternal grandmothers (mothers-in-law of the participants) were mentioned.

Grama and Tsakane has had different experiences where their mothers-in-law tried to influence their husbands to coerce the participants to switch to breastfeeding. Their husbands responded to their mothers by indicating that they had taken decisions with their wives to give formula. According to Buskens *et al.* (2007:1107), such cases are

exceptional, but constituted significant instances (positive deviance) where the mother and the father of the infant felt they could make infant feeding decisions independently of broader social networks.

In many instances the use of formula, particularly in early infancy, is in disagreement with a partner or family member's feeding expectations (Sibeko *et al.* 2009:1986). Muko *et al.* (2004:138) suggested that the focus of interventions should not only be on saving the child and providing for the long-term medical and psychological needs of the mother, but also on the father and if possible even on the entire family. The socio-cultural factors play a vital role in the choice of and adherence to infant feeding (Leshabari 2004). A South African study on the effect of the HIV epidemic on infant feeding by Doherty *et al.* (2006a:93) found that most mothers were only able to maintain feeding practices for a short period because of various community and health system constraints.

4.4.2.3 Gender-based violence

There were also participants who experienced violence from their husbands/partners because of making use of replacement infant feeding. There are those who disclosed their HIV-positive status and then experienced different forms of violence. There are also those who did not disclose their status but still experienced violence from their partners/husbands.

Bonie: *I left this place back home at Tzaneen because I had issues with my partner, he was saying he cannot give me money because the baby I was carrying was not his, suspecting that it was my first-born's father's baby too. My first-born was not his baby, I came with her so it is difficult for him to buy or give me money. He will always mention that he is paying some instalments. I have tried to take him to Magistrate's court for maintenance, with no help. I also explained to his mother but nothing is happening, and she insisted that we must settle this matter at home, not at the Magistrate's court, and she accused me of reporting her son to the Magistrate's offices. There is nothing he does for me financially. I am living with my first-born child grant money to buy food. He just buys food for himself alone. Everybody is buying food for themselves in that household. Since we were together until I got pregnant he never bought me a thing; it really hurt me. I finally moved back home to Tzaneen until they sent people to apologise for him.*

Muvhaleni: *"Angry" The problem is my partner, he really knows that we are all HIV-positive but he keeps on doing bad things like extra-marital affairs. If I try to explain how he should behave, he does not understand me. We are currently not on good terms and he now told me to pack my things and go back to my own home with*

the kids. What am I going to eat? Because I am not working, only depending on grants for children. He even beat me if I do not do what he wants. Even now, when I arrived at home from the clinic I will pack everything that belongs to me and go to my own home because he will beat me if I do not leave. How will I support these kids with grants only? I usually tell my partner to also buy other nutritious food for this baby and he does not understand and keeps on saying he has many debts. My partner's mother is not even supporting me.

Thuli: *My partner was not talking to me due to his mother's influence and reported me to the police station that I am a mad person and dangerous to the baby. He is not always sleeping at home and has many girlfriends. He is receiving calls from his girlfriends and voices how he loves them and talks other naughty and romantic language to them in front of me. When I confront him about that, he just beats me and tells me to keep quiet as a woman and respect him as a man.*

In the above quotes instances of physical, emotional and financial abuse are reported, which resulted in an attempted suicide in one case. The three participants' quotes indicated that they were having abusive partners and the situation was further complicated if partners had extra-marital affairs. One participant disclosed her status to her partner, while the other two have not yet disclosed their HIV-positive status out of fear of abuse. Buskens *et al.* (2007:1105-1107) also documented that mothers who participated in the PMTCT programme often hide their status from partners and relatives, stating their fear of rejection, physical abuse and losing financial support. Women living in sexist, patriarchal communities are regarded as adult minors, as being dependent on men, and therefore it is difficult for women to demand rights in such environments. In this study as the quote above clearly indicated, Muvhulane disclosed her status to her husband but experienced marital problems infused with gender discrimination. At the same time Bonie and Thuli also experienced serious relationship problems – even though they had not yet disclosed their status to their partners.

Other studies also found that culturally sanctioned gender roles are intimately connected with both gender-based violence (GBV) and HIV risk. Traditional gender roles of male domination over women lead men to feel that they are entitled to beat their women, and this is sometimes tolerated in the African culture (signified in the above examples by the support for unfaithful partners by their mothers). Significant shifts in power between men and women do not appear to be represented at the level of sexual negotiation in any consistent way. The theory on gender and power and women abuse explained in Chapter 2 is significant here. Women were still afraid to

report such violence or to leave an abusive partner, but in other situations more women are now fighting back and obtaining interdicts against perpetrators (Strebel, Crawford, Shefer, Cloete, Henda, Kaufman *et al.* 2006:517-526). Within an environment where double standards exist for men and women regarding aspects such as acceptable sexual behaviour, HIV-positive women with infants are in a particularly vulnerable position, as was shown in the three cases above.

4.4.2.4 Disclosure of HIV status

The study also established whether participants share their HIV-positive status with their husbands/partners and other members of the family as a coping mechanisms and for support. Disclosure to husband/partner and other family members as well as non-disclosure are pertinent issues here. Participants indicated the people whom they shared their status with and the way they did it.

a. Disclosure to husband/partner

The majority of participants who shared their status, shared it with their husbands/partners. Some of them verbalised it as follows in response to a question, to whom they had disclosed their status:

Beauty: *Husband, I sat down with him and explained clearly.*

Thanyi: *Husband and my sister, we were talking about problems of men and I eventually introduced the subject.*

Tsakane: *Husband. I told him the very same day I got the results. He immediately went to sleep after I told him.*

Nkhensani: *I told only my husband*

Ngeli: *My boyfriend. The baby was drinking bottle milk; he asked me why, because they said I'm HIV-positive. You might be lying, he answered, we need time to go and test together. I have never seen him since then. We are no longer together since that day that I told him about my status.*

Gramma: *My husband. It was difficult for me to tell him on the day I had been to the clinic for an HIV test. The following day when the children left for school I told him about the results. He then said, if it is like that then we must take precautions and follow rules "he did not act/react somehow". He is not working but we are living on money he gets from chopping wood and selling it to people.*

Rubani: *I told the father of my baby “partner”. As you know people who are pregnant are being checked. I was also checked and discovered that I am HIV-positive.*

Masindi: *I told my partner but we are not staying together, he is just visiting sometimes. I just told him that at the hospital they checked me and found that I’m HIV-positive. He did not accept it, he felt anxious and stood up from sitting down and looked so shocked and afraid. He was even sweating and looking so scared. I told him there is nothing we could do. Now he has accepted it and seems to have no problem.*

Muvhaleni: *I told my partner that I am now going to have an HIV test because I did not understand his behaviour. He said go and we will hear the results when you are back. I went to test at the clinic. The results were positive. I did not believe it. Then I went to test again at Brits. The results were negative. I came back home and re-tested, and the results were positive again. They called him at the clinic and he tested HIV-positive. At the clinic, they told him we must look after each other but now he is behaving like this and not even taking good care of me as he promised the nurses.*

The participants who were married, i.e. Beauty, Tsakane, Nkhensani, Grama and Vutshilo, disclosed their status to their husbands, and all of them experienced a positive outcome in that their partners/husbands supported them after overcoming their initial shock. Despite the fear of discrimination associated with disclosure, mothers living with HIV who disclose their status often experience a positive outcome (Sibeko *et al.* 2009:1984). Vutshilo is having discordant results with her husband but he is still supportive in general.

Yet negative experiences after disclosing a positive HIV status to a partner were also found. Some participants experienced problems after disclosure such as an ending of the relationship and abuse. In the case of Ngeli, who was not married, the partner ran away after being informed of their status. Thembi tested HIV-negative when she was still pregnant and she only discovered her HIV-positive status post-partum, meaning she tested again three months post-delivery and the results were positive. She did not hesitate to tell her partner. Muvhaleni, who was cohabiting with her partner, experienced a lack of support and abuse after she had disclosed her status to her partner. Women who had experienced two or more types of violence in the past were significantly less likely to disclose to their partners. This study found that women who were married, were far more likely to receive support from the father of the baby than those who were single or cohabiting. Makin *et al.* (2008:990) found similar results, namely that women’s decision to disclose their HIV status to a partner early after

being told their diagnosis, were primarily influenced by the nature of the couple's relationship.

Participants' disclosure of their HIV-positive status to their partners or husbands decreases the risk of HIV transmission to both the partner and the baby. Furthermore, such disclosure encourages their partners/husbands to find out what their own HIV status is, which in turn encourages the men's involvement in PMTCT programmes. The low rate of men's involvement, for example giving support, encouragement and living protective lives, leads to the women suffering a lack of support, and affects their adherence to the chosen infant feeding practice. It also leads to women being more vulnerable to violence and abuse by their male partners. Involving men in reproductive health also helps their reproductive health needs. Furthermore, women's health cannot be improved without men's involvement, particularly in the areas of HIV/AIDS, contraception and gender equality (Cooper *et al.* 2004:79).

b. Disclosure to family members

There were participants who opted to disclose their HIV status to a member of the family other than a husband or partner, mostly those who were single, although there were a few who were cohabiting and one who was married.

Thanyi: *I told my sister. We were talking about problems of men and I eventually introduced the subject.*

Khasa: *I told my mother. I just said, there is a problem I need to tell you. When I was pregnant I took a blood test and I'm HIV-positive, I am living with the virus. I did not tell my partner but I just advised him to take an HIV test, and he refused.*

Ravu: *I told my mother, I was checked at the clinic and found that I am HIV-positive.*

Marusa: *I first told my parents and I called them, informing them I have tested HIV-positive. My mother did not have any problem because she had knowledge about HIV/AIDS. The person who was always crying was my father and I was always phoning and telling him that I will be dying soon.*

Tshina: *I told my sister, I am comfortable with her. I'm not staying with her but when I am with her I feel so free. We sat down and had jokes, then I said to her, sister I have a problem; when I checked at the clinic I found that I'm HIV-positive. She first said I am joking, she did not believe it. Then she believed me and asked if she could tell my mother, and I agreed.*

Tinyiko: *I first told my brother's wife, then my mother and lastly my siblings. When I arrived home I felt scared to stay with this thing, it is a thing that I am going to live with for my whole life. It will not work to hide from people that I am living with, it is better to tell my brothers' wife, but to tell an older person bad news before you can think about... She could faint. The day I was tested in June 2005 when I was seven months pregnant with another baby, not this young one, when I arrived at home I felt that I explained to her that do you know, these days when you are pregnant they do VCT. When they did VCT on me the results came out being positive. I am HIV-positive, for me being positive does not mean I am going to die but I just have the HIV virus. The way I told her she was not even feeling bad or even sympathetic, because I did not even look like a stressed person. She even encouraged me because I did not show any problem after I told her, the way I am, she was okay and did not even change her face. Because it was for the very first time, for my mother I was still thinking how I am going to tell her because she is an older person. In 2005, it was not yet common for a person to be HIV-positive, especially in our villages.*

She reported telling her mother in the following way:

Mother, I was checked when I was pregnant and they found that I am HIV-positive. I am even now taking treatment that will protect myself and my baby.

Bonie: *Yes, I told my mother. After I was tested at the clinic and I was told that I am HIV-positive, they tried to explain to me that to be HIV-positive does not mean the end of the world. I arrived home and took so many tablets to kill myself and the baby inside me. I woke up in the hospital, my mother was at my bedside in her wheelchair as she is disabled, and asked me why did I try to kill myself and if it is the fact that I'm pregnant for a second time young, not being married, and with the different partner. She accepted that, and she will take care of me. I then replied it is not those reasons mother, I was tested HIV-positive. What surprised me more is that I was HIV-negative when pregnant with my first child. This is my second child with my second sexual partner and I am HIV-positive, and he is even denying this pregnancy and chased me from his home. It means he knew about his status and intentionally infected me. My mother tried to counsel me and promised to accept me as I was ... What makes me to suspect him is that, one day I advised my partner to go and have an HIV test because it is important, he said it is all the same, you will die even if you are HIV-negative. However, I suspect that he knows about his status because he is having so many girlfriends, it is as if he told himself that he does not want to die alone. He can even spend seven days not sleeping at home. When I ask him, he says what I want from him, because the baby is still young. Indeed, he told himself that he want to die with many people. If he could leave his cell phone on top of the bed, many girls will be calling looking for him. I did not even tell him about my status because if I did he was going to say, since you know your status it means you came here knowing that you are HIV-positive. Therefore, I did not want to be disappointed by telling him. I avoid talking and hurting myself by telling him.*

The majority of the participants, especially those who were single or cohabiting, felt comfortable with sharing the status with their relatives i.e. mothers, sisters etc. In contrast to this study, Doherty *et al.* (2006a:93) found that being HIV-positive greatly affected participants' communication with their families and friends about infant

feeding, largely because of the need to hide their status. There were few participants in the current study who stated that their partners/husbands and other family members were not accepting their status and were unsupportive towards them using formula feeding. This could be reinforced by the fact that they disclosed their HIV status to those family members with whom they feel close. Participants who were married mostly disclosed their status to their husbands only and not to other family members, like a mother-in-law, for fear of hatred, stigmatisation and discrimination. The majority of the participants who were single or cohabiting did not disclose their status, for example Maliphu, who did not disclose her HIV-positive status to anyone at home but was being supported, and her partner's relatives i.e. sister and mother accepted the infant feeding method.

Two participants had problems with their choice of infant feeding not being accepted and supported by their family members:

Thuli: *My partner and his mother do not want to hear anything to do with formula milk.*

Kharikani: *My partner did not believe me. He acted in a strange way and insulted me, saying I am the one who came with this dreadful virus. He is not accepting and gives no support.*

Thuli has not yet disclosed her status to either her partner or another family member. The fear of disclosure may in fact be an impediment to choosing the option of replacement infant feeding since the support of the partner has been identified as being important for successful replacement infant feeding (Sadoh & Sador 2009:32). Although Kharikani disclosed to her partner, she was not supported and was being blamed for the disease. Other findings also showed that women indicated that their partners and other family members did not support them emotionally (Peltzer *et al.* 2007:65).

4.3 Emotions

The participants were asked about their emotions and how they felt about choosing replacement infant feeding and disclosing their HIV-positive status. Their responses

included various emotions including feeling good, better and relieved as opposed to regret and depression.

4.3.1 Feelings related to not breastfeeding

There were seven participants that expressed positive emotions:

Ngeli: *I feel much better and really appreciate giving my baby formula milk, although people talk a lot about me while I'm not breastfeeding, but I value my baby's life.*

Rubani: *I feel better, even when the baby sucks a bottle I feel better, because there is no problem. I must just follow what they told me to do to have a better life. I am okay because formula feeding makes my baby happy, and even myself, I am happy.*

Thembi: *I accepted bottle-feeding and deeply believe in it and I could not force my baby to breastfeed.*

Vutshilo: *I feel fine, because I am protecting my baby although people judge you somehow by concluding that you are HIV-positive when not breastfeeding. I want my baby to live.*

The participants showed that they accepted and appreciated this feeding method and were even feeling better by choosing for their babies, because this way, their babies were free from the risk of HIV transmission. The participants focused on protecting their babies from HIV, looking forward to having healthy babies, even opting to ignore the stigma and shame of not breastfeeding. Oladokun et al. (2010:5) also found that the major factor influencing the choice of infant feeding was the desire to reduce the risk of transmission, and therefore mothers felt happy and relieved because they wanted to protect their babies from the risk of HIV transmission through breast milk. Another study indicated that most women with HIV infection clearly choose to protect their children from HIV, despite knowledge of the disadvantages of formula milk relative to breast milk and the potential for discrimination (Talawat, Dore, Le Coeur & Lallemand 2002:630).

Some participants stated that they regretted their choice of replacement infant feeding, as can be seen in the following quotes:

Maliphu: *It was very difficult because like other women I wanted to breastfeed my baby, as I would have if I had not been HIV-positive.*

Thuli: *As a woman, I wished to breastfeed my baby as it was a first-time experience to have a live baby, but I wanted to protect him from this virus although it was hard for me. Although I could say, I do not have any problem.*

Marusa: *In fact, I did not want to give my baby replacement infant feeding but I wanted to breastfeed my baby.*

These three participants opted for replacement infant feeding but wished they were breastfeeding their babies; as women they felt “insufficient” as mothers by not giving a breast to their babies, especially Thuli who was experiencing motherhood for the very first time. Another study also confirmed that most women who chose formula feeding for their babies regretted not being able to breastfeed them. The findings provide pointers to shortcomings in health workers’ communication and suggest that more effective communication should take normative communication views into account and be more closely attuned to the changing needs and experiences of HIV-positive mothers (Lazarus, Struthers and Violari 2009:322).

Certain participants indicated that they were feeling pain and hurt about the fact that they were not giving their babies breast milk but formula milk.

Thanyi: *I was depressed and stressed because I wanted to breastfeed him until six months. I was so concerned about what my family and partners would say seeing me not breastfeeding.*

Khasa: *It was a problem for me because when the baby was crying people would say breastfeed your baby, and I would take out a bottle. They would ask, why are you giving your baby a bottle and not breast milk? That was very painful for me and I was hurt.*

Tsakane: *At first, I had a problem because all my kids had breast milk. This is the first baby I am giving formula milk...*

Nkhensani: *When he was crying, I used to doubt if I could continue to give my baby a bottle or just give my breast once, but my heart did not agree for me to give my baby breast milk and I ended up giving formula milk. After three months, I finally accepted that my baby was drinking formula milk and not breast milk. It was not nice because it was not something I wanted to use, because they said I should not breastfeed my baby at all.*

Grama: *I had a problem because my mother-in-law came to the post-delivery room and found me giving the baby a bottle-feed, and asked why, and my heart was very painful. I did not feel nice.*

Masindi: *I have accepted it, but when I was in the hospital, it was difficult for me to accept because I did not know what to say to people at home. It was very difficult for*

me and my heart was very painful but there is nothing I could do. If it were not for this HIV virus, I would have given my baby breast milk.

Bonie: *There is nothing I could do although it is painful but I've just accepted it. I have a problem because people talk right in my eyes that these days if you give your baby milk from the clinic, we are afraid of you, because you are also giving RIF, meaning you are one of them. It is hard for me although I am trying.*

Kharikani: *I did not feel nice and just do it, because I have no choice.*

Tshina: *It was very difficult for me and my heart was very painful but there is nothing I could do.*

Participants expressed pain and hurt because as they were unable to breastfeed their babies, they felt incomplete as mothers. It was a difficult situation that they believed they could not change. Nkhensani even mentioned that initially she had doubts whether to give a breast or a bottle. These kinds of negative feelings because of not breastfeeding were also found by Lazarus *et al.* (2009:33). The authors argue that the expression of such feelings indicates emotional and psychological strain in the choice of infant feeding, and suggest that there is a need for continued psychological and emotional support of women who opt not to breastfeed their infants.

4.3.2 Feelings after disclosure of HIV status

The participants were also asked about their feelings after sharing their HIV positive status with others. The following emotions were reported: feeling better, relief, regret and depression.

The majority of the participants in this study experienced the positive side of disclosure. They felt better and relieved after sharing their status because of a good social support system, as can be seen in the following quotes:

Thanyi: *I do not have a problem because I wanted them to be aware of my HIV status. I even intend to teach and make people aware of their status.*

Tsakane: *I felt no problem and I felt good. I am no longer anxious and afraid because I told my husband and he accepted it. It would have been bad if he had not accepted it.*

Tshina: *I was always having a problem, not accepting and always crying, but after I told my sister and then my mother, I felt free and even forgot about my problems. I have no problem. I tell my sister all my secrets and I am free when I am with her or telling her anything, she is treating me well.*

Muvhaleni: *My soul rested because I now know my status, unlike if I did not know my status. If I did not come to this clinic, I would not have known my status. In addition, I feel better now and I do not want someone who always talks about it. I think a lot I do not want to be tricked because I have a short heart “short-tempered”.*

Hlamalani: *... felt better because if you told someone you halved the load, and after all, it is not me alone. Do not stay with something that is painful in your heart.*

Masindi: *I thought after telling him he will never come near me. He stayed away for a while, but now he is coming, even at the hospital he was coming. He cannot blame me because he was a soldier, he had a two-year contract at Cape Town, and we never know if he came with it.*

Bonie: *I felt I had halved something, because if there is something I communicate with her openly, but if she did not know anything, I would always hide and not be free.*

Tinyiko: *I felt relieved indeed, because I had someone to talk to, unlike before where I kept it to myself, not telling anyone. My family members were going to have a problem if I showed them that this thing gives me a problem, from the start. They were always going to think that by the way this person is going to leave us soon, but they saw me being strong.*

Vutshilo: *I was very happy because I told my husband and even though he is not transmitted with the virus, but we are one person, he is really supporting me.*

As seen in the quotes above, 15 participants stated positive emotional responses after disclosing their HIV status to immediate family members including husbands/partners. Although all participants who disclosed felt relieved, it was found that married, cohabiting and single mothers felt relieved after telling their husbands/partners and other relatives within the family circle, but married and cohabiting participants were only disclosing to their husbands/partners for comfort and support and were not disclosing to other family members like mothers-in-law or the mothers of their partners, the sisters of their husbands/partners etc. They were afraid of being blamed, hatred, stigmatisation and discrimination. Those who were single were only disclosing to immediate family members like mothers, sisters and others but not outside the family. All the participants still experienced stigmatisation and discrimination by community members for not breastfeeding. Another seven participants did not feel ready to tell anyone, and they were still not getting support from the family or from outside the family.

Vutshilo's situation was different from others because she was the only person who had a husband who was HIV-negative, and she was HIV-positive; all the other husbands/partners are also HIV-positive or their status was unknown. There have been reports on HIV sero-discordant couples in which the male partner is negative. This situation provides a basis for the partner to press for separation or divorce, on the grounds of infidelity (Sadoh & Sador 2009:32). Vutshilo's situation was different from such findings because her husband, who tested HIV-negative at the clinic, was supportive and even collected milk for her if she was busy. It was a rare and exceptional case.

However, some participants experienced the negative consequences of disclosure and this is how they voiced their feelings:

Marusa: *The time I first heard, I told everybody and talking about it everywhere, but after some time I realised that people are talking and gossiping about me. I decided to keep quiet and that was depressing.*

Muvhaleni: *I felt as if I did not tell him to keep it to myself but I ask myself if I did not tell him, what was I going to say when I am supposed to collect treatment at the hospital. But I have regretted telling him and even wish I did not tell him.*

Certain participants indicated that they felt depressed and regretted the fact that they had told someone about their HIV-positive status. This could be the result of the negative responses the participants encountered after sharing their status. Sibeko *et al.* (2009:1987) argue that a lack of disclosure of an HIV status, because of the existing stigmatisation and discrimination associated with an HIV-positive status, emerged as a key factor in the infant feeding decision process. Lack of disclosure and the continuous lack of support may lead to some women following practices they do not necessarily agree with (Sibeko *et al.* 2009:1986). It was also found that lack of disclosure of HIV status can serve as a significant impediment to the implementation of optimal infant feeding guidelines. Despite the fear of discrimination associated with disclosure, mothers living with HIV who disclosed their status have often been found to experience positive outcomes.

4.4 Coping strategies

The participants were not just passive recipients of negative experiences but indicated their coping strategies. The following strategies were mentioned: no problems experienced, withdrawal, buying different tins of milk from the shops, non-disclosure, and ignoring everything. Such strategies were reported to help them face the problems they were experiencing.

4.4.1 No problems experienced

Four participants indicated giving their babies formula milk without experiencing any problems because they have a good support system amongst their family members. Some of the quotes to indicate such support:

Ravu: *I have no problem. Even my mother approved and said that I must give formula milk for this baby “tearful”.*

Tinyiko: *According to me, I never meet with any problem. People will never stop to talk; it depends on what you want to do in life. The big thing you can do for yourself is to know what you want in life.*

The above quotes bear witness to participants who did not have problems with opting for replacement infant feeding because of the support from their relatives.

Matji *et al.* (2009:23) confirmed that making a decision on infant feeding would depend on a woman’s age, her ability to cope with her HIV status and, most importantly, her ability to disclose her status from the health facility level through to the household level. Ravu, Tinyiko and Marusa, all over the age of 21 years, were able to adhere to the chosen infant feeding method. They were coping with their HIV status and finally they disclosed their HIV status both at home and at the clinic. Tinyiko is even an HIV/AIDS activist who campaigns in the community and at a health facility.

Yet it is sometimes difficult to determine whether participants really do not experience problems, or whether they are simply avoiding talking about their problems, as the case of Hlamalani demonstrates:

Hlamalani: *Nothing, I have no problem.*

Hlamalani was not opening up to questions, and it was unclear whether she was not experiencing any problems or whether she was just avoiding the issues. Hlamalani indicated not experiencing any problems, but her face looked depressed and tearful, i.e. her emotions were the opposite of her words. She gave short answers, just yes or no, and sometimes paused without answering the question.

4.4.2 Withdrawal

Some mothers opted to withdraw themselves from other people to deal with the stigma associated with them not breastfeeding:

Thanyi: *I use cup feeding, I borrow money from relatives to buy milk when there is no supply at the clinic. I lied to my relatives about my baby's status. I always remain indoors and do not visit other people to avoid that they will gossip about me.*

Leloko: *I feel sad and just keep quiet, locking myself in my room.*

Tsakane: *I always walk alone to and from the clinic to collect milk, so as to avoid questions.*

Nkhensani: *I usually collect milk alone, hide it in a black plastic bag, and put it in my bag for people not to see.*

Bonie: *I cannot say I solved the problem, because the only way is to stay away from people... because the more I stay with them, the more they talk. It is really affecting me and I ask myself many questions. Although it is not possible to stay away or avoid people. It gives me a problem although I am trying not to show that it is a problem. I am trying to ignore it, but it is painful.*

Some participants were avoiding interacting with other people to avoid gossip and being asked many questions. This indicated that they were using social withdrawal as a coping strategy to avoid experiencing stigmatisation and discrimination. Skinner and Mfecane (2004:161) concluded that in all communities, there was discrimination against people living with HIV. This often leaves those infected alone and distanced from the rest of their communities, colleagues and even family members. The fear of discrimination could lead to prevention of HIV-status disclosure because of the side effects of rejection usually experienced by people living with HIV/AIDS and contribute to social withdrawal. Not disclosing a positive HIV status increases the risk of infection for the sexual partner of the HIV-positive person. The findings of Doherty *et al.* (2006a:93) confirm that being HIV-positive could lead to feelings of social

isolation, despair and powerlessness. Within such a context of stigmatisation towards people with HIV, especially mothers accessing free formula milk, sometimes the only option was to hide away rather than face ridicule and scorn. In Chapter 2 it was discussed how a mother of a newborn baby isolated herself and spent more time indoors.

When participants encounter problems of being asked many questions on why they are not breastfeeding, they usually protect themselves by secrecy, not disclosing their HIV-positive status. They opted not to tell anyone about their status, fearing rejection, blame and other negative consequences of disclosure; this is how some participants described it:

Leloko: *I told nobody, I just advised my partner to go and test. He refused. My heart is very painful and I'm not ready to tell anyone "tearful".*

Maliphu: *I did not tell anyone, it's still my secret... and I am not yet ready to tell anyone.*

Thuli: *No, I told nobody and I'll tell no one about my status, I told no one at home because they can insult me, especially my partner and his mother can blame me that I am the one who came with a virus, while he was also working as a truck driver when we met a year ago. They are just guessing about my status because I am not breastfeeding my baby, but no one will tell them. My partner's mother is not supportive at all, she could even accuse me of infecting her son, as she is already calling me a snake that is waiting to bite when we are fighting about her son's bad behaviour of having so many girlfriends. She said I must leave her son to enjoy life, he is still young.*

Kharikani: *I am afraid to tell my partner because he would blame me. My partner's mother will stop supporting us, as she is the only provider.*

Participants who explained that they did not tell anyone about their HIV status, had reasons for their secrecy. Leloko and Maliphu gave the reason of not yet being ready, while Kharikani was afraid that her partner would blame and reject her; her partner's mother is the only one source of income. If she would find out about her HIV status, she will discontinue her financial support. Thuli is afraid to be blamed since she is already being accused based on suspicion alone.

Sibeko *et al.* (2009:1986-1987) found that lack of disclosure of an HIV status as a result of existing stigma and discrimination associated with an HIV-positive status

emerged as a key factor in the infant feeding decision process. Failure to disclose an HIV status can serve as a significant impediment to the implementation of these optimal infant feeding guidelines.

Focusing on positive outcomes of disclosure while assessing the risk of negative outcomes should be the key in enhancing the effectiveness of post-test counselling and increasing disclosure among HIV-positive women, and thereby potentially decreasing the risks of HIV transmission to their partners and infants (Visser *et al.* 2008:1144). Disclosure after diagnosis has been identified as an important goal in decreasing HIV transmission, and the use of a screening tool has been advocated for identifying those least likely to disclose their diagnosis to partners and thus those who might require further help (Makin *et al.* 2008:914).

4.4.3 Hiding the evidence

As has been pointed out before, the tins of milk received from the clinic are regarded as confirmation of a positive HIV status, since everybody in the community seems to know that mothers who are HIV-positive receive these tins of powdered milk. It was clear in the previous section that certain participants refused to disclose their status and therefore the milk tins, which represent tangible evidence of a positive HIV status, have to be concealed. In certain cases women go to remarkable lengths to hide the tins from others. Three participants confessed to buy a tin of Nan milk, a well-known brand of formula milk from a shop and transfer the contents of the tin from the clinic into this tin when the milk is finished, so as to disguise the clinic milk:

Tsakane: *I usually buy a tin of NAN from a shop then always pour that clinic milk into that tin when it is finished, before I can prepare. I also showed my elder children to always pour the clinic milk in a Nan tin and take the clinic tin with a stamp far away where people could not even see it.*

Nkhensani: *I usually buy other milk from the supermarket and use it to pour that milk for people not to identify. I usually collect milk alone and hide it in a black plastic bag for people not to see.*

Vutshilo: *We buy extra milk with a tin of Nan and pour the clinic milk inside the empty tin of Nan and throw the stamped empty clinic tin far away. My mother-in-law knows that I have insufficient milk because I have never breastfed, not even for my first baby. The problem now is that my mother-in-law knows the clinic milk. We even throw empty tins at night far away to avoid people's talk.*

The shared characteristics of the participants who were buying a tin of Nan from a supermarket and transferring the clinic milk into that were the following: being married, older than 25 years and having experience in parenthood, such as Tsakane, Nkhensani and Vutshulo. Mothers believed that the milk from the clinic had a stamp by which family and community members could easily identify that they were HIV-positive. Doherty *et al.* (2006a:93) report the same findings, the specific stigma attached to the tins of milk and the strategies people use to conceal it.

4.4.4 Ignoring everything

The majority of the participants showed that they were coping well with their problems by just ignoring everything in order to continue with their lives.

Muvhaleni: *I just ignore everything.*

Vutshilo: *We have the pressure of people's talks and we want to be free. You just ignore those people who talk a lot to avoid having a painful heart.*

Rubani: *I always prepare milk in time and baby sucks until finished, and I just ignore what people say because after all, this is helping my baby and me. I am not shy to take out a bottle even if I am in a taxi, telling someone about this. There are many people, it is not me alone and I'm not thinking about this always "all the time".*

Bonie: *I am trying to ignore what people say, although it is painful.*

Thuli: *People talk a lot about me not breastfeeding. I do not have a problem because I am prepared to give my baby formula milk, I do not care what people say because they do not know why I choose to give my baby a bottle.*

Most of the women used "ignoring" as a coping mechanism, especially when people ask why they use formula milk and not breast milk. When people were gossiping about them, they ignored everything and went on with their lives. Sadoh and Sador (2009:31) also found that there were mothers who were ignoring the question of why they were not breastfeeding their babies.

In Chapter 2 agency was discussed, referring to a wide range of purposive actions that were associated with dealing with one's problems. In this study it was described how deception in the case of the NAN tins and resistance "ignoring gossip" are manifestations of agency, in that the participants used these as strategies to deal with difficult situations.

4.5 Support systems

This study described a formal support system that include education, counselling and empowerment by a health care worker, social worker, counsellor, peer group educator, activist and community health worker which may include home visits, while an informal support system would include family members, church members and others in the community. A support group refers to people with similar characteristics who regularly meet and discuss shared and unique experiences with the aim of supporting one another. In addition, the encouragement and support from a family member, co-workers and at church also form part of a broader support system and play a vital role for HIV-positive mothers to adhere to their infant feeding practices and to face other challenges of life. The study also looked at the support systems that mothers were engaged in. Tsakane and Nkhensani were attending a support group at the local hospital and waiting to receive food parcels. Thanyi was receiving food parcels from a magistrate's office via a local care group. Marusa was also attending a support group at a nearby hospital.

Tsakane: *We have filled in the forms to get food parcels and I have joined the support group. We talk about problems and meet with other people who had the virus for a long time and still had many children or were able to bear children but still are fine. We solve problems and feel fine.*

Nkhensani: *There is a support group at the hospital for HIV-positive mothers who are breastfeeding and on formula milk. They teach us about treatment and side effects. I have started antiretroviral therapy last year, but there is no grant for HIV-positive people who are on treatment.*

Marusa: *Hospital A is having a support group where HIV people share how they accepted their HIV-positive status. It is very nice, but for formula-feeding mothers it will be very difficult here because people talk a lot. It is better far away where they could not even see you.*

Participants who attended support groups feel accepted as their burdens are shared by others. They realise that they are not alone in dealing with their problems, getting guidance on ARVs and other issues associated with HIV. Despite such benefits, one participant suggested that such support groups should be far away where people would not recognise them because of the stigma attached to being identified as attending such groups. Peltzer *et al.* (2007:60) also found in their study that, although

more than one-third of the participants felt that people living with HIV/AIDS are stigmatised in their community, supportive mothers-in-law and husbands/partners of women interviewed indicated that emotional support, love and hope for the future, followed by a good diet and ARVs, are the most important needs of persons living with HIV/AIDS.

4.5.1 Types of support systems

The majority of participants were not attending any support group. Yet the participants gave suggestions about the type of support groups they would want and the way in which such groups could help them. Proposals included first and foremost the availability of a support group, counselling, partner involvement, money vouchers, church, activism and home visits. Yet certain participants maintained that they wanted nothing to do with a support group. Opinions about having or joining a support group were as follows:

Tsakane: *We will be happy if they can help us concerning milk or give us money. Mothers must regularly meet and discuss their problems, and it can really help.*

Maliphu: *Clinic staff must organise a support group. People meet problems when taking the formula milk for their babies.*

Ngeli: *Only here at the clinic, all of us who are HIV-positive, we meet and nurses help us by telling us about importance of replacement infant feeding. I do not trust any other place that could keep my secret, except here where we get more knowledge about RIF.*

Tinyiko: *According to my view, what can help we women who are on formula milk, we need a support group of women who are not breastfeeding to be strong women and also to be given more information on this choice of feeding, to show how others have overcome their problems they came across, it will be better. By doing this will encourage, support and help women to accept this condition and people to have knowledge on issues of HIV and infant feeding.*

Masindi: *I have no support system now, but I think it is needed although I have accepted myself, we need support against the gossip.*

In explaining the type of support group in more detail, the need for counselling was repeatedly mentioned:

Khasa: *A lot of counselling because we are always thinking when you heard a person talking about an HIV-positive person. Especially in social gatherings, social workers and nurses must combine and come out with a strong counselling to help us. Community members are really stressing us. This will help us to support and accept this condition because of stress from community members.*

Bonie: *At home, there is nothing you could do as long as they do not know your status nothing will do, so at the clinic while we are here they must make us not to be severely affected. Explain to us and teach us about issues that could disturb us through proper counselling. I need to have knowledge, being comforted, supported and encouraged.*

Gramma: *I get support only here at the clinic through counselling because at home there is no one who knows except my husband. Something more about formula feeding mothers must be done and when we come to collect milk I wish nurses must not take us somehow but really show support to us because we are going through a difficult time.*

Tshina: *I need someone who will support me, although I told my sister but there is no one who is professional who can explain more issues to me, like how will I live and for how long will I live, and I want to know could my baby become HIV-positive and could he take treatment at this age?*

Muvhaleni: *I only want to be guided here at the clinic, about how I can live. I feel better. I do not want someone who always talks about this disease, I think a lot. I do not want to be tricked because I have a short heart, so at the clinic they must counsel us every day.*

In the above quotes, support was specified in the form of information needed, emotional support needed from people in similar circumstances, counselling services and community awareness needed to prevent discrimination against mothers living with HIV. A further aspect that was highlighted was the importance of partner involvement in support groups:

Thuli: *There should be a support group for mothers who opted for formula feeding and partners must be fully involved in the testing in order to understand everything. Something must be done about people gossiping about mothers who are not breastfeeding. This could help us to take milk free from gossip, with partners and their mothers supporting and encouraging us, and not blaming us, because it is painful.*

A more practical suggestion was a money voucher instead of free formula milk:

Tshina: *About formula milk, they must change that milk or give us money to buy milk on our own at shops. We are shy to take out a bottle when you are in a taxi because of the nature of that milk.*

Vutshilo: *The question is, how about government giving us money for us to buy milk from the shops like other mothers who are HIV-negative and not receiving milk from the clinic. It is better to get money in our own accounts or vouchers to buy milk, because when coming out from the clinic with a big bag people talk a lot. Others are even our neighbours; they will tell someone and the following day it will be known all over the world.*

Tsakane: *We will be happy if they can help us concerning milk or give us money. Mothers must regularly meet and discuss their problems. It can really help.*

Nkhensani: *But I just feel something needs to be done concerning mothers on formula milk, even giving them money to buy milk or giving milk without that stamp, same as the ones from the shops.*

Maliphu: *It would be better if people were given money or vouchers to buy or to collect milk at the supermarket but not at the clinics.*

Thanyi: *There must be activities where there are many people and we must talk about the HIV issues and going from house to house to talk about HIV and advise people to test by someone who is also HIV-positive for them to trust and understand.*

Lastly home visits were also recommended:

Thembi: *People really need to be helped through home visits, those women who wear uniforms like nurses must visit and talk with relatives, especially those whose mothers, husbands, partners, parents and other relatives and people do not like formula milk, because it is difficult. The clinic is really trying by giving us free milk because it was not everyone who can be able to buy milk and it is now easy.*

Despite the suggestions for different forms of support, five of the participants did not want to engage in such activities at all, as they could not imagine any advantages from such support groups.

Rubani: *Nothing, because people gossip a lot and laugh “with” each other even in a support group they will, it will be better if it could be very far, where nobody knows you and can recognise you – a support group that is helping.*

Hlamalani: *No, nothing! “Mute and looked angry”*

Participants made certain suggestions that they believed could help them, although five participants (Ravu, Leloko, Kharikani, Hlamalani and Rubani) maintained that there was nothing that could be done to help them. The following were suggested by participants to better their coping mechanisms: knowledge, support, encouragement and comfort. Such aspects can promote the disclosing of an HIV status, acceptance of

replacement infant feeding, and coping with HIV in general, and may put an end to the labelling and gossip.

Most participants suggested that support groups and counselling were needed for them to gain more knowledge, encouragement, and support. In addition, one participant, Beauty, mentioned that the church could be helpful and encouraging with Bible verses. Overall, the VCT service is not focusing on ongoing counselling but rather some counselling only when patients are first tested. There is still a high level of stigmatisation towards people living with HIV/AIDS, including the participants of this study whose HIV status is visible since they are not breastfeeding in a cultural environment where breastfeeding is the norm. Support for adequate replacement infant feeding is needed throughout the period for which breast milk is normally recommended and during which the child is at greatest risk of malnutrition (UNICEF, UNAIDS, WHO & UNFP 2004:17).

To adhere to their infant feeding choice, mothers often have to challenge both their own and their traditional system of beliefs (Buskens and Jaffe 2008:343-344). Buskens and Jaffe further argue that adherence also requires a conversation to empower mothers to make significant behavioural change, even transformation, to challenge her traditional role, personality and identity as a woman. These women also require significant changes in the definition of counselling. For mothers to adhere to their choice of infant feeding they need more than conversations in which information is provided to help them make an informed choice. Other studies confirmed that, although many health care workers have good communication skills, the information regarding HIV-positive mothers is insufficient. Also, they were never neutral regarding the issue and very few of them discussed the possibility of the mother breastfeeding (Rea, Dos Santos & Moreno 2007:97). Poor quality counselling could have deleterious effects on mothers (Doherty *et al.* 2006a:93).

Increased uptake of PMTCT services in general and improved adherence to optimum feeding practices can be attained if factors affecting mothers' choice of feeding are identified and appropriate interventions put in place (Muko *et al.* 2004:134).

Certain participants also suggested activism, partner involvement and home visits, and reasons for this ranged from acceptance of the disease to infant feeding. A study done in Botswana also identified the lack of a male partner's support as a barrier to the programme – and many men refuse to undergo an HIV test (Kebaabetswe 2007:358).

A number of participants suggested having milk vouchers instead of receiving milk from the clinic; they felt it would help them by not being so easily identifiable and would avoid gossip and stigmatisation. This is consistent with the study done in Botswana (Kebaabetswe 2007:358) where it was found that certain participants believed that to reduce stigmatisation, free formula milk should be distributed at stores through redeemable coupons, while others were against it. In dealing with this barrier to protect their infants, women were challenged to weigh the fear of stigmatisation against the risk of exposing their infants to HIV infection. In any case, parents desire healthy children and are willing to modify their behaviour to protect them from harm (Tavengwa, Piwow, Liff, Moulton, Zunguza, Nathoo *et al.* 2007:101).

4.6 Summary

In this study the main themes that emerged were feeding patterns/practices, the role players in choosing infant feeding and emotions. The socio-cultural challenges faced by mothers who opted for replacement infant feeding were discussed and certain coping strategies were identified. Specific suggestions regarding support systems were also suggested by participants.

Some participants opted for exclusive replacement infant feeding with the aim of protecting their babies' health status because of fear of HIV transmission to their babies. There was a problem with meeting the AFASS criteria, i.e. some participants experienced a lack of material resources e.g. bottles, electricity and lack of available milk supplies at certain clinics.

The study found that participants were not alone in choosing infant feeding, although WHO guidelines state that health care workers must provide appropriate and relevant information about infant feeding and let the mother make her own decision. Health

care workers played a role in the choice of and adherence to feeding practices. There was also a power hierarchy between health care workers and participants, which could be observed in clear preferences on the part of some health care workers and some even forcing a specific feeding method. The outcome depends on the knowledge, attitude and skills of a health worker, and her preferences regarding replacement infant feeding associated with an HIV-positive status. Participants who opted for replacement infant feeding from birth adhered to this method, although there was some family pressure to breastfeed. Certain mothers-in-law, partners and other family members felt that they had authority in deciding on their grandchildren's feeding method. As repeatedly pointed out, breastfeeding is a norm in African countries and participants experienced stigmatisation and discrimination both from family and community members when they did not adhere to this norm.

Cases of gender-based violence were found in the form of emotional, financial and physical abuse. Some participants experienced lack/loss of financial and social support, husbands engaging in extra-marital affairs and even being beaten by their husbands/partners. The study found that the majority of participants disclosed their status to their partners/husbands. Most of them were married and received support from their husbands. The majority of the relatives i.e. husbands/partners and other family members accepted and supported replacement infant feeding. A few participants disclosed their HIV status to their family members and still experienced a lack of support – similar to those who did not disclose their status to anyone.

The study also found a whole array of emotional responses among the respondents after disclosure, including relief, regret and depression. Although most participants felt relieved after opting for replacement infant feeding, knowing that their babies were protected, there were others who experienced pain and hurt and felt like “incomplete” women because they could not breast feed their babies and did not meet the expectations of family and community members.

Participants used different coping strategies, such as withdrawal, secrecy, ignoring and buying a different tin of milk from the supermarket to try and cope with the stigmatisation from family and community members. Participants who usually bought

different milk brands from the shop were mostly older than 25 years of age, married and had experience in motherhood.

Some participants reported to experience no problems due to good support from husbands/partners and family members. A few participants attended a support group. There were a few support systems available for participants at health facilities and at the community level. The support system methods suggested by participants were access to a support group, health education and counselling. The latter was important to empower them in order to gain more knowledge, support, encouragement and comfort, acceptance of the disease and help with the issue of disclosing an HIV-positive status. One participant suggested partner involvement in the PMTCT programme as it could help to solve the problems she was experiencing. One participant also indicated that the church was a good support system. Other suggestions included activism and home visits. A yearning verbalised by many was acceptance of replacement infant feeding by family and community members; that would free them from the labelling and gossip and eradicate the stigmatisation and discrimination. The summary of the study, conclusion and recommendations are going to be area of focus in the next chapter.

CHAPTER 5

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

The research findings and interpretations were presented and discussed in the previous chapter. Here, a summary of the study based on the empirical and literature findings will be given, in relation to the research questions, purpose and objectives of the study. The limitations of the study will also be highlighted and suggestions for further research will be made. Finally, recommendations for both policy and practice will be made with the aim of improving PMTCT.

5.2 Research findings

This study aimed to identify the challenges experienced and the coping strategies employed to deal with such challenges by mothers living with HIV who opted for replacement infant feeding in a resource-constrained area, namely the rural area of Makhado Municipality. The research questions were:

- What challenges do mothers living with HIV face when choosing replacement infant feeding in the rural, constrained settings?
- What are the coping strategies of mothers living with HIV who opted for replacement infant feeding?

The main themes that emerged when identifying the challenges and coping strategies centred around feeding patterns/practices, the role players in choosing infant feeding and emotions.

The study used a qualitative approach, semi-structured, in-depth interviews with an interview schedule to guide the interviews in terms of the research questions. The demographic characteristics of the participants were recorded, and the reasons for choosing replacement infant feeding and the adherence to RIF were explored. The socio-cultural challenges, disclosure of an HIV status and support systems were the main themes covered in the interview schedule. In the study three clinics out of seven

were randomly sampled, and through purposive sampling, 22 participants were identified with whom the challenges and coping strategies of mothers living with HIV who opted for RIF could be explored. The data obtained was analysed by using open coding. Quotations from this process gave voice to the mothers. The researcher also engaged in a reflexive process to enhance the trustworthiness and authenticity of the findings. Ethical considerations were highlighted and adhered to in order to ensure the dignity of the participants.

The study looked at *gender* and *power* as the theoretical departure points to inform the findings. The concept *motherhood* contains certain realities and expectations that helped in understanding the socio-cultural challenges that were experienced by mothers who were not breastfeeding. The discussion of feeding practices demonstrated certain patterns that developed over time and helped to explain the positive and negative emotional responses reported by the participants. The constructs of gender and power illuminated specifically how women are shaped by the socio-cultural factors of gender inequality, and this in turn helped to understand how mothers make decisions and face daily living challenges. Empowerment and agency gave a broader view of their coping strategies.

Looking at the challenges and coping strategies of mothers living with HIV who opted for replacement infant feeding, it became apparent to the researcher that mothers are not alone when opting and adhering to replacement infant feeding. There are socio-cultural challenges that they have to meet and their coping strategies seem to be insufficient to accommodate all such situations. The fact of being women, and the expectations and historical disadvantages attached to that, further complicate the issue. The following section provides the findings and conclusions of this study.

5.3 Major findings of the study

The HIV/AIDS pandemic affects many women of childbearing age, and this gives rise to MTCT of HIV. As was discussed in Chapter 2, the infant feeding method regarded to be safe, namely replacement infant feeding, is not always practical and it goes against the established norm expected of mothers, namely breastfeeding. Yet the participants in this study chose RIF and the major reason given for choosing that was

that they wanted to protect their babies' health. The findings are consistent with other studies, as discussed in Chapter 2 (Muko *et al.* 2004 ; Doherty *et al.* 2006a:95). In the findings of this study, three major themes were discussed, namely feeding practices, the role players in choosing infant feeding and emotional reactions of mothers.

5.3.1 Feeding practices

The consistency in adherence to replacement infant feeding was better in the case of mothers who opted for replacement infant feeding at birth, than with those who opted for breastfeeding at birth. The poor adherence to infant feeding was confirmed in the reviewed literature (Kaai *et al.* 2005 ; Leshabari *et al.* 2007:544-555; Nlend *et al.* 2007).

Certain participants had misgivings about the quality of the formula milk they received at the clinic because of its nature, i.e. water and solids separating; some participants thought it was full of fats and were therefore not sure whether it was healthy and good for their babies. Participants thus lacked trust in the quality of milk. This raises a new concern regarding RIF, since there were no studies found with similar findings.

Formula milk tins from the clinic may easily lead to stigmatisation because the tins carried a government stamp and looked different from the tins bought in shops. Therefore participants felt they were easily identifiable, involuntarily disclosing their HIV-positive status if seen with such milk tins. Formula milk tins were thus associated with an HIV-positive status. Such findings were consistent with the reviewed literature (Sibeko *et al.* 2009:1983-1984; Matji *et al.* 2009:21-22).

Some participants complained of a shortage in the milk supply at some clinics and others experienced a lack of resources or utensils to prepare the milk correctly – similar to the findings of other studies (Bland *et al.* 2007:292 ; Sibeko *et al.* 2009). In such cases, certain participants in this study resorted to buying formula milk on their own, but others had no alternatives. There were participants who started giving their babies breast milk although they understood the high chances of MTCT of HIV

(Doherty *et al.* 2006b:2424). Such an irregular supply of RIF at clinics contravenes the AFASS criteria.

5.3.2 The role players in choosing infant feeding

The health care sector, the family and community played an important role in a mother's opting for and adhering to RIF. The choice of and adherence to RIF mostly resulted from the advice, recommendations or even preferences of a health care worker. In certain cases, participants were even forced by health care workers to give RIF. This shows a power hierarchy that exists between participants and health care workers, as also confirmed by Doherty *et al.* (2006a).

Family and community members were also stigmatising and discriminating against participants who were not breastfeeding. It was suspicious if one gave RIF and not breast milk to a new baby, and many participants feared gossip. There was also pressure from family members if they were found not to breastfeed – especially by mothers-in-law, who felt that they had the authority and power to intervene in the infant's feeding. Similar results were also discussed in Chapter 2 (Muko *et al.* 2004:136-137; Buskens *et al.* 2007:1106; Ntabaye & Lusiola 2004; Oladokun *et al.* 2010:6).

Some participants experienced gender-based violence in the form of physical, emotional or financial abuse. Their partners were even having extra-marital affairs and a case of an attempted suicide was reported. Some participants experienced abuse as a result of disclosing their HIV status, while others experienced abuse even without disclosing their status to their partners. In the reviewed literature, an association between disclosure and fear of abuse or actual abuse was also found (Buskens *et al.* 2007; Brou *et al.* 2007 ; Visser *et al.* 2008 & Makin *et al.* 2008).

Disclosure of an HIV status was most commonly made to husbands in the case of participants who were married. Such participants were likely to receive comfort and support from their husbands, in other words, a positive outcome. Those who were cohabiting or single mostly disclosed to another family member such as a mother or a sister. Participants felt comfortable sharing or disclosing their HIV status to family

members because they were mostly supported by them, unlike non-family community members from whom they were experiencing stigmatisation and discrimination.

Four participants experienced good informal support from their family members. The participant's age is positively associated with her ability to cope and to disclose an HIV status. Such participants were older than twenty-one years and disclosed their HIV status to immediate family members.

Coping mechanisms that were used included withdrawal or social isolation to avoid interacting with people, because they may ask why the mother did not breastfeed their baby. Others opted for secrecy, i.e. not disclosing or sharing her HIV status as a coping mechanism. Such factors as social isolation, despair and powerlessness were also discussed in the literature review (Skinner & Mfecane 2004; Doherty *et al.* 2006a & Sibeko *et al.* 2009). There were participants who simply ignored questions of why they were not breastfeeding their babies and the gossip from community members, as also reported by Sadoh and Sador (2009).

Certain participants went to extreme lengths to hide evidence associated with an HIV-positive status, by buying a different tin of milk (Nan) from the shops and transferring the milk they received from the clinic in the bought tin, so as to disguise the clinic milk from community members. Such participants were likely to be married, over the age of twenty-five years and experienced in motherhood (not their first baby). The same findings were also documented by Doherty *et al.* (2006a:93).

As was discussed in chapter 2 (Diclemente *et al.* 2002:315) on model of conceptualising the influence of gender and power on health issues, the findings confirm division of labour, power and social norms impact on experiences of mothers on their motherhood. The institutional level also whereby a relationship with medical system, there was power inequalities between health care workers and mothers. The pressure from family members influence in opting and practicing on infant feeding and expected them to breastfeed. The societal mechanism that contribute in inequalities between men and women impacted on mothers sub-ordinates their needs and live according to expected societal norms. The stigmatization and discrimination from community members also proved the theory by societal mechanism.

5.3.3 Emotional reactions by mothers

The emotions that emerged after choosing replacement infant feeding were that some participants felt relieved, accepting of their circumstances, happy and appreciative for being able to choose RIF. On the other side of the coin, there were participants who felt “incomplete” as mothers, since they were not breastfeeding their babies and wished to experience such “motherhood realities”. These findings were similar to those found by Lazarus *et al.* (2009).

After disclosing their status, most participants felt positive emotional responses, because they felt relieved as if their burden had been halved. However, there were also those who experienced negative emotional responses such as feeling depressed. Peltzer *et al.* (2007) and Sadoh & Sador (2009) found similar findings on emotions (see Chapter 2).

Support systems can be divided into formal and informal types. A formal support system is one where participants receive counselling, education and guidance on becoming empowered and also support by health care workers. Such support may extend to home visits and support groups. Informal support systems refer to support from family members, church members or other structures in the community that provide empowerment, support and comfort. There were only a few participants who attended support groups. Certain participants had negative attitudes towards support groups because they thought it could be associated with stigmatisation and discrimination. Those who attended support groups felt relieved that their burdens were shared, and they understood that they were not alone, having met other people in a similar situation with the same problems (see also Gaede *et al.* 2006 and Peltzer *et al.* 2007).

Various suggestions were made concerning support systems, which ranged from informative counselling in order to gain knowledge about HIV and RIF to support, encouragement, gaining good coping mechanisms that would enable one to disclose a positive HIV status, acceptance and adherence to RIF, free from stigmatisation and discrimination. The process could be enhanced through counselling by professional service providers, activism, partner involvement and home visits. Other suggestions

included milk vouchers and milk to be distributed in the shops through redeemable coupons, although not all participants agreed on the latter.

5.4 Limitations of the study

The study used semi-structured, in-depth interviews with 22 participants by a single young researcher working under time constraints. The study was done in the rural area of Makhado Municipality, which cannot be seen as representative of all the rural areas in the Vhembe district. Awareness of the HIV status of partners/husbands was not included when looking at the experiences of mothers who opted for RIF. The study focused on women only because they are vulnerable and most affected by the choice of infant feeding. The knowledge gained from this study can therefore not be generalised to all HIV-positive mothers with infants, although it provides insight into the life experiences of women living in rural areas in South Africa.

5.5 Recommendations for further research

The choice of and adherence to RIF remain a challenge for HIV-positive mothers because of conflicting interests of protecting the baby on the one hand, and avoiding stigmatisation on the other. The material resources needed for RIF, namely the formula milk and the necessary utensils, is associated with stigmatisation. The health care workers play an important role in a mother's opting for and adhering to RIF, because breastfeeding is the norm. The challenges faced by mothers who are HIV-positive need effective intervention to improve RIF practices.

The attitudes and knowledge of health care workers on replacement infant feeding need to be improved, inclusion of socio-cultural factors i.e husbands/partners or other family members in PMTCT counselling to be aware of infant feeding methods and coping strategies. The role of the community in PMTCT programmes e.g. churches etc, must also form integral part of PMTCT.

5.6 Recommendations for policy and practice

Based on the findings of this study, the researcher can recommend the following
Health care workers and lay counsellors need appropriate and sufficient knowledge and information to empower mothers with the relevant knowledge concerning infant feeding choices and the importance of adherence.

Strategies to eradicate stigmatisation should be aimed at health care workers, people living with HIV and community members.

There should be practical strategies of encouraging male involvement in the PMTCT programme.

Support groups and other coping mechanisms should be integrated into PMTCT programmes.

HIV/AIDS activism by mothers must be rewarded to encouraging more such initiatives.

Mothers who are living with HIV and opted for replacement feeding are experiencing challenges at health care system, family and in the community. The coping strategies that are currently employed, are not sufficient to help them leading their normal lives.

KEY TERMS:

Formula milk; Exclusive breastfeeding; Infant feeding practices; Mixed feeding; Motherhood; Mothers living with HIV; Replacement infant feeding; Prevention of mother-to-child transmission; Socio-cultural challenges; Support systems

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APPENDIX 1

INTERVIEW SCHEDULE

My name is Modipadi Rebecca Mugivhi and I am interested in knowing how mothers who are on a PMTCT programme cope with their babies' feeding routine. Do you have any questions about the study before we start with our interview?

Identification

Who are you?

Where is your home?

What is your home language?

When were you born?

Living arrangements

Who is/are living with you at your home?

Educational level

What is the highest standard you passed?

Parity

Tell me about your pregnancies and the number of children you had.

How old is your youngest baby?

Reasons for choosing Replacement Infant Feeding

Why did you choose replacement infant feeding?

Tell me about the people who helped you to choose replacement infant feeding.

How do you feel about choosing replacement infant feeding?

Replacement infant feeding consistently

The method you are currently using, is it the same since the birth of your baby?

If no, can you explain why you changed?

Socio-cultural challenges

Tell me about your experiences when using the replacement infant feeding.

What do you do to overcome the difficulties?

Who else gave you suggestions on your choice of infant feeding?

Sharing of HIV-positive status

Since you knew about your status, have you told anyone in your family?

Whom did you tell and how?

How is that person's reaction towards your using replacement infant feeding method?

Tell me about your feelings after you told someone.

Support system

Tell me about the people who support you.

In what ways do they support you?

APPENDIX 2 : INFORMATION LETTER

Dear participant

My name is Modipadi Rebecca Mugivhi and I am working as a Professional nurse at Waterval clinic. I am currently a graduate student at the University of South Africa. As part of the requirements for my Master's degree I have to complete a research dissertation. I would like to conduct an interview with you (please indicate your language preference below), which means I want to ask you a few questions such as how do you cope with the baby and your feeding routines for the baby.

A face-to-face, semi-structured interview will be conducted in your own language, using an audio-tape recorder to record our conversation at the clinic or any place of your choice. You will not have to answer any questions that you do not wish to answer. The interview will take 30 to 60 minutes.

Since you are a mother who is attending a PMTCT programme, you are a very important source of information for my study. There are 21 other participants in this study, but they are going to be interviewed at different times than you. With this letter, I invite you to participate in this study. If you want to participate, you have to fill in the consent form and hand it over to your counsellor on your next visit. After I have received a copy of this signed consent letter from you, an appointment for the interview will be made. With your permission, I would like to audiotape this interview. Only I will have access to the tape recording, which I will personally transcribe, removing any identifiers during transcription. The tape will be erased after completion of the study. Your identity will be kept confidential and will not be revealed in the final manuscript.

There are no anticipated risks, compensation or other direct benefit to you as a participant in this interview. You are free to withdraw your consent to participate and may discontinue your participation in the interview at any time without consequences. If you have any questions about this research protocol, please contact me at 0828543342 or email address: tmugivhi@yahoo.com.

Yours sincerely

MR Mugivhi

APPENDIX 3: INFORMED CONSENT FORM

Problems experienced by mothers who opted for Replacement Infant Feeding in a Prevention of Mother-to-Child Transmission programme in Makhado Municipality, Limpopo Province, South Africa.

I confirm that I have read and understood the information letter that I have received, explaining to me the purpose, procedures, and risks and benefits of the study. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participating in the study. I understand that, should I wish to discontinue with the study, my withdrawal will not affect my treatment.

Participant's name _____

(Please print)

Participant's signature _____ Date _____

Investigator's name _____

(Please print)

Investigator's signature _____ Date _____

APPENDIX 2: Tsonga version

Aka Manana

Vito ra mina i Modipadi Rebecca Mugivhi. Ndzi muongori e Waterval kliniki. Ndzi le ka mingingiriko yo yisa tidyondzo ta mina e mahlweni eka University ya Venda. Swilaveko kulu eka digiri ya mina ya vumasitara. Ndzi fanele ku endla vulavisisi na swi bumabumelo. Ndzi kombela ku burisana na nwina (ndzi nga tsaka ku va mi ndzi tivisa i ririmu leri mi nga tsakelaka ku ndzi ri tirhisa eka burisano wa hina). xikongomelo xa mina, ndzi rhandza ku kuma tihlamulo hi mayelano na ku bulabula xyimo xa HIV ka bangwane, minkarhi ya kona na leswaku xana xyimo xo bjela mungwana xi mi tikela kumbe ku mi olovela ku fika kwihi?

Burisano hi langutanile lowu nga ta endliwa hi ku tirhisa ririmu ra nwina hi ri rhadhiyo yo kandziyisa marito. Leswi swi nga endliwa eka muako wa vutsunguri kumbe ku nwana na ku nwana laha minga ta twa mi tshuxekile ku endla tano. A mi nge kombeteriwe ku nhlamula swivutiso leswi nga mi khomiku kahle. Burisano wa hina wu ta heta timinete ta makume manharhu.

Ta ni hi manana loyi a nga endzeni ka mingingiriko ya PMTCT mi munhu wa konka eka kungu leri ra tidyondzo ta mina. Hina vanhu va khume na kaye lava nga ta nghenelela kambe vata burisana na hina exihundleni ha unwe hi minkarhi yo hambana na nwina. Hi papila leri mi rhambiwa ku nghenelela eka kungu leri ra dyondzo. Papila ntsongo leri ri ta mi nyika mahungo la ma nga ta mi pfuna ku ehleketa ku nghenelela eka makungo lawa. Ku nghenelela mi ta komberiwa ku tatisa fomo ya pfumelelo mi yi nyiketa va pfuni wa nwina loko mi vuyela kambe ku kamberiwa. Loko ndzi kumile fomo ya pfumelelo leyi sayiniweke hi nwina ndzi ta lulamisa leswaku hi burisana. Ndza mi tshembisa leswaku ku ta va mina ntsena loyi anga ta fikelela kandziyiso lowu, a ku nge vi na vumbhoni lebyi kandziyisiweke lebyi nga kotaka ku mi paluxa. Loko xikongomelo xa kandziyiso na burisano wa hina xi hundzile ndzi tshembisa ku thunya vukandziyiso na vburisano wa hina leswaku wu nga fikeleriwe hi unwana munhu swi nga fanelanga. Mavito ya nwina a ma nge humeseriwi erivaleni eka matsalwa yo hetelela lama nga ta kandziyisiwa. A kun a nghozi leyi nga vaka kona eka nwina kumbe ku lahlekeriwa hambi ku ri vuyelo wo karhi lowu mi nga ta wu

kuma. Mi ta va ni fanelo kumbe matimba yaku tihumesa eka kungo leri hambi loko mi nyikile pfumelelo loko mo twa mi nga khomekanga kahle hi burisano wa hina ku nga ri na ku lahlekeriwa ko nkarhi eka nwina.

Loko kuri na swi vutiso mayelano na ndzavisiso lowu. Tihlanganise na mina eka nomboro leyi 0828543342 kumbe eka e-mail adirese leyi tmugivhi@yahoo.com.

Wa nwina

MR Mugivhi

APPENDIX 3: Tsonga Version Fomo ya pfumelelo

Swiphiqo leswi hlanganaka na va manana lava ti hlawuleleke ku mamisa bhondhlela ta ni hi ndlela yo sivela ku tlulela ka xitsongatsongana ku suka ka manana ku ya eka nwana e ndzhawini ya hina ya xifundzha xa munisipala wa Makhado, Limpopo Province, South Afrika.

Ndzi tiyisisa leswaku ndzi hlayile ni ku twisisa makungu lama nga ka papila leri ndzi ri amukeleke, ri paluxile niku humesa hlamuselo wa kungu, maendlelo na vuyelo bya kona. Ndza swi twisisa leswaku vuyelo wa kungo leri, ku katsakanya na vumbhni byo ti tivisa lebyi nga hlengeletiwaka eka kungo leri byi ta hlutiwa na ku langutisisiwa exihundleni. Ndzi nghenelela eka kungo leri hi ku tinyiketela. Ndzi nyikiwile nkarhi wa ku vutisa swi vutiso a ndzi na ku kanetana eka ku nghenelela ka kungo leri. Ndza twisisa leswaku loko ndzo tshika ndzi ti humisile eka kungo leri, ku kokela ehandle ka mina aku nge kanganyisi vutsunguri lebyi ndzi byi amukelaka.

Mavito _____(tirhisa maletere la makulu)

Sayino _____ Siku _____

Vito la mukamberi _____

(tirhisa maletere la makulu)

Sayino ya mukamberi _____ Siku _____

APPENDIX 2: Venda version

Vho Mme

Dzina langa ndi Modipadi Rebecca Mugivhi, ndi shuma sa muongi kliniki ya Waterval. Zwa zwino ndi khou isa phanad na pfudzo dzanga university ya Afurika tshipembe. Sa inwe ya thoda dza pfudzo yanga ya masters ndi tea u bveledza na tshedzolosho. Ndi khou tama u vha na nyambedzano navho, zwine zwa amba uri ndi khou toda u vha vhudzisa mbudziso dzi si gathi sa uri vha kona hani u imbedzana na nyimelo ya musu vhana nwana na zwikhakhathi zwa u nea nwana zwiliwa.

Nyambedzano ya musu ro livhana zwi fhatuwe ino do itwa nga luambo lwavho hu khou shumiswa tshirekoti maifi. Rikhou zwi itela kiliniki kana hunwe fhethu hune ha nga vha havhudi kha vhone. A vha kombetshedza u fhindula mbudziso dzine vha fha uri a vha takalelui u dzi fhindula. Nyambedzano ido dzhia tshifinga tshi linganaho mikhethe ya furaro.

Sa izwi vha mme ane a vha kha mbekanya mushumo ya PMTCT, vha tou vha ene muthu wa ndeme are na maphungo ane nda a toda kha zwa pfudzo dzanga. Hun a vha inwe ngavo vha fumitaha vhanne vha do fana navho nyambedzano vho nga zwifinga zwo fhambanaho na zwavho. Nga luriwalo ulwu ndi khou vha ramba uri na vhone vha dzhenelele kha u guda hohu. Bambiri ili li re na maphungo li do vha thusa uri vha humbule uri vha funa u dzhenelela kha pfudzo iyi naa?

Arali vha tshi funa u dzhenelela vha fanela u dadza fomo ya thendelo vha I nekedza mu khanselara wavho musu vha tshi vho vhuya. Musu ndo no wana lunwalo ulwu lwa thendelo ino bva khavonne, ndi do kona ha u fara navho nyambedzano. Uri ndi vhone vho ambedzanaho navho zwi do vha tshiphiri sa zwine mulayo wa zwi funisa zwone nahone a zwi nga vhone na kha bambiri la u fhedza.

Ahuna masia ndo itwa a si a vhudi kha heyi nyambedzano, hu dinga malamba kana dzinwe ndivhuwo. Vho tendelwa u dibvisa kha nyambedzano tshifinga tshinwe na tshinwe hu si na zwi no dina.

Arali vhana mbudziso malungana na ndingo iyi khava nkware kha nomboro I tevhelaho 0828543342 kana email aderese ya tmugivhi@yahoo.com.

Wavho a fulufhedzeaho
MR Mugivhi

APPENDIX 3: Fomu ya thendelo

Thaidzo dzine vho mme vho nangaho u sa mamisa vha tangana nadzo, vhanne vha kha mbekanya mushomo ya PMTCT vhona vha re ka masipala wa Makhado, kha Provinse ya Limpopo, Afurika Tshipembe.

Ndi khou khwathisa uri ndo vhala nda pfesesa mafhungo are a kha linwalo lwe nda wana, lu tshi khou talutshedza nga ha ndivho, zwidodombedzwa, vhudi na vhuvhi nga ha ngudo iyi.

Ndi a dhiva uri mvelelo dza heino ngudo, ri tshi katela na zwidodombedzwa zwa muthu, azwi nga sumbedzwi kha mvelelo dza ndingo.

Ndi khou dinekedzela u dzhenelela kha ngodo iyi ndi singo tou kombetshedzwa. Ndo dinea tshifinga tshau vhudziso mbudziso nda fhindulea lune a thin a thaidzo na u didzhenisa nga ngodo idzi. Ndi a pfesesa uri arali nda funa u litsha ngudo idzi vhukati, u dibvisa hanga a zwi nga kwami dzilafho langa.

Dzina-----

(Kha vha nwale madzina nga vhudalo)

Tsaino_____ Duvha_____

Dzina la mutoli_____

(Kha vha nwale madzina nga vhudalo)

Tsaino_____ Duvha_____

APPENDIX 2: Sepedi Version

Mokgathatema,

Leina la ka ke Modipadi Rebecca Mugivhi. Ke šoma bjalo ka mooki wa profešenale kliniking ya Waterval. Gabjale ke ithutela grata ya Masetase yunibesithing ya Venda. Gore ke hwetše lengwalo la grata yeo ke swanetše go ngwala puku ya dinyakišišo. Dinyakišišo di tla akaretša go go botšiša dipotšišo tše mmalwa maelana le batho bao o ba buditseng ka ga seomo sa gago sa HIV.

O tlo botšišwa dipotšišo, gomme diphetolo tša gago di o tlo di ngwala foromong ya diputsiso. O ka se gapeletšwe go fetola potšišo yeo o sa nyakego go e fetola. Go tlatša foromu e tla tšea metsotso ye e ka bago ye masometharo go nako ya gago.

Bjalo ka moimana yo a tsenetšego lenaneo la PMTCT, o motho yo bohlokwa dinyakišišong tša ka. Go na le baimana ba bangwe ba lesome senyane bao ba tsenetše dinyakišišo tše, eupša le tlo botšišwa dipotšišo ka dinako tšeo di fapanego. Ka lengwalo le ke go kgopela go kgatha tema mo dinyakišišong tše. Pampiri ye e tla go thuša go kgetha ge eba o nyaka go tšea karolo mo dinyakišišong. Ge o nyaka go ba motšeakarolo, tlatša pampiri ya go bontšha gore o a dumela, gomme o e fe mokhanselara wa gago ge o boa mo kliniking. Ge ke se no amogela tumelelo go tšwa go wena, ke tla go botšiša dipotšišo, gomme ka šomiša segatišamantšu go gaitša poledišano. Ke nna feela yo ke tlogo theeletša segatišamantšu seo. Nka se utolle leina la gago le go fihlela ke ngwala puku ya dinyakišišo. Ga go fao leina la gago le tlogo tšwelela.

Ga go na ponelopele ya ditlamorago tše mpe, tefo goba selo se sengwe seo o tlogo ikhola ka sona. O lokolotšwe go ka tlogela go kgatha tema mo dinyakišišong nako ye nngwe le ye nngwe.

Ge o na le dipotšišo o ka nteletša mo dinomorong tšeo di latelago, **0828543342** goba wa nthomela molaetša go email aterese ye: tmugivhi@yahoo.com.

Wa lena ka boikokobetso

MR Mugivh

APPENDIX 3: Fomo ya tumelano

Dihlotlo tšeo bomma bao ba kgethago go fepa bana ka lepotlelo go leka go efoga phetelo ya twatši ya HIV go tswa go mme go ya go lesea ba lebanego le tšona
Manesepala wa Makhado, Profenseng ya Limpopo, Afrika Borwa.

Ke dumela gore ke badile le go kwešiša ditaba tšeo di lego mo lengwalong le. Go lona ke boditšwe ka ga morero, lenaneo, ditlamorago le bohlokwa bja dinyakišišo tše. Ke tšea karolo mo nyakišišong tše ntle le kgapeletšo. Ke bile le nako ya go botšiša dipotšišo le go fetolwa ka go go kgotsofatšago. Ke kwešiša le gore nka no ikgogela morago naka ye nngwe le ye nngwe, seo se ka sa ame kalafo tšaka.

Leina la mokgathatema _____

(Ngwala ka mangwalo a magolo)

Tshaeno _____ Letšatši _____

Leina la monyakišiši _____

(Ngwala ka mangwalo a magolo)

Tshaeno _____ Letšatši _____

Proposed title: *Problems experienced by mothers who opted for replacement infant feeding in a prevention of mother to child transmission programme in Makhado Municipality, Limpopo Province, South Africa*

Principle investigator: Ms MR Mugivhi (student no. 33754144)

Reviewed and processed as: Class approval (see paragraph 10.7 of the UNISA Guidelines for Ethics Review)

Approval status recommended by reviewers: Approved

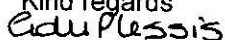
The Ethics Subcommittee of the College of Human Sciences has reviewed your proposal and considers the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed. Approval is hereby granted for the candidate to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa.

In addition, the candidate should heed the following guidelines:

- To only start this research study after obtaining informed consent from your research participants
- To carry out the research according to good research practice and in an ethical manner
- To maintain the confidentiality of all data collected from or about research participants, and maintain security procedures for the protection of privacy
- To work in close collaboration with your supervisor(s) and to record the way in which the ethical guidelines as suggested in your proposal has been implemented in your research
- To notify the Ethics Subcommittee in writing immediately if any change to the study is proposed and await approval before proceeding with the proposed change
- To notify the Ethics Subcommittee in writing immediately if any adverse event occurs.

Approvals are valid for ONE academic year after which a request for a continuation of the approval must be submitted to your supervisor(s).

Kind regards



G E Du Plessis (Dr)

M & DPhil Coordinator
Department of Sociology
Tel + 27 12 429 6507





DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT

Enquiries: Ramalivhana NJ/Malomane EL

Ref: 4/2/2

26 March, 2010

Modipadi Rebecca Mugivhi

P.O.BOX 847

Makhado

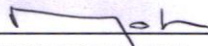
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Dear Modipadi Rebecca Mugivhi

"Problems experiences by mothers who opted for replacement infant feeding in a prevention of mother to child transmission programme in Makhado Municipality, Limpopo Province"

Permission is hereby granted Modipadi Rebecca Mugivhi to conduct a study as mentioned above in Limpopo Province, South Africa

- The Department of Health and Social Development will expect a copy of the completed research for its own resource centre after completion of the study.
- The researcher is expected to avoid disrupting services in the course of his study
- The research results must be used only for the purpose of the study
- The Researcher/s should be prepared to assist in interpretation and implementation of the recommendations where possible
- The Institution management where the study is being conducted should be made aware of this,
- A copy of the permission letter can be forwarded to Management of the Institutions concerned



HEAD OF DEPARTMENT
HEALTH AND SOCIAL DEVELOPMENT
LIMPOPO PROVINCE