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**An Assessment of the Factors that Influence the Infant
Feeding Practices of HIV-positive Mothers in
The Mothers' Programmes:
A qualitative study**

by

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DISSERTATION

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of the requirements for the degree of
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CHAPTER ONE

INTRODUCTION

Many researchers consider breastfeeding as the best way to feed an infant, as it provides numerous benefits both physical and psychological for mother and child (Baumslag & Michels, 1995; Preble & Piwoz, 1998; Smith & Kuhn, 2000; World Health Organization (WHO), 2000; WHO, 2003). However, breast milk is a body fluid, like blood or semen, which can transmit the Human Immunodeficiency Virus (HIV) from mother to baby (White, 1999). A woman infected with HIV may pass the virus on to her child via pregnancy, labour or delivery or through breastfeeding (WHO, 2003). In developing countries where the prevalence of HIV/AIDS is high, particularly among women of reproductive age, protecting children from HIV infection is a critical public health concern.

Promoting optimal infant feeding practices for all women is essential to prevent infant mortality and morbidity due to diarrhoeal and respiratory diseases, which often times can be a result of inappropriate replacement feeding practices (WHO, 2003). For women who are HIV-negative or have unknown status, the optimal feeding pattern is to “exclusively breastfeed [i.e., providing only breast milk and no other liquids or solids] for the first six months of life, with adequate and safe complementary feeding from age six months and continued breastfeeding for up to two years and beyond” (WHO, 2003:5). However, for women who are HIV-positive, it is recommended to use replacement feeding and avoid breastfeeding only if replacement feeding is “acceptable, feasible, affordable, sustainable and safe” (WHO, 2003; Appendix A for definitions). Otherwise, it is suggested that an alternative to replacement feeding, particularly in developing countries, may be to exclusively breastfeed for the first three to six months of the infant’s life with cessation by rapid weaning (WHO, 2003; Coutsoudis et al., 2001). Therefore, the risk of HIV transmission through breastfeeding must

be weighed against the nutritional and immunological advantages of breastfeeding and the potential difficulties associated with replacement feeding (Doherty et al., 2003). Mixed feeding, that is, giving breast milk and other liquids and/or solids, is reported to increase the chances for mother-to-child transmission more than exclusive breastfeeding or exclusive replacement feeding (Coutsoudis et al., 1999; Nduati et al., 2000). Thus, a woman needs to be advised about the benefits and risks of infant feeding options to make a fully informed choice and then be supported in her decision and ensuing practice (WHO, 2003).

Guidelines about HIV and infant feeding are available from the World Health Organization/United Nations Children's Fund/ United Nations Population Fund/Joint United Nations Programme on HIV/AIDS (WHO/UNICEF/UNFPA/UNAIDS) and have been adapted nationally within South Africa (WHO, 2003; Department of Health, 2005). The Joint United Nations Programme on HIV/AIDS recommends that infant feeding advice be context-specific and formulated on the basis of key factors (WHO, 2003). Much research exists on the advantages, drawbacks and outcomes of different infant feeding methods for HIV-infected mothers including investigations into safer methods of feeding (Kuhn et al., 2004; Coutsooudis et al., 2001; Coutsooudis et al., 1999; Nduati et al., 2000; WHO, 2000; Leroy et al., 1998; Bobat et al., 1997). However, studies on South African women's experience in regards to the factors that influence how these women decide and practice infant feeding in specific locations and the practicalities of the different options are lacking. Although different infant feeding options exist for HIV-infected women, exploring the reasons why they have chosen and partake in certain feeding practices can inform both policy and support programmes to reduce mother-to-child transmission of HIV/AIDS as well as diminish harmful infant feeding practices.

The aim of this qualitative study is to explore the factors that affect HIV-positive women's infant feeding choices and practices within the context of a support group in Cape Town, South Africa.

Review of Empirical Studies

The global pandemic of HIV/AIDS is increasing in many of the poorest countries in the world (Jackson, 2002). Sub-Saharan Africa bears the world's heaviest burden with just over 10% of the world's population and two-thirds of the people living with HIV/AIDS (UNAIDS, 2004). Currently there are no drugs or vaccines available to cure or prevent HIV/AIDS making the effects of the pandemic devastating. Moreover, life expectancy has dropped substantially from 62 years in 1990-1995 to 48 years in 2000-2005 in Southern Africa due to the pandemic and is projected to decrease further still to 43 years (United Nations Population Division, 2004).

South Africa has one of the highest prevalence rates of HIV/AIDS in the world where an estimated 21.5% of the adult population (15-49 years) is HIV infected (UNAIDS, 2004). At present, there are 5.3 million people living with the virus in the country out of a total population of 44.8 million (UNAIDS, 2004). Women make up more than half the number of people living with HIV/AIDS and are more susceptible to infection than men due to both biological and social reasons (UNAIDS, 2004; Hoffman et al., 1998). Moreover, HIV prevalence is highest among women aged 20-30, thereby, disproportionately impacting women at the height of their reproductive years (Department of Health, 2003). South African women attending antenatal clinics in the public health sector showed an increase in HIV prevalence from 0.8% in 1990 to 27.9% in 2003 (Department of Health, 2003). This is an indication that infection rates are on the increase and the pandemic has not yet stabilized.

In Sub-Saharan Africa, it is estimated that HIV/AIDS accounts for 8% of the deaths in children less than five years of age (WHO, 2003). An infant's immune system is not fully developed, and therefore, HIV-infected infants normally develop AIDS more quickly than adults (Jackson, 2002). Many infected babies die within the first few years, although with proper access to antiretroviral treatment children may be able to live longer lives (Jackson, 2002). Statistics shows that an estimated 200,000 children aged 0-15 are living with the virus in South Africa (UNAIDS, 2004). A majority of these children will have acquired the disease from vertical mother-to-child transmission (Jackson, 2002; WHO, 2003).

Mother-to-Child Transmission (MTCT)

There are three ways infants can acquire HIV from their mothers: during pregnancy, at delivery, or through breastfeeding. Mother-to-child transmission (MTCT) rates vary in different contexts with developing countries rates ranging from 13% to 42%, where breastfeeding is more common and HIV prevalence is high (WHO, 2003). In the absence of interventions, it is estimated that the mother-to-child transmission rate is 5-10% during pregnancy, 10-15% during labour and delivery and 10-20% through non-exclusive breastfeeding (de Cock et al., 2000). Researchers have found that pregnant women taking the antiretroviral drug Zidovudine (AZT) or Nevirapine can substantially reduce transmission of HIV to the foetus during pregnancy and labour; however, the option of antiretrovirals for mothers and/or babies as a prevention method to reduce MTCT during the period of breastfeeding is still being explored (Shaffer et al., 1999; Jackson et al., 2003; Doherty et al., 2003).

Transmission risk of HIV during breastfeeding can vary according to the maternal and child health and the duration and pattern of the breastfeeding (Coutsoudis & Rollins, 2003). There are a number of maternal factors that have been shown to increase the chances of postnatal

transmission. These are: the disease progression (low CD4 count and high viral load); breast health (e.g., mastitis: inflamed mammary glands); local immune factors in the breast milk and systemic infections (WHO, 2003). When a woman has recently been infected with HIV, the risk of transmission through breastfeeding doubles due to high viral load subsequent to the initial infection (WHO, 2003). Moreover, the longer the duration that the mother breastfeeds her baby, the higher are the chances of the child being infected with the virus. One explanation for this is that postnatal transmission is constant throughout the breastfeeding period; therefore, a longer duration of breastfeeding increases the cumulative risk for postnatal HIV transmission to the child (Breastfeeding and HIV Transmission Study Group, 2004). Other studies have noted that there may be the highest risk within the first several months of breastfeeding (Miotti et al., 1999; McCoy et al., 2003; Nduati et al., 2000).

The infant's health (e.g., oral thrush) and mode of breastfeeding can also influence the transmission rates (WHO, 2003). Studies suggest that exclusive breastfeeding (i.e., only giving breast milk and no other liquids or solids) for between three to six months compared to never breastfed infants had similar risk of HIV infection (Coutsoudis et al., 2001). Furthermore, mixed feeding during the first three months (i.e., giving breast milk and other liquids and solids) is reported to increase risk of HIV infection compared to exclusive breastfeeding (Coutsoudis et al., 1999; Nduati et al., 2000). Although more studies are planned to further test this hypothesis in Zambia and South Africa, it is suggested that exclusively breastfeeding for a short duration (four to six months) with abrupt weaning may be an alternative to reduce MTCT while minimizing the problems with formula feeding (Ilf, 2005; Kuhn et al., 2004; Coutsooudis et al., 2001).

Reasons as to why mixed feeding may increase HIV transmission are not well understood. One explanation is that the infant's gut integrity may be altered or damaged from non-breast

milk substances. This allows the ingested milk with the HI virus to more easily infect the infant (de Paoli et al., 2002). Another study explained that the promotion of the beneficial intestinal microflora might increase resistance to infection and modify infant's immune system (Rollins et al., 2002). It is also suggested that exclusive breastfeeding may maintain breast health in the mother reducing the viral load in breast milk (Smith & Kuhn, 2000). As a result of all of the above, the most potentially harmful feeding pattern for HIV-infected women to practice is claimed to be partial prolonged breastfeeding (White, 1999).

Risks and benefits of breastfeeding and replacement feeding

International guidelines suggest that the ideal infant feeding method for HIV negative women is to exclusively breastfeed particularly in the first months of life, whereas, not breastfeeding heightens the risk of infant mortality and morbidity by increasing the chances of malnutrition, diarrhoeal diseases and respiratory infections (Preble & Piwoz, 1998; Smith & Kuhn, 2000; WHO, 2003; WHO, 2000). Breastfeeding has various advantages such as: psychological benefits to infants and mothers, decreases infant morbidity and mortality by protecting the infant from a number of infections, provides child-spacing benefits by reducing fertility, costs no money, and reduces the risk of ovarian, breast and cervical cancer, as well as osteoporosis in the mother (Preble & Piwoz, 1998; UNICEF, 2005; Baumslag & Michels, 1995).

Breastfeeding is not devoid of risk as breast milk can transmit infectious diseases including HIV/AIDS, tuberculosis and hepatitis as well as damaging toxins including DDT (Goldfarb, 1993; Richter & Griesel, 1998). Additionally, reported in White (1999), other viruses spread by breast milk are human T-cell lymphotropic viruses type 1 and 2 (HTLV-I and HTLV-II), which are retroviruses in the same class as HIV, and cytomegalovirus (CMV). Women with HTLV-I and HTLV-II are recommended not to breastfeed, as well as, women with a co-

infection of CMV and HIV/AIDS, as it increases the risk of CMV becoming symptomatic (White, 1999).

Replacement feeding

Replacement feeding is providing a nutrient-sufficient diet for an infant in the absence of breast milk (WHO, 2003). During the first six months, this should be with a suitable breast milk substitute such as commercial formula, home-prepared formula with micro-nutrient supplements (WHO, 2003). The main benefit of replacement feeding is that it provides an alternative infant feeding method for women unable or not recommended to practice breastfeeding. Women living with HIV/AIDS in developed countries are typically encouraged to use replacement feeding to reduce the risk of HIV/AIDS transmission (WHO, 2003). In fact, at the 1998 World Health Assembly, the appropriateness of the 1991 Code of Marketing of Breast-Milk Substitutes (rules enforcing standards about the marketing of replacement milk products) was questioned and challenged as the Code was implemented before anyone foresaw that breast milk could pass on the HI virus (Richter & Griesel, 1998).

Much debate still exists about promoting replacement feeding in developing countries where living conditions, lack of knowledge about appropriate replacement feeding practices, cost of formula milk, and unsustainability of formula feeding have made replacement feeding practices prohibitive and dangerous (UNICEF, 2005). Recommending replacement feeding for HIV-infected women in developing countries leaves many advocates of breastfeeding concerned (Coutsoudis et al., 2002). This is because there are a number of risks related to not breastfeeding or inappropriate replacement feeding practices which may stem from unsanitary conditions and lack of clean water (UNICEF, 2005).

The risks of not breastfeeding vary according to the mother's infant feeding practice and her living environment. Infants in developing countries have a six-fold increase risk of infant mortality due to infectious diseases when infants are not breastfed within the first two months of life (WHO, 2000). The WHO (2003:8) claims, "Every year, up to 55% of infant deaths from diarrhoeal disease and acute respiratory infections may result from inappropriate feeding practices." As a result, women who use replacement feeding need to be informed of appropriate replacement feeding practices and the hazards of not breastfeeding.

Recommendations for infant feeding

It is suggested that when a woman is HIV-negative or unsure of her status, exclusive breastfeeding should be promoted especially in the early stages of the infant's life (WHO, 2003). Giving recommendations to HIV-positive women is more challenging where the risk of HIV transmission must be balanced against issues related to replacement feeding. Therefore, guidelines provided by WHO/UNICEF/UNAIDS/UNFPA state that:

When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended; otherwise, exclusive breastfeeding is recommended during the first months of life (WHO, 2003:9). (See Appendix A for definitions)

In addition, the recommendations advise that:

When HIV-infected mothers choose not to breastfeed from birth or stop breastfeeding later, they should be provided with specific guidance and support for at least the first two years of the child's life to ensure adequate replacement feeding (WHO, 2003:9).

There are a number of options for mothers living with HIV/AIDS to choose from including commercial infant formula, exclusive breastfeeding for a short duration with rapid weaning, modified animal milk, wet nursing, heat-treated expressed breast milk, and donor and breast milk banks (WHO, 2003; see Appendix B for the definitions). Recommendations also include

that cup feeding is preferable to bottle feeding. A cup is considered easier to keep clean and free of bacterial contamination whether the woman uses formula milk or breast milk.

Infant feeding in South Africa

Exclusive breastfeeding has been promoted for many years in South Africa because of the positive outcomes for infants and mothers. There are hospitals in South Africa that subscribe to the Baby-Friendly Hospital Initiative (BFHI), launched by UNICEF and WHO over a decade ago, which promotes exclusive breastfeeding immediately after a woman gives birth and requires the hospitals not to accept free or low-cost breast milk substitutes (UNICEF, 2005). There are a few documented cases where programmes that consistently promote and support exclusive breastfeeding through peer counselling efforts increase the success and duration of the practice (Haider et al., 2000; Morrow et al., 1999). However, exclusive breastfeeding practice, regardless of HIV/AIDS, tends to be difficult for many women around the world, including South Africa. Some of the reasons are concerns over the baby crying incessantly, perceived insufficient milk supply, family pressures, and cultural or traditional factors (Bland et al., 2002; Obermeyer & Castle, 1997; White, 1999). Exclusive breastfeeding for a short duration is one recommended infant feeding option for HIV-infected mothers in South Africa, and thus, there is a need to know how the social and cultural factors are anticipated and addressed by HIV-positive mothers and the people who counsel them.

Currently debate exists about the recommended infant feeding options for HIV-positive mothers in South Africa, and therefore, counselling given to pregnant women may be hindered or biased due to conflicting or mixed messages given regarding infant feeding. A study conducted in South Africa found poor quality of counselling about optimal feeding practices, thereby, reducing the potential effectiveness of PMTCT programmes (Chopra et al., 2004).

As a result of the high prevalence of HIV/AIDS in the country, the South African government has designed a policy guideline (Department of Health, 2005) on HIV and infant feeding based on the recommendations of the international guidelines from WHO/UNICEF/UNAIDS/UNFPA (1998). The guideline and recommendations state that mothers need to be counselled about the different feeding options in order to make an informed choice. HIV-positive women are expected to choose an infant feeding method keeping in mind living conditions and social context.

Exclusive breastfeeding is suggested as a better option than formula feeding when breastfeeding is the norm and HIV/AIDS stigma is high, compounded by a woman having little support to uphold consistent formula feeding practices (Epstein et al., 2002). Statistics show that as many as 87% of women breastfeed for at least some of the time in South Africa (Department of Health, 1998) indicating breastfeeding is a norm. It is also reported that people living with HIV have felt stigmatised in South Africa (Guma et al., 2005). The UNAIDS report maintains that stigma is one of the major barriers to effective AIDS responses and preventing spread of HIV/AIDS (UNAIDS, 2004).

For the HIV-positive women attending the PMTCT programme who decide to replacement feed their infants, the South African government provides the first six months of formula milk for free (South African Government, 2003). The reason for providing formula milk is to make replacement feeding a more affordable and feasible option for women using the public health sector and to reduce mother-to-child transmission of HIV. The mothers must be able to attend a clinic site that offers the formula milk, as well as, regularly retrieve new supplies. In spite of free formula, the mothers must be able to obtain the bottle(s) and other equipment for formula

feeding and have access to resources to feed the baby after six months. This may be problematic for women who rely on others for income or have very limited resources.

“Spillover” effect

There is widespread concern particularly in developing countries of a “spillover” effect, that is, that formula feeding practices will spread among uninfected mothers or mothers with unknown status due to fears about HIV, availability of breast milk substitutes or general misinformation (Kuhn et al., 2004; Department of Health, 2002; Koniz-Booher et al., 2004). The major concern is that increasing acceptance of formula feeding could unnecessarily increase infant morbidity and mortality preventable by breastfeeding among women who are HIV-negative. “Spillover” of replacement feeding would furthermore prove detrimental to efforts made to promote the benefits of breastfeeding in South Africa; thus, there is some debate about providing government-sponsored replacement feeding for PMTCT programmes despite the devastating consequences of mother-to-child transmission (Sherman et al., 2004). A study in Botswana suggested that the general population could perceive the provision of formula milk at the PMTCT facilities as endorsing formula feeding as better than breastfeeding (Willumsen et al., 2001). A baseline study conducted in South Africa in 2003 found no evidence of spillover though a follow-up study is planned to reevaluate and validate the findings (McCoy et al., 2003).

Ultimately, it is important to know how HIV-positive women go about choosing their infant feeding methods and what their perceptions are about them. HIV counsellors and lay health care workers provide information regarding infant feeding practices, and thus, it is vital to know whether the counsellors influence HIV-positive women’s feeding decisions in relation to social, cultural and/or other factors.

Problem Statement

Given the previous outline, it is clear that mothers who are HIV-positive are faced with complex issues when making decisions about infant feeding practices, as there is no consensus regarding which one method of feeding is ‘best’ or most practical for HIV-positive women living in countries with high HIV prevalence, including South Africa. Even with counselling, many factors can influence a woman to practice mixed feeding. The problem is that mixed feeding increases the infants’ risk of HIV infection (Coutsoudis et al., 1999) and inappropriate replacement feeding has detrimental outcomes for infants (UNICEF, 2005). Therefore, there is a need to understand what information mothers rely on in a local setting when making infant feeding choices, their reasons behind their preferred choice and their infant feeding practices specifically within the framework of a support group to reduce the chances of harmful infant feeding practices.

Research Purpose and Aim of Study

The purpose of the study was to determine HIV-positive mothers’ preferences for infant feeding decisions and subsequent practices and to provide this information to relevant programs so as to help to facilitate a reduction in vertical HIV/AIDS transmission and any inappropriate infant feeding practices. The aim of the study was to investigate the primary influencing factors related to HIV-positive mothers’ infant feeding decisions and practices in the context of a support group within “The Mothers’ Programmes” in Cape Town, South Africa.

This study specifically focuses on Mothers-2-Mothers programme within The Mothers’ Programmes. The Mothers’ Programmes are support groups for antenatal and postnatal women living with HIV/AIDS. Further description of The Mothers’ Programmes is provided in Chapter Two under Research Setting.

Research Objectives

- To understand the experience of making feeding decisions in light of the mothers' HIV status and to identify the counseling, social, cultural, economic or other factors affecting the mothers' choices and behaviours of infant feeding practices
- To determine the women's knowledge about exclusive breastfeeding, mixed feeding and exclusive formula feeding
- To determine feeding practices from birth up to the time of the interview, and the reasons why these practices are undertaken
- To determine if feeding practices match feeding decisions made by the mother before the birth of the infant
- To explore the study participants' experiences with the Mothers' Programmes (specifically the Mothers-2-Mothers programme) in order:
 - To learn what feeding information is given to the mother by the mentors/site coordinators
 - To determine how the mentors and site coordinators counsel the mothers on the feeding options (e.g., messages given to the mother)
- To determine the mentors' and site coordinators' thoughts of how the mothers' made feeding decisions and their ensuing infant feeding practices

Organization of Remaining Chapters

This introductory Chapter has given background about infant feeding options available to HIV-infected women and international and national recommendations in light of the potential issues faced in developing countries. The Chapter has also provided the main purpose and objectives of the study.

Chapter Two describes the methodology of the research and includes a brief overview about The Mothers' Programmes.

Chapter Three presents the findings, focussing on the major factors and themes influencing HIV-positive women's infant feeding decisions and practices.

Chapter Four engages the reader in discussion regarding the findings.

Finally, Chapter Five draws conclusions and gives recommendations derived from the study on the implications of the major themes.

CHAPTER TWO

RESEARCH METHODOLOGY

This Chapter provides an explanation of the The Mothers' Programmes, the research setting and the methodology including the study design, sampling of study participants, and data collection and analysis approaches.

The Mothers' Programmes

The Mothers' Programmes, located in various sites in South Africa, offer counselling and support to HIV-positive women both during and after pregnancy and they have been designed to be complimentary to the South African government's initiative aimed at preventing mother-to-child transmission (PMTCT). The vision of the programmes is to empower HIV-positive women in need, through education, emotional support and economic opportunities. The Mothers' Programmes consist of multiple programmes providing different services and opportunities. For instance the Mothers-2-Mothers-2-Be programme is designed for antenatal mothers, while Mothers-2-Mothers programme focuses on postnatal mothers, and Mothers' Creations offers economic opportunities to postnatal mothers who want to learn to bead.

The focus of this study is the Mothers-2-Mothers (M2M) programme, which is based on a mentorship principle that provides opportunities for women participating in the programme to counsel, educate and support the new mothers about topics such as infant feeding, treatment, health education and more. The mentors are selected according to criteria, such as having disclosed to someone outside the support group, and they mentor for a maximum of six months in order to increase the opportunity of participation for other mothers. Depending on the site location, there will be two to three mentors for each weekday. The mentors receive training and are paid for their time. Attendance is voluntary for the women they mentor and

the mothers may remain in the programme for as long as they want to continue with the support group.

Research Setting

The Mothers' Programmes operates at a number of sites around South Africa. For the purposes of focusing on an urban area and for logistical reasons the Mothers-2-Mothers sites in Cape Town were selected for the study. The four sites where interviews took place were all in Khayelitsha. At the time of data collection, these were the Mothers-2-Mothers sites that had been established in Cape Town that met the study criteria of participants being involved with the programme for at least three months.

Khayelitsha is a peri-urban settlement about 30 km outside the centre of Cape Town with approximately 400,000 residents (Municipal Demarcation Board, 2005; Hilderbrand et al., 2003). It is an area that is rapidly expanding with constant rural/urban migration (Young & Coetzee, 2000). Many of the residents live in shack dwellings with no running water inside the home (personal communication with resident, October 2004). Most areas have access to clean water taps situated on the street for communal usage. It is common that residents have no electricity inside the home and use paraffin stoves for cooking (or boiling water in the case of infant feeding).

The PMTCT programme has operated at clinics in the district since January 1999 providing access to voluntary testing and counselling about HIV for antenatal women, Zidovudine (AZT) anti-retroviral prophylaxis for HIV-positive women, HIV testing and PCP prophylaxis for the infant, and formula feeds (Young & Coetzee, 2000). Currently there are eight hospitals and clinics providing HIV/AIDS services and a number of non-governmental organizations

(NGOs) assisting in the prevention and care of HIV/AIDS in Khayelitsha (Provincial Administration of the Western Cape, 2004).

The prevalence of HIV/AIDS is estimated to be 13.1% in the Western Cape province; in Khayelitsha, it is estimated to be over double that, or 27.2%. (Provincial Administration of the Western Cape (PAWC), 2004). During 2002-2003, the prevalence of HIV has increased in all age groups in the Western Cape, except in the 40+ age group, with the highest prevalence rates detected in the 25-29 year age group (17.5%). Furthermore, the PAWC (2004) surveys demonstrate that the HIV prevalence has steadily increased for the past eight years in the less than 20 age group.

Study Design

A qualitative study was conducted to explore HIV-infected women's infant feeding decisions and practices. The philosophy behind using qualitative research approach is to understand how behaviours and social processes are determined, which is relevant to this study (Katzenellenbogen et al., 2001). Qualitative methods are able to assist the researcher to discover new information or fresh perspectives on a phenomenon from the participants' personal experiences. Rather than beginning with preconceived notions or a hypothesis, themes emerge directly from the data.

Sampling of Participants

Purposive sampling was conducted to obtain the respondents from The Mothers' Programmes. This sampling method is used to enable the researcher access to participants that are optimally positioned to give rich material within a representative spectrum of sub-groups (Katzenellenbogen et al., 2001). The study population was stratified into three groups: mothers, mentors and site coordinators. The idea was to determine the difference in

knowledge and experience between these groups. For example, the mentors were more likely to be knowledgeable on infant feeding practices than the “mothers”, as they had been previously selected from among the peer group to act and be trained as educators and role models.

The following criteria were used to determine participants’ selection:

- Women who were considered a member of or who worked for the Mothers-2-Mothers support group
- Mothers and mentors who were HIV-positive. The site coordinators did not have to be HIV-positive
- Women with a baby over the age of three months, which was determined to be a sufficient amount of infant feeding experience
- Women over the age of 18 for ethical considerations (did not need parental consent)
- Women who were conversant in English in order to have a mutually understood language between respondents and researcher

The sample of mothers selected were women in the Mothers-2-Mothers programme who had a baby between the ages of three months to nine months and had never previously been a mentor. The mentors were chosen on the basis that they were currently acting as mentors and had a baby of at least three months. Participants who had an infant older than three months were selected on the basis that it was considered they would have enough experience in feeding practices to draw from. The site coordinators were chosen on the basis that they had worked a minimum of six months at the site(s) and had adequate experience with the programme to be monitoring the site(s). All participants were conversant in English.

The study sample comprised thus:

- Five mothers
- Three mentors
- Three site coordinators

The site coordinators and mentors facilitated the selection of “mothers” by identifying individuals fitting the criteria. There was one mother, the first respondent, who was uncomfortable and afraid to answer a few pertinent questions during the interview despite informed consent. For this reason, after consulting with my supervisor, I decided to increase my sample size from the original proposed number of four mothers to five.

Data Collection

The method of data collection was an in-depth semi-structured interview with each participant. In-depth interviewing was chosen as it allows the respondents to give personal accounts of their experience. An interview lasted on average 45 minutes.

Individual in-depth interviews were chosen as the data collection method rather than focus groups because one of the objectives was to determine the infant feeding knowledge and messages gained from the support groups. Women more fluent in English and confident in their feeding choice and practices may have been more dominant in the focus groups possibly biasing the results of the study.

Interview guides (see Appendices C, D, and E) were developed for each group of participants (i.e., mothers, mentors, and site coordinators). Only the “mother” interview guide was piloted separately with two women in the programme who were not participating in the main study. The pilot interviews enabled informed changes to all of the interview guides. This process

assisted me in discovering that the arrangement of the questions resulted in different responses.

All of the interviews were conducted in English as I am not fluent in Xhosa, the primary language spoken in Khayelitsha. This is a limitation to the study because as a general rule expressing oneself comes most freely in one's first language. However, the Mothers' Programmes assured me that there would be adequate numbers of women in the Mothers-2-Mothers programme conversant in English, and I preferred to speak directly to the respondents rather than feeling distanced by an interpreter.

All of the interviews were tape recorded with permission obtained from the respondents. Each participant was informed of the contents of the consent form in English and was given the same form in Xhosa to read which had previously been translated and back translated (see Appendices F, G). The consent form was pre-approved by the UCT Research Ethics Committee. After going through the consent form to establish the interview was voluntary, confidential and no negative repercussions would exist were they to withdraw at any time, all of the women agreed to participate in the study and signed the form. Confidentiality was ensured for all participants as names and statements that might reveal a respondent's identity were omitted and only my supervisors and I have access to the data. All audiocassettes have been stored in a locked area and will remain in a safe location for a period of two years, after which time they will be erased.

Basic socio-demographic information was collected on a confidential form from each participant to develop a profile of the sample population (see Table 1). None of the participants received monetary compensation for their time, although refreshments were provided during the interview.

Table 1: Socio-demographic characteristics of study participants

Characteristic	Mother	Mentor	Site Coordinator	Total
Age Range				
20-24 years	1	0	0	1
25-30 years	4	1	0	5
31-35 years	0	2	1	3
36+ years	0	0	2	2
Baby's Age				
3-5 months	2	0	0	2
6-9 months	3	2	0	5
10-12 months	0	0	0	0
1-2 years	0	1	1	2
2+ years	0	0	2	2
Other children				
Yes	2	2	2	6
No	3	1	1	5
Length of time in The Mothers' Programme				
3-5 months	2	0	0	2
6-9 months	3	0	0	3
10-12 months	0	0	0	0
1-2 years	0	2	0	2
2+ years	0	1	3	4
Employment status				
Employed	3	3	3	9
Unemployed	2	0	0	2
Marital Status				
Married	1	1	3	5
Not married	4	2	0	6
Partner status				
Boyfriend	2	1	0	3
No boyfriend	1	1	0	2
Lives with boyfriend or husband	2	1	3	6
Education				
Grade 1-7	1	1	1	3
Grade 8-9	1	1	0	2
Matric	3	1	2	6

Permission to conduct the study was granted by the Director of the Mothers Programmes, Dr. Mitch Besser and ethical approval was obtained from UCT Research Ethics Committee prior to data collection.

A journal documenting the research process including the initial stages of forming the research question, meetings with colleagues working in the field, informal interviews, and topic-related insights and experiences was kept. The reflective journal, an essential component for qualitative research, assisted with the data analysis.

Data Analysis

A grounded theory approach was used for data analysis. The main aim of grounded theory is to generate theory from the data set to reflect the reality of the participants' experiences. The researcher must be open-minded and think outside any preconceived ideas and assumptions during the research process (Strauss & Corbin, 1990). The essence of grounded theory is to allow the themes or theories to emerge from the data through the process of coding, categorizing and being sensitive and insightful to patterns appearing in the data. The following details the data analysis process including transcribing, coding, categorizing and developing theories.

Interviews were transcribed verbatim by the researcher after each interview. The transcriptions served as the data set. Due to a variety of factors, the process of transcribing proved challenging at times. Most interviewees had children with them, and thus, some speech was inaudible due to the baby noises and the participants' soft speech. In addition, the private rooms at the clinic had ambient noise and occasional interruptions occurred with people needing to retrieve items from the room.

Despite the prolonged nature of transcribing, the process of listening carefully to the tapes improved my interviewing style and increased my sensitivity for emerging patterns in the data. It is advised when using a grounded theory approach to begin data analysis concurrently with data collection (Strauss & Corbin, 1990). Transcribing immediately following interviews allowed for this to happen.

The first step after transcribing the interviews was to read through each transcript and write codes in the margins. I began with one transcript from a mother followed by one from a site coordinator to compare similarities and differences in the interviews. Initially I avoided codes, or “borrowed concepts”, such as “stigma”, that I considered may have had too many preconceived ideas or various definitions, as was warned by Strauss & Corbin (1990). However ultimately, stigma was clearly defined and became a code and a category due to its prevalence in the interviews.

Subsequent to coding the transcripts, cards were used to record the codes that arose in the interviews matched with the quotes from the interviews. After almost completing the process I began to cluster the index cards to form groups or “categories.” A category defined by Strauss & Corbin (1990:61) is a classification of concepts:

“This classification is discovered when concepts are compared one against another and appear to pertain to a similar phenomenon. Thus the concepts are grouped together under a higher order, more abstract concept called a category.”

During this process of coding and categorizing, I kept dated memos of ideas that originated from this process as is recommended by grounded theorists (Strauss & Corbin, 1990). Memos can be important in illuminating theories and highlighting areas to analyse further.

Finally, as many qualitative researchers suggest, the analysis must be creative to derive linkages between categories and generate ideas used for theory development. There were two ways in which I derived my theory. Firstly, I wrote a “story” about what I learned from my analysis. The story line is a way to move from the descriptive elements of the data to a more conceptual level of analysis (Strauss & Corbin, 1990). Secondly, I drew diagrams of the elements that seemed central to the analysis and connected similar factors with their related issues. The diagrams provided pictures to assist in theory development comprehensive of the numerous categories and sub-categories.

The themes and sub-categories generated from the data were:

- a) Fear (fear of dying; fear of infecting one’s child)
- b) Formula feeding issues (stigma, socio-economic circumstances)
- c) Breastfeeding issues (past breastfeeding practice; questioning the feasibility of exclusive breastfeeding)
- d) Power relations (gender inequity; dynamics within the family)
- e) Reconciling beliefs, provider advice and peer pressure
- f) Support (The Mothers’ Programmes; partner and family support)
- g) Knowledge (information sharing; informed choice and infant feeding knowledge; lack of knowledge, misinformation and non-behaviour change).

These themes will be discussed in the next two chapters: Findings and Discussion.

CHAPTER THREE

RESEARCH FINDINGS

The main themes to emerge from the data were fear; formula feeding and breastfeeding issues; power relations; reconciling beliefs, provider advice and peer pressure; support and knowledge. This Chapter details how these aspects inform and impact the mothers' infant feeding decisions and practices.

The abbreviations in the interview quotes are as follows: **SC**: site coordinator; **MN**: mentor; **M**: mother; **I**: interviewer.

Fear

Fear can be an overwhelming feeling of anxiety caused by potential danger or pain. Many of the respondents encountered a variety of aspects that made them afraid with the two most poignant fears being a) dying and leaving a child behind, and b) potentially infecting one's baby with HIV/AIDS.

Fear of dying

For many respondents, discovering one has a terminal illness while pregnant was frightening. Depression and despair following the initial HIV-positive diagnosis were regular consequences suffered by the women before attending the programme. One site coordinator explained how she felt and responded after having heard she was HIV-positive.

SC: It's not. Ooo it's not easy... [after being diagnosed] I was running out of my money, because everything I didn't even know that it's night, it's day whatsoever, because I was staying in the house. Not going out. Because I thought I'm going to die, maybe tomorrow or other day whatsoever. When I woke up and then I didn't die, and then I'll say 'Oh my God, why?' Because I want to die. Not thinking about this, one day I said to my husband, 'I wish I could sleep the *whole* week and then the following week I'd wake up so I'll forget *everything*.'

Having a terminal illness and seeing no future may lead to destructive behaviour in an attempt to deny and forget the existence of the illness. For instance one woman mentioned how she developed a drinking problem after learning about being HIV-positive.

MN: I was worried, just like I didn't see nothing in my life. I told you, now I'm HIV-positive I must run away from home, go away. I can also take that drink. I want to just die.

The site coordinators, familiar with the pain and fear of being diagnosed with HIV/AIDS while pregnant, realized the mothers must receive counselling about the disease before discussing disclosure and infant feeding. After a woman began to accept her disease status and received HIV/AIDS education, she may have been more prepared to think realistically about infant feeding options.

SC: For the first time I will ask, I will give the mother everything every education, because I know that they still feel pain of having HIV and whatsoever. But when they are coming for the second time I will ask, 'Did you disclose to your family?' Maybe she said 'yes'. 'Did you decide what you are going to give your baby? Are your going to formula feed or breastfeed?'

Fear of infecting one's baby

The respondents stated that their infant feeding decisions were largely affected by their concern of passing the virus on to their babies. The respondents who attended the support group were familiar with the fact that there is a risk of HIV transmission while breastfeeding, and even more so with mixed feeding. The fear of infecting one's baby persuaded all of the HIV-positive respondents to choose formula feeding instead of breastfeeding.

MN: I was thinking because of HIV, now I'm scared. I don't want my baby to get HIV, because if I feed my baby with my breastfeeding up until six months, mustn't eat nothing. Now I'm feeling this, I can't do that because I'm scared. I choose bottle-feeding...because I am HIV-positive... I'm so afraid that to give her the breast because sometimes she is [inaudible] HIV-positive.

The same respondents said they would not consider breastfeeding because they were aware of their HIV status and knowledgeable about HIV transmission through breastfeeding. The fear of transmitting the HI virus to the baby was perceived to be a much greater risk than the potential health problems associated with formula feeding. A woman implied that if she were to breastfeed it would have meant she did not care about her baby.

MN: I decided formula feeding because I know my status. I know that I'm HIV-positive and that I don't want my baby to be infected with HIV too. So I do that. I choose that formula feeding because I care about my baby.

One site coordinator explained how if a baby were to get sick and have bouts of diarrhoea before receiving HIV test results, the mothers felt anxious the baby might be HIV-positive rather than assuming there was a replacement feeding problem. After the baby received a negative test result, mothers tended to feel the biggest issue had been overcome.

Formula Feeding Issues

All of the respondents practiced formula feeding and the main issues that surfaced with the feeding method were problems of HIV/AIDS related stigma and women's socio-economic circumstances.

Stigma

HIV/AIDS related stigma made many of the women both fearful of their status becoming known and the potential adverse consequences of disclosure. They were worried about being rejected by their family and discriminated by people in the community. Respondents discussed the lack of knowledge and the numerous misconceptions in the community about HIV/AIDS that perpetuated the stigma. During the interviews some of the mothers became emotional about the discrimination experienced outside the confines of The Mothers' Programmes.

M: Because if you tell somebody outside [the program], 'I'm I'm HIV-positive' they told, they tell you, 'Wow, you're HIV, don't stay with me, sorry.' Like that. So I'm that. I'm feel very sorry... I'm so sad. I feel sad.

The women in the programme were sometimes afraid of rejection by their partner or family if their status were to be revealed. Some respondents spoke about the negative reactions women experienced when they disclosed their status to their partners or family members.

MN: Some of us disclose to the partners and then some of us came back, 'oh my partner ran off, because he says, 'It's *your* HIV! I'm not HIV.' But he said that he's not going to test, he just say that, 'I'm not HIV-positive.' He say, 'I take my pack my things in the house, and I go.'"

The women felt exposed about which feeding method they were providing for their baby, because family, friends and others scrutinized their practices. People in the community became suspicious about why some mothers used formula feeding instead of breastfeeding, which was the norm in the community. One site coordinator spoke about women needing to provide explanations for formula feeding, as there were presumptions about their HIV status otherwise.

SC: Yo, it's not easy. Especially in our culture because... we know that the in our culture the mother must breastfeed the baby. If you're not going to breastfeed the baby,

you have to explain it. You need a lot of explanation. As a result in the location, if you're not breastfeeding your baby, they know that you are HIV-positive. It doesn't matter whether it's true or not. If you don't, don't breastfeed, it's really a problem.

Furthermore, women were assumed to be HIV-positive if using Pelargon, the government sponsored formula brand supplied at the PMTCT clinics. It was typical for the women to be questioned and sometimes harassed about their feeding practice. A mentor explained how HIV stigma was pervasive to the point that people would visit the woman after she gave birth to enquire or observe how she had chosen to feed her baby.

MN: It's difficult! Because outside there, they don't know your status so you meet so many people that ask you, 'Why don't you breastfeed? Hey! Take your breast and give it to the baby!' So you make so many problems there outside. But some of us just solve that and some of us not solve that, and they are giving the baby the breast. When you come from the hospital [after delivering] they came...to know which milk you use, you breastfeeding or not. So they give you so many questions, 'Why? What's wrong with you?'

Furthermore, there was the expectation by the respondents that the women using Pelargon must endure questions pertaining to this specific brand name recognizable by its orange coloured container. A few mothers, if they could afford to do so, bought other brands of formula besides Pelargon to avoid people's suspicions and being labelled HIV-positive. Some women could be so fearful of their status being revealed, they would go to different clinics to collect the formula milk or would only step inside the Mothers-2-Mothers room to drop off the form for formula milk supplies because of the fear of being seen by an acquaintance.

SC: So we referred them to the next clinic. Others, they don't want to go to the nearest clinic, because they will say, 'I will see someone who knows me there.'

SC: The other one [s]he got a problem, just see, pop in there, that room. They leave the card. Then [s]he come to sit with the other people outside.

Knowing that stigma exists in the community, the women fabricated “stories” or lies about why they were not breastfeeding to avoid disclosure. Depending how persistent the enquirer, the mothers found the experience of telling the story fairly simple to extremely challenging.

M: When I’m going back after birth. They ask me some questions, ‘why are you not going to give her the breast?’ I said ‘they say I have no milk in my breast.’ ‘Why?’ ‘I don’t know.’ So they have a question...They want to know why some mothers give gave Pelargon...They want know why...you feeding the baby with bottle. So I’m going to lie.

The fear of disclosure and stigma about HIV/AIDS made many of the mothers selectively tell people about their HIV status to gain support. The women strategically disclosed to the “right” people; ones who would be trustworthy in keeping the knowledge secret or a potential future caregiver were the mothers to get sick and die. An important consideration for some women was if family members abused alcohol and might divulge a woman’s status while drinking heavily, therefore, making the person an undependable confidant.

M: I don’t tell my cousin that my life has changed. Now I live HIV-positive life. I don’t tell anything, because drinking a lot and shouting things.

MN: Maybe you can tell your mom or one of your sisters. Some of our brothers and our sisters are drunk. So we are afraid to tell them because they go to the shabeens and say, ‘My sister is HIV-positive!’ So we choose in the family: I’m going to tell this one, I’m not going to tell this one, because I have this reason.

Alternatively, a few women felt forced into disclosing their status in order to stop the persistent questioning about their feeding methods. One mentor describes how it became easier to explain the real reason for formula feeding rather than continue to be barraged by questions and speculation about her HIV status.

MN: They ask me why I feed my baby with the bottle. I said, 'I like to feed my baby with the bottle. Why you asking me?' They told me, 'Maybe your HIV-positive that why you bottle feed your baby.' I said, 'No leave me alone. I won't tell.' The other neighbour beside me was talking to me and asked and I told her, I told her, 'Yes, I'm HIV, that's why I choose to feed my baby the bottle.' Because they give me lots of trouble, that's why I choose to tell them, explain... [Afterwards] they stopped asking me.

Socio-economic impacts on formula feeding

Almost all respondents said nothing would make them change from formula feeding to breastfeeding. They had all relied on access to formula milk from the clinic, and mothers who were not working were unsure how they would otherwise have been able to afford the formula. Some of the women believed if they had not received the formula from the PMTCT programmes there would have been serious consequences for their child, even death. One mentor felt strongly that nothing would persuade her to breastfeed even if she had not been supplied replacement feeding by the PMTCT programme.

MN: Ya, I don't know but I think that the baby maybe by now if I couldn't get the formula, maybe by now she is dead. She was dead by now if I didn't get the formula from the hospital. Because I don't know how I'm going to feed her, by what?

Some of the mothers who made the decision to formula feed did not know what would happen once they had completed the six-month allotment of formula milk from the clinic, as illustrated by one respondent.

M: Yes, I gave it[formula] just because it's right just because the clinic give the milk it's not difficult now. But after six months it's hard, because sometimes you don't have the money to buy milk, but now it's right just because the clinic give us the milk.

I: ...What do you plan to do after six months?

M: Ahh my...I don't know, really don't know.

The newly implemented PCR test, which detects the HI virus at 3 months 2 weeks, compared to the ELISA test at 9 months, may intensify concerns regarding the access to formula milk. One site coordinator recalled how recently a few mothers have been denied formula milk at

the clinic after receiving HIV-negative results for their baby just after 3 months regardless of the government PMTCT protocol mandating six months of formula milk access. Although none of the mothers or mentors interviewed experienced this problem, the site coordinator seemed to consider that access to an ongoing supply of replacement feeding was not guaranteed or consistently provided to all HIV-positive mothers in the PMTCT programmes.

None of the respondents expressed that formula milk being out of stock at the clinic was a problem. Although, one mother explained how she often exhausted her supply of formula milk before she was permitted to retrieve more supplies every two weeks. Other people wondered why she refused to breastfeed because they had noticed she struggled to afford formula milk. The site coordinators realized women in the programme were struggling to buy even one bottle for formula feeding. They were grateful when they could give donated bottles to the women who had serious financial constraints.

Study participants regularly spoke in the interviews about changing to less expensive brands of formula milk after completing the six months provided at the PMTCT clinics. One concern with mothers switching to cheaper brands of formula was when they based their decision on the price of the formula rather than the appropriate age for the baby. A respondent spoke about giving her baby Nespray formula, a less expensive brand, four months before the recommended age on the tin. Her child became ill and the nurses extended her access to formula at the clinic until the baby was ten months.

Respondents also spoke about how they had learned that some mothers had been either selling or saving the formula by over-diluting the formula milk mixture mostly due to their dire economic circumstances.

SC: *Sometimes* even the people in the group, but the people who doesn't ...attend the group, they are doing it. They are really doing it... One day I found the person who is selling formula. I ask, 'Why?' She told me that she is not working, her boyfriend left her and then she doesn't even have something to eat, not even a soap to wash the nappy. So if she was to get her soap she must sell her tin.

MN: You mustn't put more or less [formula milk]... Some women instead of putting five [scoops of formula milk], they put maybe three or two or two and half... I don't know why they do that. I think that they don't want that milk to be finished, the tins to be finished, until nine months old... But most of mothers they do like this.

The respondents that described the phenomenon of rationing or selling formula milk tins were unable to answer how exactly these mothers were feeding their baby. For example, if the women were supplementing by breastfeeding or semi-solid foods.

Breastfeeding Issues

Past breastfeeding history played an integral role in women's experience, choice and practice of infant feeding.

Some respondents who had older children and enjoyed breastfeeding discussed both the emotional and physical pain especially in the period soon after delivery while enduring engorged breasts.

I: And how did you feel when you made the decision to formula feed?

M: Yes, but it's hard sometimes, but ah, it's all right now.

I: And what about the decision was hard?

M: Ya, it's hard just because I like the breastfeeding...but now I learn to bottle...In 2000 I was negative, I used the breast just because I was all right, not sick. But now it's hard changing.

SC: Otherwise, it's not easy. Even for a person, for example, to myself, it was not easy. Because the first baby I did breastfeed my first-born... For two years... then I enjoy it. But to the second one, it was, it was not easy... But deep down in my heart it was so painful...for me because sometimes the pressure on the breast you know it would come full in my breasts, I wish I can give but I was know, I knew that there was a risk for putting my baby in the breast milk. So it's not easy.

A site coordinator also explained how some women believed that breastfeeding could create an emotional bond that would allow a mother to always know what was happening to her child even in his/her absence. The belief could be a pertinent consideration when mothers have decided to formula feed but have breastfed and felt the bond before and yearn to feel it again with their new baby.

SC: We believe that there is bond if you are breastfeeding your baby. Even if I'm not here, we have the belief that if you did breastfeed your child, when there is something happening to her or to him, you see it because you did breastfeed your baby... Sometimes it's true. Sometimes it's true.

Alternatively, negative outcomes such as infecting a child possibly through prior breastfeeding practices made replacement feeding the unquestionable method. One mentor mentioned how she infected her previous child before entering The Mothers' Programmes because she did not possess knowledge about HIV transmission and breastfeeding practices. Although the mentor continued to advocate for informed choice, her personal belief was that it was too risky to breastfeed due to cracked nipples, mastitis (inflamed mammary glands) and high chances of mixed feeding.

Another aspect related to past breastfeeding experience was disclosure to a partner or other family members. Women who had breastfed older children were likely to raise suspicion if they switched to formula feeding without acknowledging the reason why. Depending on the partner's reaction, the women might be forced into mixed feeding.

SC: The problem is from when you are having second baby, and then the first one you did breastfeed... [A mother said] 'My husband asked me, 'why don't you breastfeed my baby? We have 5 children, all them you did breastfeed them, why this one?'' Then this man took this bottle and throw it away and then said, 'Breastfeed this baby.' She did. She didn't have guts to say, 'Sorry, I'm HIV-positive'...she used to come to the group and pretend as if everything is okay...But sometimes women do that.

Feasibility of exclusive breastfeeding

Amongst the participants it appeared that the cultural and social norm was to do mixed feeding, which means breastfeeding and giving other liquids and solids to the infant before the age of six months. Some respondents spoke about the desire to give a little bit of water every morning to the baby and about the belief that the infant will be hungry if only getting milk (formula or breast milk). Women tended to believe that a baby crying signalled hunger for solid or semi-solid foods (e.g. Purity, porridge, yoghurt etc.) or otherwise used feeding as a way to pacify the baby regardless of appetite. It was not uncommon for support group members to start giving water and semi-solid foods starting as early as two weeks old. Therefore, women acknowledged that exclusive breastfeeding would be difficult to maintain.

MN: It's hard [not to mixed feed]... I feed my baby with the bottle but I can give my baby a little bit of boiling water.

SC: And there's a belief that *every* morning before the baby is getting food, the baby must get a bottle of water. I don't know if maybe they think that there's not enough water in the baby's body. So you can imagine if the mother chooses to breastfeed, what happens with this bottle of water everyday?

In addition, exclusive breastfeeding produced a dilemma for women who wanted to go the sangoma or had family pressure to do so, which would result in the baby ingesting herbs and other medicinal plants. It was even suggested that a woman might be stigmatised as HIV-positive if she refused to take her baby to the sangoma. Therefore, many of the respondents mentioned how they preferred formula feeding in order to continue going to a traditional healer and avoid the predicament of this situation.

M: I won't feed only with the breast, because they say if you feed with the breast you must use breast, no water, no nothing, no [traditional] medicine, so that's that's why I use bottle-feeding.

M: Just because sometimes you want to give some medicine for the baby, you can't give it... Only the treatment you get here, only the medicine you get by the nurses...not our [traditional] medicine.

SC: So it's *very* difficult to say, to be sure that the mother is exclusively breastfeeding. Exclusively in our culture is not there... If the mother doesn't want to take the baby to the sangomas and the in-laws would *insist* for the mother to go there...and when the mother is exclusively breastfeeding, this mother is disclosing her status.

Family members can also be very influential on the mother's feeding practices and a new mother may feel a lot of pressure from family members to conform to their beliefs and practices. All of the site coordinators indicated that without disclosure mothers close to their family had problems being exclusive in their practice until the infant was six months old.

SC: But they [the mothers] still keep on doing it [giving solid foods early] because the [grand]mother will say, 'I started giving you solid food when you were two weeks, so why can't I do it to your baby?'

Another opinion was that women felt that they were incapable of supplying a baby with sufficient breast milk to sustain exclusive breastfeeding for three to six months. Having been diagnosed with HIV/AIDS may exacerbate this feeling.

M: I won't give [laughs] the baby for six months no eating [food]. Even me I'm going to become so slender... because loss weight because baby must use only the milk from the breast.

Practicalities of exclusive breastfeeding

Beyond the cultural norms and social expectation to mixed feed, respondents also recognized the pragmatic issue of being with the baby at all times for a minimum of three months. For instance if the woman were to leave the baby with a caretaker, particularly without disclosing, while she went to the shop, hospital, work or elsewhere, there was an increased risk of mixed feeding. The respondents commented how it was normal to leave a child with the neighbour and suggested that even if they were to leave a bottle of expressed breast milk, there was no guarantee the child would be given the bottle instead of water or food. Relying on neighbours

as caretakers, accustomed to the norms of giving food when the baby cries, was not a simple prospect considering the fear of disclosure due to the existing stigma.

MN: It's hard because if I'm going to the doctor sick, I'm going to the doctor... I must leave the baby with you and I must go to the doctor. The whole day ... must be there with doctor?... My baby's crying, [you] can take that water and give it to her, formula milk.

SC: If you're going to town, you leave your baby with the neighbour. And if you're breastfeeding your baby and the baby starts to cry, the neighbour will not think about the [expressed breast] milk that you left, they will think about giving the baby something else.

Thus, exclusive breastfeeding only seemed a safe option to the respondents if a mother could ensure she would be with her baby at all times.

Power Relations

It was suggested by participants that women with male partners felt obligated to practice the feeding method preferred by the partner. A woman may have decided to formula feed before giving birth, but when she returned from the hospital, the partner may insist that she breastfeed, thereby causing the baby to be mixed fed increasing the chance of MTCT. It appeared the change in infant feeding decisions coincided with non-disclosure and male partners' lack of education.

SC: What I usually see is that the people, they are changing to breast milk from formula... [A] woman formula fed the baby while she was in the hospital and then when she's at home...the husband said, 'You are going to breastfeed this baby.'

However, even with disclosure, one mother explained that her husband made the decision about the method by which she fed her infant.

M: He said that I must choose the bottle-feeding not the cup feeding. My husband says so.

A woman may be also dependent on the partner for money to buy food for the baby. This puts women in a vulnerable position particularly when her six months of access to formula is finished.

M: Sometimes I stressed and I coming here. I have this problem and this and this sometimes [about] money from my boyfriend. Sometimes he does not give me money for child. So when I come in here [to the support group] I tell them... 'What can I do about this?'

The site coordinators were aware that a woman's partner could have a large influence on her infant feeding practices. Some respondents discussed having to educate the partners about the dangers of mixed feeding in order for the couple to practice safer infant feeding. One site coordinator explained how she has had to protect undisclosed women from partners probing her as to why the women were not breastfeeding. The site coordinators seemed to realize these gender dynamics exist, and therefore knew that if the partner was satisfied with the response the woman's infant feeding situation would be easier.

SC: But I'm trying to do everything because sometimes they, the mothers, don't even disclose to their partners. The partners will come to the clinic and ask *why* she doesn't breastfeed the baby. We have to say something else besides HIV. You know, I can say 'No man, the mother has a problem in the breast', you know. She has a cancer or whatsoever. You understand. So the men can say '[You] can formula feed your baby.' Otherwise, it's not easy.

Family influences

The respondents suggested that the grandmothers and great-grandmothers of the child had a strong position of authority about how a mother fed her baby. There could be numerous reasons why the grandmothers may want a young woman to breastfeed. Below a site coordinator explained how in one circumstance the grandmother sought answers from the clinic as to why her daughter was not breastfeeding. Once the daughter disclosed her status

the grandmother was able to accept the rationale for formula feeding. It was a very difficult prospect for most young women to tell their parents they were infected with HIV/AIDS for fear of rejection, shame or sadness that might follow disclosure.

SC: And I said to the [grand]mother, 'No, no I never said that [to the daughter not to breastfeed]. I didn't say that to any person. A person has a right, we all have rights, if you want to breastfeed your baby, you can breastfeed. If you don't want, then you can not.' And I said to her [the mother], 'Why don't you tell your mother why you don't want to breastfeed your baby. Here is your mother. You can tell her.' She [the mother] said 'No mom, I'm HIV-positive.' And then the [grand]mother said 'Why didn't you tell me that?'... So she [the grandmother] said 'Ok. It's fine then. She must not breast her baby then.'

Reconciling Beliefs, Provider Advice and Peer Pressure

The respondents were faced with divergent beliefs about infant feeding from the community versus the providers, which they needed to resolve for themselves. A mother described how she was confronted with differing opinions about the appropriate age to start giving complimentary semi-solid foods to the infant.

M: Ooo, others [in the community] they say you must you must feed the baby in at least one month. They gives advice. Say must feed the baby when she's one month or so...you must use Nestum or Purity or whatever. They say, 'Why you don't give this child a food' and I say, 'No, I'm going to give her this.' Stay until six months. They say, 'No you just make the baby hungry' and I told them this baby knows know nothing about that. So I just leave it... because here at the clinic, they say, 'Must feed the baby Nestum at six months' because when you feed before maybe when she's got one month, the, what's it called, the food is going to be heavy for the stomach so maybe it's going, it[the baby's] going to be sick having the the chest problem.

Sometimes it could be difficult to resolve the mixed messages that stemmed from social and cultural norms versus advice from the provider. For instance one respondent during the interview begun by saying she had given the baby semi-solid foods starting at two weeks, but changed her response during the interview. It seemed that her personal view, which correlated to the cultural and social norm that the baby was hungry for semi-solid foods at two weeks

old, conflicted with provider advice. It also appeared that she tried to resolve the issue by making Nestum “weaker” (i.e. watered down) when the baby was younger than four months.

M: I give her... Okay. Nestum starts at the age of two weeks, because she was not, this bottle was not enough for her. She was crying, so I'm going to buy a Nestum and Purity with rice. You know from four months? ...Yeah, and then make it weaker because... she is small. At the age of four, of four months, from four months up I buy Nestum, from five months, six months. Something like that. And then it's cereal like now.

One of the site coordinators mentioned how sometimes the mothers hide their feeding practices because they know they have been told otherwise. Thus, it appeared that beliefs could be strong enough to overcome knowledge gained in the Mothers-2-Mothers group about the potential health problems for the baby later in life.

SC: No, they won't do it in front of us. The people will keep on saying, 'Oh we are not doing it.' If you can go after them, they are doing it... They don't do it at the group but you never know when they are not in the group. Because they believe that a child doesn't get enough, then they must get this expensive thing, Purity, yoghurt and all those kinds of things.

Some respondents explained that diluting the formula to save the formula milk was accepted and even encouraged by mothers in the community due to socio-economic reasons. A few respondents explained how mothers encountered pressure to conform to what other mothers were doing in the community despite the information being incorrect.

MN: So you take 10 teaspoons of milk. They [people outside the group] ask me why I put 10 milk, they want, see that bottle? They want me put five teaspoons of milk, I told them, 'No. I must put 10 teaspoons in there. I make the bottle full.' They said, 'No. You mustn't, you must put five and make a bottle.' I thought no, it's not good. I won't listen to them... I don't know, they said I waste with the milk... I said, 'No, it's not right.'

A strong message conveyed by most respondents was that formula feeding was the optimal method to feed one's child if HIV-infected. The respondents implied that if a woman chose to

exclusively breastfeed, the group members would not believe the mother was truly going to be exclusive in her practice.

M: Oh, maybe I'm going to breastfeed? Yes, they they're [the support group] going to tell me that this the incorrect way to feed...because they know that no one is going to breastfeed the baby until she's six months. You can't do that.

MN: When I see the people here in...our community and here in the group, formula feeding is important because people don't understand and they don't want to understand... if you choose to breastfeed you must take six months with this with this breastfeeding without any other feeding. People making the mistakes and they infect their babies. But formula feeding is all right because she only doing this bottle and giving this bottle to her baby.

Although overall the group members perceived The Mothers' Programmes as extremely supportive, the respondents' perception was that exclusive breastfeeding was not feasible. Therefore, the mothers in the group might react strongly if a woman had decided to breastfeed her child. One site coordinator explained how attendees in the group had a very negative reaction to a woman who decided to breastfeed her baby. She said that everyone was insulting the women and asking her "Why are you killing your baby?" Hence, it is likely that some women feared this sort of response and felt pressured into formula feeding even though they wanted to breastfeed. One respondent explained her view of how some mothers may end up mixed feeding because of the support group's peer pressure to formula feed versus cultural and societal pressures to breastfeed.

M: Sometimes ... at the group, they give the baby a bottle feeding but when at home they give the breast because... at group who just asking, 'Why you give the baby the breast because you are HIV-positive?' So some of them they don't want those questions. So they bring the baby to the group and at the home give the breast. Some of them, they give the baby the breast at home because some other peoples outside ask, 'why you give the baby the bottle?' So at the group give the bottle feeding and at the home give the breast.

Support

There were two predominant sources of support described by the respondents: The Mothers' Programmes and family members.

The Mothers' Programmes support

All of the respondents found The Mothers' Programmes an incredibly helpful and safe environment where they were able to express their problems, seek advice and find comfort in knowing other women were in similar situations. Repeatedly the respondents spoke about the support group having a problem-solving effect and allowing them to feel "free." Conversely, when they were not regularly attending the support group, they felt stressed, isolated and depressed.

M: When I come to the group, I feel comfortable because I can share my views. I've got a problem I can tell the group and they say, 'Do something like that that and that.' They give me solution for that problem. All of them.

MN: If you are not going to support groups, you're going to keep yourself locked inside your room, crying every day because there is no one to go and discuss this. And it's good to have support groups, because all of us are HIV-positive so we talk about HIV.

Some participants talked about overcoming some of the fear they felt after initially being diagnosed with HIV/AIDS. There was hope instilled in many of the women, particularly the mentors and site coordinators, which gave them the strength to disclose and a positive view on life.

MN: The support group helps because we are told, 'You are HIV-positive,' told yourself, 'I'm dying.' The support group helps you because...we have these ones who have lived for five years who are HIV-positive. So those one gave us more information... They gave us the hope that you are going to live a very, very, very long time. So don't worry, you're not going to die.

Continuous support around disclosure assisted some of the attendees in reaching a stage where they became comfortable discussing their status to others outside the support group.

Two respondents in particular detailed the experience of disclosing to the community at the taxi rank in the district. The openness and ease of one mentor in identifying herself as HIV-positive made her a resource for other HIV-positive women fearful of attending the support group but desiring information about infant feeding.

The aspect of emotional support was complemented by practical support such as offering lunch to the attendees who might otherwise not get enough to eat. One site coordinator was grateful for the occasional donations of food which women could take home as “food parcels”. She also suggested establishing a vegetable garden at the clinic in order for women to consistently bring home food.

Moneymaking opportunities existed for post-natal mothers attending M2M who wanted to learn beading. Reducing the effects of poverty was likely to empower women in many ways, including helping women afford food for their baby.

SC: Eh, I feel nice in the group... they [M2M] give money for us to buy something to eat. Them [mothers] sitting there to eat. Maybe the other one don't eat at home. You see? Suffering to eat. [S]he came here to come to eat. Just to come to eat. Then after that you go home. So is nice to sit together and share.

MN: I think that if maybe sometimes you stay alone like me, I don't have someone...When I ask them, 'Hey, I don't have a boyfriend and I don't have a job, what can I do?' They told me, 'You can do this bead job. You can get some money, and forget about you don't have someone to help you at home. Do this bead job, can use for [formula] milk.' And I was just doing that bead job, until now. Now I'm getting the money from the bead job.

Partner and family support

Respondents implied that support from partners and family members might be the best protection from stigma and questioning of infant feeding practices (in this case formula feeding) from other family members and people in the community. Support usually hinged on

the fact the woman has disclosed and the partner and family are educated about infant feeding and MTCT.

SC: The boyfriend says [to his mother], ‘Don’t worry about that [formula feeding], it’s *my* business, it’s not your business.’

SC: It’s easy if a person is disclosed. It’s very very important I think if the person is HIV-positive because if your HIV [and] if you’re going to formula feed, it’s easy if the family knows, don’t mind the outsiders, what they are going to say.

Moreover, a woman’s partner may have taken part in infant feeding decisions and assisted in upholding chosen practices. Thus, as one respondent explained, exclusive breastfeeding became a feasible and desired option for one couple who understood the risks involved and were willing to practice exclusive breastfeeding the way the site coordinator had counselled them.

SC: She wanted to and then her husband... She wanted the baby to be breastfed. They wanted that. Both of them...they were saying, ‘We *want* this baby to get breast milk.’ You know that. Then I give them education. I pay a visit and ask ‘Are you so serious, you want to breastfeed this baby? Do you know there is a virus in breast milk?’ Then they said, ‘Yes, but we are going to breastfeed exclusive.’ The baby’s negative. It’s a beautiful, beautiful baby.

Knowledge

The data revealed the gaining and sharing of information was a common theme. This included infant feeding knowledge and informed choice. Alternatively, lack of knowledge and misinformation was noted in the data.

Information sharing

An essential element of The Mothers’ Programmes was sharing knowledge, whether it was teaching about infant feeding, relating health information on HIV/AIDS or learning from

others' experiences. As envisaged by the founders of The Mothers' Programmes, women could be empowered with knowledge and support.

M: Since I'm HIV-positive ...I mustn't eat[drink] like alcohol ...I must use a condom. So they teach us something like that and about maybe how to look after the baby. You mustn't touch the baby while cracked [with a cut]. You mustn't touch the blood. If you touch it, you're going to infect her and HIV will get in.

MN: I became a mentor because I have got three years. I was suffering and I've got a problems. Now I must also be a mentor to *share* with other mothers with my problems.

SC: I don't exactly give them the answers that if people ask you, 'Why don't you breastfeed your baby? This is what you must say.' But I mean, by being empowered, they know exactly what to say. They come with stories that you would never think that they would say. They would tell me these stories, tell the others in the group those stories that worked for them. The others would take the story and use the story for themselves [laughs]. So the answers for those kind of stories are coming from themselves.

There was also the aspect that all members were expected to demonstrate one's feeding knowledge to others in the group. Being exposed to the information repeatedly was likely to reinforce positive feeding practices and reduce some of the problems.

M: Maybe just because we learn, [we're] all teachers in the group. They teach us how to clean the bottle for the baby. You must take care of the methods when you use to make the bottle for the baby.

A relatively recent aspect was to have mentors in the post-labour ward teaching new mothers how to make a bottle to curb any problems, particularly if the women joined The Mothers' Programmes close to the time of giving birth.

The group was also able to provide mothers with solutions to problems they encountered with their feeding practices. Women have shared tips such as how to keep water warm for middle of the night feedings when they did not have a flask or electricity in their home, which for one mentor meant wrapping a large towel around a bottle of boiled water for insulation. Other

respondents advised women afraid of disclosure due to stigma to buy another brand name of formula and use that tin for the Pelargon formula to reduce the severity of questioning by everybody interested in the woman's feeding practices.

Informed choice and infant feeding knowledge

All of the respondents except for one spoke about being informed of two main methods for infant feeding (exclusive breastfeeding or formula feeding), and they were all aware that mixed feeding was the most dangerous feeding method for HIV/AIDS mother-to-child-transmission.

M: They say I must choose whether if I want to feed the baby the breast, breastfeeding or the bottle feeding... they say if you feed with the breast you must use breast, no water, no nothing, no medicine, so that's that's why I use bottle-feeding.

Although most respondents talked about being given a choice of feeding options, they may have interpreted their alternatives as only one feasible method, formula feeding. One mother demonstrates how infant feeding "options" were balanced against the potential guilt or blame of infecting one's child with HIV.

M: At the group, I said, 'People if you want to give the baby feeding with bottle, feed it. If you want to feed the baby with breast, feed it.' But you've got a problem. It's your fault, because sometimes you're going to infect the baby with HIV. It's not 100% [safe to] breast when you are HIV-positive.

The belief that there seemed to be only one realistic option may have been exacerbated by site coordinators who feared blame if they were to "permit" women to exclusive breastfeed and the mother or the baby were to become sick.

SC: So I have to say, 'No, you can't breastfeed because your CD4 is very low.' I have to say it directive as it is, because what if I say, 'Ok you can breastfeed'? After she gives birth, she gets sick. What are you are going to say? She's going to say, '[SC name] told me to breastfeed.' So I have to be strict by saying, 'No, not everyone's going to breastfeed their baby here.'

There was one mother who had received conflicting information whereby in Cape Town she was given only the option to use formula milk (cup feeding vs. bottle feeding), while in the Eastern Cape she claimed that breastfeeding was mandated. It should be noted that it is possible the respondent's CD4 count was low enough at the time that formula feeding was considered the optimal feeding method in Cape Town.

M: They [nurses in Cape Town] tell me, '[You] must choose either use the bottle-feeding or the cup feeding... Not breastfeeding if you are HIV-positive'... Immediately the nurse [in Cape Town] tell me that you do it [formula feeding] like that... just because I think the other nurses that I take all said, 'You don't mind if you are HIV-positive, you must breastfeed the child.'

I: Who said that?

M: The other nurses there in Transkei. But here they say, 'Uh uh [no], it's not fine with breastfeeding when you are HIV-positive.' It's not, because your body is full of HIV.

All of the site coordinators agreed that the mothers needed to be counselled and decide how they were going to feed their baby before giving birth to reduce chances of mixed feeding and consider matters like their CD4 count, their personal feasibility of exclusive breastfeeding for the woman, and disclosure to partner and family members.

The mentors and site coordinators believed preparing the mothers to expect questioning from everyone about their feeding practices and to know the potential consequences of disclosure was essential. Preparation was a core element to empower the women to follow through with their intended infant feeding choice and seemed to be a major function of the support group.

SC: I'm only empowering them. I'm only encouraging them or educating them about this, about problems that will be created because of not breastfeeding and because of breastfeeding. So they must be aware. These are the problems you can come across. So they know exactly how to answer those. They know what to say. They know. For them to go disclose, before they go to disclose I always tell them, 'You can be rejected. The person you disclose to may not want anything to do with you. Or the person you disclose to, may in a way, may become *more* closer to you.'

In terms of knowledge about feeding methods, many respondents, although not all, were aware of cup feeding and the ones familiar with cup feeding had varied perceptions of it. Some participants mentioned the hospitals where they gave birth only allowed them to use the cup feeding although they were not sure why but thought it was due to lack of bottles (rather than ease of cleaning). Cup feeding was seen by most who knew it as a more difficult method than bottle-feeding especially at night. There was a higher chance of the milk spilling on the baby making some believe that two people were required to perform this method properly.

MN: Sometimes it's difficult to cup feed the baby, because the milk just not going in the mouth. Sometimes we don't know that and maybe there's no other one to help you to feed by the cup feeding. So we use the bottle-feeding.

Heat-treated expressed breast milk was not considered an option by the respondents. A few participants knew about expressing breast milk and had expressed and disposed of their own breast milk subsequent to giving birth to relieve the pain of engorged breasts. However, only one mentor was familiar with boiling the milk to get rid of the virus. Since the mothers interviewed were formula feeding, the option of expressing breast milk seemed irrelevant to them.

Other feeding knowledge from the respondents mentioned was: washing hands before making a bottle, sterilizing the bottle with Jik (household cleaning agent), boiling water and letting it cool before mixing the formula, making level spoonfuls of milk, disposing of excess formula

and by some respondents knowing that with formula feeding one needs to be careful about germs and sickness.

Lack of knowledge, misinformation and non-behaviour change

The respondents felt the lack of information and misinformation was most notable among mothers who were not attending The Mothers' Programmes support groups. A few respondents mentioned that if an HIV-infected woman did not come to the support group then she would have limited options to receive infant feeding information elsewhere. Likewise, the women not attending the group were seen as the one's who had problems and were making mistakes.

MN: They [mothers not attending M2M] don't want to go to the group meetings. Or she comes here to fetch the formula milk, but she don't want to go to the group.

I: Sometimes those women sometimes breastfeed and formula feed?

MN: Like the ladies, who don't want to attend those groups. They make, most of them, they make the problems.

One mentor also spoke about women in the group making the formula bottles diluted with too much water, although it was not certain if it was due to lack of knowledge (being new attendees) or on purpose to save formula.

MN: We ask the mothers to put them [the bottles] in the cupboard. And then, we started to see these bottles. Maybe of the 15 people [we] find only find five bottles is all right.

A site coordinator discussed the regular problem of mothers preparing a large container of formula milk at home and using the same mixture throughout the day. The formula milk may have been prepared as long ago as the night before, increasing the risk for contamination, which may cause the baby to become sick.

SC: They've done [already mixed] the milk before they are coming here. So you can imagine the milk has to stay there for the whole day. And I always say to them, 'Don't do that. Rather bring milk with, because we do have boiling water. But for you to come with milk that has been there for the whole day and even for the whole night, it's not good for the baby because it will cause the baby to have diarrhoea. The baby will have problems because it's not right.' But [sigh] sometimes they do it.

A misconception that arose twice in interviews, once with a mother and once with a mentor, was about the acceptability of mixed feeding after six months of exclusive breastfeeding. Most worrisome was when the information came from a mentor who was responsible for explaining infant feeding methods to the new mothers.

MN: I can't give water or something else. I must just breastfeed if I choose breastfeed until six months.

I: Then after six months?

MN: Then after six months I can go on.

I: Go on?

MN: Mixed food. Anything.

I: And breastfeeding after six months?

MN: After six months, yes.

I: Breastfeeding and food, or?

MN: Yes.

Another misconception by a majority of the respondents was that formula milk was completely safe if the person preparing the bottle used the proper cleaning methods whereas other concerns to consider would be over- or under- diluting the formula milk concentration and feeding the baby too little or frequently with formula milk.

I: Is there anything that's a problem with formula? Is there anything that's dangerous or could be a problem?

SC: *No* problem in a formula, unless, just must wash your baby's bottle clean, keep it clean. No problem with a formula.

Knowledge does not always preclude behaviour change or practices. During interviews, a few mothers' expressed certain knowledge and contradicted it with their behaviour. For instance, one mother gave the baby juice after having previously said it was bad for the child. Another woman, whose baby was present, allowed the baby's bottle to be on the floor then in the

baby's mouth. Later she explained how this type of practice was not good for the baby, because the bottle needs to be washed after it touches the floor to reduce the opportunity of the baby getting germs.

Only one respondent alluded to practicing mixed feeding as she was afraid to answer some interview questions and contradicted herself when asked if she had ever breastfed and once replied "sometimes" and later replied "never." Furthermore, she was extremely worried to retrieve her baby's test results possibly due to mixed feeding. The woman had been confident and correct when she described exclusive breastfeeding and the increased danger of mixed feeding, and yet, her behaviour may not have matched her knowledge.

The issues raised in the findings will be discussed in more detail in the subsequent chapters: Discussion and Conclusions and Recommendations.

University of Cape Town

CHAPTER FOUR

DISCUSSION

The themes that emerged from the interviews have suggested that the women participating in the Mothers-2-Mothers programme were influenced by a number of interconnected and overlapping factors when choosing and practicing infant feeding methods. The findings imply that it was difficult for the respondents to separate their infant feeding decisions from the social context of their lives. The women appeared to realize the impact of social and cultural norms on infant feeding practices, and as a result, they questioned the feasibility of exclusive breastfeeding and took measures to justify formula feeding if they were undisclosed. Notably the element of disclosure was interspersed throughout all the major themes, as the women who were able to be open about their HIV/AIDS status without rejection, stigma or discrimination could more easily practice their preferred feeding choice.

The study findings have expanded and appear to corroborate on findings in previous quantitative and qualitative research and also have highlighted areas for further consideration, such as past infant feeding history influencing a mother's current infant feeding experience and peer pressure to formula feed in the support group. In the following discussion, these findings are explored in more detail as are the implications of the findings in regards to policy and support program recommendations.

Fear: Issues to Emerge

Fear seemed to be the universal experience for the study respondents at some level whether it was fear of dying, the turmoil about leaving a child behind or the concern about infecting the baby with a deadly disease. These fears had very real implications on a mother's choice and

behaviour surrounding infant feeding, such as the readiness to accept one's disease status and make decisions based on the best interests for the baby and oneself.

Many times women in The Mothers' Programmes had discovered their HIV-positive status for the first time while pregnant. This resulted in a heavy burden as they had to come to terms with having a terminal illness, making choices about infant feeding and disclosure, and living in an environment filled with stigma and misconceptions about HIV/AIDS.

Most of the study respondents believed that death was imminent after they received the diagnosis because they were unaware of the distinction between HIV and AIDS. As a result, the women had feelings of helplessness, depression and denial. The fear of dying was at times overpowering to the point that decisions about infant feeding seemed inconsequential, and furthermore, might have hindered a woman's clear judgement about feeding options. Sometimes a mother's feelings of depression, denial and anxiety resulted in destructive behaviour increasing the chances of adverse outcomes for both the mother and the baby. The site coordinators understood that women were initially overwhelmed with the news of their diagnosis; therefore, infant feeding options and disclosure were normally discussed at subsequent group sessions. Another study noted that follow-up meetings were a preferred time to speak to newly diagnosed women about infant feeding, because otherwise women became too overloaded with information (Epstein et al., 2002).

It was only after attending The Mothers' Programmes that the respondents learned about the distinction between HIV and AIDS and were introduced to other women who had lived with the disease for years. This gave the new attendees a sense of hope and ability to foresee a future as a reasonably healthy individual. Similar findings have been found in a qualitative study on the lived experience of HIV-positive women in Cape Town, which detailed how the

participants initially felt the diagnosis was similar to a death sentence (Allen, 2003). They had suffered emotionally with the impact that their diagnosis was going have on themselves, their children and their family; however, with time and support they had learned to live with their illness and planned for the future. The realization and hope that one will not die in the immediate future has important psychological and health implications. Mothers with a sense of longevity may be able to approach life more positively and feel empowered to take part in their babies' lives while also making healthy decisions to increase their own life span.

Fear of infecting the baby with HIV/AIDS was another important issue to arise. This finding also has been noted in other studies as an influencing aspect of mothers' infant feeding decisions (Rollins et al., 2002; Piwoz et al., 2003; de Paoli et al., 2002). For example, a study conducted in South Africa suggested that extreme fear of infecting one's child with HIV/AIDS made some women choose replacement feeding over exclusive breastfeeding (Rollins et al., 2002). The intentions of the participants were motivated by the erroneous belief that all babies would be infected by breastfeeding. Although fear of infecting the child was an influencing factor to select formula feeding for a few women in the Rollins et al. (2002) study, the notable differences between the respondents were that the participants came from rural areas in Kwa-Zulu Natal and the majority (91%) had opted for exclusive breastfeeding primarily due to stigma. Similarly, a study in Malawi established that all of the mothers interviewed would have avoided breastfeeding for fear of transmitting the virus to their baby if there were safe alternative options (Piwoz et al., 2003).

Understanding and helping women living with HIV to address their fears in a positive and supportive way is likely to assist them in making and adhering to decisions and practices for the safety of their life and their child's life. Reducing exposure to some of the aspects that

contributed to the fear of disclosure may facilitate a mother practicing her preferred infant feeding option.

Key Feeding Issues to Emerge

All of the mothers and mentors had been questioned by family members or the community about why they were formula feeding. Most respondents indicated that often HIV-positive women went through many measures to conceal their status and feeding practices from family or community members. These constant measures taken to avoid exposing their status to others may create inconveniences that negatively impact their infant feeding abilities.

Stigma

HIV/AIDS associated stigma has been defined as the attitudes and perceptions of shame, disgrace, blame or dishonour regarding the disease (de Cock et al., 2002). Stigma may be experienced on a continuum between extreme to minimal as well as externally (discrimination) and/or internally (low self esteem and self blame) (Deacon et al., 2005). Applying this definition to respondents in this study, each woman may have had a very different experience of stigma or approach to disclosure. Even if a few respondents had not personally felt stigma or discrimination associated with HIV/AIDS, there was mutual understanding in the support group that HIV/AIDS was a disease that created fear, shame and blame. Therefore, the group members respected keeping confidential about everyone's status and honoured this as a high priority.

The fear of disclosure and potential rejection due to stigma were powerful factors in determining how a mother decided and practiced her chosen infant feeding method. As a result of stigma, women who have been fully informed about the infant feeding options may still have difficulty in practicing their desired feeding choice. For instance, some women may

breastfeed, not from personal desire, but because of fear about their status being discovered and the potential rejection. Choosing to breastfeed out of a fear of disclosure may lead to mixed feeding. This can be a result of the socio-cultural norms in the community, and the family expectations to mixed feed. Similarly pressure from the support group to formula feed may lead to mixed feeding if it clashes with the mother's preferred desire to breastfeed.

It has been suggested that helping to empower HIV-positive women may reduce the power imbalances that are associated with stigma (Deacon et al., 2005). Women living with HIV/AIDS are at a disadvantaged position in society (Cooper et al., 2004). Therefore, the Mothers-2-Mothers programme provided tactics to reduce the potential stigma and discrimination a mother might experience. The mentors and site coordinators employed strategies and prepared women with ways to avoid the stigma and disclosure until the mothers were ready to be open about their status. A particularly critical time for mothers appeared to be immediately following birth when the women felt the most exposed to people scrutinizing and suspicious of their feeding behaviour, particularly when formula feeding. Aiding women to maintain secrecy about their status may give the women the time and strength needed to eventually disclose.

Studies conducted in the same district as this study found variations in the stigma experienced by HIV-positive women who did not breastfeed from low (Chopra et al., 2002) to high (Hilderbrand et al., 2003). Although HIV/AIDS related stigma was portrayed to be rife within the community, the Mothers-2-Mothers programme tried to provide solutions to reduce the stigma of not breastfeeding experienced both on an external level (education in the community) and an internal or individual level (emotional support and empowerment).

Breastfeeding

Past infant feeding experience impacted the women's current feeding choices and practices. Both positive and negative outcomes derived from past infant feeding outcomes framed women's current feeding choice and experience. Positive past breastfeeding experiences made the switch to formula feeding emotionally challenging because the women had taken pleasure in breastfeeding. Compared to women who had never breastfed, these women felt they were forgoing an experience that held gratifying outcomes such as bonding with one's child. The potential for these women to mixed feed may be increased if they choose to formula feed but still desire to breastfeed.

Alternatively, the one respondent who had a past history of breastfeeding and had infected her first child before knowing her status felt there was too much risk involved with breastfeeding. An outcome of infecting one's previous child may make replacement feeding the obvious choice. Health care workers may also imply, through lack of knowledge, that an infant has been infected by breastfeeding whereas it may have occurred in-utero or intra-partum. With the high statistics of children living with the HI virus in South Africa (UNAIDS, 2004), there is a definite probability that other women entering the PMTCT programme have infected previous children.

Past feeding experience may also coincide with an increased need for disclosure. For instance, a woman who had breastfed older children may find it difficult to practice replacement feeding without disclosing to one's partner. A partner was likely to become suspicious or angry if the woman, who had previously breastfed, arrived home with tins of Pelargon from the hospital without any "reasonable" explanation for the change. This finding suggests that women in relationships who have older children may require more discussion with

counsellors about replacement feeding issues that could potentially arise if they do not plan to disclose to their partner.

Past feeding history has been a neglected factor in other research concerning HIV-positive women's decisions and practices about infant feeding. Only one study mentioned how the respondents who had previously breastfed felt regret and pain about not breastfeeding (Hilderbrand et al., 2003). Emphasizing the aspect of past infant feeding history with HIV-positive women in the decision-making stage may prepare them for their upcoming feeding experience.

Feasibility of exclusive breastfeeding

Exclusive breastfeeding is rarely practiced anywhere in the world, and the practice of mixed feeding has been reported in many Southern African studies (White, 1999; Bland et al., 2002; Poggensee et al., 2004; Sikotoyi, 2004). Respondents in this study believed that formula feeding would be easier than exclusive breastfeeding due to:

- The desire or cultural obligations to give traditional herbal remedies to the infant
- The custom of giving the infant water regularly
- The practice of starting semi-solid foods soon after birth
- The ability to leave the child with other caregivers and
- The influence of family members to conform to mixed feeding practices.

It is possible that many of these aspects impacting the feasibility of exclusive breastfeeding could be resolved through education and disclosure to the caretakers and by peers and family members providing continuous support to the woman.

Women who did not choose to exclusively breastfeed were advised to exclusively formula feed for at least four to six months. However, the respondents indicated that it was not often that the mothers exclusively formula fed for the recommended time frame despite the health risks of starting to give foods too early. This demonstrates that cultural expectations and social pressures are extremely difficult to overcome even with knowledge and in the context of support groups. The extent of the cultural and societal pressures on one's infant feeding behaviour appeared to be understood by the respondents. Hence, the findings suggest that the women perceived giving foods too early (e.g., at a few weeks old) to an infant as comparatively less of a health problem than mixed feeding while HIV-infected. The findings indicate that optimal practices for infant feeding (regardless of HIV status) need to be promoted in the community with respect to exclusivity of breastfeeding or replacement feeding for the first six months of the baby's life.

International infant feeding recommendations have suggested that mothers may want to choose exclusive breastfeeding in communities where women who replacement feed are stigmatised because they are believed to be HIV-infected (Epstein et al., 2002; WHO, 2003). The recommendation is based on the assumption that exclusive breastfeeding might reduce the repercussions that could result from formula feeding. However, the respondents in this study believed exclusive breastfeeding might create more problems if a woman refused to participate in cultural practices, such as taking the baby to a traditional healer or giving water to the infant daily. Denying a baby the healing powers of the traditional healer seemed to indicate to family members or people in the community that the woman was either HIV-infected or did not care about her baby.

The site coordinators felt obligated to discuss with the mothers the difficulties of practicing "exclusive" breastfeeding without having disclosed to family and/or one's partner. Deciding

to exclusively breastfeed out of fear of disclosure was believed to be a great cause for concern and an indication the woman was likely to mixed feed. Thus, exclusive breastfeeding was not seen as a way to reduce the troubles related to disclosure and stigma, but in fact thought to result in increased stigmatisation from family and community. These findings are antithetical to the perception given by the international infant feeding guidelines (Epstein et al., 2002; WHO, 2003). Furthermore, the findings signify that more work community-wide is needed to encourage exclusive breastfeeding among women of HIV-negative and unknown status to make this highly recommended behaviour more accepted and practiced among women. The promotion of exclusive breastfeeding in the community may create an environment where HIV-positive women can practice this option more successfully if desired.

Socio-economic circumstances

Socio-economic circumstances strike at the root of the problems and concerns associated with infant feeding choices in resource-poor areas with high HIV/AIDS prevalence. The findings suggest that even with formula milk provisions, education and support, continued work is required to empower women through economic means to reduce potentially harmful replacement feeding practices.

The South African government has acknowledged that HIV-positive women living in poverty, after being informed of different infant feeding options, need to be afforded the right to choose replacement feeding without the cost of formula being an impediment (Department of Health, 2003). The provision of six months of formula milk at PMTCT clinics has allowed many HIV-positive women the ability to select replacement feeding for their infant. However, owing to the extreme disparities created by the past apartheid government's policies, previously disadvantaged women may be unable to meet the criteria set by WHO (2003) for

affordable replacement feeding (see Appendix A). Their ability to practice formula feeding may be hindered by the cost of paraffin or electricity, bottles and other feeding equipment.

All of the HIV-positive women in this study had relied on access to formula milk. Despite the provisions of formula milk, some respondents struggled to afford more when their supply was depleted. Another concern that emerged from this study and others was the reported over-dilution of formula milk (Chopra et al., 2000; Bergstrom, 2003). This indicates that formula milk may not be a sustainable option for some women and may result in serious repercussions for the child, including malnutrition and susceptibility to other illnesses. Selling formula milk tins, which emerged in this study, has not been reported in other studies but also alludes to sub-optimum infant feeding practices and extreme poverty.

Most of the women in the Mothers-2-Mothers programme received a child support grant of R170 per month, which was awarded to parents or primary care givers whose financial resources were under a certain level (South African Social Security Agency, 2005). The parent(s) or care giver(s) had to have passed a “means” test determining their level of income and other socio-demographics. For example, South African citizens living in an informal urban dwelling must not have exceeded an annual income of R13 200 to qualify for the grant (Paralegal Advice Website and Education Training Unit, 2004). The respondents generally used the grant to pay for food for their baby. However, the small income did not afford much when one tin of formula costs about R32 in the shops and the standard allotment was 10 tins from the PMTCT programmes per month. Some women took advantage of the beading opportunity offered by the Mothers’ Creations to increase household funds or were fortunate to earn an income by being a mentor for six months.

As a result of socio-economic circumstances, often respondents reported changing to other less expensive brands of formula. However, it was unknown whether the change was based entirely on the cost or also due to the stigma associated with the formula milk brand name, Pelargon. The brand name, available in stores, was recognized by community members to be the same one provisioned by the PMTCT clinics for HIV-positive mothers. One respondent implied her choice of a cheaper formula milk product was not appropriate for the age of the baby, which caused the infant to get sick. This highlights the necessity of on-going infant feeding support for women who select replacement feeding as recommended by WHO (2003).

Power Relations

Infant feeding choices and practices were mediated by the power dynamics that shape a woman's intimate and familial relationships. To conceptualize how power differences impact gender relations, a brief explanation of gender inequity will be provided.

Gender refers to the "social and cultural constructs that differentiates women from men and defines the ways in which women and men interact with each other" (Gupta, 2000:1). Across almost all cultures women and men have distinct roles with different degrees of access to productive resources and decision-making authority, and it has been widely accepted that the power balances between the two genders are uneven favouring men (Gupta, 2000). These gender inequities and the socially constructed roles of men and women tend to result in women not having autonomous decision-making power in their intimate relationships.

These dynamics may play out in a woman's infant feeding choices and practices. Even if a woman decides to exclusively breastfeed, it is advised that she use a condom to protect against re-infection with a different strain of HIV and reduce the chances of MTCT (WHO, 2003). Given the inequitable gender dynamics, negotiating condom usage may be difficult for

women, particularly in long-term relationships (Jewkes, 2001). Asking a partner to use a condom or disregarding his preference for a certain feeding choice may unearth issues of trust and fidelity.

Ameliorating problems associated with gender inequities requires changes at a broader societal level. However, as a start, involving and educating the male partners of the women attending the PMTCT programmes about HIV/AIDS and other aspects of motherhood may generate a more supportive home environment. At a minimum, men may assist women in practicing their preferred feeding choice by serving as support when others question the woman's feeding behaviours. Moreover, men are bound to have some of the similar fears related to an HIV/AIDS diagnosis as women, such as fear of dying. As some of the respondents suggested, men in the community would benefit greatly by being involved in a similar mentorship programme.

Family members, such as the grandmothers of the baby, also played an integral part in care giving and decision-making regarding infant feeding practices of the study respondents. Negotiating infant feeding practices may be a challenge for women when partners and family members expect to have input into how a woman feeds her newborn, and furthermore, may not value the practice of exclusivity. Mothers may need to consider the family power dynamics with their chosen method of infant feeding. These findings resonate with other studies on infant feeding wherein the mother's mother, baby's father and mother-in-law are involved in decision-making regarding infant feeding practices (Shifona et al., 2004; Thairu et al., 2005; Bland et al., 2002). Disclosure and education to family members are fundamental aspects to assist the mothers with providing optimum infant feeding particularly when family members may question the feeding practices.

Poverty is inextricably linked to gender inequities (Doyal, 1995), therefore, women living in poverty may be more likely to be influenced by partners and family members or dependent on outside support to assist them in infant feeding. Increasing women's economic power may reduce some of the dependency on others and decrease the familial impact on feeding practices as was intended by The Mothers' Programmes.

Support

A successful programme in empowering and supporting women is said to be one that increases women's access to information, skills, services and technologies (Gupta, 2000). An essential component is to promote decision-making among women and establish a group identity (Gupta, 2000). The group identity is one that can be a source of power to mitigate against issues such as stigma (Deacon et al, 2005). The Mothers' Programmes seemed to aim at providing a group identity where the attendees could empower each other and reduce the stigma in the community.

Support from The Mothers' Programme and family members assisted the women in adhering to their chosen infant feeding method and maintaining a positive outlook on life. The Mothers' Programmes provided emotional, educational and practical support including access to job opportunities and other resources. From the respondents' perspectives, the support group was a comfortable, helpful place to be where one could feel solace in knowing other women were in similar situations and were able to provide advice for issues in their life that might arise. Many of the women came to accept their disease status over time and recognized a self-identity outside of being HIV-positive. The only area of concern appeared to be mothers who chose to exclusively breastfeed as it was not the norm in the group. Health care workers and support group attendees ought to ensure a more supportive environment for exclusive breastfeeding mothers to increase the potential of this method as a viable feeding option.

An important aspect in The Mothers' Programmes was encouraging and supporting women to disclose to someone outside the group. The mentors and site coordinators felt that disclosure was important to gain strength, accept one's disease status, reduce the stigma in the community and increase confidence to live a healthy lifestyle. The more the women were able to disclose and educate the people around them, the more likely it would be that stigma and myths about HIV/AIDS would be dispelled. Support of each other allowed many of the women to overcome the fears they had about disclosure and rejection. It has been reported that individuals who have someone to discuss stressful events in their lives tend to cope better with their situation (Sethosa & Peltzer 2005).

Family members including partners were also able to be a positive influence in a woman's life, protecting her from outside stigma and questioning. However, support was more likely to be forthcoming if a woman had disclosed her status to her partner and/or family members.

Reconciling Beliefs, Provider Advice and Peer Pressure

As suggested in the findings, the HIV-infected mothers were practicing infant feeding in a community containing conflicting beliefs and expectations. The information given at the clinics and hospitals was liable to conflict with beliefs and practices within the community. Furthermore, the promotion of Baby Friendly Hospital Initiative in some locations may have had health care providers promoting exclusive breastfeeding, while other locations such as PMTCT clinics may have encouraged formula feeding. Mixed messages from different sources might have resulted in confusion or distrust about information relayed and received between health care providers and clients.

The findings suggest that women in the Mothers-2-Mothers support group may have been influenced to practice formula feeding because the majority of other attendees around them

were using this method and the PMTCT programme was encouraging this option. Young women feeling vulnerable and anxious about being a new mother might look to others for support and guidance. Ultimately, the woman must find strength within herself to decide what is best for her and the baby because the answer to that question comes from evaluating one's personal situation with regards to infant feeding options.

The conflicting messages can be a challenge to resolve when there is pressure to conform to different feeding methods and social and cultural practices. The HIV/AIDS counsellors need to be aware and sensitive to these aspects seems imperative in order for HIV-positive women to follow through with their desired feeding choice.

Knowledge

The theme of knowledge had many facets and encompassed not only information sharing, but information that may hold a bias, as well as lack of information, misconceptions and knowledge not transforming into behaviour change.

Information sharing

Information sharing was critical for women to become familiar with the optimal feeding methods, as well as broader HIV related issues such as usage of medications and ways to maintain a healthy lifestyle. The women in the support group relied on each other for information and sharing of experiences. Knowledge was a powerful tool in facilitating best practices about infant feeding options and relating ways to reduce stigma. The respondents felt the aspect of sharing HIV information was essential as many times they were unaware of other sources to retrieve this kind of information.

Informed choice

Conveying unbiased information about infant feeding has been a big challenge for PMTCT programmes in Southern Africa, as depicted in other studies (Chopra et al., 2002; Dadian et al., 2003; Siwale et al., 2003). Even when women have been told they have a choice and are informed of the options, nonverbal and even verbal communication by counsellors and peers may dictate women's infant feeding choices.

Peer pressure from the group members to formula feed was implied by the respondents in this study. Verbal responses to women that practiced breastfeeding in the group were said to be derogatory such as "why are you killing your baby?" or the perception by some respondents it was the "incorrect way" to feed one's child. A paradox seemed to exist: the women were informed of two possible infant feeding choices and yet there appeared to be an underlying belief amongst Mothers' Programmes members generally that there was really only one acceptable option - to formula feed. To avoid being questioned by both the support group for breastfeeding and by family members for not breastfeeding, some mothers might have thus ultimately opted to mixed fed. Moreover, a woman may have been blamed if she chose to exclusively breastfeed and her baby was found to be HIV-positive despite the possibility transmission could have occurred before breastfeeding. Therefore, infant feeding "options" were balanced against the potential blame of infecting one's child with HIV, which typically led the women in Mothers-2-Mothers programme to replacement feed.

The site coordinators also experienced fear of blame when support group attendees chose to exclusively breastfeed. Therefore, the site coordinators were cautious to ensure the women choosing to exclusively breastfeed were aware of the risks and possible difficulties one might encounter with exclusive breastfeeding especially without disclosure to the family.

It also became evident that after the women were diagnosed as HIV-positive, their identity changed from that of a healthy individual to a person with a terminal illness. As the support group members learned about infant feeding and the options available, the new self-identity altered their perspective on infant feeding. Before being diagnosed and educated about infant feeding, the respondents assumed they were going to non-exclusively breastfeed. However this practice of mixed feeding had suddenly become forbidden among the HIV-positive mothers and replacement feeding was now the norm. If a mother in the Mothers-2-Mothers group did not subscribe to the norm of replacement feeding after being aware of mother-to-child transmission through breastfeeding, she might incur negative reactions from others in the support group.

Ultimately, there is a need for the women in the program to feel they have two options in this context and a right to choose exclusive breastfeeding backed by full support and understanding.

Lack of Knowledge, Misinformation and Non-behaviour Change

The respondents suggested that many of the infant feeding problems, lack of knowledge and misconceptions originated from mothers not attending The Mothers' Programmes. It appears that women in The Mothers' Programmes were more successful at following through with their chosen infant feeding choice and only a few were known to be mixed feeding. This seemed to be a result of successful preparation and counselling of women in The Mothers' Programmes, as well as, the on-going support and encouragement regarding disclosure. The successes of the mothers and mentors may be due to the women being a self-selected group who voluntarily join. The women living with HIV who are the most marginalized and experience the extreme internal stigma (self-blame and low self esteem) may be less inclined to attend at HIV/AIDS support group and most in need of education and support about infant

feeding practices. Seeking out ways to reach these women appears critical in reducing mother-to-child transmission in South Africa.

Translating knowledge into behaviour practices has been one of the biggest challenges with the HIV/AIDS epidemic and continues to be a vital aspect in HIV prevention efforts. The findings suggest that even when women were equipped with knowledge and support about optimal feeding practices, some women still struggled to abide by these practices. In general, women want to do what is best for their child. However, it seems evident that other influencing aspects may supersede the ability of the respondents to translate their knowledge into behaviour change.

Overall, the majority of respondents reported feeling confident about practicing and counselling about infant feeding. Yet, even with knowledge, emotional and practical support provided by The Mothers' Programmes, some mothers still seemed to struggle with issues of fear, stigma, socio-economic pressures and family and partner influences relating to their infant feeding practice.

Contributions and Limitations of Research

Public health studies aimed at infant feeding and HIV have in general been quantitative in approach, mainly by focusing on which method of infant feeding is better for HIV-infected women living in developing countries and the outcomes of their practices. However, few studies have focused on what women would prefer in a localized context and the challenges and influences they face when deciding and practicing their chosen infant feeding method. The strength of this study is that it looks at what the women themselves say about the factors influencing their decisions and practices as well as from what lay counsellors of a support group find familiar among the attendees' experiences.

It is critical for support programmes and policymakers to have a greater understanding of how and why HIV-positive women have chosen a particular infant feeding option. The information may assist with policy formulation, educating health providers who work with mothers who are HIV-infected, and stimulate thoughts about making infant feeding easier for HIV-positive women in this context.

Limitations of the research include that the findings are contextually bound to a geographical location; therefore, cultural and social differences in other areas of South Africa may reflect different findings.

Another limitation, previously mentioned in the methods section, is the language and cultural differences between the participants and the researcher. All respondents spoke English as a second language, which may have hindered the ease of some participants to express themselves. However, this limitation was difficult to supersede, as many of the suggestions explored, such as hiring an interpreter, were not possible due to financial and time constraints. Furthermore, as previously stated there was assurance from The Mothers' Programmes of an adequate number of participants would meet the research criteria without adding more external variables such as translators and training other interviewers. As a result, conducting interviews with women conversant in English may reflect experiences of women with more education or better access to resources.

CHAPTER FIVE

CONCLUSION AND RECOMMENDATIONS

A number of themes emerged from the interviews, which implied that an HIV-positive woman's experience with infant feeding could not be separated from her position in society. This includes her personal and financial circumstances, as well as, the broader societal constructions such as gender roles and family relations. It is essential to understand and hear women's experiences related to infant feeding in different contexts, because the social expectations and culturally-specific beliefs and value systems can inform and determine behaviour and infant feeding practices.

The women attending the Mothers-2-Mothers support group had been informed of two main infant feeding options: exclusive breastfeeding for the first three to six months or replacement feeding. Despite the issues and concerns related to replacement feeding in developing countries, all of the study respondents had chosen to formula feed in addition to an overwhelming majority of women in the Mothers-2-Mothers support group as reported by the respondents. The respondents acknowledged that formula feeding in the community, where breastfeeding was the norm, held potential problems of stigma, discrimination, and monetary difficulties. Even with the problematic nature of formula feeding in the community, all of the respondents believed that these issues were not enough to overcome their preference to use this option. The most powerful reasons given by the respondents for choosing formula feeding resulted from fear of infecting one's baby with HIV and the disbelief about the feasibility of exclusive breastfeeding.

The Mothers' Programmes appears to be an ideal location for HIV-positive women to learn about infant feeding options and obtain emotional support. Ensuring that as many HIV-

infected prenatal and postnatal women are aware of the support group and are able to access it seems imperative. However, the knowledge that is disseminated must be factual and as unbiased as possible. Women who may choose to exclusively breastfeed need to feel that the Mothers-2-Mothers support group accepts and supports this as a viable feeding alternative bearing in mind the challenges that were foreseen by respondents in this study. Reducing stigma both on external level within the community, as well as, internally on a psychological level may be essential to remove barriers associated with feeding choices and disclosure. Optimal goals for women to exercise their infant feeding choices and practices must also include income generation opportunities, positive male involvement and redefining gender roles to empower women.

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Recommendations

- Work with counsellors and other health providers to convey consistent infant feeding messages to decrease conflicting information and confusion among women.
- Continue the expansion of support groups for HIV-infected mothers in order to make them more accessible for the women in need. This needs to be in combination with promotional efforts to include HIV-infected antenatal and postnatal not utilizing support groups for reasons such as stigma.
- Encourage and support women's disclosure to partners, family and community to assist in following through with their desired feeding choice.
- Promote male partner (and extended family when appropriate) involvement and education for all stages of a woman's experience during pregnancy and after birth.
- Implement mentorship and support groups for men living with HIV/AIDS
- Continue to promote efforts to reduce stigma, discrimination and increase knowledge regarding HIV/AIDS in the community.
- Consider a woman's past breastfeeding experience during counselling. More emphasis and support may be needed to uphold chosen feeding practices.
- Increase options of income-generation projects similar to the Mothers' Creations in impoverished areas.

- Change policy to expand access to formula milk supply in clinics beyond the six months to a minimum of nine months to twelve months when milk is still a substantial part of an infant's diet and nutrition. One possibility may be to offer Pelargon at reduced price from the baby's age of six months to twelve months in order to ease the economic burden of buying formula milk.
- Educate and work with traditional healers and leaders within the communities to promote optimal infant feeding practices (e.g. exclusive breastfeeding or exclusive formula feeding for the first six months of an infant's life).
- Establish community-wide efforts to promote optimal feeding practices regardless of a woman's status.

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Appendix A

Definitions of acceptable, feasible, affordable, sustainable and safe (WHO, 2003:10):

- **Acceptable:** The mother perceives no barrier to replacement feeding. Barriers may have cultural or social reasons, or be due to fear of stigma or discrimination. According to this concept the mother is under no social or cultural pressure not to use replacement feeding; and she is supported by family and community in opting for replacement feeding, or she will be able to cope with pressure from family and friends to breastfeed, and she can deal with possible stigma attached to being seen with replacement food.
- **Feasible:** The mother (of family) has adequate time, knowledge, skills and other resources to prepare the replacement food and feed the infant up to 12 times in 24 hours. According to this concept the mother can understand and follow the instructions for preparing infant formula, and with support from family can prepare enough replacement feeds correctly every day, and at night, despite disruptions to preparation of the family food or other work.
- **Affordable:** The mother and family, with community or health-system support if necessary, can pay the cost of purchasing/producing, preparing and using replacement feeding, including all ingredients, fuel, clean water, soap and equipment, without compromising the health and nutrition of the family. This concept also includes access to medical care if necessary for diarrhoea and the cost of such care.

- **Sustainable:** Availability of a continuous and uninterrupted supply and dependable system of distribution for all ingredients and products needed for safe replacement feeding, for as long as the infant needs it, up to one year of age or longer. According to this concept there is little risk that formula will ever be unavailable or inaccessible, and another person is available to feed the child in the mother's absence, and can prepare and give replacement feeds.

- **Safe:** Replacement foods are correctly and hygienically prepared and stored, and fed in nutritionally adequate quantities, with clean hands and using clean utensils, preferably by cup. This concept means that the mother or caregiver:
 - has access to a reliable supply of safe water (from a piped or protected-well source)
 - prepares replacement feeds that are nutritionally sound and free of pathogens
 - is able to wash hands and utensils thoroughly with soap, and to regularly boil the utensils to sterilize them
 - can boil water for preparing each of the baby's feeds
 - can store unprepared feeds in clean, covered containers and protect them from rodents, insects and other animals.

Appendix B: Options for Infant Feeding

Below are infant feeding options for women living with HIV/AIDS as stated in the WHO/UNICEF/UNAIDS/UNFPA HIV and infant feeding guidelines (2003:10) and by White in Breastfeeding and HIV/AIDS (1999:165-69).

- **Commercial Infant Formula:** the specially formulated milk is a provided in shops or by the government and other health programmes. Formula can be given in a bottle or cup.
- **Cup feeding:** The cup is used rather than the bottle to feed the infant (normally suggested for formula milk). The cup is recommended as a safer option than the bottle, which tends to be more difficult to clean and rid of bacteria.
- **Exclusive breastfeeding:** Feeding only breast milk and prescribed medication, but no water, other liquids or solids given during the first months of life.
- **Home-modified animal milk:** Animal milk is diluted with water and supplemented with sugar and micronutrients.
- **Wet-nursing:** When another woman breastfeeds the baby while ensuring she is and remains HIV-negative.
- **Heat-treated breast milk from mother:** the mother expresses and pasteurises the milk by heating it to kill the HI-virus.
- **Donor and breast milk banks:** Donors' breast milk is heat-treated and kept frozen or chilled in the centres until requested for infants.

APPENDIX C

Infant Feeding Practices of HIV-positive mothers INTERVIEW GUIDE

MOTHERS:

As I mentioned, I would like to ask you some questions about feeding your baby.

1. Firstly, can you explain to me what you know about different infant feeding methods? What are the advantages/disadvantages of the infant feeding methods?

- EBF, FF, MX, Heating expressed breast milk, cup feeding

2. And you personally, when and how to you feed your baby?

Depending on how she responds to the questions, ask:

2.1 Why did you choose to [breastfeed, formula feed, mixed feed] your baby?

Probe:

- How did your family or friends help you to choose?
- How did mentors/MP help you to choose?
- What other things help you to choose?
 - People in your community or health workers
 - Religious reasons
 - Traditional/cultural reasons
 - Economic- free formula
 - Other?

3. Can you tell me how you felt when making the decision to [EBF, FF, MF]?

Probe:

- What about the decision was easy or difficult?

4. Before your baby was born, how did you think you would feed her/him?

5. After your baby was born up until now, have you always [EBF, FF, MF], or have you ever [EBF, FF, MF] or [EBF, FF, MF]?

- If you did, why did you?
- If you didn't, why not?

- What would make you change to either [?] or [?]?

5.1 Are there any feeding methods you would NOT do, and why?

Probe:

- 5.1.1 How possible is it to only breastfeed your baby for 4-6 months with giving the baby no other things such as water, herbs, food, etc.?
- 5.1.2 Cultural traditions: e.g. not having sex while breastfeeding?
- 5.1.3 Did your breasts become engorged? What did you do?

6. [If baby younger than 6 months] How do you plan to feed your baby after 6 months?

- FF- expensive? BF- weaning abruptly?

7. What advice have you received outside M2M on how to feed your baby?

8. Has anyone questioned the way you feed your baby? And if so, how did you respond?

- Partner, family & friends
- Community members or religious groups
- Nurses or doctors
- Other?

9. How do other mothers around you feed their baby?

- Mothers in the community, family, friends, M2M, etc.

10. What are some instances where you or other mothers in the programme have experienced problems when feeding your babies?

Probe:

- Such as, difficulties only BF or cleaning the bottle, getting formula?
- Or pressure to feed a certain way?
- What do you do to calm your baby when she/he cries?

11. If you were HIV-negative, how would you feed your baby, and why?

Probe: [check demo form]

- [If other children] Did you feed your other children differently?

12. Who have you disclosed your status to?

- How have they responded to you?

13. Who helps take care of your baby?

- Family? Friends? Other?

14. Ask if working: [check demo form]

- Who feeds your baby when you're at work?
- What do they give your baby for food when you are away?

I would like to ask you a few questions about The MP:

15. Tell me about how your experience with The MP?

Probe:

- What do you like (find helpful, supportive) or don't like (find unsupportive, difficult)?

16. How do you think The MP affects how mothers feed their baby?

- Do you feel one infant feeding method is encouraged over another?
- If you were to feed your baby differently (such as BF, FF, MX), how would they feel or react? Why?

17. If you were a mentor, what would you say to women in the program about infant feeding?

- Do you know anything that can make it easier for HIV-positive women to choose how to feed their baby and reduce mixed feeding?

18. Is infant feeding an important issue when you go to MP?

- If yes, why do you think so?
- If not, what are important issues?
- What do you feel is important?

APPENDIX D

Infant Feeding Practices of HIV-positive mothers INTERVIEW GUIDE

MENTORS:

As I mentioned, I would like to ask you some questions about feeding your baby.

1. Firstly, can you explain to me what you know about different infant feeding methods? What are the advantages/disadvantages of the infant feeding methods?

- EBF, FF, MX, Heating expressed breast milk, cup feeding

2. And you personally, when and how to you feed your baby?

Depending on how she responds to the questions, ask:

2.1 Why did you choose to [breastfeed, formula feed, mixed feed] your baby?

Probe:

- How did your family or friends help you to choose?
- How did mentors/MP help you to choose?
- What other things help you to choose?
 - People in your community or health workers
 - Religious reasons
 - Traditional/cultural reasons
 - Economic- free formula
 - Other?

3. Can you tell me how you felt when making the decision to [EBF, FF, MF]?

Probe:

- What about the decision was easy or difficult?

4. Before your baby was born, how did you think you would feed her/him?

5. After your baby was born up until now, have you always [EBF, FF, MF], or have you ever [EBF, FF, MF] or [EBF, FF, MF]?

- If you did, why did you?
- If you didn't, why not?

- What would make you change to either [?] or [?]?

6.1 Are there any feeding methods you would NOT do, and why?

Probe:

6.1.1 How possible is it to only breastfeed your baby for 4-6 months with giving the baby no other things such as water, herbs, food, etc.?

6.1.2 Cultural traditions: e.g. not having sex while breastfeeding?

6. [If baby younger than 6 months] How do you plan to feed your baby after 6 months?

- FF- expensive? BF- weaning abruptly?

7. What advice have you received outside M2M on how to feed your baby?

8. Has anyone questioned the way you feed your baby? And if so, how did you respond?

- Partner, family & friends
- Community members or religious groups
- Nurses or doctors
- Other?

9. How do other mothers around you feed their baby?

- Mothers in the community, family, friends, M2M, etc.

10. What are some instances where you or other mothers in the programme have experienced problems when feeding your babies?

Probe:

- Such as, difficulties only BF or cleaning the bottle, getting formula?
- Or pressure to feed a certain way?
- What do you do to calm your baby when she/he cries?

11. What are some reasons mothers change their decision about how they are going to feed their baby from before giving birth to after giving birth?

12. Have you made recommendations to other mothers about their feeding decisions or practices?

- Culture, disclosure, family issues, etc.

13. If you were HIV-negative, how would you feed your baby, and why?

Probe:

- Have you had any other children and fed them differently?

14. Who have you disclosed your status to?

- How have they responded to you?

15. Who helps take care of your baby?

- Family? Friends? Other?

16. Ask if working:

- Who feeds your baby when you're at work?
- What do they give your baby for food when you are away?

I would like to ask you a few questions about The MP:

17. Tell me about how your experience with The MP?

Probe:

- What do you like (find helpful, supportive) or don't like (find unsupportive, difficult)?

18. How do you think The MP affects how mothers feed their baby?

- Do you feel one infant feeding method is encouraged over another?
- If you were to feed your baby differently (such as BF, FF, MX), how would they feel or react? Why?

19. What do you feel your role as a mentor is for other mothers?

- And with respect to infant feeding?

20. Is infant feeding an important issue when you go to MP?

- If yes, why do you think so?
- If not, what are important issues?
- What do you feel is important?

University of Cape Town

APPENDIX E

Infant Feeding Decisions and Practices of HIV-positive mothers INTERVIEW GUIDE

SITE COORDINATOR:

As I mentioned, I would like to ask you some questions about infant feeding practices.

1. Firstly, what do you feel your role is as a site coordinator for mother in the programme?
Probe:
 - How are you deciding which mothers become mentors?
 - In what ways do you help mothers with infant feeding decisions or practices?
2. How important is the topic of infant feeding in the group? (e.g. Is infant feeding something that is talked about a lot? How important is infant feeding compare to other things like taking treatment or safe sex?)
 - If important, what are mothers saying about infant feeding?
 - If not that important, what are they concerned about?
3. What are mentors explaining to mothers about infant feeding?
 - (what about) Advantages or disadvantages of different feeding methods for HIV-infected mothers?
e.g. risks/benefits of exclusive breastfeeding?
e.g. risks/benefits of formula feeding
4. From your experience, what are some problems that mothers have when **making the decision** of how to feed their baby? (e.g. FF or EBF)
 - Partner/family influence
 - Community influence
 - Access to electricity/water
 - Other?

- 4.a How does access to formula affect a mother's decision to feed her baby?
- Would mothers change their decision to formula (bottle) feed if formula were not easily available?
5. What are some challenges for mothers in the programme to properly feed their baby after they have decided to FF or EBF?
- Mixed feeding
 - Too weak/too strong formula, formula not available at clinic
 - Transportation to get formula, access to water/electricity
 - Influence of partners, family, stigma
 - Other?
6. Let's say a mother changed her decision about how to feed her baby from before giving birth to after giving birth, for example from breastfeeding to formula feeding. Can you think of any reasons why that might happen?
7. When formula from the clinic stops, how are women feeding their babies after 6 months?
- Probe:**
- Have there been any problems with mothers being able to afford formula?
 - If yes, what do they do?
- If no, how are the mothers getting money to buy the formula milk?
8. From your experience, what recommendations do you have that would make HIV-infected mothers' feeding decisions or practices easier?
- Probe:**
- What effect does disclosure have on infant feeding practices?
9. In your opinion, how does disclosure help or hurt women?
- Probe:**
- What effect does disclosure have on infant feeding practices?
10. How do you think the group affects mothers' feeding practices?

Probe:

- Do you feel one method of infant feeding is encouraged?
- How do [would] mothers breastfeeding fit in with other mothers who are formula feeding in the programme?

11. Besides The Mothers' Programmes, where are mothers getting feeding information?

- Counsellors at MOU
- Family
- Community
- Other?

Probe:

- Does the information from elsewhere ever conflict with what is talked about in the group? If so, how?

12. Can you tell me about how you feel being a site coordinator for HIV-positive mothers?

13. Can you think of anything that would make the group more successful?
(could be factors inside or outside the group or new ideas)

Appendix F: English Back Translated Consent Form

Child feeding done by mothers who live with HIV: A qualitative research investigating decisions and practices in The Mothers' Programmes.

Informed Consent

Hello, my name is Amy Mackowski. I am a student at the University of Cape Town studying public health. I am doing research on mothers' feeding practices of their baby. I am interested in your thoughts, ideas and experiences with infant feeding decisions and your experience with The Mothers' Programmes and would like to ask you some questions about this.

Participants Rights

If you agree to participate in this research, it would take no longer than one and half hours of your time. Your participation in this discussion is completely voluntary. You are not required to answer any questions that make you feel uncomfortable. You can also stop participating at any time. If you agree to participate, I will ask you to tell me your thoughts on some issues. There are no wrong answers or right answers. I only want to know your thoughts and views.

I would like to tape record this interview to help me to remember what you say today. I am the only one who will review the tape or perhaps my supervisors. Your name will not be used as a part of any of the results from this research. Your discussion with me will be kept confidential. The information you give me will help counselling on infant in informing Preventing Mother-to-Child-Transmission (PMTCT) programs and counselling of mothers who are infected with HIV.

Would you like to ask any questions about this research? If you don't have any questions and agree to participate in this study than I will go ahead and begin. But first, I will ask you to sign this form stating that I, the interviewer, have informed you of your rights as a research participant and that you have agreed to participate in today's discussion. This is the only place where your name will be indicated.

Thank you for your time.

Participant Signature

Date

Interviewer Signature

Date

Appendix G: Xhosa Consent Form

Ufunzo lwemveku olwenziwa ngoomama abaphila nentsholongwane kagawulayo: uphando olungena nzuli ekufumaniseni ukuba kukhethwa kwaye lwenziwa njani ufunzo kwinkqubo yoMama nakwabazakuba ngoMama

Imvume Ecacisiweyo

Molo, igama lam ngu Amy Mackowski. Ndingumfundi kwiDyunivesithi yase Kapa ndifunda ngezempilo zoluntu. Ndenza uphando ngofunzo olwenziwa ngomama kubantwana babo. Ndinomdla kwingcinga zakho, imbono kunye namava kwizigqibo zokufunza kunye namava akho kwinkqubo yoMama nakwabazakuba ngoMama, kwaye ndithanda ukukubiza eminye imibuzo malunga noku.

Amalungelo Abathathi-nxaxheba

Ukuba uyavuma ukuthatha inxaxheba koluphando, akusayi kukuthatha ixesha elide kuneyure enesiqingatha sexesha lakho. Ukuthatha inxaxheba kule ngxoxo kungokuzithandela okugqibeleleyo. Awunyanzelekanga ukuba uphendule nayiphi na imibuzo ekwenza ungakhululeki. Kananjalo ungayeka ukuthatha inxaxheba nagaliphi na ixesha. Ukuba uyavuma ukuthatha inxaxheba, ndizakukucela ukuba undixelele iingcinga zakho kwimiba ethile. Akukho zimpendulo zilungileyo okanye ezingalunganga. Ndifuna nje ukwazi iingcinga zakho kunye neembono zakho qha.

Ndithanda ukurekhoda olu dliwano-ndlebe, ukuncedana nam ukuba ndikhumbule okutshileyo namhlanje. Ndim kuphela ozakuphengulula iteyipu okanye ukuba kuyenzeka abandijongileyo. Igama lakho alisayikusetyenziswa njengenxalenye yaziphi na iziphumo zoluphando. Iingxoxo yakho kunye nam izkugcinwa ekhusini. Ulwazi ondinika lona luzakunceda ekucebiseni ngemveku ekwaziseni kwinkqubo yoKukhusela-Usuleleko-Lwabantwana –Ngomama (PMTCT) kwaye ekucebiseni oomama abosuleleke yintsholongwane kagawulayo.

Ungathanda ukubuzwa nayiphi na imibuzo malunga noluphando? Ukuba awunayo nayiphi na imibuzo kwaye uyavuma ukuthatha inxaxheba koluphando ndizakuqhubeka ndiqale. Kodwa okokuqala, ndizakukucela ukuba utyikitye le fomu echaza ukuba mna, mbuzi, ndikwazisile ngamalungelo akho njengomthathi-nxaxheba kwaye uye wavuma ukuthatha inxaxheba kule ngxoxo yanamhlanje. Le yiyo kuphela indawo apho igama lakho lizakufakwa khona.

Enkosi ngexesha lakho.

Utyikityo lomthathi-nxaxheba

Umhla

Utyikityo lombuzi

Umhla