

**Factors influencing HIV positive mothers' choices
regarding infant feeding in a rural African context**

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DEDICATION

I hereby dedicate this research to my family – Dad, Mom, Garth, and Tegan, and to my husband, Sven. I would not be where I am today if it were not for these five very special people who have supported me tirelessly and loved me unconditionally. I also dedicate this work to the devoted health care workers of St. Apollinaris Hospital – a place where need is great, but resources few, and where the human spirit triumphs. The community of Centocow will always hold a special place in my heart.


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DECLARATION

Except for referenced citations in text, this is the
researcher's original work.

Signature 
Date 5.3.2005

ABSTRACT

The purpose of this study was to determine the efficacy of infant feeding choices and support provided in the current PMTCT programme in KwaZulu-Natal.

A case study format was utilised. Follow-up was done over six months with ten HIV positive women enrolled in the PMTCT programme at St. Apollinaris Hospital. Transcripts of interviews were made, pattern-matching was done, and the process of replication was used to develop a cross-case report as the final analysis of the study.

All of the women decided to and intended to exclusively breastfeed for between four and six months at the time of the first interview. There was a poor rate of return for follow-up interviews, therefore the actual feeding practice of half of the women after six weeks could not be determined. The case studies were developed with the information available, and thus conclusions were reached during cross-case analysis.

Decision-making ability and the capacity to overcome the barriers to the maintenance of their original feeding choice were related to the women's educational levels, employment status, financial and social circumstances and support systems, knowledge and experience of HIV/AIDS, quality of PMTCT education and support, cultural beliefs, and parenting and family values. The age of respondents and differences in marital status had no obvious

correlation to maintenance of feeding choice. Parity and level of education had only a limited effect on maintenance of feeding choice.

Cues to mixed feeding included a fatalistic view and a loss of hope for preventing transmission of HIV to their infants. Some of the women did not seem to believe that maintaining a specific infant feeding regime was enough to prevent transmission of HIV to their infants. Fear of stigmatisation due to disclosure of their positive HIV status led to non-disclosure of many women, and this in turn led to a lack of support for their feeding choice.

Cues to exclusive feeding included an internal pressure to succeed and so decrease the chances of HIV transmission to her infant. Those women who disclosed their HIV status to a significant other and established a good support system were more likely to maintain their original decision. Although none of the women enjoyed good social circumstances, those who were more financially secure, employed, and who had a stable home environment were more likely to maintain their exclusive feeding regime.

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CHAPTER ONE

INTRODUCTION

1.1. Background to the study

As the rate of HIV infection in the childbearing female population in sub-Saharan Africa continues to escalate, attention needs to be focussed on the prevention of mother to child transmission (MTCT) of the virus (De Cock, Fowler, Mercier, de Vincenzi, Saba, Hoff, Alnwick, Rogers & Shaffer, 2000). One route of transmission is through breastfeeding and thus it might be concluded that HIV positive mothers should be discouraged from breastfeeding (Humphrey & Iliff, 2001). However, in the developing world that is sub-Saharan Africa, the risks to infants who are not breastfed are substantial (Soderlund, 1999; Humphrey & Iliff, 2001). The relative risks of breastfeeding and HIV infection, and formula feeding and malnutrition and decreased immunity to other diseases need to be compared (Eastman, Tompson, Brussel, Buchanan, Crowe, LeVan Fram, Hathaway, McClain, Morrison & Sachs, 2002).

Current practice in community settings and cultural beliefs need to be considered before any infant feeding education programmes are initiated (Humphrey & Iliff, 2001). Exclusive breastfeeding, exclusive formula feeding, pasteurisation of expressed breast milk, and the use of appropriate donor milk are all options that need to be examined (Latham, 2000). The efficacy of different infant feeding practices, the cost effectiveness of proposed programmes, and the policies of both national and international health care

agencies need to be examined and evaluated in the light of the impact of MTCT of HIV in sub-Saharan Africa (Coutsoudis, 2000; Latham, 2000).

The HIV/AIDS epidemic poses a severe threat to sub-Saharan Africa. Mozambique, South Africa, and Zimbabwe are listed among the ten countries in the world with the largest number of HIV infections, with South Africa topping the list (Van Rensburg, Friedman, Ngwena, Pelser, Steyn, Booysen, and Adendorff, 2002). South Africa, Namibia, and Zimbabwe are also among the top ten countries with the highest adult HIV prevalence rate (Van Rensburg et al, 2002). "Compounding the problem is the considerable ignorance and denial of the disease. HIV is not only a health related concern; it additionally has social, cultural, economic, and political ramifications that, together, accelerate the spread of the epidemic. African socio-economic and socio-cultural dynamics hastens infection and to a large extent impedes intervention initiatives. Every sexually active person in Africa is indeed at risk" (Van Rensburg et al, 2002, p1).

Statistics have shown a sharp rise in the AIDS epidemic in the past ten years and have continually reported KwaZulu-Natal as the epicentre of the AIDS pandemic, with the 2001 Annual South African Antenatal HIV Seroprevalence Surveillance report revealing a 40% seroprevalence at antenatal clinics in KwaZulu-Natal (KwaZulu-Natal Department of Health, 2002).

The National Department of Health considered the scientific evidence confirming the efficacy of various antiretroviral drug regimens in reducing the

transmission of HIV from mother to child, and decided it was viable to launch a pilot programme for the implementation of a short course antiretroviral regimen at 18 pilot sites in the country (KwaZulu-Natal Department of Health, 2002). The aim of the pilot programme was to assess the operational challenges of the proposed intervention.

A six month analysis of data collected at the two pilot sites in KwaZulu-Natal between June and December 2001 indicated that at least 12 000 women had access to the Prevention of Mother-to-Child Transmission (PMTCT) services, and more than 70% of the women at these sites were subsequently tested for HIV (KwaZulu-Natal Department of Health, 2002). The HIV seroprevalence ranged between 20 and 49% between antenatal clinics (KwaZulu-Natal Department of Health, 2002). Return rates for results were more than 70%, and the more than 70% of the women who tested positive for HIV received the single dose Nevirapine regimen (KwaZulu-Natal Department of Health, 2002). Almost all (99%) of the babies born to these women received their single dose of Nevirapine between 12 and 72 hours of birth. In the light of these achievements, the Provincial Department of Health decided to provide all pregnant women in KwaZulu-Natal access to this expanded programme that includes voluntary and confidential counselling and HIV testing, Nevirapine, revised obstetric practices and revised infant feeding practices.

This expanded programme was envisioned to be implemented in 3 phases over an 18 month period commencing on May 1st 2002 (KwaZulu Natal Department of Health, 2002). Appendix 1 contains the protocol for the phased

implementation of this PMTCT programme. The proposal for the phased implementation of the programme was reviewed, and phase one including the analysis of data, recruitment and identifying personnel, and seeking funding began in January 2002. Phase two which involved the provision of the service to all major hospitals in every district of KwaZulu-Natal was to be commenced in August 2002, but due to numerous hurdles it was decided that all institutions would commence an expanded prevention of mother-to-child transmission (EPMTCT) on March 1st 2003.

1.2. Problem statement

Much research has been done to establish the safest possible infant feeding options for HIV positive mothers. Obviously, exclusive formula feeding would be the safest option in terms of transmission of HIV since the infant would not be exposed to the virus present in breast milk (De Cock et al, 2000, Humphrey & Iliff, 2001). Exclusive breastfeeding for a limited time period (four to six months) has been found to have similar favourable outcomes; not conveying any excess risk of HIV transmission over formula feeding (Coutsoudis, Pillay, Spooner, Kuhn, & Coovadia, 1999 & Coutsooudis, Pillay, Kuhn, Spooner, Tsai & Coovadia, 2001). There is as of yet no scientific evidence that infants of mothers who are HIV positive would be better off if they were not breastfed (Kent, 1999). A reduced duration of breastfeeding by HIV positive women is recommended since the morbidity and mortality resulting from not breastfeeding is higher in the first six months of life than at older ages (Latham, 2000). Mixed feeding (ingestion of contaminated water, fluids and food in addition to breast milk) is strongly discouraged since it

increases the risk of HIV transmission through breast milk by interrupting the integrity of the gut epithelial barrier and allowing passage of the HI virus (Coutsoudis et al, 1999 & 2001)

There are a number of factors which affect infant feeding in a rural African context. Formula feeding in a rural African situation is associated with high rates of malnutrition, morbidity, and mortality (Hormann, 1999). Most African mothers cannot afford infant formula milk, and even if it is provided free, equipment, fuel, potable water, time knowledge, adequate and accessible health care and education are also needed (Hormann, 1999). In order for formula feeding to be a viable and safe option there needs to be access to safe water, uninterrupted supply of infant formula, intensive counselling, and skills training with follow-up in the home regarding preparation and delivery of replacement feedings, good hygiene, a supportive home environment, and frequent, conscientious, and affordable clinical follow-up with early intervention for growth faltering and illness (Humphrey & Iliff, 2001).

Exclusive breastfeeding is very difficult to practise in the rural African context due to a number of social and cultural factors (Fowler, Bertolli & Nieburg, 1999; Humphrey & Iliff, 2001, Coutsooudis et al, 1999). Breastfeeding is the norm in most of Africa; *not* breastfeeding may label a woman as being HIV-positive, as having an evil spirit, or being sexually promiscuous and unfaithful to her husband (Humphrey and Iliff, 2001). Even if a woman decides to formula feed, given all the social constraints *not* to replacement feed in Africa, the pressure to breastfeed, even occasionally or for a short time, can be

intense for some women (Humphrey & Iliff, 2001, Coutsoudis et al, 1999). On the other hand, exclusive breastfeeding is also not the norm in most of the world, including Africa (Humphrey & Iliff, 2001; Taren, 2000). It is culturally acceptable to give water and herbal teas early during breastfeeding and to introduce solids, such as infant cereals, within the first month of life (Coutsoudis et al, 1999). Thus the PMTCT initiative of discouraging mixed feeding faces a barrier.

Factors affecting decision-making regarding infant feeding

There are also a number of factors affecting decision-making of HIV positive mothers regarding infant feeding in the rural African context. The decision to formula feed necessitates ability and willingness to prepare, store and feed infant formula safely, regular attendance at health care facilities to access infant formula, and family support (Humphrey & Iliff, 2001). The greatest barrier to women taking this decision will probably be family and societal perceptions of formula feeding as different and the likelihood that inferences will be made about the HIV status of the woman (Humphrey & Iliff, 2001).

It is the efficacy of the infant feeding interventions and health education and follow-up provided to HIV positive mothers within the context of the PMTCT programme that is one of the topics to be explored. The risk-benefit ratio of breastfeeding versus formula feeding in HIV positive mothers and their infants is difficult to assess, and the PMTCT programme will ultimately involve a HIV positive mother's individual decision as to what is best for herself and her

infant in their current social-cultural-economic-psychological environment (Guay & Ruff, 2002).

1.3. Purpose of the study

To determine the efficacy of one aspect of the current PMTCT programme in KwaZulu-Natal, specifically in the sphere of encouraging and supporting effective infant feeding choices. To explore challenges to avoiding the common practice of mixed feeding and viable intervention solutions for the future.

1.4. Objectives of the study

1. Identify the perceptions of the women in the study which influence their original infant feeding choice (either exclusive breastfeeding or exclusive formula feeding).
2. Identify the influence of demographic and other regulating factors on the original feeding choice of the women in the study.
3. Describe factors influencing either maintenance of original infant feeding choice or alteration of infant feeding choice over a four to six month postpartum period.

1.5. Research questions

1. What are the belief, value and attitude systems of the women towards infant feeding options?

2. What are the regulating factors (demographic and other factors) that affect the women's decisions to either exclusively breastfeed or to exclusively formula feed?

1.6. Conceptual framework

Social cognitive theory focuses essentially on the social context of health-related behavioural change and its associated cognitive processes (Whitehead, 2001). Social cognitive models are models based on the client's reaction to a perceived or actual threat of disease/illness and seek to identify the processes that lead to any action taken or not taken (Whitehead, 2001). The conceptual framework used in this study is a social cognitive model for health promotion practice in nursing described by Whitehead (2001). See Appendix 2 for a diagrammatic representation of the conceptual framework.

Whenever a nurse attempts to influence the health-related behaviour of a client, he/she needs to take into account the multifaceted factors that contribute to this behaviour. Merely to expect an individual will change their behaviour when presented with a certain scenario, such as the threat of an illness or disease, is limited and naïve. Clients are not consistent in the way they approach their health, and therefore, we need to be aware of the many variations that may take place within any health encounter (Whitehead, 2001). Likewise, the decision-making of HIV positive mothers regarding infant feeding is influenced by multifaceted factors, and is not categorically based on their HIV status (Humphrey & Iliff, 2001; Coutoudis et al, 1999 & 2001). Each HIV positive mother will face different challenges to a specific infant feeding

regimen, and so each woman's individual case must be considered in terms of the conceptual framework.

The strength of this theory lies in its ability to highlight an individual's reasons for considering and possibly adopting any health-related behavioural change, for example, their belief, knowledge, attitude, value, drive, motivation, and self-efficacy systems – this will be vital in examining the decision-making of HIV positive mothers regarding infant feeding (Whitehead, 2001). There are many social, cultural and demographic factors that influence infant feeding practice and what choice is viable for a specific HIV positive mother (Humphrey & Iliff, 2001; Coutsooudis et al, 1999; Fowler et al, 1999).

Appropriately, this model seeks to consider the complex relationships between health behaviours and the factors that determine social norms as a framework for how the client is likely to behave under any given circumstances (Whitehead, 2001). Any health education intervention, including the PMTCT programme, is far more likely to have a successful outcome if we understand the reasons why a client may or may not adopt a particular health-related behaviour before we embark on a programme of change (Whitehead, 2001).

This framework is relevant to this study since it will assist in interpreting the findings of the case studies, identifying cues to action, as well as cues to non-action. It will guide the investigation of regulating factors and the perceptions of the participating women with reference to their HIV status and health promotion in general, as well as perceptions of the PMTCT programme itself,

the health interventions involved, and the health care providers they encounter during the programme.

1.7. Terminology

1.7.1. Prevention of Mother-To-Child Transmission (PMTCT)

Prevention of mother to child transmission of the human immunodeficiency virus during pregnancy, childbirth, and lactation. PMTCT in the context of this study involves voluntary and confidential counselling and testing, revised obstetric practices, providing counselling on safe infant feeding practices, and the provision of short course antiretroviral drugs to HIV positive pregnant women and their new born infants, and providing follow-up care and prophylactic treatment to the HIV positive mothers and their children (KwaZulu Natal Department of Health, 2002).

1.7.2. Voluntary Confidential Counselling and Testing (VCCT)

Voluntary confidential counselling and testing includes the process of pre-test counselling, HIV testing, and post-test counselling. Participation in the process must be voluntary, and test results must be kept confidential. Informed consent must be obtained from the participant. Informed consent implies that the individual understands what the test is, why it is necessary, and the benefits, risks, alternatives and possible social implications of the outcome (National Department of Health, 1999).

1.7.3. HIV positive

If a rapid screening HIV blood test (Determine® or another rapid test approved for use in the PMTCT programme by the KwaZulu-Natal Department of Health) shows a positive result, a second rapid HIV blood test (Smartchek® or another rapid test approved for use in the PMTCT programme by the KwaZulu-Natal Department of Health) will be conducted to confirm the positive status. If the second blood test also shows a positive result, the client is considered to be HIV positive.

1.7.4. Exclusive breastfeeding

Exclusive breastfeeding means providing an infant with only breast milk from birth for the first four to six months of life, and excluding any other form of feeding including water, tea, cereals, and formula feeds (Coutsoudis et al, 1999).

1.7.5. Exclusive formula feeding

Formula feeding means feeding a child who is not receiving any breast milk from birth to 2 years with a diet that provides all the nutrients the child needs (De Cock et al, 2000). For the first six months breast milk substitute is essential, such as commercially prepared infant feeding which needs clean water, accurate measurements of powder and water, and good hygiene and clean utensils (De Cock et al, 2000).

1.7.6. Mixed feeding

Mixed feeding is the infant feeding practice in which the infant receives both formula feeds and breast milk during the first four to six months of life (Bobat et al, 1997).

1.8. Significance of the study

Available literature in the field of PMTCT has focused mainly on the clinical efficacy of antiretroviral drug regimens in preventing mother to child transmission of HIV. Some authors have mentioned the link between social and cultural factors in Africa and difficulties in promoting exclusive breastfeeding or exclusive formula feeding (Humphrey & Iliff, 2001; Coutoudis et al, 1999 & 2001; Fowler et al, 1999; Taren, 2000). These are the two infant feeding choices offered to HIV positive mothers and yet it seems to be profoundly difficult for women to adhere to these feeding patterns in the community. It is anticipated that the results from this study will identify the specific and real challenges faced by HIV positive women in terms of infant feeding regimens, and will provide practical guidelines to improve counselling and support for these women in the context of the Department of Health's PMTCT programme.

CHAPTER 2

LITERATURE REVIEW

2.1. Breastfeeding and HIV

2.1.1. Risk of MTCT through breast milk

While numerous case reports and epidemiologic studies have shown that HIV can be transmitted from mother to infant in human milk, the exact risk is unknown (De Cock et al, 2000). Kaplan (2000) cites a specific meta-analysis that estimated a 14% risk of transmission for mothers who were infected during pregnancy and a 29% risk if primary infection occurred in the postpartum period. Transmission is probably more likely in mothers with higher viral loads (De Cock et al, 2000). Even though it is difficult to establish with any certainty the relative contribution of pregnancy, labour, or breastfeeding on MTCT, Hormann (1999) asserts that even by the most conservative estimates, 80% of infants born to HIV positive mothers are not infected during pregnancy and labour. In addition, the most common current estimate is that the additional risk of HIV infection when an infant is breastfed is about 15%. She concludes that if we accept these estimates as correct, of every 100 infants born to HIV positive mothers, twenty (those who acquired an HIV infection in utero or during labour and delivery) should probably be breastfed because they are likely to need all the immunologic protection they can get; fifteen (those who would acquire an HIV infection through breastfeeding) should not be breastfed if there is any safe alternative; and sixty-five probably could be breastfed safely because they are unlikely (for reasons we do not yet understand) to acquire an HIV infection (Hormann, 1999).

Recommendations for infant feeding practices for HIV positive mothers are complex. Kaplan (2000) asserts that in the United States and other areas of the world where safe alternatives to breastfeeding are readily available, HIV positive women should be advised not to breastfeed their babies. However, in areas of the world where sanitation is inadequate, and safe, affordable infant formula preparations are not available, the recommendations are not as clean cut. As Latham (2000) states, if preventing a child from acquiring HIV infection through breast milk were the sole consideration, infected mothers would be advised not to breastfeed but to give their infants formula milk. However, for HIV positive mothers living in poor households in developing countries, it is important to consider the risks related to not breastfeeding and to explore the possibility of alternative feeding methods (Soderlund, 1999).

Hormann (1999) states that the decision not to breastfeed involves a risk that becomes greater as hygienic standards and family income decreases.

Soderlund (1999) points out that when breastfeeding is associated with a strong protective effect or when infant mortality exceeds around 70 to 140 per 1000, formula feeding interventions to decrease MTCT are contraindicated. The majority of infants of HIV positive mothers will not become infected as a result of breastfeeding (Kent, 1999). Therefore depriving all infants born to HIV positive mothers of the benefits of breastfeeding seems unwarranted, especially if breastfed infants receive some protective effects from breast milk (Kent, 1999).

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Until recently, the World Health Organisation (WHO) felt that nutritional and safety considerations outweighed the risk of transmitting infection and recommended breastfeeding regardless of HIV status (Kaplan, 2000). A 1997 WHO statement held that artificial feeding was still a greater risk to children than maternal to child transmission (MTCT) of HIV (Kaplan, 2000). However, as the death toll from HIV/AIDS continued to mount, WHO substantially modified its position in September 1998 (Kaplan, 2000). In a series of new manuals for policy makers and health workers issued jointly by WHO, the United Nations Children's Fund, and The Joint United Nations Programme on HIV/AIDS, it is stated that it may be preferable to replace human milk to reduce the risk of HIV transmission – provided the risk of replacement is less than the potential risk of HIV transmission (Kaplan, 2000). To meet that condition, there needs to be in place continued support for breastfeeding mothers who are HIV negative or of unknown status; improved access to HIV counselling and testing; and governmental efforts to ensure uninterrupted access to nutritionally adequate human milk substitutes that can be safely prepared and stored, but many are sceptical that these objectives are attainable in Third World countries with high rates of HIV infection (Kaplan, 2000; Hormann, 1999).

South Africa falls into this category with statistics that reflect that one in four pregnant women in the country have HIV (Sidley, 2001). The South African Government's annual figures on HIV/AIDS, as published in the British Medical Journal (Sidley, 2001), show a continued increase in the numbers of people

contracting the virus. According to a survey of 16 548 blood samples in the year 2000, 24, 5% of pregnant women were infected with HIV (Sidley, 2001). The equivalent figures for 1998 and 1999 were 22, 8% and 22, 4% respectively (Sidley, 2001). Several provinces showed a substantial rise in prevalence, such as Kwazulu-Natal, which showed a rate among pregnant women of 36, 2%, compared with 32, 5% in the previous year (Sidley, 2001).

Latham (2000) quotes the official policies on infant feeding:

“Where infectious diseases and malnutrition are the main cause of infant deaths and the infant mortality rate is high, breastfeeding should be the usual advice given to pregnant women including those who are HIV infected. This is because their baby’s risk of HIV infection through breast milk is likely to be lower than the risk of death from other causes if it is not breastfed.” (World Health Organisation/Unicef. Consensus Statement. In: The WHO/Unicef consultation on HIV transmission and breastfeeding. Geneva: WHO, 1992, cited in Latham, 2000, p6).

“When children born to HIV infected women can be assured of uninterrupted access to nutritionally adequate breast milk substitutes that are safely prepared and fed to them, they are at less risk of illness and death if they are not breastfed. However, when these conditions cannot be met – in particular in environments where infectious diseases and malnutrition are the primary causes of death during infancy – then artificial feeding substantially increases children’s risk of

illness and death. The policy objective must be to minimise all infant feeding risks and to urgently expand access to adequate alternatives so that HIV infected women have a range of choices. The policy should also stipulate what measures are being taken to make breast milk substitutes available and affordable; to teach the safest means of feeding them to infants; and to provide the conditions which will diminish the risks of using them.” (World Health Organisation. HIV and infant feeding. Guidelines for decision makers. Geneva: WHO, 1998 cited in Latham, 2000, p6).

Latham (2000) questions whether it was wise for WHO to change policy when so little was known about the feasibility of the different feeding options described in the UNAIDS/WHO/Unicef guidelines and when the disadvantages and harmful outcomes of not breastfeeding still applied, or may even have become more serious in sub-Saharan Africa because of deteriorating economies. Hormann (1999) also questions the encouragement of replacement feeding even in developing countries, where it is associated with high rates of malnutrition, morbidity, and mortality. She acknowledges that the 1998 policy emphasises informed choice for all mothers, but points out that the assumption of the document is that mothers known to be HIV positive will be encouraged to use replacement feeding for their infants.

Transmission of HIV from mother to child mainly occurs in utero and during delivery, but in a few cases it occurs through breastfeeding (De Cock et al, 2000). Latham (2000), in his article “Appropriate feeding methods for infants

of HIV infected mothers in sub-Saharan Africa”, asserts that even responsible health agencies have tended to exaggerate the role of breastfeeding in MTCT. He states that it is estimated that in countries with a low seroprevalence of HIV (5% of women affected) less than 1% of all infants are likely to become infected through breastfeeding, whereas in those with a high prevalence (25% of women affected) fewer than 4% of infants will be affected through lengthy breastfeeding.

Guay and Ruff (2002, p1113) make a poignant comment: “Support of breastfeeding among HIV-infected women in resource poor settings who cannot safely provide or choose not to use alternative feeding strategies does not reflect a double standard. Recommendations regarding infant feeding practices should be based on an individual’s known risks and benefits; that the same recommendation cannot be made for everyone reflects global health inequities. The fact that HIV infected women will continue to breastfeed their infants is a reality, and the obligation of health care workers is to try to make whatever infant feeding option a mother chooses as safe as possible.”

2.1.2. Comparison of risk and benefit of breastfeeding by HIV positive mothers

Breastfeeding has many benefits – from protection against otitis media and gastrointestinal disease to boosting the infant’s immune response to the polio vaccine, and protecting against diabetes (Kaplan, 2000). Breast milk provides all of the nutrients an infant needs for about four to six months, and many of these nutrients have not been duplicated in replacement feeding or are not

bio-available in the way they are in human milk (Hormann, 1999). It also contains numerous anti-infective factors, including immunoglobulins and white blood cells, and growth factors which stimulate the development of the infant's gut (Hormann, 1999). Coburn (2000) summarises the benefits of breastfeeding: breast milk contains four hundred nutrients that cannot be recreated in a laboratory, and several studies suggest that breastfeeding reduces the risk of sudden infant death syndrome. An absence of breastfeeding has been linked to an increased risk of hospitalisation, childhood cancer, diarrhoeal diseases, lower respiratory illness, ear infections, bacterial infections, diabetes, infant botulism, Crohn's disease, ulcerative colitis, and even cavities (Coburn, 2000; Kaplan, 2000).

Wise (2001) quotes estimates that 1, 7 million babies have been passed the HIV virus through breast milk, but this has to be compared with the 1, 5 million babies who die every year because they are not breastfed. Breastfeeding a baby for at least six months is considered the best way to prevent early childhood malnutrition (Haggerty, 1999). In addition, many studies have shown that exclusively breastfed infants are less likely to have diarrhoea than infants who are bottle-fed (Kaplan, 2000). Data from developing countries show that mortality from diarrhoea, acute respiratory infections, and other infectious diseases is five or six times higher in infants who are not breastfed than in those who are breastfed for the first two months of life (Latham, 2000; Hormann, 1999).

On the other hand, the many disadvantages and harmful outcomes of artificial feeding have been widely documented (Hormann, 2000; Latham, 2000; Soderlund, 1999; De Cock et al, 2000; Fowler, 1999). Most African mothers cannot afford infant formula milk, and even if it is provided free, equipment, fuel, potable water, time knowledge, adequate and accessible health care and education are also needed (Hormann, 1999). Alternatives to formula feeding must also be considered. These include a modified shorter duration of exclusive breastfeeding, heat treating expressed breast milk to kill the virus, use of modified animal milk, or use of breast milk from appropriate donors (Latham, 2000; Hormann, 1999). However, as Latham (2000) asserts, inadequate research has been conducted on these alternatives.

Kaplan (2000) claims that there are circumstances in which breastfeeding should not be encouraged, even though these circumstances are limited. Mothers with transmissible viral infections, particularly HIV, and mothers who must take medications that can have adverse effects on their infants should consider alternatives to breastfeeding (Kaplan, 2000). Kent (1999) states that, outside the HIV context, in practically every situation, infants are better off breastfeeding than not. The use of breast milk substitutes is medically indicated only when the mother is unable to sustain breastfeeding or is taking pharmaceutical or recreational drugs that may be dangerous for the infant (Kent, 1999; Kaplan, 2000). Kent (1999) proceeds to assert that the same conclusion applies if the mother has HIV, since there is as of yet no scientific evidence that infants of mothers who are HIV positive would be better off if they were not breastfed. Kent (1999) acknowledges that many authors have

inferred this conclusion, but there is no hard evidence to support it. What is needed is evidence based on actual health outcomes (morbidity and mortality), and not just blood test results (Kent, 1999).

2.1.3. Antiretroviral use

In reviewing the use of antiretrovirals for reducing the risk of mother-to child transmission (MTCT) of HIV infection, Brocklehurst and Volmink (2002) concluded that evidence suggests that short course zidovudine and single dose nevirapine are effective therapies for reducing MTCT of HIV, but the challenge is for low and middle income countries to institute this therapy in practice. They suggest that further research be done to determine the potential value of nevirapine used for longer durations in breastfeeding populations, since it may further reduce the risk of MTCT, particularly if combined with early weaning (Brocklehurst & Volmink, 2002; De Cock et al, 2000). Brocklehurst and Volmink (2002) further insist that the search for effective, affordable, safe, and acceptable alternatives to combination long-course antiretroviral therapy for reducing MTCT in developing countries remains a research priority.

2.1.4. Other practices linked to MTCT

Humphrey & Iliff (2001) cite findings that suggest that breast pathology may be an important risk factor for breastfeeding-associated HIV transmission. In addition, unprotected sex can re-infect HIV-positive women and increase plasma viral load, thus practising safe sex during the breastfeeding period is

advisable to reduce breastfeeding-associated transmissions (Hormann, 1999; Humphrey and Iliff, 2001).

Some related issues that have to be addressed to decrease MTCT of HIV are the association between poor nutritional status and HIV transmission, and the association between late breast milk transmission of HIV and cracked nipples and breast abscess (Hormann, 1999). All HIV positive pregnant and breastfeeding women should be enrolled in food and vitamin supplementation programmes (Hormann, 1999; Humphrey & Iliff, 2001). Cracked nipples and breast abscess are known to be associated with poor positioning at the breast and inappropriate breastfeeding management, and so education should be provided (Hormann, 1999).

2.1.5. Breastfeeding support

Supplementary breastfeeding support should be part of routine health service provision since there is clear evidence for the effectiveness of professional support on the duration of any breastfeeding, although the strength on its effect on the rate of exclusive breastfeeding is uncertain (Sikorski, Renfrew, Pindoria, and Wade, 2002). Lay support has been shown to be effective in promoting exclusive breastfeeding while its effect on the duration of any breastfeeding is uncertain (Sikorski et al, 2002).

Clearly, providing strong social support to inexperienced mothers and teaching the doctrine of exclusive breastfeeding may be an important factor to decreasing MTCT of HIV (Coutsoudis et al, 1999; Taren, 2000). This support

needs to focus on improving maternal nutritional status, increasing lactation support, and maintaining proper infant feeding practices (Taren, 2000).

2.2. Breastfeeding in an African rural community

2.2.1. Challenges and norms

Humphrey & Iliff (2001) illustrate one of the tragedies of the HIV pandemic: “whereas breastfeeding prevents an estimated 6 million infant deaths each year throughout the world, it also results in 200,000-300,000 infant HIV infections.” (p119). In addition, the period when breastfeeding is most critical to preventing infant deaths, and *not* breastfeeding is associated with more infant deaths in developing countries, the first four to six months of life, is also the period when the majority of breastfeeding associated HIV transmission probably occurs (Latham, 2000; Humphrey & Iliff, 2001).

Recently, formula feeding has become the norm for babies of HIV-positive women in intermediate-economy countries such as Thailand, Brazil and parts of South Africa (Humphrey & Iliff, 2001). But in sub-Saharan Africa this is not possible, and yet this is the area where two-thirds of the global total of HIV-infected women of childbearing age lives (Latham, 2000; Hormann, 1999; Humphrey & Iliff, 2001). The gross national product in these countries is roughly equivalent to the cost of a six month supply of infant formula, the infant mortality rate is 100/1000 births, and 45% of women don't have access to safe water (Humphrey & Iliff, 2001). While the United Nations organisations (WHO, UNICEF, and UNAIDS) in their revised recommendations say that all women should have access to testing and counselling for HIV, and “be

empowered to make fully informed decisions about infant feeding”, this is also not a reality in sub-Saharan Africa (Humphrey & Iliff, p 120, 2001; Hormann, 1999; Kent, 1999).

2.2.2. Nairobi clinical trial

Nduati and colleagues (2000) conducted a randomised controlled trial of breastfeeding versus formula feeding in HIV-positive women in Nairobi, Kenya. The key findings of this study were: (1) at 24 months, 36, 7% of breastfed compared with 20, 5% of formula-fed infants were HIV-infected, representing a 16, 2% excess risk of transmission in the breastfeeding group. Most of this excess transmission occurred early. Sixty-three percent, 75%, and 87% of the overall difference had already occurred at 6 weeks, 6 months, and 12 months, respectively. Thus, their study confirmed the findings of many observational studies: breastfeeding can nearly double the risk of MTCT and early breastfeeding carries the greatest risk. (2) Among children who were HIV-negative, those in the formula group were six times more likely to die in the first six months of life compared with those in the breastfeeding group. Thus, their study also confirmed decades of work demonstrating that *not* breastfeeding is associated with substantial risk of death, especially for the youngest babies. (3) HIV-free survival was greater at 24 months in the formula-fed group compared with the breastfed group. Thus, *in their study population*, the balance of risks favoured those in the formula group. These findings make us ask: (1) Will formula feeding result in a better outcome for *all* HIV-positive women in developing countries (more than 80% of whom live in sub-Saharan Africa)?, and (2) How stable is the risk-benefit ratio observed in

Kenya when applied to other diverse circumstances prevailing in sub-Saharan Africa? (Nduati, John, Mbori-Ngacha, Richardson, Overbaugh, Mwatha, Ndinya-Achola, Bwayo, Onyango, Hughes, & Kreiss, 2000).

2.2.3. Critique of Nairobi trial

However, it must be noted that there is widespread criticism of Nduati et al's (2000) randomised trial. Bulterys (2000) points out that randomisation to breastfeed or formula feed at 32 weeks of pregnancy may have led to differences in behavioural or biological risk factors for intra-partum or late prenatal HIV-1 transmission, since those in the formula feeding arm received instruction sessions in late pregnancy which may have resulted in adapted behaviour by the time of labour and delivery. Nduati et al. (2000) in reply state that they found no significant differences between the two arms for any enrolment or delivery characteristics, including sexual behaviour variables at delivery. Coutsooudis, Coovadia & Pillay (2000) assert that although the researchers claim that formula feeding results in improved outcomes, the mortality rate of the two groups after two years was similar; and a mortality rate of 20% in a group that received extensive support for formula feeding, clean water, free formula, and numerous contacts with health workers is unacceptably high. Nduati et al. (2000, p957) in reply state that the high two year mortality rate observed in both arms of the trial is an "unfortunate reflection of the hazard of being born of a mother who is infected with HIV-1" and thus primary prevention of HIV-1 infection is the real solution to the problem.

2.2.4. Applicability of Nairobi trial results to wider population

Humphrey and Iliff (2001) observe that several mathematical models have been developed, these models show that whether replacement feeding will increase or decrease HIV infection-free survival among infants of HIV-positive mothers is sensitive to the following key variables: (1) ***R*** = relative risk of death attributable to *not* breastfeeding; (2) ***IMR*** = infant mortality rate; and (3) ***T*** = risk of transmission attributable to breastfeeding. As ***R*** increases, the relative risk of replacement feeding and the relative benefit of breastfeeding increase. Factors that reduce, or are likely to reduce ***R*** include access to safe water, uninterrupted supply of infant formula, intensive counselling, and skills training with follow-up in the home regarding preparation and delivery of replacement feedings, good hygiene, a supportive home environment, and frequent, conscientious, and affordable clinical follow-up with early intervention for growth faltering and illness. In these models, the factor ***R*** is multiplied by ***IMR***. Thus, for a given ***R*** the absolute number of deaths owing to not breastfeeding increases as ***IMR*** increases. Thus, the ***R*** that will shift the net balance toward favouring breastfeeding will be lower in countries with a high ***IMR*** compared with countries with a low ***IMR***. As ***T*** increases, the relative benefits of formula feeding and the relative risks of breastfeeding increase for babies of HIV-positive women. Practices likely to reduce ***T*** include exclusive breastfeeding, practice of safe sex during the breastfeeding period, good lactation practice, avoidance of breastfeeding during breast disease, and limiting duration of breastfeeding (Humphrey & Iliff, 2001).

Humphrey and Iliff (2001) additionally attempt to estimate the number of HIV-positive African women to whom Nduati et al's findings might be relevant. To do this, they estimate the number who are likely to have a similarly low **R** based on access to safe water and literacy. Of the nearly 13 million HIV-positive women of reproductive age living in sub-Saharan Africa, 55% (7.2 million) have access to safe water and nearly the same number (7.1 million) is literate (and these groups probably represent the same women). Therefore, they conclude, replacement feeding might be favourable for roughly 7 million babies if factors to minimise **R** are put in place and if women accept and comply with these interventions. But what proportion of these 7 million women will be willing to learn their HIV status, disclose it to others, prepare and feed the replacement feed safely, limit rural travel so they can attend frequent medical care and access replacement feedings, and have husbands and other close family members who will support them in this process? (Humphrey & Iliff, 2001).

2.2.5. Timing of breast milk HIV transmission

Another significant finding of Nduati et al's (2000) study concerns the timing of breast milk HIV transmission. Since cumulative HIV infection rates in the two groups were significantly different as early as six weeks of life, the data suggest that substantial transmission occurs early during breastfeeding (Nduati et al, 2000).

Miotti and colleagues (1999), in their study in Malawi, found a high risk of MTCT of HIV-1 in the first six months of breastfeeding. This finding limits the

value of early weaning as a way of reducing the risk of late postnatal HIV transmission (Miotti, Taha, Kumwenda, Broadhead, Mtimavalye, Van der Hoeven, Chipangwi, Liomba, & Biggar, 1999). They admit that some infections would be prevented by early weaning, but there might also be additional illnesses and deaths due to early weaning (Miotti et al, 1999). They, like many other authors, point out that the risk-benefit ratio is likely to be widely different in different populations, so it would be very difficult to generalise any weaning recommendation and its optimal timing (Miotti et al, 1999; De Cock et al, 2000; Latham, 2000). Miotti et al's (1999) study also illustrated that HIV transmission due to breastfeeding remained substantial for as long as the infant continued to breastfeed.

Latham (2000) concludes that major efforts to promote exclusive breastfeeding would do great good and no harm. Exclusive breastfeeding is clearly optimal for HIV negative women, and for babies infected in utero or during childbirth it would be the best feeding method unless the mother was too ill to do this (Latham, 2000; De Cock et al, 2000). One alternative is to reduce the duration of breastfeeding by HIV positive women since the morbidity and mortality resulting from not breastfeeding is higher in the first six months of life than at older ages (Latham, 2000).

2.2.6. Benefits of breastfeeding

Coutsoudis et al (1999) found that exclusive breastfeeding does not seem to convey any excess risk of HIV-1 transmission over formula feeding. Interestingly, they found that among infants not already HIV-1 infected at birth,

those who were exclusively breastfed had a lower probability of infection than those never breastfed. The researchers note that this difference was not significant, but it raises the possibility that the virus acquired during delivery could have been neutralised by immune factors present in breast milk but not in formula feeds (Coutsoudis et al, 1999).

2.2.7. Risks of breastfeeding

Nduati et al. (2000) also highlight the community-specific nature of risks associated with formula feeding. Thus although the results of their trial suggest that breast milk avoidance could potentially decrease overall MTCT by 44%, they urge caution in applying the findings to other groups. In their trial, participants had access to clean water and extensive instruction in the safe use of formula (Nduati et al, 2000).

2.2.8. Comparative morbidity and mortality between breastfeeding and formula feeding

Mbori-Ngacha et al. (2001) used the same trial groups as Nduati and colleagues (2000) to compare morbidity and mortality in children according to randomised feeding modality. They found no significant difference in two year mortality rates between infants randomly assigned to be formula fed or to be breastfed (Mbori-Ngacha, Nduati, John, Reilly, Richardson, Mwatha, Ndinya-Achola, Bwayo, & Kreiss, 2001). The researchers assert that the two years of follow-up was sufficient to capture any potential adverse consequences of formula feeding but not all the adverse consequences of breastfeeding with respect to HIV-1 related mortality (Mbori-Ngacha et al, 2001). Consequently,

HIV-1 free survival (the percentage of children who remained alive and HIV-1 uninfected) best captures the combined risks of feeding modality and HIV-1 infection (Mbori-Ngacha et al, 2001). In this trial, HIV-1 free survival at 2 years was significantly higher in the formula arm (Mbori-Ngacha et al, 2001).

In Bobat et al's (1997) prospective study of a cohort of babies born to black HIV-1 infected South African women; they did not find the expected benefits of exclusive breastfeeding. They used four outcome criteria to measure benefit: mortality, infections, failure to thrive, and progression to AIDS (Bobat, Moodley, Coutoudis, & Coovadia, 1997). Morbidity due to common childhood infections (diarrhoea, pneumonia, otitis media) and failure to thrive, were as frequent in babies who were exclusively breastfed as in those who were either given formula exclusively or a mix of formula and breast milk; this observation was true for both HIV-infected and non-infected infants and children (Bobat et al, 1997).

2.2.9. Risks of formula feeding

Mbori-Ngacha et al. (2001) also refer to the widespread concern that the use of formula by women infected with HIV-1 in resource-poor settings would result in increases in diarrhoeal morbidity and mortality, but they found no such correlation in their study population. Overall, they did not observe increased risk of any major childhood morbidities, including pneumonia, sepsis, malaria, or otitis media associated with formula feeding (Mbori-Ngacha et al, 2001). They do however highlight that infants in the breastfeeding arm had better nutritional status than those in the formula

feeding arm, particularly during the first six months of life (Mbori-Ngacha et al, 2001). The researchers do again assert that their estimates of morbidity and mortality risk can not be generalised to all women in developing countries, since their results represent the best case scenario (Mbori-Ngacha et al, 2001). Because of these differences, they advocate specific counselling for HIV-1 infected expectant mothers so that each woman can select a feeding method that maximises benefits and minimises risks in her individual situation, as is recommended by the World Health Organisation (Mbori-Ngacha et al, 2001).

Once again, this study received widespread criticism: Kent (2002, p1110) asserts after listing various objections to the results of the study that: "Nothing in this study showed any good reason for mothers to choose formula. While we accept that under ideal conditions, formula might not be as dangerous as it usually is in developing countries, there is as yet no compelling evidence based on observed health outcomes to support the use of formula for infants whose mothers have HIV."

Eastman and colleagues (2002) argue that although Mbori-Ngacha and colleagues (2001) found a similar incidence of diarrhoea in the two study groups, dehydration was actually more common among the formula-fed infants, and it is dehydration, and not diarrhoea that leads to mortality in infants. They also assert that although the difference was not statistically significant, more than twice as many HIV-1 positive infants were malnourished in the formula group, and the rate of malnutrition was higher in the formula fed

HIV-negative infants as well (Eastman et al, 2002). Thus, if this trend were replicated in a larger trial, it could indicate that the negative health effects of formula feeding extend beyond 2 years (Eastman et al, 2002). Eastman et al. (2002) also point out that although Mbori-Ngacha et al. (2001) claim that their study compares breastfeeding with formula feeding, due to poor compliance to exclusive feeding regimens in both groups, the trial actually compares mixed feeding with mixed feeding. Thus the critics categorically state: “until the true, long-term consequences of the two approaches can be established by more tightly controlled trials with treatment groups that follow up infants with more distinct feeding patterns, we believe that the safest alternative is exclusively breastfeeding” (Eastman et al, 2002, p1111).

Farley et al. (2001) assert that since Mbori-Ngacha and colleagues (2001) found no excess mortality or morbidity in mothers who breastfed their infants compared with those who did not, the results of the study “warrant no change in current policies on infant feeding by HIV-1 infected women, which are: when replacement feeding is acceptable, feasible, affordable, sustainable, and safe, avoidance of all breastfeeding by HIV-1 infected mothers is recommended, otherwise, exclusive breastfeeding is recommended during the first months of life; to keep to a minimum risk of HIV-1 transmission, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation and the risks of replacement feeding (including infections other than HIV-1 and malnutrition); HIV-1 infected women should have access to information, follow-up clinical

care, and support, including family planning services and nutritional support” (Farley, Fontaine, Gaillard, de Zoysa, & Osborne, 2001, p1701).

In their report on the lessons and recommendations learnt from the interim findings on the South African national PMTCT pilot sites in February 2002, McCoy, Besser, Visser, and Doherty (2002) state that there is a real danger that the provision of free formula milk by the government will do more harm than good in many communities. The authors maintain that some public health specialists recommend that the Department of Health stop providing free infant formula, but continue to inform women about the risks and benefits of all feeding options, and to encourage exclusive formula feeding only for those who can afford to buy the formula themselves. McCoy et al (2002) support the consideration of the option to provide post-natal administration of antiretroviral treatment to mothers and/or babies to make breastfeeding safer.

2.2.10. Social stigma

Women in resource-poor settings have limited infant feeding choices, and risk social stigmatisation of both themselves and their infants, including possible violence and abandonment by their families and society if they choose not to breastfeed (Fowler et al, 1999).

Breastfeeding in Africa has attached to it many cultural and social factors (Fowler et al, 1999; Humphrey & Iliff, 2001, Coutsooudis et al, 1999).

Humphrey and Iliff (2001) point out that breastfeeding is the norm in most of Africa; *not* breastfeeding may label a woman as being HIV-positive, as having

an evil spirit, or being sexually promiscuous and unfaithful to her husband. Even if a woman decides to formula feed, given all the social constraints *not* to replacement feed in Africa, the pressure to breastfeed, even occasionally or for a short time, can be intense for some women (Humphrey & Iliff, 2001, Coutsoudis et al, 1999). In their work in Zimbabwe, Humphrey and Iliff (2001) were told by some women that they formula-feed in private, but breastfeed in public. They also report from some of the MTCT pilot projects offering antiretroviral drugs and free infant formula that many women accept the formula, but then also breastfeed (Humphrey & Iliff, 2001). On the other hand, exclusive breastfeeding is also not the norm in most of the world, including Africa (Humphrey & Iliff, 2001; Taren, 2000). Humphrey and Iliff (2001) state that in KwaZulu-Natal, nearly half of the mothers in a longitudinal study of infant feeding had supplemented breast milk within 48 hours of delivery, mostly because of perceived insufficiency of breast milk.

Coutsoudis and colleagues (1999) describe one of the difficulties in their prospective cohort study of infant feeding patterns: women who chose to breastfeed were counselled to consider exclusive breastfeeding because of the possible dangers of gut wall damage, which was a difficult concept for most of the mothers because it is culturally acceptable to give water and herbal teas early during breastfeeding and to introduce solids, such as infant cereals, within the first month of life (Coutsoudis et al, 1999).

All the evidence suggests that mixed breast and formula feeding is the most

dangerous feeding option for the young infant since it increases the risks of HIV and other infections (Coutsoudis et al, 2001; Latham, 2000; Taren, 2000). The popular regimens that support formula feeding as a way of reducing MTCT of HIV need to consider the risks of non-compliance (Latham, 2000). Latham (2000) quotes the report of a clinical trial in which urban Kenyan women were assigned to either breast or formula milk feeding groups. Poor compliance was reported in the formula group and it was postulated that this was due to community, family or spousal pressure to breastfeed, and the concern of the women that they could not maintain confidentiality of their HIV status if they refused to breastfeed (Latham, 2000) These are factors that are universally applicable (Latham, 2000).

2.2.11. Risks of mixed feeding

It must be noted that the majority of studies into MTCT of HIV through breastfeeding do not take into consideration the relative mortality in infants who had been exclusively breastfed and those who had been partly breastfed in the first few months of life (Latham, 2000). In contrast, a recent study conducted in Durban, South Africa, showed that the risk of vertical transmission of HIV associated with exclusive breastfeeding was considerably lower than that associated with mixed feeding (Coutsoudis et al, 1999 & 2001; Humphrey & Iliff, 2001). At three months of age there was little difference in the probabilities of HIV infection in infants whose mothers elected to breastfeed and in those whose mothers did not breastfeed at all (Coutsoudis et al, 1999 & 2001). Study infants who received mixed feeding (breast milk plus other fluids) had an appreciably higher risk of HIV transmission than

other groups (Coutsoudis et al, 1999 & 2001). This study, by Coutsooudis and the Vitamin A Study Group in August 1999, using multivariate logistic regression in a prospective cohort study, estimated that the proportion of HIV infection in exclusively breastfed infants was 14, 6% compared with 18, 8% in infants who were never breastfed and 24, 1% for infants who started mixed feedings before three months of age (Coutsoudis et al, 1999). This is a vital finding that may change health policy if it can be verified (Taren, 2000). However, a representative of the Department of Child and Adolescent Health and Development at the World Health Organisation said: "The study...is not good enough to enable the WHO to recommend that HIV positive women breastfeed exclusively as first choice" (Wise, 2001, p2).

Coutsoudis et al (1999 & 2001) have been pioneers in research into the effect of healthy gastrointestinal mucosa linked to prevention of MTCT. They state that breast milk contains growth factors which may enhance the maturation of the gut epithelial barrier, thus maintaining its integrity and hindering passage of the HI virus (Coutsoudis et al, 1999 & 2001, Taren, 2000). Conversely, ingestion of contaminated water, fluids, and food may lead to gut mucosal injury and disruption of immune barriers (Coutsoudis et al, 1999 & 2001). Since mixed feeding is unlikely to involve hygienic food preparation practices, bacteria and other contaminants may be introduced into the gut and result in inflammatory responses and subsequent damage to the mucosa (Coutsoudis et al, 1999 & 2001). HIV-1 is less likely to penetrate intact and healthy gastrointestinal mucosa than damaged mucosa (Coutsoudis et al, 1999 & 2001; Taren, 2000). The early report of the Vitamin A study group prospective

cohort study (1999) showed that exclusive breastfeeding carries a significantly lower risk (almost half the risk) of MTCT of HIV than mixed feeding. In their final report after completion of the 15 month study (2000), Coutoudis et al. (2001) highlighted that the results demonstrate that infants on exclusive breastfeeding had no excess risk of MTCT of HIV-1 over 6 months when compared to infants who were not breastfed at all but given formula and other feeds.

2.2.12. Recommended strategies for PMTCT in African rural communities

De Cock et al (2000) suggest that the most feasible strategy for reducing breastfeeding-related MTCT of HIV in resource poor settings would be to combine several weeks to months of postnatal antiretroviral prophylaxis of HIV-exposed infants with weaning at about four to six months (since breast milk provides infants with complete nutrition from age four to six months).

The prevention of vertical transmission of HIV is the focus of Soderlund's (1999) analysis of viable options for South Africa. He considers the impact of different infant feeding practices on the morbidity and mortality rates: whereas the number of lives saved from the prevention of ante-partum and intra-partum HIV peak in the first year of follow-up, the net deaths prevented by formula feeding interventions tend to be later on (Soderlund, 1999). This is partly because of the later onset of HIV disease and partly because lives saved by formula feeding in the first year are offset by lives lost due to the lack of protective effect of breast milk in HIV negative children (Soderlund,

1999). The study he reviews suggests that the infant feeding option which recommends breastfeeding early on, with a change to formula feeding after three or six months, saves the least number of lives as most HIV transmission through breast milk seems to occur early on (Soderlund, 1999). Other strategies which Soderlund (1999) reviews involve formula feeding from birth, but he asserts that these result in considerable costs because of diseases other than HIV. Soderlund (1999) concludes that the administration of a low cost antiretroviral regimen or advocating formula feeding for infants of HIV infected women, or both, would save lives and, in many cases, save money as well. However, he goes on to state that the provision of formula feed seems to be relatively expensive given the modest increase in effectiveness that it generates (Soderlund, 1999). He thus advocates antiretroviral interventions as a primary method of preventing vertical transmission of HIV (Soderlund, 1999).

2.2.13. Alternatives to formula feeding

As mentioned before, alternatives to formula feeding need to be considered. An HIV positive mother could breastfeed for a short time – Hormann (1999) cites a study that indicates that the risk of breastfeeding for four months is very low, and even up to nine months is under 1%. Another alternative is pasteurisation of expressed breast milk – heating milk to 62.5 degrees Celsius for thirty minutes, or brief boiling followed by cooling kills the virus but preserves most of the nutrients and vitamins (Hormann, 1999). Some anti-infective agents, particularly IgA, lactoferrin, and milk cells are compromised

by this process, but pasteurised breast milk retains many immunologic properties (Hormann, 1999).

2.3. Government policy

The South African government, in response to a report on mortality statistics in the country, and the finding that tuberculosis (TB), human immunodeficiency virus (HIV), and pneumonia/ influenza play a significant role in causing deaths in South Africa, made Cabinet statements issued on the 17th of April and the 9th of October 2002 committing itself to a multifaceted strategy on HIV/AIDS (National Department of Health, 2002). The Health Department (2002, p2) on the Polity.org.za website states that: "This confirms the need for all South Africans to intensify the implementation of the country's AIDS strategy, combining awareness and change in lifestyles, systematic treatment of opportunistic infections, research into a vaccine and use of both anti-retrovirals and alternative medication to reduce the impact of HIV as such."

Cullinan, in her "AIDS in 2002" article in The Daily News of Thursday, December, 5, 2002, summarises the government's HIV/AIDS policy. On April 17, the government announced in a cabinet briefing that anti-retrovirals would be provided to survivors of sexual assault in an attempt to prevent HIV infection (Cullinan, 2002). She points out though that this decision contrasted with a declaration in March by the ANC's National Executive Committee that anti-retrovirals should not be provided as post-exposure prophylaxis for health care workers or survivors of sexual assault since there was no proof of their

efficacy (Cullinan, 2002). In 2001 the High Court ordered the government to provide nevirapine to all HIV-positive pregnant women after the Treatment Action Campaign took the government to court (Cullinan, 2002). This decision was upheld by the Constitutional Court in July 2002 (Cullinan, 2002). The Constitutional Court also stated that the government was violating the constitutional rights of women and their babies by restricting access to nevirapine to 18 pilot sites (Cullinan, 2002). In October, during the launch of its "Campaign of Hope" on AIDS, the cabinet acknowledged that anti-retrovirals could "improve the condition of people living with AIDS" and said government was addressing challenges such as drug prices "to make it feasible and effective to use anti-retrovirals in the public sector." (Cullinan, 2002, p20) Sadly, health minister Tshabalala-Msimang continued to question the toxicity of nevirapine after the Constitutional Court's ruling (Cullinan, 2002). Tshabalala-Msimang also expressed disapproval of Gauteng's prevention of mother-to-child transmission programme including the provision of nevirapine, and Anglo-American's offer of anti-retrovirals to its employees, saying that she was not consulted on these programmes (Cullinan, 2002). Even more tragically, the health minister blocked a multi-million dollar grant from the Global AIDS Fund to KwaZulu-Natal because its granting "was unprocedural", although procedures were set down very late and government officials in the province were an integral part of the grant application (Cullinan, 2002, p20). As Cullinan (2002, p20) poignantly states: "the most aspiring HIV/AIDS leaders still remain outside government, a worrying trend when UNAIDS has identified leadership and political commitment as two critical factors in the fight against the disease."

In their report on the lessons and recommendations learnt from the interim findings on the South African national PMTCT pilot sites in February 2002, McCoy, Besser, Visser, and Doherty (2002) point out that with the vast amount of publicity surrounding the government's position on the provision of antiretroviral medication, their policy on infant feeding and providing free infant formula milk has been neglected (this is evident by the astonishing lack of available literature on the government's position on infant feeding choices for HIV positive mothers). They also assert that there needs to be a broader response from government and civil society to address the unacceptably high levels of child poverty and mortality due to preventable causes (thus making formula feeding a highly undesirable option for HIV positive mothers in the rural African context). Vital to the success of the PMTCT programme is a concurrent governmental focus on household food security, poverty alleviation, access to social welfare grants, care systems for orphans, and the provision of clean water to all households (McCoy et al, 2002).

The KwaZulu-Natal Department of Health has committed itself to a comprehensive PMTCT programme to be launched in most provincial health institutions on March 1st 2003 (KwaZulu-Natal Department of Health, 2002). This initiative follows review of the data collected from the National Department of Health's PMTCT pilot programme's two sites in KwaZulu Natal (Durban and Pietermaritzburg); and the conclusion that the programme, including the provision of a single dose of Nevirapine to participating HIV positive women in labour, and to their infants 12 to 72 hours post delivery, has

been effective in these pilot sites and should now be expanded (KwaZulu-Natal Department of Health, 2002).

CHAPTER 3

METHODOLOGY

3.1. Introduction

A case study format will be utilised for this study since the study population is not easily accessible in the focal community. Certain criteria will be set, but the study sample will include the first ten women admitted to the maternity ward of St. Apollinaris Hospital who fulfil the set criteria within a certain time period and who consent to participate in the study.

3.2. Design

A case study is an in-depth study of one individual, a group of individuals, or an institution (Brink, 1999). A case study is frequently used when there is a phenomenon about which not much is known or very rare events in which few subjects can be found (Brink, 1999). While the study population may not be rare, women who fulfil all the necessary criteria for participation in the study will be difficult to access in an institution with an average of one hundred to one hundred and twenty deliveries per month. Case studies provide significant amounts of descriptive information, and they can also provide some explanatory information (Brink, 1999). An advantage is the detailed level of analysis that results when research is confined to a small number of subjects (Brink, 1999). The topic under investigation requires a detailed and specific personal account of the experiences of each woman, and thus case studies are the most applicable design. A holistic multiple case design will be used in this study (Yin, 1989). The unit of analysis for these case studies will

be an individual HIV positive mother who satisfies the criteria set out in the study.

The main interest and focus of interviews will be factors affecting original infant feeding choice and factors affecting subsequent feeding practices over the six month postpartum follow-up period. The social cognitive model for health promotion practice in nursing described by Whitehead (2001) will be the basis of collecting and analysing data in terms of the research questions previously outlined.

3.3. Population and sample

The focal population for this study are HIV positive mothers who are permanent residents of rural KwaZulu-Natal.

The sample used will be a convenience sample due to a number of factors constraining the use of any other kind of sample. In order to obtain a probability sample, every element of the population must be known, and there must be an available listing of all members of the population, so that the sample can be randomly selected from this list (Brink, 1999). This is impossible in terms of the study population, since many pregnant women do not attend antenatal care and thus cannot participate in the voluntary HIV counselling and testing programme; and other women who do attend antenatal care refuse HIV tests after pre-test counselling. Non-probability sampling will thus be used. Non-probability sampling is also more convenient and economical in financial and time terms due in part to the clinical nature of the study and the necessity of a six month follow-up period (Brink, 1999). The

sample should be selected carefully, results interpreted conservatively and future replication of the study should be done with a new sample – if these criteria are followed, the quality of the data collected from this non-probability sample should be of high quality (Brink, 1999).

3.3.1. Inclusion criteria

3.3.1.1. Women must be HIV positive – pre-test counselled, tested with rapid HIV test, and result confirmed with a second rapid HIV test, and post-test counselled at St. Apollinaris Hospital during the antenatal period.

3.3.1.2. Women must live in the rural catchment area of St. Apollinaris Hospital, and commit to use St. Apollinaris Hospital as a follow-up institution.

3.3.1.3. Women must deliver a live infant at St. Apollinaris.

3.3.1.4. Women must be Zulu-speaking and of the African race.

3.3.2. Exclusion criterion

Women must be physically well, and not in the end stages of AIDS when enrolled in the study.

3.4. Data collection and analysis

3.4.1. Method

Ten HIV positive women who are enrolled in the PMTCT programme run by the KwaZulu-Natal Department of Health at St. Apollinaris Hospital, who deliver live infants in the maternity unit of the hospital, and who consent to participate in the study will be the subjects of the case studies.

The women will be enrolled in a follow-up programme commencing at the time of delivery, and including the first six months of the postpartum period. The

first interview will be conducted before discharge from the ward, and the second follow-up will be at the six week postnatal visit. The final interview will be conducted six months post-delivery.

Analytic generalisation will be the method of primary analysis (Yin, 1989). This means that the conceptual framework will be used as a template with which to compare the empirical results of the case studies. If two or more cases are shown to support the same theory, replication may be claimed.

See Appendix 3 for the Case study protocol.

3.4.2. Instruments

Interviews are to be used for each case, and individual case reports written. Interviews will be conducted with the assistance of a Zulu-English translator and will be tape recorded. Notes will be made during interviews, but a full transcript of the interview will be typed after its conclusion. The transcripts will be reviewed with the assistance of a Zulu speaker to ensure that no errors in translation have been made in retrospect. Pattern-matching will be done, by relating several pieces of information from the same case to some theoretical proposition or research question. The process of replication will assist to draw cross-case conclusions, modify theory, develop policy implications, and finally write a cross-case report as the final analysis of the study.

See Appendix 4 for the interview schedules.

3.4.3. Analysis

Academic rigour will be used instead of the quantitative constructs of reliability and validity to analyse data quality. The consistency, stability and repeatability

of the participant's accounts as well as the investigator's ability to collect and record information accurately will be checked by application of a case study protocol, and future replication of the study should be done with a new sample. The credibility of the findings will be achieved by having research participants and a peer researcher review, validate and verify the researcher's interpretations and conclusions. Authenticity will be ensured by using context-rich and meaningful descriptions in case reports. Transferability and/or fittingness of the conclusions of the study to other contexts will be judged by an outsider through the researcher's detailed database and thick description in case reports. Dependability or trustworthiness will also be judged by a peer auditor who will follow the process and procedures used by the researcher in the study to determine whether they are acceptable and dependable. Confirmability (guarantee that the findings, conclusions and recommendations are supported by the data and that there is an internal agreement between the interpretation and the actual evidence) will also be judged by an audit procedure.

3.5. Ethical considerations

Women have the right to decide voluntarily whether or not to participate in the study, without the risk of penalty or prejudicial treatment. They have the right to withdraw from the study at any time, to refuse to give information or to ask for clarification about the purpose of the study. See Appendix 5: Information sheet and informed consent form for participants.

Information related to participants or to the fact that certain individuals have participated in the study will not be available to anyone beyond the immediate research team. Informed consent will be obtained in writing. The information given to the participants will include: the purpose of the study; the method to be followed; the duration of the study; the nature of the participation expected from the person; how the results will be used and published; the identity and qualifications of the researchers involved; possible detrimental aspects; and the manner in which confidentiality and privacy will be ensured. See Appendix 5: Information sheet and informed consent form.

Permission will be sought from the hospital management for the use of patient records and the conduction of interviews within the hospital environment.

Permission will also be sought from the KwaZulu-Natal Department of Health, the University of KwaZulu-Natal's School of Nursing, and the University of KwaZulu-Natal's Faculty of Community and Development Disciplines Ethics Committee. See Appendix 6 for copies of the consent obtained.

CHAPTER 4

RESULTS

4.1. Introduction

Individual case reports were drawn up after full transcripts of the interviews were reviewed in terms of the case protocol. Pattern-matching was done; relating the case report information to the conceptual framework and the research questions. The process of replication was then used to draw up a cross-case analysis.

4.2. Case reports

4.2.1. Case report 1

Decision:

The client decided to breastfeed her infant exclusively for the first four months, and then replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 30 years old, single, completed schooling up to Std 9, worked in a tuck shop, and had two living children (including the newborn infant).

Socio-psychological factors: The client lived with her mother, her sister, her brother, and her two children. The father of the client's first child was deceased. The father of her newborn infant was supportive, financially and emotionally; but he was not living with them.

“And is he supportive of you? Yes, and he’s working and helps me with money.”

Structural issues: The client gained information about HIV/AIDS from the media, and from health care services including the PHC clinic, hospital and PMTCT counsellors. She had no previous experience of the disease.

Access to appropriate health professional support: The client lived near to the local clinic and could use public transport to get to the hospital. She described good, clear education about feeding choices given by the PMTCT counsellors and strong support given for her feeding choice. She attended all follow-up appointments and benefited from the continuity of care.

General case description:

The client was confident, and had good social support with supportive family members and a supportive father of her child. The client was positive and enthusiastic about breastfeeding, and had a good understanding of HIV and the risks of mixed feeding. She did not at first disclose her HIV status to anyone due to fear of stigmatisation.

“If I tell them, they will ask why? Where have you been? Who have you slept with? And all those things – they won’t understand.”

However, the client had disclosed her positive HIV status to her mother and her sister by the third interview – her mother and sister were supportive.

“So have you disclosed your HIV status to your mother and your sister?”

Yes.

And do they accept it? Are they supportive of you? Yes.”

The client planned to stay at home with the baby for a few months – she went back to work after three and a half months. When the client returned to work, she planned to express breast milk so that her mother would be able to feed the baby while she was at work until four months were completed. After four

months, the client planned to start formula feeding and she had had previous experience with formula preparation. The client's home environment remained stable with good family support for the duration of the client-researcher interaction. The client always demonstrated active contemplation about HIV, the plan to disclose her HIV status, and the plan for the future.

"I'm going to disclose when I stop breastfeeding the baby, because they are going to ask why I am weaning the baby early. That is when I will disclose."

The client also demonstrated critically thinking about health, HIV and the available health services.

"I would like to know – if we are not well, are we allowed to any clinic? Do I have to disclose my HIV status to any sister or doctor I consult?"

The client remained confident about exclusive breastfeeding as the best alternative for her child after six weeks and after three and a half months. The client remained confident about her baby's health and the outcome of exclusive breastfeeding. The client returned on the follow-up dates for all three interviews.

Perceptions of client and researcher:

The client felt capable of maintaining her original choice to breastfeed exclusively for four months. The client had a good self-concept, showed internal pressure to succeed, and positive contemplation and anticipation. The client did not foresee any barriers at the first interview, and did not encounter any barriers within the three and a half months of the client-researcher interaction. The researcher perceived the client to be motivated to maintain her original feeding choice, and evaluated the client as *likely* to maintain that choice.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client had a good support system – support from significant others was apparent even during the first interviews when the client had not yet disclosed her HIV status. Her mother and sister remained supportive after she disclosed her HIV status to them. The client had comparably good social circumstances, with predictable cues – she had not been working during the last few months of pregnancy, but went back to work after three and a half months; and the father of her baby was emotionally and financially supportive, as were her mother and sister. The client had to face the barrier of not adhering to social norms (norm being mixed feeding of infants from birth), but this would be a barrier to every woman in the PMTCT programme. The client was positive and had a good understanding of the programme and the implications of her choice to exclusively breastfeed for four months from the first interview.

Although aware of presiding cultural and social beliefs about mixed feeding, the client was willing to do her best to maintain her choice to exclusively breastfeed. No apparent religious beliefs influenced any decision she made.

The client's parenting and family values were strong – she was very aware of the risk of HIV transmission to her child and was willing to do whatever it took to prevent that in so far as was possible. The client's decision to have a tubal ligation performed at the same time as her caesarean section was for the stated reason that she didn't want to put another baby's life at risk, and she wanted to look after her own health – clearly an example of foresight into the disease and forward thinking.

4.2.2. Case report 2

Decision:

The client decided to exclusively breastfeed her infant for the first four months and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 18 years old, and was engaged to be married (her boyfriend still had to pay *lobola*). The highest level of schooling which the client completed was Std 2 at the age of 12, she had never worked, and her boyfriend did not work.

Socio-psychological factors: The client lived with the father of her newborn child, his mother and his brother; but she would be living with her own mother for the initial postpartum period.

Structural issues: The client had no prior knowledge or experience of HIV/AIDS before antenatal care.

Access to appropriate health professional support: The client did not return for follow-up – perhaps due to lack of transport. It was not known whether she attended another of the outlying clinics for PMTCT follow-up. In teaching about feeding choices by the PMTCT counsellors and nurses in the antenatal clinic, apparently more emphasis was placed on breastfeeding as a better option for the client. It is impossible to assess the support given for the client's feeding choice since the client did not return to the hospital clinic for PMTCT follow-up.

General case description:

The client's original decision to exclusively breastfeed was seemingly motivated by the lack of information given on the alternate feeding choice, and the emphasis placed on breastfeeding by antenatal clinic staff.

"How did you make your decision? I was told by another nurse that I must breastfeed exclusively for four months."

The client's decision to breastfeed was also motivated by her lack of money to buy formula.

"What does breastfeeding mean for you? Will it be easy for you? Because my boyfriend isn't working, I wouldn't be able to afford to buy formula."

The client had a poor educational background (functionally illiterate) and she became pregnant as an unmarried teenager. She had no prior knowledge of HIV before antenatal care. The client disclosed her HIV status to her mother, but not to her boyfriend or her boyfriend's family with whom she was living at the time of the interview. The client demonstrated limited individual critical thinking and problem-solving skills.

"I was told by the nurse that I must breastfeed for four months and then formula feed after that."

The client missed her second and third appointments.

Perceptions of client and researcher:

The researcher's perception was that the client did not feel able or capable of maintaining her original decision, but would do as she was told by others in her environment. The client did not envision any barriers, although the researcher considered the client's age, educational background, and limited

foresight as barriers. Another barrier might be the possible future influence of family, especially elders. The client did not consider the risk of transmitting HIV to her baby significant. Her locus of control was external – she saw her mother and her other elders in the community as being in control of her destiny.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client did not deny her problematic health status, but she seemed to underestimate the risk of transmission of HIV to the baby. She did not demonstrate internal pressure or motivation to succeed. The issue of adhering to social norms would have been a potential problem since the client did not seem confident enough to stand up for her original decision if challenged to mixed feed by her mother-in-law or other elders. She was not in a good social situation – she would be staying with her own mother at first and then would have moved to her boyfriend's family's home, therefore she would not have been in a stable environment for the crucial first few months. The client had no well structured support system (also a consequence of her movement between the two families and homes).

4.2.3. Case report 3

Decision:

The client decided to exclusively breastfeed her infant for the first four months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 29 years old, single, unemployed, and highest level of schooling which she completed was Std. 5. She had two living children (including the newborn infant).

Socio-psychological factors: The client lived with her boyfriend (the father of her two children). Her boyfriend did temporary work when possible – he was the only source of income. The client said she was afraid of her boyfriend, and of his reaction to the knowledge that she was HIV positive. She was very reluctant to tell him; since she was scared he would kill her.

Structural issues: The client gained information about HIV/AIDS from the media and from the PHC clinic when she was counselled and tested. She had no previous experience of the disease.

Access to appropriate health professional support: The client lived near to the local clinic and could use public transport to get to the hospital, although she lacked sufficient finances to travel. She described good teaching by the PMTCT counsellors about feeding choices and the risks of mixed feeding, although she showed poor understanding of the concept of exclusive breastfeeding. Support given for her chosen feeding regime was good, although reinforcement had to be given during the interviews, specifically encouragement not to give up exclusive breastfeeding before four months.

General case description:

The client had good insight into the benefits of breastfeeding and was positive about her own experience of breastfeeding. The client displayed foresight and

forward thinking – she was especially worried about her boyfriend's reaction if he discovered she was HIV positive (she seemed to be afraid of him).

“Have you disclosed your HIV status to anyone? No.

And you don't want to? Definitely not.

Why? Are you afraid they will stigmatise you? If I tell my boyfriend, maybe he will kill me.”

The client did not initially understand the necessity of the exclusivity of breastfeeding, but showed good understanding of the dangers of mixed feeding after an explanation was given by the researcher. She had an unstable source of income. She was independent in infant care, but was very apprehensive about her extended family finding out that she was HIV positive and part of the PMTCT programme.

“I have a problem – I don't know what I'm going to do about collecting the formula tins from the hospital after 4 months. They will be suspicious at home if I bring tins, knowing I have no money – they will know there is some problem with me...the problem is we are part of an extended family and surely some know about free formula provided to HIV positive mothers and they will talk.”

By the second interview at six weeks, the client verbalised her fear that her baby was not satisfied with breast milk only. She had been able to defend exclusive breastfeeding when challenged by outsiders even though she had not disclosed her positive HIV status to anyone.

“Who have you found most supportive of you at home? With breastfeeding especially.

Everyone is supportive – they are happy I am breastfeeding. But at those times that I don't have much milk in my breasts, then they encourage me to mixed feed, but I say no."

Her sister-in-law pressured her to introduce other foods, and she was subsequently worried that a member of the extended family would feed the child while she was not home. The client had a source of running water at home and was seriously considering starting formula feeding at two months, but financial factors influenced her to continue until four months. The client missed the third appointment.

Perceptions of client and researcher:

The client felt capable of maintaining her original decision, but her boyfriend was a significant barrier. The researcher believed that the client could cope if she overcame the problem with her boyfriend, but the problem was due to entrenched community beliefs and the stigmatisation of people living with HIV and may have been impossible to overcome. It seemed as if the client did not realise the magnitude of the risk and consequences of HIV infection, but this was understandable since she was more concerned about issues like her boyfriend's reaction and disclosure of her HIV status.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client was anxious and feared the consequences of her decision. She faced overwhelming barriers and her participation in the PMTCT programme seemed to result in more "cost" than "benefit". She lacked adequate support mechanisms since she had not disclosed her HIV status and did not feel able to. The issue of acceptance by significant others was very important to her, as

was adhering to social norms (i.e.: mixed feeding) so that no one could deduce that she was HIV positive. The client also had unstable social circumstances and demonstrated negative contemplation and anticipation of negative things to come.

4.2.4. Case report 4

Decision:

The client decided to exclusively breastfeed her infant for the first six months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 30 years old, married, had three living children (including the newborn infant), and the highest level of schooling which she completed was Std 4.

Socio-psychological factors: The client lived with her children and her 15-year-old niece. Her husband was a migrant labourer in Durban, but he had no work at the time of the first interview. The client looked after the home (subsistence farming), and was the only adult in the household.

Structural issues: The client gained information about HIV/AIDS from the media and from the primary health care clinic when she was counselled and tested. She had previous experience of the disease in the community.

Access to appropriate health professional support: The client lived near to the hospital, although she lacked sufficient finances to travel with public transport and usually had to walk. The teaching given by the PMTCT counsellors and antenatal clinic staff was insufficient – the client did not understand the

necessity of exclusive breastfeeding nor the need to limit the duration of breastfeeding.

General case description:

When originally asked, the client stated that she wanted to breastfeed for two years because of the abundance of breast milk. The client did not clearly understand the risks of mixed feeding or the exclusivity of breastfeeding issue, but she did believe in the value of breastfeeding.

“Were you told about the two options that are best for your baby – either breastfeeding exclusively for six months or formula feeding and never breastfeeding?”

Yes, I was told that, but I’m not sure because now the milk is here and it’s a lot. I want to hear from you what I should do.”

She was in a poor financial situation and had only a primary education. She was worried that the baby would be hungry if only breastfed. She had no structured support, and was the primary care giver in the home.

“Who will help you at home?”

Nobody. My 15-year-old niece stays with me, but she is attending school and won’t really help with the baby.”

She had little prior knowledge of HIV, but was aware of community members with HIV. The client was at first scared to disclose her HIV status to her husband. At the time of the first interview, she was supported by her sister-in-law to whom she had disclosed her HIV status.

“She [my sister-in-law] accepts my status and encouraged me saying that the baby and I are healthy and we can stay healthy for a long time.”

She wanted to use traditional medicine to prevent the baby getting HIV.

By the second interview, the client had attended the clinic routinely for follow-up – of both minor ailments at the PHC clinic and PMTCT follow-up. She was still facing poor support at home – she was still the primary care giver and responsible adult, and her sister-in-law remained supportive. Her husband visited from Durban for one week after baby was born and she disclosed her HIV status to him, but he had poor understanding of the disease and encouraged mixed feeding.

“There is nobody really [who has been supportive]. The people at home are all old, and then there are my young children. My sister-in-law is the only one who is really supportive because she has children of her own. My husband doesn’t want me to only breastfeed.”

The client stated that she was losing weight and complained of general malaise – she was worried about her future health, but was happy about the baby’s health at the time of the second interview.

By the third interview, the client still claimed to be exclusively breastfeeding, but did give re-hydration solution when the baby was dehydrated (baby had chronic diarrhoea). The client’s husband was more supportive at the time of the third interview, encouraging his wife to attend the clinic for follow-up.

“My husband is supportive – he encourages me to go to the clinic whenever the baby and I are not well, and to collect my medicines.”

The client’s husband was at the time of the third interview permanently returned from Durban - he was sick and unable to work (he had not yet been tested for HIV). The client was worried that her breast milk was not enough to satisfy her baby, and had changed her mind about the duration of breastfeeding – she would now stop breastfeeding after four months instead

of after six months. She was still happy with her original decision, but was worried that her baby would get HIV – she still desired to use traditional medicine to prevent her baby from getting HIV. The client was planning to apply for a third child care grant.

Perceptions of client and researcher:

The client felt capable of maintaining her original decision, but the researcher recognised that her insufficient foresight and understanding may be a barrier. The client felt susceptible of transmitting HIV to her baby, but did not seem to think that maintaining feeding choice was enough of a preventative strategy – she strongly believed in the power of traditional medicine to prevent transmission of HIV. It was the researcher's evaluation that the client was motivated to maintain her original feeding choice because she would do whatever was possible to prevent her baby from becoming infected. The client did not feel she was in control of her destiny - stress at home, her poor financial situation with her husband being out of work, her lack of adult company and support, and the necessity of hard manual labour on her part placed great stress on her, over and above the stress of her HIV status.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client demonstrated an internal pressure to succeed – she knew it is up to her to do the best she could for her child, and was willing to do whatever it took to prevent the child from becoming HIV positive. The community did have an influence due to the stigmatisation of people living with HIV, and the client faced pressure to adhere to the social norm of mixed feeding. She faced poor

social circumstances, but displayed positive contemplation and anticipation. She had a poor support system, but this improved after she disclosed her HIV status to her husband.

4.2.5. Case report 5

Decision:

The client decided to exclusively breastfeed her infant for the first four months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 23 years old, unmarried, the highest level of schooling that she had completed was Std 9, and she was unemployed.

Socio-psychological factors: The father of baby was not at all supportive of the client.

“My boyfriend said he won’t give me any money or help until he sees the baby”

The client lived with her cousin due to family tension when she fell pregnant (her own father kicked her out of the house).

Structural issues: The client gained information about HIV/AIDS from the media and from the PHC clinic when she was counselled and tested. She had no previous experience of the disease.

Access to appropriate health professional support: The client lived near to the local clinic and could use public transport to get to the hospital, although she lacked sufficient finances to travel. The teaching given by the PMTCT counsellors and antenatal clinic staff was insufficient – the client did not

understand the necessity of exclusive breastfeeding or the need to limit the duration of breastfeeding, but encouragement of breastfeeding in general was evident.

General case description:

Financial constraints were the client's primary motivation to breastfeed. The client was given information about breastfeeding by the PMTCT counsellors, but seemingly not enough information was given on the alternate choice of formula feeding from birth.

“Were you told about the advantages and disadvantages of breastfeeding?”

No, but I was told by the PMTCT counsellors about the importance of breastfeeding.”

The client had no insight into the dangers of mixed feeding. She had a good educational background, and had disclosed her HIV status to her cousin who was supportive.

“Who will be helping you with the baby at home?”

Nobody. I haven't disclosed my HIV status to my family, but my cousin knows.

Is your cousin supportive? Yes.”

The client was planning to live with her cousin for the first two months, and then to move back to her parents' home. Her mother was a possible barrier to exclusive breastfeeding.

“My mother might ask me why I don't feed the baby something else [in addition to breast milk]”

The client was worried about her future health and that of her baby – she suffered a severe postpartum haemorrhage and was anaemic and quite weak at the time of the first interview.

By the second interview, the client was ill and admitted to hospital – she was weak, anaemic, and coughing. The interview was conducted from the hospital ward. The client's anaemia was being treated, a blood transfusion was given, and tuberculosis investigations were being done. The baby was staying with the client's mother. The client started collecting formula from her local clinic two weeks before when she became sick and could no longer breastfeed. The baby was not sick and was immunised at six weeks. The client had not yet disclosed her HIV status to parents.

By three months after delivery, the news from the community was that the client was still ill (the client missed her third appointment).

Perceptions of client and researcher:

The client did not have a good self-concept – she was not sure if she would be capable of maintaining her original feeding choice. The client demonstrated poor understanding and inaccurate assessment of risk of transmitting HIV to baby if she changed her original feeding choice. She did perceive and feel susceptible to HIV and its effect on her own health. The client's primary motivation for making her original decision was financial – she did not seem to grasp the implications of infant feeding choices. The client did not feel she was in control of her own destiny – her estrangement from her

parents and difficult relationship with her boyfriend placed enormous stress on her.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client had poor social circumstances – she was estranged from her parents, and she would have no structured support in caring for the baby. She had no income and depended on her cousin to financially support her. The father of her child was not at all supportive and he did not even believe the child was his. The client was a primigravida and would have needed assistance and encouragement specifically with breastfeeding, but lacked this. She had a poor support system. She had disclosed her HIV status to her cousin with whom she was living at that time, but not to her parents. The client was very anxious and feared failure. After six weeks, the client had to start formula feeding since she was too weak and ill to continue breastfeeding – it was an unavoidable situation on her part since she was willing to continue breastfeeding until four months. The severe postpartum haemorrhage she experienced together with her compromised immune system as a result of HIV infection led to a disproportionately severe effect on her general health.

4.2.6. Case report 6

Decision:

The client decided to exclusively breastfeed her infant for the first four months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 41 years old, unmarried, had had five children, four still living (including the newborn infant), and the highest level of schooling which she had completed was Std 3.

Socio-psychological factors: The client lived alone with her four children, and did temporary jobs (mostly working as a nanny for her neighbours' children). The client's parents were deceased; the father of the newborn infant did not live with her and did not give her any financial support.

Structural issues: The client gained information about HIV/AIDS from the media and from the PHC clinic when she was counselled and tested. She had previous experience of the disease in the community.

Access to appropriate health professional support: The client lived near to the local clinic, but far from the hospital – she could use public transport to get to the hospital, although she lacked sufficient finances to travel (perhaps the reason she did not return for follow-up, but it was not known whether she attended her local clinic for PMTCT follow-up). The teaching and support provided by the PMTCT counsellors and antenatal staff was good in some areas and poor in others – the client had a good understanding of feeding choices, but did not understand the necessity of exclusive breastfeeding.

General case description:

The client had a good understanding of the feeding programme, but a poor understanding of the risks of mixed feeding.

“Can't I feed the baby formula if I have a problem like not enough breast milk?”

She was confident about the benefits of breastfeeding. The client had only a primary education. She was a victim of poverty – she often went without food and was worried that this would affect her breast milk supply. The client needed a child care grant. She worked as a nanny when there was work available, and she planned to take her infant to work with her and continue breastfeeding. The client's sister-in-law was a barrier, since she was an advocate of mixed feeding.

“My sister-in-law especially [may ask why I don't give supplemental feeds of formula] because she believes in mixed feeding – she did it with her own children.”

Her sister-in-law did not live with her, but lived nearby and visited often with client's brother. The client missed her second and third appointments.

Perceptions of client and researcher:

The client had a poor self-concept due to her situation in life – she had no steady source of income since she relied on neighbours to give her nanny jobs when available. She was unmarried and was the only adult in the household, although her oldest children were teenagers. She was concerned that she would not be able to produce enough breast milk for her baby and was keen to introduce formula as a top-up feed if the baby was still hungry. The client did not feel capable of exclusive breastfeeding, but it was the only option available to her due to financial constraints. The client seemed motivated to maintain her original feeding choice, but did not feel in control of her own destiny – she had to fight for basic survival. The researcher had to spend much of the interview reiterating the importance of avoiding mixed feeding in the HIV context.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client had poor social circumstances which were a serious barrier to being able to implement her decision. Formula feeding her infant from birth was not a choice since she would never be able to afford to feed the child a balanced diet after the free six month supply of formula was completed, but exclusive breastfeeding would also prove difficult due to her poverty and poor diet. The client demonstrated negative contemplation and anticipation of the worst – she was not very optimistic about being able to implement the decision. She had a very poor support system – she had no adult to confide in or with whom to disclose her HIV status. She would have had to face the pressure of adhering to social norms since her sister-in-law was going to encourage her to formula feed. The client would have found it difficult to defend her choice of exclusive breastfeeding since she had not disclosed her HIV status.

4.2.7. Case report 7

Decision:

The client decided to exclusively breastfeed her infant for the first six months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 31 years old, unmarried, had three living children (including the newborn infant), and the highest level of schooling which she completed was Std 4.

Socio-psychological factors: The father of the client's baby was not very supportive.

“Is the father of the baby supportive? Not that much.”

The client worked as a labourer in a timber factory until seven months pregnant. She was the only source of income in the home; lived with her adult niece, her niece's children and her own children; and she had not disclosed her HIV status to anyone.

Structural issues: The client gained information about HIV/AIDS from the media and from the PHC clinic when she was counselled and tested. She had previous experience of the disease in the community.

Access to appropriate health professional support: The client lived near to the local clinic, but far from the hospital – she could use public transport to get to the hospital, although she lacked sufficient finances to travel (perhaps this was the reason that she did not return for follow-up, but it was not known whether she attended her local clinic for PMTCT follow-up). Initially the client received poor teaching and support at Ixopo clinic (she did not even understand that she was HIV positive), but the client was re-counselled at Centocow and at the interview showed good understanding of what was taught.

General case description:

The client had a poor support system, and her primary motivation to breastfeed was financial, but she believed breastfeeding would enhance the health of her infant too. The client did not feel capable of maintaining exclusive breastfeeding for six months.

“I don’t know [if I’ll be able to implement the decision to exclusively breastfeed for 6 months] because I must look for a job, then maybe I will have to feed the baby formula.”

The client thought her aunt might encourage her to mixed feed. It was evident that the client was originally given poor education about exclusive breastfeeding, but was re-counselled at the hospital clinic.

*“**Was the concept of exclusive breastfeeding explained to you?** No, not initially at Ixopo, but when I was re-counselled here at Centocow, they did tell me.”*

Since the client was the only source of income in the household, she may have had to go back to work after four or five months – this would have been a possible barrier to breastfeeding exclusively for six months, therefore the client would possibly stop breastfeeding at four months. The client had only a primary education, and her previous knowledge of HIV was from the media. At the time of the interview, the client was very emotional and worried about the future, about dying and leaving her children as orphans. The client did not return for her second and third interviews, and it was not known whether she attended another local clinic for PMTCT follow-up.

Perceptions of client and researcher:

The client did not have a very good self-concept – she felt overwhelmed by the situation, by the knowledge that she was HIV positive, and did not feel capable of maintaining her original feeding choice for six months. The client felt completely susceptible to HIV herself, and feared transmitting the virus to her infant. Her primary motivation to initially exclusively breastfeed was

financial. The client did not feel in control of her own destiny – she felt and feared that HIV/AIDS would dictate her future.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

In weighing up the client's barriers compared to her opportunities, it was evident that she faced overwhelming barriers and was negative, anxious and feared failure. She had a lack of support – the father of her children was not supportive, she lived with her niece, her niece's children and her own children and they all depended on her to bring a steady income to the household. She did not have any adult support and would not consider disclosing her HIV status to anyone at the time of the interview. The client would have faced pressure to adhere to social norms, and people in the family and community may have asked questions as to why she was not mixed feeding. Her social circumstances were poor and this had led her to a situation of negative contemplation and anticipation of the worst case scenario. The client did not return for follow-up – it is not known whether she attended another of the local clinics for PMTCT follow-up. It is not known whether she gave up on the programme or if her non-attendance was due to a transport or more practical problem.

4.2.8. Case report 8

Decision:

The client decided to exclusively breastfeed her infant for the first four to six months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 20 years old, unmarried, had two living children (including her newborn infant), she was unemployed, and the highest level of schooling which she completed was Std 6.

Socio-psychological factors: The father of the client's baby was supportive.

“Is the father of your child supportive? Is he around? Does he help you with money? Yes.”

The client lived with her sister-in-law, her sister-in-law's children, and her uncle. Her uncle was working and was the only source of income for the household. The client had not disclosed her HIV status to anyone.

Structural issues: The client gained information about HIV/AIDS from the media, from school and from the PHC clinic when she was counselled and tested. She had no previous experience of the disease in the community.

Access to appropriate health professional support: The client lived near to the local clinic and could use public transport to get to the hospital, although she lacked sufficient finances to travel. The teaching and support provided by the PMTCT counsellors and antenatal clinic staff was poor – the client could not have been adequately post-test counselled since she denied her positive HIV status.

General case description:

The client initially denied her HIV positive result and participation in the PMTCT programme, but after probing, she admitted that pre-test counselling and testing was done, but claimed that the PMTCT staff never told her her HIV status. It was impossible to ascertain whether this was true or whether

the client simply did not accept the result. An explanation was given by the researcher and the client accepted that she was HIV positive.

“Do you accept the result, that you are HIV positive? Do you know what that means? Yes.

Do you remember that when you came into the ward in labour, we gave you a white tablet called Nevirapine? Yes, and they also told me about that tablet at the clinic. They told me all about HIV and breastfeeding and using condoms.”

The client claimed that she was not told to limit the duration of breastfeeding. She breastfed her first child and believed in the benefits of breastfeeding for general health. Her prior knowledge of HIV was from the media and from school. Her sister-in-law with whom she lived breastfed exclusively, and so should not have been a barrier. The client foresaw no problems or barriers. The client did not return for her second and third interviews – it was not known whether she attended another local clinic for PMTCT follow-up.

Perceptions of client and researcher:

Central to this case was the client's denial of her HIV status – without acceptance of a positive HIV result, she could not be expected to make the crucial feeding choice decision and stick to it. Thus this case perhaps should have been excluded as invalid, but it seemed relevant that such a case should be included in a study of this kind due to the reality of denial in many people living with HIV. The client had not accepted her HIV status and therefore did not rate her susceptibility, and she would have had no motivation to maintain her feeding choice until she came to terms with her HIV positive status.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client demonstrated denial of her problematic health status. She would have had to accept her positive HIV status before any further analysis could be done. It was unfortunate that the client did not return for further interviews, because it would have been valuable to have been able to trace her progress and to further encourage her in the maintenance of her original feeding choice and disclosure of her status to an individual she trusted.

4.2.9. Case report 9

Decision:

The client decided to exclusively breastfeed her infant for the first four months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 21 years old, this was her first child, she was engaged to be married, she was unemployed, and the highest level of schooling which she completed was Std 4.

Socio-psychological factors: The father of the client's baby was supportive of the client and lived nearby.

“And the father of the baby - is he supportive? Yes, he lives nearby.”

The client lived with her mother and her three sisters. Her mother was working and was the primary source of income in the household.

Structural issues: The client gained information about HIV/AIDS from the media and from the PHC clinic when she was counselled and tested. She had no previous experience of the disease in the community.

Access to appropriate health professional support: The client lived near to the local clinic and could use public transport to get to the hospital. Good support and teaching by the PMTCT counsellors and antenatal clinic staff was evident, although the client seemed to need some reinforcement of teaching - after some probing by the researcher, the client showed good understanding of feeding options, exclusive breastfeeding and the reasoning therefore.

General case description:

The client initially expressed the desire to breastfeed for one year, but after discussion conceded that she would limit the duration to four months and then reassess the situation and decide whether to continue breastfeeding until six months.

“They discussed the issue with me and I decided to breastfeed for six months, and then I will collect the tins of formula from the clinic. But I think I will try to exclusively breastfeed for four months and then see how it’s going.”

The client initially showed poor understanding of the reasons for the limited duration of breastfeeding (thought it was due to the availability of formula).

After probing, education about prevention of transmission of HIV to baby was recalled by the client, and she showed good understanding of exclusivity and abrupt weaning at four months. The client had a good support system since she had disclosed her HIV status to her mother who would be helping her to care for the baby.

“Is your mother supportive of you [after disclosure of HIV status]? Yes, I don’t think she has a problem with it.”

The father of the baby was also supportive of the client, financially and emotionally and had committed to marry her as soon as he could pay *lobola*.

The client's prior knowledge of HIV was from the media. The client did not return for her second and third interviews – the reason was unknown. It was also not known whether she attended another local clinic for PMTCT follow-up.

Perceptions of client and researcher:

The client demonstrated poor retention of health education information. However, after probing, the client was able to recall the information given about exclusive breastfeeding very well. She therefore would have needed regular reinforcement and encouragement. However, the client did not return for her second or third interviews (although she may have attended another local clinic for PMTCT follow-up) – this was a pity since it would have been good to have been able to provide that ongoing reinforcement. The client had a fairly good self-concept and felt capable of maintaining her original feeding choice. The researcher evaluated the client as likely to succeed as long as the vital health education information was positively reinforced during follow-up.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client demonstrated an internal pressure and will to succeed. She was engaged to be married, and had a vision for her future which obviously included herself and her child remaining healthy. She had the distinct advantage of a mother to whom she had disclosed her HIV status and who accepted it and encouraged the client – this acceptance by others would have been very important if she was to succeed in maintaining her original choice. She would still face the problem of not adhering to the social norm of mixed

feeding and faced opposition, but with her mother's support she might have been able to cope. Her mother would also hopefully have helped her to stand up to opposition from family and community elders. The client's social circumstances were comparatively good – her mother provided a steady source of income, and her boyfriend and his family were financially and emotionally supportive. Her support system was also good, especially since her mother knew her HIV status and was supportive of her chosen feeding practice.

4.2.10. Case report 10

Decision:

The client decided to exclusively breastfeed her infant for the first six months, and then to replace breastfeeding with formula feeding.

Regulating factors:

Demographics: The client was 35 years old, had five children (including the newborn infant), and she was unmarried. The client had temporary employment until she was seven months pregnant, and the highest level of schooling which she completed was Std 4.

Socio-psychological factors: The client lived in an extended family village, the father of her children lived with them, and she had not disclosed her HIV status to anyone.

Structural issues: The client gained information about HIV/AIDS from the media and from the PHC clinic when she was counselled and tested. She had no previous experience of the disease in the community.

Access to appropriate health professional support: The client lived near to the hospital. The support and teaching provided by the PMTCT counsellors and antenatal clinic staff was not sufficient, since the client did not grasp the necessity of the limited duration of breastfeeding and this information had to be reinforced in the interviews.

General case description:

The client initially expressed a desire to breastfeed for two years due to her previous experience of breastfeeding, but she agreed to limit the duration of breastfeeding after a discussion and recall of the reasons for limiting the duration outlined to her by the PMTCT counsellors. The client believed in the health and financial benefits of breastfeeding. Her mother and extended family were supportive.

“Who is going to help you at home with looking after the baby and with supporting you to breastfeed? My mother.”

However, the client had not yet disclosed her HIV status to anyone. The client was independent in child care, therefore foresaw little interference from family and community members.

“Are they [the extended family] going to understand that you only want to breastfeed exclusively for 6 months? They won’t ask any questions because that is what I did with my other children.”

The client had only a primary education, and was planning to go back to work but was unsure at what stage she would do so.

By the second interview, the client was still exclusively breastfeeding, and had encountered no interference by family members or encouragement to mixed feed.

“Who has been supportive of you, to encourage breastfeeding? My mother, but everybody is happy with breastfeeding in the family.”

She had not yet disclosed HIV status to anyone, and was planning to continue breastfeeding for six months, and then to start working again and leave the baby with her mother to look after and formula feed. The client returned for PMTCT follow-up, but the researcher was unable to be at the hospital for a third interview.

Perceptions of client and researcher:

The client demonstrated a good self-concept and belief in her ability to succeed in maintaining her original feeding choice. Her experience as a mother (this was her fifth child) counted strongly in her favour. She had only discovered her positive HIV status in this pregnancy, but she was independent and strong-willed and she should have been able to cope with the feeding choice, although she did not have the courage to disclose her HIV status to anyone. She also had not been able to identify an individual she thought she could trust with the information and she was fearful of repercussions and stigmatisation if she disclosed that she was HIV positive. The client was well-motivated to continue exclusive breastfeeding and avoid mixed feeding in so far as was possible to prevent her child from transmission of HIV. She was still very healthy and was keen to live positively with HIV. The client had a well-structured lifestyle and worked to be able to support her

family – she made no mention of her boyfriend's contribution to the household. The researcher's only concern was that the client may be tempted to continue breastfeeding after six months due to her previous experience of breastfeeding her children for two years.

Barriers, opportunities, beliefs, knowledge, values and attitudes:

The client demonstrated an internal pressure to succeed, and especially to keep her HIV status secret. Her motivation to keep herself and her child healthy was also strong. The issue of not adhering to social norms was not as significant a problem as in other cases because the client was an experienced mother and the community recognised that and were unlikely to interfere. The client had fairly good social circumstances with predictable cues because she had plans for the future and was financially more secure than those clients without steady jobs. She showed positive contemplation and anticipation of the challenge of exclusive breastfeeding. She had a fairly good support system, although it would have been much more secure if she could have found a trustworthy person to confide in so that she could have had support in the HIV context.

4.3. Cross-case analysis

4.3.1. Sample description

Table 1: Sample description

<u>CASE</u>	<u>AGE</u>	<u>MARITAL</u> <u>STATUS</u>	<u>GRAV</u> <u>PARA</u> <u>ALIVE</u>	<u>INFANT</u> <u>FEEDING</u> <u>DECISION</u>	<u>EDUCAT-</u> <u>IONAL</u> <u>LEVEL</u>	<u>EMPLOYMENT</u>	<u>INCOME</u> <u>SOURCE</u>	<u>1ST</u>	<u>2ND</u>	<u>3RD</u>
1	30	Single	G2 P2 A2	Breastfeed 4/12	Std 9	Tuckshop	Boyfriend + self	Y	Y	Y
2	18	Engaged	G1 P1 A1	Breastfeed 4/12	Std 2	None	None	Y	N	N
3	29	Single	G3 P3 A2	Breastfeed 4/12	Std 5	None	Boyfriend	Y	Y	N
4	30	Married	G3 P3 A3	Breastfeed 6/12	Std 4	None	Husband	Y	Y	Y
5	23	Single	G1 P1 A1	Breastfeed 4/12	Std 9	None	Cousin	Y	Y	N
6	41	Single	G5 P5 A4	Breastfeed 4/12	Std 3	Part-time nanny	Self	Y	N	N
7	31	Single	G3 P3 A3	Breastfeed 6/12	Std 4	Factory labourer	Self	Y	N	N
8	20	Single	G2 P2 A2	Breastfeed 4/12 – 6/12	Std 6	None	Uncle + boyfriend	Y	N	N
9	21	Engaged	G1 P1 A1	Breastfeed 4/12	Std 4	None	Mother + boyfriend	Y	N	N
10	35	Single	G5 P5 A5	Breastfeed 6/12	Std 4	Part-time housekeeper	Self	Y	Y	N

In the planning of the methodology for this study, follow-up interviews were to be done before discharge from the Maternity ward, at six weeks post-delivery, and at six months post-delivery. However, during the course of data collection, the researcher's circumstances changed and necessitated relocation to Gauteng province in November 2003. Thus, after consultation

with members of the University of Natal School of Nursing Research Committee, it was decided that the third follow-up interview would be done at three to four months post-delivery, instead of at six months post-delivery.

4.3.2. Regulating factors

Regulating factors other than those included in the sample description table included structural issues and access to appropriate health professional support. Structural issues (current level of knowledge of HIV/AIDS and previous experience of HIV/AIDS – personal and significant others) were similar for all women. Most had heard about HIV/AIDS from the media; some were more aware of HIV/AIDS in the community than others; and none knew of family members or significant others living with HIV.

Access to appropriate health professional support included both physical access to health services and the type and quality of teaching and support the women received during PMTCT counselling. The value of the PMTCT education depended on the level of understanding and insight of the client. It was evident that some of the women did not grasp the concepts taught to them regarding infant feeding (case 2, 4), some of them showed excellent recall and understanding of concepts (case 1, 5), and others showed the need for reinforcement and probing to recall some of the concepts (case 3, 6, 7, 8, 9, 10). Educational level may have been related to the level of retention of knowledge, although life experience and age would also have had some influence which is impossible to quantify.

4.3.3. Barriers

In general, there was a lack of understanding amongst the women of concepts vital to the PMTCT programme. The majority of the women could not clearly explain concepts such as *exclusive* breastfeeding and the avoidance of mixed feeding. These are complex concepts to grasp specifically since they are exceptions to the societal norm. The limited time and staff dedicated to teaching of these vital concepts in the course of antenatal care was not sufficient. As a result, many of the interviews had to include an element of teaching and reiteration of the importance of the avoidance of mixed feeding in the HIV context. This lack of sufficient teaching and support in the course of PMTCT counselling and antenatal care may have been due either to lack of time, staff and resources, or to lack of sufficient in-service training of staff.

All of the women were aware of the general benefits of breastfeeding (promotion of immune response, prevention of diarrhoeal diseases and malnutrition) and were positive about breastfeeding, but many were not clear on the reasons for the promotion of exclusivity of breastfeeding in the case of HIV positive mothers.

It was a common finding across cases that more emphasis was placed on the choice to exclusively breastfeed during PMTCT counselling. Equal information was not given on both feeding choices empowering women to evaluate which choice was most appropriate for them in their particular situation.

Case 9 specifically highlighted the importance of reinforcement of teaching of all aspects of recommended feeding practices for HIV positive mothers. It must be recognised that many of these women were so overwhelmed by the initial diagnosis of HIV infection at the post-test counselling sessions that they were simply incapable of absorbing the important facts of feeding practices. This highlights the importance of group information sessions and individual pre-test counselling sessions, but active reinforcement of information is also necessary in the post-test period.

Fear of stigmatisation was common and prevented many of the women from disclosing their HIV status to anyone – an issue discussed in the literature. This may also have been one of the strong motivating factors to breastfeed – since if a woman formula feeds from birth, community members will definitely question her decision and might even infer her participation in the PMTCT programme and thus her HIV status would become public knowledge. This was evident in case 3 where the client admitted that she was reluctant to utilise the free formula from the hospital after four months since her boyfriend would question her HIV status. The client also stated that she was afraid her boyfriend would kill her if he discovered that she was HIV positive.

Family and significant others had a marked influence on many of the women's decision making and behaviour. One of the most significant barriers for most of the women was non-disclosure of their HIV status and thus lack of support for the maintenance of their infant feeding choice from their family members and significant others. Case 2 disclosed her HIV status to her mother, but not

to her boyfriend or his family with whom she would be living and who would be the ones involved in encouraging or discouraging mixed feeding. Case 5 disclosed her HIV status to her cousin, but not to her mother, and it was her mother who had to look after her infant when she was hospitalised. Disclosure is a very complex concept since the woman might disclose to the person she believes will be most supportive, but she also needs to consider who will be involved in care of the baby and disclose on a 'need to know' basis. However, that said, the woman may not trust more than one individual enough to disclose her HIV status to them. This again highlights how important it is for the issue of stigmatisation of HIV positive individuals to be addressed as noted in the literature.

Some of the women demonstrated a fatalistic view and loss of hope for preventing HIV transmission to their infants. Case 6 was not very optimistic about being able to implement the decision to exclusively breastfeed due to her situation of poverty and poor diet – the barriers she faced were overwhelming (no income, a large family, a poor diet, a sister-in-law who was an advocate of mixed feeding, and the absence of a trustworthy adult to disclose her HIV status to). Case 7 was overwhelmed by her HIV positive diagnosis and did not feel capable of maintaining her choice to exclusively breastfeed for six months. She also faced barriers such as the need to return to her full-time job since she was the sole breadwinner, lack of adult support, and lack of someone to disclose her HIV status to.

All of the women faced pressure to conform to culturally acceptable feeding practices, i.e. mixed feeding from birth, although some would have been able to stand up to this pressure better than others. Case 10 was an experienced mother of five children and did not foresee any of her extended family interfering with her feeding choice, whereas case 2 was a young primipara who would have faced pressure from her boyfriend's family with whom she lived but to whom she had not yet disclosed her HIV status.

Poor access to health care services or insufficient education and information provided by health care professionals was also a significant barrier to many of the women (this topic is discussed under the heading "Regulating Factors").

Financial burden was shown to be a significant factor influencing many of the women to continue exclusive breastfeeding, although they stated that they would have preferred to exclusively formula feed. Some of the women would have preferred to exclusively formula feed their infants from birth, but this was not a viable choice since they would then have had to buy their own supply of formula after the six month free supply from the government was finished.

These women did not have enough income to be able to afford that. Most of them had a single breadwinner in the home, and some had no steady source of income at all. Case 6 was a single mother of five children and had no source of income but her own – she was concerned that she would have insufficient breast milk to satisfy her baby because she had a poor diet herself and often had to go without food. Unfortunately it is likely that she would have had an insufficient supply of breast milk if her diet did not improve – this is

another of the overwhelming barriers to maintenance of exclusive breastfeeding that many rural African women will face.

Some of the women were the sole breadwinners in their homes and needed to go back to work before the period of exclusive breastfeeding was completed. Their only option then was to express breast milk and leave the baby in someone else's care. In cases such as these, there was always the possibility that the caretaker of the baby would feed the child something other than the expressed breast milk. Some of the mothers did not envision having to return to work within four months but circumstances changed and forced them to do so.

Other specific barriers encountered by individual women included: Case 4 was given rehydration solution to give to her baby when the baby was assessed to be dehydrated by the PHC clinic staff during the second month. The exclusivity of breastfeeding was thus interrupted and the baby was at a greater risk of contracting HIV from her mother's breast milk. There are no guidelines as to what should be done in situations such as this – perhaps the mother should have been told to discontinue breastfeeding as soon as it was evident that rehydration solution would have to be given to the baby.

Case 5 became ill and too weak to continue breastfeeding 6 weeks after delivery. No provision has been made in PMTCT guidelines for mothers who may become ill in the immediate post-partum period. Obviously, it would be optimal for HIV positive mothers who are already ill to formula feed their

infants from birth, but as in cases like these, illness cannot always be predicted.

Case 8 initially denied that she was post-test counselled and told that she was HIV positive. As is noted, perhaps the case should have been excluded and considered invalid in this study, but denial is in reality the response of many individuals to the knowledge that they are HIV positive. During the course of the interview, it became apparent that the client had absorbed all of the information of the pre-test counselling sessions, but it was impossible to ascertain whether post-test counselling was truly overlooked or whether the client had simply denied the test result.

4.3.4. Opportunities

Internal pressure to succeed at maintaining their original feeding choice and motivation to prevent transmission of HIV to their infants were demonstrated by some of the women who returned for follow-up. For example, case 1 reacted to the knowledge that she was HIV positive by showing a determination to modify her infant feeding practice and prevent transmission of HIV to her infant. She maintained exclusive breastfeeding for three and a half months, and still planned to continue breastfeeding for another two weeks after the final interview. Case 10 was also a good example of a client who was motivated to succeed and who had a good self-concept. This sense of belief in their own ability to succeed at maintaining the original feeding choice set these two women apart from the others.

Acceptance of health status by significant others, in this context meant HIV disclosure to significant others and the acceptance of the woman's positive HIV status by those significant others. None of the women who did disclose their HIV status to a significant other/s faced opposition. Case 1 disclosed her status to her mother and sister after three and a half months and found them to be supportive; case 2 disclosed her status to her mother after she was post-test counselled; case 4 disclosed her status to her husband one week after delivery of their baby; case 5 disclosed her status to her cousin after post-test counselling; and case 9 disclosed her status to her mother after post-test counselling.

Good social circumstances with predictable and comfortable cues are cited in the literature as opportunities to facilitate maintenance of a particular health behaviour. Although none of the women in the study could be considered to enjoy *good* social circumstances, case 1 had comparably good social circumstances with a steady job and income, a supportive family, and a good educational background which led her to critically analyse her situation and make a determined effort to succeed. Case 10 also was self-sufficient in that she did not have to rely on another person as a source of income; she was respected as an experienced mother of five children, and had a generally supportive extended family although she had not yet disclosed her HIV status to anyone.

Good support systems enabled some of the women to maintain their original feeding choices, but the women had to have disclosed their HIV status to a

significant other in order for this support to be possible. Some of the women had disclosed their HIV status, but would still not have adequate support since there were significant others that they had not disclosed to who would be significant barriers to maintaining their original feeding choice.

The influence of mass media was evident in all cases – all women but one gained knowledge about HIV/AIDS and PMTCT from the media, specifically the radio. This shows that HIV/AIDS awareness campaigns are achieving their aims to some extent. Unfortunately mass media have not yet focussed on promoting avoidance of mixed feeding – if the public begins to accept that mixed feeding is unnecessary, it will become much easier for HIV positive women to maintain their exclusive feeding choice (whether exclusive breastfeeding or exclusive formula feeding).

4.3.5. Beliefs, knowledge, attitudes and values

The case studies highlighted that it is a common community belief that a baby's appetite will not be satisfied if he/she is exclusively breastfed. Thus the community in general endorses mixed feeding as an acceptable and widely utilised practice, as is stated in the literature. It was also evident that the infant feeding options promoted as part of the PMTCT programme are completely foreign to the community, and have not been included as part of public awareness campaigns. It has been noted by the researcher that most members of the nursing community were not even aware of the infant feeding options suggested for HIV positive mothers – there is therefore a distinct shortcoming in the education, in-service and awareness campaigns

surrounding the PMTCT programme. It does not help that only the PMTCT counsellors and others directly involved in the PMTCT programme are aware of the suggested infant feeding options for HIV positive mothers – all health professionals involved in the care of HIV positive childbearing and childrearing women should be aware of the guidelines as set out in the PMTCT programme.

Cultural, social and religious beliefs influenced women's infant feeding choices and whether or not they were able to maintain their original choice. In African rural society, it is not the position of a young woman to oppose her elders. Some of the younger, unmarried women in the study lived with their boyfriends' families and as such would have been supervised in infant care by their boyfriends' mothers and other elders. It would be very difficult for these women to be able to stand up against the common community practice of mixed feeding and insist that their babies were not given any supplemental feeds.

A few of the women (case 3 and 4) expressed the desire to use traditional medicine techniques to prevent transmission of HIV to the baby. The use of traditional medicine and its interaction with PMTCT guidelines has not been adequately researched. The influence of traditional medicine would depend on whether it was an ingested form of medicine and whether it would interfere with the integrity of the gut. Guidelines on the use of traditional medicine in conjunction with the current PMTCT programme need to be provided so that appropriate advice can be given to HIV positive mothers.

Parenting and family values also had an influence on maintenance of original infant feeding choice. It was evident that some of the women were very concerned about the possibility of transmitting HIV to their infants – case 1 decided to have a tubal ligation performed when she found out she was HIV positive for the stated reason that she didn't want to risk transmission of HIV to another child, and was committed to her original feeding choice because she strongly believed exclusive breastfeeding and then formula feeding after 4 months would decrease her infant's chances of contracting HIV. Another completely different influence of parenting and family values was seen in case 5 where the mother was kicked out of her parents' home because she fell pregnant out of wedlock – this in turn led to a very difficult situation of estrangement from her parents, lack of income, dependence on her cousin, and lack of an adequate support system.

4.3.6. Summary

The findings can be summarized as follows:

Direction of change of behaviour (intention versus actual):

All of the women decided to and intended to exclusively breastfeed for between four and six months at the time of the first interview. Only half of the women returned for their second interviews, and only two returned for all three follow-up interviews, therefore the actual feeding practice of half of the women after six weeks could not be determined. Of the five women who returned for their second interview, four were still exclusively breastfeeding, and one had stopped breastfeeding and was exclusively formula feeding her baby (due to illness). Of the two women who returned for their third interview, one was still

exclusively breastfeeding at three and a half months, and the other had given her infant rehydration solution but was still breastfeeding at three and a half months (she changed her original decision from exclusive breastfeeding for six months to four months).

Influence of regulating factors on feeding practices:

Age had no obvious correlation to maintenance of feeding choice. Decision-making ability and the capacity to overcome the barriers to the maintenance of their original feeding choice were also related to the women's educational levels, social circumstances and support systems.

Differences in marital status also had no correlation to differences in feeding practices. Only one woman of the ten was married, but some co-habited with their partners, or were engaged to be married, and so would have had similar support systems.

Although it may be assumed that multiparous women might find the feeding choices and maintenance thereof easier, this was not necessarily the case. All of the women were tested for HIV during their most recent pregnancy, and so all were in a similar situation of having to cope with the tough decisions that being HIV positive faced them with. On the other hand, multiparous women would have had previous experience with breastfeeding, and so lack of experience would not be a factor leading to the abandonment of exclusive breastfeeding (as it might be for primiparous women).

Differences in educational level were notable – two of the women completed Std 9, six of the women completed between Std 4 and 6, and two of the women completed only Std 2 to 3. While it was evident that the two women who completed Std 9 had a much better grasp of the English language (could speak and understand English fairly well), this is the only notable difference between them and the others with lower educational levels in terms of the study.

Employment status of the women would have had an effect on the decision-making and infant feeding practice when the time came for those women who had jobs to return to work. Employment status is obviously also related to household income, and although some women were financially more independent than others, all of the women had limited financial resources. Their financial resources were all limited to the extent that formula feeding their infants from birth was not a viable option since they would not be able to afford to buy formula after the government stopped supplying them after six months.

Current level of knowledge of HIV/AIDS and previous experience of HIV/AIDS were similar for all women. Most had heard about HIV/AIDS from the media; some were more aware of HIV/AIDS in the community than others; and none knew of family members or significant others living with HIV.

In terms of access to appropriate health professional support, the value of the PMTCT education depended on the level of understanding and insight of the

client. It was evident that some of the women did not grasp the concepts taught to them regarding infant feeding, some of them showed excellent recall and understanding of concepts, and others showed the need for reinforcement and probing to recall some of the concepts.

Influences of client perceptions, knowledge, beliefs and values on feeding practices:

Lack of understanding of the concepts involved, i.e. exclusivity of breastfeeding and avoidance of mixed feeding, had a profound effect on feeding practices. Women could have started mixed feeding simply because they did not understand why they shouldn't do what other women in the community do, and not actually because of a conscious decision to mixed feed. Lack of adequate teaching and support and lack of sufficient reinforcement of concepts could have led to women simply returning to the norm of practising mixed feeding. Mass media has improved the general knowledge of the community about HIV/AIDS, but the media does not discourage mixed feeding which is the norm even amongst middle class communities due to the belief that exclusive breastfeeding will not satisfy an infant.

Cultural, social and religious beliefs also have an effect on feeding practices – as mentioned; it is culturally acceptable to mixed feed infants from birth and to introduce solid foods as early as at the age of two months. Cultural belief in the value of traditional medicine also has an effect on feeding practices, since mothers might abandon the PMTCT programme guidelines in favour of

traditional methods. Also, ingested traditional herbal remedies may contain contaminated water and facilitate passage of the HI virus to breastfed infants. Parenting and family values affect decision-making and feeding practice since the PMTCT feeding guidelines may result in family tension due to the deviance from the norm.

Cues to mixed feeding (barriers):

Cues to mixed feeding included a fatalistic view of the future and a loss of hope for preventing transmission of HIV to their infants. Some of the women did not seem to believe that maintaining a specific infant feeding regime was enough to prevent transmission of HIV to their infants. Thus they were not motivated to maintain their original feeding choice.

The women faced tremendous pressure to conform to the norm of mixed feeding from birth practised by the community. The feeding choices outlined for HIV positive mothers both go against the grain of societal practice.

Financial burden was another cue to mixed feeding. All of the women were in poor financial situations and so formula feeding from birth was not a viable option for them – so even if they did not want to breastfeed, they were forced to do so. Some of the women were the sole breadwinners in their households and so the necessity of going back to work also resulted in an increased possibility of mixed feeding.

Fear of stigmatisation due to disclosure of their positive HIV status led to non-disclosure of many women, and this in turn led to a lack of support for their feeding choice. With no-one to support their decisions and feeding practices, it is probable that exclusive breastfeeding could be abandoned. In addition, these women could not defend their decision to exclusively breastfeed to significant others since that would necessitate disclosure.

Cues to exclusive feeding (breast or formula) (opportunities):

Cues to exclusive feeding include an internal pressure to succeed in maintaining her original feeding choice and so decreasing the chances of HIV transmission to her infant. In addition, those women who had disclosed their HIV status to a significant other and established a good support system of acceptance and encouragement were more likely to maintain their original decision. Although none of the women enjoyed good social circumstances with predictable and comfortable cues, those who were more financially secure, employed, and who had a stable home environment were more likely to maintain their exclusive feeding regime.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

The government's PMTCT feeding guidelines (KwaZulu-Natal Department of Health, 2002) advised HIV positive mothers to breastfeed for either four or six months. Most of the women in the study decided that four months was a more viable option, probably since this meant they could introduce solids and formula at the same time and this practice would be more in line with common community practice of introducing solids into an infant's diet as early as the first or second month of life.

According to the social cognitive model for health promotion practice in nursing, before health education or health promotion programmes are planned, an individual client's behavioural intention to change should be evaluated based on the client's attitude towards the behaviour, subjective norms, and perceived control; and only when an actual behaviour change intention is established, should the programme be planned. In terms of the PMTCT programme and infant feeding choices, the HIV positive population can be considered the client, and the behaviour change necessary is the maintenance of a chosen infant feeding regime. HIV positive mothers as a population should thus have been evaluated in terms of their attitude towards the behaviour, their subjective norms, and their perceived control to establish whether maintenance of either of the two infant feeding regimens is viable for the majority of the population. The results of this study suggest that neither of

the infant feeding options suggested are viable for HIV positive women living in rural Africa.

Case 10 highlights an important issue – experienced mothers who have raised healthy children in the past are respected by the community to make decisions about their children's upbringing independently. This client did not face the barrier of other family members encouraging her to mixed feed because they believed she knew what she was doing. Community health services may be able to utilise women like these to empower other women and spread the teaching about exclusive breastfeeding for all newborn babies.

The study also indicates that the knowledge of nurses in general on this topic, is poor. The media also does not seem to address this topic sufficiently for the general population to be knowledgeable about this aspect of the illness. This should be addressed in in-service education for nurses and midwives and in mass health education on the radio specifically.

According to the findings of the study, those HIV positive mothers most at risk of not adhering to their original feeding choice are those who initially deny their HIV positive status, those that do not have a reliable significant other to whom they can disclose their HIV status, those who become ill in the immediate post-partum period, and those who are disempowered by society and cannot defend their decision to elders, fathers of their children and community members. These are the types of women who will need additional counselling, teaching and support.

It is significant that all of the ten women enrolled in the study chose to exclusively breastfeed their infants from birth until four to six months. This option seems thus to be the most viable option for HIV positive women in rural African settings. Most of the women cited financial reasons and community pressure to conform to the norm of breastfeeding as the reasons for their decision. They foresaw that they would not have the resources to provide formula feeds for their infants after the six month free infant formula supply from the government was completed. Thus formula feeding from birth was not a viable option for these HIV positive rural women.

The literature highlights the fact that if a HIV positive woman decides to exclusively breastfeed her infant, she should be followed up with breastfeeding support to ensure correct latching technique and to prevent cracked nipples, mastitis and other breast problems which may increase the chances of transmission of HIV to the infant (Hormann, 1999; Humphrey and Iliff, 2001). However, in the environment in which this study was conducted (and in most state hospitals and clinics), breastfeeding support is very poor or non-existent. St. Apollinaris Hospital as an example does not have sufficient nursing staff to provide breastfeeding support and education, and the high turnover of patients (typical discharge of a new mother is 24 hours after delivery) also makes it impossible for adequate follow-up to be done. Postpartum follow-up of women should be done routinely with a visit to the health care provider three to fourteen days after discharge from the hospital or clinic, every two weeks during the first month, and once a month thereafter.

This is an issue which needs urgent attention since with the current poor staffing levels at most government health care institutions it is impossible to provide this vital service.

Further research should be done on the topic of the decision-making of HIV positive mothers regarding infant feeding with a larger sample. Due to constraints of time and distance, follow-up interviews with the women in the study could not be scheduled for six months post-delivery as originally planned. There are numerous difficulties faced when conducting a research study in a rural population. One of the most significant is difficulty in tracing participants for follow-up due to the lack of infrastructure. Thus many of the participants in this study were lost to follow-up and the available information gained from a single interview was used to formulate the case study. Although not ideal, this compromise did prove acceptable. The individual researcher was unable to use a larger sample, but information gained in the case study format by a research team would prove valuable.

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APPENDIX 1

PROTOCOL FOR THE PHASED IMPLEMENTATION OF THE PMTCT PROGRAMME IN KWAZULU NATAL

APPENDIX 2

CONCEPTUAL FRAMEWORK

Figure 1.1 A social cognitive model for health promotion practice in
nursing

APPENDIX 3

CASE STUDY PROTOCOL

Each individual case study will be analysed according to the concepts outlined in the conceptual framework. The following concepts will be highlighted from each case and compared by a process of pattern-matching.

Perceptions of the woman

-Beliefs, values and attitudes of the woman towards infant feeding options

- 1) Cultural and social beliefs
- 2) Religious beliefs
- 3) Health beliefs and attitude towards HIV/AIDS (personal risk/benefit analysis)
- 4) Parenting and family values
- 5) Other

-Does the woman feel capable of making the infant feeding choice and of maintaining that practice for a six month period?

- 1) Yes
- 2) No

-What barriers or opportunities exist to prevent or facilitate the maintenance of the original feeding choice, in the mind of the woman (before she actually experiences any barriers or opportunities)?

- 1) Family or significant others' influence
- 2) Disclosure of HIV status and stigmatisation
- 3) Lack of support from family and significant others
- 4) Fatalistic view, loss of hope for preventing transmission of HIV to infant
- 5) Pressure to conform to peer practice, culturally acceptable feeding practices
- 6) Poor access to health care services and support
- 7) Financial burden
- 8) Other

-How severe does the woman consider the risk of transmitting the HI virus to her infant if she changes her original feeding practice?

- 1) Severe risk
- 2) Moderate risk
- 3) Little or no risk

-How motivated is the woman to fully implement the preferred feeding choice?

- 1) Well motivated
- 2) Neutral
- 3) Not motivated, complacent

Regulating factors

-What are the regulating factors (demographic and other factors) that affect the woman's decision to either exclusively breastfeed or exclusively formula feed, and that affect the maintenance of that original choice?

- 1) Age
- 2) Parity
- 3) Marital status
- 4) Structure of household
- 5) Working status
- 6) Educational level
- 7) Family and personal income
- 8) Influence of family members and significant others
- 9) Environmental conditions
- 10) Level of knowledge of HIV, previous experience of HIV/AIDS
- 11) Other

Cues to action/ non-action

-What barriers exist to prevent the maintenance of the original feeding choice?

- 1) Negativity, anxiety and fear of failure and disclosure of HIV status
- 2) Peer conformity and the impact of role models/national media, adhering to social norms and feeding practices
- 3) Being suspicious of authority, health professionals, and paternalistic health services
- 4) Denial of problematic health status, leaving things to chance

5) Overwhelming barriers, more 'cost' than 'benefit', lack of support

6) Other

-Which factors or opportunities exist to facilitate the maintenance of the original feeding choice?

1) Intention to adhere to feeding practice

2) Motivation to prevent transmission of HIV to infant

3) Internal/external pressures to succeed

4) Influence of media

5) Good social circumstances – predictable and comfortable cues

6) Positive contemplation/anticipation

7) Good support systems (i.e. family, friends, community, health services and health professionals)

8) Other

APPENDIX 4

INTERVIEW SCHEDULE

First Interview

Date: _____

Time: _____

Code name: _____

<u>QUESTIONS ASKED</u>	<u>INFORMATION SOUGHT</u>
<p>1. How have you decided to feed your baby?</p> <ul style="list-style-type: none"> • How did you come to this decision? • What do you think this will mean for you? And for the baby? • Why do you think so? 	<p>Knowledge Beliefs Values</p> <p>Attitudes</p> <p><i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p> <p>Regulating factors</p> <p><i>Age, parity, marital status, structure of household, working status, educational level, family and personal income, influence of family members and significant others, environmental conditions, level of knowledge of HIV, previous experience of HIV</i></p>
<p>2. Do you think you will be able to implement this decision?</p> <ul style="list-style-type: none"> • Why? • Who will help you? • Who will support this decision? In what way? • Who will hinder this decision? In what way? • Why? • What about financial and other costs related to the decision? 	<p>Barriers and Opportunities</p> <p><i>Family and significant others' influence; disclosure of HIV status and stigmatisation; lack of support; fatalistic view, loss of hope for preventing transmission of HIV to infant; pressure to conform to culturally acceptable feeding practices; poor access to health care services; financial burden</i></p>

3. What makes this decision important to you?	<p>Motivation – <i>to fully implement the preferred feeding choice</i></p> <p>Risk – <i>personal assessment of risk of transmitting the HI virus to her infant if the woman changes her original feeding practice</i></p>
4. Demographics, example: age, parity, marital status, structure of household, working status, educational level	<p>Regulating factors</p> <p><i>Age, parity, marital status, structure of household, working status, educational level, family and personal income, influence of family members and significant others, environmental conditions, level of knowledge of HIV, previous experience of HIV</i></p>

- Suggested probes, although any relevant problem can be used.

2nd Interview**Date:** _____**Time:** _____**Code Name:** _____

<p>1. How are you now feeding your baby?</p> <ul style="list-style-type: none"> • Why? 	<p>Reasons for change</p> <p>Barriers - <i>Negativity, anxiety and fear of failure and disclosure of HIV status; Peer conformity and the impact of role models/national media, adhering to social norms and feeding practices; Being suspicious of authority, health professionals, and paternalistic health services; Denial of problematic health status, leaving things to chance; Overwhelming barriers, more 'cost' than 'benefit', lack of support</i></p> <p>Opportunities - <i>Intention to adhere to feeding practice; Motivation to prevent transmission of HIV to infant; Internal/external pressures to succeed; Influence of media; Good social circumstances – predictable and comfortable cues; Positive contemplation/anticipation; Good support systems (i.e. family, friends, community, health services and health professionals)</i></p>
<p>2. If feeding practice has changed, probe reasons for change</p> <ul style="list-style-type: none"> • Did you underestimate the problems associated with your first choice? • How? 	<p>Barriers - <i>Negativity, anxiety and fear of failure and disclosure of HIV status; Peer conformity and the impact of role models/national media, adhering to social</i></p>

<ul style="list-style-type: none"> • How did your support work out? • Did you overestimate the support you would get? • How? • What caused the problems? 	<p><i>norms and feeding practices; Being suspicious of authority, health professionals, and paternalistic health services; Denial of problematic health status, leaving things to chance; Overwhelming barriers, more 'cost' than 'benefit', lack of support</i></p> <p>Opportunities - <i>Intention to adhere to feeding practice; Motivation to prevent transmission of HIV to infant; Internal/external pressures to succeed; Influence of media; Good social circumstances – predictable and comfortable cues; Positive contemplation/anticipation; Good support systems (i.e. family, friends, community, health services and health professionals)</i></p> <p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p>
<p>3. <i>If feeding practice is the same, probe reasons for ability to maintain choice</i></p> <ul style="list-style-type: none"> • Who or what have you found most supportive? • Have you had any problems and how did you cope with them? 	<p>Opportunities - <i>Intention to adhere to feeding practice; Motivation to prevent transmission of HIV to infant; Internal/external pressures to succeed; Influence of media; Good social circumstances – predictable and comfortable cues; Positive contemplation/anticipation; Good support systems (i.e. family, friends, community, health services and health professionals)</i></p> <p>Barriers - <i>Negativity, anxiety and fear of failure and disclosure of HIV status; Peer conformity and the impact of role</i></p>

	<p><i>models/national media, adhering to social norms and feeding practices; Being suspicious of authority, health professionals, and paternalistic health services; Denial of problematic health status, leaving things to chance; Overwhelming barriers, more 'cost' than 'benefit', lack of support</i></p> <p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p>
<p>4. How do you now feel about your decision?</p> <ul style="list-style-type: none"> • Explore thinking and feeling. 	<p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p>
<p>5. How do you now feel about your baby's risk and condition?</p> <ul style="list-style-type: none"> • Explore thinking and feeling. 	<p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p> <p>Risk – <i>personal assessment of risk of transmitting the HI virus to her infant if the woman changes her original feeding practice</i></p>

3rd Interview**Date:** _____**Time:** _____**Code Name:** _____

<p>1. How are you now feeding your baby?</p> <ul style="list-style-type: none"> • Why? 	<p>Reasons for change</p> <p>Barriers - <i>Negativity, anxiety and fear of failure and disclosure of HIV status; Peer conformity and the impact of role models/national media, adhering to social norms and feeding practices; Being suspicious of authority, health professionals, and paternalistic health services; Denial of problematic health status, leaving things to chance; Overwhelming barriers, more 'cost' than 'benefit', lack of support</i></p> <p>Opportunities - <i>Intention to adhere to feeding practice; Motivation to prevent transmission of HIV to infant; Internal/external pressures to succeed; Influence of media; Good social circumstances – predictable and comfortable cues; Positive contemplation/anticipation; Good support systems (i.e. family, friends, community, health services and health professionals)</i></p>
<p>2. If feeding practice has changed, probe reasons for change</p> <ul style="list-style-type: none"> • Did you underestimate the problems associated with your first choice? • How? 	<p>Barriers - <i>Negativity, anxiety and fear of failure and disclosure of HIV status; Peer conformity and the impact of role models/national media, adhering to social</i></p>

<ul style="list-style-type: none"> • How did your support work out? • Did you overestimate the support you would get? • How? • What caused the problems? 	<p><i>norms and feeding practices; Being suspicious of authority, health professionals, and paternalistic health services; Denial of problematic health status, leaving things to chance; Overwhelming barriers, more 'cost' than 'benefit', lack of support</i></p> <p>Opportunities - <i>Intention to adhere to feeding practice; Motivation to prevent transmission of HIV to infant; Internal/external pressures to succeed; Influence of media; Good social circumstances – predictable and comfortable cues; Positive contemplation/anticipation; Good support systems (i.e. family, friends, community, health services and health professionals)</i></p> <p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p>
<p>3. <i>If feeding practice is the same, probe reasons for ability to maintain choice</i></p> <ul style="list-style-type: none"> • Who or what have you found most supportive? • Have you had any problems and how did you cope with them? 	<p>Opportunities - <i>Intention to adhere to feeding practice; Motivation to prevent transmission of HIV to infant; Internal/external pressures to succeed; Influence of media; Good social circumstances – predictable and comfortable cues; Positive contemplation/anticipation; Good support systems (i.e. family, friends, community, health services and health professionals)</i></p> <p>Barriers - <i>Negativity, anxiety and fear of failure and disclosure of HIV status; Peer conformity and the impact of role</i></p>

	<p><i>models/national media, adhering to social norms and feeding practices; Being suspicious of authority, health professionals, and paternalistic health services; Denial of problematic health status, leaving things to chance; Overwhelming barriers, more 'cost' than 'benefit', lack of support</i></p> <p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p>
<p>6. How do you now feel about your decision?</p> <ul style="list-style-type: none"> • Explore thinking and feeling. 	<p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p>
<p>7. How do you now feel about your baby's risk and condition?</p> <ul style="list-style-type: none"> • Explore thinking and feeling. 	<p>Beliefs Knowledge Values</p> <p>Attitudes <i>Towards infant feeding options and HIV; cultural, social, religious beliefs; parenting and family values</i></p> <p>Risk – <i>personal assessment of risk of transmitting the HI virus to her infant if the woman changes her original feeding practice</i></p>

APPENDIX 5

INFORMATION SHEET AND INFORMED CONSENT FORM

English translation

Title of study: The decision-making of HIV positive mothers regarding infant feeding in a rural African context.

Researcher: Linda de Kock (Registered nurse, Masters' student in Maternal and Child Health at University of Natal, Durban)

Translator: Khuphukile Hlope

You have been selected to participate in a research study on the decision-making of HIV positive mothers regarding infant feeding in a rural African context. The purpose of the study is to determine what factors (demographic, social, cultural etc) affect the original decision of HIV positive mothers whether to exclusively breastfeed or exclusive formula feed, and also what factors affect the maintenance of the original feeding practice or the alteration of the original feeding practice. Although this study will not benefit you directly, the information obtained may help to identify the real problems and challenges that HIV positive women face in their family and community situations and thus help to improve the efficacy of future programmes for HIV positive mothers.

As far as I can tell, there should be no risks or discomforts to you in sharing your own story and information. Your participation will mean that you will meet

with the researcher and the translator for an audio-taped interview lasting 30 minutes before your discharge from the maternity ward, again when you attend the clinic when your baby is six weeks old, and finally when your baby is six months old. You will be able to discuss issues in your home language, Zulu, and a translator will be present to interpret your answers to the researcher.

I will keep a record of who has participated in the study, and I will keep the tapes of our interviews together with a transcription and Zulu translation of those tapes. Your name will not be on the tape or on the transcription, so that the data will not be linked to your name. You will be provided with a code name, and this will be used when discussing and publishing data and labelling tapes and transcriptions. All data will be stored in a secure place and no one except the research team will have access to your interviews. Your identity will not be revealed when the study is reported or published. Your HIV status will likewise be protected, and you will receive all of the same services as all other women participating in the PMTCT programme.

If you have any questions about the study or about participating in the study, please feel free to ask me (Linda de Kock). You may contact me at St. Apollinaris Hospital maternity ward personally or at (039) 8331045 (ask for maternity).

Your participation in the study is totally voluntary: you are under no obligation to participate. You have the right to withdraw at any time if you want to,

without repercussion or penalty. You have the right to refuse to give information or to ask for clarification about the purpose of the study.

Consent

The study and its procedures have been approved by the appropriate people and research committees of the University of Natal, Durban.

I have discussed the above points with the subject. It is my opinion that the subject understands the risks, benefits and obligations involved in participating in this project.

Signature of investigator

Date

I understand that my participation is voluntary and that I may refuse to participate or withdraw my consent and stop taking part at any time without penalty.

I hereby freely consent to take part in this project.

Signature of subject

Date

Zulu translation

Isihloko socwaningo: Ukuthatha isinqumo sokuncelisa komama

abanegciwane ezindaweni zasemakhaya eAfrika.

Umcwaningi: Linda de Kock (umhlengikazi, umfundi weMasters in Maternal and Child Health, eUniversity yaseNatal, eThekwini.

Utolika: Khuphukile Hlope

Ukhethiwe ukuba ubambe iqhaza kucwaningo lomama abanegciwane leHIV ekuthatheni isinqumo sokuncelisa ngokwa seAfrika. Inhloso yalolucwaningo ukubheka ngokwendawo nangokwesiko ukuthi yini ebona abanye omama abanegciwane leHIV bakhethe ukuncelisa ibele lodwa abanye bakhethe ukuncelisa ibhodlela, yini eyenza abanye bathathe ukuncelisa ngendlela ejwayelikile yebele. Noma ucwaningo lungeke lukusize wena ngqo, kodwa ulwazi oluyotholakala kulolucwaningo lungasiza ekutholeni izinkinga nobunzima obubhekene nomama abanegciwane leHIV emindenini yabo nasemphakathini bese kusiza ukuthi kusungulwe izindlela ezingasiza labomama.

Akukho bungozi ozobhekana nabo ngokuthi ungixolele ngawe ukuthatha iqhaza kusho ukuthi uzohlangana nomcwaningi nozobe emtolikela. Ingxoxo yenu izobe lrekhodwa ezothatha imizuzu engaba u-30 ngaphambi kokuba ukhishwe esibhedlela. Nanoma usulethe umntwana wakho emtholampilo enamasonto ayisithupha, kuze kube esenezinyanga eziyisithupha. Konke

kuzobe kukhulunywa ngesiZulu, utolika uzolokhu ekhona ukuhumlusha zonke izimpendulo zakho kumcwaningi.

Mina mcwaningi ngizozigcina zonke izinto esizobesibhalekuzo kanye necassette. Igama lakho ngeke libhalwe ndawo, nqkwicassette ngeke libekhona. Uzophiwa inamba eyosetshenziswa esikhundleni segama lakho. Yonke into ngawe izobekwa endaweni engeke itholwe muntu ngaphandle komcwaningi notolika wakhe. Kuzoba imfihlo yakho nomcwaningi ukuthi unegciwane, futhi uzoyithola yonke imithi etholwa abanye omama abenegciwane leHIV.

Uma unemibuzo mayelana nalolucwaningo wamukelekile ukuba ubuze mina uSista de Kock. Ngitholakala esibhedlela eSt Apollinaris, ewodini yababelethayo noma ungifanele kulenamba 039-8331045 ucele eMaternity, iwodi yababelethayo.

Ukubamba iqhaza kulolucwaningo kukhululekile, awuphoqiwe. Unelungelo lokuyeka noma inini ngaphandle kwenkinga. Unelungelo lokunqaba ukuphendula eminye imibuzo noma ukubuza ngenhlogo yalolucwaningo.

Invume

Ucwaningo lonke nendlela oluzokwenziwa ngayo iphasisiwe abantu abafanele nekomiti lezocwaningo eUniversity yaseNatal, eThekwini.

isiginesha yomcwaningi

usuku

Nginyaqonda kahle ukuthi ukubamba iqhaza kulolucwaningo kungokukhululekile, nokuthi nginga nqaba ukuzibandakanya noma ngiyeke ukuzibandakanya nocwaningo noma inini ngaphandle kokuthola inkinga noma isijekiso.

Ngiyazikhethela ngokwami ngokukhululeka ukubamba iqhaza kulolucwaningo.

isiginesha kamama

usuku

APPENDIX 6

CONSENT TO CONDUCT STUDY