

Rapid Cessation of Exclusive Breastfeeding in Durban, South Africa: A Qualitative Assessment of the Experiences of HIV-infected Mothers and the Perspectives of Their Counsellors and Close Social Networks.

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DEDICATION

This thesis is dedicated to all HIV-infected women in poor resourced settings who have to struggle with infant feeding choices. May the research help them to find the best way to feed their babies in order to prevent mother-to-child transmission of HIV. I hope HIV free generation will become a reality one day.

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ABSTRACT

Rapid Cessation of Exclusive Breastfeeding in Durban, South Africa: A Qualitative Assessment of the Experiences of HIV-infected Mothers and the Perspectives of Their Counsellors and Close Social Networks.

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BACKGROUND AND INTRODUCTION

At the end of 2007 an estimated 2.1 million children were living with HIV/AIDS, and 2 million of those were in sub-Saharan Africa. It is estimated that 90% of children living with HIV acquired the virus through mother-to-child transmission (MTCT). The United Nation's Millennium Development Goal (MDG) number four is to reduce child mortality by two-thirds from 1990 to 2015. In order for this goal to be achieved PMTCT should be part of a comprehensive approach in maternal and child health services.

In the recent guidelines the World Health Organisation (WHO) has endorsed exclusive breast milk as ideal food for all infected and uninfected infants from birth to six months because of its nutritional superiority over commercial formulas and the significant protection it gives infants against acute and chronic illnesses. Without specific support exclusive breastfeeding is only practised by a minority of women worldwide. Some studies have shown that with enough support breastfeeding can be made safe through promotion of exclusive breastfeeding in communities where replacement feeding is not AFASS (acceptable, feasible, affordable, sustainable and safe).

AIMS AND OBJECTIVES:

To assess how HIV-infected women experience abrupt cessation of exclusive breastfeeding
To explore the perspectives of social networks of HIV-infected mothers when stopping breastfeeding

METHODS: In-depth interviews with HIV-infected mothers (n=16), counsellors (n=13) and focus group discussions (n=68)

RESULTS:

HIV-infected mothers chose rapid cessation of exclusive breastfeeding because they were motivated not to infect their babies even though it was extremely difficult. The counsellors were also pro-breastfeeding therefore they influenced mothers' choices. The counsellors did not have much practical advice on how to stop breastfeeding. In the focus group discussions the participants said that there need to be partner, family, and community involvement infant feeding issues. They stated that it should be emphasized that exclusive breastfeeding is for

everyone not just the HIV-infected mothers. Mixed feeding is a normal practice in the study area and there is a lot of family and cultural influence on a mother's infant feeding choice.

CONCLUSION

The constantly changing infant feeding guidelines are confusing. It is important for the policy makers to acknowledge that a mother does not live in isolation. When making infant feeding recommendations there is a need to take into consideration that the mother is influenced by her close social networks when she carries out her infant feeding option.

SEARCH TERMS

Breastfeeding, exclusive breastfeeding, rapid cessation, HIV, AIDS, MTCT, PMTCT, early cessation of breastfeeding, vertical transmission and weaning

SOURCES

Pubmed, Google Scholar, Snow ball technique, Books, Journals, WHO/UNICEF/UNAIDS websites, theses and BIBSYS

PROFILE OF SOUTH AFRICA

Map of South Africa



Location

South Africa is situated at the southern tip of Africa. The neighbouring countries are Namibia, Botswana, Zimbabwe, Mozambique and Swaziland. South Africa has three capitals: Cape Town, Bloemfontein and Pretoria. The Western Cape city of Cape Town, where the country's Parliament is found, is the legislative capital. In the Free State, Bloemfontein is the judicial capital, and home to the Supreme Court of Appeal. In Gauteng province, Pretoria, where the

Union Buildings and a large proportion of the civil service are found, is the administrative capital, and the ultimate capital of the country.(1).

The largest and most important city is Johannesburg, the economic heartland of the country. Other important centres include Durban and Pietermaritzburg in KwaZulu-Natal, and Port Elizabeth in the Eastern Cape.(1).

History

On 27 April 2009 South Africa celebrated 15 years of democracy. In 1994 the country had first democratic elections after being under white minority rule which had racial segregation policy known as apartheid. (1).

Population and Demographics

According to Statistics South Africa's mid-2006 estimates, the country's population stands at some 47.4-million. Africans are in the majority at 37.7-million, making up 80% of the total population. The white population is estimated at 4.4-million (9.2%), the coloured population is at 4.2-million (8.9%) and the Indian/Asian population at 1.2-million (2.5%). South Africa is also commonly known as the rainbow nation because of diversity and a very colourful flag.

Economy

South Africa is a middle-income emerging market with abundant natural resources, well-developed financial, legal, communications, energy and transport sectors, a stock exchange ranked among the top 20 in the world, and a modern infrastructure supporting efficient distribution of goods throughout the southern African region. Economic growth has been steady and unprecedented. Real gross domestic product (GDP) rose by 3.7% in 2002, 3.1% in 2003, 4.9% in 2004, 5% in 2005, 5.4% in 2006 - the highest since 1981 - and 5.1% in 2007. In the fourth quarter of 2007, South Africa recorded its 33rd quarter of uninterrupted expansion in real GDP since September 1999 - the longest economic upswing in the country's history.

Health Indicators

Life expectancy at birth is 52 years. Under 5 years mortality rate per 1000 live births is 67. Maternal mortality rate per 100 000 live births is 230 (2). Among adults (ages 15-49) HIV prevalence was 18.3% in 2006. Evidence points to a significant decline in HIV prevalence among young people (below age 20), where prevalence was 13.7% in 2006 compared to 15.9% in 2005 (3).

ACRONYMS

3TC-Lamivudine (antiretroviral)

AFASS- Affordable, Feasible, Acceptable, Sustainable, and Safe

AIDS- Acquired Immuno Deficiency Syndrome

ART- Antiretroviral Therapy

ARV- Antiretroviral

AZT- Zidovudine (antiretroviral)

BFHI- Baby Friendly Hospital Initiative

FGD- Focus Group Discussion

HIV- Human Immunodeficiency Virus

MDG- Millennium Development Goal

MTCT- Mother-to-Child Transmission

NRM- Narrative Research Method

NVP-Nevirapine (antiretroviral)

PMTCT- Prevention of Mother-to-Child Transmission

RF-Replacement Feeding

Sd-NVP- Single dose Nevirapine

UN- United Nations

UNAIDS- Joint United Nations Programme on HIV/AIDS

UNGASS- United Nations General Assembly Special Session on HIV/AIDS

UNICEF- United Nations Children's Fund

VCT- Voluntary Counselling and Testing

VTS- Vertical Transmission Study

WHO-World Health Organisation

DEFINITIONS OF TERMS

AFASS-conditions for replacement feeding

Acceptable- the mother perceives no social and cultural barriers like stigma and discrimination to replacement feeding

Feasible- the mother or family has adequate time, knowledge, skills and other resources to prepare the replacement food and feed the infant up to 12 times in 24 hours

Affordable- the mother and family can pay the replacement feeding cost without compromising the health and nutrition of the family

Sustainable- there is a continuous and uninterrupted supply and dependable system of distribution of all ingredients and products needed for safe replacement feeding, for as long as the infant needs

Safe- replacement foods are correctly and hygienically prepared and stored, and fed in nutritionally adequate quantities

Bottlefeeding

Feeding from the bottle, whatever its contents, which may be expressed breast milk, water, infant formula or another food or liquid.

Cessation of Breastfeeding

Completely stopping breastfeeding including suckling usually at 6 months to prevent MTCT of HIV or sooner.

Complementary Feeding

The child receives both breast milk or a breast milk substitute and solid or semi-solid food.

Cup feeding

The act of feeding an infant or child using a cup regardless of what the cup contains.

Exclusive Breastfeeding

Feeding an infant only breast milk and no other liquids, or solids not even water but the infant may receive drops/syrups of vitamins, mineral supplements or medicines that are deemed necessary and essential for the child. When expressed milk is given the preferred term is breast milkfeeding. This is recommended during the first 6 months of life.

Exclusive Replacement Feeding

Feeding infants who are receiving no breast milk with a diet that provides adequate nutrients until the age at which they can be fully fed family foods.

Heat Treatment of Expressed Breast Milk

The method of expressing human breast milk and heating in specific temperatures in order to destroy the HIV as a PMTCT strategy

Mixed Feeding

Breastfeeding as well as giving other milks (such as commercial formula or home-prepared milk), foods or liquids. In this context this refers to the first 6 months of life and this type of feeding is not recommended.

Mother-to-Child Transmission (¹MTCT)

Transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery or breastfeeding.

Rapid Cessation of Exclusive Breastfeeding

Stopping breastfeeding abruptly and then completely avoiding it in order to avoid mixing breast milk with other foods; this was a previous UN recommendation for PMTCT during the first 6 months of life (4)

¹ For the purposes of this thesis the term MTCT will be used because it has been consistently used in published papers. However the term has been criticised because even though it acknowledges that the source of the child's HIV-infection is the mother either during pregnancy, delivery or breastfeeding. It seems to ignore the father's role in transmission since the mother might have been infected by her sexual partner or through contaminated blood.

CHAPTER ONE: BACKGROUND AND INTRODUCTION

The Global Picture of HIV and AIDS

There were 33 million people living with HIV at the end of 2007 according to the Joint United Nations Programme on HIV/AIDS (UNAIDS)(5). Of all the people living with HIV, 67% come from Sub-Saharan Africa and half of them are women (5). At the end of 2007 an estimated 2.1 million children were living with HIV/AIDS, and 2 million of those were in sub-Saharan Africa (5). It is estimated that 90% of children living with HIV acquired the virus through mother-to-child transmission (MTCT) i.e. during pregnancy, delivery and breastfeeding (5). In the absence of interventions like the antiretrovirals (ARVs), the risk of (MTCT) of HIV is 20-50% with the highest rates in the populations with prolonged breastfeeding (6). An estimated 5-20% of infants born to HIV-infected mothers acquire infection through breastfeeding (4). Without appropriate care and treatment 50% of newly infected children will die before their second birthday (6).

There is a number of organisations that are jointly and independently working together in order to fight HIV/AIDS globally. United Nations General Assembly Special Session (UNGASS) on HIV/AIDS has the following goals; the reduction of paediatric infections by 50% and provision of prevention of mother-to-child transmission (PMTCT) services to 80% to those in need by 2010 (7). The United Nation's Millennium Development Goal (MDG) number four is to reduce child mortality by two-thirds from 1990 to 2015 (8). In order for these goals to be achieved, prevention of HIV infection to pregnant women, mothers and children including PMTCT should be part of a comprehensive approach in maternal and child health services (4). Several PMTCT programmes have been implemented in most of the countries including Sub-Saharan Africa (7;9-21).

In the recent guidelines the World Health Organisation (WHO) has endorsed exclusive breast milk as ideal food for all infected and uninfected infants from birth to six months because of its nutritional superiority over commercial formulas and the significant protection it gives infants against acute and chronic illnesses (22). However, it is also worth mentioning that exclusive breastfeeding is not a common infant feeding practice in an African cultural context including South Africa where mixed feeding is a norm (21). Without specific support

exclusive breastfeeding is only practised by a minority of women worldwide (21;23;24). In resource poor settings it becomes important to promote exclusive breastfeeding because using formula in such settings is even more hazardous for the babies (15). Some studies have shown that with enough support breastfeeding can be made safe through promotion of exclusive breastfeeding in communities where replacement feeding is not AFASS. (12;14;15;25).

The Global PMTCT Overview

The two-thirds of all MTCT is accounted for by ten countries (6). These are South Africa, Uganda, Kenya, Tanzania, Zimbabwe, Mozambique, Nigeria, Democratic Republic of Congo, Ethiopia and India. Except for India all the above countries are in Sub-Saharan Africa (6). The WHO first issued recommendations for the use of ARV drugs for PMTCT in 2000. By the end of 2006, 71 countries had implemented national PMTCT programmes and they had defined their country specific policies and strategies (6). Globally about 11% of HIV-infected pregnant women received ARVs to prevent MTCT by the end of 2006 ranging from 77% and 29% in Eastern Europe and Latin America to 3% and 2% in West Africa and South Asia respectively (6). In Sub-Saharan Africa the provision of maternal ARV prophylaxis for MTCT has more than doubled from 2004 to 2005 in the three of the most affected countries; Namibia, Swaziland and South Africa (6).

Treatment Regimens

In order to prevent MTCT of HIV mothers can take ARVs during pregnancy, delivery and after delivery. The infant should also receive ARVs after delivery. According to the PMTCT guidelines the mothers' and babies' regimens should be as follows (6);

Mothers' and Babies' ART Regimen

The HIV-infected mother is supposed to receive Zidovudine (AZT), Lamivudine (3TC), and Nevirapine (NVP) twice daily during pregnancy, labour and after delivery. The infant is supposed to receive AZT for seven days except for the cases where the mother received less

than four weeks of ART during pregnancy, then the infant is required to receive AZT for four weeks.

Mothers' and Babies' ARV Prophylaxis

At 28 weeks gestation (pregnancy) or as as soon as possible thereafter the mother is supposed to take AZT twice daily. During labour she is supposed to take single dose Nevirapine (Sd-NVP) and AZT/3TC, and after delivery for seven days take AZT/3TC. The infant is supposed to receive Sd-NVP and AZT for seven days.

The South African HIV and AIDS Situation

South Africa is one of the countries that is most hardly hit by HIV and has the sixth highest prevalence of HIV in the world (26). It is estimated that 5.7 million people are living with HIV in South Africa, approximately 3.2 million are women and 280 000 are children between 0-14 years (3). The HIV prevalence among women attending antenatal clinics was 29% in 2006 compared to 30.2% in 2005 (3). Local statistics from 2006 indicate that KwaZulu-Natal Province had the highest recordings of 37.4% (27).

In 2001 the South African government implemented a PMTCT programme (26). Since the inception of PMTCT services, more than 90% of primary health care centres have provided PMTCT services. Local statistics show that from 2005 to 2006 70% of antenatal clinic (ANC) attendees were counselled and tested for HIV. Twenty six percent were HIV-infected and they received Nevirapine (28).

In 2008 the then South African Minister of Health issued a statement that; *“Recent research and advice from experts now suggest that dual therapy is recommended. After consultation between Department of Health and experts it was decided that the PMTCT guidelines should be revised and that dual therapy using Nevirapine and Zidovudine (AZT) should be used instead of Nevirapine only for the PMTCT of HIV”* (28).

This may have led to a more determined and comprehensive response to HIV and AIDS pandemic after years of mixed messages from the South African Ministry of Health and a lot

of confusion and mixed messages prior to that (27). The old Minister of Health was replaced and there was a promotion of a National Strategic Plan (NSP) with clear targets for prevention, care and treatment to save lives. The NSP set a target of 100% national coverage in the public sector antenatal services sites for 2009 (29).

The Current South African PMTCT Services Package among other services include (28);

- Promoting acceptability of VCT
- Promoting routine offer of VCT
- Providing appropriate regimens to PMTCT of HIV according to the risk profile based on HIV test, CD4 cell count and clinical staging
- Providing other appropriate treatment such as for opportunistic infections (OI) management, nutritional support and antiretroviral therapy depending on CD4 cell count, nutritional status and staging
- Providing individualised counselling on safe infant feeding practices
- Providing infant formula for at least 6-months for women who meet AFASS criteria and who opt for exclusive breastfeeding, and in that way ensures that women have formula when they stop breastfeeding for PMTCT purposes
- Early infant HIV-testing using HIV Polymerase Chain Reaction (PCR) at 6 weeks (integrated with Expanded Immunisation Programme; EPI) 6 weeks visit irrespective of feeding option
- Repeat HIV test to HIV negative infants after cessation of breastfeeding

The South African Infant Feeding Guidelines

In 2001 when PMTCT services were implemented in South Africa the counsellors were following the 2000-2005 UN recommendation that “*When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first six months of life and should be then discontinued as soon as feasible*”. Furthermore it stated that when HIV-infected mothers choose not to breastfeed from birth or choose to stop later they should be provided with specific guidance and support for at least the first two years of a child’s life to ensure adequate replacement feeding (4). In 2006 the UN recommendations were updated, and currently state that; “*At 6 months if replacement feeding is still not AFASS,*

continuation of breastfeeding with additional complementary foods is recommended, while the mother and a baby continue to be regularly assessed. All breastfeeding should stop once a nutritionally adequate and safe diet without breast milk can be provided” (22). South Africa is now following the current guidelines. The difference between these guidelines is that while the former proposed rapid cessation of exclusive breastfeeding, the latter states that cessation should be gradual until the child can receive an adequate and a safe diet.

Core Functions of PMTCT in KwaZulu-Natal’s Department of Health

The KwaZulu-Natal’s Department of Health has further stipulated that the core function of the PMTCT is to reduce maternal and child mortality due to HIV/AIDS and improve the care of the HIV positive mother and her child (30). This it aims to do by reducing maternal and child morbidity and mortality due to HIV/AIDS. The main role of the PMTCT services is to address the impact of HIV/AIDS through; advisory, facilitation and initiation, coordination and integration, capacity building and supportive management, as well as monitoring and evaluation (30).

Rationale

Even though the guidelines now recommend gradual as opposed to rapid cessation of breastfeeding it was still important to do more qualitative studies on how the women experience this process of stopping breastfeeding as a PMTCT strategy. The reality in South Africa demonstrates that it is difficult for all the HIV-infected mothers to avoid breastfeeding due to various reasons like the fact that breastfeeding is a norm (31) and women sometimes fear being stigmatised for not breastfeeding (32).

When this study was initiated in 2005 the infant feeding guidelines were still recommending rapid cessation of breastfeeding until they were updated in 2006. Even though cessation is no longer rapid but gradual it was important to explore it because there are other conditions other than safe water and enough complementary foods that make cessation of breastfeeding work or not work. These include, dealing with a crying baby, engorged breasts and addressing questions from others on reasons why the mother is stopping breastfeeding irrespective of whether cessation is gradual or not.

In 2005 we conducted a study (which preceded this Masters Thesis) in South Africa and explored how the HIV-infected mothers experienced the process of rapidly stopping breastfeeding as part of the PMTCT strategy (33). We conducted in-depth interviews with mothers before, during and after they had attempted to stop breastfeeding rapidly. We also interviewed counsellors in order to assess what kind of infant feeding advice they were providing the mothers. We sought to determine what kind of support the mothers need and receive from their close social networks in order to make this seemingly challenging process of stopping exclusive breastfeeding more feasible.

On reflection, we realised that the 2005 study did not fully investigate the emergent theme of social networks of HIV-infected mothers and how they influence infant feeding choices made by women. The mothers were hiding their status from their family members and thus not receiving support they needed. It was also clear that most women were struggling during the period of rapid cessation of exclusive breastfeeding at six months because they received very limited practical about the actual process. From the interviews the counsellors revealed that they did not have much practical advice (33).

Women are not alone in making the infant feeding decisions. It is important to recognise that the HIV-infected mothers do not live in isolation but their families, and the society at large have a strong influence on how they make their infant feeding decisions. Social norms and family expectations are significant constraints to informed choice and implementation of feeding options. Experiences from pilot PMTCT programmes and research studies have shown that one of the main challenges to enabling HIV-infected women to implement antenatal feeding preferences has been to raise social and community awareness (3;15;21)

This influence of social networks on mothers' ability to stop breastfeeding became the focus of the follow-up study. In 2008 we explored the opinions of significant others through focus group discussions (FGDs). By significant others we mean the people in an HIV-infected mother's life who have influence on decisions that the mother makes. We wanted to complement the in-depth interviews from 2005 study and fill the existing gaps. The aim of the FGDs was to gain deeper insight and understanding from participants' perspective, in this case about issues surrounding the rapid cessation of exclusive breastfeeding. In 2005 we conducted only one FGD using the Narrative Research Method (NRM), in 2008 we conducted five more FGDs. The NRM will be explained in detail later.

The importance and influence of mothers' social network cannot be underestimated when attempting to change behaviours, yet to date relatively little attention has been given by the policy makers to the attitudes of significant community and family members , especially with regards to cessation of breastfeeding.

CHAPTER TWO: LITERATURE REVIEW

Before conducting the study I did a search for relevant literature on the quantitative and qualitative studies that have been conducted on the topic. The focus of the literature review was: 1) implementation of infant feeding guidelines, 2) exclusive breastfeeding in South Africa, 3) early cessation of exclusive breastfeeding and 4) effect of HIV on infant feeding practices. It is difficult to find literature that just deals with rapid cessation of breastfeeding. This is due to the fact that as a PMTCT strategy rapid cessation goes hand in hand with exclusive breastfeeding therefore you cannot discuss the other without mentioning the other one.

Implementation of Infant Feeding Guidelines

Doherty et al conducted a prospective cohort quantitative study in South Africa which assessed the effectiveness of the WHO/UNICEF/UNFPA/UNAIDS guidelines on infant feeding for HIV-infected women. They used semi-structured questionnaires. These were the findings. Only 13% of those who intended to exclusively breastfeed managed to do so by 12 weeks, the rest were mixed feeding. The characteristics of women who were intending to exclusively formula feed or exclusively breastfeed did not differ that much except that those who chose exclusive replacement feeding had a higher viral load. Despite counselling, mothers' infant feeding intentions did not appear to be influenced by economic and environmental conditions like availability of water, fuel etc. Some women who were not meeting AFASS criteria during counseling sessions chose replacement feeding (25).

The strengths of this study were that it took place in an urban, peri-urban and rural settings and that reflects the diversity of South African society. It was the first study to attempt providing a practical definition for UN infant feeding guidelines according to the authors' knowledge. The study's weakness is that some cases of intra-partum MTCT could have been wrongly attributed to postnatal transmission due to early testing between 3-4 weeks according to the authors (25).

Coutsoudis et al wrote a review paper on three large cohort studies on exclusive breastfeeding (31). They found that exclusive breastfeeding was associated with a three-to

fourfold decreased risk of MTCT compared to non-exclusive breastfeeding. The risk of MTCT and death was similar whether infants were formula fed or breastfed from birth. Early cessation of breastfeeding was associated with increased risk of morbidity and child mortality in infants born to HIV-infected mothers (31). The paper also addressed the provision of free formula in poor communities and concluded that this will not improve the health status of the mothers but it will increase poverty levels. This would be due to morbidity and mortality risks associated with formula feeding. The authors of the paper argue that instead of trying to reverse the poverty, what is needed is to have two processes running parallel. These processes are developing safer infant-feeding options for infants of HIV-infected mothers and at the same time develop poverty alleviation programmes (31).

Evidence has shown that providing free formula, clean water and electricity so that replacement feeding is AFASS is not the solution for MTCT (31). There are a lot of other underlying issues that need to be considered like the biological, economic, social, cultural and political context in which breastfeeding is embedded (31). Even though exclusive breastfeeding is not widely practiced in the developing world, with skilled support from well-trained infant-feeding counselors this can be addressed (31).

In a study by de Paoli et al which investigated women's views on infant feeding options for HIV-infected women in Tanzania, 500 women participated in surveys and that was complemented by six focus group discussions with 46 women (16). It was found that 82% of the women participating in the surveys said that they would choose infant feeding formula if they were found to be HIV-infected provided they received it free of charge whereas in the FDGs participants were concerned about the negative reactions they would receive from their communities if they were not breastfeeding (16). The FDGs participants also questioned the safety of exclusive breastfeeding followed by rapid cessation as an MTCT strategy but at the same time they said they would follow such advice from the healthcare worker if they were infected in order to prevent MTCT of HIV (16). Combining both quantitative and qualitative methods helped to address the topic in different angles thereby providing more insight. The weakness of the study is that the participants' HIV status was unknown therefore it is difficult to conclude how those women who are HIV-infected really feel about the infant feeding advice for HIV-infected women.

Exclusive Breastfeeding in South Africa

Coovadia et al conducted a non-randomised intervention cohort study of 2722 HIV-Infected and HIV negative women attending ANC in South Africa. This study was conducted in seven rural clinics, one semi-urban clinic and one urban clinic. They found that infants who were mixed fed were nearly 11 times more likely to acquire infection than the exclusively breastfed children. The strengths of the study were that; several sites combination of rural, semi-urban and urban were representative of South African diversity. The combination of home visits and clinic visits also strengthened their data.

This study achieved a higher rate of exclusive breastfeeding than other studies because it provided intensive exclusive breastfeeding support through home visits. The analysis methods were very well explained, and the very large number of 2722 participants strengthened their data (14). This study confirmed that exclusive breastfeeding is safer than partial and mixed breastfeeding but there need to be more focus on how this exclusive breastfeeding can be achieved. The weaknesses of this study are that; 1) frequent home visits might have prompted mothers to over report exclusive breastfeeding and under report mixed feeding and 2) intensive infant feeding support that was provided by the study in an operational setting might be very expensive and time consuming in a non-operational setting (14).

Early Rapid Cessation of Exclusive Breastfeeding

Kuhn et al conducted a quantitative study on the effects of early, abrupt weaning on HIV-free survival of children in Lusaka, Zambia (34). A total number of 958 HIV-infected women were randomised into two groups; 481 were randomly assigned to a counselling programme that encouraged abrupt weaning at 4 months whilst the other 477 were randomly assigned to a programme that encouraged continued breastfeeding for as long as women chose.

The authors expected that the babies that weaned early would have higher infection rates. This was due to the fact that rapid weaning is associated with increased levels of HIV and mastitis therefore any exposure to breast milk during this time maybe associated with an increased risk of infection. This might seem confusing because the mothers were supposed to have stopped exposing their infants to breast milk anyway, but the infant feeding practices in

Zambia indicate that prolonged breast feeding is a norm. Early cessation of breastfeeding was not universally accepted in the study population, only approximately 70% in the intervention group managed to wean their infants early.

The findings of the study were rather surprising. It was found that there was no significant difference between the groups in HIV-free survival at 24 months. Between 4 and 24 months the rates of postnatal transmission were not significantly different. Children who were already infected with HIV before weaning had significantly worse outcomes if they were assigned to the group that stopped early. After this study the authors concluded that early, abrupt cessation of breastfeeding should be avoided in low resource settings. This conclusion is consistent with the current updated WHO recommendation that breastfeeding with complementary foods should continue for HIV-infected women if replacement feeding is still not AFASS (22).

The weakness of the study is that it is possible that the 70% that claimed to have stopped at 4 months did not but continued breastfeeding while also giving the formula and weaning food that they were provided with. This could have led to their outcome being the same as those of the control group which was mixed feeding. The authors mentioned it themselves that in Zambia prolonged breastfeeding is a norm (34). The strength of the study was that women in the intervention group were prepared for weaning early and provided with infant formula and fortified weaning food.

Another breastfeeding study was conducted in Cote d'Ivoire in 2005 by Becquet et al (11). This was a prospective cohort study that assessed acceptability of exclusive breastfeeding cessation to prevent HIV transmission through breast milk. Structured questionnaires were used. There were 557 HIV-infected pregnant women who were investigated. The findings were that; 1) only 5% of the 557 HIV-infected women succeeded in practice of exclusive breastfeeding until weaning in 3-4 months, 2) women who did not succeed had fewer living children and had advanced stages of HIV disease and 3) living in shared housing and having delivered at home were associated with failure of the proposed intervention (11). This study defined infant feeding methods very well. The weakness of the study is that qualitative approach was not used but it could have also been employed with HIV-infected women's close social networks.

In a qualitative study that we conducted in South Africa which assessed how HIV-infected mothers planned and experienced breastfeeding cessation and how counselors facilitated this process. We conducted in-depth interviews with 13 counsellors and 16 HIV-infected mothers (33). We also had one FGD with 14 participants including community members and health workers. The findings were that both the counselors and the mothers expressed concerns about practical issues like social consequences associated with early cessation of exclusive breastfeeding. In this study it was also apparent that guidance that acknowledges cultural context and psychological stresses involved during this period is urgently needed to direct policy, training, and service delivery (33).

The strength of this study is that it had flexibility in the sense that it allowed the experiences of the mothers to determine the direction of the interviews e.g. there was no standardized number of interviews scheduled, it depended on where in the process of rapid cessation the mother was thereby capturing the whole transition until the mother completely stopped breastfeeding. The weakness of this study is that only the mothers and counselors were interviewed, other people who are involved in making infant feeding decisions like grandmothers could have been included in the interviews as well.

A qualitative study which explored the perspectives and experiences of mothers and their communities of early breastfeeding cessation in rural Harare, Zimbabwe was conducted by Lunney et al (18). This was a prospective cohort study with 43 breastfeeding mothers, 8 health workers, and 29 community members using in-depth interviews and FGDs. It was found that; 1) motivated mothers can wean early. Eleven out of 12 who had intended to stop after receiving HIV- negative results at 6 months managed to do so. 2) eight out of the 11 did not have access to replacement milk. They therefore ended up feeding the infants fermented porridge and very thick porridge. 3) main motivation for weaning was prevention of transmission. 4) the most common barrier to early weaning was shortage of nutritious food according to 12 out of 15 mothers that were interviewed in one group. 5) none of the mothers believed they could afford formula. 6) several mothers were sceptical of heat treating their milk because they did not understand the heat-treating method and they said it was time consuming. Heat-treating of the milk refers to another PMTCT strategy of heating expressed breast milk in specific temperatures in order to destroy the virus. The strengths of this study were that they combined in-depth interviews with FGD to strengthen results. One week long infant feeding workshops were conducted in the hospital to strengthen health workers' infant

feeding counselling skills after the study was concluded. The weakness was that there was more focus on food shortage, and not so much on preparation and the experiences of HIV-infected women.

Another quantitative study was conducted by Goga et al in South Africa (35). This study investigated the feasibility of complete breastfeeding cessation in three governmental PMTCT sites. Six hundred and sixty five HIV-infected and 218 HIV-uninfected women and their babies were recruited from ANC before or at a time of delivery. The national recommendation at the time was that they were supposed to stop breastfeeding rapidly at 24 weeks as a PMTCT strategy.

The study found that only 39-44% women that were practicing exclusive breastfeeding adhered to this recommendation. Women reported breast problems immediately after stopping. Engorgement, inflamed and tender breasts were also reported at the time of stopping breastfeeding. The other finding was that early cessation of breastfeeding may carry no significant benefit for HIV-free survival. The same finding was reported in study that was conducted in Zambia (34). The strength of the study was that it took place in three diverse settings in South Africa. The weakness is that the study could have also explored reasons for adhering and not adhering qualitatively.

Effect of HIV on Infant Feeding Practices

In South Africa, Doherty et al explored how the HIV pandemic has affected the infant feeding experiences of HIV-infected mothers using in-depth interviews with sub-sample of 40 HIV-infected mothers from a prospective cohort (21). The study sites were in three of the nine South African provinces. These were the findings of the study; most of the mothers were only able to maintain exclusive breastfeeding practices for a short time due to various health system constraints. Five key findings characterised infant feeding experiences of HIV-infected mothers; 1) protecting the child, 2) the influence of health workers and significant others, 3) hiding the truth, 4) realities of free formula milk, 5) self efficacy- being HIV-infected led to feelings of social isolation, despair and powerlessness (21). The strengths of the study were that; 1) it captured many angles to the infant feeding dilemma caused by

HIV and 2) the interviews were conducted in local and preferred languages of the mothers as they took place in three different provinces.

More recently Sibeko et al in another South African study investigated the enabling and challenging factors impacting on infant feeding practices in communities with high HIV prevalence through in-depth interviews and observation of mothers (36). There were also discussions with health service providers. The study found that mixed feeding remained a common feeding practice and that the availability of free formula did not guarantee exclusive formula feeding but led to inappropriate feeding practices and that disclosing HIV status at home made it easier to practice exclusive breastfeeding (36).

In a review article, Coovadia and Bland acknowledge that there is a dilemma in developing countries to make infant feeding choices in accordance with social, cultural and economic circumstances in the face of HIV pandemic (24). They argue that the most pertinent issue in the populations affected by HIV is to weigh the hazards of MTCT through breastfeeding against increased infant mortality and morbidity through exposure to formula milks (24). It is not enough just to say that formula milk does not have HIV therefore avoidance of breastfeeding is the answer for all HIV-infected women and at the same time exposing infants to other risks associated with formula milk (24).

There have been studies on how HIV-infected women experience exclusive breastfeeding but very few on rapid cessation. Most of the studies focus on the definitions of infant feeding methods, explanations of the UN guidelines but little is known of the actual experiences of women who try to use rapid cessation of exclusive breastfeeding method. More needs to be done to illustrate how cessation of breastfeeding can be achieved and how HIV-infected mothers can stop breastfeeding safely. In a country with limited resources like South Africa, most women do not meet the AFASS requirements for replacement feeding (15).

CHAPTER THREE: PURPOSE OF THE STUDY

Main Aims and Objectives (2005 Study)

- **To assess how HIV-infected women experience rapid cessation of exclusive breastfeeding**
- **To explore infant feeding advice provided by the counsellors**
- **To explore the role of local community and local care workers in supporting HIV-infected women in this strategy**

Main Aim and Objective (2008 Study)

- **To explore the perspectives of social networks of HIV-infected mothers when stopping breastfeeding**

Specific Objectives (2005 study)

- To describe perceptions and attitudes to abrupt cessation of exclusive breastfeeding and early weaning amongst HIV-infected mothers
- To explore the attitudes of local community and health care workers to infant feeding options for PMTCT e.g. exclusive breastfeeding followed by rapid cessation

Specific Objectives (2008 study)

- To explore what kind of support can be offered to HIV-infected mothers who have chosen exclusive breastfeeding with the intention of stopping early
- To explore how the community at large can be supportive to exclusive breastfeeding
- To explore enablers and barriers to exclusive breastfeeding and stopping

The specific objectives led to the following research questions;

Research Questions (2005 study)

What kind of infant feeding advice do the HIV-infected mothers receive?

What kind of support do HIV-infected mothers need during rapid cessation of exclusive breastfeeding?

What are the main problems when stopping exclusive breastfeeding at six months?

Research questions (2008 study)

How can the close social networks of HIV-infected mothers support them during cessation of breastfeeding?

How to make the process of stopping breastfeeding more bearable?

CHAPTER FOUR: METHODOLOGY

The 2005 Study Setting

This study was conducted in three clinics and one hospital in Durban, KwaZulu-Natal Province in South Africa. The interviews were conducted from April until October in 2005. The main research site was at the KwaDabeka Community Health Centre (CHC). KwaDabeka CHC is situated at KwaDabeka Township in eThekweni (Durban) Health District. It serves a population of approximately 175 000 people who reside in KwaDabeka catchment area. There are also eleven other clinics which are under KwaDabeka CHC but only two of those; Clermont and Halley Stott clinics were selected. Marianhill Hospital which is a nearby referral hospital was also selected. Breastfeeding is practised in the area. KwaDabeka CHC follows Breastfeeding Hospital Initiative (BFHI) and was the first CHC in KwaZulu-Natal to be awarded Baby Friendly status in 2000 and as such has a long tradition of supporting breastfeeding (37). KwaDabeka CHC was also one of the sites for the large cohort the Vertical Transmission Study (VTS) by Coovadia et al (14). The above sites were selected because the staff working there have already been sensitised about research. This was because there had been research conducted in those clinics before. In addition, the infrastructure of those clinics was better equipped to accommodate us, whereas other clinics in the area have serious shortage of space.

The 2005 Study Design and Participants

Sixteen HIV-infected mothers were sampled, nine from the provincial PMTCT programme, and seven from the clinical research setting the VTS. We conducted a qualitative study using sequential in-depth interviews before, during and after rapid cessation of exclusive breastfeeding with HIV-infected mothers. We also explored infant feeding guidance provided by 13 counsellors through in-depth interviews. Nine counsellors were from PMTCT and four from the VTS. We wanted to compare the routine services from the provincial programme with an operational research setting. All the counsellors that were interviewed were trained in

both breastfeeding and HIV counselling. In addition they also perform infant feeding counselling. The participating counsellors were asked to refer the mothers to us for recruitment; PMTCT counsellors referred the mothers from PMTCT programme and VTS counsellors referred mothers from the VTS for recruitment. We also conducted one focus group discussion with 14 participants. Included in this FGD were five community health workers, two grandmothers/ mothers-in-laws, two breastfeeding mothers, one HIV counsellor, two professional nurses, and two male partners/fathers. The FGD participants were recruited through our liaison with the KwaDabeka CHC management, and they were able to refer us to relevant people like the supervisor of the community health workers (CHWs). The CHWs helped to recruit other participants. We approached the health staff including professional nurses and counsellors ourselves and invited them to participate. The FGD was conducted using the Narrative Research Method (NRM) which will be explained in detail later

The 2008 Study Setting

The study in 2008 was conducted in KwaDabeka Municipality Library Hall. The participants were from the KwaDabeka catchment which also included Clermont area but excluded the other areas from the 2005 study. This was due to the fact that there was already a relationship with the supervisor of the CHWs in KwaDabeka CHC. It was convenient to communicate the study in the area where we had already done previous work in 2005. In the short time allocated to Master Thesis fieldwork, it was going to be difficult to go through all the logistics of asking permission to conduct the study in the other areas.

The 2008 Study Participants

In 2008 five focus group discussions involving key community members like community health workers, breastfeeding mothers, grandmothers, mothers-in-law and partners were conducted. These FGD participants were identified through the already existing collaboration between the KwaDabeka CHC and community health workers who are visiting homes in the community everyday. Once identified, they were requested to participate. Those willing to do so were asked to provide signed consent form. The group sizes varied from 9-15 and altogether (n=54) participated. In addition the NRM was used with the same participants

The Study Design

This was qualitative research. There is no agreed definition for qualitative research but it has been defined as “an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem” (38). Qualitative research takes place in a circle which includes; data collection, data analysis, developing a working hypothesis, reporting and identifying a problem and this circle is discontinued only when saturation is reached (38). This study employed qualitative methods; the in-depth interviews and focus group discussions as well as the NRM. The interviews, FDGs as well as the NRM will be discussed in detail below.

The Interviews

The interview is described as a conversation that has a structure and a purpose (39). One might argue that the interviews do not give a true picture because different participants might give totally different views on the same scenario, on the contrary the richness and the strength of the interview lies exactly there on its ability to capture different views of the same matter (39). There is no single answer to the same question. This is the reason why the interview is referred to as a craft that, if well carried out can become an art (39). The main disadvantage of the interview is that data collected is enormous and time consuming but with good time management that can be sorted (40).

The interviews that we conducted lasted for about 40 minutes to one and half hours. Research tool like an interview becomes important so that the researcher clearly thinks about the questions she or he might want to ask in order to give the interaction a purpose. For this study we piloted one in-depth interview with one mother who had already stopped exclusive breastfeeding rapidly as well as one in-depth interview with one counsellor. This way we tested that the questions were acceptable and understood clearly.

The advantage that we had with interviews is that they granted us liberty to use open-ended questions. That gave the participants freedom to express themselves freely and comfortably but at the same time we endeavoured to steer the interviews back on track if they moved away

from the topic. This however was done cautiously in order not to offend respondents or make them uncomfortable.

The number of interviews we had with each mother ranged from 1-5 depending on where in the process of rapid cessation of exclusive breastfeeding she was and, how she was coping at the time. Some mothers were interviewed only once because they had already stopped breastfeeding while others were interviewed before, during, and afterwards. Even more sessions were scheduled if the mothers were still struggling with stopping breastfeeding. One mother even though she had intentions of stopping breastfeeding rapidly at six months, could no longer do so because she received five months results of the baby and which indicated that the baby was already infected. She therefore continued breastfeeding and we could not interview her about cessation anymore.

Both the mothers and counsellors were good informants if we consider the definition of good participants provided by Dahlgren et al that they had to be still actively participating in the culture of interest except for three of the 16 mothers who had already stopped breastfeeding but were recalling their experiences (38). Even though they were no longer 'active' they provided valuable information.

The disadvantage that we had while conducting the interviews with mothers was that we were using both English and isiZulu and translating simultaneously. This can disturb the flow of the interview and meanings are sometimes lost in translation but, for us the translation also became an advantage in the sense that it helped us in keeping the interview on track as the participants automatically ended up waiting for the translation before proceeding. In this way we were prevented from interrupting or cutting in while they were still speaking which can easily happen in any interview.

We scheduled two-three interviews per week in order to allocate enough time and started transcription immediately. After 32 interviews with 16 mothers we reached a point of saturation as we could no longer find substantial new information. We interviewed all the counsellors that were available in the study sites.

Focus Group Discussions

The second method which was used was focus group discussions. A focus group discussion is defined as a research technique that collects data through group interaction on a topic determined by the researcher (41). What makes focus groups unique to other qualitative methods is the social interaction that occurs between the moderator and participants and how they feed off of each others' responses (41). The whole process is facilitated by the moderator who is there to steer the discussion in the 'right' direction and also make sure that all participants get a chance to air their views. Participants that share similar characteristics like geographic location, culture, occupational status, ethnicity etc. are brought together. These shared characteristics are seen as social glue that adds fluidity and depth to discussions (41). These are also referred to as control characteristics as they are common to all groups (42).

The advantages of focus group discussions are that; their cost is relatively low and they provide quick results. Their results have high 'face validity' because the method is readily understood, the findings appear believable (40). The FGDs can increase the sample size of qualitative studies by allowing more people to be interviewed at one time (40). The main disadvantage of focus group discussions is the power dynamics that can be found in one group despite the social glue. The other disadvantages are that there is huge amounts of data that needs to be transcribed, translated and interpreted, and also with good time management skills and proper allocation of resources that can be overcome (40).

Different people were brought together in a group. They had a specific topic that is defined by the researcher which they had to focus on. The topic in this case was rapid cessation of exclusive breastfeeding. I was the moderator for all focus group discussions conducted in this study. As a moderator I had to be aware of the people who dominate discussions so that other participants did not 'lose their voice' so to speak. Invaluable information was obtained through focus group discussions in the issue of rapid cessation of exclusive breastfeeding.

In this study ethnicity, geographical area, breastfeeding knowledge and breastfeeding experience became the 'social glue'. However there were differences which impacted negatively like their positions in the society. In our study for instance some community health workers came wearing uniform and that became a barrier. One of the participants who was a

breastfeeding mother even said they know more and I had to assure her that there was no right or wrong response, all their views were important.

It was very difficult to find male participants and in one group we only had one male. I noticed that he was feeling overpowered by many women and encouraged him to speak. That was done tactfully because at the same time I did not want him to feel that he was being put on the spot. The ages of the participants varied from 21-70. There was no way of avoiding such a big variation because we wanted to include grandmothers who play a very significant role in infant feeding decisions at home. We wanted to exploit the wide range of experiences including involving breastfeeding mothers who happened to be young because of teenage pregnancy which is a reality in South Africa. Being conscious of this variation made us extra cautious and tried hard to make everybody comfortable enough to air their views and therefore it did not appear like the age differences impacted negatively on the groups but it could have.

We had a very large number of participants e.g. the maximum number we had in one group was 15 participants. That might seem too big but I explained in the beginning that it was important that we respect one another and not speak at the same time. We were using a small digital tape recorder and since we were sitting in a circle it was explained that before anyone speaks they should use it as a microphone and in that way order was established and maintained. In our study the FGDs participants in 2008 ranged from 8-15.

The Narrative Research Method (NRM)

Narrative research refers to any study that uses or analyzes narrative materials (43). A central focus of the NRM is the development of a generalized case study illustrating the circumstances surrounding and situations concerning an individual's experience of the issue (in this case a mother's experience of rapid cessation of exclusive breastfeeding).

The NRM allows for more flexibility and openness since people are playing out roles and they can hide behind this role in order to freely say what they could not have said maybe if they directly faced with some questions. Thus, a primary overall aim of using the NRM in this

study was to illustrate different 'pathways' with the potential to differentially affect women's infant feeding practices. Under supervision the group reviewed and developed a hypothetical case of a breastfeeding HIV-infected mother who has been advised to rapidly stop exclusive breastfeeding.

In our role plays for instance we had participants assume the role of an HIV-infected mother and her close social networks e.g. the father of the child or partner. These 'actors' had to even adopt the terminology that would be used by such people in real life. What was interesting was that even though there were no scripts the different participants on different days played out the scenarios in almost the same way depicting what was really happening in the society. Illustrating the kind of issues that an HIV-infected women deal with in their everyday existence. In almost all the role plays the men were portrayed as womanisers and the audience agreed that the scenes that were acted out were very realistic of the situation in the study areas.

"The use of narrative methodology results in a unique and rich data that cannot be obtained from experiments, questionnaires and observations" (43). Narratives should not be taken at face value, as complete and accurate representation of reality. However, stories are constructed around a core of facts or life events, yet allow a wide periphery for the freedom of individuality and creativity in selection, addition to, emphasis on, and interpretation of these 'remembered facts' (43). It was up to the participants to shape the story as they see fit, and to 'fill in' what they felt were the most important factors and players in a given situation. Volunteers from the focus group discussion played key episodes from the narrative, while others in the group critique the narrative play and develop and change it until they feel that it accurately depicts a likely story outcome. Through the storylines the issues, dynamics and factors influencing an HIV-infected mother who has been advised to stop breastfeeding rapidly were explored.

The disadvantage of the NRM is that the case study is limited by focus on a single generalised case profile however this can be fixed by asking the participants to construct stories around several character types that are representative of the socio-demographic profile of the study population. (44). In our role plays for there was a taxi driver, policeman, and those are the most common occupations for men in the study area.

Theoretical Model

We collected data according to the Grounded Theory method. The theoretical root of Grounded Theory, symbolic interactionism was developed between 1920 and 1950 at the Chicago School of Sociology by Glaser and Strauss (45). The basic assumptions of the symbolic interactionism are that human beings act toward things on the basis of the meaning those things have for them. These meanings arise from the interaction one has with one's fellows. These meanings are handled and modified through an interpretive process by the person dealing with things that are encountered. The aim of the grounded theory is to generate theoretical frameworks which explain the collected data (45). According to Dahlgren et al, one of the most ambitions in the Grounded Theory approach is to discover something new, and the ultimate aim is to develop new tools to understand new types of problems and to cope with new situations (38). We used interview guides to help us remember the points that we wanted to explore. The Grounded Theory proposes that the researchers ideally should go to the field without preconceived ideas. However, we experienced that this was quite a challenge because of our pre-knowledge of the topic. We tried as much as possible to put this knowledge aside and be open to new knowledge.

Data Collection

In 2005 interviews with the counsellors took place in all the sites mentioned. The study was first explained orally and study information sheet was also given, after which signed consent was sought. The counsellors were assured that participation was completely voluntary. We first interviewed counsellors and that made it easy for them to have an idea of the type of mothers we were looking for. The interviews with the counsellors were conducted by my supervisor in English. All the counsellors that were requested to participate did. The interviews with counsellors took place in their counselling rooms when there were no more clients in the afternoon. The counsellors were then asked to refer the mothers who were about to stop exclusive breastfeeding to us for recruitment. There was only one interview scheduled for each counsellor and these lasted for 40 minutes to about an hour.

For the mothers' interviews the counsellors organised rooms in all the sites where we could work without disturbances, but disturbances are bound to happen in a public place like a clinic because people are always knocking and seeking help. On sunny days it was even more conducive for us to find an isolated area outside and away from the buildings in order to minimise disturbances. I had translated the study information sheet and consent form from English to isiZulu (the local language) and it had also been back translated by other independent translators from isiZulu to English and was verified by my supervisor that they had been translated properly and the meaning had not been lost during translation. I explained the study orally in isiZulu and went through the Zulu information sheet and Zulu consent forms with all the mothers after which signed consent was sought. I explained to the mothers that participation was completely voluntary and they were not going to be ill-treated in any way if they did not want to participate. All the mothers that were referred to us agreed to participate. My supervisor asked questions in English, I translated them to the mothers in isiZulu, then mothers responded in isiZulu and I translated the mothers' responses to my supervisor in English.

The 2005 NRM took place in a municipality hall in Clermont. The 2005 FGD was conducted in both English and Zulu because I was co-facilitating with English speaking co-facilitator while my supervisor was taking notes. All the participants could speak English and they were informed that they were free to use isiZulu or English and I was available to translate if and when the need arose. Most of them were comfortable speaking isiZulu, therefore I translated. We needed the co-facilitator because we were learning the NRM and she was an expert in it. The 2008 FGDs took place in KwaDabeka Library Hall. All the interviews and discussions were tape recorded with participants' permission.

Procedures and Analyses

Collecting data through the grounded theory method means that there were following the model of five phases as described by Starrin et al (46). These five phases do not strictly follow each other but they may run parallel each other. The first phase defines the scope of the problem. In this case we were investigating how the HIV-infected mothers experience

abrupt cessation of exclusive breastfeeding. We also wanted to explore the perspectives of the health workers as well as those of the mothers' close social networks. This was done through the in-depth interviews and FGDs.

In the second phase we sought new perspectives with the help of information and observations collected in the first phase. Firstly all the interviews and discussions were transcribed verbatim and then they were entered into Open Code software (47). We started coding and patterns began to emerge as we were coding. We were going back and forth because we were still continuing with the first phase and doing more interviews.

In our case we did not do the third phase as described by this five phase model because we felt that in a way through the second phase, (coding) we could see which themes were emerging. In the fourth phase we searched systematically for indicators through selective coding. Through this process it became easier to systematise the main categories that were emerging from the data. We then entered the last phase which is phase five. In phase five we constructed concepts and established relations. We made connections with all the data through what stood out throughout all data collection; the interviews, the FGDs and the narrative research methods.

Ethical Considerations

Inclusion and Exclusion Criteria

In 2005 the mothers had to be HIV-infected and be breastfeeding with the intention of stopping rapidly at six months or had recently stopped exclusive breastfeeding. The counsellors had to be providing infant feeding counselling in the participating clinics. All the participants had to be willing to have their interviews tape recorded and they all had to sign an informed consent.

In 2008 study the participants were relevant community role-players regarding cessation of breastfeeding. They had to be willing to take part in the role-plays and have all sessions tape recorded. Having no breastfeeding knowledge and unwillingness to sign a consent form or make a thumb print was an exclusion criterion.

Informed Consent and Confidentiality

Signed consent form was one of the requirements for the participation in the study. I took about one hour to go through the study information sheet with the participants and obtained informed consent. Only the researchers have access to all the information obtained from all the discussions and strict measures have been taken to protect this by removing their names from the transcripts and calling them by their roles e.g. mother etc. A digital tape recorder was used in 2008, and after all the data was transferred to the personal computers with passwords only known by the researchers all the discussions were deleted from the recorder.

Vulnerable Individuals

Some participants by the virtue of being women and being HIV-infected fall under vulnerable individuals. This however was not be used to exploit them in any way, it was thoroughly explained that nobody was forced to participate in this research, and if they chose not to participate that was not going to be used against them in any way and they could stop participation whenever they wished to do so. In 2005 participants were given ZAR100 (South African Rand). All the 2008 participants were given R200 to cover their transport and one day's earnings they might have lost by participating in the study. It was emphasized that they were not being paid to participate in the research because no amount of money can be put to their valuable input. Even though it was mentioned that there would be reimbursement for transport in the information sheet the amount was purposely not included. This was done in order not to lure participants with money because the study information sheet was distributed to community health workers before so that they could understand the type of participants that were needed. We also provided tea and lunch.

The mothers might have felt obligated to participate in the study since they were referred by the counsellors. None of the mothers that were invited to participate refused to participate in the study. The counsellors could have also felt obligated because before talking to them we had to ask permission from the sister-in-charge. When going through the study information sheet and consent form it was emphasized that participation is voluntary.

Ethical Clearance and Approval

Ethical clearance was obtained from the University of KwaZulu- Natal's Research Ethics Committee. Ethical clearance from the Regional Committees for Medical Research Ethics (REK) in Norway was also granted. Permission to conduct the project in the study area was also obtained from KwaDabeka CHC Management.

CHAPTER FIVE: FINDINGS

DEMOGRAPHICS OF THE PARTICIPANTS

These are based on the 2005 in-depth interviews, 2005 NRM as well as the 2008 FGD and NRM role plays. The characteristics of the participants will be presented in tables below.

The Mothers (2005)

The 16 mothers were from KwaDabeka, Clermont, Halley Stott, as well as Marianhill. Their ages ranged from 20-35 years. Half of the mothers had immigrated to KwaZulu-Natal Province from Eastern Cape Province which is in the South of KwaZulu- Natal. They had immigrated in order to join their partners who came to Durban for work. They live in the hostel near KwaDabeka CHC with their partners. Those who are from the Eastern Cape are originally isiXhosa speakers but they were accurately speaking isiZulu with isiXhosa accent so there was no difficulty in understanding them as the two languages are almost the same. The other half were originally from KwaZulu-Natal. Two out of 16 had completed high school and only one had had tertiary education. Five had primary schooling and eight had high school education. The educational level was fairly low, only two had completed high school. The rest had primary and secondary schooling. Only two were employed, the rest were not working. There were seven who were cohabiting and those are the ones who had joined their partners in the hostels. None of the mothers were married. There was a high level of cohabitation among those who have joined their partners in the hostels. Even though they might be in stable relationships sometimes they cannot afford a wedding.

The counsellors (2005)

The 13 counsellors were working at KwaDabeka, Clermont, Halley Stott clinics and Marianhill Hospital. Their ages ranged from 22-58. They had all finished high school and three of those from the research setting were also professional nurses. Seven of 13 had breastfeeding experience themselves as mothers. They were all females.

Table 1**Sample Characteristics for 2005 participants**

Age	Mothers n=16	Counsellors=13
16-20	2	
21-29	12	6
30-39	2	1
40-49		2
50-59		4
Attending Provincial/VTS	9/7	9/4
Previous breastfeeding experience	10	7
Education		
Less than 8 years	5	
8-11 years	8	
Completed 12 years	2	5
Tertiary Education	1	8
Marital Status		
Single	9	8
Cohabiting	7	
Married		3
Widowed/Divorced		2
Employment		
	2	13

The FGD/NRM participants (2005 and 2008)

The 2005 FGD was the most diverse group in terms of community roles. There were community health workers, professional nurses, an HIV counsellor, male partners, breastfeeding mothers, grandmothers, mothers-in-law. The community health care workers were used to recruit other community members because they go to the community everyday and they were also invited to participate if they so wished. Even though they are employed by the clinic they said they do not get a salary but receive a stipend to cover basic needs. Except for the professional nurses and an HIV counsellor the rest of the participants were unemployed. There were only six male participants; two in 2005 and four in 2008. There is a difference between the mothers in 2005 and FGDs participants in the marital status. We had a high number of married participants in FGDs. This could be due to the fact that most of the FGDs participants were CHW who are local people. They are wives and mothers in the study area. Most of them were also older than the mothers from 2005.

There could have been selection bias as they were recruited by CHWs. They could have picked their friends even though they were asked not to do so but bring people with knowledge and views on rapid cessation of exclusive breastfeeding. They could have had different views from other people in the community.

Table 2
Characteristics of 2005 NRM participants n=14

Age	Number
21-30	4
31-40	3
41-50	5
51-60	1
61-70	1
Sex	
Male	2
Female	12
Community role	
Community health workers	5
Breastfeeding mothers	2
Grandmothers/ Mothers-in-law	2
Professional nurses	2
HIV counsellor	1
Fathers/ male partners	2
Marital status	
Single	8
Married	4
Widowed/ Divorced	2

Table 3**Sample Characteristics of 2008 close social networks n=54**

Age	
21-30	9
31-39	22
41-50	13
51-60	7
61-70	3
Sex	
Male	4
Female	50
Community role	
Community health workers	24
Breastfeeding mothers	5
Grandmothers/ Mothers-in-law	13
Fathers/ male partners	4
Breastfeeding experience	49
Marital status	
Single	22
Cohabiting	15
Married	15
Widowed/ Divorced	2

The findings will be presented according to four themes reflected in the study objectives.

These themes are:

A: Mothers' experiences

B: Counsellors' advice

C: Close social networks

D: Cultural influence on infant feeding patterns

A: Mothers' experiences

Reasons for choosing rapid cessation of exclusive breastfeeding

Many mothers chose rapid cessation of exclusive breastfeeding because they believed that the breast milk is the best food for the babies. They articulated that breast milk has all the nutrients that the baby needs. All of the mothers said they chose this method for the safety of the baby.

"I chose breastfeeding because it is the best way to feed your child, and it helps the child grow strong. Breastfeeding is safe it makes the child grow strong"

(28 year old-HIV-infected mother)

"I continued with exclusive breastfeeding because I got motivated when I saw her looking so satisfied all the time....Really there was no need for me to give something else. I just stuck with this method".

(22 year-old HIV-infected mother)

Most mothers also strongly believed that breast milk is quite safe (in terms of MTCT) if mothers follow advice from the clinic of not mixed feeding. Some mothers also pointed out that they appreciated that they could feed their babies for a short period of time as opposed to not breastfeeding at all.

"You love your baby so much that you really do not want him to be infected. Therefore you have to follow the advice from the clinic...Even if the baby gets sick after stopping breastfeeding, at least you know that he got the foundation".

(28 year-old HIV-infected mother)

Some mothers also said they chose rapid cessation of exclusive breastfeeding because they had enjoyed breastfeeding their previous babies prior to when they got to know their HIV infection.

Another rationale reported by some of the mothers was that they had chosen breastfeeding because that is what they were told by the counsellors. Most of them had made their infant feeding decision alone. However, their decision was strongly influenced by the advice that they had been given at the clinic. An ‘*obedient- to-the- clinic*’ and ‘*do-as-you-are-told*’ attitude was often expressed among the mothers. This was also evident in some of the counsellors’ interviews.

“I was told that it is safe, very safe to breastfeed, to give the baby breast milk only. They told me that if I give breast milk only the baby will not be infected. I was told that it is safe, very safe to breastfeed... to give the baby breast milk only. They told me that if I give breast milk only the baby will not be infected.” (27 year old HIV-infected mother)

Most mothers did not have specific advice on how to successfully stop exclusive breastfeeding. They said you just have to be committed and persevere because stopping breastfeeding is a very painful process. They all expressed that it is not easy. Some mothers just said you have to be brave and be prepared to stop breastfeeding. And never take things for granted that it will be easy.

“I tried not to put the baby back on the breast but it was difficult even my family was not used to me not breastfeeding. I knew my secret so even when they were scolding me I persevered because I knew what I was doing it was for the safety of my child. In the end my baby got used to it.” (31 year-old HIV-infected mother)

Most mothers chose rapid cessation of exclusive breastfeeding because of economic reasons. They expressed concerns that they could not afford to buy formula therefore it was better to start by breastfeeding even just for six months. They felt it would be better to get formula the free formula milk after six months. This would mean that they will only have to worry about formula for 12 months instead of 18 months if they start with formula from birth as the baby needs milk for 24 months. Even though the government provides free formula for six months in South Africa, some mothers chose exclusive breastfeeding because they feared that free formula is sometimes unavailable in the clinics.

Most mothers were dependent on their partners for financial support. Some mothers chose rapid cessation of exclusive breastfeeding for security reasons. They were uncertain about the future as they did not know what would happen if they broke up with their partners since their partners were their main source of income.

“I thought he might run away after I had delivered the baby.... Or when he hears that I am HIV-positive. Therefore I decided to breastfeed because I would not be able to afford to buy the formula milk without his financial support”. (23 year-old HIV-infected mother)

Challenges to rapid cessation of exclusive breastfeeding

All the mothers expressed a crying baby as the most frustrating and difficult challenge they experienced when they were stopping breastfeeding. With the crying baby also came sleepless nights. It was very emotionally draining for the mothers to watch their babies cry. One of the mothers reported that she had never seen her twins cry as much as they did when she stopped breastfeeding. She felt so sorry and sad for the babies. Another mother reported that when the baby cries there are even labour pains that are felt.

“You know why the baby is crying; he is crying for what he is used to and you know that there is nothing you can do. And when the baby is crying you become irritable yourself. You get frustrated. You may even want to hit the baby, so you have to know that you do not do that.. You have to be gentle and patient and brave and persevere, because you know why you are doing this... Do not be short tempered...think about the safety of your child”.

(20 year-old HIV-infected mother)

“As the baby has been used to the breast it will not sleep at night when you have stopped. You can no longer quickly feed the baby. At night you will have to sit on your buttocks and comfort your baby. The hands will get tired from holding the baby. The baby has been used to breast milk and now it is no longer there for the baby. The baby will refuse everything, it does not want anything else...the baby cries a lot and you have to sit up cuddling the baby until your hands hurt at night”

(31 year-old HIV-infected mother)

The interviews with the mothers clearly revealed that they suffered from emotional pain of seeing their babies cry. They were subjected to physical pain as well during rapid cessation of exclusive breastfeeding. They told us that their breasts caused them a lot of pain when they were full from not removing the milk. The breasts that are not nursing get very full thus causing pain, according to the mothers. The mothers used the words painful, engorged, hard, heavy, leaking and full to describe the state of the breasts during cessation. Some mothers also reported headaches, fever and upper back pains. Even before stopping breastfeeding some mothers were already anticipating the problems they might experience with their breasts.

“Stopping breastfeeding is extremely painful. My breasts were so painful and this lasted for about the whole week. They became so big because they filled up. It gets so painful that you

cannot even wear a bra. You have to stop wearing a bra until you get relieved from all the pain”.

(27 year-old HIV-infected mother)

“I got so sick I had to lie down. I had headaches, fever, and engorged breasts”.

(27 year-old HIV-infected mother)

“The breasts get so painful that you feel like being by yourself and not with others”.

(35 year- old HIV-infected mother)

Mothers also suggested wearing a bra and a tight top when sleeping. This they reasoned that it makes breast inaccessible to the baby was one practical advice given by some mothers.

Another suggestion was to leave the baby with the other people so that the mother does not see the baby cry and then be tempted to put the baby back on the breast.

“I put the bra at night so that the baby cannot reach my breasts. And when he cries I have to wake up and give him all the attention”

(27 year- old HIV-infected mother)

Some mothers had heard of different remedies they could use to alleviate the pain like taking pain killers, expressing the breasts, and putting ice cubes on the breasts. Drinking a sour drink like *Lemon Twist* (South African soda) was also suggested by some mothers. They said it helps to dry the milk from the breasts so that the breasts do not produce milk anymore.

“Lemon Twist worked for me. I tried it and the breasts were not that painful”

(22 year-old HIV-infected mother)

Another suggestion by some mothers was the use of Epsom salt. Epsom salt is used as a laxative which makes people pass a lot of fluids from the body. The reasoning behind is that when a person loses water the breast milk also dries up from the breasts. Putting frozen cabbage leaves on the breasts was also suggested for the relief of engorgement. Feeding the baby a lot before bedtime was also another suggestion by some members so that the baby sleeps through the night.

“I heard from one lady who was stopping breastfeeding that you can drink Epsom salt, so I drank it. It makes you pass water more. However I am not sure if it works because I started drinking it very late in the process .. my breasts were not producing much milk”.

(27 year-old HIV-infected mother)

Yet another suggestion for putting the baby off the breast was by applying chillies and aloe vera on the breasts. The idea behind this practice is that when the baby tries to put the breast in the mouth the chilly or bitter taste will put him off and he will avoid the breast altogether.

Other suggestions were using warm compresses to massage the engorged breasts. One of the mothers suggested expressing breastmilk over an open fire. We probed for rationale for this and we were told that because if you do that there is a belief that breast milk will dry up from the breasts .

“You can put aloe on the breasts.....It is this wild plant with thick and thorny leaves. You break it and there is very bitter water that comes out. You put that on the breast and the baby will taste it and then leave the breasts” (27 year-old HIV-infected mother)

B: Counsellors’ Advice

All of the counsellors that were interviewed were very pro-breastfeeding. They articulated that they would opt for rapid cessation of exclusive breastfeeding if they were HIV-infected. They would do so even if they could afford replacement milk because breast is best and it has all the nutrients.

“I would choose exclusive breastfeeding even if financially stable because formula milk does not give the baby those nutrients in the breast milk”. (27 year-old counsellor)

The counsellors because they were pro-breastfeeding had an influence on the mothers’ infant feeding choice of rapid cessation of exclusive breastfeeding. Counsellors from both settings expressed varied attitudes about how HIV-infected women should choose whether to breastfeed (and then to stop rapidly) or not. Most of the counsellors (12/13) believed that exclusive breastfeeding followed by rapid cessation was very safe (if there were no cracked nipples), but they were aware of the difficulties involved.

“Mothers choose breastfeeding because we have told them that it is the best milk for the child”. (36 year-old counsellor)

“The mothers choose breastfeeding if the counsellor convinces them that breastfeeding is good”. (22 year-old counsellor)

“I just tell them that if the child is given breast milk only, there is no entry point for the HIV-virus.” (43 year-old counsellor)

The counsellors from the provincial programme did not have confidence that the mothers could adhere to exclusive breastfeeding with rapid cessation. They consistently reported their doubts on whether mothers practise their infant feeding choices at home.

“I wouldn’t say that is really common for them to be able to just to stop breastfeeding. A mother who is breastfeeding has a strong bond with her child and she will find it very difficult to cut that bond. ...out of 100 mothers, I think that maybe 25 manage to really practise exclusive breastfeeding for six months. [Silence].. And out of these 25, may be 5 manage to practise rapid cessation.”
(55 year-old counsellor)

Counsellors from the provincial programme were unaware if, or how, mothers managed to stop breastfeeding rapidly and about other feeding practices at home. This was different from the operational setting counsellors who were following mothers every two weeks after delivery.

“They only come here once a month. I have never experienced that a mother comes back to us and asks for help because she does not manage to stop breastfeeding. No, never. They just do it home in their own way.”
(22 year-old counsellor)

We found that most counsellors had two specific advices to give the mothers. These were expression of breast milk and early introduction to cup feeding. This would make the baby accustomed to the cup thereby making cessation of breastfeeding a smooth transition. A few counsellors advised mothers to gradually decrease the number of breastfeeding times as a practical strategy that the mothers could use. Some counsellors also advised mothers to prepare a variety of complementary foods. This would be done not to bore the baby with same foods during transition.

“You need family support and maybe if you can be separated from your baby and the baby can sleep with someone else”
(41 year-old counsellor)

“I so wish there was a place like a creche where mothers could leave their babies during this time.”
(23 year-old counsellor)

There were negative attitudes associated with expressed breast milk that were reported. Inasmuch as the study area is pro-breastfeeding, however, putting breast milk in a shared refrigerator was not viewed as an acceptable behaviour by other family members. One breastfeeding mother even said that breast milk is disgusting therefore she could not express and cup feed when she was preparing for the transition period.

C: Close Social Networks

According to most participants in FGDs stigma is still a big issue despite the fact that there are many HIV-infected people in South Africa. It was also reported that for women not to

breastfeed in the usual way (beyond six months) might be seen as a sign that they are HIV-infected. Most of the participants in the FGDs reported that it might be seen as problematic for a woman to stop breastfeeding at six months as traditionally most women breastfeed for about two years. Some counsellors also reported that many teenage mothers who are still at school only come to the clinic when it is quieter in the afternoons (as the mornings are usually crowded) in order to avoid stigma when they have to fetch the free formula. The free formula that is available in the clinic is another source of stigma, as it is common knowledge that it is only received by HIV-infected mothers.

“Most pregnancies are teenage ones...16-19 years. To avoid stigma they come to collect milk at the clinic after school when it is a bit quiet....they tell white lies at home in order to avoid stigma”.
(36 year-old counsellor)

Most participants in FGDs reported that one of the reasons mothers might struggle with their choice of exclusive breastfeeding and stopping rapidly, is because they have not disclosed their HIV status at home. Most HIV-infected mothers in our study had only disclosed only to their partners. Some participants in FGDs reported that the mothers of HIV-infected daughters are usually supportive when their daughters (HIV-infected mothers) disclose to them but others have difficulties. . It also seemed that there were various reasons given by mothers for not disclosing their status to their family members other than perceived stigma. Some mothers felt that it would be too much a burden for their own mothers if they heard that they had a fatal disease. In some cases the decision not to disclose was to spare family members some emotional pain.

“It was easier to disclose to my partner than my mother because she has a heart condition. I think this would destroy her”.
(28 year-old HIV-infected mother)

“No, no, no, I will never disclose to my parents, only when I am unable to walk! It is because of my mother’s attitude. I have seen how she behaves around HIV-infected people. She has a really bad attitude she will tell me that I am reaping what I sow”.
(30-year old HIV-infected mother)

Not disclosing their HIV status at home made it extremely difficult to exclusively breastfeed, and then stop. It also made it difficult to receive necessary support to adhere to their infant feeding method. Communicating their infant feeding intentions to the family members also became difficult without disclosure.

“I have to take my baby with me all the time in order to avoid mixed feeding by my other family members. I had this problem at home because they were ..., whenever maybe ... when they were eating breakfast in the morning they would take a slice of bread and give to the child but, I would snatch that from him and give him something else to play with. Even if he was full they would still want to give him bread”. (20 year-old HIV-infected mother)

With disclosure also come blame. Some of the mothers feared that if they disclosed they would be accused of bringing the disease to their partners. Most of the mothers said that their partners refused to have an HIV test after they disclosed their status to them.

“Sometimes you speak with a young mother and she understands everything you tell her, she tells you how she’s going to feed the baby and you support her but the problem is she has to go back home, and at home she’s got her own mother who’s used to breastfeeding in another way and mixed feeding. So even if she discloses to the community health worker, at home eh....she hasn’t disclosed maybe then she faces a difficulty because the mother will say; ”I raised five of you like this, this is how you are going to feed your baby”. (55 year-old CHW)

“It’s not easy if you haven’t disclosed but if you have disclosed it’s much easier. If you haven’t disclosed you’ll leave the breastmilk maybe it does not last for an hour and you are gone for a long time and then if you haven’t disclosed your mother will just take anything sugar solution or water and just give to the baby or anything but if you have disclosed then they will know that the baby doesn’t take this and this and this” (24 year-old FGD mother)

Most participants in FGDs shared the view that there should be more partner, family and community involvement in breastfeeding awareness campaigns. They said in these campaigns it should be emphasized that exclusive breastfeeding for the first six months is for everyone, not just the HIV-infected mothers. The FGDs participants proposed that formation of breastfeeding support groups can be instrumental in helping mothers cope with exclusive breastfeeding challenges. This was the reason for emphasizing family involvement so that the baby gets attached to other family members other than just the breastfeeding mother. Family support, involving the father and involving people representing the close social network were viewed as pivotal factors to enable HIV-infected mothers to practise exclusive breastfeeding for six months and to stop rapidly. Community involvement and restoration of *ubuntu* (humanity) by getting involved in one another’s business was another suggestion. *Ubuntu* is a South African concept from Zulu word meaning humanity. This concept emphasizes togetherness and interconnectedness of people. Some FGDs participants felt that if *ubuntu* is instilled there would be less HIV related stigma.

Some mothers also felt that if they had support groups in the process when they were stopping breastfeeding it may have been easier. They felt that if mothers encouraged one another to

exclusively breastfed and then stop rapidly, perhaps they could succeed. They emphasized that for support groups in order to work support groups in order to work should have income generation opportunities like gardens and craftwork. Infact some CHW reported that they had already initiated such support groups and that they were working well.

“I think the support group will help.... Because even when I was pregnant and knew that I was HIV positive I felt that I needed that support group so that I could have somebody to talk to, and explain what I was going through”. (28 year-old HIV-infected mother)

D: Cultural influence on infant feeding patterns

Most FGDs participants reported that the most common infant feeding practice in the study area was mixed feeding regardless of a woman’s HIV status. They cited foods like porridge, butternut, pumpkin, mashed potatoes, sour cream with brown bread and grated chicken breasts as some of the foods fed to babies before six months. They said these foods can be fed to babies as early as six weeks in some homes.

“To be realistic, women have not undergone training, so they usually mixed feed”. (57 year old professional nurse)

Some FGD participants felt that there is a strong family influence and pressure to mixed feed especially from grandmothers and mothers-in-law. Grandmothers are in charge of the households and they usually have the last word in the infant feeding decisions despite what the mother had opted for. In most cases grandmothers are the ones who take care of the babies in the mothers’ absence. The mothers-in-law were also reported to have a lot of authority including infant feeding decision matters. The mothers-in-law were also responsible for conflict resolution in the household The grandmothers and mothers-in-law are usually not updated with the current information on how infants should be fed as per national guidelines.

“It happens sometimes that the grandmothers do not want to learn new things because if the grandmother sees that the baby has been weaned from the breast, you will hear her say “Put the baby back to the breast! Why have you removed him? We know about breastfeeding because were breastfeeding while your fathers were digging gold in Johannesburg mines long time ago”. (41 year-old CHW)

Some participants said that if you only give breast milk there is a perception that you are a bad mother. The normal common practice is to give breastmilk with something else like porridge, butternut etc. Exclusive breastfeeding was reported to be practised by only a few in the society even though breastfeeding was common.

“If you just give the baby breast, the people will say you are treating the baby badly, you are a harsh mother”. (23 year-old FGD mother)

Traditional beliefs were also reported by participants in FGD to play a major role in most mothers’ infant feeding practices. It was reported that sometimes even though the HIV-infected mother can accept her status, other family members might tell her she has been bewitched. She can even stop breastfeeding because she believes that there is an animal *isilwane* sucking her breasts. This is also one of the most common breastfeeding myths among African communities in South Africa. There is a belief that there is a supernatural being with demonic spirits that comes and suck breastfeeding mother’s breasts. For this reason the mother stops breastfeeding because she does not want her baby to share breasts with the supernatural being. This is a common challenge faced by those who promote breastfeeding in the communities including the CHWs.

Giving enemas to infants is also another common practice amongst African communities in South Africa. Usually it is the grandmothers or mothers-in-law who are responsible for administering these enemas when they ‘cleanse’ infants. Giving enema refers to giving some fluids or traditional medicine anally. This practise goes against exclusive breastfeeding as the baby is only supposed to receive only breastmilk for the first six months. Traditionally grandmothers and mothers-in-law like to give these enemas as early as six weeks as part of the ‘cleansing ceremony’ to the newborns.

Another concern which was expressed by the CHWs in the FGDs was of that of conveying the infant feeding messages of the constantly changing guidelines to the community. They said they appreciate the importance of conducting research but they felt they lose their credibility in the community. For instance before they were told to say mixed feeding is dangerous and that has changed, they now have to encourage gradual cessation of breastfeeding.

Some participants in FGD and counsellors stated that the society where the study was conducted is patriarchal. It is a predominantly a Zulu area. The Zulu culture is very patriarchal whereby the man of the house usually has the last word. Usually the women are submissive. In addition to being patriarchal, women in the study area also assume a subservient position because of their financial dependency on men. This makes disclosure and negotiating safe sex very difficult. Some of the counsellors and participants in the FGD stated that sometimes

women might agree to HIV-testing without their partners' approval. However, they may not communicate their results for the fear of blame by their partners. Respecting and holding men in the highest regard is part of the Zulu culture and patriarchal society according to participants in FGDs and some counsellors. The men were portrayed as being dominant even in the NRM role plays. Women were portrayed as submissive and obedient.

“Most mothers are living in the hostel so they have to listen to their men because they are dependent on them...Respect is very important in our culture. Men get angry when women test without their approval and women may get the blame for HIV-positive results”.

(23-year old -counsellor)

Taxi (mini buses) industry is one of the biggest employer of men in the study area. The participants were given a scenario to act out. In the scenario the father of the baby was a taxi driver. In the study area, taxi drivers have a reputation of having a string of girlfriends according to the NRM participants. As a result they often have children with more than one woman.

Even when we were conducting interviews in 2005, six of the HIV-infected were not receiving child maintenance from the fathers of their children. They were undergoing cases. This also emerged in separate role plays where a 'taxi driver' started questioning paternity of the child when he was asked for maintenance. Men were always portrayed as having more than one sexual partner in the role plays and they seemed to lose interest in their women after the birth of a child.

To further illustrate the common challenges that an HIV-infected mother usually faces in order to adhere to her infant feeding choices the role plays from NRM have been inserted. These role plays illustrate the kind of communication and interaction that occurs between a mother and her significant during the transition from breastfeeding to stopping. This transition becomes even more difficult if the mother is unemployed and has to ask her partner or her father for the money to buy formula milk.

Below are the inserts from one of the 2008 NRM plays

(Insert from 2008 NRM, in this insert Nana is a mother who is about to stop breastfeeding. In this insert she goes to the father of the baby to ask for money for formula as she is approaching six months and has to stop breastfeeding soon)

Nana: I have come to ask for the money because I have to buy formula

Taxi driver: What! Are you out of your mind? Where do you think I will get the money from? You knew very well that I was not working. Where did you think I was going to get the money from, have you ever seen a taxi driver with money?

Nana: Oh my God! What am I supposed to do now, the baby needs this milk..

Taxi driver: You brought this upon yourself, I never said I wanted a baby from you, I don't care what you say but I will not give you any money. This baby is not even mine. Sell those shoes you are wearing and that cellphone, then you will have money.

Nana: : Ever since we got the baby you have become a tsunami (*referring to his angry and violent state*)

You left me for those jeans wearing girls...What do you mean the baby is not yours?

Taxi driver: I mean just that, that this baby is not mine. Don't they give you the milk at the clini, why are you bothering me?

Nana: If I take the milk from the clinic everybody will know that we are HIV-infected. Is that what you want?

Taxi driver: By all means go and get your milk because as far as I am concerned you are no longer my girlfriend.

Nana then went home and begged her mother to ask her father for formula money.

(In the insert the mother is pleading with the father (her husband) to give their daughter money for formula after she was rejected by the boyfriend who happens to be a taxi driver)

Mother: Oh father can't you help us please! I beg you Gcwabe, Ngunezi! (*Calling him affectionately with his clan names showing respect*) Nana needs this money and that useless taxi driver boyfriend of hers has chased her away with nothing.

Father: No ways! Is she not the one who got pregnant by the taxi driver, why should this be our business now? I don't have money that money!

(Insert from 2008 NRM a policeman married to an HIV-infected mother with an infant is visiting one of his girlfriends. The HIV-infected mother has not disclosed her status but has been abstaining from sex because of breastfeeding. The husband has many girlfriends including the one he is visiting in the insert below)

Girlfriend (Opening the door): Oh darling, it's you, I am so happy. It has been a long time! How are you, sweetheart?

Policeman: Now that I'm seeing you, I know I'm gonna be fine. Give me a kiss. Oh. I have missed you so much! No more worries, your one and only Siphos is here! (*they walk towards the bedroom*)

Yes let's go to the bedroom. You know our love will conquer all. You know even though I have a wife I have to steal some time and come to see you. You know she has a baby and she is leaking milk. And this baby is like a cat miaow, miaow," all the time (*Laughter*) Our love my darling is higher than the mountains...

Cut

CHAPTER SIX: DISCUSSION

Methodological Discussion

Reliability and Validity

Reliability refers to the degree to which the finding is independent of accidental circumstances of the research, and validity is the degree to which the finding is interpreted the correct way (48). Qualitative research is often criticised for lacking objectivity but Mays and Pope propose various ways of improving validity. These among others include triangulation, reflexivity and relevance (49).

Triangulation

Triangulation is the method of using more than one data collection methods. In our case we used interviews, focus group discussions and the narrative research method. The researcher looks for common patterns in order to develop an overall interpretation of all the data (49). If there are varying views between the methods, they do not mean that one method is better than the other but they add to the richness of the meaning. For instance in our study the FGD participants portrayed the partners of HIV-infected as generally unsupportive. On the contrary some of the HIV-infected mothers that were interviewed had very supportive partners. These partners even helped them cuddle crying babies at night during rapid cessation of breastfeeding. This depicts different interpretation of reality which is the reality of the society.

Reflexivity

Reflexivity refers to the sensitivity to the ways in which the researcher and the research process have shaped the collected data (49). In qualitative research there is always a risk that the researcher affects all steps of the research process; the objective observer does not exist, it is a myth (45). It is very important for the researcher to always guard against his or her own interpretations as these are heavily based on his or her own background, race, culture, beliefs, personality, values etc. All of the above may have a positive or negative impact on the data.

The challenge is to be as objectively as possible. Our disciplinary background, professional experiences could have affected the methods as well as questions chosen (45).

Dahlgren et al argue that the researcher should exhibit ‘cultural ignorance’ and not come across as already knowing what to expect which can be quite a challenge (38). I was interviewing mothers from the VTS while I was employed by the VTS. For instance I had to ask questions pertaining to the HIV results of the infants when I already knew about them as I was the one giving them out. At one time we had to fulfil our ethical obligations as researchers and refer one mother for further infant feeding counselling sessions because upon interviewing her, we realised that she was really struggling with rapid cessation of exclusive breastfeeding. She did not even understand why she was doing it.

For this study the research team consisted of my self a single, African female with social science background and a European female with public health nutrition background. In addition I had also been trained and working as a breastfeeding, HIV as well as an infant feeding counsellor. In South Africa because of the past racial segregation policies the black South Africans’ first impressions of a white person is that of an oppressor or an authoritative figure. However the approach or reception is much friendlier towards European whites than South African whites once their origin and their role have been established. The fact that my supervisor was from Norway might have dissolved that negative attitude as compared to a local white person.

This may also be supported by the fact that when I conducted the other focus groups by myself in the absence of my supervisor I did not notice any difference in the tone and manners of the participants. This was compared to the times when she was present. I consciously sought for such differences during the analyses. In hindsight I think it would have been useful to double check with the participants themselves afterwards and find out how the presence of a white female impacted on them. It would have been interesting to also find out how the other groups would have felt if the white female was present during our discussions.

Our research team is what is described as a good team because it consisted of an insider (me) and an outsider (my supervisor). While the insider helps with interpretation and better understanding of culture etc. The outsider analyses data with fresh eyes and is better at asking real open-minded questions which the insider might perhaps take for granted when in fact

they need further probing (38). In a way I was both an insider and an outsider because even though I was from the same culture, speaking the same language; 1) I do not have a child, 2) I have never breastfed, 3) I had not experienced poverty, and 4) I had never had to deal with dilemmas of being an HIV-infected, young, unemployed and black woman in South Africa.

This becomes even more important because the researcher defines and controls the situation by careful questioning and listening and at the same time critically following up on the interviewee's answers (39). It is also very important that the researcher is aware of his or her own pre-conceived ideas, attitudes etc, before undertaking any type of research (39). The researcher should always guard against his or her own interpretations as these are largely based on the researcher's own background, culture, beliefs and attitudes. For instance it was a challenge for me to conduct research in the area where I was working because I already had some understanding of infant feeding practices in the area.

When we conducted the interviews with the mothers, I was still an HIV/ breastfeeding/infant feeding counsellor at one of the study sites. It is possible that the mothers could have over reported their exclusive breastfeeding practices despite the fact that I had redefined my role and explained that I was not there to monitor but wanted to know about real experiences. However this might be overcome by building trust with the interviewee and emphasizing the issue of confidentiality which I tried to emphasize.

A good and skilled interviewer will have superb listening skills, probe gently for elaboration and also be skilful at personal interaction (40). As a result we got to hear about the mothers' real experiences of 'stealing the breast' and 'breaking the law' when they were referring to their mixed feeding experiences whereas they had reported that they were breastfeeding exclusively to the counsellors. In dealing with a sensitive issue like HIV it is important to use some humour not to make fun of the serious situation but to make people at ease. One of the ways the South Africans escape from their daily troubles is through humour. In South Africa there are even lots of humorous names given to HIV and AIDS as serious as it is.

Relevance

Mays and Pope argue that research can be relevant when it either adds knowledge or increases the confidence with which the knowledge is regarded (49). Conducting research on rapid cessation of breastfeeding as a PMTCT strategy in a country with high HIV prevalence like South Africa where breastfeeding is also a norm seemed relevant.

Discussion of Findings

When the 2005 study was conducted rapid cessation of exclusive breastfeeding was still a UN recommendation if replacement feeding conditions were not AFASS for HIV-infected women (4). The recommendation was updated in 2006 and it then stated that cessation should be gradual instead of rapid (22). This is due to the new evidence that has come up from studies like the one in Zambia (4). The new evidence suggests that early cessation of breastfeeding was associated with an increased risk of infant morbidity in HIV-infected children (22;34;35). Breastfeeding of HIV-infected infants beyond six months was associated with improved survival compared to stopping breastfeeding (22;34)

Rapid cessation of exclusive breastfeeding as an infant feeding method has two components to it. The first part is an exclusive breastfeeding to be followed by the second part which is rapid cessation. Even in the published literature there is a constant overlap because it is difficult to discuss one without the other. Both of these methods are not part of the usual traditional infant feeding methods, at least in South Africa and many other settings. The most common infant feeding method is mixing breastfeeding with other foods before six months and continuing with breastfeeding for two years. The HIV-infection has however, changed that pattern, hence the introduction of exclusive breastfeeding with rapid cessation in order to reduce MTCT. In 2005 it seemed that mothers that were interviewed did not understand the concept of rapid cessation of exclusive breastfeeding.

The mothers' lack of understanding of the concept, however, did not stop them from attempting to practice this infant feeding method. The HIV-infected mothers were determined

to follow the advice they received from the counsellors in order to prevent MTCT of HIV. It was a struggle, but their motivation was not to infect their babies. They had no previous experience with the method and they had not seen anyone do it before. However, the knowledge that this method could prevent them from passing the HIV to their children was enough to keep them motivated.

The mothers reported many reasons for choosing rapid cessation of exclusive breastfeeding. These reasons included the fact that breastfeeding has many advantages. For instance it protects the child from infections, it is always readily available and it has no cost. Another main reason for choosing breastfeeding was because of their previous breastfeeding experience prior to their knowledge of their HIV status. Some mothers had seen how well their previous children grew when they were breastfed. For some mothers the only reason for choosing rapid cessation of exclusive breastfeeding was that they had enjoyed breastfeeding before. Another main reason was that they perceived breast milk to be the best. That belief was also instilled by many counsellors who were very pro-breastfeeding when they were also interviewed.

Even though formula is provided through PMTCT services in South Africa, the HIV-infected all the mothers that were interviewed opted for exclusive breastfeeding with rapid cessation for the first six months of life. The mothers had an option of not breastfeeding at all but receive the free formula from birth until six months and then after six months try to get formula on their own. They chose rapid cessation of exclusive breastfeeding because they believed that breastfeeding for six months was better than not breastfeeding at all. At least the babies will get the foundation of breast milk then they could introduce formula with other foods after six months.

Another reason for choosing rapid cessation of exclusive breastfeeding was the economic reason. The majority of the mothers were unemployed, only two were employed. They thought it was better to start with breast milk and then take the free milk after six months. The mothers seemed to be also driven by fear that in case they broke up with their partners then they could not sustain buying formula milk. By doing so there would be six months less burden of worrying about formula. They will only have to worry about formula for 12 months instead of 18 months if they start with formula from birth as the baby needs milk for 24 months.

The other fear was that they had heard that the free formula milk was sometimes not available in the clinics for various reasons. In the study area not all the clinics were providing free formula but some mothers were referred to other clinics other than their closest clinics. Mothers would sometimes not go to other clinics because they did not have money for transport. When we were conducting the interviews in 2005 the free formula was not available in the clinics for more than two weeks. This was because Nestle the biggest formula milk manufacturer in South Africa, embarked on a strike.

The strike went on for about more than two weeks. During this time all the clinics and shops ran out of formula milk. This put a lot of strain on the mothers who had planned to stop breastfeeding and even those who were already formula feeding. In the year 2007 there was another national strike by health professionals that went on for a month and it became very dangerous and difficult to access health institutions. This means that providing free formula does not solve other problems that emerge from infant feeding decisions that mothers make. A lot of circumstances can change from a moment a mother makes an infant feeding choice until the time she has to actually put that choice into practice. There are a lot of economic, social, political and environmental factors which most of the time are beyond the mothers' control. (31). All these factors influence the mother's infant feeding decision and practice. It was also reported in another South African study that despite the provision of free formula, over one third of the mothers had run out within first three months due to insufficient supplies and sometimes mothers cannot fetch the milk because they do not have money for transport to the clinics (32).

We were also informed by participants in FGDs that because of poverty other mothers collect the free milk but instead of feeding the babies, they sell it on order to get money. This commercialisation of governmental free milk was also reported in another South African study (36). Poverty in poor resourced settings perpetuates the infant feeding dilemma that is cause by HIV and AIDS thus causing a vicious cycle. Free formula which was supposed to solve the infant feeding problem caused by HIV, ends up creating another problem. It is wrongly seen as an income generation scheme. Children who were supposed to be beneficiaries become victims in the end and get deprived of nutrients If the milk is sold instead of being fed children, morbidity and mortality of children will further increase.

Some mothers said the HIV negative babies were also great motivators for mothers to continue with exclusive breastfeeding especially in the research setting where PCR was done as early as 6 weeks when the study was conducted in 2005. In 2006 even the PMTCT services started providing PCR testing for babies at six weeks.

Even though the mothers chose rapid cessation of exclusive breastfeeding they reported a lot of emotional distress during the transition period. The crying baby was the most difficult part. All of the mothers experienced the crying baby due to cessation of breastfeeding, but some more so than others. The only remedy for the crying baby which was suggested by mothers was cuddling, even waking up at night and just focusing on the baby if they had to. The transition was extremely difficult. On top of that the mothers had to deal with their own physical pain because of engorged and full breasts that were no longer nursing. Breast conditions like engorgement and inflamed breasts were also reported in other South African studies during rapid cessation of breastfeeding (15;35).

The mothers mentioned quite a few number of remedies for engorged breasts including drinking Epsom salt and a sour fizzy drink which are believed to dry the milk up from the breasts. More traditional beliefs like expressing the breast on open fire were also reported in our study. Some remedies which were reported in our study were also reported in another study in Durban (15). These remedies included using cabbage leaves, warm compresses and expressing breast milk in order to relieve engorgement. Applying aloe and chillies to make the breast bitter for the baby and binding the breasts were also reported in both our study and another Durban study (15;33). Separation from the baby during the transition period as mentioned by counsellors and FGDs participants was also reported as another useful suggestion in Coutsoadis' study and our study (15;33).

Both provincial programme and research operation counsellors said they would opt for rapid cessation of exclusive breastfeeding if they were HIV-infected. However, most of the provincial counsellors expressed doubt in mothers' abilities to adhere to this infant feeding practice. This could be linked to the fact that the provincial counsellors did not think they were better equipped to perform their duties. They reported that they were short staffed, overworked and even had a shortage of rooms to do proper counselling. That made their counselling compromised as they could not do frequent follow-up and support the mothers in their choice intensively. On the contrary, counsellors in the research setting were confident

that they were able to offer mothers appropriate support, because they had time and resources to do so.

Provincial counsellors did their follow-up of the mothers on a monthly basis. This was different from research operation counsellors who met with the mothers every two weeks. The research operation counsellors believed mothers could adhere to the rapid cessation of exclusive breastfeeding method. In fact most of the mothers from the research operation managed to cease exclusive breastfeeding with less difficulties than the mothers from the provincial programme. Perhaps with enough resources like more staff, space etc. the provincial programme can manage to provide intensive counselling and follow-up in order to support mothers more.

Both provincial and operational research counsellors did not seem to have much practical advice on how mothers can cope during the transition period. The main advice they both gave was to start expressing breast milk early and start feeding the babies through the cup feeding. This makes the baby get used to feeding through something else other than the breasts. When the time to stop breastfeeding it becomes more bearable for the baby. It seemed succeeding had to do with will power.

One mother succeeded in rapid cessation of exclusive breastfeeding under extremely difficult conditions. One condition was that she had not disclosed to the family. The second one was that she had to sleep in the same bedroom as the family that she had not disclosed. It was extremely difficult when the baby was crying at night. Separation from the baby was also another practical advice offered by the counsellors. The baby can be taken to someone else during the transition period. This helps because the mother does not see the baby cry and thus does not get tempted to put him back on the breast.

The separation from the baby was also suggested by close social networks in the FGDs. They felt that there should be partner, family and community involvement in infant feeding issues. If everyone is involved people would be more supportive of the mother's infant feeding choice. Other family members can familiarise themselves with the baby so that they can sleep with the baby during the transition period.

The close social networks also felt that community involvement would help in reduction of stigma. This could be done through HIV and AIDS campaigns. It was also felt by the social networks that it should be emphasized in the communities that exclusive breastfeeding is for everyone, not just the HIV-infected breastfeeding mothers. Most of the participants (mothers, counsellors and close social networks) acknowledged that HIV-related stigma is a big issue in South Africa. One mother mentioned that she would bring a big bag to the clinic for collecting free milk in order to avoid stigma. Similar findings about stigma were also reported in a recent study that was conducted in Durban (36). There are many HIV awareness campaigns but more still needs to be done in order to reduce stigma. The stigma led often led to non-disclosure of HIV status to close family members.

It was interesting to note that from the interviews with HIV-infected mothers, most of them had disclosed to their partners. However, they also reported that they had not disclosed to their close family members like their mothers for various reasons. Their reasons included shame, guilt and protecting the family members from distress. It could be because they did not fear stigma from their partners. The explanation for that could be that, the majority of the mothers reported that they suspected their partners to have infected them with HIV. For those who had disclosed their partners were supportive during the transition period. Some even went to the extent of helping with the crying baby at night. There was a similar finding in another South African study that those women who had disclosed to their supportive partners or husbands were able to maintain exclusive breastfeeding, and disclosure at home was associated with maintenance of exclusive breastfeeding (32).

The other study in South Africa found that most mothers singled out stigma and disclosure as significant considerations when they make infant feeding decisions (36). Another South African study also reported that even though the fear of discrimination is associated with disclosure, HIV-infected mothers who have disclosed have received a positive response from their significant others (36). The mothers who had such supportive partners acknowledged that they are a few lucky ones. Their partners are special because most men in the study area are not involved in taking care of children that way. This also demonstrates the importance of male involvement in issues regarding the bringing up of children.

There has to be a way of involving men in all health related matters. Even finding male participants for this research was extremely difficult. The very few men that participated were

those who were already exposed to health issues through their line of work e.g the CHWs. Ignorance of health related issues by men was also evident in the fact that women HIV-infected mothers disclosed their HIV status to their partners. The majority of the partners of the HIV-infected mothers that were interviewed refused to also have an HIV-test. The only one partner who agreed was a CHW. Such non-cooperation from men makes it difficult for women to negotiate safe sex if the other partner does not know his status. This has a negative impact on women who are breastfeeding because if they get reinfected through unsafe sex, it becomes easier for them to pass the virus to their babies

The close social networks reported the study area to be patriarchal where male domination and female subordination prevail. Some men went as far as disregarding their duties of providing for their children as men. This trend of irresponsible men in the society was also portrayed through the role plays on the NRM. It is not unusual in the study area for a man to impregnate a woman and then move on to the next woman without even seeing the baby according to the participants. That put a lot of strain on already financially dependent women who have to fend for themselves in order to be able to feed children properly after cessation of breastfeeding. Four of the sixteen mothers were no longer on good terms with the fathers of their babies since giving birth. They were in the process of charging them for maintenance because they were refusing to provide money for their children

Despite the HIV pandemic most participants in the FGDs said that infant feeding patterns have not changed. They said this when asked to discuss how mothers usually feed their babies. They said the most common way of feeding is mixed feeding. The study in Zambia had similar findings where it was reported that rapid cessation of exclusive breastfeeding was not universally accepted in the study area, and prolonged breastfeeding was a norm (34). According to them most mothers do not believe that the baby can survive on breast milk alone for six months. There is always pressure from other family members to give something else (32). The breastfeeding women in nearly all parts of the world give breast milk together with other fluids, exclusive breastfeeding is uncommon (25;50).

It has also been proven that with enough resources well trained counsellors are able to provide quality infant feeding counselling and help women make appropriate choices that suit their individual circumstances (12). A multi centre cohort study that was conducted in three developing countries also revealed that non-breastfed infants had a tenfold higher risk of

dying when compared to predominantly breastfed infants (51). Exclusive breastfeeding has been proven to carry less risk of postnatal HIV transmission compared to mixed feeding (52). It has also been argued that there has not been a single well designed study that has reported that formula feeding is significantly better than breastfeeding for HIV-infected mothers in developing countries (50).

Infant feeding research is an evolving process. Studies are being carried out with different findings. This has been evident in the constantly changing guidelines. Dissemination of new and constantly changing information can be quite a challenge for everyone involved. The CHWs in the FGDs expressed their concern with constantly changing guidelines. They said that as much as they appreciated the importance of constantly doing more research, it is quite a challenge to report back to the community because when they report back conflicting messages they lose their credibility. Until 2006 mixing breast milk with other foods was dangerous hence rapid cessation of exclusive breastfeeding. After 2006 the recommendation has been if HIV-infected to continue breastfeeding whilst giving other foods until an adequate diet can be found for the baby.

CONCLUSION AND RECOMMENDATIONS

The impact of HIV and AIDS in infant feeding decisions cannot be ignored. There is a lot of confusion and debates about the best infant feeding option for HIV-infected mothers. This is evident from many infant feeding studies that have been conducted around the world. Some studies have provided similar results while others have conflicting results. Dissemination of the information from the researchers to the policy makers, and then to the various health departments until it reaches the people on the ground, is a complex process.

From this study and many others before it is clear that the HIV-infected mother does not live in isolation but she is part of a family, community, and the society at large. All the decisions the HIV-infected mother makes are highly influenced by her family, community and her society at large. When an HIV-infected mother makes that decision of how she will feed her baby, usually she is alone with her counsellor in the clinic. The evidence has shown that when she goes back to her home and community she is no longer alone in carrying out of her decision.

The circumstances at home and her physical environment are constantly changing, and that also affects her infant feeding option. Yes the current infant feeding recommendations state that the most appropriate infant feeding option for an HIV-infected mother should continue to depend on her individual circumstances, including her status and her local situation, but should take greater consideration of health services available and the counselling she is likely to receive (22). Perhaps the family, community and society at large should also be taken into consideration in infant feeding guidance. It is not enough for the guidelines to state that governments and stakeholders should revitalize breastfeeding protection promotion and support in the general population. Before it goes to the general population it should start with the family. As most participants stated that more male, family and community involvement is required through awareness campaigns. It makes sense to involve men because in the study area they are given more power by the patriarchal system. There is a strong need for couple counselling and also partner involvement in infant feeding counselling. Even if the guidelines change the strong community base will make it possible to support mothers in any choice they make because ultimately the mother belongs to the family, community and society and that is where all the final infant feeding decisions are made.

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APPENDICES

Zulu consent form

Zulu study information sheet

English consent form

English study information sheet

2005 Interview guide for mothers

2005 Interview guide for counsellors

2008 Focus Group Facilitation Guide

2005 Narrative Research Method Stories

2008 Narrative Research Method Stories

INFORMATION SHEET AND INFORMED CONSENT (English) – Focus Groups

An assessment of the experiences of women when stopping breastfeeding rapidly

Who are we?

We are from the University of Oslo in Norway but we are continuing with the work that we started as members of the University of KwaZulu-Natal's Department of Maternal and Child Health Department in 2005.

What are we doing and why?

We are doing research on how mothers, with HIV infection, stop breastfeeding. This means that we will be trying to get answers to the questions that we have.

Previous research shows that exclusive breastfeeding might reduce the transmission of the HIV-virus from an infected mother to her child. After 4-6 months all children need to start on food and so in order to reduce the chances of HIV infection in the child the time of giving both breast milk, together with any other food should be as short as possible. In this study we want to learn how women stop breastfeeding, how they feel about it and what they experience as it happens. We also want to hear from other members of the community how they see this issue. This research will help us to better understand if, or how, women follow any advice given and the problems they face.

What are we asking from you?

In order to do this we want to talk to mothers who are breastfeeding, those who help them such as family or friends or clinic staff as well and also talk to others in the community who have an opinion on breastfeeding and who might influence the way that women think about breastfeeding and how they manage it.

We are inviting you to join in group discussions about these issues. In these discussions we will also ask you to do role plays i.e. we will ask you to pretend to be a type of person e.g. a nurse at the clinic or a 'gogo' at home and to say the things or do what that person might do - a bit like the 'soap plays' on TV. People can sometime say things differently when they play these roles rather than just saying what they think for themselves.

Other discussion groups will simply be people talking about the issues. Altogether about 60 different people from the key community will be asked to join in. The discussions might last up to 4 hours in total. We want to tape record all the discussions so that we can listen to them again at a later time. **All information, personal experiences and opinions expressed by any of the participants will be confidential - We also ask that what is discussed during these group discussions is not discussed by the group members at other times.**

We are inviting you to participate in this study and, if you are agreeable, then we will ask you for your written consent. We may ask you to participate in such a discussion more than once but with a different group of people.

What type of questions will be asked?

The questions in the discussion groups will focus on issues related to infant feeding and how mothers stop breastfeeding and what people in the community think about those things.

Where will the group discussions take place?

The discussion groups will take place at the clinic or some other place in the community e.g. the library. You will be given R200 for the bus fare and we will also provide something to eat and drink during the discussions.

What if I do not want to take part or change my mind later?

Your participation is voluntary and you do not have to participate if you do not want to. Choosing not to participate or stopping even during the discussions will not stop you from going to the clinic any time that you need to and seeing the staff there.

What if you are not happy with the way you are treated in the study?

You can talk to Ntombizodumo Mkwanazi (082 291 0898) or Dr Marina de Paoli (082 631 8419) who are both involved with the study. You can also speak to Cheryl Borreson or Professor Dhali from the Ethics office at the University of KwaZulu-Natal (031 260 4495) – none of these people are involved in the study but can listen and register your complaint.

Who will be able to read these reports and what about your name and other personal details?

Your name will not be written down; only your role in your community i.e. a nurse or teacher or feeding mother will be tape recorded. Names will not be included in any report. The information from this work will be given to the Department of Health, the local clinic managers and counsellors as well as the local councillors. Your answers will help programme planners and health workers plan training of nurses and counsellors.

If you are willing to participate, we will ask you to sign the 'Consent form'. Thank you for your time, help and co-operation.

CONSENT

To Participate in the focus groups of the Study

'An assessment of the experiences of women when stopping breastfeeding rapidly'

I have been asked to participate in a research study investigating the experiences and feasibility of rapid cessation of breastfeeding as a way to reduce HIV transmission to young infants.

I have been informed about the study by the study team. I am aware that if I want more information before deciding to participate or have questions later, I can talk to Ntombizodumo Mkwanazi (082 291 0898) or Dr Marina de Paoli (082 631 8419).

I am aware that taking part in this study is voluntary. I know that if I choose now or later that I do not want to take part in the study I will not be penalized or lose any benefits at the clinic.

I know that if I agree to participate I will be given a signed copy of the consent document and the participant information sheet (which is a written summary of the research).

The research study, including the above information, has been described to me orally. I understand what my involvement in the study means and I voluntarily agree to participate. I am aware of the fact that information disclosed during the focus group discussions is confidential and I will not talk about what was discussed in the group with anyone after the discussions have ended.

I know that if I am unhappy about the way I am treated at any time that I can speak to Cheryl Borreson or Professor Dhai from the Ethics office at the University of KwaZulu-Natal (031 260 4495).

Name of Participant

Signature of Participant

Date

Name of Witness

Signature of Witness

Date

IMINININGWANE NGOCWANINGO

Ukuhlola ukuthi kwenzekanjani kwabesifazane uma benqamula ingane ebeleni ngokushesha nokuthola imibono yabantu abaqavile ezimpilweni zabo.

Thina singobani?

Sivela eNyuvesi yase-Oslo eNorway kepha siqhubeka nomsebenzi esawuqala sisaseNyuvesi yaKwaZulu-Natal eMnyangweni wezoMama naBantwana ngonyaka ka 2005.

Senzani futhi sikwenzelani lokho?

Senza ucwaningo lokuthi omama abathelekile ngesandulela ngculazi bakunqamula kanjani ukuncelisa ngokushesha. Ucwaningo yindlela eqhubekayo yokuthola impendulo embuzweni othile.

Ucwaningo olwenziwa ngaphambilini lukhombisa ukuthi ukuncelisa ibele lodwa kungalehlisa izinga lokuthelaka komntwana ethelelwa umama wakhe. Emva kwezinyanga ezine kuya kwezisithupha abantwana badinga ukuqala ukudla ngakho ke ukuze kwehliswe amazinga okuthelaka komntwana kufuneka isikhathi lapho umntwana ephiwa ubisi lwebele nokunye ukudla sibe sifishane kakhulu. Kulolu cwaningo sifuna ukufunda ukuthi abantu besifazane bayeka kanjani ukuncelisa, bazizwa benjani ngalesikhathi kwenzeka. Sifuna nokuzwa ukuthi amanye amalunga omphakathi alubona kanjani lolu daba. Lolucwaningo luzosisiza ukwazi kangcono ukuthi abesifazane bazilandela kanjani izeluleko mayelana nalokhu nokuthi sazi nezinkinga abahlangabezana nazo.

Sicelani kuwena?

Ukuze senze lokhu sidinga ukukhuluma nomama abancelisayo, labo ababasizayo abanjengomndeni, abangani, abasebenza emtholampilo, sifuna futhi ukukhuluma nabanye abasemphakathini abanezimvo ngokuncelisa futhi abangaba nomthelela endleleni abesifazane abacabanga ngayo ngokuncelisa nangokuthi bakwenza kanjani.

Siyakumema ukuthi uhlanganyele ezingxoxweni neqoqo labanye abantu mayelana nalezi zindaba. Kulezi zingxoxo sibuye sikucele ukuthi ulingise wenze sengathi ungomunye umuntu njengomhlengikazi emtholampilo, ugoto ekhaya, usho izinto lomuntu omlingisayo angazisho, noma wenze njengoba kwenziwa kumabonakude. Ngesinye isikhathi abantu bangasho izinto ezihlukile uma belingisa kunokuba basho abazicabangela khona ngokwabo.

Kwezinye zalezi zingxoxo zamaqoqo kuyokuba abantu bezixoxela ngezindaba nje. Siyocela amalunga aqavile omphakathi ukuba abambe iqhaza ezingxoxweni. Izingxoxo ziyothatha isikhathi esingamahora amabili. Sithanda ukuziqopha ezingxoxo khona siyobuye sikwazi ukuzilalela kamuva.

Yonke into eyobe ixoxwa lapho iyoba isifuba. Siyanxusa ukuthi okuyoxoxwa kungabuye kukhulunywe ngaphandle ngoba sizama ukuhlonipha izimvo zawo wonke umuntu oyobe ebambe iqhaza kulezi zingxoxo nokuvikela noma yini umuntu angayidalula ngaye.

LOKHU KUBALULEKE KAKHULU.

Siyakumema ukuba ube yingxenye yalolucwaningo uma uvuma, siyocela imvume yakho ebhaliwe. Kungenzeka sikucele ube sezingxoxweni izikhathi ezingaphezu kwesisodwa kodwa neqoqo labantu abahlukile.

Mibuzo mini ebuzwayo?

Imibuzo ezingxoxweni iyobe igxile ezindabeni ezimayelana nokondliwa kwabantwana, ukuthi omama bayeka kanjani ukuncelisa nokuthi abantu emphakathini bacabangani ngalokho.

Ziyokwenzekela kuphi lezi zingxoxo zamaqoqo?

Lezi zingxoxo ziyokwenzekela KwaDabeka Library. Okuya ngasethunjini kanye nemali yokugibela kuyohlinzekwa.

Uma ngingathandi ukuba yingxenye noma ngishintsha umqondo kamuva kuyokwenzekani?

Ukuba yingxenye yalezi zingxoxo kusothandweni lwakho, awuphoqelekile uma ungathandi.

Kwenzeka kanjani uma ungajabule ngendlela ophathwe ngayo ocwaningweni?

Ungakhuluma noNtombizodumo Mkwanazi (082 291 0898) noma uDr. Marina de Paoli (082 631 8419) bobabili abayingxenywe yalolucwaningo. Futhi ungakhuluma no Cheryl Borreson noma uDhai baseHhovisi ye-Ethics eNyuvesi kakwaZulu-Natal (031 260 4495), akekho ke kulaba oyingxenywe yalolucwaningo kodwa bangalalela izikhalo zakho bazibhale phansi.

Ubani oyofunda lemi biko, kuyokwenzekani futhi ngemininingwane yakho efana negama nokunye?

Igama lakho ngeke libhalwe phansi kulemi biko kodwa kuyobhalawa kuqoshwe isikhundla noma iqhaza olibambe emphakathini njengokuthi uwugogo noma umhlengikazi. Ulwazi oluyotholakala luyobe seludluliselwa eMnyangweni WezeMpilo, emitholampilo yendawo nakubeluleki bezokondliwa kwabantwana. Izimpendulo zenu ziyolekelela abahleli bezinhlelo zempilo nasekuqeqesheni abahlengikazi nabaeluleki bokondliwa kwabantwana.

Uma uthanda ukuzibandakanya sizicela usayine "Imvume Yokuzibandakanya" Siyabonga ngesikhathi nosizo lwakho

IMVUME

Yokuzibandakanya ezingxoxweni zamaqoqo mayelana "Nokuhlola ukuthi abesifazane bayinquma kanjani ingane ebeleni ngokushesha"

Ngicelwe ukuba ngibe yingxenywe yocwaningo oluhlola ukuthi kwenzekanjani kwabesifazane uma benqamula ingane ebeleni ngokushesha nokuthola imibono yabantu abaqavile ezimpilweni zabo.

Ngazisiwe ngalolucwaningo yithimba locwaningo. Ngियाqonda ukuthi uma nginemibuzo ngaphambi kokuthi ngizibandakanye noma nginemibuzo kamuva ngingakhuluma noNtombizodumo Mkwanazi (0822910898) noma noDr. Marina de Paoli (082 631 8419).

Ngियाqonda futhi ukuthi ukuba yingxenywe yalolucwaningo kuzisukela kimina, angiphokelekile uma ngingathandi futhi ngeke ngijeziwe ngalokho.

Ngiyazi ukuthi uma ngikhetha ukuzibandakanye ngizosayina imvume ngiphinde nginikwe nelinye iphepha elineminingwane efinqiwe ngalolu cwaningo.

Ngichazeliwe ngalolucwaningo ngomlomo, ngaphinde ngachazelwa nalokhu okungenhla. Ngियाqonda ukuthi ngizivumelwa ngokwami ukuba yingxenywe.

Ngियाqonda futhi ukuthi konke okuzoxoxwa kulamaqoqo kuyisifuba angivumelekile ukubuye ngikuxoxe ngaphandle uma ucwaningo seluphelile.

Ngazisiwe ukuthi uma ngingathokozile ngendlela engiphethwe ngayo noma nini ngingakhuluma noCheryl Borreson noma uProfessor uDhai baseHhovisi leEthics eNyuvesi yakwaZulu-Natal (031 260 4495).

Igama lozibandakanya kucwaningo	Ukusayina	Usuku
.....
Igama likafakazi	Ukusayina	Usuku
.....

Interview Guide

2005 Mothers

- MTCT Knowledge
- Difference between PMTCT Programme and research operation
- Previous breastfeeding experience
- Disclosure
- Preparations for cessation
- Safe sex

Interview Guide

2005 Counsellors

PMTCT/Research

Infant feeding advice

Counsellor's (personal) choice

Challenges with rapid cessation of exclusive breastfeeding

Timing of infant feeding counselling

Focus Group Facilitation Guide

2008

Introduce ourselves and to tell them what we are interested in. Infant feeding for HIV-infected mothers with a focus on rapid cessation, their choices, the constantly changing infant feeding guidelines, mothers' coping strategies and social pressures that they face in their home environment. Follow-up study of a study conducted in 2005. Questions for the participants;

1. What is your impression of how HIV-infected mothers feed their children?
2. What do you know about the infant feeding advice they are given at the clinic?
3. How do you feel about the constantly changing infant feeding guidelines?
4. What is the most feasible/practical choice for HIV-infected mothers?
5. Is it easy for mothers to practise one of these choices?
6. What do you know about RCEBF?
7. Is it a useful strategy to prevent MTCT? How practical is this strategy?
8. What makes it easy? What makes it difficult?
9. How does lack of formula milk contribute to problems mothers are facing when adhering to RCEBF?
10. How does disclosure of HIV status affect this strategy?
11. Is there stigma attached to this strategy?

12. In general, what can be done to reduce stigma for HIV-infected mothers who have had to change their infant feeding practices?
13. How does the family influence contribute to this strategy? Is their support important for mothers to be able to adhere to this strategy?
14. When stopping breastfeeding rapidly at six months what are the main problems a mother is facing? Probing for crying, engorged breasts, a distressed surrounding (from crying at inconvenient hours)?
15. How to help a crying baby?
16. Does separation from baby help or does it make things worse?
17. What kind of help do mothers need? How can health services help?
18. What role can family members play in mothers succeeding in adhering to their infant feeding choice?
19. If you were about to stop breastfeeding at six months because of HIV-infection and due to the advice that you had been given at the clinic - what kind of help do you think you would need?
20. What role do you think this group can play in this in general for HIV-infected mothers being able to practise a certain infant feeding advice?

2005

The first character is Ntombi:

She is 26 year old HIV positive. She didn't disclose to anyone. She is not married. She has one child. Dwinkie is the name of her baby girl. She stays with her boyfriend. Mandla is a 30 year old boyfriend of Ntombi. She is unemployed and the boyfriend is also unemployed. They are living on child support grant. Boyfriend is physically abusing her for money. He is alcoholic. Sometimes they don't have food at home. She is irresponsible. Her family is nearby. She is disobedient at home that is why she left. She has got two brothers and one sister. Her two brothers are Siphon and Prince. Her sister's name is Queen. Her mother is Mazondo. Her father is Shozi. Ntombi's friend is Cleo

C: Let's talk about what, what who she will be? What would she look like?

HM: NGIPHAKAMISA UKUTHI KUBE UMAMA ONGASHADILE ONOMNTWANA IGAMA LAKHE KUBE UNTOMBIZIYAKEKA. I am suggesting that we have an unmarried mother with a child and by the name Ntombiziyakeka.

(All laughing because of a silly name that has been made up)

D: UNTOMBI, UTHE UNEMINYAKA EMINGAKI? How old is Ntombi?

HM: Una 26years

D: UNa 26 ya, unmarried, YA SIKHULUME SIQHUBEKE FUTHI KUNTOMBI. Yes let us carry on with Ntombi

HM: UHLALA NEBOYFRIEND YAKHE

D: Staying with her boyfriend yes, ABANYE ? ASIZAKHELENI UMAMA WETHU.YEBO NANGU UNTOMBI.

DX: UHLUKUMEZEKILE NJE UNTOMBI INDODA IHLALE IMSHIYA ENDLINI.

D: He says Ntombi is abused and the boyfriend is always leaving her alone in the house. AND AYEPHI UBOYFRIEND? Where does the boyfriend go?

C: How many children does she have?

DX: One.

D: One

C: This is now her first child?

CM: AKASEBENZI FUTHI UBOYFRIEND ...ABASEBENZI BOBABILI BACHITHA ISIKHATHI NGOKWENZA UCANSI BAPHILA NGEMALI

The second Character is Zanele:

She is 17 years old. She is in grade 10 (Std 8). She is a teen mom. She lives at Sub 5. Her parents are working. She has two sisters (no brother) and she is the eldest of them. Her mother is a domestic worker and her father is a factory worker. Zanele is HIV-infected and she has one baby. She has one boyfriend, who is a taxi driver. She has bad friends

(party animals). The rest of the family is at Mtubatuba, boyfriend's family is around. Zanele's boyfriend is Boysie 25 years old, Zanele's mother is Deborah her father is Thulani, her girlfriends are Dudu and Nellie, the baby care giver is MaDlomo and the baby's name is Olwethu a baby boy.

C: How old is Zanele?

CM: 17

C: What grade I don't know I always get mixed up standards, grade, I come from the days of standard.

HM: Let's give her grade eleven.

DX: Grade ten.

C: Grade ten ok.

FD: Grade ten is Standard eight.

The Third Character is Busi:

She is 35 years old. She is a housewife. She has four children. The name of her youngest daughter is Lihle. She is married. She lives with her husband and her in laws. Busi's husband is a teacher. She stopped at grade seven. She from KwaNyuswa, her family is at KwaNyuswa. Busi's husband is very strict, he controls her social life, the family money etc. He drinks a lot during weekends and gets abusive. Busi's husband has many girlfriends. She used to have lots of STIs. The name of her husband is Dan. The name of her mother-in-law is MaMkhize. The name of her sister- in-law is Khethiwe and her father-in-law is Stompie.

HM: Married mom.

C: Married mother? Ok let's do a married mother (*Putting another paper on the wall*) so what is the married mother's name?

FD: Christina.

(All laughing loudly)

C: That's the real true Christina

D: Let's give another.

2008

Narrative Research Method (Role play) Number One

Nana is a 30 years old graduate, but she has not been able to find employment for the past five years. She is living at home in KwaDabeka with both parents. In desperation she ended up having a baby with a TAXIMAN who is known to be HIV positive in the area because she feels she is too old to be asking money from her parents. She also tested positive and disclosed to her mother but not her father. The reason for not disclosing to her father is that he has high blood pressure and is quite temperamental and tends to drink if he faces problems and is abusive when intoxicated. Her baby is five months old and she plans to stop breastfeeding at six months. For the first five months she has been exclusively breastfeeding despite pressures from the surroundings. One of her strategies has been to always have her child with her, as she knows that family members might give the child something in addition to her expressed breast milk. Recently she had a big fight with her boyfriend and she does not think he will give her money for formula. There is a strike going on in the clinic which makes it difficult to access free formula and now she is panicking as six months is drawing near. She had also been offered a full-time job as a clerk in the clinic. She realizes that taking the job put her in a dilemma as she has to give the baby to someone else during working hours, but she would be in an economic advantage (no longer dependent on her unreliable and useless boyfriend for support or free formula from the clinic).

Will she accept the job offer? What are the disadvantages/ advantages of this in terms of her feeding her infant?

How do you think Nana is going to feed her baby after six months?

Will she succeed or will she practise mixed feeding?

What will be her main problems?

If the child is crying a lot, what will she tell people in the surroundings who she has not yet disclosed to?

Will she disclose to her father?

Narrative Research Method (Role play) Number Two

Zodwa is a 35 years old. She is married with three children. Her youngest baby is 5 months old. She tested HIV positive when she was pregnant with the youngest child. She has not disclosed her HIV status to her husband Siphoh. At the clinic she chose EBF for 6 months. Zodwa is an active church member and leads the church choir. Siphoh is a police man at a nearby Police Station in Sub 5. He never goes to church and he is known to have many girlfriends including school girls. Zodwa is a housewife but Siphoh provides everything needed in the house. Zodwa has managed to abstain from sex because she has been breastfeeding but fears what will happen at six months when she has to negotiate condom use. Zodwa's mother-in-law MaZungu stays with them. MaZungu is very empathetic towards Zodwa because she knows that her son is a womaniser. She does not believe in EBF. Zodwa caught her twice offering the baby an orange that she was eating.

Will Zodwa manage to stop breastfeeding at 6 months?

What will she say to MaZungu?

If she stops breastfeeding, Siphoh will want to have unprotected sex with her, then what will she do?

Will she disclose to Siphoh?

Will she disclose to MaZungu?