FACTORS INFLUENCING INFANT FEEDING PRACTICES FOR HIV POSITIVE MOTHERS IN A LOW RESOURCE COMMUNITY

LYN MUZONDO

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STUDY LEADER: Dr. T Qubuda

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DECLARATION

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

ACRONYMS

HIV Human Immune Virus

AIDS Acquired Immuno Deficiency Syndrome

ARV Antiretroviral Therapy

HAART Highly Effective Antiretroviral Treatment

PMTCT Prevention of Mother to Child Transmission

MTCT Mother to Child Transmission

WHO World Health Organisation

UNAIDS United Nations Joint Programme on HIV/AIDS

UN United Nations

NGO None Governmental Organisation

m2m mothers2mothers

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ABSTRACT

This research is on factors influencing the infant feeding practices of HIV positive mothers in a low resource community in Khayelitsha at Michael Mapongwana clinic. The aim of the study was to establish the mother's current feeding practices, to determine the various factors influencing their practices and to establish the relationship between these factors and their practices. Questionnaires were used on 20 HIV positive mothers who had children up to 2 years and attended the ARV clinic or the PMTCT clinic. Further, 2 healthcare workers who directly work with these mothers were also surveyed. Findings were that the majority, (95%) were practicing the replacement feeding method with a minority of (5%) practicing mixed feeding. Most mothers chose replacement feeding because it was free of charge, to avoid MTCT of HIV and also the healthcare workers recommended the mothers to use infant formula. The safety of exclusive breastfeeding was questioned by (90%) of the mothers making it very unpopular. Several factors influencing against exclusive replacement feeding were stigma, discrimination, pressure from the family and lack of support from partner or significant family member.

Conclusion: Future research on infant mortality rate on mothers who practice replacement feeding and exclusive breastfeeding to establish effectiveness of providing free infant formula to curb MTCT of HIV. Further, implement policies that target stigma and discrimination reduction aligned to cultural beliefs to address stigma and discrimination.

OPSOMMING

Hierdie navorsing is gebasseer op faktore wat die babavoedings praktyke van HIV positiewe moeders van lae inkomste en hulpbronne gemeenskap (in Khayelistha in die Michael Mapongwana kliniek) beïnvloed.

Die doel van die studie was om te bepaal wat die huidige voedings praktyke van die moeder is, die faktore wat die praktyke beïnvloed asook die verhouding tussen die faktore en die praktyke. 'n Vraelys was gebruik op 20 HIV positiewe moeders met kinders tot en met die ouderdom van 2 jaar, wat die ARV of PMTCT klinieke bygewoon het. 'n Verdere 2 gesondheidswerkers wat direk met die moeders werk, ook by die navorsing betrek. Bevindings was dat die meerderheid (95%) beoefen die voedings vervangings metode, met 'n minderheid van 5% wat albei vorme van voeding be-oefen.

Meeste moeders het vervangingsvoeding verkies omdat dit verniet is. Meeste gesondheidswerkers stel voor dat die moeders baba formulas gebruik om sodoende MTCT of HIV te voorkom. Die veiligheid van eksklusiewe borsvoeding word bevraagteken deur (90%) van die moeders wat gevolglik hierdie praktyk nadelig beïnvloed. Ander faktore wat eksklusiewe vervangings voeding beïnvloed is stigma, diskriminasie, familie druk en 'n te kort aan ondersteuning van metgesel of familielid.

Samevatting: Meer navorsing in die toekoms oor baba oorlewings syfers op moeders wat vervangings voeding be-oefen asook eksklusiewe borsvoeding. Met die doel om die effektiwiteit van gratis baba formule om MCTC of HIV te voorkom beskikbaar te maak. Verder moet daar ook wetgewing wat daarop gerig is om stigma en diskriminasie wat gebasseer is op kulturele opvatting, te addresseer.

Chapter 1: INTRODUCTION

Chapter 1 is the introduction which comprises of the background and rationale, research problem/question, aims and objectives; Chapter 2 is the Literature review which contains a discussion on infant feeding practices of HIV positive mothers in a low resource community. Chapter 3 outlines the Research design and methodology, Chapter 4 contains the research findings and discussion and Chapter 5 is the conclusion and implications

1.1 Background/ Everyday Problem

The majority of people living with HIV in the world are women. Women aged 15 years and older make up 58% of the people living with HIV/AIDS and over 90% of these women live in the developing world (UNAIDS 2002). For the Sub-Saharan region as a whole, women are disproportionately affected in contrast with men, with especially austere differences between the sexes in HIV prevalence among young people. Although globally, the percentage of women among people living with HIV has remained stable for several years, women's share of infections is increasing in several countries (UN Report on the Global AIDS Epidemic, 2008).

An estimated 420 000 children were newly infected with HIV in 2007, the vast majority of them through MTCT (Avert, 2009). This is attributed to the high fertility rates and high HIV prevalence in women in the developing countries.

Mother to child transmission (MTCT) is the main route of transmission in children under 10 years and more than 5.1 million children become infected with HIV yearly with the majority in Africa (Journal of Social aspects of HIV/AIDS, 2004). Infection routes of HIV from an HIV-positive mother to her child are during pregnancy, labor, and delivery or through breastfeeding.

The successful implementation of two interventions using antiretroviral drugs, nevirapine and azodothymidine used concomitantly has proven effective to avoid MTCT during pregnancy and at birth (UNAIDS, 1999). The two drugs simultaneously

used with effective infant feeding adjustments can reduce MTCT of HIV considerably.

Breastfeeding is regarded the best way to feed infants, as breast milk is a rich source of nutrients for infants. Breast milk is also highly recommended for infant feeding because it contains agents, which increase resistance against disease ensuring good health. This would be an aspect which influences mothers to breast-feed their infants. This does not necessarily apply to HIV positive mothers who are faced with the challenge to choose the best feeding practice for their infants to best suit their situation.

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These factors have provoked critical considerations for policy and programs targeted towards mitigation of adverse effects caused by HIV in women and children. Governments and non-governmental organizations are rolling-out Anti-Retroviral treatment (ART) in order to improve the health and well-being of infected women, through programs that couple prevention of mother-to-child transmission with continuing treatment to help mothers remain alive and in good health to care for their children.

1.2 Research Problem

HIV positive mothers have to decide on the best feeding practice for their infants. The choice ultimately lies with them although there are various external factors, which may influence the ultimate decision on whether to breastfeed or use replacement feeding. The two safe recommended infant feeding practices for HIV positive mothers are exclusive breastfeeding or exclusive replacement feeding.

In communities with fewer resources, where replacement feeding can be much more dangerous, the recommendations for infant feeding usually depend on a mother's individual situation. Although there is some variation in national and local policies, most are influenced by the guidance published by the World Health Organisation

(WHO). According to the latest version of this guidance, "When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life" (WHO, 2007).

This means that some mothers should be counseled to breastfeed and others should be encouraged to give replacement foods as an alternative, depending on personal circumstances. The final decision, however, should be taken by the mother who determines the appropriate infant feeding practice for her circumstances.

Although these guidelines acknowledge the various circumstances which HIV positive women face, they do not communicate the complexities of women in low resource communities in making such decisions. Although the HIV positive mothers want to keep their children HIV free, they also face various challenges which contribute to their infant feeding choices. The knowledge gap which exists and poses challenges to adapting policies on infant feeding is what factors influence infant feeding practices for HIV positive mothers in a low resource community?

1.3 Research Question

What are the factors that influence infant feeding choices for HIV positive mothers in a low resource community?

1.4 Aim

To establish the factors that influence the infant feeding choices for HIV positive mothers in order to adapt current PMTCT support programs to their needs.

1.5 Objectives

- To identify current infant feeding practices in HIV positive mothers
- To establish factors that influence the infant feeding choices for HIV positive mothers
- To identify the infant feeding needs for HIV positive mothers
- To identify gaps between the current and recommended feeding practices for HIV positive mothers

• To provide guidelines for a needs-driven infant feeding program

2 CHAPTER 2: Literature Review

The HIV infected mother's biggest challenge is to protect her children from contracting the HI virus through the chosen feeding practice. When a mother has HIV, she has to weigh the dangers of breastfeeding against the risk of HIV transmission. The result is a painful dilemma for millions of women in developing countries, for whom there are no easy options (Avert, 2009).

2.1 Mother-to-child-transmission (MTCT)

Transmission of HIV from an HIV-positive mother to her child during pregnancy, labor, delivery or breastfeeding is called mother-to-child transmission (MTCT) or vertical transmission, (WHO, 2007). Among women who are infected with HIV and receiving no antiretroviral drugs or other interventions, breastfeeding for two or more years can double infection rate of MTCT to around 40% (Avert, 2009). In Africa about a third to one half of HIV transmissions are attributed to breastfeeding.

2.2 Breastfeeding in Africa

Breastfeeding is considered a major food source for infants and a widespread practice among the African mothers. "Prolonged breastfeeding is common, and the median duration of breastfeeding ranges between 16 and 18 months," Sante (2002). Early weaning is considered a risk to the child's nutritional needs and therefore not recommended. The child loses out on nutrients and will have many illnesses, with a weak immune system; Taylor (2009) Mothers feed their children throughout the day and night and do not complement their milk with any other milk. Coovadia (2000) agrees to the notion that "breastfeeding is one of the major benefits of humankind to children." Unfortunately the advent of HIV/AIDS has led to this practice of feeding to become less recognised since HIV is also found in breast milk.

A mother begins to breast feed right after birth and this is widely practiced in Africa. Contrary to this practice in Western hospitals where breastfeeding is discouraged, newborns are separated from their mothers for long periods, Small (1998). Moreover, Small (1998) points out that successful breastfeeding is within the first 30minutes when the infant's sucking reflex is strongest.

2.3 Benefits of breastfeeding

Breastfeeding has traditionally been the best way to feed an infant. This is supported by the recommendations made by The Global Strategy of Infant and Young Child Feeding, "the optimal feeding pattern for survival in the general population is exclusive breastfeeding for the first six months of life, with adequate and safe complementary feeding from age six months and continued breastfeeding for up to two years and beyond, and related maternal nutrition and beyond (WHO, 2007). This is probably found only in the ideal state of affairs and there is need to recognise the needs of children in difficult situations or those born to HIV positive mothers.

Breastfed children have less chances of becoming ill than those given replacement foods. These are exposed to bacteria and infection especially in low resource communities where access to clean water, sanitation and health services is minimal (Avert, 2009).

Breastfeeding also promotes creating the bond between mother and child and for child spacing.

2.4 Infant feeding practices

Feeding practices are distinguished into the following categories:

Exclusive breastfeeding – giving an infant breast milk only (no other foods or liquids, not even water. This practice is recommended for a child up to 2 years as this provides the best nutrition for the infant, WHO (2003).

Exclusive replacement feeding – giving an infant who is not receiving any breast milk a nutritionally adequate diet until the age at which the child can be fully fed on family

foods, AED (2004) Infant formula, where available, has been the most common replacement food.

Mixed feeding - giving infant breast milk and other liquids or solids or infant formula with other solids or liquids. This practice is often associated with different risks of gastrointestinal and other infections in early infancy.

The chosen feeding practice will influence the total various nutrients absorbed and infant growth. This suggests that HIV is passed through the infant's gut wall especially when it is disrupted through mixed feeding practices. Exclusive breastfeeding therefore is the recommended ideal feeding practice especially for women in low resource communities, (WHO, 2007). If this is not subsidized, replacement feeding is beyond the reach of most families. It is highly likely that the mothers, left with no alternatives may contravene the guidelines for breastfeeding for HIV positive mothers and increase the risk of infecting their infants ((Doherty et al, 2007).

2.5 HI virus in breast milk

Children born to HIV positive mothers may be born HIV negative but however contract the virus through breastfeeding. Breast milk contains the HI virus and thus if a mother decides to breast-feed, this exposes the child to contracting the virus. HIV is found in colostrum, the first collection of a thick creamy liquid, without blood or infection, produced by the mammary gland of a parturient mother shortly after birth, usually within the first six hours. Colostrum contains high concentrations of cells, immunoglobulins, and other anti-infective proteins. Cell-associated HIV DNA has been found in colostrum samples taken from HIV-seropositive women. As a result, some researchers have speculated that colostrum consumption may increase the risk of HIV transmission because of its high concentration of cells (possibly containing viral DNA) consumed at a vulnerable time, when the newborn has a relatively immature immune system (Preble & Piwoz, 1998).

This study is supported by (Rousseau et al, 2003) who did a longitudinal study and established that within women who breast-fed, median virus load in colostrum/early

milk was significantly higher than that in mature breast milk collected 14 days after delivery. This indicates that the risk of infant HIV infection is influenced by viral load in the breast milk, which is highest soon after birth.

Studies have been conducted which examine the concentration of HIV in breast milk and an analysis of studies conducted between 1988 and 1992 (four studies in which mothers acquired HIV post-natal in Africa and Australia; and five studies in which mothers acquired HIV prenatal in Europe, the U.S., Africa, and Australia) estimated a breastfeeding transmission rate of 14 percent from mothers who were seropositive at the time of delivery and 29 percent from mothers who had primary infection during the postpartum period (Dunn et al, 1992).

These studies prove that HIV can indeed be found in breast milk, although there may be various opinions on the quantity of HIV DNA or RNA. Whatever option an HIV positive mother has, if breastfeeding is one of the practices then the infant is exposed to contracting HIV.

2.4 Risks in varying breastfeeding practices

Variations in breastfeeding practices may pose varying risks to the infant in contracting HIV. Simply categorizing HIV positive mothers as breastfeeding or not or infants as breastfeed or not is not enough to explore the transmission risks associated with the various infant feeding practices. (Dewey et al, 1995; Launer et al 1990; Brown et al, 1989; Wright et al, 1989) examined the risk of HIV transmission by breastfeeding duration. These findings are supported by (NIAID, 1999) that HIV transmission is highest in the early months but continued through breastfeeding.

Early weaning has been proposed as a possible approach to limit HIV transmission through breast milk. Discontinuing breastfeeding at six months can cut the risk of HIV infections but this also exposes the infants to respiratory diseases and diarrhea, which are inhibited by agents in the breast milk

2.5 Deactivating HI virus in breast milk

Formula is not always a practical replacement feeding method in developing countries as it is expensive, stigmatizing for the mother, and frequently a source of disease when mixed with local sources of contaminated water. Various methods of deactivating the HI virus in breast milk have been proposed to curb transmission from mother to child. The suggestions are mainly for the HIV positive mothers in low resource areas who may not be able to afford replacement-feeding methods. These are flash heating, copper filtrations and the nipple shield.

2.5.1 Flash heating and pretoria pasteurization

Flash heating and pretoria pasteurization (longer duration heating); have been shown to effectively remove HIV from breast milk. The flash-heating method involves a mother first expressing 75-150 ml of breast milk into a glass jar. This jar is then placed in a pot of water, which is made to boil and then at this point the milk can be removed, and fed to the baby once it cools to an acceptable temperature (Ballard, I. 2007).

Flash heating utilizes materials that are readily available around the home, which could put the mother's cost of the device at almost zero. There is not much inconvenience as the boiling of the milk can be done during daily cooking. Again, both the flash heating and pretoria pasteurization methods have been proven to effectively remove HIV from breast milk, (Ballard, I. et al, 2005).

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Further research has also been conducted into the degree to which these methods damage the vitamin content of breast milk. No significant damage to the nutritional content of the milk was detected; though flash heating seemed slightly more nutritionally preservative, (Ballard, I. et al, 2008).

On the adverse side, the flash heating method requires more boiling, which may not be part of the mother's habit; require more effort, time and money for additional fuel. Incorporating the boiling may be easily done but manually expressing enough milk (often 600ml/day); storing milk and then feeding it to the baby may not be practical for the mother.

part of the mother's habit; require more effort, time and money for additional fuel. Incorporating the boiling may be easily done but manually expressing enough milk (often 600ml/day); storing milk and then feeding it to the baby may not be practical for the mother.

If a woman chooses not to breast feed a child, she may often be subject to stigma of being HIV positive, which many people are reluctant to admit. Acceptability studies looking into the heat treatment of breast milk in a Zimbabwean society have been performed (Ballard, I. et al, 2006). The results signify that flash heating could be acceptable if correctly used and understood. It was established that many people were hesitant of the flash heating method effectiveness and the boiling water on a frequent basis.

2.5.2 Copper

Research has shown that impregnating fibers and/or polypropylene filters with a copper-oxide mixture (70% Cu2O and 30% CuO, >99% purity (Borkow, G. 2008), can be used as a biocidal method of removing HIV-1. There has been no user-oriented device for a breastfeeding application. Copper, along with copper impregnated fibers, is very cheap (Borkow, G. 2008). They also suspect that copper-based filters might be more easily marketed ("all-natural") than chemical microbicide based ones.

Possible nutritional side effects of copper compounds intake in breast milk have not yet been fully researched, there is still need for extensive research. However, copper filtration is a prospective method for preventing MTCT and if proven effective and appropriate; it could be easily incorporated into the preparation of infants' milk.

2.5.3 Nipple shield

Another way to address the MTCT problem was proposed by a team headed by Stephen Gerrard from Cambridge University who designed a nipple shield. First they soaked a very thin cotton pad with sodium dodecyl sulphate (SDS), a detergent used by scientists to break down proteins for analysis. They then joined the cotton pad to a traditional nipple shield made of a very thin layer of silicone. Gerrard argued that SDS deactivates HIV in breast milk as it passes through the cotton layer (IDDS, 2008).

The major concern of this method notably that the shield could readily identify a woman as HIV positive. The researchers have countered the concern by proposing to market the shield as a route to deliver medicines or supplementary micronutrients.

identify a woman as HIV positive. The researchers have countered the concern by proposing to market the shield as a route to deliver medicines or supplementary micronutrients.

However, similar to copper, possible nutritional side effects of infant SDS intake via breast milk have not been extensively researched. In this case though, nutritional studies have been carried out and established that SDS can also cause skin irritation, depending on the concentration and duration of contact. Further concerns of SDS affecting taste, SDS has been shown to temporarily decrease the reception of sweet tastes (Urdaneta, S. 2004).

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Exploring the feasibility of the shield in different settings is crucial to assess its uptake in various communities considering cultural and customary practices, which differ from place to place. Flash heating could be culturally impossible to adopt as the main method to prevent MTCT. The nipple shield brings more optimism as HIV positive mothers can continue to breast feed which is culturally acceptable. This area needs to be explored further as it will benefit women in low resource communities who may find adopting alternative feeding practices challenging.

2.5.4 Wet-nursing

A less popular feeding method is wet-nursing which entails a woman breastfeeding a baby that is not her biological child. This method will help HIV positive mothers' infants to be breast-fed and receive all the nutritional value of breast milk. This practice was investigated in Tanzania and one participant in response to wet nursing said 'Oh, this is not easy! People will start asking the wet-nurse why she is breast-feeding so and so's child. So every time. . .[laughter]. . . your child is crying, you will have to run to the neighbour? The breast milk of another mother is not safe. Even if the wet-nurse was HIV-tested today, she might become infected while she is wet-nursing, and she will then infect the child,' (De Paoli, M. et al 2003). All the concerns raised in the study reflect socio-cultural barriers, which influence HIV prevention. These have to be incorporated into any successful prevention intervention.

2.6 Mother and child considerations in PMTCT

The above considerations for prevention of mother to child transmission (PMTCT) of HIV through breastfeeding need to fulfill the needs of both mother and child for them to be effective. These should be low cost and affordable by the family without affecting their livelihood. The convenience of the nipple shield devise is critical in terms of time and ability to use it away from home. For the child, if the devise can imitate breastfeeding as close as possible it is best. The devise must be easy to clean and maintain with no side effects on both the child and mother.

2.7 WHO Infant feeding framework

The HIV and Infant Feeding Framework for Priority Action, (WHO, 2003) recommends actions related to infant and young child feeding taking into consideration the special circumstances associated with HIV/AIDS. The aim is to reduce child mortality and HIV transmission while improving breastfeeding among the general population.

The World Health Organisation (WHO) recommends the following for mothers with HIV:

 Avoid breastfeeding entirely when replacement feeding is acceptable, feasible, affordable, sustainable and safe

- Breast-milk should be fed exclusively during the first months in cases where the mother chooses to breastfeed
- If mothers choose not to breastfeed from birth or stop breastfeeding later, they should be provided with specific guidance and support for at least the first 2 years of the child's life to ensure adequate replacement feeding.

Other preventive measures jointly proposed by the WHO, UNICEF and UNAIDS include the expression of colostrum, artificial feeding with formula or animal milk, pasteurisation of maternal milk, reduction of breastfeeding duration or resorting to a seronegative wet-nurse (WHO, 2003; UNAIDS, 2001).

The guideline supports the idea that exclusive breastfeeding is superior to any feeding method. Not breastfeeding for the first two months in low resource areas is associated with high infant mortality due to infectious diseases. Due to the need to minimize HIV transmission and reduce mortality and morbidity, the guidelines state that, "when replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of breastfeeding by HIV infected mothers is recommended. Otherwise exclusive breastfeeding is recommended during the first months of life," (WHO, 2003).

Although the guidelines address the recommended infant practices for breastfeeding mothers, and especially the HIV infected, they do not articulate how these choices or decisions should be made other than that HIV infected women should receive specific guidance through counseling (De Paoli, 2003). Many external factors influence these choices like income, marital status, occupation, educational status and other factors militating against breastfeeding or replacement feeding as suggested by (Muko et al, 2004).

3 CHAPTER 3: Research design and methodology

This study was conducted in January 2010. The Michael Mapongwana clinic is situated in a low resource community of Khayelitsha in the Western Cape region of South Africa. This suburb is estimated to have one of the highest HIV prevalence rates in South Africa with a population of about 500 000 and an HIV adult prevalence of 32%. The HIV prevalence for mothers at antenatal clinics is 29.1%, (TAC, 2008). The HIV clinic offers treatment of opportunistic infections and ARV treatment, counselling and support. At the antenatal clinic, trained staff, counsellors and mentor mothers offer PMTCT services.

3.1 Target group and sampling method

A total of 22 women with children up to 2 years old were approached and asked to participate in an interview during their clinic visit. Of those approached, 20 participated. In addition, two healthcare workers were also approached and asked to participate in the same study.

The participants were recruited in collaboration with the healthcare staff at the clinic. The staff had been thoroughly informed about the purpose of the study and asked to help with the identification of HIV positive women with a child or children up to 2 years of age to participate in the study. This was important, as some of the mothers did not visit the clinic with their children so it would be difficult to identify them.

The study employed the random sampling method. The researcher approached the identified HIV positive women randomly and asked them to participate in the study. Two healthcare workers were also randomly approached to participate in the survey.

The interview guide designed by the researcher was be used to find out and capture the information on factors that influence infant feeding practices for HIV positive mothers with infants up to two years.

The study was carried out by use of questionnaires. The researcher administered 20 questionnaires to 20 HIV positive mothers. A different survey was held with 2 randomly selected healthcare workers who directly deal with the infected mothers.

The criteria excluded HIV positive mothers or healthcare staff that refused to participate or withdrew during the interview. The inclusion criterion was HIV positive mothers with a child or children aged 2 or below who were collecting ARV's, visiting a doctor at the ARV clinic or visiting the PMTCT counsellors at the clinic on the day of the interviews. Also included were healthcare workers directly involved in giving service to the HIV positive mothers.

Document with WHO breastfeeding guidelines for HIV positive mothers will be used as a secondary source of data. A document analysis on the WHO breastfeeding guidelines for HIV positive mothers has also been done. Finally, the questionnaire allowed the researcher to explore whether the MTCT services meet the need of the participants.

3.2 Ethical Clearance

Research and ethical clearances were obtained from the Stellenbosch University Ethics Committee, Africa Centre for HIV/AIDS Management at Stellenbosch University and The Provincial Government of the Western Cape, Department of Health.

Prior to administering the questionnaire, the mothers were informed the purpose of the study and their consent sought. They were asked to sign informed consent forms, which they gave to the researcher, and they were also given their own copy.

No names or data that could identify individuals surveyed was collected. The forms were numbered 1 to 20 and the data was treated in a strictly confidential manner.

3.3 Data Analysis

All the data was recorded on the questionnaire by the researcher during the survey. During the analysis, data was analysed for themes concerning infant feeding in order to determine which factors influenced infant feeding practices.

4 CHAPTER 4: Key findings and discussion

A total of n=20 HIV infected mothers with a child or children up to 2 years participated in the study and 2 healthcare workers from the clinic and m2m. Mothers2mothers is an NGO at the clinic who provide education and support for pregnant women and new mothers living with HIV/AIDS.

Results indicated that the majority of mothers in the study (95%) were using or used formula only to feed their children for the first 6months while the remaining (5%) chose mixed feeding for their children.

The results show that amongst the infants up to 2 years, whose mothers were surveyed, (45%) were HIV negative and (20%) were HIV positive. (25%) of the children had not been tested since the children were not yet 2 months of age. The mothers confirmed that the clinic had given them dates to bring their children for testing. The rest, (10%) reported that they were not sure and they had not been asked to test the children for HIV at the clinic. Of these children, (40%) were less than 6 months and the rest (60%) were above 6 months.

It emerged in the discussions with the women that mothers initially used formula feeding before introducing other foods in the children's diet. It came forward in the discussion with the healthcare workers that all HIV positive mothers registered at any PMTCT clinic could collect formula to feed their children for the first six months. All the mothers (100%) also confirmed that they were supplied with ten tins of formula at the PMTCT clinic monthly although less confirmed that they were actually collecting it.

Replacement feeding (formula) was highly valued by the 20 surveyed mothers and the 2 healthcare workers. 90 % of the women completely agreed that infant feeding formula was the best way to feed the child. Formula feeding is the preferred infant feeding practice whilst only 10% agreed that exclusive breastfeeding was good.

The reported popular feeding practice among the HIV women was formula feeding and the response to why they chose this was,

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[&]quot; always follow what the clinic says."

"Breast milk is not good. The best thing is not to breast feed because child might become infected."

The discussion with the healthcare workers established the antenatal and post natal care given to the mothers. All pregnant women are advised and recommended to test for HIV and those whose results are positive are referred to the support group for HIV infected women. According to the healthcare workers, the women are educated on,

"Mothers' nutrition, feeding options, the right to breastfeed exclusively as well as formula feeding. We always tell them the pros and cons of both. We teach them it is very bad to mix feed, do not mix breast with formula. If you give pap with formula the child may have stomach problems. We teach them how to prepare formula and how to put the baby on the breast. This is done before they go to labour."

The infant feeding formula is made available free of charge from the clinics monthly to HIV infected mothers. They refer to it as "*Pelagon*" and the government subsidises the cost.

The healthcare workers mentioned that,

"Many mothers usually choose formula feeding. They just do not want to infect their children, so why not choose free milk with no risk. The mothers have responded very well to this program"

The healthcare workers did not mention a specific follow up program to monitor the mothers' feeding practices and preparation of infant food. They reported that mothers continued collecting the formula for the allotted six months. The mentor mothers from the support group do home visits only to mothers who request them.

The initiative by the South African government has provided the mothers an option for their feeding methods. The surveyed mothers reported that this provision led to their preference for the replacement feeding practice. The healthcare workers pointed out that about (5%) of the mothers who attended PMTCT chose to breast feed if they knew they were infected by HIV.

The age group 31 - 40 years had the highest number of mothers (50%), followed by the age group of 20 - 30 years (40%) with the fewest mothers in the age group above 40 years (10%). Table 1 shows the correlation of the age of the mothers involved in the study and their feeding choice. Exclusive formula feeding was found to be consistently practiced throughout the varying age groups and mixed feeding only observed in the older age group.

| TABLE 1. AGE OF MOTHER AND FEEDING PRACTICE | | | | |
|---|----------|--------------------------------------|-------------------------|---------------|
| Age | Number | Exclusive formula for first 6 months | Exclusive breastfeeding | Mixed feeding |
| 20 – 30 | 8 (40%) | 8 (40%) | | |
| 31 - 40 | 10 (50%) | 10 (50%) | | |
| 41 - 50 | 2 (10%) | 1 (5%) | | 1 (5%) |

Table 2 shows the educational level and feeding practice. A large proportion of the mothers have received secondary education (60%) although some have not completed and passed the standard matric requirements. Of the mothers, only (30%) had attended primary school up to Grade 7 (30%). The smallest group was that of mothers who had received tertiary education at (10%). From the mothers who received only primary education (5%) practice mixed feeding. The more educated the mother, the more chances she would choose replacement or formula feeding. It was found that there is no strong relationship existing between education level and infant feeding.

| TABLE 2. EDUCATIONAL LEVEL AND FEEDING PRACTICE | | | | |
|---|----------|--------------------------------------|-------------------------|---------------|
| Formal Education | Number | Exclusive formula for first 6 months | Exclusive breastfeeding | Mixed feeding |
| Primary | 6 (30%) | 5 (25%) | | 1(5%) |
| Secondary | 12 (60%) | 12 (60%) | | |
| Tertiary | 2 (10%) | 2 (10%) | | |

Table 3 shows the marital status of the mothers and their feeding practices. The majority of participants are single (60%). It emerged from the respondents that their partners had deserted most of the single mothers once they discovered and disclosed their HIV status. Several mothers said, "My partner ran away after I disclosed my status so now I am single." Few mothers are cohabiting with their partners (15%) and the rest (25%) are married either traditionally or in the court of law. It was observed that despite marital status, a great number of mothers chose to feed their children with formula only for the first six months after birth.

| TABLE 3. MARITAL STATUS AND FEEDING PRACTICE | | | | |
|--|----------|--------------------------------------|-------------------------|---------------|
| Marital Status | Number | Exclusive formula for first 6 months | Exclusive breastfeeding | Mixed feeding |
| Single | 12 (60%) | 11 (55%) | | 1 (5%) |
| Married | 5 (25%) | 5 (25%) | | |
| Cohabiting | 3 (15%) | 3 (15%) | | |

Table 4 displays the occupation of the respondents and their feeding practices. The majority of mothers are unemployed (55%). The respondents revealed that they relied on the government grant to survive and care for their children. Among those who are employed (25%), they revealed that they do part time work, which is not reliable, and the rest (20%) were self-employed doing menial tasks like selling sweets and chips to earn an income. The participants who chose formula feeding mentioned that it was solely because the government was providing it for free in the PMTCT clinics. There was no direct relationship observed between method of feeding and occupation.

| TABLE 4. OCCUPATION AND FEEDING PRACTICE | | | | |
|--|---------|--------------------------------------|-------------------------|---------------|
| Occupation | Number | Exclusive formula for first 6 months | Exclusive breastfeeding | Mixed feeding |
| Self employed | 4 (20%) | 4 (20%) | | |
| Employed | 5 (20%) | 5 (25%) | | |
| Unemployed | 11(55%) | 10 (50%) | | 1 (5%) |

The respondents' knowledge of mother to child transmission of HIV is shown in Table 5. The results outline that most of the mothers (95%) have knowledge on one or more aspects of PMTCT and this has directly influenced their feeding practices. Of the remaining 5% knows nothing about PMTCT and this has a direct relationship to their infant feeding practice.

| TABLE 5. KNOWLEDGE OF PMTCT | | |
|--------------------------------------|----------|--|
| PMTCT aspect | Number | |
| Transmission during pregnancy | 11 (55%) | |
| Transmission during delivery | 13 (65%) | |
| Transmission during breastfeeding | 13 (65%) | |
| ARV prophylaxis / dual therapy | 17 (85%) | |
| Exclusive breastfeeding for 6 months | 2 (10%) | |
| Safer sex practice (use condoms) | 7 (35%) | |
| Caesarean birth | 10 (50%) | |
| Do not know anything | 1 (5%) | |

Table 6 below depicts some factors that influence against formula feeding option. The most common is social at 55%. The social concept covered issues of stigma and discrimination, no support from family, child not getting enough food, disclosure and time constraints to prepare formula.

| TABLE 6. FACTORS THAT INFLUEN | CE AGAINST FORMULA FEEDING |
|-------------------------------|----------------------------|
| Economic | 6 (30%) |
| Cultural | 2 (10%) |
| Social | 11 (55%) |

Stigma and discrimination is a major barrier in feeding practices. Of the surveyed mothers (55%) mentioned that society was inquisitive as to their feeding options. One respondent said,

"People that I met at the ARV clinic revealed my status to my neighbours and now they laugh at me and do not want my children near them, they beat them up. Look at my child's head they beat him. I have to breastfeed."

"I have not told anyone, I am scared. It has affected my feeding because I have to hide and lie that I have a breast problem."

"There is a lot of stigma; people ask why I give pelagon instead of breastfeeding. I do not care what they say, I have to be strong for my baby, and I am strong."

Many societies are now aware that HIV infected mothers are not recommended to breastfeed if there is alternative feeding. If a mother uses replacement feeding, this raises a lot of suspicion especially in the close-knit societies

Economic factors included cost of formula, cost of transport to go to clinic to collect milk and a lack of clean water. Respondents all appreciate the initiative by the government to provide them with formula for replacement feeding. Only 30% of the respondents mentioned an economic factor as a barrier influencing against formula feeding.

"Sometimes water is closed by the department of water and my child gets hungry, because formula must be made from clean water. When the child gets older the formula is not enough, I cannot afford to buy."

"The clinic is far, I can't travel twice to collect ARV's and then collect pelagon. I do not know I will see. I do not have money because I am not working."

The least social factor is cultural, 10% of the mothers had directly experienced any cultural influence against formula feeding. Furthermore, respondents mentioned that their families gave them pressure to breastfeed as it is the cultural practice.

"My mother did not want me to formula feed; she said it is cultural to clean the baby's eyes and ears with the breast milk. I am accused of adopting another people's culture."

"My mother does not understand, she argues that the baby grew inside of me living in a body with HIV, how can he be negative? She insists that I must breastfeed. I have come with her to the support group so the mentor mother can speak to her."

Table 7 below illustrates some of the factors that influence against breastfeeding. The most prominent factor is the mothers' medical condition. Some mothers (65%) did not breastfeed and acknowledged that they were too ill to do so. They alluded to low CD4 count and feared HIV transmission risk would be higher. Furthermore some mentioned that although they were taking ARV's, they did not feel safe to breastfeed as these did not destroy all the HIV in the body. Noteworthy are the (40%) who took the advice of the healthcare worker. Those who ascribed their not breastfeeding to free formula (30%) alluded to the fact that the clinic provided for this need.

| TABLE 7. FACTORS THAT INFLUENCE AGAINST BREASTFEEDING | | |
|---|----------|--|
| Medical condition | 13 (65%) | |
| Advice of healthcare worker | 8 (40%) | |
| Free milk | 6 (30%) | |

Respondents who had a child after discovering their HIV status were (55%) and (45%) had not had another child. Out of these children, (10%) tested HIV positive, (30%) tested negative and (15%) have not yet been tested. The clinic tests the children after two months and some of the children had not reached that age yet. In addition, only (15%) of the mothers mentioned that previous experience with other children influenced their feeding practices. (10%) believed that they should have refrained from breastfeeding and their babies would have been negative. The (5%) chose to breastfeed because the first child was growing up fine hence there would be no problem with the small one.

The respondents acknowledged the availability of PMTCT services at the clinic. The highest rating was the availability of ARV therapy to the infected mothers (100%), nutritional support, family planning services, early infant diagnosis and ante natal testing and counselling all got a rating of (90%). The least available services was said to be psychosocial support (25%). Only (5%) had no idea of the PMTCT services at the clinic. The healthcare workers informed the researcher that the clinic was very busy and they were not adequately staffed.

Respondents (60%) required additional psychosocial services, as they had to deal with their status and also caring for the infants. Mothers (60%) mentioned the need to be educated on what else they can give their children if they refuse the formula supplied at the clinic. (40%) of the surveyed mothers required additional information on how to give their children solid food. (35%) require information on what else to feed their children if the pelagon is not enough. The least (10%) need information on how to impart lessons to the people they leave their children with, as there is a risk that they might be fed with solids.

Table 8 below depicts the need places where further PMTCT information can be given. Some respondents, (40%) emphasized the need to give PMTCT at church gatherings to help everyone understand the concept. They think this would ensure that the men are also included in PMTCT education.

| TABLE 8. PMTCT INFORMATION DISEMINATION PLACES | | | |
|--|----------|--|--|
| Church gathering | 8 (40%) | | |
| Funeral gatherings | 2 (10%) | | |
| Support groups | 10 (50%) | | |

Funeral gatherings are at (10%) as respondents felt that people will be mourning and they will not listen to any information. Support groups are the most popular at (50%). Other respondents who cannot attend support groups further suggested other alternatives as means to disseminate PMTCT information.

Mothers (20%) also suggested use of the media (radio, television, newspapers, and pamphlets in public areas). These could involve the whole communities and even the men so there is no stigma and cultural pressures. This would also reach the mothers who work. Moreover, the respondents (40%) suggested community mobilisation where volunteers could go door to door as some people were dying in their home with their children. Only (10%) felt that this information should remain in the clinic, as it would trigger a lot of discrimination.

4.1 Discussion

In South Africa, breastfeeding is culturally acceptable and regarded as the best feeding practice for a child. The strong cultural practice and benefits of breastfeeding for the baby and the social norms in favour of breastfeeding lead to stigma and discrimination against the mothers who choose infant formula. In a study by Small (1998) it is highlighted that not breastfeeding would be not be easily acceptable in the African society.

Despite the strong breastfeeding practice in the African culture, in the study (95%) of the mothers chose to give their children infant formula exclusively. The practice of replacement feeding amongst the surveyed mothers is high. The women did not show any knowledge of alternative replacement feeding practices except for infant formula. Other forms of replacement feeding like cow's milk were not suggested, as the only form known to them is infant formula.

There seemed to be a lack of information on other replacement feeding practices such as wet nursing, Pretoria pasteurisation (heat treating breast milk) and cow's milk. In an earlier study, De Paoli (2003) reported that these practices would also increase society's stigma towards mothers who chose this. They would be easily identified as HIV positive. Further to this, the issue of wet nursing is not absolutely safe as the wet mother could contract HIV during feeding and the HIV infected mother would have to disclose her status to her. Cost would also be a barrier decided against alternative replacement feeding practices, as the mothers would need to buy the cow's milk or fuel for heat treatment.

Heat treatment is not popular and only (5%) of the surveyed women alluded to any knowledge of it. Although she was informed this by a healthcare worker in another hospital, she still was very suspicious as to the effectiveness of destroying the virus through heat treatment. This highlights that it would be a challenge to introduce this form of replacement feeding. The challenges it would pause are availability of fuel to heat the milk and specific training of the mothers to practice this alternative.

(55%) of the mothers reported that their partners had deserted them when they had disclosed their HIV status to them. The women's marital status however did not have much of a negative impact on the infant feeding practices. Some mothers, (30%) mentioned a lack of family or partner support and (90%) confirmed that the clinic gave them this support. Although they report that this has no influence over their feeding practice, an earlier study by Muko et al (2004) shows that strong family support has been shown to increase adherence to chosen infant feeding practice. The PMTCT program in place should consider allowing the women's partners to attend PMTCT programs, test for HIV and receive education on infant feeding.

A majority of the mothers were between 20 – 39 years. Most mothers only tested for HIV because if they were pregnant which may suggest that they have not chosen to establish their HIV status and that of their partner before engaging in sexual activities. The healthcare workers educate them on safer sex practices at antenatal clinic to minimise new infections. The reason is to minimise new infections, which may increase their viral load at acute stages of infection. This in turn might increase the chances of MTCT especially for those who choose breastfeed. The challenge is that education alone does not change risky behaviour especially if they receive it in the absence of their partners.

Several studies have reported that women find it difficult to use replacement feeding practices because of the related social stigma, Muko et al (2004) & De Paoli et al (2003). The mothers surveyed were confident about their feeding practice although (55%) mentioned their experiences related to stigma and discrimination from the communities they belonged to, their partners and families. It seems that despite this social barrier, they have chosen to face it to protect their children from the possibilities of contracting HIV through feeding their children with breast milk.

The fact that (95%) of these women had never breastfed their children, might show their level of inexperience in this feeding practice, breastfeeding. They have an exaggerated confidence in infant formula. Of the women surveyed, only (10%) expressed the fact that exclusive breastfeeding would be a possible feeding practice that would limit the chances of the child contracting HIV. This could also indicate a change, where the once culturally and socially upheld breastfeeding practice may be on the decline.

The safety of exclusive breastfeeding was regarded with suspicion and questioned by most of the mothers. This remains a challenge in the community to encourage the mothers to consider adopting it. Further research is needed to establish whether mothers who want to breast feed their children because of the various barriers against replacement feeding would adopt this as a feeding practice if educated on how to do it despite the availability of infant formula.

The WHO (2003) Feeding Framework recommends that replacement feeding should only be given where it is feasible and safe. In the study, (10%) of the mothers

mentioned that sometimes there is no clean water to prepare the formula. This is a low resource community where a chance that they can afford to buy water to prepare the formula is minimal, pausing a health risk to the infants.

With (55%) of the women unemployed and a further (20%) self-employed with menial jobs, affordability of infant formula would be beyond their reach. This would compromise their commitments to practice replacement feeding using infant formula.

The education on infant nutrition is limited to advice on what feeding practice mothers should adopt. Since most mothers (95%) practice replacement feeding using infant formula, there is no emphasis on the issue of transition from breastfeeding to replacement feeding. Of the surveyed mothers, (60%) of their children were older than 6 months. They continue to use formula and have introduced other solid food gradually.

Other critical education such as introduction of other foods and liquids into the child's diet to avoid mixed feeding therefore increasing the chances of MTCT should be addressed. The clinic healthcare worker has an important role in assisting the mothers with their feeding choices, as well as the actual practice.

The time after birth is critical for re-counselling on infant feeding and additional support for the woman's decision to lower the risk of mixed feeding, Community and International Nutrition (2003). The challenge for the clinic is to ensure that the counsellors implement this critical stage effectively.

The (10%) group of the surveyed mothers mentioned the need for training on giving their infants solid foods. The challenge for the healthcare workers is to give adequate training to the mothers on the transition from exclusive breastfeeding or infant formula only to solid food and other liquids.

The Western Cape Department of Health offers free infant formula as a method of replacement feeding to the HIV infected mothers. This is an approach to minimise transmission of HIV through breast milk especially through mixed feeding practices. In an earlier study, Sante (2002) submits that the feasibility of replacement feeding with other substitutes is uncertain. In this study, the mothers are given free formula

for the first 6 months. The mortality of the infants is not known, it may be a safe practice to minimise the risk of HIV transmission but pauses a challenge to ensure correct preparation. Unfortunately if the mothers do not prepare the formula precisely as required to ensure it is free from contamination, infant mortality may remain high. Sante (2002) further suggests that exclusive breastfeeding for a few months could carry a lower risk of death than replacement feeding. A further comparison of infant mortality due to HIV and other causes would assist to establish the effectiveness of this program.

The provision of free formula has indirectly communicated to the HIV infected mother the fact that they do not have to breast feed because there is free formula. Coovadia (2000) put forward the argument that providing free formula poses dangers by destroying the culture of breastfeeding among the mothers. "The balance between breastfeeding and its advantages and the balance between bottle-feeding and its serious disadvantages to the child's health," Coovadia proposes that this has been lost. Therefore he further suggests that disadvantaged and women who will not have access nor the means to continuously prepare and provide for the safe bottle-feeding of her child, are better off breastfeeding exclusively for 6 months and then switching to local and family food."

The preference for breastfeeding in this study was related with stigma rather than cost, as infant formula is free of charge. The mother only collects the formula on specified dates. (5%) chose to breastfeed their baby, this group is also single and this may be attributed to the lack of support from family among other factors.

Aside from cost and stigma, which are factors influencing against replacement feeding; pressure from significant family members was also detected to be a tough factor by most of the participants. Mothers who were seen with infant formula, specifically pelagon given in the clinic, would heighten societal stigma against replacement feeding as they were automatically labelled HIV positive. Since the African culture emphasises breastfeeding, it will take some time for people to accept replacement feeding with infant formula.

As illustrated in the results, mothers rely on healthcare workers' advice especially the mentor mothers in the support groups. All the mothers who attend antenatal care and

are HIV positive are sent for counselling and advised to join a support group. Only (10%) of the mothers were not in a support group. This heavy reliance is a challenge on healthcare workers and mentor mothers as the mothers' decision making is much challenged. In an earlier study, De Paoli et al (2003) established that given the complexity of the information to be conveyed, informed decision-making also entails educational challenges for the counsellors.

It was observed during the survey that the counsellors were biased towards promoting replacement practice since formula milk is available for free. It is paramount that HIV infected mothers are furnished with all the correct information and empowered to make their own decisions. Whatever choice they make, the healthcare workers must always give them support.

The healthcare workers might have an imposing attitude to the HIV infected mothers. Moreover in this community where only (10%) of the mothers have attended a tertiary institution, mothers rely on the guidance of the healthcare workers. The surveyed women lacked knowledge of other replacement feeding methods except for infant formula and exclusive breastfeeding. The challenge is to ensure continuous training of the healthcare workers, which is critical to the information they will impart to mothers. The mentor mothers should be trained to abstain from personal biases when they educate mothers.

Apart from the advice given by the healthcare workers to avoid breastfeeding, (40%) of the mother attributed their choice of feeding to the fact that their CD4 count was low. Mothers risk higher chances of infecting their children with HIV if their viral load is high and therefore an increased chance of opportunistic infections. (60%) received AZT and nevirapine as HIV prophylaxis during labour and (40%) were already on HAART prior to falling pregnant.

Another study done on HAART therapy showed that, "an ideal situation would be safe, exclusive breastfeeding to be used in conjunction with HAART. There is almost a zero percent chance of mothers who take the medication and who give their offspring only breast milk, to pass the virus on to their babies," Coovadia cited by Taylor (2009).

At the clinic, HIV seems to be an overwhelming problem but the mothers seem to have no difficulties in sharing their HIV status and that of their children. The provision of free formula at the baby clinic seems to have highly influenced their feeding practices. A further study in a low resource rural community where clinics are few and dispersed will be important to establish the factors influencing the infant feeding practices adopted by mothers.

4.2 Limitation

The population sample was small (n=20) therefore the findings may not be representative of the wider Khayelitsha population but are specific to the participants. This warrants further study at a wider scale.

Another limitation of this study is that the interview tool designed for this study seems to be useful on identifying infant feeding practices but did not encompass the barrier that is created by providing free formula.

5 CHAPTER 5: Conclusion and Recommendations

The study has shown that despite the strong African culture supporting breastfeeding, the mothers surveyed reported practicing replacement feeding for their infants. Most mothers practice replacement feeding and infant feeding formula is used in place of breast milk.

Numerous factors were found to be barriers against replacement feeding in the survey. These include cost, stigma and discrimination and a lack of support from a significant family member especially amongst the single mothers. The mothers' infant feeding practice can be influenced by many socio-cultural factors. For the HIV infected mothers, this decision is mainly influenced by the immediate need to avoid mother to child transmission of HIV. The feeding practice adopted is to eliminate any possible contact with the mother's HI virus.

The PMTCT program by m2m at the clinic has been a useful tool in educating mothers on infant feeding and other dimensions of HIV transmission from mother to child. The PMTCT program in Michael Mapongwana clinic addresses issues on personal health for the HIV positive mothers, good nutrition during pregnancy, infant feeding practices and psychosocial support at the support groups. Concerns about stigma and discrimination are not addressed and the mothers experience these in the community. Aligning all the PMTCT intervention programs with the cultural practices of the people may be helpful. This may help to remove much of the stigma around mothers who choose not to breastfeed. Moreover, the women are already targets of stigma and discrimination because of their known or assumed HIV status. There is a need for practical ways to empower women to be able to deal with these issues in their families and community at large.

Furthermore, the focus of the intervention has been to minimize MTCT of HIV, provide infant feeding formula to the mothers to practice replacement feeding, medical attention in providing HAART therapy or dual therapy. The long-term psychosocial needs of the mother and child are not part of the PMTCT program. These services should find suitable ways to include the mothers' partners to ensure that they will get support in the chosen feeding practice. Male involvement in

supporting further PMTCT outcomes is critical for the success of these ongoing efforts to curb MTCT at the clinic.

Blanket policies on providing free infant formula to HIV infected mothers disregards the diverse social, economic and cultural alternative resources. These may not work in all areas and therefore the healthcare workers should be trained and empowered to adopt the best policy for their specific district. It is also critical to promote exclusive breast-feeding practices for infant feeding as other mothers will end up adopting mixed feeding increasing the chances of MTCT.

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Annexes

| Tool 1: Questionnaire on Factors influencing infant feeding practices for HIV positive mothers |
|--|
| Questionnaire ID |
| Name of Interviewer |
| Date of interview |
| Guidance for introducing self and the purpose of the interview: |
| My name is and I am a student at Stellenbosch University conducting research on factors influencing infant feeding practices for HIV positive mothers. The purpose of this interview is to obtain information that will help me to understand the current infant feeding practices for HIV positive mothers and what influences these. |
| The survey is voluntary and the information that you give will be confidential. |
| Could you please spare some time for the interview? |
| SECTION 1: CLIENT DEMOGRAPHIC DATA |
| • Age of Client |
| Age of child |
| Marital Status 1. Single 2. Married 3. Co-habiting 4. Widowed 5. Divorced/Separated |
| Education 1. Never been to school 2. Primary 3. Secondary 4. Tertiary or more |
| Occupation1. Self employed |

2. Employed

| | 3. Unemployed | |
|---|---|--|
| | | |
| • | Treatment being taken at birth of child | |
| | 1. Dual therapy | |
| | 2. HAART | |
| | 3. No treatment | |
| | 4. Other | |
| | | |
| • | HIV status of child | |
| | 1. HIV negative | |
| | 2. HIV positive | |
| | | |

SECTION 2

| 1. | Do you know about Prevention of Mother to Child Transmission (PMTCT) of HIV? |
|----|--|
| | a. Yes b. No |
| 2. | If yes what do you know? If no skip to number 3 |
| | |
| | |
| | |
| 3. | In what ways can HIV be transmitted from a mother to child? |
| | a. During pregnancy b. During delivery c. During breast-feeding d. Other |
| | |
| 4. | In what ways can transmission of HIV from mother to child be prevented? |
| | a. ARV prophylaxis b. Exclusive breast-feeding for six months c. Safer sex practices (use of condom) d. Caesarean birth e. Other |
| 5. | What is your current feeding practice for your child? |
| | a. Formula only b. Breastfeeding only c. Mixed feeding (breast feeding and other foods or liquids) d. Other |

| 6. | What are the factors that have influenced your infant feeding choice? |
|----|---|
| | |
| | Economic |
| | a. Cost of formula |
| | b. Lack of clean water |
| | c. Formula not accessible regularly in PMTCT clinics |
| | · · |
| | |
| | |
| | |
| | Cultural |
| | a. Cultural practice to breast-feed |
| | • |
| | Social |
| | a. Stigma and discrimination from family and society |
| | b. No support from family |
| | c. Child not getting enough food |
| | d. Time constraints to prepare formula |
| | d. Time constraints to propure formula |
| | Medical condition |
| | a. CD4 count high – specific figure if known |
| | b. CD4 count low – specific figure if known |
| | c. On HAART |
| | |
| | d. On dual therapy |
| | e. Not on any medication |
| | Other |
| | Offici |
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| | |

7. Do you get support to care and feed the child? If no skip to no. 9

| | a. Yes b. No |
|----|--|
| 8. | If yes, who are the key support people? a. Partner b. Significant family member c. Community d. Other |
| | u. Other |
| | |
| | |
| 9. | Who have you disclosed your HIV status to? a. Partner b. Significant family member c. No one |
| | d. Other |
| | |
| | |
| 11 | . Have you had other children since discovering your HIV status? If no skip to 13 a. Yes b. No |
| 12 | If yes, what is the child's / children's HIV status?a. HIV negativeb. HIV positive |

| 13. | | hat was | | | | feedin | ng p | oracti | ce | and | have | they | influence | d your |
|-----|---------|---|-------------------|---------------|-----------|---------------|-----------|-------------|-----------|-----------|-------------|---------------|---|-----------------|
| | | | | | | | | | | | | | | |
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| | ••• | | | | •••• | ••••• | | | | •••• | | | | •••• |
| 14. | Wl | hat PM | ГСТ se | ervices | are | availa | ble i | in yo | ur c | omn | nunity | y? | | |
| | a. | Basic a | antenat | tal care | e | | | | | | | | | |
| | b. | Ante n | atal te | sting a | nd c | ounse | ling | | | | | | | |
| | c. | ARV 1 | egime | ns for | PM7 | ГСТ | | | | | | | | |
| | | Cotrin | | | | axis | | | | | | | | |
| | | Early i | | _ | | | | | | | | | | |
| | | Care/s | | | | d child | ren | | | | | | | |
| | _ | Psycho | | | rt | | | | | | | | | |
| | | Nutriti Family | | | m vi o c | 20 | | | | | | | | |
| | j. | ARV t | - | _ | IVICC | <i>-</i> 3 | | | | | | | | |
| 15. | Do | you fir | nd thes | e servi | ices | adequ | ate? | | | | | | | |
| | a | Yes | | | | | | | | | | | | |
| | | No | | | | | | | | | | | | |
| 16. | | no, wha ogramm | | tional | servi | ices do | o yo | u fee | el sh | oulo | l be i | nclude | ed in the F | PMTCT |
| | ••• | • • • • • • • • • | | • • • • • • • | • • • • • | ••••• | • • • • • | • • • • • • | •••• | • • • • • | • • • • • • | • • • • • • | ••••• | ••••• |
| | ••• | • • • • • • • • • | • • • • • • • • | • • • • • • • | • • • • • | ••••• | • • • • | • • • • • | •••• | • • • • • | • • • • • • | • • • • • • | ••••• | ••••• |
| | • • • | | | | • • • • • | | • • • • • | • • • • • | •••• | • • • • • | • • • • • | • • • • • • | ••••• | ••••• |
| | ••• | ••••• | • • • • • • • • • | • • • • • • • | •••• | ••••• | • • • • | ••••• | •••• | •••• | • • • • • • | ••••• | | ••••• |
| 17. | Wl | hat othe | r infor | mation | ı wo | uld yo | u lil | ke to | get | in P | MTC | T infa | nt nutrition | n? |
| | | | | | | | | | | | • • • • • • | | | |
| | ••• | • | • • • • • • • | • • • • • • • | • • • • • | • • • • • • | • • • • • | • • • • • | • • • • • | • • • • | | • • • • • • • | • | • • • • • • • • |
| | ••• | • | • • • • • • • | | • • • • • | • • • • • • • | • • • • • | • • • • • | •••• | • • • • • | • • • • • • | • • • • • • | • | ••••• |
| | | | | | | | | | | | | | | |

| 18. large? | . How | would | you like | that | informa | ition 1 | to re | ach | you | and | the | communi | ity at | |
|---------------|---|-----------------|--|-------------|-------------------|-------------|-----------|-----------|-------------|-----------|-----------|---|---------|--|
| | a. b. l c. d. | Funeral Sı | hurch gat gathering upport gro MTCT cli | gs oups | gs | | | | | | | | | |
| | Other | | | | | | | | | | | | | |
| | | | | | | | • • • • • | • • • • • | | | | • | | |
| | • | | • | • • • • • • | • • • • • • • • • | • • • • • • | • • • • • | • • • • • | • • • • • • | • • • • • | • • • • • | • | •••• | |
| | • | | • • • • • • • • • • • • | • • • • • • | • • • • • • • • • | • • • • • • | • • • • • | • • • • • | | • • • • • | • • • • • | • | • • • • | |
| | ••••• | • • • • • • • • | • • • • • • • • • • • • | • • • • • • | | | • • • • • | • • • • • | • • • • • | | • • • • • | • | • • • • | |
| | • • • • • • • • | • • • • • • • • | • • • • • • • • • • • • | • • • • • • | • • • • • • • • | • • • • • • | • • • • • | • • • • • | • • • • • | • • • • • | | | | |

Thank you for the responses; do you have anything else that you need clarity on?

Tool 2: Interview Guide for Healthcare worker

I am here today conducting research on factors that influence infant feeding practices for HIV positive mothers in a low resource community. The purpose of this interview is to obtain information that will help to understand the current factors that influence infant feeding for HIV positive mothers. I will share a few questions with you and I would like to ask you to be as open and free as you can be, as this will help the future of PMTCT through infant feeding choice in HIV positive mothers. When I ask questions, I kindly ask you to share as much as you can.

| 1. | Ple | ease share with me what education you offer the HIV positive mothers on infant | | | | | | | | | | |
|----|------------------------|---|--|--|--|--|--|--|--|--|--|--|
| | feeding and nutrition? | | | | | | | | | | | |
| | | | | | | | | | | | | |
| | 2. | At what stage do you give infant feeding counseling? a. Pre partum b. Post partum c. Both pre partum and post partum d. Other | | | | | | | | | | |
| | | | | | | | | | | | | |
| | 3. | Where is this information given? a. In support groups at PMTCT b. One on one session at PMTCT c. Healthcare workers go around in the community d. Other | | | | | | | | | | |
| 4. | Ap | art from organized counseling, are there any other known sources of information | | | | | | | | | | |
| | kno | own to you on infant nutrition? | | | | | | | | | | |
| | | | | | | | | | | | | |

| 5. | Are there other orgs that you collaborate with or who take over educating the women? |
|-------|---|
| | |
| 6. | Do you have ways of monitoring how HIV positive mothers feed the children? a. Yes b. No |
| 7. | If yes, what are they? |
| | |
| 8. | Do you provide replacement feeding (formula) at the clinic? a. Yes b. No |
| 9. If | yes, how often? |
| | |
| 10. | If not where do they get the formula? |
| | |
| 8. | What are the main infant feeding practices chosen by the HIV positive mothers? |
| | |
| 9. | Can you share with me the women's response to the program? |
| | |

Thank you for participating in this study, your information is very valuable.