

**Infant Feeding Experiences of HIV Positive Mothers Enrolled in Prevention of
Mother to Child Transmission (PMTCT) Programs - *The Case for Rural Malawi***

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ABSTRACT

Background

The transmission of HIV from a mother to her child is one of the most tragic aspects of the HIV/AIDS pandemic. For most HIV infected mothers in developing countries, choosing a suitable infant feeding option represent a desperate dilemma. On one hand, health care providers expect mothers to abide by WHO recommended infant feeding choices in order to reduce the risk of HIV transmission to infants. On the other hand, PMTCT enrolled mothers go back home to a society where WHO's recommended infant feeding methods are found to be practically, socially and culturally irrelevant. This study explored infant feeding experiences of HIV positive mothers, their partners and health care workers linked to Prevention of Mother To Child Transmission (PMTCT) of HIV programs in Chiradzulu district, Southern Malawi.

Methods

A qualitative study using in-depth semi structured interviews, focus group discussion (FGDs) and case studies was carried at two PMTCT sites. In-depth interviews and focus group discussions were recorded and transcribed. Case studies involved a deeper inquiry into the past, present and situational factors of selected participants. Analysis was done using principles of thematic content analysis. Research findings are presented in the form of a thesis for a Master of Philosophy Degree.

Results

None of the participants managed to adhere to the WHO prescriptions of infant feeding for HIV positive mothers. Findings revealed wide spread mixed feeding among HIV positive mothers as they yielded to social pressure from a community in which individuals, families

and neighbours freely intervened in each others' child rearing activities. Adherence was further challenged by customary use of traditional medicines and prolonged breast feeding practices. One important aspect was that mothers reported that their spouses abandoned them after they had disclosed their HIV positive status; disclosure being a precondition for enrolment in the PMTCT program. In a context of customary matrilineal kinship, matrilineal residence pattern and complete male absence from the PMTCT program; the demand by the PMTCT service for partner disclosure played up fears of rejection among men given accusations of infidelity by the wives' family. This situation forced many men to abandon their families. In the end, affected mothers faced not only the fear of transmitting the virus to their infants, but also the loss of income associated with a departed husband as well as the social disgrace of a ruined family. Community members referred to the PMTCT program as 'the divorce program'.

Conclusion

In large parts of the world, infant feeding is located at the heart of local customs and traditions. The demand by PMTCT programs for essential modification of breast feeding practices are often met with opposition and non adherence. There is an urgent need for PMTCT programs to use 'cultural competency techniques' in order to remain effective in diverse cultural settings. Equally important is the need for PMTCT programs in this part of the world, to incorporate modules where assessment of potential husband participation is sensitively dealt with from the early stages in the PMTCT process.

ACRONYMS AND ABBREVIATIONS

AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CHAM	Christian Health Association of Malawi
FHI	Family Health International
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MCH	Mother and Child Health
MK	Malawi Kwacha
MoHP	Ministry of Health and Population
MTCT	Mother to Child Transmission
NGO	Non Governmental Organization
NSO	National Statistics Office
NRCM	National Research Council of Malawi
NORAD	Norwegian Agency for International Cooperation
PMTCT	Prevention of Mother to Child Transmission
TB	Tuberculosis
UNAIDS	United Nations Joint Program on HIV/AIDS
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
UNICEF	United Nations Children Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1

1.0 BACKGROUND AND LITERATURE REVIEW

1.1 HIV/AIDS: The global picture

Since its first recorded case, HIV/AIDS has grown to become one of the most serious public health challenges globally, causing the death of 25 million people from 1981. An estimated 39.5 million people were living with HIV worldwide by the end of year 2006, of whom 2.9 million were children (WHO2, 2006: 6)

Women and children take on a disproportionate burden of HIV/AIDS as they continue to experience high rates of new HIV infection and HIV related illness and death (WHO, 2006: 6). More than 17 million women world wide are today living with HIV and infection among women is on the rise in every region of the world. (UNAIDS, 2006: 1))

AIDS is presently the fourth leading cause of death in the world, and the number one cause of death in Africa. Yet its overall impact on the global population has not reached its peak.

HIV/AIDS is on track to be the worst epidemic in history with projected death toll reaching 100 million by 2020. (Kates J.2003: 3).

1.2 HIV/AIDS: The African picture

Sub-Saharan Africa remains the global epicentre of the AIDS pandemic. At the end of year 2006, an estimated 25 million of the 37 million people infected with HIV world wide, lived in Sub Saharan Africa. (WHO 1, 2006: 13.) This region is also home to approximately 13.3 million HIV positive women of child bearing age, representing 59 percent of the adult population living with HIV in the region. It is moreover estimated that about 2 million children under 15 years of age were infected with HIV in Sub Saharan Africa by the end of

2006.¹Of the total number of HIV infected persons in Southern Africa, an estimated 700,000 to 1,000,000 currently have AIDS. However, only one in 25,000 eligible persons are currently on treatment with Antiretroviral Therapy (AVERT, 2006).

1.3 HIV/AIDS and women

At the end of year 2003, there were more than three HIV infected young women for every two HIV infected young men worldwide (UNAIDS fact sheet, 2003). While the infection rates for men increase after the age 25, they nonetheless remain below those of women until the age 35, at which point the death of women begins to pull down the female prevalence rate (Michael K, 2007). This has two key implications: Firstly the proportion of HIV infected women of child bearing and child rearing age will continue to increase and will in turn lead to increases in the number of infants likely to be born with HIV or to acquire HIV through the so called Mother to Child Transmission (MTCT) after birth.

Secondly; women will have AIDS related illnesses at a younger age than men, unless they receive ART. A recent study done in Zambia (Chapoto A, Jayne, 2006:40,41) found that in a large cohort followed for over three years, sixty one percent of all HIV/AIDS deaths occurred among women, and that women on average died younger than men. This has enormous implications on the care of upcoming generations as the burden of orphan care increasingly falls on grand parents.

1.4 Mother to Child Transmission of HIV/AIDS

One of the most tragic aspects of HIV/AIDS infection is the discovery of transmission of the virus from mothers to their children, the so called ‘Mother to Child Transmission of HIV’ which takes place when HIV passes from a mother to her baby during pregnancy, labour or through breast feeding. Current evidence suggests that most mother to child HIV transmission

¹ Southern Africa Region comprise of Zimbabwe, Mozambique, Botswana, Malawi, Zambia, Namibia, Angola, Swaziland, South Africa and Madagascar.

occur late in pregnancy, or during labour and delivery (Tylleskar, 2007: 4-6). Without any interventions, between 20 and 45 percent of infants may become infected with HIV through mother to child transmission. (WHO, 2007: 1). According to the year 2005 UNAIDS update, seven hundred thousand infants are infected with HIV every year. (UNAIDS, 2005:13).

1.5 PMTCT and infant feeding options

The optimal way to avoid Mother to Child Transmission (MTCT) is to prevent HIV infection among women of reproductive age. However, due to high HIV infection among women of this age group, there is substantial need for interventions to help reduce the risk of infecting the child. Antiretroviral (ARV) prophylaxis to reduce vertical transmission during delivery and modified infant feeding methods that would help mothers prevent transmission through breast milk are the prominent ways of confronting this challenge. The following infant feeding options were practiced or recommended for practice at the time of field work:

1.5.1 Exclusive breast feeding

Exclusive breast feeding involves giving the infant only breast milk and prescribed medicines. No water, liquids or food are given to the infants for at least the first six months of life. (UNAIDS, 2003: 3). After six months, breast feeding alone is perceived inadequate to meet the baby's growing nutritional needs. Hence, for HIV positive mothers: abrupt cessation of breast feeding and a shift to an appropriate replacement feeding is suitable. We shall return to this in a moment.

1.5.2 The dangers of mixed breast-feeding

The reason why exclusive breastfeeding is recommended is because evidence has shown that mixed feeding; which involves giving the infant breast milk and other drinks, such as porridge, formula, glucose water, gripe water or traditional medicines; increases the risk of HIV transmission from mother to child. (UNAIDS, 2003: 56)

Mixed feeding is riskier than exclusive breast or formula feeding. The physiological explanation being that foods, traditional medicines or drinks damage the babies lining of the stomach and intestines, making it easier for HIV in the breast milk to infect the baby (Perinatal HIV Research Unit, 2006:21). In an early South African study of HIV-positive women and their babies, 36 percent of babies who received mixed feeding were reported infected compared to about 25 percent of those who were exclusively breast-fed and 19.5 percent of formula-fed babies. (A. Coustaudis, 1999:127-33)

In many African countries, mixed feeding is a social norm, a fact that has enormous challenges for PMTCT programs. In these countries; women who choose to formula feed will often breast feed due to social pressure from relatives and fear of stigma if their friends discovered their HIV status. (International Community of Women Living with HIV/AIDS, 2005:9)

1.5.3 Early cessation of breast feeding

Early cessation of breast feeding is a method whereby a mother decides to breast feed her baby for six months or less and then abruptly discontinues breast feeding to initiate replacement feeding (The AIDS Reader, 2005:4). This method of breast feeding decreases the risk of HIV transmission by reducing the length of time during which an infant is exposed to HIV through breast milk. For HIV positive mothers who choose to exclusively breast feed their children, early cessation of breast feeding has been required as the baby will in due time

demand more food than the mother can provide. If the mother continues to breast feed beyond this point she will move into mixed feeding patterns. Studies have confirmed the presence of HIV both in colostrum or early milk and late milk. However the prevalence of HIV has been shown to be lower in colostrum (27 percent) than in mature milk (47 percent) (Lewis P, Nduati R, Kreiss J, et al. 1998; 177:34-39.).

In a study conducted in Tanzania, 8 of 139 children born to HIV-infected mothers who were themselves, known to be uninfected at six months of age, became infected through late breast-feeding. (Karlsson, 1997.) Similar findings from other African countries support early cessation of breast feeding as an effective infant feeding option for prevention of mother to child transmission of HIV. (Leroy et al, 2003; Fawtzi et al, 2002; Coustoudis, 2001; Illif et al, 2005). Findings from other studies however, question early cessation of breast feeding. A study in Rwanda found that 70 percent of mother-to-child transmissions occur prior to the age of 6 months (Simonon A, Lepage P, Karita E, et al. 1994; 7:952-957.). Another study conducted in the Ivory Coast found that 28 percent of children born to HIV-seropositive mothers were infected by 6 months of age. After accounting for the effect of early breast cessation on the rate of HIV infection; the risk of late postnatal transmission after 6 months of age was only 12 percent among children born to HIV-infected mothers. (Ekpini et al. 1997.). These findings suggest that the largest proportion of HIV infected mothers will have already transmitted the virus to their children through breast milk by the time the baby reaches the age of six months.

The World Health Organization recommends that an HIV infected mother should stop breast feeding as soon as she is able to prepare and give her infant adequate and hygienic replacement feeding. WHO guidelines also recommend early cessation of breast feeding when

the mother develops symptoms of AIDS (UNAIDS, 2003: 54) .We shall return to the WHO infant feeding guidelines later in this chapter.

1.5.4 Modified breast feeding

WHO recommended modified breast feeding options include: exclusive breast feeding with early cessation, expressed and heat treated breast milk and also wet nursing.

Expressed and heat treated milk involves removing the milk from the breast manually and heating it to boil, in order to kill HIV. The milk is then cooled, stored and given to the infant within 12 hours, if stored at room temperature. Alternatively; it can be given to infants within 72 hours if refrigerated. (UNAIDS, 2003:52)

Research has demonstrated that heating HIV infected breast milk at 62.5 degrees for a period of thirty minutes (a process called holder pasteurization) can inactivate the HIV virus making the breast milk safer for infants (Eglin and Wilkinson 1987; Orloff et al. 1993; Giles and Mijch 2005). This method however requires timers and thermometers; devices which are hard to get in most resource poor communities hardest hit by the HIV/AIDS pandemic. Holder pasteurisation also destroys some nutritional and immunological properties of the treated breast milk.

A recent study in this area has shown that flash heating HIV infected milk inactivates the HIV while maintaining the nutritional and immunological benefits of breast milk (Israel Ballard et al. 2007). The process of flash heating involves heating a glass jar of expressed breast milk in a pan of water over a flame (Yang S. 2007). This method uses low tech materials readily available in poor communities. Moreover flash heating brings the milk to a high temperature within a short time, making it easy for a mother in a rural setting to implement it in her kitchen.

Wet nursing implies that a voluntary HIV negative woman breast feeds the baby on behalf of the HIV positive mother. There is a risk of transmitting HIV from the wet nurse to the infant if the wet nurse is infected and an equal risk of transmitting HIV to the nurse if the infant is HIV infected. The wet nurse would hence have been counselled, tested and expected to practice safer sex through out the breast feeding period. Wet nursing is already a traditional practice in most African cultures especially in situations where a baby has lost a mother or the mother is too ill to breast feed her baby. A study done in Tanzania revealed that some PMTCT counsellors in Kilimanjaro region were reluctant to promote wet nursing citing an incident where a grandmother who had contracted HIV from a grandchild she was nursing following the death of child's mother (Leshabari et al. 2007). Similar concerns have been reported in a study on wet nursing among communities in Zimbabwe (Gavin et al. 1999)

1.5.5 Replacement feeding options

Replacement feeding ideally involves feeding an infant with a diet that provides the child with all needed nutrients without giving the child any breast milk. WHO Replacement feeding options recommended for HIV positive mothers include: commercial infant formula and modified cows milk during the first six months of life. After six months, complementary feeding is appropriate. (UNAIDS, 2003: 39).

Commercial infant formulas are industry formulated milk based on modified cows' milk and are made in form of powder to be reconstituted with water at home. Infant formula comes closest in nutrient content to breast milk. Feeding an infant for six months requires at least 40 of 500gram tins of formula powder. (UNAIDS, 2003: 53). The cost of infant formula in low income countries is beyond the reach of a large majority of families. To safely use

commercial infant formula diet; requires that a family has reliable income and access to a sufficient supply for at least 6 months. The family must also have resources such as safe clean water, fuel, utensils, skill and time- to prepare commercial infants formula accurately and hygienically. (UNAIDS, 2003: 53)

Research has shown that in communities providing free infant formula to HIV infected mothers, the combined risk of HIV transmission and death was similar whether infants were formula fed or breast fed from birth (In Coutoudis A. et al. 2008). These findings inspired the so called 'formula plus' programmes in Haiti and Botswana which provided HIV infected mothers with free formula, growth monitoring services, regular medical assessment, skills on safe preparation and appropriate treatment and care (Noel F et al. 2006). After six months of implementation, the 'formula plus' program in Haiti reported reduced Mother To Child HIV transmission but very high infant mortality rates (217/1000) (Noel F et al. 2006).

A similar program in Botswana also reported 35,000 cases of diarrhoea, resulting in 532 deaths within the first six months (Creek T, 2006). The experiences in these two programmes underscored the dangers of formula feeding in impoverished communities despite the provision of free formula feeding. Further research has also shown that infant milk in form of powder may contain low levels of salmonella (Brouard C et al, 2007) or other contaminants causing diarrhoea outbreaks (Weir, 2002 and Threlfall E.J et al. 1998).

Modified cows milk implies fresh or processed animal milk that is modified by adding water, sugar and micronutrients supplements. (UNAIDS, 2003:10).

Cow's milk has more protein and a greater concentration of sodium, phosphorus and other salts than breast milk (WHO, 1999). Modification of cow's milk therefore involves dilution with boiled water to reduce the concentration of salts. Dilution however, reduces energy

concentration hence sugar must be added. The milk, water and sugar must be mixed in right proportions. (UNAIDS, 2003: 52)

Goat milk is similar in composition to cow milk; hence modification is done in the same way. It is however deficient in folic acids which must be given to infants in form of micronutrient supplement. Camels' milk is also similar in composition and is modified and supplemented largely the same way. Sheep and buffalo milk however, have more fat and energy than cow milk. Protein content in sheep milk is very high; hence both require more dilution than cows' milk. (UNAIDS, 2003: 52)

1.6 2001 International guidelines on HIV and infant feeding

In 2001, the inter-agency task team on mother to child HIV transmission comprising WHO, UNICEF, UNFPA and UNAIDS released recommendations on HIV and Infant feeding.

The international guidelines on infant feeding (WHO 2001, HIV and Infant feeding; Guidelines for Decision Makers) state that:

“When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), HIV positive mothers should avoid breastfeeding altogether. Otherwise, exclusive breastfeeding is recommended during the first months of life. To minimize the risk of HIV transmission, HIV infected mothers should discontinue breast feeding as soon as feasible, taking into account local circumstances, individual woman's situation and risks of replacement feeding (including infections other than HIV and malnutrition). When HIV positive mothers choose not to breast feed from birth or stop breastfeeding later, they should be provided with specific guidance and support for at least the first two years of the child's life to ensure adequate replacement feeding”.

(WHO, 2001:13)

In relation to infant feeding counselling, the Interagency task Team recommended that all HIV infected mothers should receive counselling, including general information about the risks and benefits of various WHO recommended infant feeding options, and specific guidance in selecting the infant feeding method most suitable for their situation. The notion of choice was emphasized pointing out that whatever a mother decides; she should be supported in her 'choice'. Assessment should be conducted locally to identify the range of feeding options that are acceptable, feasible, affordable, sustainable and safe within a particular context. These are the so called AFASS assessment criteria

1.7 Differences in infant feeding policy

In most western countries, HIV positive women are not allowed to breast feed their infants at all (WHO, 2007: 1). WHO/UNICEF/UNAIDS nonetheless recommends exclusive breastfeeding with early and abrupt cessation for HIV positive mothers in developing countries. (Paediatrics, 2005: 496-506)

These conflicting messages raise ethical questions as to the fairness of recommending different methods of infant feeding to HIV positive mothers in the global north and global south. HIV positive women in resource poor countries have been forced to make the so called "informed choice" where the alternatives in practice are not available for the majority of mothers (Blystad A, Moland C, 2007: 48). While the basic principle of informed choice is appropriate; its application depends on the mothers being aware of and having access to a range of practical feeding alternatives and on going PMTCT program and community support. (Kent G, 1999: 3- 4)

1.8 Adhering to infant feeding options

Research has shown that even when HIV positive mothers go through infant feeding counselling, real care and feeding of the infant is ultimately influenced by circumstances and interests beyond HIV infected mothers' direct control. These include socio economic conditions, expectations of partners, mother in laws, extended families and the community: Studies in Botswana (Shapiro RL et al. 2003: 220-30), where formula feeding among HIV positive women is strongly encouraged and offered free in PMTCT programs as was mentioned above, found that women accepted formula feed given from the clinic and went home only to practice both formula feeding and breastfeeding.

A study in Zambia (Omari AA et al. 2003: 156-62) reported that HIV positive women changed to mixed feeding very early, whether they started out with replacement feeding or exclusive breastfeeding.

Another study in Tanzania (Leshabari, 2006: 5) showed that mothers who had started out with replacement feeding ended up breastfeeding. Women explained that they could not withstand the social pressure to breastfeed and were concerned about their reputation as good mothers. These studies agree on the complexity and difficulty among HIV positive mothers to stick firmly to any of the WHO recommended infant feeding methods. Despite such early evidence however, very few studies have focused on the experiences of adherence among HIV positive mothers who have been counselled, have chosen an infant feeding methods and are enrolled in a PMTCT program.

1.9 Continuing debates on infant feeding options in the face of HIV

As mentioned above, infant feeding options for HIV positive mothers have been governed by WHO guidelines. These guidelines offer women choices on infant feeding options according to their socio economic conditions. According to the year 2001 WHO guidelines, formula feeding is recommended for HIV positive women who find the formula ‘acceptable, feasible, affordable, sustainable and safe’. This choice requires access to clean water, sanitation and clean home surrounding.

In contrast, where formula feeding is not ‘acceptable, feasible, affordable, sustainable and safe’, HIV infected women are encouraged to exclusively breast feed for the first six months of life.

The year 2001 WHO statement on HIV and infant feeding underscores the initial dilemma and debate as to whether the HIV transmission resulting from breast feeding can be outweighed by the benefits of breast feeding and therefore morally justified.

1.10 2006 WHO updated HIV and infant feeding guidelines

During the 2006 International HIV and Infant Feeding Consultation Meeting held in Geneva, Switzerland; the interagency task team on the prevention of HIV infections in pregnant women, mothers and children clarified the 2001 UN guidelines as follows:

“Exclusive breast feeding is recommended for HIV positive women for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants before that time”.

“When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breast feeding by HIV positive women is recommended”. (WHO, 2007)

The newly modified guidelines have drawn lessons from the tragic outcomes of replacement feeding as recommended in the 2001 WHO guidelines, and have instead turned to exclusive breastfeeding as the way forward for HIV positive and HIV negative infant feeding mothers. In this most recent WHO infant feeding guide for HIV positive women, formula feeding as an option has increasingly been ruled out for most resource poor contexts , thereby further diminishing choices available to these mother and their infant in these settings, and raising new dilemma as to how HIV infected women will feed their children.

CHAPTER 2

2.0 STUDY SETTING

This chapter describes the social, demographic, geographical and health service context of the study area. The chapter also outlines objectives of our research. This study was conducted in the southern region of Malawi at two PMTCT sites linked to Chiradzulu district hospital and St. Joseph mission hospital, between May and August 2007.

2.1 Geographical location

Malawi is a small densely populated country south of the equator in Sub Saharan Africa with no access to the sea. It is bordered to the North and North East by the United Republic of Tanzania, in the East, South and South West by the Peoples Republic of Mozambique and to the West and North West by the Republic Zambia.

The country has been a democratic state since 1994 with a bill of rights and a free market economy (Zanela D, 2005:1).

Figure 1: Map of Malawi showing Chiradzulu district



2.2 Demographic profile

Malawi has a total population of 11.6million people (Zanela D, 2005:2). Its population grew from 8 million in 1987 to 9.9 million in 1998 as enumerated by the 1998 population and housing census. This growth represents an overall increase of 24 percent and an annual population growth rate of 2 percent. Eighty nine percent of the people live in urban areas while the eleven percent reside in the rural areas. The age structure in Malawi indicates that it is a young nation with 43 percent of the population comprising young people less than 15 years of age. (Malawi National Youth Policy, 1999:17)

2.3 Development and health indicators

Malawi is one of the poorest countries in the world. The economy is agro based, depending mainly on labour intensive farming and rain fed agriculture. Life expectancy at birth stood at 39 years having dropped from 45 in 1995. The 2006 UNDP human development index ranks Malawi 166th of 177 countries (UNDP, 2006: 4).

Although the maternal mortality rate of 984 per 100,000 live births (as reported in the 2004 Malawi Demographic Health Survey) was lower than reported by the same survey in year 2000, (1120 per 100,000), it nevertheless remains very high. In Malawi an estimated 48 percent of all children are chronically malnourished (NSO, 2005: 179). These combined with the high neonatal death rate of 42 per 1000 live births are indicative of the poor health condition of communities and health services in the country. (Ministry of Health and Population, 2006:1)

2.4 HIV/AIDS profile

The first AIDS case in Malawi was reported in 1985 (Muula A, 2007:880-883). The main mode of HIV transmission remains heterosexual sex. Malawi has an adult HIV prevalence rate of 14.4% (MoHP1, 2004:11). About 720,708 adults and children have died of HIV/AIDS between 1985 and 2004. It is estimated that by year 2010, over one million people would have died of AIDS in the country (MoHP2, 2004: 26).

The HIV/AIDS data in Malawi indicate a gender bias in the risk of HIV transmission. In the adult population, HIV prevalence is higher among women than men (Miteka I., 2004).

Prevalence in the younger age group (15 – 24 years) is four times higher among women. (MoHP, 2006: 25)

The HIV/AIDS situation in Malawi has led to a huge increase in the number of HIV/AIDS orphans and vulnerable children, which in year 2005 alone, were approximately 70,000. (MoHP. 2006: 25)

2.5 Mother to Child Transmission (MTCT) in Malawi

In Malawi, mother to child transmission comprise roughly 25,000 of the 100,000 HIV infections every year (MoHP, 2006: 3). Prevalence of HIV among pregnant mothers who are attending antenatal services is estimated at 15 percent (MoHP, 2006:6). The high HIV prevalence among pregnant mothers contributes heavily to mother to child HIV transmission. Among HIV infected mothers, high levels of poverty including high malnutrition rates, contaminated water and poor hygiene increase risk of infant morbidity and mortality from replacement feeding, thus diminishing options for safe and feasible infant feeding.

It is estimated that 90 percent of children below five years infected with HIV acquired the infection through mother to child transmission such as during pregnancy, labour, delivery or breast feeding.

2.6 The PMTCT of HIV services in Malawi

PMTCT services in Malawi were pioneered in the year 2001. Three pilot sites were established at Embangweni Mission Hospital, Thyolo and Chiradzulu District Hospital. The Malawi government officially launched the National PMTCT Programme on 12 June 2003. (MoHP, 2005: 3). In the year 2006, there were 119 health facilities offering PMTCT services out of a total of 542 health facilities in Malawi (MoHP,2006:11).The goal of the national PMTCT programme is to reduce mother to child transmission of HIV by 50 percent by year 2010 (MoHP, 2006:13).

The PMTCT programme is provided as part of the comprehensive Mother Child Care (MCH) services. The overall PMTCT strategy is to increase acceptance through community mobilization and partner involvement, promote HIV testing and PMTCT services in existing PMTCT sites and rapidly increase the number of sites offering comprehensive PMTCT services.

2.7 Brief information on the organization of health services in Malawi

Health Services in Malawi are provided at three levels; primary, secondary and tertiary. At primary level, services are delivered through rural hospitals, health centers, health posts, outreach clinics and community health initiatives such as Drug Revolving Funds.

District and CHAM (Christian Health Association of Malawi) hospitals provide secondary level health care services. The secondary level provide surgical back up services, mostly for obstetric emergencies and general medical and pediatric in-patient care for common acute conditions. The tertiary or central hospitals act as referral hospitals, to which district hospitals send their difficult cases.

In short, the health system in Malawi works through a referral network. Patients are first expected to contact one of the points at the lower level of the system – usually the health

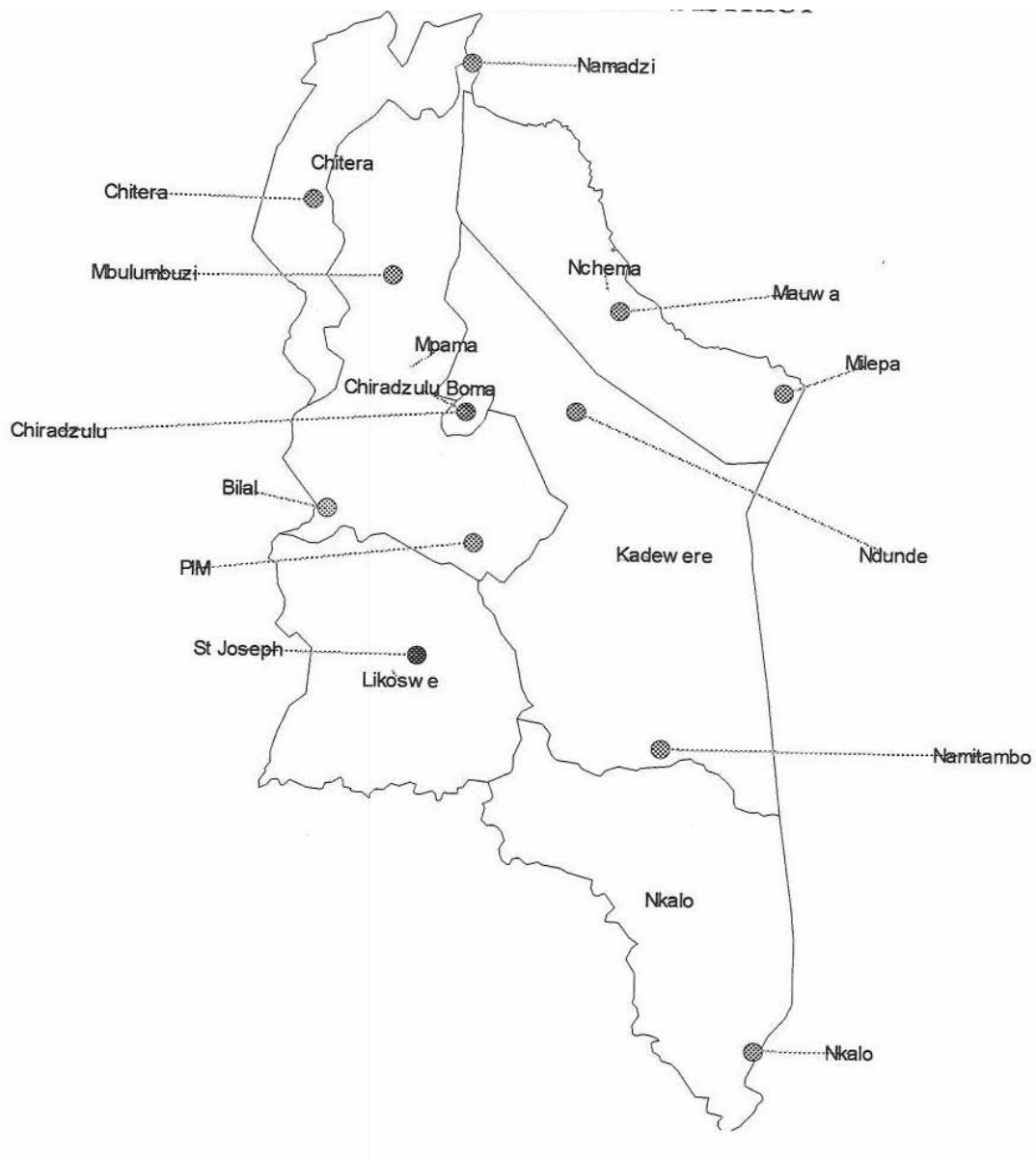
centre. If the patient needs more complicated treatment than the health centre can offer, the patient is referred to the district hospital. In-turn, if the district hospital cannot cope, the patient is referred to the central hospital.

2.8 Chiradzulu district profile

Chiradzulu district is one of the 14 districts in the southern region of Malawi and has a population of 210, 912 people (Chiradzulu District Commission, 2007:13). The population density in Chiradzulu, defined as the number of people per square kilometer is at 308 (Chiradzulu District Commission, 2007:14). Crude birth rate stands at 47 births per 1000, while crude death rate is 26 per 1000 (Chiradzulu District Commission, 2007:15). Total Fertility Rate defined as the average number of children a woman is likely to have by the time she completes child bearing if she experiences the prevailing age specific fertility rates, stands at 5.1 (Chiradzulu District Commission, 2007:15).

Health services in Chiradzulu are provided through hospitals, health centers and clinics distributed through out the district.

Figure 2: Map of Chiradzulu showing health facilities



There are two major hospitals in Chiradzulu district. Chiradzulu district hospital is a 300 bed referral hospital situated at the district town. It was opened in 2005. St. Joseph Nguludi Mission Hospital is a Christian mission hospital which was opened more than 30 years ago.

2.9 Main objective

The main objective of our study was to generate knowledge around experiences of mothers, their partners and health care workers linked to Prevention of Mother to Child Transmission (PMTCT) of HIV/AIDS in Malawi.

2.9.1 Specific objectives

- To assess the challenges related to infant feeding encountered by HIV positive mothers enrolled in PMTCT programs.
- To explore the experiences of health care providers in the counseling and follow up of HIV positive mothers in relation to infant feeding.
- To explore HIV positive men's experiences with Prevention of Mother To Child Transmission (PMTCT) programs.
- To explore suggestions for improving PMTCT programs among HIV positive women, their partners (men) and health care providers

CHAPTER 3

3.0 RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the research methods employed in this study. It describes the design, recruitment of informants, data collection methods, data analysis, ethical considerations and other practical issues related to field work.

3.2 Study Design

Richie and Lewis (2003) described qualitative research as a naturalistic, interpretive research approach concerned with understanding the meanings which people attach to actions, decisions, beliefs and values within their social world. They further write that qualitative methods provide an understanding of the processes that people use to make sense of and interpret the world around them. Norman Denzin (1994) explains how qualitative research methods emphasize rich description of people, places, conversations and the meaning given to experiences that constitute social reality. Qualitative research are characterised by their flexibility. A flexible and iterative strategy is used which allows the discovery of unexpected and important findings. Such findings would remain invisible if the researcher is limited to pre determined sets of questions. The qualitative designs is also characterised by holistic or comprehensive understanding of the social setting in which research is done. Social life is viewed as contextual and 'dynamic' and commonly involving a series of events which must be grasped in order to explain the reality of every day life.

Qualitative ventures are also subjective in the sense that they describe and analyse culture and behaviours of individuals and their groups from the vantage point of those being studied.

According to Bryman A. (1994: 176) and Hudelson A (1994: 2), one of the most fundamental

characteristic of qualitative research is “the express commitment to view events, actions, norms, values etc. from the perspective of the people who are being studied.”

Bogdan and Biklen (1992) write that qualitative data is commonly collected through sustained contact with informants in settings where they normally spend their time. In a famous statement, Bogdan and Biklen (1992:103) asserted that “ a qualitative researcher enters the world of people he or she plans to study , gets to know, be known, and trusted by them, and systematically keeps a detailed record of what is heard and observed”.

In order to explore infant feeding experiences of mothers enrolled in PMTCT programs in Chiradzulu district, a qualitative design was deemed appropriate because of the contextual, emotional and sensitive nature of infant feeding for HIV positive mothers. Our research questions required greater depth of response iterating not only mother’s intricate experiences on infant feeding but also the significance and meaning given to such experiences.

Qualitative methods selected for this research assignment were; in-depth interviews (including key informant interviews), focus group discussions and case studies. The researcher did not employ participant observation although a fairly long term presence in the infant feeding clinics for HIV positive mothers generated substantial knowledge from daily observation and informal discussions with differently positioned actors.

3.2.1 Sampling

The study employed purposeful sampling. This type of sampling implies an intentional selection of informants with a wide range of variation on key characteristics of interest such as age, education, parity, distance from the hospital, religion, marriage and choice of infant diet; within a defined criterion of inclusion. This type of sampling also ensures that core themes emerging from the study cut across a broad variety of persons who themselves have

undergone a typical infant feeding and PMTCT experience. Sampling was done by the researcher assisted by the PMTCT nurse counsellors.

The criteria for mothers included for this study were:

Any HIV positive mother, who is enrolled in a PMTCT program at Chiradzulu district hospital or St. Joseph Mission hospital, and is willing to participate in the study and share their experiences voluntarily.

For men, the criteria were:

Partners of PMTCT enrolees or any HIV positive man, of known HIV status who tested for HIV at Chiradzulu district hospital or St. Joseph mission hospital and participated in, or was aware of the PMTCT program, and was willing to voluntarily share their views and experiences.

For health workers, the criterion was those PMTCT nurses and other health workers involved in the PMTCT and infant feeding clinic.

3.3 Recruitment of informants

Recruitment of informants was done at the study sites through the PMTCT nurses. The first two days were used for orientation and preparation. During the first day, the researcher presented and discussed with PMTCT staff the content of the study, including rationale, objectives, methods and ethical principles guiding the research assignment. The ethical aspects were emphasized given the sensitivity of the subject under study.

The second day was used for a thorough discussion with two contact nurses on strategies of recruiting informants. Together with contact nurses, potential informants were identified from a PMTCT register while attending to issues around informant diversity in age, distance from the hospital, education, parity, religion, marital status and infant feeding method. The contact nurses and the researcher discussed the appropriate venue for conducting interviews in case an

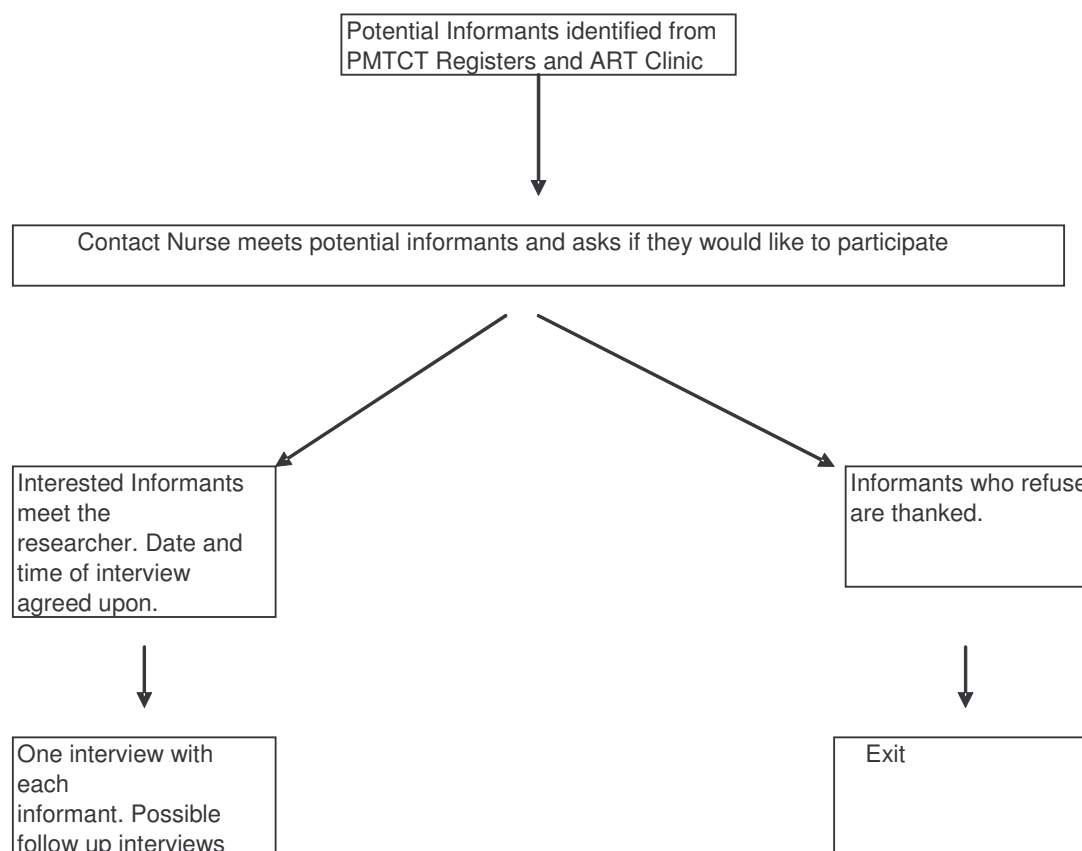
informant preferred to be interviewed at the hospital or other place. A room was identified to ensure that the venue for meeting informants attended to privacy and confidentiality.

3.3.1 Mothers

A message was sent to the identified mothers asking them to show up at the hospital to meet the contact nurse within the following two days. The ten mothers who reported were asked to participate and were given information by the nurse about the research and its usefulness in generating knowledge that would potentially improve the PMTCT program. One mother refused to participate, while nine accepted and these met the researcher who provided them further information about the study content and purpose as well as principles of voluntary consent, rights of withdrawal, confidentiality and anonymity. An interview appointment was then fixed after settling any concerns or questions on the part of the mothers.

One mother who refused to participate was thanked for her honesty. She was replaced in a subsequent round of recruitment.

Figure 1: Study profile



3.3.2 Men

Recruited HIV positive mothers were asked if their partners would be willing to participate in the research. Only two partners of the recruited mothers accepted to be interviewed. The rest of the male informants had to be recruited through the ART clinic. During ARV clinic days, men were identified from among those attending the ARV clinic.

Similarly, a contact nurse together with the main researcher identified men ensuring variation in age, education, occupation, distance to the hospital and religion so as to provide broad perspective. Identified men met with the contact nurse who provided information about the research and its usefulness in generating knowledge that would potentially improve PMTCT services. Men who accepted to participate were given further information about study's

content and purpose as well as principles of voluntary consent, rights of withdrawal, confidentiality and anonymity. Upon agreement on the informants' preferred venue for an interview and after settling any concerns or questions, an interview appointment date was arranged. Three men refused to participate from among this group. These were replaced in subsequent recruitment.

3.4 Description of study participants

The study enrolled a total of fourteen women, ten men, four nurses and three key informants including the village chief, the district health officer and a representative of the district commissioner.

Of the fourteen women who participated, eight were from villages around St. Joseph hospital while six were from Chiradzulu District Hospital. Among the men, six were from St. Joseph hospital while four were from Chiradzulu District Hospital. Except for two HIV positive men who accepted to talk with us following an interview with their HIV positive PMTCT partner; the rest of the men participants had no relation with the women.

Women reported ages ranging from 22 to 46 years. The median age for the women was 31 years. The men were slightly older with median age of 35 years, and their age ranged from 21 to 50 years.

Women had an average of seven years of primary school education. While the men had on average 10 years of school. The most educated reported twelve years of school while the least educated had no formal education at all.

3.5 Data collection

All interviews were conducted in Chichewa, the national language of Malawi. The researcher who is himself a trained counsellor, community mobilizer and public health officer, with

knowledge of the local vernacular carried out all in-depth interviews. The present study employed triangulation of qualitative research methods including in-depth semi structured interviews, focus group discussion and case studies as described below:

3.5.1 In-depth semi-structured interviews

In-depth semi structured interviews were carried out with 14 HIV positive mothers enrolled in PMTCT programs and with 10 HIV positive men and 4 health care providers using an interview guide. An interview guide is a flexible tool that guides the conversation between an informant and an interviewer (see appendices B, C, D, E, F, G and H). The interview guide provides general direction and flow of topics discussed.

Ten HIV positive mothers were planned for individual interviews; however the samples for mothers was increased from ten to fourteen in order to elaborate and seek a (subjective) point of saturation in the emerging core themes. Data 'saturation' is the subjective sense of confirming findings when they keep reoccurring with subsequent informants.

Patton (1990) explains that qualitative samples are flexible and can be changed if information emerges that underscores the importance of such change. The interviewer employed interview guides which differed between the various categories of informants as described below:

Interviews with HIV positive mothers

Interviews with the 14 HIV positive mothers were conducted with the aim of understanding informants' experiences and challenges with the infant feeding aspect of the PMTCT programs. Some of the HIV positive mothers were followed up with two to three subsequent visits in order to gain deeper insight into their experience. Initial interviews lasted for about one hour, while subsequent interviews ranged from thirty minutes to one hour. A total of 27 interviews were carried out. This meant three follow up interviews for three mothers and two

follow up interviews for two mothers on top of the initial 14 interviews. Follow up interviews were arranged when informants reported to the clinic for their routine PMTCT meetings.

A typical Interview with an HIV positive mother informant started with a discussion of demographic characteristics of the study informant. Asking informants simple social demographic questions proved to be a good conversation opener which allowed informants to feel at ease while settling into a relaxed interview atmosphere. The informant was then asked about customary infant feeding practices. This question allowed the interview to grow naturally as informants talked about feeding practices that are familiar in their community. The interview then continued and developed spontaneously through an outline of topics with open ended questions covering the following aspects: experiences with PMTCT services, experiences with infant feeding choice, including experiences with implementing a chosen infant feeding practice and challenges faced, on going support from the clinic and community, issues of family and community reaction to chosen infant feeding method were also discussed. Changes on the interview guide, in wording or sequence were common in order to fit the empirical reality emerging in the interviews. Changing the wording of some questions proved useful among timid mothers who appeared less relaxed in answering more direct sensitive questions but loosened up when the same question was framed hypothetically. For these few mothers, a question like; ‘why did your husband abandon you?’ would sometimes not yield as much as more hypothetical format: ‘why do husbands in this community abandon their HIV positive wives?’ .As the interview proceeded many of the informants would then reveal their own stories of becoming abandoned upon disclosure.

Interview with HIV positive men

Interviews with 10 men were also conducted to assess their level of knowledge of the PMTCT programs and their opinions on improving PMTCT services. The men interview guide also

opened with a set of questions on socio demographic characteristics. The interview then developed into an open ended questions outline, with the following topics: knowledge of Mother to Child Transmission (MTCT), experiences with infant feeding options and suggestions for improving PMTCT services.

Throughout the interview, the informants were encouraged to give elaborate responses with minimal intervention from the interviewer. Non verbal communication cues were observed and recorded. The interview lasted for about one hour.

Interview with health care providers

Interview conducted with four Nurse Counsellors (two nurses in each hospital) aimed at assessing experiences and challenges in connection with counselling mothers on infant feeding options. These interviews also explored the nurses' views and experiences working with the WHO supported infant feeding guidelines for HIV positive mothers. Each interview lasted about one hour.

Interviews with district bureaucrats

A key informant is an experienced person with direct, expert knowledge of the community or the topic of study (FHI, 2006). Key informant interviews were conducted with the District Health Officer, District Commissioner and Village Headman of Mwenye village, the biggest village closest to St. Joseph hospital. This interviews which lasted for about one hour, explored key informants views about the PMTCT program and experiences with recommended infant feeding options for HIV positive women. The interviews also explored views on how the PMTCT program could be improved.

3.5.2 Focus group discussion

Focus group discussion is a “naturalistic” method of data collection because in many ways it represents the kind of interaction people have in every day life. FGDs helped to increase depth of inquiry and accentuated the range and diversity of views and experiences in a group discussion context. (Freeman et al, 2001).

The focus group method helped to explore and clarify informant’s views in ways, less accessible through one-on-one interviews. The group interaction inherent in a Focus Group Discussion tapped into different forms of communication including anecdotes, teasing and arguing. Access to such variety of communication forms was useful because people’s knowledge and experiences are commonly not entirely encapsulated in reasoned response to direct questions (Pope C. Mays.N.2006: 22).

A total of four focus group discussion involving around six participants per session were conducted with groups of HIV positive women, men and health care providers. Each focus group discussion lasted between one hour and one hour thirty minutes. The Focus Group Discussions that were conducted were:

- 2 FGD with HIV positive mothers enrolled in PMTCT program
- 1 FGD with men
- FGD with health care providers

Participants were invited to the focus group discussion two days in advance, and the purpose of the focus group discussion was explained before hand. When conducting a Focus Group Discussion, the researcher separated participants into groups with similar socio- economic status, age and sex, in order to facilitate free discussion.

During all interviews, the investigator tried to create a friendly atmosphere by a warm handshake with every informant. Words such as: ‘good to meet you again, thank you for

accepting to talk with me' were said to make informants feel appreciated and counted. At the end of an in-depth interview, every informant was provided with a soft drink. At the study sites, we were not allowed to bring soft drinks into the hospital campus as required by their 'baby friendly' policy. However, arrangements were made for participants to get their soft drinks from a place outside the hospital campuses

During the course of the interviews, men generally appeared more relaxed than the women. Nonetheless, most men were not as articulate as the women and often had scanty information repeatedly confessing that PMTCT and infant feeding is a women's area. This resulted in low depth individual interviews for some men.

Women hence appeared generally more informed. A few women were timid and did not talk enough, however a large majority were relaxed, talkative and produced rich interviews. We tried to address the challenge of the shy women by recruiting four extra women for the in-depth interview so as to 'saturate' emerging themes.

During focus group discussion, the atmosphere was livelier. Women sang and laughed together before they sat down for the focus group discussions. This created a good feeling of "get together" among them, some of whom may not have met before this event.

3.5.3 Case study description

Pilot and Back (2008: 236) define case studies as an attempt at understanding issues that are important to the development, history or circumstances of the entity under study. Case studies provide researchers with opportunities for an intimate knowledge of a person's condition, thoughts, feelings, actions, intentions and environment.

In this study, Case studies were carried out to collect comprehensive and in-depth information about four cases of particular interest. The case studies allowed the experience of infant

feeding within the PMTCT program to be laid out in a manner that provided great insight and detail and also demonstrated diversity, richness, ambiguity and contradiction as well as an emerging contextual backdrop.

Five HIV positive mothers were recruited for the case studies towards the end of the data collection exercise. This was done in order to allow identification of articulate and information rich participants in the course of in-depth interviews and focus group discussions. Data on past experiences, present state and situational factors related to infant feeding experiences was collected. Case studies took about 120 minutes per informant. Depending on how much time the informant was available, one or two subsequent visits were made to complete the process. It was also not unusual to complete the case study during one sitting. Intensive probing provided a deeper insight into the infant feeding experiences of participants in ways not seen with in-depth interviews or focus group discussions.

3.6 Data analysis

Green and Thorogood (2004: 175) contend that approaches to analyzing qualitative data should intervene to draw out 'meaning' of the data that are not obvious at a journalistic reading. Qualitative analysis should reflect the complexity of a phenomena studied and present the underlying structures that 'make sense' of that complexity. The task of analyzing qualitative data is a dual process of simultaneously 'telling the story' from the point of view of the informants, while at the same time 'unpacking' the story in such a way that the broader meaning can be elicited.

For our data analysis, all in-depth interviews and focus group discussions were recorded with permission from the informants and transcribed for analysis. Analysis of data was done manually using principles of thematic content analysis as described below.

3.6.1 Thematic content analysis

Thematic Content Analysis involves analyzing the content of data in order to categorize emerging common themes (Green and Thorogood, 2004: 177).

Data collection and analysis did not take place in rigorously separate phases; indeed the continuous reflection over emerging topics was part of the initial data analysis that was used to shape continuing data collection. This provided the main the researcher with opportunities to explore recurring themes, as well as to check and follow up on expected and unexpected findings.

3.6.2 Translation and transcription

All in-depth interviews and focus group discussions were recorded with permission from the informants and transcribed for analysis. All the interviews were first transcribed verbatim from the tape recording into Chichewa. The Chichewa transcripts were then translated into English. The tedious process of transcribing and translating from Chichewa to English was largely done by the researcher; himself a native speaker of Chichewa. A nursing student from the study community with some experience with focus group discussions (FGDs) was hired to help the researcher with translation to clarify certain issue. This was done to ensure that the process of translation lent itself not only to ‘bilingualism’ but also to the extent possible ‘biculturalism’. In their book, qualitative methods for health research, Green and Thorogood (2004: 89) argue that “*working with ones own language does not eradicate problems of translation. To some extent all language use implies a translation in which we assume shared meanings but cannot take them for granted*”.

The assistant’s local background was therefore useful in minimising the risk that the cultural, emotional or lexical implications of spoken words did not get lost in translation.

3.6.3 Coding

Qualitative coding process involves a deeper understanding of the data in which the researcher identifies categories and their properties (Schriber and Stern, 2001:68). Using transcribed material, terms or concepts that best summarize or capture unit of meaning in a given paragraph were written in the margins of the transcripts.

Two levels of coding were employed as follows:

First level coding

During the first level coding, the researcher read, re-read and carefully examined the data, selecting words or phrases which, when read individually contained a single unit of meaning. These words were written in the paper margin, adjacent to the segment of data being labelled. At this level of coding, the researcher tried as far as possible to use the direct words or terms used by informants to mark the unit.

At the end of first level coding, a long list of words and phrases had been written in the margin of the transcripts. First level codes included words and phrases as, “husband run off”, “remarried”, “feel misunderstood”, “child cried too much”, etc.

Second level coding

The second level coding began as soon as the researcher noticed similarities in the codes determined during the first level coding. As the first level coding was done, identified first level codes were continuously compared with emerging codes and where similarities were observed, these codes were then collapsed into second level codes. Second level codes included: “length of breastfeeding”, “traditional medicines”, “initial contact with PMTCT” etc.

3.6.6 Identification of themes

During the second level coding, the researcher was careful to examine any relationships among identified second level codes. The codes and categories that occurred again and again in the material, built up core themes.

The following emerging core themes were identified; “customary infant feeding practices”, “experiences with PMTCT”, “adherence to PMTCT advise”, “adherence to infant feeding methods” and “male involvement in PMTCT” etc.

3.7 Ethical consideration

This research venture was approved by the National research council of Malawi (NRCM) and the Health sciences research committee of the ministry of health in Malawi. Permission to conduct this study was also obtained verbally from district and community level authorities in Chiradzulu district.

Special attention was made to ensure that the study did not violate ethical principles governing medical research as stipulated in paragraph 20 and 21 of the declaration of Helsinki (amended by the 48th World Medical Association’s general assembly). Special attention was paid to concerns around voluntary informed consent, rights of withdrawal and confidentiality and anonymity of the informants. (Refer to Appendix A for the verbal consent form.)

3.7.1 Voluntary informed consent

Verbal voluntary consent was sought from all informants to allow them make a voluntary decision as to whether they wanted to participate in this research (refer to appendix A). The following steps were followed in obtaining informed consent.

Disclosure of information

Potential informants were informed details about what this research is about and what their participation would involve. Participants were informed on a general level about what data would be collected and how such data will be used. Research objectives, content and process were also articulated. Participants were then encouraged to ask questions on any aspect that had not been adequately explained.

Understanding

Having provided information about the research, the investigator tried to ensure that participants had understood the information provided by asking them questions and repeating those aspects that did not seem to be properly understood.

Voluntary decision

Following this round of information, the researcher sought a voluntary decision from the informant. During this process, the potential informant was assured that there would be no consequence whatsoever if they refused to participate. Those that needed time to consult family members were allowed to go and come back within two days.

3.7.2 Confidentiality

Confidentiality is defined as the right of individuals to have their personal information kept private. In this research, protecting informants' confidentiality involved carrying out interviews in a private location where informants felt safe to express themselves. At St. Joseph hospital, a counselling room was made available for this task. At Chiradzulu district hospital, an unoccupied office in the maternity wing was used for interviews. Caution was taken to always ask individual participants where they would like their interview to take place.

3.7.3 Anonymity

Anonymity involved ensuring that all personally identifiable information about the informants was not accessible by people other than the researcher or those directly involved with the research. This was achieved by making sure that all transcribed material was kept in a password protected computer. During the interviews, participants were allowed to introduce themselves off record, before the voice recorder was switched on. This voice recorder was kept out of reach of others.

CHAPTER 4

4.0 RESULTS AND FINDINGS

This chapter will present main findings of the study. It starts with a brief elicitation of a few central aspects of the social organization of the community in which this study was done. This is followed by a discussion on infant feeding experiences in the context of PMTCT services.

The results and findings are condensed into the following core themes:

- Social organization of the study community
- Customary infant feeding practices
- PMTCT and infant feeding services offered at the study sites
- Adherence to recommended infant feeding methods
- Gender implications of PMTCT programs
- Men's roles in PMTCT programs

All quotations are from the tape recorded interviews. These are presented to depict informants' voices as concretely as possible and display the diversity and patterns of experiences conveyed by study informants. Glimpses from case studies are also presented to exemplify life stories of people who have experienced PMTCT and Infant Feeding.

4.1 Social Organization of the Study Community

Chiradzulu district where this study was carried out is home to two major ethnic groups, namely; the Lomwe and the Yao. The Lomwe have their roots in Mozambique from where they migrated into Malawi over two hundred years ago. (Kayambazinthu, 1994) The Yao migrated from Tanzania and settled along the lakeshore in Malawi. Some moved further down to the south east and settled around the Phalombe- Thuchira plain (Chiradzulu District Commission, 2007:1). These two ethnic groups are found in all parts of Chiradzulu district,

and the percent distribution between them shows that the Yao are in a slight minority compared to the Lomwe (Chiradzulu District Commission, 2007:1). There are also smaller ethnic groups in the district, such as the Ngoni, Nyanja and Chewa. Following years of inter marriages between the Yao and Lomwe, many traditions common between the two tribes such as circumcision for boys and girls, and chieftaincy derived from the maternal side are well recognized. Both groups maintain a matrilineal residence pattern where the couple resides at the female's home, a practice also called "*Chikamwini*" in the local vernacular. This practice has proven to be of importance in understanding the study findings.

4.2 The Matrilineal system or Chikamwini

The matrilineal tradition in this study implies that kinship relations spring out of female generational ties. This system carries with it matrilineal residence meaning in which a man moves to his wife's village where he builds a family house, which becomes their residence during marriage. This practice derives from the fundamental understanding that women are key reproducers of the family lineage. According to the practice, relatives trace their roots to a common ancestress or a "common breast" (*bele limodzi*) – the source of their lineage (Miller, 1996).

Having a suitor move to the woman's village ensures that the woman remains united with her brothers, sisters and parents who will help bring up the children born in her family.

4.2.1 The status of the in-marrying man

When a man joins his wife at her home, his status in this community will depend on good conduct and hard work. He is required to build a family house and can be asked to assist his in-laws through work in the field. Pleasing his in-laws, obedience to elders and producing many children will help improve his communal status and will eventually earn him land. In

case of marital breakdown, the man has to leave and return to his village empty handed. The man's dependence on his wife's family for land and a place of residence provides an element of social control over the in-marrying man and typically implies a source of tension and exploitation.

4.2.2 Pressures of Development on Chikamwini Matrilineal System

Modern development has opened opportunities for in-marrying men, who have taken up cash earning jobs in the nearest trading centres, towns or cities, leaving their wives to take care of the domestic labour on the farm. Men now work as drivers, tailors, security guards and engage in small businesses. This has implied that men now access resources outside control of the wife's family. We will return to this matrilineal scenario in the sections below.

4.3 Customary Infant Feeding Practices

4.3.1 Prolonged Breastfeeding

Prolonged breastfeeding was reported to be the infant feeding norm among mothers in this community. Mothers reported that they breastfed from birth and stopped breast feeding when the child was two to three years old. Some of the mothers indicated a shorter or longer breast feeding duration. One informant said:

“My sister breast feeds her children for two years. I breastfed my children for two and half years. One friend of mine breast fed for one and half years...it is not the same in all families”. (34 year HIV+ mother of four children)

When one mother was asked how long she would ideally breast feed, she said:

“I will breast feed my child until she learns to eat *nsima* and relish by herself”. (42 year old HIV positive mother of 5 children)(*Nsima* is Malawi's local staple made of hardened maize porridge)

The breastfeeding duration is extended as conveyed by most informants. It partly depends on the choice of mothers, but is also highly dependent upon the influence of older women. New mothers continually said that they are likely to adopt the breast feeding duration patterns common in their family circle or those of their peers in the community.

Variation was also linked to individual factors such as whether children learnt to eat the 'family dishes' early. Those children who managed to eat 'family dishes' early, were more likely to have shorter breast feeding duration than those who were unable to eat such foods. Children who were ill and weak would commonly be breastfed for a longer time.

4.3.2 Mixed feeding

Another common customary infant feeding practice is mixed feeding. Mothers reported that they introduced soft maize porridge at around three months. They also gave other foods such as tea, homemade fruit juice, relish soup, *thobwa* (a local beverage made of a mixture of maize and millet flour, sweetened with sugar) and soft maize porridge. One mother explained her experience with mixed feeding this way:

“I first gave my baby porridge at three months. I decided to give her porridge because she cried frequently which made me suspect that the breast milk I gave was not sufficient. When I tried- I was pleased because he received it well. Soon he got used to eating porridge. He cried much less and slept longer.” (36 year old HIV positive mother of 4 children)

Another mother reflected:

‘When I feed my child I want him to be satisfied. When he eats porridge, he gets full and therefore sleeps most of the time. If I give my child breast milk only, he will cry too much and it will disturb me as I run my house chores. I will of course give breast milk through out the day, but that is usually on top of some porridge in the morning

and afternoon- so the child is full and goes to sleep'. (31 year old HIV positive mother of 3 children)

Most informants observed that adding food to breast feeding made the child satisfied so it would sleep more and cry less. For these informants, any reduced duration of infant sleep was a cause of concern. It is not a good sign when the infant is awake for a large part of the day. Mixed feeding induces the desired longer sleep duration in their infants which also leaves them with time to provide for the family.

Mothers also observed that as their infants grow, they naturally demanded more and more breast milk. According to some mothers, by the time the baby is three months or older, their demand for breast milk outgrew the mothers supply. At this point, the mother begins to lose the fullness in her breasts, as she fails to keep up with her baby's demands. Soon the baby would cry and agitate for more breast milk, and very soon the mothers would know; it is time to give additional nutrients.

4.3.3 Medication

All mothers in this present study gave their babies what they referred to as 'medicines' (*zitsamba*) during the first month of life. Informants reported that they gave traditional medicine to help heal the child's fontanel. The customary belief among informants was that by administering traditional herbs orally, the fontanel would close or even be 'healed' quicker and the infant will be protected from migraine headache and possible death.

One mother had this to say:

"I give all my children medicine to protect them from migraine headaches. My mother told me that she gave me the same medicine when I was a baby and that it protected me". (46 year old HIV positive mother of 6 children)

When the researcher asked when and how the medication was administered, the mother responded:

“We give this medicine during the baby’s first week at home- it’s OK to give it at least during the first month. The baby is orally receives the first portion mixed with water. The remaining portion is mixed with a little hair shaved from the baby’s head and tied around the infant’s neck and the waist to protect them from diarrhoea”. (29 year old HIV positive mother of 3 children)

Mothers pointed out that the use of traditional medicine also protects their children from diarrhoea and gives the baby a ‘*first defence*’ from other diseases such as malaria. They moreover indicated that use of herbs obtained from village traditional healers is a cultural heritage that has been handed down from their parents and that they wish to do the same to their kids.

During a focus group discussion of female village counsellors, a seventy year old village counsellor informant observed:

‘I am very sad when a young boy or girl suffers from chronic migraine, simply because their mother did not heal their fontanel. So I advise young couples that they ensure that they have sought medicine to protect their children from migraine and from *Likankho*’

Likankho is a concept of a disease which is transmissible from mother to child through breast milk leading to serial death of children. According to informants, *likankho* enters the family when a spouse is infected through marital infidelity. Victims of *Likankho* do not show any signs or symptoms. The condition is confirmed only through serial death of infant children. Mothers reported that it is common in this community, for mothers who have recently given birth to seek presumptive traditional treatment for their infants in case they themselves or their husband have contracted the disease.

It is also important to mention that the two conditions mentioned above are not an exhaustive list of disease that the new born infants have to be protected from through orally administered drugs. Hence the total effect of these medication regimes adds up to a pattern of mixed feeding.

4.4 PMTCT and Infant Feeding Services offered at Study Sites

PMTCT and Infant Feeding services at Chiradzulu and St. Joseph Hospitals consist of the following components:

- Group pre- test counselling and education
- Short individual counselling and individual consent to HIV testing
- Post test counselling
- Clinical staging
- ARV prophylaxis

4.4.1 Group pre – test counselling and education

When women come to the antenatal clinic, they receive a group pre – test counselling and education session. This session provides women with general information on HIV testing and prevention of mother to child transmission. The pre- test education is done by PMTCT nurses and is sometimes supported by volunteers living with HIV as motivators. Flip charts for counselling and testing developed by the Ministry of Health are used at both clinics, together with other health education messages.

4.4.2 Short individual counselling and individual consent

After the group pre-test, mothers go through a short individual counselling session where HIV test is routinely offered by PMTCT nurse counsellors. Mothers who accept the routine HIV offer go through Voluntary Counselling and Testing (VCT). The Mothers who refuse the HIV

test are encouraged to reconsider the importance of PMTCT and are assured that testing can be arranged in subsequent antenatal visits.

4.4.3 Post Test Counselling

Post test counseling is carried out with both HIV positive and HIV negative mothers.

Counseling for HIV positive pregnant mothers focuses on promoting optimal infant feeding.

The HIV positive mothers are also motivated to deliver at hospital. At St. Joseph Hospital

mothers are encouraged to exclusively breastfeed. Personnel hold that some of the WHO

Infant feeding options such as expressed heat treated breast milk and wet nursing are

challenging and therefore rarely presented to the mother. Personnel also mentioned that

formula is rather expensive and is presented in detail to only those mothers who they believe

could afford to carry out such regimen. One PMTCT nurse counsellor observed:

“I think its good that we remain focused on what works in this community .This area is very poor; very few people will afford methods such as formula.”

Another nurse said:

“I find that wet nursing is a dangerous method because you cannot really be sure that the wet nurse will protect herself to remain HIV negative through out the nursing period. I also need to say that mothers are already aware of this method... because, you know, this method is not new. Mothers have been using wet nursing for along time when a mother dies and leaves behind a small baby”

Nurses mentioned that the wet nursing method was in most people’s minds; linked to disease or death, and emerged as rather unacceptable in a PMTCT context as it would certainly reveal a mother’s HIV status and moreover was believed to imply a risk to the HIV positive mother.

In contrast, mothers at Chiradzulu District Hospital were at least in theory informed about all available infant feeding options with a special emphasis on exclusive breast feeding and formula feeding. One Counsellor explained

“You know we receive mothers from different parts of the district, sometimes we get mothers from outside the district- so we always provide information on all methods, so that mothers are able to choose an infant feeding method themselves according to their own personal circumstances.”

At both facilities, mothers in need of nutritional food were provided with soya flour and plumpy nut with support from Ministry of Health and NGOs such as Medicens Sanfrontiers and Hope Humana Project.

4.4.4 Clinical Staging

Mothers who test HIV positive and have gone through post test counselling are clinically staged by a nurse/midwife, using HIV clinical symptoms with reference to the WHO staging system. Mothers found in WHO clinical stage III or IV qualify for antiretroviral (ART) therapy. Since access to CD4 count is not available at the two facilities, clinical staging is used to guide medical decision as to whether the mother can begin antiretroviral treatment. HIV pregnant women eligible for highly active antiretroviral therapy (HAART) are referred to the ART clinic.

4.4.5 ARV prophylaxis for the mother and child

The current national policy on ARV prophylaxis in Malawi is a single dose of Nevarapine for mother and child². Mothers who test HIV positive at Chiradzulu District Hospital are usually given a “take home” dose of Nevarapine for themselves and infant. The “take home” dose of

² When data was being collected, this policy was under review. Implementation of a more complex ARV prophylaxis schedule would be introduced soon.

nevarapine is usually provided after 32 weeks gestation. At both facilities, mothers are advised to deliver at the hospital. In the event of a home delivery, mothers are encouraged to return with the baby within 72 hours for the hospital to administer drugs (Nevarapine) to the baby and mother.

Although the PMTCT staff acknowledged the importance of follow up of HI V pregnant and new mothers not the least in connection with choice of breastfeeding options, neither facility was able to offer regular home support or follow up visits due to shortage of staff and resources (such as fuel or bicycles). Follow up visits occurred only in rare instances when resources were available.

As the researcher was not allowed to take part in the counselling session for confidentiality reasons, the content of the sessions were however investigated both from the mothers and the counsellors. PMTCT nurse counsellors explained key messages during post counselling session. Key messages centred around ; medication (neverapine and antiretroviral therapy), optimal infant feeding, disclosure of HIV to partner and other key people in the mother's life , safer sex through use of condoms and testing infants for HIV at 18 months. These messages are discussed here below.

Infant feeding messages for HIV infected pregnant and lactating women

PMTCT nurses at St. Joseph hospital reported that during post test counselling for HIV positive mothers, they emphasize exclusive breast feeding. HIV positive mothers are told to exclusively breast feed without giving water or any other solid or liquid until the child is six months old. In contrast, staff at Chiradzulu District Hospital reported that counseling and education for HIV positive mothers focus on all methods including exclusive breastfeeding, modified cows' milk and wet nursing. One nurse at Chiradzulu district hospital explained:

“Since I started counseling in 2003, I have not had a single client who wanted to use wet nursing So, although I mention these infant feeding methods in the counseling room, my experience has shown that a majority of the mothers will choose exclusive breast feeding and a small minority will go for formula. In the end, the message we emphasize is therefore about exclusive breast feeding and formula feeding”.

A nurse at St. Joseph hospital observed that lack of training in PMTCT Infant feeding Counselling represented major obstacles on how messages on infant feeding for HIV infected mothers were provided. She observed:

“I have had no training in PMTCT infant feeding counseling. I was just given an infant feeding training manual to study- but you know, self study is not the same thing as being trained. I am sure my messages to HIV infected mothers will improve after training”.

At both clinics, PMTCT nurses reported that they do bring up issues of traditional medicines and the dangers such medicines pose on exclusively breastfed infants.

Messages on disclosing HIV test result to partner

PMTCT nurses reported that they encourage HIV infected mothers to disclose their status to partners and motivate them to come for Voluntary Counselling and Testing (VCT). In their messages, PMTCT nurses explain to mothers, that disclosure will open doors of support from partners and will reduce stress and loneliness that mothers may suffer from as a result of non disclosure. They also explained that partner testing promotes adherence to PMTCT infant feeding choice and prevent further HIV infection for both the mother and partner.

Other Messages

Messages on using condoms aim at encouraging HIV positive mothers to practice safer sex.

Women are taught to ask their partners to use condoms to protect themselves from further infection.

PMTCT nurses also reported that they ask mothers to test their babies for HIV at 18 months of age. Through this message, mothers are encouraged to adhere to their chosen infant feeding method in an effort to increase their infants' chances of testing negative at 18 months.

Nurses explain to mothers that infants maintain antibodies from their mothers for several months after birth. Infants therefore would not be ready for an HIV antibody test until 18 months when they have developed their own antibodies.

Mothers are assured that if infants are found HIV positive at 18 months, they would “graduate” from PMTCT into ART where they would be assessed for ART eligibility. On the other hand, infants found negative move into normal child care.

In the section that follows, will see how the HIV positive women related to and handled the infant feeding prescriptions given to them.

4.5 Adherence to Infant feeding Methods

4.5.1 Experiences with Exclusive Breastfeeding with Rapid Cessation

The predominant message from the counsellors was as we have seen; exclusive breastfeeding with early abrupt cessation as it seemed the most feasible alternative in this setting. Despite the fact that this appeared like the most feasible option, none of the informants of the present study said that they managed to adhere to exclusive breast feeding for six months as advised by the nurse. The main reasons given for their failure are outlined below:

4.5.2 Pressure from mothers, peers and elders

Mothers explained that they faced substantial pressure to mixed feed from their mothers, peers and elders in their community. One 31 year old HIV positive mother of three, with a three months old baby explained her experience;

“I tried to follow what the nurse told me (to exclusively breastfeed)... but you know when he cried too long, my mother said that breast milk is not enough- that’s why my baby cries a lot. So she has given him water, tea and sometimes porridge”. (22 year old HIV positive mother of 1 child)

Another mother explained that her house is adjacent to the village headman’s house.

Whenever her child cried a lot, the wife of the village headman came to find out what went wrong and insisted that she breast feeds the child. The mother said:

“One day-when my child cried during the night, the village chief and his wife knocked on my door. They asked if my child was alright. When I told them that she is fine, they asked me to breastfeed her. I did not disclose my HIV status to them and that I was to stop breastfeeding him when he was 6 months, and that I had just completed a week of breast withdrawal. Because they insisted that I breast feed, I did not know what to say... I just breastfed”. (28 year old HIV positive mother of 4 children)

4.5.3 Cracked nipples, Mastitis and Tuberculosis

A lot of mothers failed to stick with their decision to exclusively breast feed due to breast conditions such as cracked nipples or mastitis. The story of Chifundo described in Case 1 below illustrates this point.

Case 1: Mothers failing health – Cracked nipples and Mastitis

Chifundo is a 32 year old HIV positive mother of 2 children. She has had two years of primary school but could not continue due to lack of school fees. She married her husband three years ago. He works as a watch guard with a security company in Limbe town. When Chifundo was pregnant with her current child, she got tested for HIV and was found to be HIV positive. She went through PMTCT counseling and disclosed her HIV status to her husband. Her husband however refused to take an HIV test, but they continued to live together as family. When the child was born, Chifundo was determined to exclusively breast feed her baby up to six months as advised during the PMTCT counselling. She managed to stick to her decision, until suddenly after two months of breast feeding she felt heat inside her left breast. When the heat persisted through out the day, she could breastfeed her child only from the right breast. The next day, Chifundo noticed that her nipple on the affected breast was cracked and painful. She went to hospital where she was given pills and her breast was bandaged. When she arrived home, she continued to feed her baby from one breast only but she soon realized that that her milk was not sufficient for the baby. Her child cried for more milk and Chifundo felt helpless. As the days turned into weeks, Chifundo made a slow recovery but her breast was still bandaged. One day, her baby could not stop crying even while nursing. That day she cooked porridge and gave her baby. This continued until Chifundo completely recovered. When she went back to the hospital for the removal of the bandages, Chifundo was too scared to tell the truth to the PMTCT staff.

Mothers with breast conditions such as cracked nipples were advised at the PMTCT clinics to stop breastfeeding and start formula feeding. Most of them however could not afford formula,

so they opted for sachet powder milk available locally in 25milligram sachets at a cost ten times less that of lactogen. The sachet milk is not an infant product and nurses said it would potentially threaten infant growth because they do not contain vital compounds found in standard infant formula.

4.5.4 Lack of breast milk

Mothers also mentioned that they experienced low milk production when they started working outside the home to support their family. One mother said

‘The nurse told me that HIV positive mothers should not work too hard. But this is not possible for me.....When my husband left me I became the only provider for my family. I have to do piece work to keep my other children in school. But since I started working, my breast milk is no longer sufficient’ (40 year old HIV positive mother of 4 children)

Various manual jobs which mothers carried out included; collecting and selling firewood, fetching water for brick moulders or builders and cultivating in peoples garden. A 32 year old HIV positive mother of four explained her experience with labour intensive work and breast feeding this way:

‘I fetch water for brick moulders and cultivate peoples’ gardens. I get so busy and this work reduces the milk in my breasts. Recently, when I came back from my work and tried to breastfeed my child. He sucked for a few moments, and then started crying. I put him back on my breast. Then he cried again. There was very little milk for him to suckle’ (32 year old HIV positive mother of 4 children)

Other informants, diagnosed with conditions such as TB, reported that the TB drugs lowered their milk production forcing them to mix feed. One HIV positive mother on tuberculosis treatment said:

“Since I started taking TB drugs, I noticed a reduction of my breast milk. When I reported at the hospital, I was advised to start formula feed. I could not afford it however, so I started giving porridge to supplement my breast milk”. (29 year old HIV positive mother of 4 children)

Some mothers complained that they frequently suffered from malaria and diarrhoea which caused fever and weakness, and hence disturbed or at least shortened nursing episodes.

Mothers also indicated that lack of adequate food caused low milk production and forced them to mix feed their babies.

4.5.6 Experiences with rapid cessation

Mothers who were prescribed exclusive breast feeding reported their toughest experiences to be at the time of switching from breast milk to a replacements food, commonly to maize porridge. The mother at this time is supposed to abruptly discontinue breast feeding and continue only with supplements. During this time; mothers reported that ‘babies cried for breast milk for days and nights,’ or that ‘child cried for the whole week’. One mother said:

‘He cried uncontrollably- it didn’t matter what I did- sing to him, play with him, walk with him, hold him...Nothing could stop him from crying. It is was so difficult’ (25 year old HIV positive mother of 3 children)

For many mothers, a crying baby incited social stigma. People teased and asked ‘why not breast feed her and stop him from crying?’ In addition to the stigma, mothers who cannot stop their infant from crying are considered lazy and lacking good character.

In addition to a distraught infant to deal with as well as severe scrutiny from kin or neighbours living in the vicinity, mothers also reported various other complications following rapid cessation as outlined in the story of Chikondi below:

Case 2: Nurses' Assurance Versus Mother's Advice

Chikondi is a divorced 32 year old mother with four children. Three of her children had died (She had hence given birth to a total of seven children). Her husband recently abandoned her following disclosure of her positive HIV result. Her husband had been found HIV negative. Their recently born child was six months old when her husband left her. Chikondi was prescribed exclusive breast feeding, but found that the most difficult time was when she implemented abrupt breast cessation. During that week, her child cried excessively, had diarrhoea and fever.

After the cessation was completed, and just as everything was turning back to normal, Chikondi fell ill. Both her breasts swelled up and felt painful. Chikondi then went to the hospital, where she explained to the nurse that she had just switched her baby from breast milk to a replacement food and that her breasts swelled. The nurse reassured Chikondi that everything would be fine if she went back home and took plenty of rest. She received some tablets to relieve her pain.

When Chikondi went back home, she did as advised at the hospital. However, her condition did not improve. She became weaker and had bad bouts of fever and was sweating profusely. At this point, Chikondi sent her oldest child to call her mother who lived three villages away. When her mother came, Chikondi explained to her what had happened. Her mother told Chikondi that her condition was a result of the discontinuation of breast feeding. She said to her; 'if you don't breast feed your child.

You will die!’ Chikondi was afraid, she started breast feeding again and recovered fully within days.

In this case study, Chikondi knew that prolonged breast feeding in HIV positive mothers would increase the likelihood of transmitting HIV to her child. However, faced with a serious condition, the advice of her mother was more believable than the advice received at the PMTCT clinic. The need to save her life became immediately important for the child than the possible transmission of HIV to her child.

4.5.7 Experiences with Formula Feeding

Three mothers of the fourteen HIV positive mothers interviewed chose formula feeding. All the mothers who formula fed engaged in petty business such as selling beans, groundnut flour or other farm produce. Two of them moreover had husbands who worked as driver and policeman. Mothers who chose formula just like those who opted for exclusive breast feeding reported a number of challenges. The case study below underscores some of these challenges:

Case 3: Feeding twins on formula

When Chimwemwe completed her secondary school education at the age 21, she moved from the village where her family lived to stay with a maternal uncle who worked as a driver at the district town. Her family wanted her to go away from the village to live with her uncle because they suspected that Chimwemwe was sexually involved with a married man. During the first month of living with her uncle Chimwemwe discovered that she was pregnant. Her parents however refused to accept that the father of the child marry Chimwemwe as a second wife. Unfortunately when Chimwemwe gave birth, the baby was born prematurely and died.

Two years later, Chimwemwe got married to a police man and later became pregnant. At the hospital, Chimwemwe was found to be HIV positive. Both Chimwemwe and her husband went through PMTCT counselling and they chose to formula feed their baby. While still pregnant the couple started to save money and even started to buy formula tins (lactogen tins). When Chimwemwe was ready to deliver, she went to the hospital. Three days later Chimwemwe gave birth to twin girls. At this point, the family discovered that what they saved would not be enough for two children. Between their twin children, one tin of lactogen lasted only for one week and cost the family MK700. (5.1 US dollars)

Chimwemwe and her husband were determined to stick firmly to their choice of infant feeding. However, as the babies grew so did the amount of formula milk they needed. Soon, Chimwemwe and her husband had to sell household items to raise enough money. They sold their table and chairs. By the time the twin babies were six months old, Chimwemwe and her husband had not only sold a number of household items, they had also borrowed extensively from friends and relatives. When their children were 18 months, they were tested for HIV and were found HIV negative.

As can be noticed from the case study above and repeated by other informants, families who chose formula feeding tried to start preparation early in pregnancy by saving money. Some couples found it easier to buy and stock formula than to keep cash and buy the tins when the baby is born. The present material demonstrates that success with formula feeding was forerun by a mutual decision made by husband and wife early during pregnancy which gave the families time to put together money for formula feed. Notably, success with formula feeding was also dependent upon at least one income from waged labour.

The major challenge for mothers who opted for formula feeding was the prohibitive cost involved. In the case above, the family reportedly spent more than MK20, 000 (145.40 US dollars) on buying formula for their children from the time their twins were born to the time they reached the age of six months. This sum translates to an average of nearly one dollar a day for formula feeding alone. This is a huge cost given that most rural households in Malawi live in extreme poverty (defined as living on a less than a dollar a day).

Mothers also reported being subject to social stigma, gossip and suspicion for failing to adhere to the culturally acceptable ways of feeding infants. One mother said

‘I have been asked many times why I don’t breast feed my child. ...These days I respond by simply telling them that my child is breast fed by God’. (33 year old, HIV positive mother of 4 children.)

4.6 Disclosure and Adherence

PMTCT counselors intensely attempted to persuade mothers to disclose their status to their partners in order to facilitate adherence to infant feeding methods and hence reduce the chance of infecting their children. For many mothers however, disclosure was met by denial and immense anger from their partners. Statements conveyed by partners such as: “I will not go for that test”, “I do not have that virus”, “Why did you test without telling me?” paint a graphic picture of partner anxiety, fear and denial. For most mothers, their disclosure did little to convince their partner to get a test for HIV.

All mothers who participated in this study reported that they had disclosed their status to their partners. Informants explained the stress and anger they felt at the time, and the burden of having to disclose to their partners uncertain of how their partner would react or what such disclosure would mean for family. At the same time, a sense of responsibility to secure the support of their partner made disclosure almost unavoidable. One mother said:

“I wanted my husband to know that I tested HIV positiveand that if we follow the advice from hospital we can protect our child from getting infected with HIV” (30 year old HIV positive mother of 4 children)

This mother demonstrated her belief that disclosing to her husband would help her adhere to her chosen infant feeding method. Another mother said:

“I disclosed to my husband because; if I didn’t, he would have asked why I stopped breast feeding at six months and why I cannot have unprotected sex with him.” (25 year old HIV positive mother of 3 children)

For some mothers, disclosure was experienced as holding their spouse responsible for infecting them. One such mother said:

“When I tested positive, I was furious and I wanted to disclose to my husband because I knew in my heart that it was him who infected me. I have lived my life faithful- He hasn’t!” (40 year old HIV positive mother of 5)

One mother shared her experience during the moment of disclosure to her husband:

“When he came home that day- I waited until after we ate the food and the children were in bed. When I started telling him, I tried to control myself; I did not want to cry. But suddenly, I could not control myself- I was so angry- I broke into tears .I had lived my life pure.” (40 year old HIV positive mother of 5)

The tragic consequence of partner disclosure was however a fleeing husband and a broken family rather than partner support and increased adherence to exclusive infant feeding as was anticipated in the PMTCT program.

4.6.1 Consequences of disclosure

Reflecting upon their experiences of being abandoned by their husbands on the basis of an HIV positive result, mothers observed that may be they should have waited for one or two

weeks for their anger to subside before they discussed the HIV status with their partners. In hind sight, informants observed that they ought to have disclosed to their partners with skill and etiquette similar to that of the PMTCT nurse(s) who counselled them. They rationalised that their husbands deserved a chance at the same quality of information, encouragement and motivation which the mothers received during PMTCT counselling. They however did not have any assistance at the time of disclosure and felt helpless in their extremely vulnerable situation.

A total of nine mothers in this study, reported that their families disrupted after they disclosed their HIV positive status, their partners abandoned them and when four of them got remarried and disclosed, the new partners in the end, also left. The case study below is illustrative of this situation:

Case 4: A vicious cycle of HIV, PMTCT, disclosure and family disruption

Julita is a 30 year old mother of three live children, two children died. She first got married in 1995. When she was pregnant with her third child, Julita was tested for HIV and was found positive .She disclosed her status to her husband. Three weeks before her expected day of delivery, Julita left home to stay with a relative who lived close to the hospital. After a delivery message was sent to her husband about the new born baby. The boy sent to deliver the message however, reported that Julia's husband was not at home. When Julita and her new born baby were discharged from the hospital and arrived home, her husband was no where to be seen. Inside the house, Julita noticed that her husband had moved out with all his belongings. Soon rumours were rife that her husband was living in another village with a girl friend. Efforts to reach him did not yield. Julita accepted her fate and moved on with life.

A friendly shop owner supported and provided for Julita and her children with money and food .Two years later, Julita's child was grown and tested HIV negative. At about the same time, the shop owner who had been supporting her family for a long time proposed to Julita. She was interested but disclosed her HIV status and told him about the advice she got through PMTCT. For a while, everything was well, until suddenly, Julita fell ill, had nausea, was vomiting and felt very tired. That month, when Julita missed her monthly period- she was certain that she was pregnant. When she told her partner what was happening in her body, he appeared indifferent.

Unfortunately, Julita did not get better, she became very weak and had diarrhoea. She developed a general skin rash all over her body and lost substantial weight. At this point, her partner left the village and moved his shop to a village located on the border of a neighbouring district. At the time of the interview Julita had a baby and two other children to look after. She was unemployed and had no husband to help her. She said disclosure of her status frightened both her husbands and forced them to leave her.

The story of Julita is one that speaks to the experience of nine other women where disclosure led to family break up. In this research communities, the PMTCT program is indeed commonly referred to the 'family disruption program' (*pulojekiti yothetsa mabanja*) During focus group discussions participants observed that one reason why many pregnant women do not enrol in the PMTCT program is that they are frightened that like most PMTCT enrolees, they would face similar family problems like what they had witnessed among women in the PMTCT programs. Instead of support and adherence to exclusive infant feeding, disclosure has led to ruined marriages. This scenario cannot be fully appreciated without understanding the non-presence of men in the PMTCT programs. PMTCT programs are gender inclusive and advocate male involvement in their activities but the reality is different. The section below presents men's experiences and their suggestions for improving PMTCT services.

4.6.2 Men, Disclosure and the PMTCT programs

When confronted with the issue of abandoning their wives upon disclosing HIV positive status, men rationalised such actions by explaining their vulnerability and powerlessness in a context of a matrilineal society where they are separated from their own relatives to live with their wives at their mothers' home. In a community where in marrying men are called; '*akamwini*' which in English translates to 'guest' or 'stranger' – women who disclosed their HIV positive status to their mothers or brothers often provoked feelings of animosity against their husband who would be regarded as "*the 'stranger' who infected their child and sister with HIV*". When this hostility towards the man grew, it was not unlikely that the man would leave to start a new life elsewhere. It became clear during in-depth interviews with men that the problem of family abandonment was further compounded by the virtual absence of men from the PMTCT program. Among the ten men that we talked to during the individual interviews, eight indicated clearly that PMTCT is women's issue as it has to do with the mother and her child. One of them said:

“If you want to find PMTCT, you will find it at the antenatal care section...this is the place where women seek help on various issues of motherhood. What will people think of me, if I a man went and sat at the door to antenatal? This is not a section where you see men, except if they are part of the hospital staff.” (36 year old HIV positive man)

The men interviewed stated a keen interest of getting to know more on issues around PMTCT. They wished to know enough so they are able to explain things and assist their wives. Men explained that receiving knowledge about PMTCT early would help them to improve support given to their wives in adhering to a chosen infant feeding option.

One man said:

“I knew little about issues of mother to child transmission until when my wife was found HIV positive during her pregnancy. I was asked to show up at the hospital for counselling where I learnt all these issues about how mothers can prevent transmitting HIV to their babies. I am sure that if I knew the infant feeding choices before hand, we would have chosen formula feeding. But as it happened, we chose exclusive breast feeding simply because we did not have enough time between the counselling and the birth of our child to put together money for formula feeding”.(50 year old HIV positive man)

Informants further indicated that if men who tested HIV positive, talked openly about their participation in PMTCT, they could motivate other men to do the same, potentially increasing the number of positive role models in the community. Since the program was so strongly structured around women, this option remained almost impossible. One of the key informant interviewed said:

“Men who are HIV positive and are participating in PMTCT do not come out publicly to encourage other men – if such men were encouraged and trained to motivate other men, they would open doors for other men who either do not have the information or are simply shy”.(46 year old key informant)

In line with this thought, men suggested that they would be comfortable to hear more PMTCT messages from their fellow men rather than from staff at the ANC or PMTCT clinics.

One key informant remarked:

“We need a trained group of men to go out into the community with a special PMTCT message for men. Men to men messages are likely to help address the information needs specific for men and will put men at ease.” (50 year old key informant)

Men emphasized that PMTCT messages targeting them should aim to address common misconceptions about MTCT, reproduction and sexuality as well as how they themselves could assist in ensuring their infant's survival.

4.6.3 Communication challenges

Men explained that an HIV positive result can create immense communication problems among couples which if not handled wisely would only get worse and eventually lead to family disruption. When the trauma of dealing with an HIV positive result becomes too much to bear, and when the mother in laws and son in laws are involved, some men would find it easier to walk away and simply abandon their homes.

Men also suggested, that wherever a man refuses to accompany wife for an HIV test, PMTCT counselors should discuss with the concerned women on an appropriate disclosure strategy that may involve a trusted third party such as a "religious leader" or "best friend" to mediate the disclosure process, so that the issues of family disruption are prevented.

One man said:

"Women must change the way they communicate with their husbands when tested HIV positive... most women will come home from the hospital furious and will shout at their husband for infecting them. Women should calm down and explain nicely. I think they should be taught at the hospital how they should communicate their HIV result to their husband...and handle this situation without raising blood pressure for themselves and their husband".(36 year old HIV positive man)

4.6.4 Roles in PMTCT

The men who were informed about the PMTCT concept explained their perceived roles in PMTCT. The most commonly mentioned roles included “providing food for the family”, “being faithful to wife”, “adhering to all advice given at hospital”, “overcoming fear and living positively with HIV”.

Men explained that their role as providers is important in the context of PMTCT to ensure the infant would have enough ‘milk’ during formula feeding thereby ensuring adherence to the selected method of feeding.

Another important dimension of their role in PMTCT was overcoming fear. Men explained that fear is the major factor preventing them from coming forward to test for HIV. One man said

‘No one wants to be HIV positive... no one would like to be told that they are HIV positive. Because telling you that you are HIV positive is like announcing death to your ears. This is why some men would rather stay ignorant of their status. This is why it is painful when your wife takes the HIV test and just snaps at you- ‘I am HIV positive’. (35 year old HIV positive man)

4.6.5 Sources of information

When asked about what sources of information reaches them with PMTCT messages men reported that the radio is the most common source of information. In this community, it is common to see men walking about listening to small radios and others with radios strapped around the neck while cycling to work. One man explained the moment he first heard about PMTCT through the radio

“I like listening to the *Zimachitika* radio drama on radio one. One day two women in this drama were discussing with each other: one said to the other, ‘why did you get

pregnant again when you knew you were HIV positive?’ The other one responded, ‘these days if one is HIV and pregnant, one can get medication at the hospital to prevent mother to child transmission’. After listening to this radio program I started finding out more about this issue. At that time, I was in the village health committee, so it was easy for me to come and ask at the hospital”. (26 year old HIV positive man)

The male informants however stated that communication through the radio did not provide them with the necessary two way communication where they could ask questions. They also observed that messages from the radio are not always tuned to their knowledge gaps.

Medical staff at the hospital explained that one of the many ways they reach out to men is through community health education meetings. On the other hand, when men were asked why health education meetings were hardly mentioned as a source of PMTCT messages: men explained that they do not like to attend community health meetings .They reported that such health meetings are attended by women, girls and young un-married men.

One man explained:

“I usually do not attend such community health meetings. Some men will attend but most men will not. You know we are used to thinking that such meetings are for women, girls and unmarried boys. If I attended my friends would laugh at me. Married men learn about what was discussed in such meetings through their wives at home. They do not attend. The only meetings where all men attend are meetings called by the village headman”. (40 year old HIV positive man)

These findings will be discussed in the following chapter.

CHAPTER 5

5.0 DISCUSSION OF RESEARCH FINDINGS AND RESEARCH METHODS

This chapter will discuss and locate our research findings within a landscape of findings from similar studies. We shall also draw loosely from the cultural competency model and the theory of gender and power to seek to illuminate our research findings further. The chapter also reflects on the insights, experiences and challenges encountered while using qualitative research methods.

Our results revealed that mothers found it difficult to stick to exclusive breast feeding in a culture where mixed feeding, extended breast feeding and extensive use of traditional medicines were the established norm of child rearing. For most mothers, the concept of exclusive breastfeeding was a severe departure from acceptable customary infant feeding practices.

In this community where individuals, family and neighbours freely intervene in each others child bearing and child rearing activities, HIV infected mothers practicing “new” infant feeding methods faced huge social disapproval.

Our findings on family and neighbour involvement in child rearing activities including infant feeding are similar to those reported in a study done in Kilimanjaro Region of Tanzania where breast feeding decision were a concern not only of the mother and her infant but also her affinal kin (Moland, 2004)

In Cote d’ Ivoire, HIV positive mothers who failed to exclusively breast feed but instead extended breast feeding beyond six months while providing supplementary foods to their infants rationalized their actions by reporting that they were under pressure from their mother in laws (Becquet et al, 2005). Various studies have shown that extended breast feeding is wide spread in most African countries. Given this statement, it is less surprising that abrupt

cessation proved difficult among mothers in our study as exemplified by Chikondi's story in Case 2. Our findings also demonstrated the cultural, social and physical challenges mothers faced in carrying out exclusive breast feeding. In agreement with this claim; some researchers have argued that it is near impossible to adhere to exclusive breast feeding and early breast cessation because both are strange concepts in Africa (Magoni and Giuliano, 2005).

Our results and findings also showed that some HIV infected mothers purportedly experienced insufficient breast milk due to frequent illnesses as well as mothers' absence from the child due to heavy workloads. The issue of increased workloads was an increasing challenge as mothers had to engage in income-generating activities to support their families because their husbands disappeared. All these circumstances converged to reduce the cultural, social and physical feasibility of exclusive breast feeding.

The demand by the PMTCT service and the persuasion for partner disclosure in a context where men were virtually absent from the PMTCT counselling and information often resulted in shock, fear and denial on the part of the men. This implied a very challenging vantage point for infant feeding collaboration between couples, and as mentioned earlier; commonly led to divorce and tragic family disruption to the point where community members referred to the PMTCT project as the divorce program.

Our finding that partner disclosure often resulted into family disruption adds evidence to a study done in Tanzania, which showed that mothers feared for their families social and economic future should they disclose their HIV status (Leshabari et al, 2007). It does however not conform to findings from studies done in other African countries, which maintain that partner disclosure brings about family support and improves adherence to infant feeding options (see e.g. Medley et al, 2004).

In the following section, we discuss our findings further in light of the cultural competency model and the theory of gender and power.

5.1 Cultural competency model

Helman (1994) a medical anthropologist, defines culture as a set of guidelines, both explicit and implicit, which individuals inherit as members of a particular society and which teaches them how to view the world, how to experience it and how to behave in relation to other people, to supernatural forces and to the natural environment (Helman,1994). Cultural Competency implies the capacity to function effectively within the context of the cultural behaviour, belief and needs presented by a client and their communities (Anderson et al, 2003). A Cultural competency Model is hence based on a ‘set of practices, policies, attitudes and behaviours that come together in a system, agency or program and enables that system, agency or program to work effectively in diverse cultural situations’ (Anderson et al, 2003: 68). A culturally competency program is one that is uniquely tailored to its target community by integrating or being responsive to the spectrum of cultural factors that influence experience, behaviour and attitudes (Rankow E, 1998) .

Experience has shown that health programs could be effective in one cultural setting but may vary in effectiveness in a different cultural situation. When used in a health program, cultural competency approaches ensure that services are provided in a fashion that reflects the needs of particular cultures. Cultural competency approaches also serve as tools for measuring real program outcomes in terms of their differential impact between cultures. The basic idea of cultural competency model is the explicit recognition that one-size-fits-all health programs cannot meet the needs of an increasingly diverse population (Brach C., Fraser I., 2000). The cultural competency model contends that different cultural groups have an equal entitlement

to benefits of health programs regardless of the impact of their culture on health outcomes such as illness behaviour, illness perception and acceptability of health interventions.

A key assumption of the cultural competency model is that health programs that actively engage cultural competency techniques will deliver improved outcomes in culturally diverse settings. Such cultural competency techniques go beyond mere cultural awareness or the respect for different cultural perspectives.

Several cultural competency techniques are suggested by Brach and Fraser (2000), however for purposes of this study we focus only on organizational techniques of the cultural competency model and locate these within our research findings. These five aspects are listed below :(Brach C., Fraser I., 2000: 184 -187)

- Coordinating with traditional healers
- Including family and/or community members
- Use of community health workers
- Culturally competent health promotion
- Administrative and organizational accommodation

5.1.1 Coordinating with traditional healers

Our research findings show that women sought the formal health care for PMTCT services and at the same time sought traditional treatment of fontanel and *likango* among infants.

Despite counselling against mixed feeding, mothers received and gave their children herbs from traditional healers and by this action appeared to value the traditional medicine higher than the PMTCT advice. The customary medication regimes were also highly appreciated by their social surrounding who pressured the women to adhere to the these traditions

Previous research has shown that between 20 and 85 percent of the clients do not tell their clinicians about their patronage of traditional medicines (Druss, Rosenberg; 1999).

Various studies on this topic show that traditional medicines, herbal medicines and other forms of complementary medicines are used widely and perceived as effective among mothers in most developing countries (K.Sydala et al, 2005:199-205). In a study done among pregnant women seeking care in Lusaka, the capital city of Zambia; 30 percent of mothers reported using traditional healers in their previous pregnancy and 21 percent in the current pregnancy (Yolen Banda et al, 2007:123-127). Given that Lusaka is an urban setting, the use of traditional herbs would likely be more prevalent among mothers in rural areas.

According to the cultural competency model, collaborating with traditional healers as with any other care providers such as traditional birth attendants would provide opportunities to discuss various types of therapies, and in the long run work with local healers to avoid 'harmful therapies'. Initial collaboration may include recognizing traditional healers as legitimate health care providers. The provision of licences to traditional healers in Zimbabwe is a case in point (Barret, 1996). More advanced collaboration would, for example- draw traditional healers into providing non-oral methods of treating fontanel or *likankho* for infants born to HIV positive mothers. In general, the development of appropriate legislation and the formation of regulatory mechanisms related to the practice of traditional medicine represent a key opportunity for improving infant feeding and PMTCT outcomes.

5.1.2 Including family or community members

Our study has shown that despite contrary advice from PMTCT, HIV positive breast feeding mothers yielded to social pressure to mixed feed from their family and community. In this rural matrilineal community with strong customs on infant care, mothers were clearly apprehensive in their attempt to deviate from what is considered 'normal' child rearing practice by their society. A majority of the mothers who started out exclusively breast feeding

were already mix feeding their infants at three months. These results are in line with findings from other African countries.

In a study done in Kilimanjaro Region of Tanzania, Sebalda Leshabari writes about the social pressure to mixed feed among HIV positive mothers and their lack of control on how to feed their own infants (Leshabari S.C, etal, 2006: 22). Another study done in Uganda (Bakaki, 2002) found that all HIV positive mothers who started out with exclusive breastfeeding switched to mixed feeding by the third month.

According to the cultural competency theory; the “business”-like western styled health care system with its emphasis on patient autonomy and informed consent may not necessarily be effective in family-centred communities where involvement of community as well as family members is crucial in ensuring adherence to infant feeding recommendations among HIV positive mothers.

In our research, the HIV positive men as well as the interviewed suggested that HIV test result should not be given to wives in the absence of their husband, unless the concerned husband refuses to know or is uncooperative. This assertion that women need the presence of their husband to get an HIV test result indicates that the notion of informed consent with its emphasis on individual autonomy is not necessarily universally applicable and in some cases conflicting with specific cultural values.

5.1.3 Use of community health workers

PMTCT nurses reported that they were unable to carry out community out-reach activities due to lack of resources such as fuel and shortage of staff. Community based volunteers were not enlisted for PMTCT outreach activities.

In ‘culturally competent’ health programs, community volunteers provide a necessary liaison with ordinary community members and serve as a cultural linkage between service providers and targeted community. Such volunteers will work far more closely with the community as they in principle are normal community members, and will ideally be able to help communities overcome their mistrust with health programs and increase the effectiveness of outreach education activities as well as client follow up.

5.1.4 Culturally competent health promotion

Cultural competency models hold that health education and communication, designed for majority populations will not always work equally well for all groups. Our study found that while health officers at the study sites conveyed that community meetings were a key avenue for delivering PMTCT messages, married men reported shunning such community health meetings claiming they were for women, girls, and young unmarried men. Married men contend that they only attend community meetings convened by the village headman.

A culturally competent approach for health promotion would take into account such simple dynamics and work through the village headman in order to increase coverage and acceptability among men of PMTCT and infant feeding health promotion messages.

5.1.5 Administrative and organizational accommodation

According to cultural competency approaches, a variety of administrative and organizational arrangements related to physical environment, hours of operation, written materials and clinic location may affect access to and utilization of health care services by specific groups in the targeted community.

Our research findings showed that men connected the location of PMTCT services (PMTCT section was usually housed in mother and child care department of the hospital) with a perceived notion that PMTCT are for pregnant women or mothers and not men.

Culturally competent health systems would modify such physical environments to make them welcoming to specific group members, in this case; men. The fact that mother and child health (MCH) and PMTCT programs are designed for women and children prevent men from finding such services attractive.

5.2 The theory of gender and power

The theory of gender and power is a social structural theory developed by Robert Connell which describes three major relationships characterizing the gendered relationships between men and women. (Connell RW, 1987. In: Wingood and Diclemente, 2000:540)

Robert Connell submits that the three major structures that characterize the gender relationship between men and women are: the sexual division of labour, the sexual division of power and the structure of cathesis.

Sexual division of labour refers to the well known allocation of men and women to specific occupations. Women are ascribed different and unequal assignments in relation to men which limit their potential and growth. (WingoodG., Diclemente , 2000)

Sexual division of power refers to the inequalities between sexes on the basis of having power to act or change or having power over others. For example women in power imbalanced relationships tend to depend on their male partners because of the financial assets that men bring into the relationship. (WingoodG., Diclemente R., 2000)

According to Connell, these three structures exist at the societal and institutional levels. While it is important to examine all the three structures together in applying the gender and power

theory, this study focuses on the structure of cathesis because it addresses the issue of social norms and their effect on relationships between men and women as explained below.

5.2.1 Structure of cathesis

At societal level, the structure of cathesis dictates the appropriate sexual behaviour for men and women. The structure of cathesis shapes self perception and the expectations society has on women. Women are supposed to be submissive to their husbands and to preserve their virginity until marriage while men are allowed to explore and experience with sex. Research in many parts of the world; show that men have a greater life time number of sex partners than women. In many cultures, coercive sex and violence perpetrated by men against their own wife are not unusual. (Bruyn et al, 1995)

As we have seen in this thesis, the PMTCT program supported disclosure of HIV positive status among women led to spouses abandoning their wives. HIV infected women also mentioned how this cycle of disclosure and abandonment repeated itself in their subsequent relationship.

This scenario may be difficult to understand in the context of a matrilineal system which would supposedly provide women with the protection of their brothers and parents and most importantly the right to inherit resources such as land. Writing on matrilineity in Malawi, Mandala and Phiri argue that matrilineity does not necessarily equate matriarchy or control by women (Mandala, 1990 and Phiri 1983). The power of women in these communities is only a symbolic homage due to their reproductive and motherhood role in society. At community level, this 'motherhood' power does not translate into true political power; instead it is the men who become chiefs and village men. At household level, it is again the men who make all critical decisions and women are expected to remain obedient and submissive to both their husbands and community leaders. Phiri argues that, carefully speaking, matrilineal systems as

practiced in most communities in Malawi are in fact, patriarchal systems tracing lineage through the female folk (Miller, 1996)

It is also important to note, how the matrilineal system has been affected in recent history by economic development. In-marrying men, who would otherwise depend on their wives' family for land and livelihood, now work and earn cash leading to access and control of resources outside the family domain. Economic power of men over women has made women more dependent on men. This dependency has only reinforced cultural norms and stereotypical beliefs about the 'masculinity'; of men, the 'femininity' of women and how men and women should express their sexuality. (Wingood G. and Diclemente, 2000)

In the light of our findings, it is not surprising that men in this study community used the prevailing 'masculinities' or sex freedom to move away from scenarios of HIV in fear of reproach and continuous accusations of unfaithfulness from their wives family. On the other hand, women find themselves conforming to stereotypical versions of 'femininity' including submissiveness and compliance, with many women reportedly refusing to attend PMTCT because of fear of having to be abandoned by their husband.

5.3 Discussion of research findings and research methods

This research used triangulation of qualitative research methods in order to achieve stronger internal validity and better comprehensiveness of findings. In the process of qualitative triangulation, the researcher started with in-depth interviews which were carried out with individual informants. Common themes emerging in the in-depth interviews guided a richer and wider discussion during focus group discussion. Data from both in-depth interview and focus group discussion facilitated a deeper inquiry during case studies. A combined synthesis

of material obtained from these various sources strengthens the trustworthiness of our research findings.

5.3.1 Individual interviews

As indicated in the methods chapter, in-depth interviews were carried out in order to understand informants' experiences with infant feeding aspects of the PMTCT program. The researcher's fluency in the vernacular language and his experience as a counsellor and community mobilizer were important in facilitating the interview conversation and creating a relaxed atmosphere in which informants felt at ease to express themselves.

The in-depth interviews generated a substantial amount of knowledge of the enormous dilemmas at work for the women who struggle to feed their infants with the knowledge of possibly infecting their infants with HIV. The privacy of the individual interviews and the passion on the part of the women to share their extreme worries with someone paved the way for many touching interviews where women seemed to openly talk about most sensitive aspects of their challenging life situations. In general, the in-depth interviews provided space for confidential one-on-one conversation with both men and women.

The major challenge noted in some of the in-depth interviews, was the difficulty for a male researcher to connect deeply with rural mothers in a culture where female interaction with male strangers is incorrect or at least discouraged. These prevailing cultural undertones may have prevented some mothers from divulging salient issues or from responding fully to certain questions.

Mothers who were followed up more than once, became used to the researcher and were able to relay their experiences in greater detail.

5.3.2 Focus group discussion

During focus group discussion with HIV positive women, the researcher noticed that 'sensitive' issues were more readily discussed than during the individual interviews. For example, women's dissatisfaction with the small amounts of nutritional support received at PMTCT was expressed more forcefully during the focus groups than during the individual interviews. It appeared that women found it less threatening to express dissatisfaction in a group rather than individually.

During the focus group discussion with health staff, it was interesting to observe not only what was said but also the fact that comments by certain participants were always taken more seriously than comments from other participants. This probably had to do with differences in length of relevant work experiences among participants.

The major challenge with focus group discussion was to ensure that dominant participants did not affect contribution from other participants. Of equal importance was the need to encourage passive informants to participate without making them feel uncomfortable.

The main experience from the focus group discussions is that they added substantially to the themes that had emerged from the individual interviews. The information would however have remained scant if it did not draw upon the findings generated during the individual interview sessions.

5.4 Further research

This research project has highlighted several findings which are themselves areas of further inquiry. The issue of male involvement in PMTCT is one area which requires a bigger and more rigorous qualitative research on how best PMTCT programmes can attract both men and women and thereby rally the support of entire families and communities rather than just individual mothers.

It will be important at this point to measure quantitatively; levels of adherence to the prescribed infant feeding options. This is not least important in terms of the most recently published WHO guidelines on infant feeding and HIV which to a much stronger degree promote exclusive breastfeeding

CHAPTER 6

6.0 CONCLUSION AND RECOMMENDATIONS

This final chapter presents conclusions from the study. It also discusses implications of the findings and recommendations.

6.1 Conclusion

Culture and traditions have a profound influence on people's lives. In this study, the cultural norms of prolonged breastfeeding, mix feeding and oral medication interfered with the requirements of the prevention of mother to child transmission of HIV programs and challenged the recommended exclusive feeding regimes. The individual woman's intentions to adhere to recommended infant feeding were challenged by a culture and society where people intervened in each others' child rearing activities on a day to day basis. In the end, none of the HIV positive women interviewed managed to adhere to the infant feeding options prescribed by the program. This study argues that a program like PMTCT may simply not deliver unless it is fundamentally responsive to the wide spectrum of socio-cultural factors that influence infant feeding. The success of PMTCT programs will simply depend on its ability to integrate beliefs, values and practices of different cultural settings into the program design.

6.2 Implications and recommendations

Mixed feeding

Mixed feeding was customary and prevalent in our study community. HIV positive mothers faced tremendous pressure to breastfeed in the community where they lived. For most mothers, adhering to an exclusive infant feeding choice only made them the subject of stigma, and gossip.

Rather than engaging only the individual mother and expecting that she would single handedly navigate the societal pressure to mix feed, PMTCT programs should engage community leaders as well as family members to build awareness on infant feeding. This will ensure that when the mother chooses a recommended infant feeding regime, she is able to go back home to a community and family that will support her intentions.

Medication

There is an urgent need for increasing access to the ART services for both men and women implied in the PMTCT + concept, so that women and men who enrol in the PMTCT program feel assured that they can continue to live for many years after they test HIV positive. In light of the immense challenges with exclusive breastfeeding, the need to develop and roll out drugs that can reduce the viral load in breast milk should be given top priority.

The study revealed the wide spread patronage of traditional healers among HIV positive women seeking to heal their infants of fontanel and *likankho*. Seeking traditional medicines is usually done outside the awareness of the medical staff. There is hence urgent need for PMTCT programs and indeed health systems in general to collaborate with traditional healers to enhance beneficial practices and aim at modifying practices that imply a health risk.

Insufficient breast milk

Some mothers complained that they experienced low milk production which they attributed to a number of factors including heavy work and diseases such as malaria, diarrhoea and tuberculosis. Such mothers reported that they felt pressured to mixed feed as they got increasingly concerned of the inadequacy of their breast milk supply.

The psychological impact of their HIV status and the fear of possibly infecting their babies may result into growing maternal anxiety and strong feelings of insecurities. In this regard,

HIV positive breast feeding mothers need special motivation, confidence building and on going counselling, and importantly home support and follow up. PMTCT nurses need resources and specialized training to provide this kind of support to HIV positive mothers. About half of the nurses we talked to at PMTCT sites were not trained in PMTCT and infant feeding. There is urgent need to train nurses to improve quality services available to PMTCT enrollees.

Disclosure and its consequences

In a community where a woman's economic survival is tied to being a wife, family disruption on the basis of a disclosed HIV positive test, had negative consequences for both women and infants. At the level of society, these abandoned women were a subject of gossip from community members and the same ridicule and stigma was directed at the PMTCT program, as people commonly label it; 'a family disruption program.'

It is important for the PMTCT program to directly engage men on these issues. There is an urgent need for an open and honest discussion about masculinities, femininities and gender equality between men and women. The PMTCT program should seek to facilitate a community transformative process that draws men to examine their own behaviour, values and attitudes using their life stories; focusing on how their behaviour affects them and their families. Through this process of reflection, men could be drawn to appreciate the injustices related to their behaviour and be encouraged to suggest proposals for change and to take responsibilities for making such changes.

There is also urgent need for comprehensive PMTCT and ART services for both men and women that go beyond counselling and medicines to empower couples with skills on partnership, negotiation and communication. Acquiring skills in partnering, negotiating and

communicating will enable couples to make important choices and decisions on an equal position of power in order to achieve a common goal.

Reaching men with PMTCT and infant feeding messages

Instead of relying on traditional community health campaigns, PMTCT programs should reach out to men where they socialise such as during football games. The use of social marketing approaches to deliver messages to men has yielded results in other districts in Malawi. A case in point is the male championship initiative which brings together men actively involved in PMTCT to interact with other men in their community through activities such as football. In the course of these social events, men that are involved in PMTCT will share their testimonies and motivate peers in their community to follow their example and join PMTCT. In this way, these men are able to model out a positive lifestyle for their peers.

Male friendly PMTCT services

In order to ensure services that are welcoming to men, PMTCT programs need to consider setting aside separate rooms or spaces for men and create in these rooms an atmosphere that is welcoming and culturally acceptable for men. PMTCT services should also consider allowing men to walk in without waiting on a queue and should remove any décor that is overly feminine or welcoming only to women.

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APPENDICES

APPENDIX A

Consent Form for In-depth Interviews

Research Project Title: Health Education and Counselling in Prevention and Mother To Child Transmission of HIV programs (PMTCT): The case for Rural Malawi

Researcher :

This consent form will be left with you for your records and reference. The consent form should give you an idea of what this research is about and what your participation will involve. If you would like more information about something mentioned here or not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I,, understand that John Njunga, a student at the Centre for International Health, University of Bergen, Norway is conducting research on Health Education and Counselling in Prevention and Mother To Child Transmission of HIV Programs in Chiradzulu district of Malawi, as explained to me by the PMTCT/VCT provider.

I understand that I will participate in an interview that will last about one hour. I understand that with my permission the interview will be audio- recorded and later transcribed. I do not have to answer any questions I do not want to, and at any time, I may stop the interview and speak off the record and still be able to continue with the interview if I want to. I am aware that the audio tapes and transcripts will be used only by the research team. No other person will have access to them. The audio tapes and transcripts will not have my name or any other identifying information on them. A research code number will be used instead. All data will be kept on a secure computer which will be password protected. Access to the computer will be secured by use of a specific password which will be known only to the researcher. The completed interview schedules, transcriptions, audiotapes and other research data will be

stored in a secure locked cabinet. No information will be released or printed that would disclose any personal identity and all such research data will be destroyed after three years.

Any questions that I have about the survey have been answered to my satisfaction. I have been assured that no information will be released or printed that would disclose my personal identity and that my responses will be completely confidential. Any risks or benefits that might arise out of my participation have been explained to my satisfaction. In particular, I am aware that my decision to participate or not **will not affect** the services that I receive from my Chiradzulu District Hospital.

I understand that my participation is **completely voluntary** and that my decision either to participate or not to participate will be kept **completely confidential**. I further understand that I can withdraw from the study at anytime without explanation.

I hereby consent to participate in this study - *Oral Consent*

APPENDIX B

Interview Guide with HIV positive mothers

Interview No:

Date of Interview:

Time of Interview..... Start.....Finish

1. Socio demographic characteristics

Age?

Highest level of education?

Number of living children....

Have you had any infant deaths/miscarriages/still birth?

If Yes; how many?

Marital status: Single/Separated/Widow/Married/Cohabiting

What do you do for a living?

What does your husband do for a living?

What is your religion?

2. Experience with PMTCT services

What did you learn about MTCT from the PMTCT services at the hospital?

What more information would you have liked in your consultation with PMTCT service?

3. Experience with Infant Feeding Choice

What infant feeding options were explained to you?

Which feeding option have you decided for your baby?

Why did you choose this feeding option?

Who were involved in deciding for the feeding option you chose?

4. Exclusive Breastfeeding with abrupt cessation

How did you feel about this feeding option, when you first decided for it? How are you feeling about the decision now?

How were you able to implement exclusive breast feeding with abrupt cessation? Tell me the story of your experience so far

What challenges did you face?

What are you doing to address the mentioned challenges?

What on going support are you receiving from the hospital to help you with exclusive breastfeeding with abrupt cessation?

Did you discuss your infant feeding decision with any one?

If you were to make this decision again, would you choose the same feeding option for you baby, why

How are women who do not breastfeed treated in your community?

5. Infant Feeding Formula

How did you feel about this feeding option, when you first decided for it? How are you feeling about the decision now?

How were you able to implement infant formula feeding? Tell me the story of your experience so far

What challenges did you face?

What are you doing to address the mentioned challenges?

What on going support are you receiving from the hospital to help you with the infant formula feeding?

Did you discuss your infant feeding decision with any one?

If you were to make this decision again, would you choose the same feeding option for you baby, why

How are women who do not breastfeed treated in your community?

6. Modified Cows Milk

How did you feel about this feeding option, when you first decided for it? How are you feeling about the decision now?

How were you able to implement modified cows feeding? Tell me the story of your experience so far

What challenges did you face?

What are you doing to address the mentioned challenges?

What on going support are you receiving from the hospital to help you with the infant formula feeding?

Did you discuss your infant feeding decision with any one?

If you were to make this decision again, would you choose the same feeding option for you baby, why
How are women who do not breastfeed treated in your community?

7. Expressed heat treated breast milk

How did you feel about this feeding option, when you first decided for it? How are you feeling about the decision now?
How were you able to implement expressed heat treated breast milk feeding? Tell me the story of your experience so far.
What challenges did you face?
What are you doing to address the mentioned challenges?
What on going support are you receiving from the hospital to help you with the expressed heat treated breast milk feeding?
Did you discuss your infant feeding decision with any one?
If you were to make this decision again, would you choose the same feeding option for you baby, why
How are women who do not breastfeed treated in your community?

8. Wet Nursing

How did you feel about this feeding option, when you first decided for it? How are you feeling about the decision now?
How were you able to implement wet nursing for your baby? Tell me the story of your experience so far
What challenges did you face if any?
What are you doing to address the mentioned challenges?
What on going support are you receiving from the hospital to help you with the infant wet nursing?
Did you discuss your infant feeding decision with any one?
If you were to make this decision again, would you choose the same feeding option for you baby, why
How are women who do not breastfeed treated in your community?

9. Other

Do you have anything that you want to say which I did not ask?
Do you have any questions for me?

Thank You For Your Time!

APPENDIX C

Interview Guide for Men

Interview No:

Date of Interview:

Time of Interview..... Start.....Finish

Socio demographic characteristics

Age?

Marital status: Single/Separated/Widow/Married/Cohabiting

Highest level of education?

How many living children do you have?

Has your wife had any infant deaths/miscarriages/still birth?

If Yes; how many?

What do you do for a living?

What does your wife do for a living?

What is your religion?

Knowledge of MTCT and Involvement with PMTCT services

How did you learn about MTCT and how it can be prevented?

Are you aware of the PMTCT program at the hospital?

How did you know about this program?

How are men in this community participating in the activities of the PMTCT program?

What should the PMTCT program do to get more men involved?

Knowledge and Experience with Infant Feeding Options

Are you aware of any infant feeding options available to HIV positive mothers to help them prevent transmitting HIV to their breastfeeding infants?

What infant feeding options have you heard about?

How did you learn about these infant feeding options?

What challenges do you face in implementing the infant feeding option of your choice?

How are women who do not breast feed treated in your community?

Suggestions for Improving PMTCT services

Are you satisfied with the level of involvement of men in the PMTCT program?

What should the role of men be in PMTCT?

What should be done to get more men involved?

Which other group of people should be involved apart from men?

What do you suggest should be done to improve PMTCT services in this area?

APPENDIX D

Interview Guide with Health Care Workers

Interview No:

Date of Interview:

Time of Interview..... Start.....Finish

Socio demographic characteristics

Age?

Marital status: Single/Separated/Widow/Married/Cohabiting

Occupation

Do you have any breast feeding experience?

Have you been trained in PMTCT and Infant feeding Counselling

How long was the training?

Experience with clients on exclusive breastfeeding with abrupt cessation

What has been the experience of mothers that you counseled and opted for exclusive breast feeding with abrupt cessation?

Were these mothers able to implement breast feeding and abrupt cessation? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

What on going support did these mothers get from the hospital to help with the infant feeding method of their choice?

Did these women discuss their infant feeding decision with any one?

Experience with Clients on Infant Feeding Formula

What has been the experience of mothers that you counseled and opted for formula feeding?

Were these mothers able to implement formula feeding? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

What on going support did these mothers get from the hospital to help with the infant feeding method of their choice?

Did these women discuss their infant feeding decision with any one?

How are women who do not breastfeed treated in this community?

Experience with clients on modified cow's milk

What has been the experience of mothers that you counseled and opted for modified cow's milk?

Were these mothers able to implement modified cows milk feeding? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

What on going support did these mothers get from the hospital to help with the infant feeding method of their choice?

Did these women discuss their infant feeding decision with any one?

Experience with clients on heat treated breast milk

What has been the experience of mothers that you counseled and opted for heat treated breast milk

Were these mothers able to implement heat treated breast milk feeding ? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

What on going support did these mothers get from the hospital to help with the infant feeding method of their choice?

Did these women discuss their infant feeding decision with any one?

Experience with clients on wet nursing

What has been the experience of mothers that you counseled and opted for wet nursing

Were these mothers able to implement wet nursing? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

What on going support did these mothers get from the hospital to help with the infant feeding method of their choice?

Did these women discuss their infant feeding decision with any one?

How are women who do not breastfeed treated in this community?

Involvement of Men

To what extent are men in this community, aware of the PMTCT program at the hospital?

How do men know about the PMTCT program?

How are men in this community participating in the activities of the PMTCT program?

What should the PMTCT program do to get more men involved?

Other

To what extent are opinion leaders, traditional birth attendants and members of the community health committee aware of the PMTCT program?

How did these people get to know the program?

How are they involved in the PMTCT program?

What role do they play in the PMTCT program?

What challenges do you face in your work (infant feeding counselling and following up clients)?

What do you think should be done to improve PMTCT services?

Do you have anything that you want to say which I did not ask?

Do you have any questions for me?

APPENDIX E

Key Informant Interview Guide

Interview No:

Date of Interview:

Time of Interview..... Start.....Finish

How many of HIV infected women are able to stick to the end with the infant feeding decision of their choice?

What on going health system support is provided to these women to help them with the infant feeding method of their choice?

What challenges do these women report?

What are you doing to address the mentioned challenges?

Are men in this community participating in the PMTCT program?

To what extent do men support their wives in implementing infant feeding option of their choice?

What challenges do men face in supporting their wives to implement the infant feeding option of their choice?

What is being done to support the involvement of men in PMTCT?

Which other group of people should be involved apart from men?

To what extent are opinion leaders, traditional birth attendants and members of the community health committee aware of the PMTCT program?

How are they involved in the PMTCT program?

What role do they play in the PMTCT program?

How are women who do not breastfeed treated in the communities?

What is being done to stop stigma against such women?

What do you suggest should be done to improve PMTCT services in general?

Interview with key informants will depend on emerging issues with the other categories of informants

APPENDIX F

Focus Group Discussion with HIV positive women

Date of FGD:

No. of participants.....

Time of interview.....start.....finish

Exclusive Breastfeeding with abrupt cessation

Are HIV positive women that you know of able to implement exclusive breastfeeding with abrupt cessation? (*Share stories*)What challenges do these women face?

How do they address the mentioned challenges?

Infant Feeding Formula

Are HIV positive women that you know of able to implement infant formula feeding? (*Share stories*)What challenges do these women you face?

How do they address the mentioned challenges?

Modified Cows Milk

Are HIV positive women that you know of able to implement modified cows milk feeding? (*Share stories*) What challenges do these women face if any?

How do they address the mentioned challenges?

Expressed heat treated breast milk

Are HIV positive women that you know of able to implement expresses heat treated breast milk? (*Share stories*) What challenges do these women face?

What do they do to address the mentioned challenges?

Wet Nursing

Are HIV positive women that you know of able to implement wet nursing? (*share stories*)

What challenges do these women face if any? What do they do to address the mentioned challenges?

Community and Health System Support

What on going support do women that are HIV positive and breastfeeding receive from the hospital?

Do you think it is important for such women to discuss their infant feeding decision with any one? Why

How does your community treat such women?

What suggestions do you have for improving the quality of women who breast feed

Other

Do you have anything that you want to say which I did not ask?

Thank You For Your Time!

APPENDIX G

Focus Group Discussion with Men

Date of FGD:

No. of participants.....

Time of interview.....start.....finish

Knowledge and Experience with Infant Feeding Options

How are men involved in making choices for an infant feeding option?

To what extent do men support their wives in implementing infant feeding option of their choice?

What challenges do men face in supporting their wives to implement the infant feeding option of their choice?

How are women who do not breast feed treated in your community?

What should be done to improve PMTCT services?

Other

Do you have anything that you want to say which I did not ask?

Thank You For Your Time!

APPENDIX H

Focus Group Discussion with Health Care Workers

Date of FGD:

No. of participants.....

Time of interview.....start.....finish

Experience with clients on exclusive breastfeeding with abrupt cessation

What has been the experience of mothers that you counseled and opted for exclusive breast feeding with abrupt cessation?

Were these mothers able to implement breast feeding and abrupt cessation? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

Experience with Clients on Infant Feeding Formula

What has been the experience of mothers that you counseled and opted for formula feeding?

Were these mothers able to implement formula feeding? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

Experience with clients on modified cows' milk

What has been the experience of mothers that you counseled and opted for modified cows' milk?

Were these mothers able to implement modified cows milk feeding? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

Experience with clients on heat treated breast milk

What has been the experience of mothers that you counseled and opted for heat treated breast milk

Were these mothers able to implement heat treated breast milk feeding? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

Experience with clients on wet nursing

What has been the experience of mothers that you counseled and opted for wet nursing

Were these mothers able to implement wet nursing? Tell me the stories of their experience

What challenges did they face if any?

What did you do to help them address the mentioned challenges?

Health System and Community Support

What on going support do these mothers get from the hospital to help them with the infant feeding method of their choice? What challenges do you face in providing this support?

Who do these HIV positive mothers discuss their infant feeding decision with?

What support do these mothers get from the community to help with the infant feeding method of their choice?

How are women who do not breastfeed treated in this community?

Did these women discuss their infant feeding decision with any one?

Involvement of Men

To what extent are men in this community, aware of the PMTCT program at the hospital?

How do men know about the PMTCT program?

How are men in this community participating in the activities of the PMTCT program?

What should the PMTCT program do to get more men involved?

Other

To what extent are opinion leaders, traditional birth attendants and members of the community health committee aware of the PMTCT program?

How did these people get to know the program?

How are they involved in the PMTCT program?

What challenges do you face in your work (infant feeding counselling and following up clients?)

What do you think should be done to improve PMTCT services?

Do you have anything that you want to say which I did not ask?

Do you have any questions for me?

Thank You For Your Time!

APPENDIX I

Telephone: +265 789 400
Facsimile: +265 789 431
e-mail doccentre@malawi.net
**All Communications should be addressed to:
The Secretary for Health and Population**



In reply please quote No. MED/4/36c

MINISTRY OF HEALTH
P.O. BOX 30377
LILONGWE 3
MALAWI

10 July 2007

John Njunga
Centre for International Health

Dear Sir,

**RE: PROTOCOL # 462: HEALTH EDUCATION AND COUNSELLING IN PREVENTION OF
MOTHER TO CHILD TRANSMISSION OF HIV PROGRAMS (PMTCT) : THE CASE FOR
RURAL MALAWI**

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has reviewed and approved the study.

APPROVAL NUMBER : 462

The above details should be used on all correspondences, consent forms and documents as appropriate.

- **APPROVAL DATE : 26th June 2007**
- **EXPIRATION DATE 25th June 2008**
After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS:** Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS:** Please contact the NHSRC on telephone number +265 1 789 400/314 or by email on doccentre@malawi.net.
- **OTHER:** Please be reminded to send in copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat.


For: **CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE**
Promoting Ethical Conduct of Research

Executive Committee: Dr C. Mwanambo (Chairperson), Prof. E. Molyneux (Vice-Chairperson)
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