



UNIVERSITY OF MALAWI

KAMUZU COLLEGE OF NURSING

**EXPERIENCES OF HIV POSITIVE MOTHERS
WHO STOP BREAST FEEDING AT SIX MONTHS
AT LIMBE CLINIC**

BY

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SUBMITTED TO

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THE AWARD OF THE BACHELOR OF SCIENCE
DEGREE IN HEALTH SERVICES MANAGEMENT**

SUPERVISED BY

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DUE DATE: 04TH DECEMBER, 2009

DECLARATION

I hereby declare that this dissertation is solely the result of my own work and has not been presented or submitted in candidature for any degree at any other university.

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DEDICATION

This work is dedicated to Lisungu and Hope my children and Wanangwa my niece for their endurance during my absence at home.

Hope: you've had to grow from three to five without a mom constantly there with you.

Lee and WA: you had to assume the role of a mother to your younger brother at very tender ages.

Having you as family is all I could ask for. Thank you for always being there for me. I can not take that for granted.

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ACRONYMS/ABBREVIATIONS

HIV	:	Human Immunodeficiency Virus
AIDS	:	Acquired Immuno Deficiency Syndrome
PMTCT	:	Prevention of Mother to Child Transmission (of HIV)
EBF	:	Exclusive Breast Feeding
MTCT	:	Mother to Child Transmission (of HIV)
VCT	:	Voluntary Counselling and Testing (for HIV)
HCT	:	HIV Testing and Counselling
UNAIDS	:	The Joint United Nations Program on HIV/AIDS (UNICEF, UNDP, UNDCP, ILO, UNESCO, WHO, and World Bank) – United Nations Joint efforts against HIV and AIDS.
WHO	:	World Health Organization
NAC	:	National AIDS Commission
MOHP	:	Ministry of Health and Population
NGOs	:	Non Governmental Organization
AFASS	:	Acceptable, Feasible, Affordable, Sustainable and Safe
MDHS	:	Malawi Demographic and Health Survey
NSO	:	National Statistical Office
MHRC	:	Malawi Human Rights Commission
ART/ARV	:	Anti Retro Viral Therapy
HBM	:	Health Belief Model.
RPC	:	Research Publications Committee.

DEFINITION OF TERMS

Infant feeding options

These are infant feeding choices that HIV positive mothers are oriented to and later choose, in the context of HIV/AIDS with the aim of preventing their children from acquiring the epidemic.

Infant formula

Modified processed cow milk from manufacturing companies, which is readily mixed to fit baby's body requirements in replacement for breast milk.

Heterosexual transmission

Is the transmission of HIV/AIDS through unprotected sexual intercourse with an infected individual.

Vertical transmission

Transmission of HIV from an infected mother to her child.

Mastitis

Inflammation of the breast due to infection.

Increased viral load

Increased number of HIV copies in the blood of an infected individual.

Nevirapine

Is the drug which is used for PMTCT for mothers and babies. It has got few side effects and it is easy to give. It is used for prophylaxis purposes in these groups.

Counselling

Discussions done with a client by service provider that will help the client make an informed decision.

Discrimination

Unfair treatment of somebody on the basis of a certain status.

HIV

The virus that causes AIDS disease

AIDS

A collection or group of signs and symptoms that characterize HIV infection.

Early cessation

Stopping babies from breastfeeding early (at least six months and below), to initiate replacement feeding. This is one of the most recommended strategies of a PMTCT program. It is an element of the program.

Prolonged breastfeeding

Is when the baby is continuously breastfed after the age of six months and reaching up to two years, in the context of HIV/AIDS.

Exclusive breastfeeding

The feeding of an infant with breast milk only, without any other food stuff added, not even water, for the first six months of age.

Mixed feeding

Is when an infant is given other food stuffs and liquids on top of being breastfed, in the context of HIV/AIDS.

Postnatal period

The period between the birth of a baby and the time the continued attendance of a midwife on the mother and baby is requisite (Sweet, 1997).

Replacement feeding options

Ideally involves feeding an infant with a diet that provides the child with all needed nutrients without giving the child any breast milk.

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 an infant within 12 hours if stored at room temperature.

AFASS

WHO's term of reference for the necessary conditions for replacement feeding in infants, in the context of HIV/AIDS.

Prophylaxis

This means an intervention or drug aimed at the prevention of disease.

Current study

Refers to this study of experiences of HIV positive mothers with early cessation. The study whose report is contained in here.

Current participants

Refers to this study's participants. These are the mothers that took part in the study, whose experiences are contained in this report.

ABSTRACT

The transmission of HIV from a mother to her child is one of the most tragic aspects of the HIV/AIDS pandemic. World Health Organization advocates for early cessation of breastfeeding by HIV infected mothers, followed by replacement feeds in order to prevent mother to child transmission of HIV. For most HIV infected mothers in developing countries, following this recommendation represents a big dilemma because of several factors. On one hand, health care providers expect mothers to abide by WHO's recommendations in order to reduce the risk of HIV transmission to their infants. On the other hand, PMTCT enrolled mothers go back home to a society where those recommendations are found to be practically, socially and culturally unacceptable and irrelevant. This study explored Experiences of HIV positive mothers who stop breastfeeding at six months. The aim was to find out what experiences these mothers go through, with a view of making recommendations that would help to improve PMTCT programs, thereby empowering women in matters concerning HIV/AIDS and infant feeding choices. The study focused on mothers that enrolled in the Prevention of Mother To Child Transmission of HIV programs at Limbe health center, in Blantyre district. Qualitative study design was used on a sample of ten participants, who were recruited using convenience sampling method. An interview guide was used as a data collection tool and data was analyzed manually using content analysis. The study revealed that early cessation of breast feeding as a feeding option to PMTCT of HIV is the best choice that HIV positive mothers can make. However, these mothers face a lot of challenges in form of stigma, discrimination and dealing with inquisitive people. Lack of material and financial resources, babies crying a lot and frequently falling sick are also some of the challenges encountered in relation to the weaned children. The study also revealed the big role that health workers or counselors played in facilitating early cessation for it to be a success in the studied population. Based on the findings, relevant recommendations were made to all stake holders like the community, health workers, spouses and family members, government, MOHP, donors, non governmental organizations, research organizations and many more, with the aim of improving PMTCT strategies like early cessation.

CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.0 INTRODUCTION

This section of the dissertation introduces the problem under study. It also provides an insight of what was specifically studied its importance and also why the researcher felt the study needed to be done.

Mainly what the researcher wanted to study were the experiences that HIV positive mothers went through after they had stopped breastfeeding their infants at a tender age of six months (early cessation of breast feeding). These were experiences that they went through on their own (that is psychologically, did they feel good about their decisions or not, did they blame themselves? Did they regret? Why and why not). Some of the experiences that the researcher was looking for were experiences that the mothers went through in their communities. This was so because it is a well known norm in most of the settings that a child has to be breastfed at least up to 24 months of his/her age. The researcher wanted to know what these women who took the decision of early stopping of breastfeeding had to go through amidst their relatives, families, neighbors and the like. The researcher also wanted to know how these mothers dealt with the challenges with the aim of empowering such kind of mothers on HIV /AIDS issues.

In Malawi, mother to child transmission of HIV (MTCT) is the main source of HIV infection in children. This is so because of the high prevalence rate of HIV among women of child bearing age. According to MOHP/NAC's 2008 report, the 2007 HIV sentinel surveillance reported a prevalence rate of 19.85% among antenatal mothers in Blantyre, while national antenatal HIV prevalence rate was 13.8%. According to NAC (2004), MTCT is the second leading route of HIV transmission in the world, following Heterosexual intercourse as the principal route, and that in 2004, about 640,000 children became infected with HIV primarily through MTCT.

The biggest dilemma of the HIV epidemic is the knowledge that breast feeding; one of the most effective child survival interventions also results in a lot of HIV infections and eventually deaths.

The government of Malawi put in place strategies to prevent mother to child transmission of HIV with the aim of reducing HIV prevalence among children (MOHP, 2003).

As observed, in many of the Malawi's antenatal clinics, pregnant women are encouraged to go for HIV testing and counseling services so that they know their status and measures be taken to save the life of the child. This service is done under the prevention of mother to child transmission (PMTCT) program (MOHP, 2006).

A diagnosis of HIV during pregnancy facilitates decision making process by HIV positive women on the need to participate in PMTCT programs especially if counseling is done well. It was also in response to the problem mentioned above that several measures were put up in order to prevent the transmission of HIV from mother to child postnatally (MOHP, 2003). One of such measures is exclusive breast feeding by mothers for six months followed by an abrupt cessation of the breast feeding and shifting to an appropriate replacement feed suitable for the baby. 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. If the mother continues to breast feed beyond this point, then she will move into mixed feeding patterns, thereby putting her baby at risk for HIV transmission and infection.

The other reason that six months of an infant's life is taken as crucial time, is because at this age most of the infants would have started developing their first teeth and it also becomes a risk when an infant bites on its mother's breast, thereby suckling on blood that has HIV, ending up getting infected. Replacement feeding is the most effective and reliable way to prevent mother to child transmission of HIV after birth. This benefit however must be weighed against practical difficulties and the risk from other illnesses, which is increased by not breast feeding.

When a mother has HIV, the dangers of not breast feeding must be balanced against the risk of HIV transmission. This results in a painful dilemma for millions of women in developing countries, for whom there are no easy options, as choosing a suitable infant feeding option represents a very big dilemma for them.

For most babies, breast feeding is the best way to be fed. It is important and essential for child's growth and health. Breast milk provides all the nutrients needed during the first few months of life, and it contains agents that help to protect against common childhood illnesses such as diarrhea and respiratory infections. It is very unfortunate that breastfeeding can also transmit HIV from mother to baby.

Exclusive breast feeding involves giving the infant only breast milk and prescribed medicines. No water, liquids or food should be given to the infants for at least six months of life. Baby is fed on breast milk only and nothing else. Breast milk in this age group is believed to provide all of the fluids and nutrients that a young baby requires, so it means that even water can and should be avoided.

Mixed feeding should be avoided at all cost during this time. Four major studies have shown that mixed feeding (giving other foods or liquids such as gripe water, traditional medicines, other drinks, porridge, formula, glucose water together with breast milk) should be avoided because it substantially increases the chances of HIV transmission and deaths (UNAIDS, 2003). The reason why exclusive breast feeding is recommended is because evidence has shown that mixed feeding is riskier than exclusive breast feeding. The physiological explanation being that foods and other drinks damage the baby's immature digestive system (lining of the stomach and intestines) making it easier for HIV in the breast milk to infect the baby through entering the damaged tissues of the mucosa linings. In addition, mixed feeding may introduce harmful germs and may reduce the baby's gut acidity, making it easier for infections to take hold.

Early cessation of breast feeding is a method whereby a mother decides to exclusively breast feed her baby for six months or less and then abruptly discontinues breast feeding

to initiate replacement feeding (the AIDS reader, 2005). For HIV positive mothers who choose to exclusively breastfeed their children, early cessation of breast feeding is a requirement since the baby will in due time (at least at the age of 6 months) demand more food than the mother can provide.

In Malawi, likewise many African countries, mixed feeding is a social norm, a fact that has serious challenges for PMTCT programs. In this country women are expected to breast feed their children up to possibly two years. Women often conform to social pressure from relatives, family members, neighbors and members of their community for fear of stigma if their friends discovered their HIV status.

Very little is known about mothers' perspectives and experiences of early breast feeding cessation as a strategy to reduce postnatal HIV transmission in rural, resource-constrained settings (other countries). In Malawi, literally nothing was done in this area. As such this study was aimed at exploring experiences that such women faced and still go through.

1.1

BACKGROUND

The HIV and AIDS epidemic is a major problem worldwide with an estimated 39.5 million people living with HIV and AIDS by the year 2006. 38 million adults were infected with HIV out of whom 17.5 million were women. There were 2.9 million children under the age of 15 who were living with HIV and AIDS. The majority of the people with HIV infection live in the developing world and most of them are unaware that they are infected (WHO, 2006).

According to Kates (2003), AIDS is presently the fourth leading cause of death in the world and the number one cause of death in Africa. The epidemic is on track to be the worst in world history with a projected death toll reaching 100 million by 2020.

Since its first recorded case, HIV/AIDS has grown to become one of the most serious public health challenges globally, causing the death of over 25 million people from 1981. From the moment scientists identified HIV and AIDS, social response of fear, denial, stigma and discrimination have accompanied the epidemic. In many societies, people living with HIV and AIDS are seen as shameful.

Sub Saharan Africa remains the world's worst centre of the AIDS pandemic. At the end of year 2006, an estimated 25 million of the 37 million people infected with HIV worldwide, lived in sub Saharan Africa. This region is also home to approximately 13.3 million HIV positive women of child bearing age, representing 59% of the adult population living with HIV in the region. Of the total number of HIV infected persons in Southern Africa, an estimated 700,000 to 1,000,000 currently have AIDS (Avert International AIDS Charity 2006).

Worldwide the impact of HIV and AIDS on women is literally acute. In many developing countries, women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education.

In other societies, women are mistakenly perceived as the main transmitters of sexually transmitted diseases.

Malawi, being one of the countries within the Sub Saharan region has not been spared. HIV and AIDS is a biggest health problem in the country, which had affected about 898,888 people by 2007 (NAC:/MOHP: National HIV prevalence and AIDS estimates report for 2007). According to this report, the national prevalence rate in 2007 in the age group between 15 to 49 years was estimated at 12%. From the total figure, 89,055 were children less than 15 years. Women especially in the child bearing age are at the highest risk of infection due to their biological makeup.

One of the worst aspects of HIV and AIDS is the discovery of transmission of the virus from mothers to their children, the so called “mother to child transmission (MTCT) of HIV,” which takes place when HIV passes from a mother to her baby during pregnancy, labor and delivery or through breastfeeding. Current evidence suggests that some mother to child transmissions occur late in pregnancy or during labor and delivery but most of them occur during breastfeeding (postnatally). Without any interventions, between 20 and 45 percent of infants may become infected with HIV through MTCT (WHO, 2007).

Data from Michael (2007) revealed that at the end of year 2003, there were more than three HIV infected young women for every two HIV infected young men world wide. While the infection rates for men increase after the age of 25, they nonetheless remain below those of women until the age of 35, at which point the death of women begins to pull down the female prevalence rate. 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.

The second implication is in line with findings from a recent study done in Zambia by Chapote (2006). She 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.

According to the year 2005 UNAIDS update, seven hundred thousand infants are infected with HIV every year.

An alarming number of infants in Africa have already contracted HIV/AIDS from their HIV infected mothers through MTCT. At least half a million infants and children have already died from AIDS, undermining child survival gains made in earlier years through comprehensive child health programmes. Between one third and one half of infant HIV transmission and infections in Africa are due to breastfeeding.

Many governments and agencies in Africa recognized the severity of this problem of MTCT some time back, but lacked clear guidance on how to go about it or to address it, until WHO came in with its programs and later recommendations.

Programs to prevent mother to child transmission of HIV were introduced and these provide HIV testing and counseling before birth, short courses of antiretroviral prophylaxis for HIV positive mothers as well as for their infants once born. Counselling about infant feeding is also included to prevent postnatal transmission of the virus (UNAIDS/WHO/AIDS Epidemic).

The comprehensive services offered by this program are as follows:

- Provision of drugs such as Nevirapine upon onset of labor to pregnant HIV positive women, and Nevirapine and Zidovudine to the HIV exposed children for at least a week or up to fourteen weeks.
- Provision of Cotrimoxazole to HIV exposed infants from 6 weeks of age as pneumocystic carini pneumonia prophylaxis, to prevent the babies from this type of deadly pneumonia which does not respond to any kind of treatment.

- Provision of advice to the HIV positive mothers on infant feeding options, their benefits as well as their risks. Sometimes even provision of replacement feeds is done in advance depending on where the services are, situation and many more factors.
- Prevention of HIV infection in women of child bearing age through education, testing and counseling.
- Provision of comprehensive reproductive health care including family planning to HIV positive women.
- Improving antenatal, labor and delivery services.
- Provision of continuous support as well as counseling and follow up of mother-child pairs through routine health services.

Though the requirement is as presented above, not all health facilities are doing that because of lack of resources; be it trained staff or even the actual materials. However at other facilities the resources are there but the services are just not provided because of negligence.

Traditionally, most mothers in Sub-Saharan Africa breast feed their infants, introducing water and other foods gradually after a few months, but often they don't totally wean their babies until they are between one to two years of age. Diarrhea is common once mothers start giving their infants these complementary foods, but breast milk protects against more serious cases, particularly early in life.

Knowledge of the risk of MTCT of HIV that is cumulative over the course of breastfeeding and the evidence that prolonged mixed feeding erodes the benefits of antiretroviral prophylaxis given to these children in preventing MTCT led to WHO/UNICEF guidance that mothers with HIV avoid breastfeeding whenever

replacement feeding options are acceptable, feasible, affordable, sustainable and safe (AFASS).

However when complete avoidance of breastfeeding is not possible from birth, it was recommended that mothers exclusively breastfeed and wean their infants as quickly as possible, that is as soon as replacement feeding options do become acceptable, feasible, affordable, sustainable and safe. As of now, the guidelines have been modified to recommend that if the circumstances for replacement feeding are not AFASS sooner, the mother should continue breastfeeding for 6 months (Kafulafula G. et al, 2007).

In countries where resources are few, where replacement feeding can be much more hazardous, the recommendations for infant feeding usually depends on a mother's individual situation. Culture comes in to play a part even when formula feed or any replacement feed is freely provided because it may not be culturally acceptable and often puts the mother at risk of having her HIV status disclosed involuntarily to her family and community and of being stigmatized as a result (UNAIDS/UNICEF/WHO-2007).

As already discussed, Malawi is experiencing one of the worst HIV/AIDS epidemics in the world with a total population of about 12 million inhabitants. Approximately 460,000 women are infected, leaving the other half of the total infected figure to be shared by men and children. General health indicators in Malawi are also alarming. Nearly 50% of all children are chronically malnourished. The country's infant mortality rate of 104 deaths per 1,000 live births is one of the highest in Sub-Saharan Africa and is partially due to malnutrition and poor environmental conditions (NSO : Malawi demographic and health survey, 2000). However, HIV infections from MTCT are also taking a leading role in these infant deaths these days than anything else.

For HIV infected mothers, high rates of malnutrition, contaminated water, and poor hygiene increases the risk of infant morbidity and mortality from replacement feeds and thus safe options for infant feeding are limited.

Infant feeding practices in Malawi are far from optimal and implementing recommendations for infant feeding among HIV infected mothers in light of these patterns poses a challenge. For example, prolonged breastfeeding is common but a long duration of exclusive breastfeeding is not. The Malawi Demographic Health survey of 2000 reported that more than half of all infants were continuing to breastfeed at 24 months, but the median duration of exclusive breastfeeding was just two months (NSO:MDHS, 2000). Thirty one percent of 2-3 months old infants and 80% of infants aged 4-5 months were already consuming solid foods. This means that a good percentage of mothers do not adhere to exclusive breast feeding.

The World Health Organization's founded term of AFASS (the necessary conditions for replacement feeding) can be summarized as follows:-

A – ACCEPTABILITY: - Breastfeeding is the norm in most cultures, and is generally encouraged by health workers. By choosing not to breastfeed, a mother risks revealing that she is HIV positive and becoming a target for stigma and discrimination. She must be able to cope with this problem and resist pressure from friends and relatives to breastfeed.

F – FEASIBILITY:- A mother who chooses replacement feeding must have adequate time, knowledge, skills and other resources to prepare the replacement food and feed her baby up to twelve times in 24 hours. Boiling water over a charcoal stove, for instance can take up to 15 minutes per feed. Unless refrigerated, prepared formula becomes unsafe after just two hours. It is better to feed with a cup rather than a bottle, because cups are easier to clean and because cup feeding promotes greater interaction between the mother and her baby.

A-AFFORDABILITY: - Someone has to pay for the ingredients, fuel, water and other equipment needed for replacement feeding. In some countries, the cost of infant formula alone is similar to the minimum urban wage and unless heavily subsidized, is well

beyond the reach of most families. This means the mother or family must afford to buy or pay for the needed resources.

S – SUSTAINABILITY: - Feeding an infant for the first six months of life requires 20 kg of formula and regular access to water. Even a brief disruption in supplies may have serious health implications. This means the must have enough of the supplies to sustain her baby.

S – SAFETY: - Replacement food should be nutritionally sound and free from germs. The water it is mixed with should be boiled, and utensils should be cleaned (preferably boiled) before each use. This means the mother must have access to a reliable supply of safe water and fuel.

Of the five conditions for replacement feeding, safety is often the most critical.

The WHO AFASS declaration means that some mothers should be advised to breastfeed and others be encouraged to give replacement foods instead, depending on personal circumstances. The final decision however should be down to the mother. This means that all HIV infected mothers should receive counseling which includes provision of general information about the benefits and risks of various infant feeding options, and specific guidance in selecting the option most likely suitable for their situation. Whatever a mother decides, she should be supported in her choice (UNICEF/UNAIDS/WHO/UNFPA, 2003). It is also especially important for counselors to establish whether the mother has access to clean water and food and whether she has disclosed her HIV status to her partner or family members.

It is unfortunate that though mothers are encouraged to practice exclusive breastfeeding, it is not that easy for them. In many societies, especially in Sub-Saharan Africa, it is normal for a baby to be given water, tea, porridge, traditional medicines or other foods as well as breast milk, even during the first weeks of life. This is still practiced even with

the knowledge that the longer an HIV positive mother breastfeeds or mix feeds, the more likely she is to infect her baby. (Leshabari et al, 2006).

Although there is some variation in national and local policies regarding early cessation and replacement feeds, most are influenced by the AFASS guidance published by WHO, as discussed above, whereby the avoidance of all breast feeding by HIV infected mothers is recommended. Otherwise, exclusive breast feeding is recommended during the first months of life – preferably six months only or less (WHO/UNAIDS, 2007).

1.2

PROBLEM STATEMENT

Following WHO's/ MOHP's recommendations is challenging for HIV positive women. Despite everything associated with these, some mothers firmly stick to the recommended infant feeding methods; this is done amidst mothers who do not adhere. The biggest question is why is the situation like this? What is it mainly that is causing these other women to 'drop out'? What is it that those women who adhere and stop breastfeeding at six months go through, that the other women don't want to experience?

1.3

SIGNIFICANCE OF THE STUDY

Not much was studied on the experiences of HIV positive mothers who practice early cessation of breastfeeding. Very little was recorded on the matter. This study and its results therefore want to:

- Assist stakeholders in PMTCT programmes to design the most appropriate approach in communities in order to ensure that the program remains effective in diverse cultural settings so that many people should access the services.
- Help empower women on the issues of HIV/AIDS and infant feeding and later be in the fore front in the fight against this AIDS pandemic (As they will be equipped with knowledge regarding rights and benefits of their decisions).
- Act as a basis for further investigations on issues regarding early cessation of breastfeeding among HIV positive mothers.
- Assist HIV and AIDS organisations such as HIV research institutions and the like, in improving the way they had been doing things previously and help them in developing policies on how best to deal with the situation at hand, such as sensitizing the community at large and dealing away with stigma.
- Benefit all Malawians, but more so the HIV positive women who still aspire to have children of their own.

BROAD OBJECTIVE

The main aim or objective of the study was to find out what experiences, HIV positive mothers that stop breastfeeding their infants at an early age (such as six months) go through, with a view of making recommendations that would help to improve PMTCT programs, thereby empowering mothers in matters concerning HIV/AIDS and infant feeding choices.

SPECIFIC OBJECTIVES

1. To explore the perception of the mothers towards cessation of breastfeeding at six months.
2. To identify factors that facilitate early stopping of breastfeeding by HIV infected mothers.
3. To assess/identify the challenges that the mothers meet in their communities in relation to early stopping of breastfeeding.
4. To explore the measures taken by the mothers in order to deal with and overcome the challenges.
5. To explore suggestions for improving such a PMTCT program among HIV positive mothers.

CHAPTER TWO : LITERATURE REVIEW

2.0 INTRODUCTION

This section provides a researcher with relevant information about what is known or not known about the topic of study and the relationship between/among dependent variables. Literature review is critical to the research process as it puts the researcher in a better position to assess the feasibility of a proposed study by increasing familiarity with related work. It inspires new research ideas and lays the foundation for studies (Polit & Beck, 2006). This chapter discusses the available literature relevant to the topic under study. The focus is on those studies carried out in Malawi, but other countries were included too, since there are a few studies related to the topic that were done in Malawi. The areas of focus are:-perceptions of mothers towards early cessation of breastfeeding, factors that facilitate early cessation of breastfeeding and challenges that these mothers face.

2.1 PERCEPTIONS OF MOTHERS TOWARDS EARLY CESSATION OF BREASTFEEDING.

A study was done in Durban, South Africa, to assess how HIV-infected mothers planned and experienced breastfeeding cessation as part of an HIV prevention strategy and how counselors facilitated this process. Results revealed that mothers enrolled in the research setting reported many success stories in contrast to mothers attending routine services. Consistent counseling and ongoing support from counselors facilitated this. Their primary motivation for wanting to rapidly stop breastfeeding was to avoid infecting their children with HIV, in spite of all the difficulties involved. Both counselors and HIV infected mothers expressed concern over practical issues, including social consequences, associated with early cessation. In conclusion it was indicated that the experiences of HIV-infected mothers planning for and stopping breastfeeding early show how complex and difficult the feeding recommendations are. It further concludes that guidance that acknowledges the cultural context and psychological stresses is urgently needed to direct policy, training and service delivery (De Paoli et al, 2008).

In a clinical trial conducted by Piwoz et al in Lilongwe, Malawi (2007), to find out perceptions of women on early stopping of breastfeeding, data demonstrated that rapid breastfeeding cessation would be difficult and malnutrition could be a risk if infants were weaned early.

Some studies were done to assess the knowledge, attitudes and perceptions of people on PMTCT services in Malawi. The findings indicate that most people especially women have knowledge on mother to child transmission of HIV and the importance of PMTCT services in reducing the risk of transmission to babies.

Muula, Misiri and Tadesse (2004) conducted a study in Blantyre, to determine potential partners for pregnant women in PMTCT and the women's perception towards selected potential HIV preventive efforts. Almost all (99%) planned to exclusively breastfeed with 91.8% reporting an intended breastfeeding period of at least 6 months. The study found out that close relatives, spouses and the media are important stakeholders in the health of the pregnant women; therefore programs aimed at prevention of MTCT of HIV should give serious considerations to these partners.

A study was done by Medicines Sans Frontiers (Luxemburg) in 2005 on the utilization of PMTCT services by women at Thyolo district hospital, Malawi. The study indicated that in rural settings or hospitals, there is high acceptability of HCT services but unacceptable loss to follow up in PMTCT program. This study found out that at least 9 out of every 10 mothers (96%) attending antenatal services accepted HCT, of which approximately a quarter (22%) were HIV positive and included in PMTCT program. It was also discovered that there was progressive loss to follow up of more than three quarters (81%) of this cohort by the 6 months postnatal visit.

The University of Malawi Centre for Social Studies conducted a formative research study on MTCT in nine districts in Malawi and the results indicated that MTCT is widely known even in areas where there are no PMTCT programs. However, it was also found that few people particularly men were still not aware of MTCT while others could

determine the possibility of MTCT but they could not confidently describe how it happens (Munthali, et al. 2003). The study also indicated that most participants, especially local villagers believed that there is no possibility of preventing mother to child transmission of HIV during pregnancy and delivery and some participants indicated that they had heard that children could get infected through breastfeeding.

Tadesse (2004) carried out a study in Blantyre to determine the antenatal mothers' knowledge and perceptions on PMTCT of HIV. The study revealed that the majority had the knowledge on how the virus can be transmitted and how it can be prevented. They also suggested that the knowledge about the HIV status of the pregnant women can be important and of benefit in the prevention and control of HIV.

Similar findings were got from another related study done by Kumwenda (2005) though the only difference is that there was knowledge gap on proper infant feeding practices in the latter.

A research was conducted by the UNC project BAN study team in Lilongwe (Piwoz, 2007) to establish perceptions and attitudes of health workers towards early breast feeding cessation and how these influence the feeding counseling messages they give to such mothers. Although none of the workers had received formal training, several reported having counseled HIV-positive mothers about infant feeding. Health workers with counseling experience believed that HIV-infected mothers should breastfeed exclusively, rather than infant formula feed, citing poverty as the primary reason. Because of high levels of malnutrition, all the workers had concerns about early cessation of breastfeeding.

2.2 FACTORS THAT FACILITATE EARLY CESSATION OF BREASTFEEDING.

In a study conducted in Tanzania, 8 of 139 children born to HIV infected mothers, known to be uninfected at six months of age, became infected through late breast feeding (Karlsson, 1997). Knowledge of this can motivate mothers and facilitate decision making in relation to early cessation.

Similar findings from other African countries support early cessation of breastfeeding as an effective infant feeding option for PMTCT of HIV (Leroy, et al. 2003; Fawtzi, et al, 2002; Coustoudis, 2001 & Illif, et al. 2005).

In a study conducted by Lunney (2008), findings showed that factors facilitating early breast-feeding cessation were mothers' knowledge about HIV transmission, family support, and disclosure of their HIV status; food unavailability was the primary barrier. It was concluded that HIV-positive mothers in resource-constrained settings may be so motivated to protect their children from HIV that they stop breast-feeding early even when they cannot provide an adequate replacement diet.

Findings from other studies however, question early cessation of breastfeeding. A study in Rwanda found that 10% of mother to child transmission occur prior to the age of six months (Simonon, Lepage & Karita, et al. 1994). Having accounted for the effect of early breastfeeding cessation on the rate of HIV infection, the risk of late postnatal transmission after six months of age was only 12 percent among HIV exposed children. 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.

In another development, a study conducted in the Ivory Coast found that 28 percent of children born to HIV-sero positive mothers were infected by six months of age (Ekpini,

et al. 1997). According to Ekpini, et al, Most of the HIV transmissions that occur from mother to child before the age of six months are associated with the following:

- Mother's increased viral load in the breast milk
- Mother's reduced CD4 count in her blood, eventually leading to development of signs and symptoms of AIDS in her.
- Mother's breast conditions such as cracked nipples or mastitis.
- Mother's newly acquired HIV infection while already breastfeeding.
- Baby's gastro intestinal conditions such as oral thrush, gastro-enteritis, etc.
- Early mixed feeding before the recommended age of weaning, which is six months.

The findings above can be an explanation to Simonon et al's findings earlier on. The findings below here are a back up to Ekpini's explanations above.

Semba, et al (1999) conducted a clinical study in Blantyre, Malawi to examine HIV viral load in breast milk and mastitis as risk factors for MTCT. The results indicated overall MTCT of 26.8% at age of 6 weeks among 328 of women-infant pairs. Median breast milk HIV load was 700 copies/ml among women with HIV infected infants and was not detected in those with uninfected babies. It was also found that there were increased cases of mastitis in HIV infected women (16.4%) and these were associated with increased MTCT. Therefore it was concluded that mastitis and breast milk HIV load may increase the risk of MTCT through breastfeeding.

In another study done in Kenya in 2000 by Nduati on 425 pregnant women, results revealed that 63% of postnatal HIV infections occurred by six weeks, 75% of the infections occurred by six months and 87% occurred by 12 months of age. The study above shows that HIV transmission risk increases with continued breast feeding as well as mixed feeding. The study findings also agree with Ekpini's.

A study done in India on infant feeding and HIV by Dr. P.L. Joshi in 2002, showed that mortality in breastfeeding children (n=54) was nil compared to 11 mixed fed children (n=231). He made the following three conclusions, that:

- (a) Each community needs to assess the relative risks and benefits of their own available feeding options for infants born to HIV infected mothers.
- (b) New interventions that make exclusive breastfeeding safe for both infant and mother are needed in situations where access to affordable safe infant formula is limited.
- (c) There is high social stigma attached to non-breastfeeding mothers.

In Thailand, a study on experiences of using infant formula for all babies born to HIV positive women was done by Dr. Nipunporn Voramongkol in 2002. With this, she showed that the number of AIDS cases of children aged 0-4 years from vertical transmission went down from 1250 in 1997/1998 to 29 in 2003. This shows the success of Thailand program in using infant formula for all babies born to HIV positive mothers.

A Ugandan study showed that even though many HIV positive mothers chose to mix-feed, education and advice from health care workers greatly reduced the duration of breastfeeding as a component of their babies' diet. High rates of exclusive breastfeeding have been achieved in some settings where mothers are provided intensive counseling, education and support services.

Still in Uganda, a study done by Namukose, Samalie and Bananuka in 2003, on integrated infant and young child feeding counseling, showed that the use of appropriate infant feeding practices is a key strategy for child survival. To ensure effective and adequate support for HIV infected mothers, there is need for on-going counseling, education and training.

2.3 CHALLENGES FACED BY SUCH MOTHERS IN RELATION TO EARLY BREASTFEEDING CESSATION.

A qualitative study done in South Africa by Doherty, in 2005, on the effect of the HIV epidemic on infant feeding from 20 HIV positive women, revealed that infant feeding experiences of HIV positive mothers have serious implications for the operational effectiveness of programs that aim at preventing HIV transmission from mother to child.

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 breastfed from birth (Coutsoudis, 2008). These findings inspired the so called “formula plus” programs 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, et al, 2006). After six months of implementation, the ‘formula plus’ program in Haiti reported reduced MTCT of HIV but very high infant mortality rates (217/1000). Botswana reported 35,000 cases of diarrhea, resulting in 532 deaths within the first six months (Creek, 2006).

Further research has also shown that infant milk in form of powder may contain low levels of salmonella or other contaminants which cause diarrhea outbreaks in the infants (Brouard, et al, 2007). This may be an explanation for some of the diarrheal problems in these children.

Another clinical trial was done in Nairobi, Kenya by the Alan Cuttmader Institute in 2000 on breastfeeding versus formula feeding on 250 HIV positive mothers and their newborn babies. The findings showed that although 96% of those mothers assigned to the breastfeeding group did breastfeed their newborns, only 70% of those in the formula group completely avoided use of breastfeeding. The study also revealed that women on formula feeding often experienced pressure from their families, or from the community about maintaining confidentiality of their HIV status. After 24 months follow up, the cumulative risk of newborn HIV infection was 36.7% in those on breastfeeding as compared to 20.5% of those on formula feeding. Those on formula feeding secretly

breastfed their babies because of the pressure from family members (they were forced to breastfeed their babies although they were on formula feeding).

The findings above correlate with those from Studies in Botswana (Shapiro et al, 2003), Zambia (Omari et al, 2003) and Tanzania (Leshabari et al 2006) where Women also explained that they were concerned about their reputation as good mothers apart from their failure to withstand the social pressure to breastfeed.

Social pressure also causes some women with HIV to choose exclusive breastfeeding even if they could replace feeds safely and thus better avoid risks of mother to child transmission. In South Africa, most women with HIV who met the five criteria for safe replacement feeding decided to exclusively breastfeed. They cited family expectations, stigma and disclosure of their HIV status, as their reasons (Koniz-Booker, et al. 2004).

In a study by Eneroth (2004), where infant formula was being provided for free as part of the program and mothers counseled on early cessation; the focus was on how mothers in the South African National program for prevention of mother-to child transmission of HIV (PMTCT) stop breast feeding early and rapidly as a strategy to prevent vertical transmission of HIV. Findings showed that Women in this study population experienced difficulties with breasts and with their babies when they stopped breast-feeding early and rapidly.

The study findings above agree with those of Bakaki below.

In a study by Bakaki (2002) on Lessons and Experiences with early abrupt cessation of breast feeding among HIV infected women in Kampala Uganda; Mothers who were single, employed or in business, had less than 3 children, or had spouse support tended to stop breast feeding by 4 months. The problems mothers experienced during early cessation of breast feeding like breast engorgement, financial constraints, babies crying a lot and pressure from spouses, family or neighbors were overcome with the help of health workers. None of the mothers resumed breast feeding after cessation. It was concluded

that this group of motivated HIV infected mothers was able to stop breast feeding their babies by at least 7 months of age using locally available foods.

Similar findings were got from a study by Kisyake et al (2002) on the same experiences.

According to Suniti Solomon, Director of YRG care in Chenna, India, 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. Researchers also found that a lot of mothers who choose exclusive breastfeeding have difficulty complying, especially when there is pressure from those mentioned above (Bacquet et al, 2005, Shankar et al 2005, Boskens et al, 2007).

A research was done in Ndola, Zambia in 2003 to learn from community and health providers about infant feeding practices, knowledge of MTCT, attitudes towards HIV testing, and safety on the UN/WHO's recommended replacement feeding options. The results revealed that infant feeding options were very limited in the area because of economic and social concerns. Replacement feeding costs were so expensive. Another revelation was that women who do not breastfeed are at risk of stigmatization. In addition to these, there are many misperceptions among health providers and families about MTCT (Piwoz & Preble, 2000).

Tawalat et al (2000) conducted a study on infant feeding practices and attitudes among women with HIV infection in northern Thailand. Findings showed that out of the 202 women enrolled, the majority (71%) said that formula feeding could indicate that the mothers were working outside the home, and almost half (45%) thought formula feeding could indicate that mothers were HIV infected. He also stated that the mothers were worried that they could not afford the formula feed and changed their minds to breast feed their babies. They felt sorry that they could not breast feed their children and were

also afraid that someone would ask why they were not breast feeding. Tawalat's study findings show that women with HIV infection are able to respond positively to potentially discriminative attitudes such as questions about their mode of feeding.

In one study, Marquis and associates in 1998 followed a sample of 32 mother/infant pairs for eight months to assess breastfeeding practices around the time of weaning. They found that the median age at first attempt at weaning was 17.5 months. 20% of the women had tried and failed to take the children completely off the breast by 12 months of age and 59% attempted but restarted breastfeeding. The stopping-restarting cycle of breast milk was found to occur as early as three months of age. Two thirds of mothers who restarted breastfeeding did so because their children were crying excessively, while 16% of the mothers did so because their children were refusing to eat other foods.

Similar findings were obtained from Studies done in Sudan, Ethiopia and Uganda (Almedom & Dewaal, 1995). Such failure among HIV positive mothers may increase the risks of postnatal HIV transmission, since a return to breast milk after the introduction of replacement foods may increase an infant's vulnerability to HIV infection, as mixed feeding will be practiced.

A cohort study was done in Tanzania by linkage project between 2001 and 2004 to evaluate the impact of introduction of PMTCT services including HCT, short course of ARV, counseling and support for infant feeding into maternal and child health services. The study included a sample of 358 women. It was found out that despite achieving a reduction in MTCT, a lot of women (72%) dropped out of the program for different reasons, including fear and denial of HIV test results, lack of partner support and insufficient clinics to handle the demand. The other problems that were identified were: stigma and discrimination surrounding HIV and AIDS.

In a study to evaluate a PMTCT pilot program in Zambia, Ngacha, et al. (2004) found that out of the 320 women recruited in the study, the acceptance of HIV testing reached 93% and of the pregnant women tested, 74.3% returned to collect results and 24%

mother-child pairs received Nevirapine Prophylaxis. It was also learnt that follow up of mothers and children during the postnatal period was one of the most challenging problems because of poor access to health facilities and limited trained staff.

Social-economic factors have been identified as potential contributors to poor follow up as evidenced by results of a study done in Johannesburg, South Africa by Jones and Varga (2005) where a study to examine social economic circumstances of 115 women attending PMTCT program was undertaken in 2004. Fifty seven percent of mothers were unemployed, 25% of fathers did not support their children, and only 58% of children remained resident in Johannesburg at the 12 month visit. The results of this study revealed that social economic factors such as poverty, geographical location and lack of paternal support might affect the capacity of families to comply with the PMTCT follow up services.

Findings above are in line with those from a research project conducted by USAID in 2002 in Uganda.

Ingram(1999), in her study on HIV positive mothers and stigma stated that mothers valued being perceived as normal but the normalcy was lost for them because of stigma of HIV, though they tried to cover their illness by lying and pretending by telling people that they were not sick.

A study on infant feeding dilemmas created by HIV (South African experiences) was conducted in 2005 in Durban, South Africa on PMTCT mothers. Findings revealed that from 56 mothers who had stopped breastfeeding between six and 9 months, only 10.7% had no problems in early cessation. 39% of the mothers cited emotional distress on the part of the mother and/or the baby. Other problems cited were breast engorgement, stigma and financial problems. In conclusion, it was noted that mothers found it difficult to stop breastfeeding earlier than the norm, and that it is therefore important that mothers considering early cessation of breastfeeding be given sufficient preparation and support and that care must be taken to ensure that the infant is not nutritionally compromised by the mother's early cessation of breastfeeding (Coutsoudis, 2005).

The conclusion from the above text is in line with a report from a symposium on breast feeding and HIV/AIDS (2005), where it was agreed that the right of the mother to decide on her choice of infant feeding should not absolve the policy maker and counsellors from being responsible for the health consequences for infants and mothers. It further stated that while the human rights framework should be used to empower mothers to make informed decisions, policy makers should be forthright about the knowledge gaps that exist in identifying the route of transmission of HIV (e.g. during pregnancy, birth or breastfeeding) and about the competing risks between breastfeeding and formula feeding for the HIV-exposed baby.

In an evaluation of UN-supported PMTCT pilot projects in 11 countries, the population council concluded that infant feeding remains the most challenging component of PMTCT programs and that despite training, staff knowledge and counseling abilities remain weak. Counselors frequently steer a woman towards an infant feeding method based solely on her HIV status rather than a comprehensive assessment of her social and economic resources for implementing various feeding options. Very few programs provide ongoing support for women to carry out their infant feeding choice once their babies are born (Global Health Council, 2004).

Becquet, et al. (2005) reports of a study conducted in Abidjan, Cote d'Ivoire for two years. The purpose was to assess acceptability of exclusive breastfeeding with early cessation to prevent HIV transmission through breast milk on infants aged between 3 and 4 months of age. Results revealed that complete cessation of breastfeeding were obtained in 45% and 63% by 4 and 6 months of age respectively. Environmental factors such as living with a partner's family were associated with failure to initiate early cessation of breastfeeding. Concluding remarks were that acceptability of exclusive breastfeeding was low in this urban population.

According to WHO; 2005, Key issues around early breastfeeding cessation for non-breastfed infants and young children of HIV - positive mothers are timing and safe

transition and care. Among the infants who will not enjoy the benefits of breastfeeding, or will stop breastfeeding early, are the infants of mothers who are HIV - positive. Mothers living with HIV may themselves suffer from ill health and deteriorating socioeconomic conditions in addition to facing the challenge of feeding their young children adequately. Children born to HIV - positive women are a vulnerable risk group, in part because of their early exposure to HIV and possible infection, as well as because of the possible effects of HIV on their mothers' impact of HIV infection on the family. This heightened vulnerability and the possible constraints on nutrition, health, and caring practices should not be overlooked in counseling and HIV care programs. Early breastfeeding cessation may lead to poor caring practices and neglect, and to malnutrition. Some of the risks associated with early breastfeeding cessation include mastitis and breast abscesses in the mother; distress, restlessness, loss of appetite and diarrhea in the infant; and family and community objections. To prevent or mitigate these risks, counseling and support to prepare for early breastfeeding cessation is needed.

Doherty (2006) conducted a Study on Infant-Feeding Decision Making and Practices among HIV-Positive Women in South Africa. Just under one-half of the women who initiated breast-feeding maintained exclusivity and over two-thirds of the women who initiated formula-feeding maintained exclusivity. Key characteristics of women who achieved success in exclusivity included those with the ability to resist pressure from the family to introduce other fluids and to recall key messages on mother-to-child transmission risks and mixed feeding. Among women who maintained exclusive breast-feeding, a strong belief in the benefits of breast-feeding and a supportive home environment were important. For women using formula milk, having resources such as electricity, a kettle, and flask made feeding at night easier. It was concluded that support for infant feeding that extends beyond the antenatal period is important to enable mothers to cope with new challenges and pressures at critical times during the early postpartum period.

In Malawi, reports have shown that many divorces occur as a result of HIV positive results, especially if it is a woman who is positive (Malawi Human Rights, 2006). In many Malawian societies a mother who does not breastfeed is labelled as being HIV

positive, promiscuous, proud or bad mother, therefore early cessation of breastfeeding may not be acceptable in many societies. Most of the times, the situation is worsened when a man discovers by himself that his spouse is HIV positive. It sometimes leads to gender violence. That is why the Malawi Human Rights Commission (MHRC) describes HIV and AIDS as not only a health problem but also a human rights issue. This is so because it impacts negatively in the psychological, physical and emotional well being of an individual or society. It is also a human rights issue because some of the responses to HIV and AIDS pandemic have often tended to promote stigma, discrimination and denial, thereby violating human rights and promoting non disclosure by most people, especially pregnant women to their spouses. People living with HIV and AIDS have their human rights being violated on the basis of their status. The fight against HIV and AIDS cannot be fully addressed if the rights based approach to the issue is ignored.

In a study by Njunga (2008) on infant feeding experiences of HIV positive mothers enrolled in PMTCT program, findings were that 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 neighbors 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 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'.

Sitima (2007) conducted a study on knowledge and perceptions among women of child bearing age on prevention of mother to child transmission of HIV at Kawale in Lilongwe. This was a quantitative study where by 30 participants were recruited. The results of the study revealed that there is high knowledge of PMTCT of HIV among women of child

bearing age, though the respondents were not able to outline the specific strategies under PMTCT of HIV program. The results also indicated the following as reasons that act as barriers for some women not to participate in PMTCT activities:

- Lack of knowledge
- Fear of stigma and discrimination
- Fear of knowing one's status

Chirwa (2006) conducted a study on challenges faced by postnatal mothers on infant feeding options at Thyolo district hospital. The findings revealed that the subjects had the following challenges:

- Lack of resources, especially food to give to the baby after being weaned.
- Difficulties with abrupt weaning, since the baby is used to breastfeeding.
- Stigma and discrimination
- Men's refusal to be tested and lack of support from their families, counselors and communities.
- Blame from families
- Difficulties in making choices of whether to continue breastfeeding or to stop.

2.4

SUMMARY OF LITERATURE REVIEW

Literature shows that comprehensive services for PMTCT are feasible and effective for communities, poor in resources, though implementation faces some challenges.

The studies mentioned above agree on the complexity and difficulty among HIV positive mothers to stick firmly to any of the WHO recommended infant feeding methods. Despite such abundant evidence however, very few studies have focussed on the experiences faced by those mothers who adhered to the WHO recommendations(were counselled, chose to exclusively breastfeed, followed by abrupt cessation, then put their babies on replacement feeds). Most of the studies concentrated on infant feeding options and challenges rather than on the psycho social aspects of the mothers

Despite all the important clinical interventions aimed at reducing mother-to child transmission of HIV, including giving women information and the choice of whether or not to breastfeed or for how long, it has not been considered a priority to elicit or document women's experiences following an informed choice of early breastfeeding cessation followed by replacement feeding. This gap needed to be addressed by micro studies. This is one of the micro studies that meant to address the gap.

CHAPTER THREE: CONCEPTUAL FRAMEWORK

3.0 INTRODUCTION

Conceptual framework guides the researcher to understand the variables under study and their relationships and how these relationships affect their outcomes (Mieller, 1996).

When nursing research is performed within the context of the theoretical framework, its findings are significant and are utilized in nursing (Polit & Hungler, 1995).

3.1 BRIEF DESCRIPTION OF THE HEALTH BELIEF MODEL

This study was based on Health Belief Model (HBM). The model seeks to explain why some people take specific actions and some do not. It is useful in explaining the behaviors and actions taken by people to prevent illness and injury. The model integrates psychological theories of goal setting, decision making and social learning (Bullough & Bullough, 1990).

It is also important in identifying the factors that influence behavioural change.

This model has three principle concepts and these are: individual perceptions, modifying factors and variables affecting the likelihood of initiating actions.

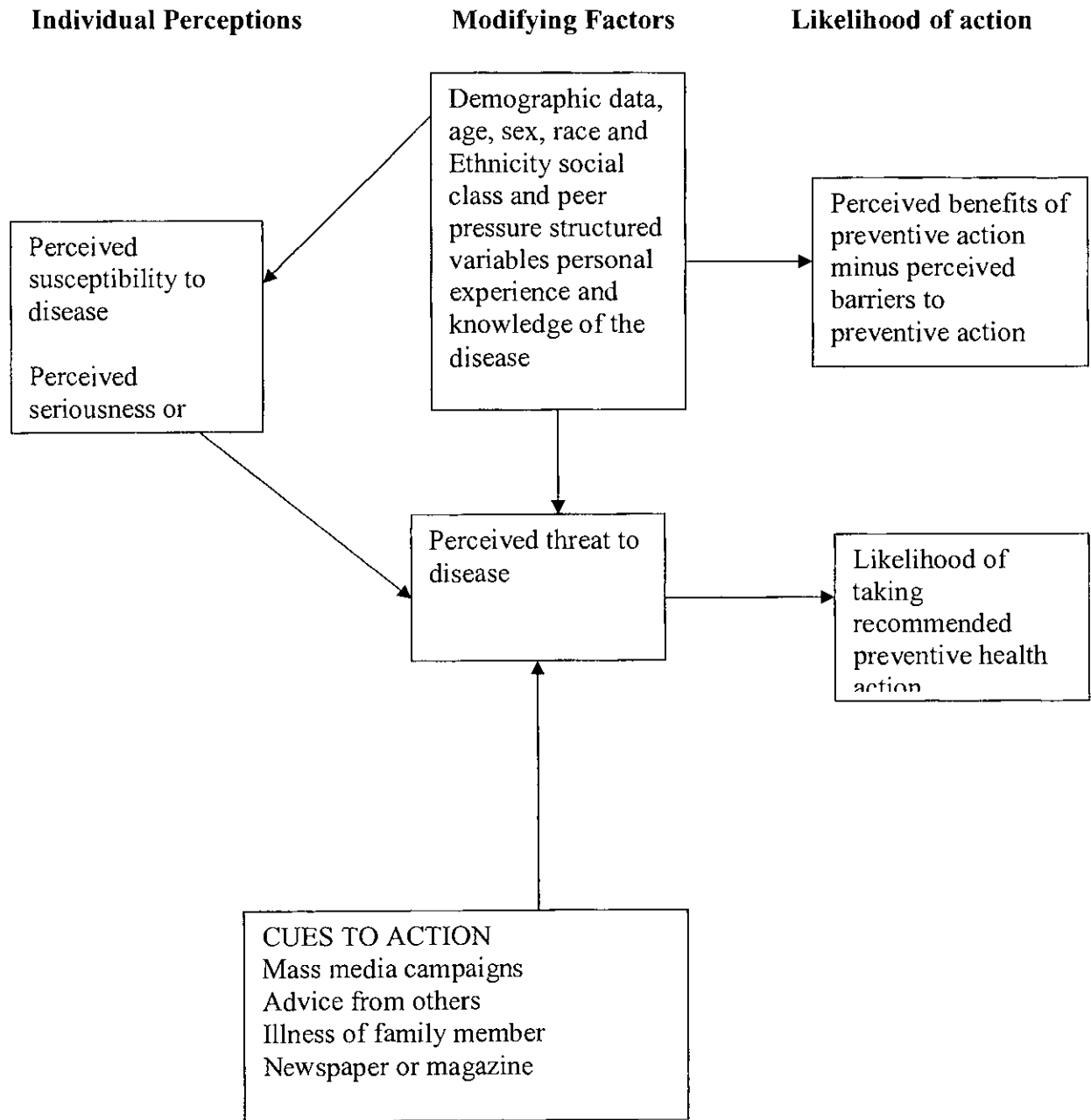
It postulates that readiness to act on behalf of a person's own health is predicted by the perceived susceptibility to the particular disease, perceived seriousness of the disease, perceived benefits of taking action and the perceived barriers to taking actions, cues to action and the modifying factors, such as the knowledge, social economic, culture and personal experience. For example when the illness is perceived as serious and the barriers are low, the person is likely to seek medical care and follow the treatment instructions. In addition, people are more likely to engage in preventive health behaviors when the barriers are low and when they perceive that they are susceptible (Smith, 1995 p. 409).

The health belief model suggests that people are more likely to take preventive action to comply with professional medical advice if they feel concerned about their health and are motivated to protect it, feel susceptible to or at risk of the disease in question. It says that people will comply with treatment if they believe that the consequences of the disease would be serious if left untreated and that these out-weigh any costs or drawbacks involved in following the treatment.

The clients' perception of health status and value placed on taking preventive action may also be affected by demographic data (age, sex, race, and ethnicity), socio-psychological variables (social class and peer pressure), Structural variables (personal experience of a disease, knowledge of the disease, internal and external cues (advice from others).

This model provides an insight into the connection between the way the person sees his or her state of health and his or her response to health, illness and treatment.

3.2 DEMOCRAMATIC PRESENTATION OF HEALTH BELIEF MODEL



3.3 APPLICATION OF THE MODEL TO THE STUDY

The health belief model explores factors that influence an individual's willingness to take action. The modifying factors such as knowledge, culture and socio economic status would determine decision making in the person.

The health belief model can be used to explain factors that would influence women to utilize PMTCT services. The socio economic factors like cultural beliefs, social class educational status, gender, personality and knowledge about HIV and AIDS affect how a woman perceives the severity of HIV as well as her decision to access and utilize PMTCT services. If she perceives the threat of mother to child transmission of HIV, she is likely to take action.

Women of child bearing age are perceived to be at risk of transmitting the HIV to their infants. Given adequate information on PMTCT of HIV, these women would develop ideas that would be put to action. If postnatal/breastfeeding mothers perceive the epidemic as being serious and knowing that continuous breastfeeding after 6 months and mixed feeding may lead to MTCT, they are likely to follow PMTCT strategies of stopping breastfeeding their infants early, then starting them on replacement feeds, with the aim of preventing their children from HIV infection.

This decision would depend on the mother's perception that the benefits of following such a PMTCT strategy outweigh the costs and social challenges that she can encounter. The health belief model states that perceived benefits should outweigh the perceived barriers. These benefits may include the reduced risk of MTCT of HIV. The barriers may include lack of support from the partner, stigma and discrimination and some other factors such as lack of adequate knowledge. However if a woman does not perceive HIV and AIDS as serious and believes she cannot infect her baby with the virus, then she is more likely not to comply with PMTCT strategies. If she believes that no matter what she under goes, the baby will still get the virus, then she is likely not to cope.

3.4 DIAGRAMATIC PRESENTATION OF THE HEALTH BELIEF MODEL AS APPLIED TO THE STUDY

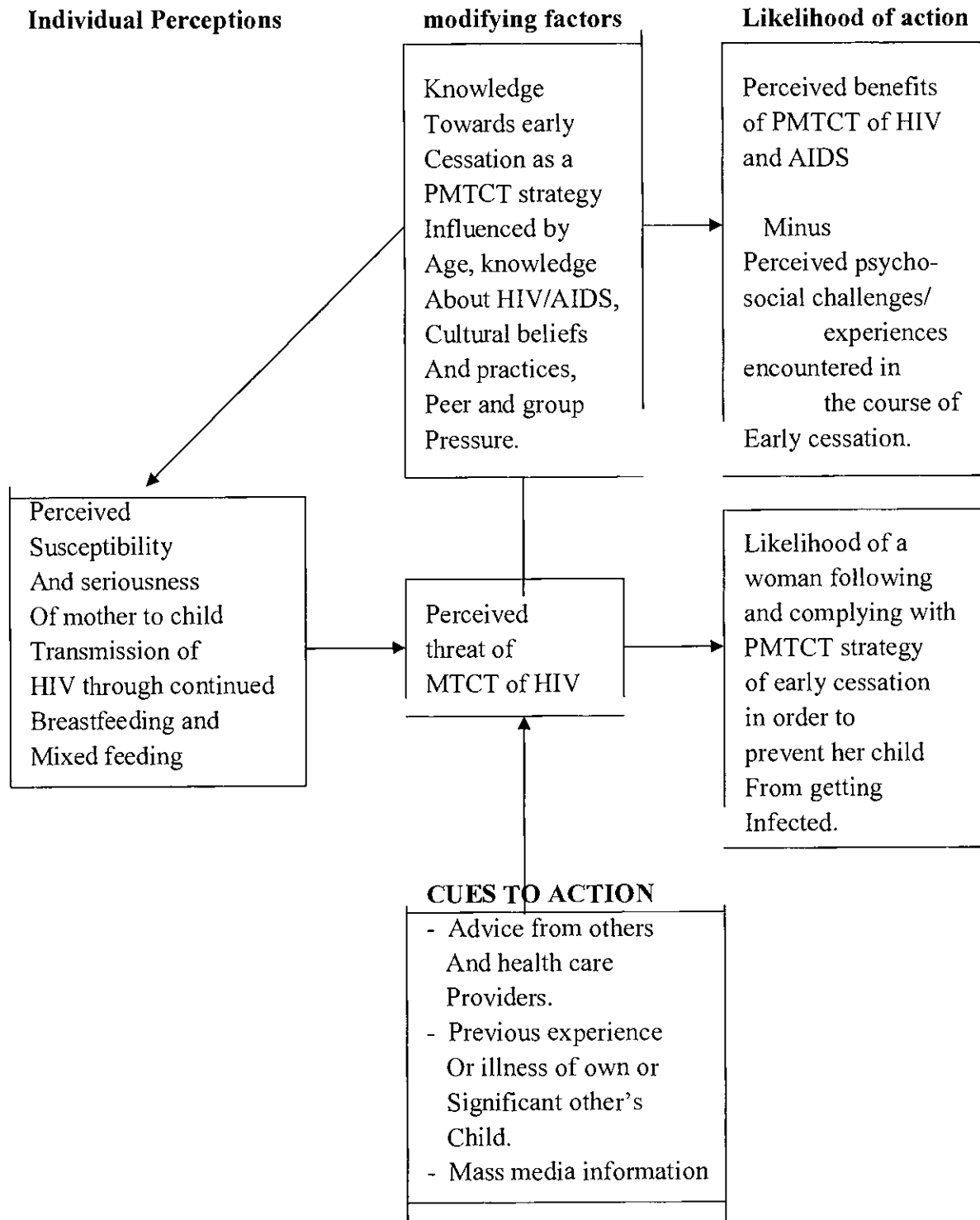


Fig. 2: Application of Health Belief Model to the study

CHAPTER FOUR: METHODOLOGY

4.0 INTRODUCTION

This section aims at describing the research methodology that was used to study the experiences of HIV positive mothers who stop breastfeeding at six months. The main focus was on the research design, sample size and sampling method, data collection, data collection instruments, data analysis, place where the research was conducted and ethical considerations.

4.1 RESEARCH DESIGN

Polit and Hungler (1999), defines a research design as the researcher's overall plan for obtaining answers to the research questions and for testing the research hypotheses.

In this study, a qualitative research approach was used, with main focus on the phenomenological design, because the aim was to describe the experiences as they are lived by the HIV positive mothers who stop breastfeeding at six months.

Qualitative research is a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live. It is a systematic, subjective approach used to describe life experiences and give them meaning. It helps develop an understanding of human experience which is important for health professionals who focus on caring, communication and interaction. Qualitative research is also used as a means of understanding and interpreting human experience (Burns & Grove, 2001).

In a qualitative study design, data collected is in a narrative or non numeric form and qualitative studies are primarily concerned with in-depth study of human phenomena in order to understand their nature and the meaning they have for individuals involved (Desmond,1991).

Phenomenology on the other hand may be defined as the study of structures of experiences or consciousness. It studies conscious experience as experienced from the subjective or first person's point of view. The structures of experiences range from perception, thought, memory, imagination, emotion, desire, volition and action. This design was ideal for this study, since the experiences, feelings and perceptions of HIV positive mothers that stop breastfeeding at six months were explored and known.

4.2 SETTING

The study was conducted at Limbe Health Centre, under Blantyre district health office. Limbe's catchment area is big. This setting was chosen as it is one of the biggest and busiest clinics that promote prevention of mother to child transmission of HIV in Blantyre district and it caters for women from different locations/townships. The centre enrolls a lot of infant/mother pairs into their PMTCT program as evidenced by their log books.

4.3 SAMPLE SIZE (POPULATION) AND SAMPLING METHOD

Population is a set of individuals that meet a certain criteria for inclusion in a given universe (Burns & Grove, 2001). The population of interest in this study was that of HIV positive mothers who stopped breastfeeding their infants at six months. These were supposed to be mothers that had experiences to share in relation to early cessation of breastfeeding. That being the case, another criterion used was that the weaned children should not be less than eighteen months of age by the time of the interview. This meant that their mothers would have had experiences for more than one year. The sample for the study was drawn from under five clinics, where mothers bring their children for their routine follow up, family planning clinic, where they go for family planning services and from their PMTCT support group which had a meeting on one of the days of data collection.

In total, a sample size of ten (10) participants was selected to participate in this study. Only ten were chosen because being a qualitative research, the study involved a lot of data collection, which would have been difficult to analyze if the number of participants was going to be large. The recruitment criterion in terms of age was that mothers aged between 18 and 45 were to be recruited into the study. This was so because the researcher believed that this was an appropriate age group that could freely give consent on their own and at the same time they could be able to explain their experiences well, as compared to the very young or very old.

Burns and Grove (2001) defined sampling as the process of selecting a group of people, events, behaviors or other elements with which to conduct a study. The sample was recruited using convenience sampling.

Polit and Hungler (1999) state that convenience sampling entails the use of the most conveniently available person/people for use as subjects in a study. Therefore, in this study, those HIV positive mothers who experienced early cessation of breastfeeding, met the criteria for recruitment and were available in the clinic during data collection days were recruited into the study after their willingness to take part upon being consented was verified.

A convenient sampling of these mothers was used in this study in order to select subjects while avoiding biasness since there might have been many such women attending the clinic. This type of sampling takes advantage of subjects that fall within the population of interest and are readily accessible by the researcher. This also helped to reduce stigma, since the study was dealing with issues related to HIV status, which is a sensitive issue in the community.

4.4 DATA COLLECTION

Data was collected using in-depth interviews on the selected subjects as an interview guide was used. The guide was translated in Chichewa language for easy communication between the researcher and participants. The data collection tool was developed by the

researcher herself, with just a few questions borrowed from somewhere else; hence it was a semi structured interview guide. It was developed based on the objectives of the study, so that the intended questions in the objectives were met. It comprised of closed and open-ended questions, which enabled participants to describe their experiences after they had stopped breastfeeding early without being limited. The interviews were conducted by the researcher herself, in order to ensure consistency in the way the questions were asked. The interviews were on a one to one basis in order to ensure privacy, and make the participants feel free to talk. Data collected was in form of subjects' views.

Interview guides are good tools for data collection as they offer guidance and direction during data collection. Interviews helped the researcher get relevant information from participants concerning the matter being researched. The average time each interview took was fifty two and half (52.5) minutes since they ranged from forty five (45) minutes to one hour depending on the conversations. The interviews were conducted in two separate days; thus the 23rd and 28th September, 2009 respectively.

4.5 PILOT TESTING

Pilot testing was done in order to test the validity and reliability of the data collecting instrument. It also helped the researcher to see the clarity of the questions and the time it took to finish an interview. Validity of the instrument refers to the degree to which an instrument measures what it is intended to measure. In qualitative research, it refers to the credibility of description, conclusion, explanation and conclusion of the study. Reliability is the degree of consistency with which an instrument measures the attribute it is designed to measure (Holloway & Heeler, 2002). The tool was pretested in a pilot study done at Queen Elizabeth Central Hospital, on two HIV positive mothers who stopped breastfeeding at six months. The interviews for each client took at least one hour and ten minutes. The results assisted the researcher to devise better ways of phrasing some of the questions in the interview guide to ensure that the data collected is in line with what the researcher intended to find out.

4.6 DATA ANALYSIS

Data is analyzed in order to reduce, summarize, organize, evaluate, interpret and communicate the information gathered (Polit & Hungler, 1999). The data generated from the participants was analyzed manually using content analysis, a method that is used to analyze narrative data by grouping the data into thematic areas. The analysis was done using percentages and frequencies, when presenting the demographic data, while the rest of the information was analyzed by explaining the phenomena. Data analysis was done by the researcher herself.

4.7 ETHICAL CONSIDERATIONS

Prior to commencement of the study, the research proposal passed through the Kamuzu College of Nursing's Research and Publications Committee for approval.

Following the approval, letters seeking permission were written by the researcher to Blantyre District Health Office, specifically to the district health officer (DHO) and the in charge for Limbe health centre before the study was conducted. Following the approval from Blantyre DHO, the research was then conducted.

Consent forms were designed, which explained the purpose of the study, its nature, the part that the participant was going to play in the study, benefits and risks, how anonymity, privacy and confidentiality were to be handled and maintained in the process. All information that was in the consent form was given to the participants, in order for them to make informed decisions/choices. Clients only signed after they had fully understood the contents of the consent form and were interested to join the study. This was an indication that they were not forced to join the study but that they had willingly accepted to do so voluntarily. The consent form was translated in Chichewa to facilitate communication.

The subjects were given a chance to choose whether to participate in the study or not, since it is one of their rights to accept or refuse participation in any study. Therefore rights were observed and respected.

Subjects were also told of the right to withdraw from the study whenever they felt like doing so, even in the middle of an interview, without any consequences such as being affected in accessing health care services and the like. Benefits of the study to the society were also highlighted. Confidentiality was maintained by ensuring anonymity, where by code numbers were used instead of participants' name on the interview guide forms.

The right to privacy was exercised during data collection; where by a private room was utilized for interviews on a one to one basis. The place was free from interferences to ensure total privacy of the participants. The used forms were kept in a safe place after data collection as well as during data analysis so as to prevent them from being accessed by other people that were not concerned with the study. The forms will need to be destroyed later.

Subjects were pre-warned that the data was going to be used by the researcher, her supervisor and possibly other health personnel, who may want to use the information in future to improve the situation at hand.

4.8 DISSEMINATION OF RESULTS

The results of the study would be disseminated to the following:

- Kamuzu College of Nursing Library
- The supervisor of this research study
- Basic Studies Department of KCN.

CHAPTER FIVE

5.0 PRESENTATION OF FINDINGS

5.1 INTRODUCTION

This chapter presents the findings of the study that was conducted to find out the experiences of HIV positive mothers who stop breastfeeding their infants at the age of six months at Limbe Health Centre, Blantyre.

To meet the objectives, ten (10) in-depth interviews were conducted on ten HIV positive mothers who stopped breastfeeding breast feeding their babies when they turned six months. By the time of the interview, most of these babies were over eighteen months of age.

This section describes the demographic data that was analyzed manually. The chapter also contains narrative findings from the participants.

5.2 DEMOGRAPHIC DATA

The study involved interviews of ten mothers who participated in the study. All the ten were females and these were HIV positive mothers who had at one point experienced early cessation of breastfeeding. All of them were Malawians, with the majority (70%) from the southern region. The remaining (30%) were from the central region. The distribution of participants according to race is displayed in table 1 below:

Table 1: TRIBE DISTRIBUTION OF STUDY PARTICIPANTS

RACE	REGION OF THE COUNTRY	NUMBER OF PARTICIPANTS	PERCENTAGE (%)
Chewa	Central	3	30%
Yao	Southern	4	40%
Lomwe	Southern	2	20%
Mang'anja	Southern	1	10%
TOTAL		10	100%

The ages of participants were in the range of 21 to over 30 years. The findings showed that 70% of the participants were above 30 years of age (n=7), 20% between 26-30 years of age (n=2) while 10% were between 21-25 years of age (n=1).

The majority of the participants (60%, n=6) were married, 20% (n=2) widowed, 10% (n=1) single and 10% (n=1) divorced.

The findings also revealed that 100% of the participants were Christians. Table 2 below shows the distribution of clients according to their religion.

Table 2: DISTRIBUTION OF STUDY CLIENTS ACCORDING TO THEIR FAITH

RELIGION/CHURCH	NUMBER OF PARTICIPANTS	PERCENTAGE (%)
CCAP	2	20%
Roman Catholic	1	10%
Church of Christ	1	10%
Seventh Day Adventist	1	10%
Anglican	1	10%
Assemblies of God	1	10%
Baptist	1	10%
Miracle	1	10%
Topic	1	10%
	10	100%

The findings showed that majority of the participants had more than 4 children each (50%, n=5), 20% (n=2) had 3 children each, 20% (n=2) had 2 children, and 10% (n=1) had one child. Findings also showed that the majority of the participants (70%, n=7) did not have any history of children dying before the age of 5 while as 30% (n=3) had that. Table 3 below shows the distribution of clients who experienced that history:

Table 3: DISTRIBUTION OF PARTICIPANTS WHO EXPERIENCED UNDER FIVE DEATHS

NUMBER OF UNDERFIVE DEATHS	NUMBER OF PARTICIPANTS	PERCENTAGE (%)
4	1	10%
2	1	10%
1	1	10%

The findings also revealed that majority of the participants (60%, n=6) attended primary education and 30% (n=3) attended secondary education. The remaining 10% (n=1) did not attend formal education. None of the participants attended tertiary education.

Table 4: DISTRIBUTION OF PARTICIPANTS ACCORDING TO THEIR ATTAINED LEVELS OF EDUCATION

LEVEL OF EDUCATION	NUMBER OF PARTICIPANTS	PERCENTAGE (%)
Secondary Education	3	30%
Primary Education	6	60%
None	1	10%
total	10	100

Findings also showed that 70% (n=7) of the participants were unemployed and that only (30%) were working as counselors for mother to mother project. Out of the 7 unemployed, 6 are running small scale businesses (60%) while one (10%) is a house wife.

The findings also showed that 30% (n=3) of the spouses to these clients were employed. Two (2) were working as policemen and one (1) as a garden boy. Twenty percent (n=2) of the spouses run small scale businesses while 10% (n=1) stays idle. Results also revealed that 50% (n=5) of the families depend on business for their livelihood, 30%

(n=3) depend on employment including business, 10% (n=1) depends on employment alone while the remaining family (10%, n=1) depends on relatives for their day to day needs.

It also transpired through the process of data collection that all the ten participants were from different locations, all being catchment areas for Limbe Health Centre.

5.3 PERCEPTIONS ABOUT EARLY CESSATION OF BREASTFEEDING AS A FEEDING OPTION, BEFORE THE MOTHERS PRACTICED IT

The views of participants were sought in order to find out what their attitudes were towards early cessation of breast feeding, as an infant feeding option. These were views prior to their experience.

From their explanations, it was clear that almost all participants were worried and had some concerns towards the option. However, in the end they still decided to try it after thorough counsellings and having weighed risks against benefits of adopting the feeding option.

Thirty percent(30%) of the women (n=3) explained that they had concerns when they heard about early cessation of breastfeeding as a way of preventing transmission of HIV from mother to child, and their concerns came from different reasons as given below:

One participant said that:

"I was really concerned at first when I heard about this, because my other children were stopping breastfeeding at the age of 2 years, so for this one to stop at an early age of 6 months, my worry was that the child was still too small. I later on, however decided to adopt the method because of the benefit attached."

Another participant said:

"When I learnt about this, and before I decided for it, my concerns were on what will other people say or what I was going to answer them if they ask why the baby

had stopped breastfeeding so early. On the other hand, I was worried because my first born child got the virus through the same route of breastfeeding and I constantly kept on thinking about this, so it was like I didn't know what to choose."

The third participant said:

"I had concerns especially when I looked at this very small child who needed to be stopped from breastfeeding at an early age but then I understood the importance of doing that and felt the need to have my child protected from contracting the HIV that I had."

Twenty percent (20%) of the participants (n=2) expressed the fears they had when they learnt about the option, before they actually got involved. Their responses are recorded below:

One participant said:

"I had fears that the child may die because of this early cessation of breastfeeding. I also had feelings that maybe the baby would have already contracted HIV through breastfeeding, so the early cessation of breastfeeding was not going to make any difference. I thought that that can only worsen the baby's condition."

The other participant had this to say:

"My greatest fears were on how a small child was going to survive without breast milk. I was troubled in mind whenever I thought of the child's welfare for survival." The last point was translated from the following expression from the mother: *"Ndimakhala wotangwanika zedi m'malingaliro ndikaganizira zachisamaliro cha mwanayo kuti kodi adzakula bwanji."*

Twenty percent (20%) of the participants (n=2) felt it was an unimaginable idea to completely wean a child from the breast at an early age of 6 months. They had reasons to believe that as described below:

One of the participants' expressions was as follows:

"Nditamva, ndinkawona ngati nkhabakamwa kapena kuti zosatheka kuchitika kumene." This means that she felt like it was just hearsay and that it could not be feasible to do that or it was something that was impossible. She went on to say: *"Having been informed of the importance and benefits of early cessation of breastfeeding, I thought it wise to adopt the idea with the aim of having my child protected from getting infected with HIV."*

The other participant said:

"My feelings were that there was no way a child could grow without breast milk and I thought people had just brought in this idea as a way of ensuring population reduction through deaths of such children. After a number of counseling sessions, I developed the need to have my child prevented from acquiring HIV."

Ten percent (10%) of the participants (n=1) had no choice in the matter.

"Nditangomva zimenezi, malingaliro anga anali woti ndibwino kuti ndizasiyitse msanga kumuyamwitsa mwana wanga chifukwa sindinafuno kuti ndizakhale kapolo wa ku chipatala chifukwa choti mwana watengera kachiroambo"

This means that when she heard about early cessation of breastfeeding, her feelings were that she should stop breastfeeding her baby early because she did not want to frequent the hospital just because the child had contracted HIV.

Ten percent (10%) of the participants (n=1) felt sorry for her child:

"I was just feeling very sorry for my child but I felt the need to have the child protected."

The last 10% of the participants (n=1) had a negative attitude towards the option:

"At first, I had a negative attitude towards the option when it was first introduced to me. However after explanations I got from one of the nurses at the clinic, I was

relieved and my fears subsided. Later on, I developed a positive attitude towards the option.”

5.4 PERCEPTIONS TOWARDS EARLY CESSATION OF BREASTFEEDING AS A FEEDING OPTION AFTER THE MOTHERS ACTUALLY PRACTICED IT

The views of participants following experience with early cessation of breastfeeding were sought. This was done with an aim of finding out what their attitudes were now that they had actually gone through with this as a feeding option.

From their explanations, it shows that almost all women were satisfied with early cessation of breastfeeding as a feeding option and none of them regretted their choice.

Forty percent (40%) of the participants (n=4) felt that or perceived early cessation of breastfeeding as the best feeding option for infants born to HIV positive mothers. Below are some of the individual responses:

One participant said:

“I feel that early cessation of breastfeeding as a feeding option was the best choice I made for my child because the child is growing well and is HIV free.”

Another participant said:

“I feel happy that I made the right decision and I think this is the best option that an HIV positive mother can choose because it is helpful.”

Another participant said:

“I feel that early cessation of breastfeeding is the best option one can give to a child but I don't feel like subjecting any more children to this kind of torture. Hence I am thinking of having no more children by going through tubal ligation.”

The other participant said:

“I feel early cessation is the best feeding option though it is a bit challenging since there are a lot of things involved and needs a mother’s full commitment. I feel that I made the best choice because I already lost one child to the virus through prolonged breast/mixed feeding.”

Forty percent (40%) of the participants (n=4) reported that they felt good and happy because their children have benefited from the decision, since they are HIV free and they owe that to the right decisions they made concerning early cessation of breastfeeding.

One client further said:

“I feel that I made the right choice because many people that found themselves in a position/situation like mine have been assisted through my services since I always tell them about myself as a living example and some women have made decision to follow this feeding option because of my testimony.”

Ten percent (10%) of the participants (n=1) feels that she made a very fruitful decision:

“When I see the child, I just see the glory of God on my life because the child did not suck for a long time and yet it survived. I feel that the decision was very fruitful because I have had 4 children previously, who all died while below the age of 5 and I feel that they died because I lacked knowledge of how to protect them since my HIV sero status was unknown then. I wish I knew about this earlier because I could have protected them.”

Ten percent (10%) of the participants (n=1) feels proud that she made the right decision of choosing a good feeding option for her baby:

I feel proud that I made the right decision of choosing such a good feeding option for my baby since the baby got protected from HIV infection but it is an experience that I do not want to go through again. Because of that experience, I am thinking of going for tubal ligation as I don’t want to have any more children.”

5.5 FACTORS THAT HELPED TO FACILITATE THE MOTHERS' DECISIONS AND IMPLEMENTATION OF EARLY CESSATION OF BREASTFEEDING

Factors that helped to facilitate the women's decision as well as implementation of early cessation of breastfeeding were elicited from the participants. These factors were sought to find out what it was that made these participants stick to their decisions and later on implement them.

From the findings, a total of 7 different factors were identified. From the ten participants, 2 participants' decisions were influenced by four of the seven factors. One (1) participant by three factors; 4 participants by two factors and 3 participants by 1 factor each.

Loss of a child/children previously influenced decision making in 20% of the clients (n=2). Husband's support facilitated implementation of early cessation in 40% (n=4) of the clients. Counseling sessions by health personnel and knowledge gained from these facilitated decision making and implementation in all the mothers (100% (n=10)). Knowledge of one's status facilitated decision making and implementation in 10% (n=1) of the clients. Provision of baby feeds by a research institution facilitated decision making in 30% (n=3) of the clients. Previous experience of feeding fellow siblings on artificial milk following her mother's breast removal facilitated on client's decision making (10%). Baby's failure to get satisfied with breast milk only and showing signs of wanting to eat other foods at 5 months. This coupled with fear of mixed feeding from mother facilitated decision making in the mother (10%).

Table 5 illustrates specific factors that influenced the decision making and implementation of the planned decision by the participants:

Table 5: DISTRIBUTION OF CLIENTS AGAINST FACILITATINGFACTORS OF EARLY CESSATION

factors	Loss of children previously	Husband's support	Counselling sessions and knowledge gained	Provision of baby feeds by a research institution	OTHERS SPECIFY
frequency	1 1	1 1	1 1 1 1 1 1 1 1	- - - 1 1 1	-Knowing one's sero status. -Previous experience of feeding fellow siblings on artificial feeds following mother's breast removal. -Baby wanted to start eating at 5 months. Mother's and sisters' support and encouragement
Total number of clients	2	4	10	3	3 with other different factors

5.6 CHALLENGES ENCOUNTERED BY THE PARTICIPANTS AFTER IMPLEMENTING EARLY CESSATION OF BREASTFEEDING

The researcher sought and analyzed Participants' different experiences. These were sought in relation to challenges encountered after implementation of early cessation of breastfeeding. The challenges were those that the participants encountered on their own, from the babies that had been abruptly weaned as well as from the community in general. The study revealed that the challenges the mothers encountered were in three groups: physical, economic and psychosocial.

The physical challenges were mainly from the babies while as the other two were solely for the participants themselves. These challenges have been discussed in length in the

paragraphs to follow. The results however indicate that not all participants encountered challenges. Eighty percent (80%) of the participants encountered challenges after the implementation phase but 20% (n=2) faced no problems at all. From the 80%, 10% (n=1) faced physical problems from the baby only while as the remaining 70% (n=7) at least faced all kinds of challenges (physical, economic and psychosocial).

Seventy-five percent (75%) of the participants, who encountered challenges, encountered these problems in relation with their children. Twenty five percent (25%) of them reported that their children cried a lot as they waited for feeds and during the night. One participant expressed concern over the availability of breast milk versus replacement feeds:

“Problems were there considering that breast milk is something that is readily available at all times from a mother’s breast, while as replacement feeds such as milk involves a lot of procedures like boiling water, making the milk, cooling it before being given to a child. Because of the processes and the long waiting, my baby used to cry a lot.”

Another client has this to say:

“Another burden was coming in during the night when I had to get up and make milk for my baby instead of just giving it the breast as I usually did before 6 months of its age. Usually the baby would not go back to sleep just because it needed to be fed and during this time, it would cry without stopping until fed.”

Twelve percent (12%) reported that she observed that her baby had become weaker shortly following the implementation of her decision (following abrupt cessation) and she related this weakness to the early cessation of breastfeeding.

Another 25% (25%) reported that their babies suffered a lot after the early cessation:
“The baby had frequent attacks of diarrhea and later ended up being treated for

Tuberculosis.” Another participant said: *“My child was often sick following the early cessation and my fears were that she would get malnourished.”*

The last 12% (n=1) reported that baby was refusing to eat ‘mgaiwa’ only porridge, saying it preferred Likuni Phala.

Almost 100% of the participants who encountered all sorts of challenges (n=7) were being asked why their babies had stopped breastfeeding so early in their life. These questions were coming from their neighbours, relatives, in-laws and other people who just visited them and had a chance to see that these children were being bottle fed instead of being breastfed.

Seventy-one percent (n=5) of these reported experiences concerning stigma and social isolation. They said they were being laughed at; further more, there was a lot of backbiting and bickering from fellow women. Another challenge was that they were being referred to as HIV positive by the people in their communities. Things were like this because of their implementation of the early cessation. Below are some of the experiences they shared:

One participant said:

“When I had stopped breastfeeding, news got around that I had done so because of the virus. Because of this I became stigmatized and socially isolated by some people within the community, some of whom I used to call friends. Other family friends stopped their children from coming to my house where they used to play with my two older children. Even my children were affected because they were no longer being welcomed in these people’s homes as was the case before.”

Another participant narrated the following ordeal:

“.... It was like I had done something very unusual or committed a very big offence.” She relates to some of her experiences where everybody would stop talking once she appeared or joined a group of women from within her

community and yet the people were seen talking and some even laughing prior to her joining them." *In situations like this one, even though no one confirmed that they were talking about me, I could actually feel that the talk was mine from the way these women behaved. My instincts told me so, and I did not even need to be told."*

Another participant said:

"Through the backbiting and talking concerning the issue of early cessation of breastfeeding, I overheard a number of people referring to the reason for my decision as being the 'usual one/the famous one nowadays, what else can it be' translated from ("zomwezi za masiku anozizi, zomwe zatchukazi, nanga chingakhale chianinso china?")

Another participant expressed concern over the behaviour over some of her trusted friends:

"A number of reports reached me saying certain people were telling others about me, saying I had stopped breastfeeding at that tender age of the child because I have AIDS. I suspect some of the people I used to take as trusted friends, whom I had confided in about my status and my decision to abruptly stop breastfeeding with the aim of preventing my child from contracting the virus. I thought I had friends then. I wish I had known."

Sixty-two percent (62%) of the participants who experienced challenges admitted to having had problems psychologically within themselves, in relation to the implementation of early cessation. The participants reported that they felt sorry for subjecting their children to early cessation because of their statuses.

One participant said:

"I really felt bad and sorry whenever my baby cried a lot for any other reason, thinking that I could have easily pacified this baby with my breast if all was well."

Another participant said:

"I was deeply concerned in my heart for what I had done to my child. The constant questions from people on why I had stopped breastfeeding just worsened my guilt."

Another participant said:

"Most of the times, I felt sorry for myself as well as for my child, thinking our health was going to be, with the knowledge that I delivered this baby having a positive HIV sero status. I felt that my baby did not deserve this kind of treatment."

Another participant said she felt very sorry and constantly guilty because she felt that the child was too small to be completely stopped from breastfeeding.

Thirty seven percent (37.5%) of the participants (n=3) faced challenges in relation to their socio economic status. Most of the experiences shared were in connection with not being able at times to buy the right foods needed for the baby because of monetary problems.

One participant reported that her baby could be selective, preferring other kinds of food and refusing those that the family could afford at that particular time. She further said: *"There were also times when we were completely running short of all the necessary food items to give to the baby, with no hope of finding something very soon and that was very challenging for us."*

Twenty five percent (25%) of the participants who faced challenges (n=2) reported their experiences on how involving the feeding option was. They referred to it as too involving, time consuming and not convenient. In addition to those mentioned above, one of them said: *"Another burden was always there whenever I had to travel. I had the challenge of having to carry a hot water flask, baby feeds and utensils whenever I went for functions such as funerals, church services, wedding ceremonies and many more. I had to take the baby with me to all these functions because there was no one at home to look after her. Preparation of these feeds outside the home was a problem on its own,*

because in these gatherings I had to make baby feed and feed her in the presence of other people, some of whom did not question. It was difficult”.

The other participant reported that because of the problem presented above, she was failing to attend and participate in fellow women’s activities and other community activities. She decided to refrain from going out unnecessarily with the aim of protecting herself and her child from questioning eyes. Because of this absence to social gatherings, she was referred to as a bad citizen in the community who did not go out when her services were needed by others.

One of the participants who faced challenges (n=1) reported that she went through a physical challenge with her breasts. They got swollen and were very painful for almost three weeks following early and abrupt cessation of breastfeeding. She said it was an experience that she doesn’t want to relieve. She even started wondering at that particular time if she had made the right choice after all.

Thirty percent (30%) of the participants who denied facing any problems in relation to early cessation of breastfeeding feel that was the case because they did not reveal their secrets to anybody.

One participant believes that apart from that, it is also because she does not associate with many people where she lives. She said that is the situation because their house is within the same fence with their master’s house, where her husband works as a garden boy. Such being the case, unnecessary visitations are prohibited at the entrance.

5.7 MEASURES TAKEN TO DEAL WITH AND OVERCOME THE CHALLENGES FACED

The participants were asked what measures they took to deal with and overcome the challenges they faced. This was done to establish how the participants dealt with the challenges they faced. The findings revealed that the participants took several types of measures in order to deal with the challenges.

Seventy percent (70%) of the total number of participants (n=7) are the only ones that were faced with challenges while 30% experienced no problems. In this section, the measures taken are only dealing with the 70% since the question was not applicable to the other 30%.

The findings also reveal that some participants applied different types of measures to their situations. They did not just stick to one depending on the situation or challenge faced.

Seventy one percent (71%) of the participants (n=5) reported that they coped with their challenges by ignoring the situations and pretending as if nothing happened. They reported that they were doing this deliberately because they knew that the decisions they had made benefited them and were more fruitful than whatever people talked about.

One participant said: *"I had already informed people who mattered in my life, like my parents, parents in-laws and very close relatives about my situation and these people were understanding and very supportive and this is what mattered most to me. Because of this, whatever others said (people outside this circle), I did not care."*

Another participant said: *"I was getting all the support I needed from my husband and encouragement as well from my mother and sisters so I never took to heart the many things that people were talking and saying about me. I ignored most of it, knowing that the decision I had made was for the sake of my child."*

Another participant said: *"I dealt with the challenges by minding my business and pretending as if I was not hearing what was being said or seeing what was happening around."*

Another participant said: *"I ignored the problems and pretended as if they did not exist."*

One other participant said that she was just encouraging herself by telling herself that what ever was being said did not matter at all. She further said: *"Even though the situation was like this, I was still concerned at times."*

42% of the participants (n=3) reported that giving different answers to the people who were questioning them a lot helped to deal with the challenges/problems they were facing. One client reported that she did this without disclosing her status or the real reason for her choice. She further said: *"To my persuasive relatives, I put them off by telling them that I was advised to do so at the hospital because of the condition of my breasts."*

The other client said: *"I used to give them all sorts of reasons that the hospital could give, the sort of advice that a client can be given such as not to breast feed because she has got problems with her breasts. I was deliberately doing that in order for them to choose whether to believe or not."*

The other client also said that she used to do the same to the inquisitive people. She told others that her baby likes to suck a lot during the night, to such an extent that she doesn't care about being breastfed again during the day, after taking the other feeds like porridge. *"I feel that the different explanations given to the people somehow helped to overcome some of the challenges of inquisitiveness"* she concluded.

Fifty six (56%) of the participants (n=4) reported that they felt that disclosing their status and their decisions to other key people in their lives, apart from their husbands helped a lot in dealing with the challenges. They reported that the support and encouragement

they were getting from these people and family members helped a lot in strengthening them during these trying times. They felt that this could not have been the case, had they decided to keep the things to themselves.

Twenty eight percent (28%) disclosed the news to their trusted close friends. One participant said that she believed that a problem shared was half solved and that is what prompted her to entrust a few of her friends with her secret. She also said that she did that with a belief that true or real friends can confide in each other without anyone within them breaching that confidentiality. She further said: *"I also decided to tell them so that in case they too are faced with the same situation like mine, they should not make the same mistakes that I did previously but that they should know that there is a way out and decide on what to do or how to handle it, knowing that somebody familiar before went through the same and survived or had a good outcome."*

The other twenty eight (28%) disclosed the news to their parents, parents in-laws and very close relatives (especially sisters). They reported that they believed in family and that no matter what families went through, they usually stick together. They also believed in the 'blood is thicker than water' adage. This made them believe that their relatives were going to keep their secrets and could even be relied upon in terms of other types of help that would be needed during such situations.

Another 28% (n=2) reported that for the physical challenges, they usually sought help from the health workers at the same health facility and were being assisted accordingly. Whenever there was need for referral, they were being referred to the big health facility in the area and felt that assisted a lot in dealing with the physical challenges faced.

Fourteen percent (14%) reported that she sourced the food that her baby required through her personal efforts. The baby feeds she used to get from a research institution at the health facility also assisted a lot in meeting the baby needs.

5.7.1 FACTORS THAT FACILITATED THE PARTICIPANTS' EFFORTS IN DEALING WITH THE CHALLENGES

Participants were asked to describe factors that facilitated their efforts in dealing with the challenges they faced. This was with the aim of finding out what it was that assisted these participants to deal with and overcome the challenges they faced. As in the previous section, the findings in this section are responses from 70% (n=7) of the sample size that faced the challenges. Since the other 30% (n=3) did not face any challenges, this section was not applicable to them.

Findings show that different factors assisted different individuals in different ways. Results also show that some participants had more than one factor that assisted them while as others were assisted by a single factor.

Twenty eight percent (28%) of the participants (n=2) explained that the support and encouragement they got from husbands, friends and relatives assisted a lot. It made it easier for them to deal with the problems they encountered.

Another 28% of the participants (n=2) explained that the encouragement they got from continuous counseling sessions by the health workers as well as the care that was being rendered to them or their babies when sick helped them to deal with their problems better.

One of the participants further said: *"I was always reminded to see or look at the benefit of my decision behind all the talk and everything else, and to weigh one against the other."*

A third 28% (n=2) reported that they felt that being courageous and humble in different situations they faced also assisted a lot.

Another 28% (n=2) also reported that ignoring the situations and pretending as if everything is alright assisted them a lot.

Fourteen percent (14%) of the participants felt that explaining clearly to the inquisitive people made it easier for them to deal with their problems.

5.7.2 FACTORS HINDERING THE PARTICIPANTS' EFFORTS OF DEALING WITH THE PROBLEMS AND DIFFICULTIES ENCOUNTERED IN THE PROCESS OF DEALING WITH THE CHALLENGES.

Participants were asked about factors that hindered their efforts in dealing with the challenges they faced. Participants were also asked about the difficulties that they encountered in the process of dealing with the challenges. The aim was to establish what stood in the way of dealing with the challenges that these participants faced.

Seventy percent (70%) of the participants were targeted because the questions were not applicable the remaining 30%. The study findings showed that 28% (n=2) of the participants responded to the questions while as 72% (n=5) had nothing to say. They said there was nothing that was making it difficult for them to deal with the problems.

Fourteen percent (14%) reported that frequent illnesses from her child coupled with what people were saying about the situation to a certain extent, were things that were interrupting with her efforts to deal with the challenges she was already facing. She had this to say "*fellow women/mothers were saying that I desperately wanted my own child to die quickly so that I should be free again to start enjoying myself as I used to.*" The stigma she was subjected to by some of her friends is one of the difficulties she encountered in the process of dealing with the challenges. The stigma came in because of the child's frequent illnesses.

The other 14% (n=1) reported that their efforts to deal with challenges were tampered with when the backbiting was just too much for them to bear. These were also some of the difficulties encountered in the process of trying to deal with the challenges.

5.8 ASSESSMENT OF HOW MANY PARTICIPANTS WOULD CHOOSE EARLY CESSATION AGAIN IF GIVEN A SECOND CHANCE

All ten Participants were asked whether they would or not go for early cessation again as a feeding option if they were given a second chance. This was done to establish what each participant's stand was in relation to early cessation of breastfeeding at the time of interview. Findings revealed that 100% of the participants said yes, they would go for the option again if they were given a second chance. The reasons for the positive response were in relation to the fact that they saw and experienced benefits at the end of the whole process. The benefits were in relation to the prevention of HIV transmission from the mothers to their children. They felt that their children's lives were saved because of that practice. As a result, they felt like they owed those children's lives to the feeding option of early cessation of breastfeeding.

Below are some of the comments made by the participants in relation to why they would choose that option again:

"The feeding option gave life to my child"

"I cannot go for another method or option whose results I have never seen. At least I have seen the benefit in this one"

"I feel this is the most helpful option instead of the other one where the baby completely does not suck from the mother's breast at all from birth"

"Even though I went through a lot, in the end my baby got saved from contracting the virus, so I would surely go for it again"

"Of course, I have seen the fruits of this option"

5.9 CONSTRAINTS OTHER MOTHERS IN SIMILAR POSITION WENT THROUGH

Participants were asked to narrate stories or experiences of other women they knew or heard about who also stopped breastfeeding at an early age in their community. This was with an aim of finding out if these people's experiences were the same as the ones experienced by the study participants. This was also a way of trying to poke into the minds of the participants. If they had forgotten about something in their own experiences, the other mothers' experiences were going to remind them if they were similar.

Study findings showed that 60% (n=6) of the participants heard about something concerning such women while 40% (n=4) said they never heard of anything or seen anyone in that situation before, so they never contributed to the other responses in this section.

The findings revealed that the stories the participants heard about were in relation to the children that had been stopped from breastfeeding at an early age such as that these children's health was not good at all. The mothers did not have the proper food to feed the children, and that they were not growing well. The children were often sickly and a lot of them are ended up with malnutrition.

One participant went on to add that the children were mostly suffering from diarrheal diseases. This was because of mishandling of food and failure to follow the advice that was given to the mothers by health workers.

Another participant reported that she witnessed an informal group of women in their community, talking about mothers who stop breastfeeding their children at very tender ages, wondering what the mothers' motives were in relation to the children's survival or deaths. The participant further stated that she was impressed with a certain woman within the same group who stood up for the affected mothers. She said that if the mothers

choose to stop breastfeeding early, then it means they have good reasons for doing that and needed to be treated with respect.

One participant, who also works as a counselor of fellow women in a certain project said she heard a lot of stories from the clients in her program. This participant reported these stories amongst those that she was told by the concerned women:

- Some mothers who failed to cope with buying baby food resorted to breastfeeding again, thereby ending up with mixed feeding.
- Some families are poor and cannot manage on their own and that they need assistance.
- Some of the children who were stopped from breastfeeding at an early age died from malnutrition.
- Certain women groups sit, talk and laugh about this decision of early cessation of breastfeeding, wondering how a child can grow up and survive without breast milk.
- Since these days, early cessation is mostly associated with prevention of mother to child transmission of HIV virus, those mothers that stop breastfeeding early are associated with this and when the concerned mothers hear about such stories, they get worried a lot.

5.10 SUGGESTIONS OF PARTICIPANTS

Participants were asked on what they think or suggest should be done in order to improve PMTCT programs in the country. The aim was to establish what other views or suggestions these participants had to improve the PMTCT services. The reason is that these people had experienced the current system. In other words, the researcher wanted to find out from the participants what was wrong with the current system and how best they could improve it.

90% (n=9) of the participants responded while 10% (n=1) said she had no suggestion to make.

Findings show that some clients had more than one suggestion to make as evidenced by the number of responses. 56% (n=5) of the respondents suggested that government and other organizations should continue to support the program by providing food aid to those children that have been stopped from breastfeeding. They suggested that this should be from the age of 6 months up to 2 years. Some also suggested if the food aid could be extended to their mothers as well in order to ensure good nutrition for both children and mothers. One participant went on to say: *“If government could put a measure or rule like the one working for civil servants on ARVs, that they get an extra MK5, 000 on top of their salaries, but in this case, the special focus should be on all women that get pregnant and deliver children while HIV positive in order to ensure that they are provided for nutritionally up until their children are 2 years old.”*

Twenty two (22%) of the respondents suggested that government and other organizations should source drugs that could either be given to mothers or children during breastfeeding. In so doing, HIV transmissions would be prevented while at the same time, their children enjoying extended breastfeeding.

One participant further went on to say *“the situation right now is that most mothers are still continuing to breastfeed their children after the age of 6 months because they are poor and cannot afford to find proper food for their babies in case of early cessation of*

breastfeeding. The mothers are doing this unhappily and most children are contracting the virus after the age of 6 months."

Eleven percent (11%) of respondents suggested that government should declare or make it a rule or law that children born from HIV positive mothers should stop breastfeeding at six months of age. She believes that people always stick to laws and she feels this is the only way PMTCT services can be improved. The participant however went on to say "*In putting up this law, the government should take full control over food supplements to those children, with special attention to the very needy families who cannot afford to buy the right foods needed for the baby*".

Eleven percent (11%) of the respondents suggested that the government officials and officials from other organizations that are already involved in providing aid need to enlighten the mothers on the aid they are giving and why. "*There are conflicting messages on the media concerning PMTCT. Some messages are saying children are dying due to malnutrition and not HIV infection, at the same time, some messages are saying those children who continue to breastfeed after the age of 6 months are at risk of getting HIV infection. These messages are confusing the mothers or even other interested parties. There is need for the officials mentioned above to sort out this problem.*"

Another 28% (n=2) of the respondents suggested that those mothers who cannot cope with the demands of early cessation should decide to stop bearing children instead of practicing mixed feeding when they have full knowledge of what that practice can do to their children. The other participant went on to say: "*The best and only way to improve PMTCT services is if HIV positive women and men (families) could be convinced to stop having children because that is the only reliable way of ensuring that all children born in the nation are HIV free since the children will be born from HIV free parents.*"

The last 28% (n=2) of the respondents felt that the best way to improve PMTCT program is by ensuring that mothers stop breastfeeding their children at the age of 6 months or less and be able to follow the advice given to them by health workers.

5.11 OTHER CONTRIBUTIONS

Participants were asked to make any contributions concerning the matter of early cessation that was being discussed during the interviews specifically on areas they felt the interview guide omitted.

Only 20% (n=2) of the participants had something to say while the rest of them 80% (n=8) said they had nothing to contribute. One participant just commented on the possibility that other HIV positive women may not want to stop breastfeeding their infants at an early age because they are afraid of being asked why they decided to do so by the people in their community since women like talking too much.

The other participant was interested to find out whether Malawi, as a nation will continue to help or assist HIV positive people/individuals.

5.12 QUESTIONS ASKED BY PARTICIPANTS

At the end of each interview, participants were given a chance to ask questions to the researcher in relation to the subject under discussion. 70% (n=7) of the participants did not have any questions to ask while as 30% (n=3) had questions.

One participant wanted to know if children that do not breastfeed at all cannot experience some severe problems. She asked this question because she learnt that breast milk contains elements that are responsible for development of intelligence and immunity in humans.

Another participant wanted to know the government's stand in terms of food aid provision to the mothers that practice early cessation of breastfeeding. The last participant wanted to know the relationship of ARVs and family planning drugs. She

heard that the combination of the two does not go well or rather that one is not in favour of the other. So she wanted to know also what can be done in a situation like this one.

This client also wanted to know why it is that children from different parents still get HIV and others do not, yet their mothers followed the same patterns of preventing these children. She wanted to know what happens for this difference to happen.

5.13 SUMMARY OF RESULTS

Study findings reveal some of the experiences HIV positive mothers that stopped breastfeeding their infants at an early age such as six months went through or encountered. These results were from the ten participants that were included in the study. Specifically the results revealed the perceptions of the mothers towards cessation of breastfeeding at six months. They also revealed factors that facilitated early cessation of breast feeding. Further more, challenges that these mothers met in relation to early cessation were uncovered as well in the results. Measures taken by the mothers in order to deal with and overcome these challenges were highlighted in the results. Lastly, the results also revealed suggestions from the mothers on how such a PMTCT program could be improved among HIV positive mothers.

In brief, there are different types of challenges that such mothers meet in the process of implementing such a useful idea. However, the good thing is that at least most of them are able to deal with these challenges and carry on with the implementation of their decisions.

CHAPTER SIX

6.0 DISCUSSION OF FINDINGS

6.1 INTRODUCTION

The discussion ties the other sections of the research report and gives them a meaning (Kovacs, 1985). The study aimed at exploring experiences of HIV positive mothers who stop breastfeeding at 6 months. This chapter presents the discussion of the results of the study. Findings are discussed in relation to the available literature and Health Belief Model. It focuses on demographic data, perceptions of the HIV positive mothers towards cessation of breastfeeding at six months. Factors that facilitated early cessation, challenges faced in relation to early cessation are also some areas of focus. Additionally, measures taken in order to deal with and overcome the challenges as well as suggestions on how to improve the PMTCT program are also included.

6.2 DEMOGRAPHIC DATA

A sample of 10 (n=10) HIV positive mothers who stopped breastfeeding at 6 months participated in the study, of which 70% (n=7) were above 30 years of age. In fact, all participants were between the ages of 21 to over 30 years, but below 50 years. This was the right population group to be targeted for their experiences as they were mature, not very young and not very old. Because of this, they were able to narrate their experiences maturely without unnecessary interruptions which might have arisen from immaturity, or forgetfulness from old age. They were also able to withstand the length of the interviews. This is also the right population group to target if a PMTCT activity such as early cessation of breastfeeding is to be successful.

Most of the participants were from the Southern region of Malawi 70% (n=7). This could be possibly because the targeted institution was also there. Knowing clients' places of origin enables a health worker to have ideas on their tribes and cultural beliefs. Knowledge of these assists the health worker on how best to introduce certain health issues or counsel the clients. Health care providers need to be cautious and sensitive to

cultural beliefs of an individual. Some of these beliefs could point out areas which could hinder successful implementation of PMTCT activities like early cessation of breastfeeding. An example would be a culture where women are not expected to make decisions on their own regarding breastfeeding cessation. In a situation like this, even if HIV positive women could think and decide to stop breastfeeding their babies at an early age, they could not implement it despite having knowledge of benefits attached to that. They could be restricted to the cultural beliefs. Since all the participants are from a matrilineal origin, and in such a society, they are decision makers, may be that is why it did not pose as a very big challenge for some of these mothers to decide on their own to implement early cessation of breastfeeding.

Findings revealed that all participants (n=10) were Christians. They belonged to one denomination or the other. This indicates that if churches were involved in disseminating such type of information, PMTCT activities and all those associated issues like early cessation, could easily reach the women of child bearing age, their significant others as well as all the population.

Findings further revealed that 60% (n=6) of the participants were married, 20% (n=2) widowed and the other 20% (n=2) divorced and single respectively. The marital status played a big role for some of the women, as 40% (n=4) of them had their husbands' support in the matter, both psychologically and financially.

Findings also showed that the majority of the participants had more than 4 children each (50% of participants; n=5). Two (2) had 3 children each and another 2 had 2 children each while only one had one child. Thirty percent (30%) of the participants (n=3) had history of children dying before the age of five. Data shows that the researcher was dealing with mothers and not just mere women. It also shows that all participants were women who had vast experience concerning child rearing because even the one that had one child, had other children before, unfortunately they died. These were the right people to be targeted as they were in a better position to differentiate what would be termed as the normal way of feeding a child and what would be termed as abnormal or deviating

from the normal, since they had practiced both methods. History of number of children dying before the age of five alerted some of the participants to go for proper check ups and investigations and seek proper advice from health workers in order to prevent further deaths.

Findings further revealed that 60% (n=6) of the participants had low educational status since they had only attended primary school. Thirty percent (30%) attended secondary school education while 10% did not attend any formal education. This correlates with the results on occupational status, where the majority are house wives though involved in small scale businesses. Data also shows that most of the spouses to these participants are working and others running small scale businesses. Fifty percent (50%) of the families depended on business as a way of livelihood. Thirty percent (30%) depended on employment including business. Ten percent (10%) depended on employment alone while 10% depended on relatives for their survival. The information on literacy level agrees with what MDHS (2000) found that the literacy rate is higher in men (72%) than women (49%). WHO (2005) also reported that in many parts of the developing world (such as the Sub Saharan Africa), there is low education status especially among women. This makes it difficult to reach large segments of the population with information about HIV/AIDS and their latest updates.

This is also true for the study findings, where some of the participants lost a number of children previously just because they did not have adequate knowledge concerning HIV/AIDS and PMTCT. This was like that because they were ignorant of their sero status.

However, because of indulging in small scale businesses, and assisting with finding needs for their homes as well as exposure possibly because they are in town, these women seemed to have some sort of empowerment. This was evidenced by their taking decisions to go for testing, having gained knowledge on importance of testing and following the counseling given by health workers on early cessation of breastfeeding. This is something which a less empowered woman could not do.

6.3 PERCEPTIONS OF THE MOTHER TOWARDS CESSATION OF BREASTFEEDING AT SIX MONTHS

Findings revealed that all participants were worried and had concerns towards early cessation of breastfeeding as a feeding option for children born from HIV positive mothers. The concerns and worries were the mothers' first reaction when they first heard about the option before they had actually practiced it. The negative attitude was coming in for a number of reasons such as:

- Baby's age at cessation, as this was being viewed as very early. In other words, the mothers had fears in relation to the children's welfare for survival and what the outcome was going to be. They felt sorry for the children).
- What other people were going to say and what the mothers were going to answer or how they were going to explain.
- Doubted the feasibility of that happening.

The findings are in line with DePaoli's (2008) study findings where both counselors and HIV infected mothers expressed concern over practical issues, including social consequences, associated with early cessation. These also agree with what Piwoz (2007) found out on the same perceptions where data demonstrated that rapid breastfeeding cessation would be difficult and malnutrition could be a risk if infants were weaned early.

In this study, most of the mothers' fears for their children were in relation to malnutrition and early death, because of being weaned early. Nevertheless, it is encouraging to note that despite all the concerns, worries, negative attitude, these mothers eventually decided to try the feeding option. This was so because of the thorough counseling they got which made them weigh risks against benefits and then decide depending on what they felt was outweighing the other. Almost all the mothers decided to try early cessation because of the benefit attached of preventing their children from contracting HIV. They did not want their children to get the virus through extended breastfeeding which usually ends in mixed feeding as the child progresses in months.

According to Health Belief Model (HBM), a person's decision to take action to prevent illness or injury is facilitated by perceived susceptibility to the particular illnesses or disease, perceived seriousness of the disease, perceived benefits of taking action and the perceived barriers (Smith, 1995). In this case, the women's decision to take action to prevent mother to child transmission of HIV through early cessation of breastfeeding was affected by knowledge and seriousness of the disease. It was also affected by the perceived benefits of taking action against perceived barriers to taking action. They perceived the MTCT of HIV as being serious and early cessation of breastfeeding as the right action to be taken, in order to PMTCT. This would end up in having an HIV free child despite all the anticipated difficulties. These difficulties are the perceived barriers in form of stigma, discrimination, lack of support or finances and many more.

HBM suggests that people need to have some kind of cues to action for them to change behaviour or make a health related decision. This could be through health education talks given to pregnant mothers when they come for antenatal services. It could also be through one to one counseling sessions when these women get tested for HIV. It is therefore important that health workers/nurses include this information of MTCT and its prevention when working with all pregnant or lactating women. This should be the case because these are at risk of contracting HIV and transmitting it to their babies.

This study's findings on the mothers' change of attitude from negative to a positive one in relation to early cessation, concur with what DePaoli (2008) found out on the same perceptions. In that study, it was reported that the mothers' primary motivation for wanting to rapidly stop breastfeeding was to avoid infecting their children with HIV, regardless of all the difficulties involved.

The findings show that the participants were aware of some of the problems they were going to encounter in relation to early cessation. That is evidenced by the concerns.

Findings also revealed that the women's perception of early cessation of breastfeeding remained positive even after they actually practiced it. According to the results, all

mothers were satisfied with this feeding option and nobody regretted their choice. The mothers reported this despite all the difficulties they went through. They described early cessation of breastfeeding as the best and fruitful feeding option which they felt good about and happy as well as proud to have chosen. They felt like this because their children were prevented from contracting HIV, hence the benefit. The findings are in line with De Paoli's (2008) findings where results revealed that mothers enrolled in the PMTCT research setting of early cessation reported many success stories in contrast to those attending routine services.

The findings also correlate with those of Muula et al (2004) where women's perceptions towards selected potential HIV preventive efforts were elicited. 91.8% of the women reported that they intended to breastfeed for at least 6 months followed by early cessation.

The findings however, are in contrary to Munthali's (2003) findings, where most participants, especially local villagers believed that there is no possibility of preventing mother to child transmission of HIV during pregnancy, delivery or breastfeeding.

The findings show that the current participants have adequate knowledge or are exposed to lots of information on PMTCT strategies unlike their counterparts in the villages, as evidenced by the literature preceding this entry. This might however be so because that was some time ago. On the other hand, the current participants may be at an advantage because of where they are staying. They may be advantaged because of exposure.

6.4 FACTORS THAT FACILITATED EARLY CESSATION OF BREASTFEEDING BY THE MOTHERS

The findings revealed a number of factors that helped to facilitate the mothers' decision making as well as implementation of their decisions in relation to early cessation. At least all participants were at one point influenced by the counseling sessions they attended and the knowledge gained from these sessions. This means that these participants were given adequate knowledge on HIV, PMTCT, advantages and

disadvantages of continuing to breastfeed. It also means that they had adequate knowledge on infant nutrition as well as all infant feeding options. This facilitated the mothers' decision making and implementation of early cessation because they wanted to avoid infecting their babies through extended breastfeeding.

These findings re-emphasize the role of health workers in counseling mothers in relation to HIV and breastfeeding, which is sometimes neglected in the health settings.

The findings agree with those of Bakaki (2002) in relation to factors that favoured the success of early abrupt cessation of breastfeeding. Majority of the mothers reported that they were able to stop breastfeeding early because of the health education and counseling that health workers gave them. Health workers from the same study had similar responses.

Findings also revealed that a good percentage of participants' (40%) decision making and implementation of early cessation was facilitated by husbands' and relatives' support. These participants had disclosed their sero status to their husbands and some to their relatives as well. They also discussed with them on early cessation of breastfeeding and its advantages. These participants got both psychological/emotional as well as financial support from these significant others. So the findings show the importance of disclosing one's status and involving spouse and significant others in such PMTCT activities, if they are to be successful. The study findings also concur with those of Bakaki (2002) where both participants' and health workers' responses revealed that the success of early abrupt cessation of breastfeeding was also attributed to mothers whose spouses/relatives knew about their sero status and were supportive.

The findings presented above also concur with Lunney's (2008) findings which reported that factors facilitating early breastfeeding cessation were mothers' knowledge about HIV transmission, family support and disclosure of their HIV status.

According to study findings, other factors that facilitated the decision making and timely implementation of early cessation of breastfeeding by the study participants were as follows: provision of baby feeds by a research institution, death of children previously and knowledge of one's status. Previous experience of feeding baby on artificial milk only and failure to produce enough breast milk for baby were also amongst them.

Some of the findings above are similar to those of Tadesse (2004), in a study of antenatal mothers' knowledge and perceptions on PMTCT of HIV. The study revealed that the majority of his study participants knew how HIV can be transmitted and how it can be prevented. They also suggested that the knowledge about the HIV status of the pregnant women can be important and of benefit in the prevention and control of HIV. This means that knowing one's status can facilitate decision making and implementation of early cessation as a PMTCT strategy.

According to HBM, a person's decision to take action to prevent MTCT can be affected by demographic variables which include structural variables such as knowledge of the disease or prior contact with the disease or personal experience of the disease and internal and external cues (advice from others). In this study, some of the participants had experienced deaths of their children previously, resulting from HIV infection. These participants were likely to accept the PMTCT measure of early cessation because they could not risk losing another child's life again. In this case the clients were likely to comply with professional advice from health workers because they felt the need to protect their children and were motivated to do so. This was so because they perceived the threat or consequences of the disease if not prevented and had observed that the benefits were outweighing the risks, no matter how severe.

The results on infant feed provision also show the possibility that there might be a lot of mothers out there who would willingly stop breastfeeding early if there were readily available food supplements to be given to their babies. This is evidenced by those whose implementation was facilitated by the provision of free baby feeds.

The fact that most of these participants were in business and were to a certain extent empowered possibly helped to facilitate the implementation of early cessation. This is so because these clients had a certain degree of financial independence and say in decision making at home, which could be another factor that facilitated the process in this group of mothers.

Most of these participants did not go far with their education. Sixty percent (60%) went up to primary level, thirty percent (30%) secondary level while 10% did not even attend any formal education. Surprisingly these participants were able to understand the messages given to them during health education and counseling and succeeded in implementing early cessation, which is not likely the case in the less educated. Possibly it is because of at least attending some formal education. It is common knowledge that educated people easily understand things such as benefits of doing something. That is not the case with ignorant ones who might always think that a health worker has a hidden agenda behind such kind of explanations.

In another study by Bakaki(2002), findings cited single motherhood, negative HIV PCR(polymerize chain reaction) results for babies and having less number of children (i.e. less than 3) as being other factors that favored earlier abrupt cessation of breast feeding among the mothers studied. These findings however did not emerge in the current study. This means that facilitating factors could be plenty and countless, depending on situations and environments or societies.

6.5 CHALLENGES ENCOUNTERED BY THE PARTICIPANTS AFTER IMPLEMENTING EARLY CESSATION OF BREASTFEEDING

The results revealed that participants faced challenges originating from themselves, from their babies as well as from the community in relation to early cessation. The challenges encountered were in three groups: physical, economic and psychosocial. The results also indicated that 70% of the participants (n=7) is the sample that was subjected to all kinds

of challenges while 10% (n=1) only faced physical challenge from the baby. The remaining 20% (n=2) did not face any challenge at all.

It was noted that the majority of the affected clients were psychologically challenged because it was their minds that were tormented.

Looking at the percentage that denied encountering any problem or challenge, there can be a number of explanations that can be given to that. It can be a coping measure to ensure survival of the individual (Ochberg, 1998). This may be so as some victims of problems or circumstances may deny the existence of such problems/challenges in their lives, so they tend to detach themselves from the experiences or any knowledge of it. Victims may not accept their exposure to any kind of physiological or psychological trauma by actually denying that they were once involved in those kinds of problems. They do this as a way of explaining away the traumatic incidences of their lives. They often do not want to remember the traumatic experiences and forgetting their occurrence is one of the ways to get rid of the memory or erase it. They will try their best to rationalize that nothing was wrong and that is why they were able to go through it in the first place. Possibly this is what these participants were trying to do. However there is also a possibility that what they reported could be their true experiences.

Despite the HIV/AIDS awareness messages in the country and all messages concerning stigma and discrimination avoidance, study findings revealed that people are still subjected to that kind of harsh treatment by others.

All participants that faced challenges were being asked why their babies had stopped breastfeeding so early in their life. These questions were coming from neighbours, relatives, in-laws and other people who just visited them and had observed that these children were being bottle fed instead of being breast fed. This disturbed the mothers' peace psychologically as they had always to be aware that they will have to be asked such questions and at the same time make up answers for questions. These kinds of challenges

could lead to some mothers contradicting themselves in the answers they give to people, ending up painfully revealing their HIV status.

The study finding of being questioned concurred with what Tawalat (2002) found that mothers who could not breastfeed their children were afraid that someone would ask why they were not breastfeeding. The act of not breastfeeding brings speculations in the society especially the people that are close to the mothers. This indicates that people have negative attitudes towards mothers who do not breastfeed their babies, which is why they are so inquisitive. Culturally and socially a lactating woman is expected to pacify her child with a breast when the child cries and it raises people's suspicions when the mother gives formula feed instead of breast milk especially when the baby is as young as less than one year. Tawalat (2002) further stated that HIV positive women in his study were able to respond positively to potentially discriminative attitudes such as questions about their mode of feeding.

Stigma, discrimination, social isolation, being laughed at, backbiting from fellow women were cited as the biggest psychological problems faced secondary to early cessation. This was so because it is becoming common knowledge that women who do not breast feed or stop breastfeeding early may be HIV infected, in most cases, these days.

The statement above agrees with Eneroth (2004), who states that as the community becomes aware of the details of how the PMTCT program works, the risk of mothers unwillingly disclosing their status by following the recommendations of the program will increase.

The findings above are also in line with a report from the symposium on breastfeeding and HIV and AIDS held in Washington, DC, USA, July 2, 2005, which states that in a breastfeeding culture, a mother who feeds her baby on substitutes may immediately and continually be identified as HIV infected. It further states that Non-breastfeeding therefore becomes a known cause of stigma.

Fear of stigmatization could prevent people from going for testing. This results in mixed feeding, which is the worst combination for virus transmission than exclusive breastfeeding. Moreover mothers who do not know their HIV status may choose to give replacement or mixed feeding due to the fear of transmission in case they are HIV positive.

The problems listed above can be disturbing and psychologically torturing to the women who make the important decisions in order to prevent MTCT of HIV. This can also be a hindrance and biggest stumbling block to early cessation of breastfeeding for some mothers in the communities who observe what these mothers go through. The psychological problems can be so stressful and cause emotional outbursts in the affected mothers which can eventually lead to serious conditions like depression, abdominal ulcers. Some of the mothers in the current study were also discriminated against by the people to whom they disclosed their status especially friends. This worried them a lot as they felt betrayed and socially unaccepted. Some of the discrimination was even extended to the mothers' family members like children. Ingram (1999) stated that HIV positive mothers valued being perceived as normal but the normality was lost for them because of stigma attached to HIV. Though some people may accept the HIV positive mothers and live together with them normally, the attitude of discrimination breaks the normalcy that was there before.

Findings on stigma and discrimination agree with findings from Piwoz and Preble (2000) where it was reported that women who do not breastfeed are at risk of stigmatization.

Problems of crying babies, sleepless nights, and in ability to participate in other activities due to tasks involved, were some of the common challenges that these mothers met in relation to the care of their babies. Additionally, there were also challenges like lack of alternative feeds for those babies that were selective and financial constraints.

The study also revealed that some of the mothers opted to stay at home instead of going out unnecessarily. This they did because of the involvement the going out was causing in

relation to baby feeds. Because of the absence from the social gatherings, they ended up being socially isolated and subjects for discussion in the community.

The problems of engorged breasts, babies falling sick or becoming weak after stopping to breastfeed are other challenges these women faced. The sickness problem is not unique to this group. It is known that replacement feeding comes with increased infant morbidity and mortality due to increased risk of gut infection through food and water handling and lack of protective immunity from breast milk.

The study findings above concur with Eneroth (2004) where women in her study's population often experienced difficulties with breasts and with their babies when stopping breastfeeding early and rapidly.

Findings on frequent infant illnesses following early cessation above, concur with findings from Creek (2006) where there was a reduction in the MTCT rate of HIV in formula fed babies but very high infant mortality rates (217/1000) in Haiti. Botswana reported 35,000 cases of diarrhea, resulting in 532 deaths within the first six months of implementation.

The findings also concur with Brouard (2007) who reported that further research has shown that infant powdered milk may contain low levels of salmonella or other contaminants which cause diarrhea out breaks in the infants.

The study revealed that the majority of participants also experienced psychological challenges originating from within themselves, in relation to early cessation of breastfeeding. Results showed that they were either feeling sorry or bad and other mothers had some kind of guilt feelings for subjecting their children to early cessation of breast feeding just because of their sero statuses.

Problems of emotional distress on both mothers and babies, engorgement of breasts, stigma and financial constraints following early cessation were cited by Coutoudis (2005) in her study on infant feeding dilemmas created by HIV. In the same study,

findings also showed that 10.7% (n=6) of the participants had no problems with early cessation. Both study findings from Coutsoydis (about problems experienced and no problems experienced) concur with the current study's findings.

Problems of babies getting sick so often as well as those of financial constraints, mothers feeling sorry, persistent questioning and stigma can lead to some mothers resuming breastfeeding again after cessation, thereby ending up with mixed feeding just because they failed to cope with pressure from all sides.

Some of the findings in this study agree with those of Kisiyake (2002) where the major problems encountered during cessation of breastfeeding were engorgement of breasts, financial constraints, domestic violence and pressure from spouses, babies losing weight, falling sick and crying a lot.

Similarly, Bakaki (2002) found that both mothers and health workers identified the major problems encountered by the mothers during early cessation of breastfeeding as engorgement of breasts, stress due to sleepless nights, domestic violence. Other problems were pressure from in-laws and neighbours, financial constraints and intimidation from uninformed health workers, who insisted on breastfeeding. Babies losing weight, falling sick and crying a lot were also amongst the problems cited. As seen from above findings, some agree with the current study's findings but other problems are not available. This may be so possibly because of the limited sample that was used in the study.

This study's findings however do not conform to findings by Njunga (2008) which states that none of his study participants managed to adhere to the WHO prescriptions of infant feeding for HIV positive mothers, where early cessation was amongst the options to be followed. The 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 other's child rearing activities. Adherence was further challenged by customary use of traditional medicines and prolonged breastfeeding practices.

This just shows that the problems that such mothers face are not limited to the ones revealed by this study only or from those other studies that have been referred to in here. It is an indication that there are multiple problems, some of which have not yet been uncovered.

In most cultures, the blame of HIV transmission is put on the mother, when usually it is the case of 'father to mother to child transmission.' The whole responsibility is put on the mother. The man is totally left out. Often the woman is seen as the only one responsible for transmitting HIV. These women are blamed instead of being seen as the victims of circumstances or of a larger social problem.

Like the study findings above, Chirwa (2006) also found that the challenges faced by HIV positive mothers in relation to infant feeding options (early cessation being one of them) were lack of food resources to give to the baby, stigma and discrimination, and lack of support from the communities.

According to HBM, it says people will comply with treatment if, they believe that the consequences of the disease would be serious if left untreated and that these outweigh any costs or drawbacks involved in following the treatment.

Similarly in this study, the modifying factors of knowledge of the disease, its effects and past experience of the disease effects if not prevented made these participants to persevere in all the difficult situations they went through. The decision to persevere depended on their perception that the benefits of early cessation after all outweighed all the challenges encountered. The benefits of having HIV negative children despite all the challenges faced was all that the mothers were looking forward to, so to them all challenges were beneath this benefit.

6.6 MEASURES TAKEN TO DEAL WITH AND OVERCOME THE CHALLENGES

Findings revealed that the mothers visited the same health facility where they sought help from health workers in relation to their or their babies' physiological problems. It was also established that they were being assisted accordingly and that whenever there was need for referral, they were being referred to the Central hospital within the same district. The mothers felt that that assisted a lot in dealing with the physical challenges they faced. The choice made by the mothers of visiting the clinic early, helped to detect symptoms that could have led to malnutrition in their babies. These children were referred in good time and treated accordingly, thereby preventing complications that would have set in because of late care seeking behaviors. This means that the participants very well understood the counseling and education part that emphasized on need for them to come back to the clinic when they felt sick or to bring back their children when sick too.

Similarly Bakaki (2002) in his study of lessons and experiences with early abrupt cessation of breastfeeding among HIV infected women in Kampala, Uganda, found that in relation to the physiological problems faced, majority of the mothers came to the clinic where they got help in form of treatment for the children and themselves. They were also counseled, given food supplements and children with severe malnutrition were referred to a nutrition rehabilitation unit. Mothers were also taught through demonstration how to use locally available foods rich in proteins like beans, groundnuts, eggs and small fish.

Results also revealed that the clients lied to different people that were inquisitive on why the babies had been weaned at a very tender age. They had to lie and give all kinds of answers to these people, some of whom were persistent. They did this without actually disclosing their status or real reason. The lying or giving different explanations at least helped to put off the questioners. It was up to the questioners to take or leave the explanations. That did not matter to the clients, as long as they did their part of explaining.

Similarly, Tawalat et al (2002) agreed that the mode of feeding except breastfeeding indicated that the mothers were working outside the home. This indicated that the mothers masked their HIV positive status to others by lying. This was good on the other hand as this was done with the aim of preventing stigma and discrimination from friends and family members.

The findings also concur with what Bakaki (2002) found that on the problem of relatives and neighbours, the majority of mothers lied that they were sick, babies refused breast milk or had problems with their breasts and that health workers had advised them not to go on breastfeeding.

All the findings are mainly pointing out to different lies that these HIV positive mothers go on telling people in order to safe guard the confidentiality of their sero statuses, as a way of preventing stigma and discrimination.

In a related study by the Allan Cott Mader Institute (2000) results revealed that women on formula feeding often experienced pressure from their families about maintaining confidentiality of their HIV status. This shows that these women in the current study were doing well by protecting their confidentiality.

Findings revealed that the majority of participants dealt with their psychological challenges by ignoring the situations and pretending as if nothing happened. This was being done deliberately as part of diversion therapy, where one preoccupies him/herself with something else in order to take away his/her mind from an unpleasant situation such as headache or anything else. The mothers reported that deep down their hearts, they knew that the decisions they had made benefited them and were more fruitful than whatever people talked about.

It was good that these participants devised ignoring the situation as a way of dealing with their challenges, which assisted them greatly in dealing with that challenge for good. It was good for their health as well because if they had let the situations get to them

emotionally, they could have ended up with complications from stress. Obviously, the stress was there but it did not build up as much as one would expect in a situation like that because of the ways they had devised for themselves.

The findings are in line with some of the explanations from the HBM. In this case, because the participants perceived that the benefits of their actions outweighed the barriers, they managed to go ahead with their implemented decision and coped well.

The findings above are in contrary with those from Leshabari (2006) and Omari (2003) where by mothers resumed breastfeeding and eventually ended up in mixed feeding because they could not cope with the pressure that was coming from family members, spouses, communities and even some health workers. In order to make peace with them and prevent stigma or in an attempt to keep their HIV status confidential, they simply yielded in, and resumed breastfeeding. These women were more concerned with their reputation as good mothers than protecting their children.

Hence there is need for health workers/counselors to ensure that these HIV positive mothers understand very well what they are getting into when they are choosing these infant feeding options. Health workers have to ensure and be very confident that clients have been well informed before letting them implement the option when they are not ready.

Results revealed that some participants felt that disclosing their sero status and decision to practice early cessation of breastfeeding to the key people in their lives assisted them a lot in dealing with the challenges they faced. The key people in these clients' lives included spouses, parents, and very close relatives like sisters or in-laws and for some, very close friends. They felt that this assisted because these key people supported and encouraged them in many ways including financially, materially, and morally. They felt strengthened during the trying times and managed to pass through the hard times because of that. Disclosure of sero status to significant others like spouses assists very much if the spouses are understanding, accepting and supportive. Firstly, the mother's burden is

relieved, knowing that she has at least shared the problem with a significant other and secondly knowing that from there onwards it will be the two of them assisting and supporting each other in all that will be coming their way like decision on infant feeding, sourcing of replacement feeds, seeking counsel, strengthening each other in times of troubles and the like. It is a good thing that these participants shared their secrets with people they trusted and who were understanding and supportive too. It assisted to deal with the challenges they faced.

According to HBM, the participants perceived that the benefits of disclosure were going to outweigh all barriers, so they went ahead and took an action of disclosing their status. Benefits were all sorts of support and encouragement they got from the significant others while the risks or barriers would have been negative reactions from the significant others leading to stigma, discrimination, divorce, violence secondary to the fact of having one's status known. In this case it benefited them indeed.

The findings are in line with those of Bakaki (2002) where it was reported that timely disclosure of HIV status to the spouses and relatives generated support from these people for HIV infected mothers who stopped breastfeeding early. His findings go on to a part that does not conform to the current study's findings, where he further reports that for mothers who disclosed because they were about to or had stopped breastfeeding, it was a worse outcome than those who disclosed soon after they had the test in Antenatal clinics. Most of the problems these mothers faced were domestic violence in form of quarrels, withholding of food and household property, desertion or physical harm to the mothers ending up into separations. However, this last part of Bakaki's findings correlates with Njunga's (2008) findings where disclosure of HIV results by women to their spouses led to many divorces and many clients ended up with broken marriages. People in the community were even referring to the PMTCT program as a 'divorce program.' These results however do not agree with those of the current study.

According to Malawi Human Rights report (2006) many divorces occur as a result of HIV positive results, especially if it is a woman who is positive. It further reports that

most of the times, the situation is worsened when a man discovers by himself that his spouse is HIV positive. This mostly leads to gender violence.

The findings above correlate with those of Bakaki, but they are in contrary with those of the current study. This may be so because in the study, the participants disclosed the results timely.

The findings further revealed that for those mothers that were found faced with financial constraints and lack of alternative feed to give to the baby, they dealt with the problem through personal efforts. They managed to source the food that their babies required and that they were also being assisted with baby feeds by a research institution at the health facility. This assisted a lot because the challenge of food shortage was combated by the provisions of extra feed. It was encouraging that these participants had to indulge in activities like peace work ('ganyu') in order to find money to buy baby food. This shows that the mothers were really concerned for their babies and only had babies' best interests at heart in all they were doing. It is again encouraging to note that there are such research institutions that are interested in the wellbeing of children up to the point of giving free food aid to some of these babies that were stopped from breastfeeding at such an early age of six months.

Results also revealed that in the course of dealing with the challenges encountered, there were facilitating as well as hindering factors that emerged in the process. Support and encouragement from husbands, friends and relatives and continuous counseling sessions by the health workers were some of the factors that facilitated the participants' efforts in dealing with the challenges they faced. Additional factors were care rendered to them at the clinic when sick, being courageous and humble in different situations, ignoring situations and giving clear explanations. Findings revealed the importance of disclosure of status to a certain extent since these participants were able to be supported, hence carried through the difficult times. They also show how important continuous counseling sessions are, as well as the simple care that can be given to clients when they present to the health institutions with illnesses. Reception on its own is enough for a client to rate

the kind of care received at a particular institution. Being courageous in situations and giving people clear explanations makes the people that are listening to understand easily and even believe whatever they are being told. Being humble and ignoring certain situations also sometimes makes things work for you because people stop nagging you if they see that you are humble or you are acting as if you are not concerned.

Study findings also agree with findings from Namukose, Samalie and Bananuka (2003) on integrated infant and young child feeding counseling. They reported that in order to ensure effective and adequate support for HIV infected mothers in relation to early cessation and infant feeding; there is need for on-going counseling, education and training. This means that counseling and education or training should not be a one time thing but rather a continuous process. Counselors/health workers need to leave their doors open at all times. They need to be receptive so that distressed clients can come to them at any time and go back to their homes strengthened again. The study findings on counselors (health workers) also concur with Bakaki's (2002) study findings where both mothers and health workers recognized continuous counseling and health education as being the biggest enabler in the whole process of early cessation and in all processes that followed afterwards.

Baby's frequent illnesses, increased rumors despite explanations given out, were the hindering factors in the process of dealing with challenges. Increased stigma and unbearable talks were some of the difficulties encountered in the process of dealing with the challenges. However, these prohibiting factors and difficulties were only experienced by 28% (n=2) out of all the mothers who faced challenges (n=7). These were things that were pulling these participants down despite their efforts to deal and overcome the problems that were there in the first place. These participants were psychologically tortured because of the way they were treated. Psychological wellbeing of an HIV infected mother is of great importance, as increased stress can easily lead to poor health and potential progression to AIDS. It was good to learn that at the time of this study, these women had fully recovered and were free to talk about their life experiences

without an element of emotion showing that they were still affected. They were able to joke and even laugh about it, knowing that it was something of the past.

These mothers coped with the situation while sticking to their decisions and actions. It could have been an easy thing for these clients to resume breastfeeding as reported in study findings by Bacquet, Shankar (2005) and Boskens (2007) where mothers who chose exclusive breastfeeding and early cessation had difficulty complying, especially with pressure from partners, relatives and the community to follow traditional practices. Those who had followed early cessation ended up resuming breastfeeding again thereby practicing mixed feeding which even increased the risk of postnatal transmission of HIV to their children. The findings above agree with research findings from Magoni and Giuliano (2005) who argued that it is impossible for women to adhere to exclusive breastfeeding and early breastfeeding cessation because both are strange concepts in Africa. Given a statement like this, it is less surprising to note that early abrupt cessation is still proving to be difficult amongst some mothers in certain societies.

The findings from the current study just emphasize on the already discussed concepts from the Health Belief Model. This is in relation to perceived benefits outweighing all risks and barriers.

Study also revealed findings on what constraints other women in similar position as the clients in the communities out there faced or going through. Only 60% of the participants contributed to the findings as the other 40% said they did not have stories to share concerning the matter. From the results, it transpired that most of the constraints that those other women go through are the same as those already discussed in this study except for a few. The constraints mentioned were lack of proper feeds/food resources to give to the babies when they stop breastfeeding, poor health of the children resulting from frequent illnesses such as diarrhea. These lead to malnutrition, stigma and discrimination. Some mothers resume breastfeeding following failure to cope and poverty. Death of such children mostly resulting from malnutrition is also another challenge. Other women groups thinking early cessation is a laughing matter and

association of early cessation and being HIV infected were also among the constraints discussed.

The above are the findings on the constraints other mothers faced or are going through. Most of the problems are of psychological and physiological nature. Few are of social nature. It is not known how those mothers coped up with such kind of pressure as that information was not elicited. From the current study's findings, it can confidently be believed that possibly some of the strategies used are the same as the ones already discussed.

Results from the above findings on what other mothers go through as well, agree with study findings from Bakaki (2002) where poverty, children's sicknesses/malnutrition, lack of alternative feeds were identified as some of the problems faced in relation to early cessation. These results also correlate with findings from UNC project's BAN study (2008) where they wanted to establish perceptions and attitudes of health workers towards early breastfeeding cessation. Health workers with counseling experience believed that HIV infected mothers should breastfed exclusively, rather than infant formula feed, citing poverty as the primary reason and malnutrition as the second reason. high levels of malnutrition secondary to early weaning gave concerns to all the health workers.

Results revealed a 100% positive feedback from participants when they were asked if they would go for early cessation again as an infant feeding option if they were given a second chance. The results revealed that all clients responded positively, citing different reasons for their choosing it again. However all reasons put together were given in relation to the benefit they saw and experienced at the end of the whole process. The benefit was that their children were prevented from the deadly HIV virus.

This knowledge made the participants feel the importance of their decision up to the point of choosing the option again. Because of the outcome, it is easy for these participants to counsel others in relation to PMTCT or early cessation. No wonder 30% (n=3) of the

study participants ended up being employed as peer counselors for HIV pregnant and lactating mothers in one of the projects dealing with HIV and AIDS issues. Mothers who are amateurs would be ready to listen and take advice on early cessation from a fellow mother who went through the same experience before and survived (came out with a positive outcome) rather than from one who just uses book or classroom knowledge.

According to HBM, the participants attained their perceived benefits which outweighed all risks, costs and barriers and the benefits were having HIV free children. According to the same model, these clients would be in a better position to give advice to fellow HIV positive women in relation to early cessation through personal experiences (under cues to action). In relation to the same HBM, these clients would be taken as role models by the very same people in their communities if they get to know the HIV status of their children because those other people would be basing their decision on previous experience of the participants (under cues to action still). Clients themselves would be in a better position to make that decision again and practice early cessation again should they find themselves pregnant again, just because they went through that process (previous personal experience) and saw the benefit.

The findings presented above are in line with findings from Karlsson (1997) whose data showed that out of 139 children born to HIV infected mothers, and known to be HIV negative at six months, 131 who were stopped from breastfeeding early remained negative while as only 8 got infected through late breastfeeding.

Similarly Leroy (2003), Fawtz (2002), Coustoudis (2001) and Illif et al (2005) had similar findings from other African countries supporting early cessation of breastfeeding as an effective infant feeding option for PMTCT of HIV.

There are other study findings though which differ with the current findings and question the effectiveness of early cessation of breastfeeding. A study by Simonon, Lepage and Karita et al (1994) shows that the risk of late postnatal transmission after six months of age was only 12% among HIV exposed children. Having accounted for the effect of

early breastfeeding cessation on the rate of HIV infection, the study findings suggest that the largest population 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.

Another study by Ekpini et al (1997) found that 28% of children born to HIV sero positive mothers were infected by six months and in the same findings, they came up with reasons for early transmission of the virus such as mothers increased viral load in the breast, mothers reduced CD4 count in the blood leading to AIDS, breast conditions of the mother like cracked nipples or mastitis. Other factors were mothers newly acquired HIV infection while already breastfeeding, baby's gastrointestinal conditions like oral rash, gastro enteritis and early mixed feeding before the recommended age of weaning, which is six months.

Study findings to back up the findings from Ekpini (1997) on the reasons for early transmission of HIV are those from Semba et al (1999) where median breast milk's HIV viral load was 700 copies/ml among women who had HIV infected infants and was not detected in those with uninfected babies. It was also found that there were increased cases of mastitis in HIV infected women (16.4%) and these were associated with increased MTCT. Therefore it was concluded that mastitis and breast milk HIV load may increase the risk of MTCT through breastfeeding.

These could be most of the reasons for early transmissions that could have been factors that were missed out or ignored in the previous studies like that of Simonon et al (1994). Otherwise current data from many studies and different study sites support that PMTCT services such as early cessation are effective, despite reported diarrheal diseases and deaths from other sites, especially those from Africa.

6.7 PARTICIPANTS' SUGGESTIONS

Study findings also revealed suggestions from participants on how best they want the PMTCT services, such as early cessation improved.

It was interesting to go through this with the participants, discovering what they had to share for the promotion of the services.

The findings revealed that the majority of participants had things to share with the government while a few had a word or two to share with fellow women or families. Participants suggested that government and other organizations continue to support the PMTCT program and services through doing the following:

- Providing food aid to those children that have stopped breastfeeding from the age of 6 months up to 2 years and that the food aid be extended to their mothers as well in order to ensure good nutrition for both mothers and children.
- Providing all HIV positive pregnant or postnatal mothers with an extra MK5, 000 per month, whether employed or not up to 2 years of their children's age in order to ensure that these are provided for nutritionally.
- Sourcing drugs that could be given to mothers or children while breastfeeding so that breastfeeding can be extended and HIV still prevented; this will help those families that are poor and cannot afford replacement feeds.
- Declare a rule or make it a policy that all children born from HIV infected mothers should stop breastfeeding at six months because people always stick to laws, no matter what.
- Enlightening the community on the aid they are giving and why and at the same time sort out the problems of conflicting messages that are there on the media, so as to avoid confusing people.

It was encouraging to note that these participants had these kinds of dreams in order to ensure that PMTCT services change or improve for the better. Even though they had already passed through the difficult times themselves, they did not want others to pass through the same. They were ready to pave a very smooth way for the mothers coming after them, so that they don't have to experience what they experienced. It shows that these participants were selfless and very thoughtful of others, which is good and encouraging. According to many studies, replacement feeding is expensive and not many mothers from resource constrained countries can afford on their own.

The study also revealed that a few participants suggested that those mothers or families, who cannot cope with the demands of early cessation, should stop bearing children instead of practicing mixed feeding when they have full knowledge of the consequences. The participants believed or felt that the best that can be done for an HIV exposed child is to stop breastfeeding early and be able to follow advice from health workers.

These participants had these to say with hope that if it is only HIV free parents giving birth to children, then all children born in the nation will be HIV free. But under the circumstances that HIV infected parents too want to have children, then it is better for them to follow the health guidelines because by doing that then an assurance would be there that those children will be HIV free as well, thereby ensuring an HIV free generation of children. These participants were against the idea of subjecting more children to HIV and AIDS torture that is why they said if the couples cannot cope, then they should refrain.

This suggestion also from the few participants was an eye opener because it shows that people can be imaginative up to the point of thinking how they can ensure an HIV free generation.

Some of the findings in this study relate to those of Bakaki (2002) where both the mothers and health workers in his study recommended that through Ministry of Health,

government should be fully involved for the succession of programs like early cessation, since they believe that government's political will is very vital. They also recommended that the mass media should give clear messages/same information as those given by knowledgeable health workers, so as to ensure that the language is the same at the end of the day in order to avoid confusing people with different information. This shows that the participants had the best interests of others at heart.

Results also revealed that some participants (n=2) had something to contribute at the end of the interview. One of the comments for contribution was on the possibility that other HIV positive women may not want to stop breastfeeding their infants at an early age because they are afraid of questions that people (especially women) ask about. The other was just interested in knowing the plight of HIV positive people in relation to continued government's support.

This shows that the participants know or suspect that there are still a lot of people out there who would like to implement early cessation but they are failing because of fear, hence the need for health workers to intensify community awareness campaigns. It also shows that the participants lack an assurance on government's continued support or assistance to them like in form of ARVs and many more.

All questions asked by clients were answered accordingly, whereby rumors were dispelled and explanations made in clear terms for participants to understand. At the end of it all, they indeed understood.

6.8 SUMMARY

The study revealed that the HIV positive mothers' perceptions towards early cessation of breastfeeding shows why there were concerns and fears at first and how these were relieved. From the results, facilitating factors for early cessation were highlighted and it was noted that counseling and education from health workers played a very big role. Looking at the study findings, it is evident that there are lots of challenges that women who make such decisions of implementing early cessation face in relation to their decisions. In this study, stigma and discrimination were just part and parcel of the challenges. On their own, as well as with help from significant others, these mothers were to a certain extent able to deal with and overcome these challenges. According to the suggestions from study participants there is need for government's total involvement in the activities of the program if it is to succeed.

CHAPTER SEVEN

7.0 IMPLICATIONS AND RECOMMENDATIONS

This chapter presents a discussion on strengths and limitations to the study as well as the implications of the study to the Nursing disciplines and the government. Recommendations, areas for further research and conclusion follow later.

7.1 STRENGTH

The study findings revealed quite a range of experiences of HIV positive mothers who stop breastfeeding at 6 months. Even though this was done on a small sample, it still uncovered some of the experiences that these women go through and they could be experiences that most mothers out there are going through. It was an eye opener. The target population was an appropriate one because these were the people that went through the actual experiences.

7.2 LIMITATIONS TO THE STUDY

- Time for the research was limited as it was being conducted in the academic setting, together with other courses and amidst preparations for final examinations. All this demanded most of the researcher's time and attention.
- The results of this study cannot be published because this was just part of the learning process, although the experiences are real.
- This was a qualitative study, which required a small sample size (10 participants in this case). Therefore generalization of the findings to the entire population of HIV positive postnatal mothers is not possible.

7.3 IMPLICATIONS OF THE STUDY

The findings of the study have implications to nursing practice, nursing management, nursing research, nursing education and the government as a whole.

7.3.1 NURSING PRACTICE

Undiagnosed HIV infection poses a threat to the new born via breastfeeding. Diagnosed HIV infection coupled with mixed feeding is even a much bigger risk in mother to child transmission of HIV. It is the responsibility of a nurse/midwife/counselor to teach, counsel and refer such women for proper management. From the study results, it is evident that nurse counselors have a very big role to play in early cessation as a PMTCT strategy. They need to be knowledgeable and well conversant with the protocols so that they should be able to give appropriate information to the women whenever necessary. Hence the need for them to be receptive as well all times.

7.3.2 NURSING MANAGEMENT

There is need for nurse managers as policy makers and enforcers to ensure that their institutions have well stipulated protocols or policies concerning early cessation which can easily be followed and understood. At the same time, in their position, they have to ensure that these are being implemented as required.

There is also need for nurse managers to ensure that there is an allocation of adequate resources (both human and material) in order to facilitate the provision of such services. They also need to properly and adequately supervise the activities/services in order to ensure that quality care is being provided in those terms at the same time evaluate how the services are. There is therefore need to set standards against which quality care in relation to early cessation can be measured.

7.3.3 NURSING EDUCATION

Since the concept of early cessation as a PMTCT strategy is still new in Malawi, it is possible that some of the nurse practitioners are still not prepared to counsel clients competently in relation to that. This is a challenge that nurse educators have to deal with. Early cessation and PMTCT as a whole needs to be incorporated in the HIV and AIDS curriculum and should be emphasized during training of student nurses as an important aspect of care especially if prevention of HIV transmission from mother to child is to be successful. When these nurses go to the clinical areas, they will be able to provide the necessary information and ensure that things are happening as expected. Nurse educators also should plan short term and regular courses on the MTCT, its prevention and feeding options like early cessation for those nurses already in practice in order to equip them with up to date knowledge pertaining to these issues. Nurse educators also have a challenge of ensuring that the community is well educated on these concepts so that they understand and are receptive as well.

7.3.4 NURSING RESEARCH

The findings of this study will increase the body of nursing knowledge and the gaps that have been identified will act as a basis for further research. Findings will also help in the development of specific messages, production and effective use of materials. There are a lot of changes taking place in relation to PMTCT strategies such as early cessation, hence the need for further research in the area in order to determine the most effective and current practice. Community health nurses should also be involved in evaluation of such PMTCT programs/activities in the communities and identify emerging issues in relation to the concepts so as to come up with appropriate ways of addressing those issues.

7.3.5 THE GOVERNMENT

A policy provides guidance to implementation of any proposed program. Similarly in Malawi as a nation, PMTCT of HIV program has policy statements, which provide guidance in carrying out the prevention of MTCT intervention measures. However, government should know that not all people will take in or accept any thing just because it is from a policy. Policy decision makers should not make assumptions that that will be the case. There is need for them to find out what those who will be affected think about the services to be provided. Policy makers should also pay more attention and focus on providing these poor HIV positive mothers with acceptable, feasible, sustainable, safe, accessible and affordable infant feeding alternatives.

Government through Ministry of Health and Population should ensure that the health discipline that is dealing with this issue of PMTCT, early cessation is furnished with all necessary things for the good running of the program and also supervise whenever necessary.

AREAS FOR FURTHER RESEARCH

These research findings have highlighted several findings which are themselves areas of further inquiry.

- The issue of male involvement in a PMTCT activity like early cessation is one area which requires a bigger qualitative research on how best such PMTCT programs can attract both men and women, thereby rallying the support of entire families and communities rather than just individual mothers.
- It will be important to do this same study on a larger scale to describe the experiences of these mothers from a bigger sample size in order to have a true reflection of what these mothers go through and to measure quantitatively, levels of adherence to the prescribed infant feeding option of early cessation of breastfeeding.

7.4 CONCLUSION

As regards to experiences of early cessation of breastfeeding by HIV positive mothers, findings show that there are lots of challenges that these women went through. From the discussion, most of these challenges were from the community. Health workers or counselors and significant others played a very big role in the success of this program for these mothers. It can therefore be concluded that there is a lot that health workers/counselors need to do to prepare such mothers for the task ahead of them. There is also much that is needed to be done in the community and for the community in order for these people in the community to understand and be supportive to these mothers and program. There is also still much that needs to be done for spouses and family members in order to incorporate them into such programs as well. The support of these people is also very crucial in this program.

7.5 RECOMMENDATIONS

This sub-section presents the recommendations of the investigator regarding appropriate courses of action to be undertaken to ensure that early cessation of breast-feeding is successfully implemented. These recommendations are directed to all the stakeholders.

- In promoting breast feeding for women who do not know their HIV status and preventing MTCT of HIV through breast feeding among infected women, all the researchers, health workers, politicians, government, the community, mass media and donor agencies should pass on the same message regarding early cessation of breast feeding to avoid contradictions.
- Rather than engaging only the individual mother and expecting that she would single handedly deal with societal pressure, PMTCT programs should engage community leaders as well as family members to build awareness on infant feeding. All the stake holders like the government, Ministry of Health, research organizations, politicians, the concerned general public and donor agencies should

come out and embark on a major sensitization and public awareness campaign on early cessation of breast feeding. This will make it a public issue and mothers will not have anything to worry about any more. Community awareness is very important because that is where most of the problems that these mothers face originate from and doing this will ensure that when the mother chooses a recommended infant feeding option, such as early cessation, she would be able to go back home to a community and family that will support her intentions.

- Men should be involved in the implementation of early cessation of breast-feeding right from the antenatal clinics. The antenatal clinics, labor wards and postnatal clinics should be designed to be men friendly right from physical structures to health workers. In order to ensure services that are welcoming to men, these 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 the men. PMTCT services should also consider allowing the men to walk in without waiting on a queue and should remove any decoration that is very feminine or welcoming to women only. Couple Voluntary Counseling and Testing in antenatal clinics should be advocated for. Family and marital counseling should become part of the follow up package for PMTCT in order to reduce domestic violence.
- Instead of just relying on traditional community health campaigns, PMTCT programs should also reach out to men where they socialize such as during football games. The use of social marketing approaches to deliver messages to men has yielded results in other districts in Malawi.
- In order for early cessation of breast feeding to succeed in PMTCT programs, a close follow up of mother-infant pairs for on going support in terms of counseling, growth monitoring, nutrition education, food supplementation and curative services are important elements.

- The psychological impacts of their HIV status, the fear of possibly infecting their babies, concerns regarding early cessation and fear of stigma and discrimination lying ahead of them, may result into growing maternal anxiety and strong feelings of insecurities in HIV positive breast feeding mothers. In this regard, these mothers need special motivation, confidence building and on going counseling, and most importantly home support and follow up. PMTCT nurses need resources and specialized training to provide this kind of support to HIV positive mothers. Most of the nurses in PMTCT sites are not trained in PMTCT and infant feeding. Usually there is only one trained nurse per site which does not match with the workload involved with PMTCT. There is urgent need to train nurses to improve quality services available to PMTCT enrollees.
- If PMTCT program is to be successful, then traditional birth attendants and all those who conduct deliveries illegally in the communities should be counseled intensively on this. This should be so because despite government's order and declaration that these groups stop conducting deliveries, a good number of women still go there for antenatal care and deliveries. Since TBAs do not have knowledge on PMTCT and do not have the resources for conducting such a program, then the end result will be that these women will be missed out and children born from them will not be protected from HIV, in case of an HIV infection in the mothers.
- HIV positive mothers should be encouraged to form support groups, where they could share ideas and encourage each other, like one that is available at Limbe health centre. Peer group counseling by mothers who have already gone through early abrupt cessation of breast feeding should be used to show other mothers examples and assure them that early cessation of breast feeding is really possible. The experienced mothers should act as role models to others who still doubt that an HIV positive woman can produce and raise an HIV negative baby.
- There is need to scale up PMTCT interventions so that more and more mothers could access the services.

CHAPTER EIGHT: TIMELINE FOR THE RESEARCH

ACTIVITY	FEB	MAR	APR	MAY	JUN	JULY	AUG	SEPT	OCT	NOV	DEC
Problem Identification											
Literature Review											
Proposal Development											
Obtaining Clearance											
Data Collection											
Data Analysis											
Report Writing											
Dissertation Submission											
Dissemination											

CHAPTER NINE: BUDGET

A. **STATIONERY**

<u>ITEM</u>	<u>QUANTITY</u>	<u>COST/ITEM</u> <u>K</u>	<u>TOTAL</u> <u>REQUIRED</u> <u>K</u>
Reams of paper	4	750	3,000
Ball pens	10	20	200
Lead pencil	4	25	100
Eraser	1	50	50
Hard cover	1	600	600
Plastic folders	3	250	750
A4 envelopes	5	100	500
Small envelopes	5	30	150
Sharpener	1	50	50
B.	TELEPHONE BILLS (10 minutes)	140	1,400
C.	TRANSPORT COSTS (4 trips)	3,200	12,800
D.	LUNCH MEALS AND REFRESHMENTS	800	2,400
E.	INCIDENTALS		6,000
F.	SECRETARIAL SERVICES (PROJECT COPIES)		
	Typing and printing proposal and dissertation		12,000
	Photocopying proposals and dissertations		10,000
	Binding proposals and dissertations		<u>1,500</u>
	SUB TOTAL		51,500
	15% CONTINGENCY		<u>7,725</u>
	GRAND TOTAL		<u>59,225</u>

9.1 JUSTIFICATION OF THE BUDGET

STATIONERY COST

Adequate stationery was needed to cater for drafts and writing of final documents for both the research proposal and dissertation. Some papers were used for writing the in-depth interview guides/questionnaires, clearance and application letters and printing of the final things.

Pens, pencils, rubber and hard covers were used when recording the responses of the participants. Envelopes and stamps were used for posting letters seeking permission from various institutions and organizations.

TELEPHONE BILLS

The researcher needed to make a few phone calls in relation to the research, e.g. to Blantyre DHO, booking for appointment regarding the research study, as well as to others. There were also times when she had to call the district health office to sort out issues of an approval certificate which had at first been issued without the office's stamp.

TRANSPORT COSTS

The researcher was based in Lilongwe, Kamuzu College of Nursing Campus the time the research was to be conducted and the study took place at Limbe in Blantyre. She had to travel twice to and from Blantyre that is to deliver letters seeking for permission and another time for data collection.

LUNCH MEALS AND REFRESHMENTS

During the data collection days, the researcher needed meals for her lunch and refreshments, since she spent more hours at the health facility till she interviewed the required number of participants.

INCIDENTALS

This money was meant to cover for unforeseen circumstances or eventualities in the process of research e.g. Incentives for the clients for their time. At one point, she had to fax a document to Blantyre DHO when they claimed that they had lost the first request letter from the researcher.

SECRETARIAL SERVICES

Some of the typing, photocopying and binding of the research proposal and dissertations needed to be paid for. The researcher produced five bound copies of completed proposals that were already submitted and needed to produce three copies of completed dissertations that would also need submission.

15% CONTINGENCY

Contingency is money meant to cover price augments as the prices keep changing everyday e.g. raise in transport and material costs. So this served as additional money wherever necessary and whenever needed.

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11.0: APPENDICES

APPENDIX 1: INTERVIEW GUIDE

EXPERIENCES OF HIV POSITIVE MOTHERS WHO STOP BREASTFEEDING AT SIX MONTHS

Name of Interviewer: _____

Participant's CODE Number: _____

Date of Interview: _____ Time started _____

Time finished _____

SECTION A: DEMOGRAPHIC DATA

1. Age in years: (a) 15-20
(b) 21-25
(c) 26-30
(d) Above 30

2. Marital status:
(a) Single
(b) Married
(c) Divorced
(d) On separation

3. (a) Number of children:
(i) 1
(ii) 2
(iii) 3
(iv) 4 and above

(b) Have you had any infant deaths, miscarriages/stillbirths? If yes, how many? _____

4. Tribe:
- (a) Tumbuka
 - (b) Chewa
 - (c) Tonga
 - (d) Ngoni
 - (e) Other (specify) _____
5. Which denomination do you belong to?
- (a) CCAP
 - (b) Catholic
 - (c) Islam
 - (d) Other (specify) _____
6. Respondent's occupation:
- (a) Businesswoman
 - (b) Farmer
 - (c) Other (specify) _____
7. Respondent's level of education:
- (a) None
 - (b) Primary
 - (c) Secondary
 - (d) Other (specify) _____
8. Spouse's occupation:
- (a) Businesswoman
 - (b) Farmer
 - (c) Other (specify) _____
9. Area of residence: _____
10. Ways of getting money: _____

SECTION B

11. Explain how you felt about early cessation of breastfeeding as a feeding option, when you first decided for it, before you actually practiced it. (How did she perceive it or look at it from a distant point of view).
12. Explain how you feel about early cessation of breastfeeding now that you actually practiced it. (How do you perceive it or look at it or how do you feel about your decision now from experience point of view).
13. Describe the factors that helped to facilitate your early cessation of breastfeeding. (How were you able to implement early cessation – I would like to hear the story of your experience so far).
14. Explain the problems or challenges that you encountered on your own (from within yourself or from your baby) after implementing your decision.
15. Describe the problems or challenges that you encountered in your community (with your spouse, immediate family, relatives, in-laws, neighbours, church members, etc.) in relation to your implemented decision.
16. Explain how you dealt with the challenges or problems you faced, in order to overcome them (what measures did you take or do to deal with and overcome the challenges).
17. Discuss the factors that facilitated your efforts in dealing with the challenges.
18. Discuss the factors that made it difficult for you to deal with the problems.
19.
 - (a) Explain the difficulties that you encountered in the process of dealing with the challenges.
If you were to make this decision again, would you choose the same feeding option for your baby, why?
 - (c) How are other women who also stopped breastfeeding at an early age treated in your community? (From what you heard from any source before or after you yourself joined the bandwagon).
20. What do you think or suggest should be done in order to improve this PMTCT program?

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

22. Do you have any questions for me? You are welcome to do so.

Thank you for your time.

APPENDIX 2 : CHICHEWA TRANSLATED INTERVIEW GUIDE

MAFUNSO AKAFUKUFUKU WA ZOMWE AMAYI AMENE ALI NDI KACHILOMBO KA HIV NDIPO AMASIYITSA ANA AWO KUYAMWA PA MIYEZI ISANU NDI UMODZI AMAKUMANA NAZO.

Dzina la wofunsa mafunso: _____

Nambala ya otenga mbali: _____

Tsiku lofunsidwa: _____ **Nthawi yoyambila:** _____

Nthawi yomalizila: _____

GAWO LOYAMBA

1. Zaka zanu:

- a) 15-20
- (b) 21-25
- (c) 26-30
- (d) Kuposera 30

2. Muli pa banja?

- (a) Eya
- (b) Ayi
- (c) Ngati ayi, fotokozani _____

3. (a) Muli ndi ana angati?

- (i) Mmodzi
- (ii) Awiri
- (iii) Atatu
- (iv) Kuposera anayi

(b) Kodi mudayamba mwakhalako ndi mtayo, munabelekapo ana ozizila, kapena ana omwalira akadali achichepere? Ngati yankho lili inde, kangati?

4. Ndinu a fuko lanji?

- (a) Tumbuka
- (b) Tonga
- (c) Chewa
- (d) Ngoni
- (e) Lina (fotokozani) _____

5. Kodi mumapemphera kumpingo wanji?

- (a) CCAP
- (b) Katolika
- (c) Chisilamu
- (d) Wina (fotokozani) _____

6. Kodi mumagwira ntchito yanji?

- (a) Ulimi
- (b) Bizinesi
- (c) Yamtundu wina (fotokozani) _____

7. Maphunziro munafika nawo pati?

- (a) Simunapite ku sukulu
- (b) Pulayimale
- (c) Sekondale
- (d) Mundutsa apa (fotokozani) _____

8. Amuna anu amagwira ntchito yanji?

- (a) Ulimi
- (b) Bizinesi
- (c) Yamtundu wina (fotokozani) _____

9. Mumakhala kuti _____

10. Njira zopezera ndalama _____

GAWO LACHIWIRI

11. Kodi malingaliro anu pa nkhani yosiyitsa msanga mwana kuyamwa ngati njira yomtetezera anali wotani kale, mwana wanu ali ndi miyezi yochepera isanu ndi umodzi? (munkati mukamva, mumadzimva kapena kuziwona bwanji)?
12. Nanga pano malingaliro anu pankhani imeneyi ndi wotani Pokhala inu mwadutsamo? (Mukumati mukayang'ana pambuyo nkuwona, mukuti nazo bwanji/mumamva bwanji panopa)?
13. Kodi ndi zinthu zANJI zimene zidakuthandizilani kuti malingaliro anu akufuna kusiyitsa mwana kuyamwa msanga atheke pa nthawi yake? Mudakwanilitsa bwanji kupanga chisankho chanu? Ndikufuna nditadziwa mmene zidakhalira.
14. Fotokozani mavuto amene munakumana nawo mwa inu nokha komanso kuchokera kwa mwana amene anasiyitsidwa kuyamwayo, chilinganizochi chitachitika.
15. Kodi ndi mavuto ANJI amene munakumana nawo kudera kwanu, chilinganizochi chitachitika (makamaka ndi amuna anu, apa banja panu, abale onse, azilamu anu, azipongozi, anthu oyandikana nawo manyumba, aku mpingo komanso amabungwe ena).
16. Fotokozani zimene munachita pofuna kuthana ndi mavuto amene munkakumana nawowa.
17. Ndi zinthu ziti zomwe zimapangitsa kuti kuthana ndi mavutowa kuyende bwino kapena mwansanga?
18. Nanga ndi zinthu ziti zimene zimalepheletsa kuyesetsa kwanu koti muthane ndi mavuto amenewa?
19.
 - (a) Nanga ndi zovuta zANJI zimene mumakumana nazo pamene mumathana ndi mavutowa?
 - (b) Mutakhala kuti mwapatsidwanso mwayi wina wopanga chisankho cha njira yimene mungatetezere mwana wanu ka chirombo, kodi mungasankhenso njira yimene mudasankhayi? Chifukwa chiyani?
 - (c) Kodi amayi ena amenenso adasiyitsa ana awo kuyamwa mwansanga chonchi amakuma ndi zotani kudera kwanuko (izi zitha kukhala nkhani zimene inu mudamvapo kuchokera kwa wina aliyense pa nthawi ina iliyonse).

20. Ndi chiyani chimene mukuwona kapena kuganiza kuti chingachitidwe ndi cholinga chofuna kupititsa mtsogolo ndondomeko yoteteza ana ku kachiroombo ka HIV?(kuti ndondomekoyi iyende bwino kwambiri kuposera panopa)
21. Pali china chake choonjezera chimene mukufuna kunena choti sindinachifunse pa mafunso ndakufunsani aja?
22. Muli ndi mafunso ena ali onse omwe mukufuna kundifunsa? Muli wolandiridwa kutero.

Zikomo chifukwa cha nthawi yanu.

APPENDIX 3 :- ENGLISH CONSENT FORM FOR THE PARTICIPANT

INVESTIGATOR

Wezi Longwe Mwenda
University of Malawi
Kamuzu College of Nursing
P/Bag 1, Lilongwe.
Tel: 08 88 139955
09 99210394

SUPERVISOR

Dr. B.N. Nyasulu
University of Malawi
Kamuzu College of Nursing
P/Bag1, Lilongwe
Tel: 08 88410484

To whom it may concern

INFORMED CONSENT

Good morning/Afternoon

My name is Wezi Mwenda. I am a mature entry year two student from Kamuzu College of Nursing, pursuing a degree in health services management. In partial fulfillment of the requirements of this degree, I am supposed to conduct a research study.

I am conducting a research study on "experiences of HIV positive mothers who stop breastfeeding at six months".

I would like to get your consent in order for you to participate in the study because you have met the criteria for inclusion into the study. The results of the project may assist in finding solutions to the problems that will be identified in the course of the discussion. You may not directly benefit from this participation but your contributions may assist a lot of mothers in future if recommendations are made based on the findings. You will be asked questions concerning the topic mentioned above and you are expected

to answer freely and truthfully in relation to the experiences that you went through after an abrupt cessation of breast feeding and commencing your baby on replacement feeds.

The interview is expected to take an average time of one hour, subject to change depending on situations encountered. You have got a right to freely take part or not to take part in this study. You also have got a right to withdraw your consent or discontinue your participation from the study at any point if you feel like doing so. Your decision to withdraw from this study will not affect you in any way. Participation in the study is on voluntary basis. You also have got a right to privacy and to ensure that, the interviews will take place in a private room where there will just be the two of us and they will be on a one to one basis.

Your responses will be written down. Be assured that the information collected will be confidential and will be used for purposes of research only. In order to ensure anonymity, no name will be indicated on the interview guide; instead code numbers will be used. Your name will not be disclosed to anyone else. Consent forms will be kept separate from the interview guides. The materials on which information will be collected will be put in a lockable cabinet always. The researcher and her supervisor are the only people who will have direct access to the information. However the information may be used in form of publications in future in order to find better ways of dealing with PMTCT programs, but there will be no names attached.

I would therefore be grateful if you can allow me to discuss with you some questions related to this topic.

For further information or questions, you can contact the investigator or the supervisor on the details provided above.

You are requested to sign on the space provided below to show that you have understood the information provided to you and are willing to participate in the study.

DECLARATION

Iagree to participate in the above study.

I understand that my participation is totally on voluntary basis and that I can withdraw at any time. My refusal to answer some questions will neither affect my well being nor care provided to me. I have understood the information about the study and am willing to take part.

Participant's signature-----Date-----

Investigator's Name-----Date-----

Investigator's Signature-----Date-----

THANKS A LOT FOR ACCEPTING TO PARTICIPATE IN THE STUDY.

APPENDIX 4:- CHICHEWA TRANSLATED CONSENT FORM

**NDONDOMEKO YA CHIVOMEREZO CHOTENGA NAWO MBALI
MUKAFUKUFUKU.**

WOFUFUZA

**Wezi Longwe Mwenda
University of Malawi
Kamuzu College of Nursing
P/Bag 1, Lilongwe.
Tel: 08 88 139955
09 99210394**

WOYANG'ANIRA

**Dr B.N.Nyasulu
University of Malawi
Kamuzu College of Nursing
P/Bag1, Lilongwe
Tel: 08 88410484**

KALATA YA CHILOLEZO

M'mawa/masana abwino

Ine ndine mayi Wezi Mwenda ndipo ndikuphunzira maphunziro a ukachenjede wa unamwino ndi uzamba ku sukulu ya ukachenjede ya anamwino ndi azamba yotchedwa Kamuzu College of Nursing ku Lilongwe, ndipo ndili m'chaka chomaliza. Monga mbali imodzi yokwaniritsila zoyeneleza za ukachenjedewu ndikuyenera kupanga kafukufuku. Cholinga cha kafukufukuyu ndi chofuna kudziwa zomwe amayi amene ali ndi kachilombo ka HIV ndipo anasiyitsa ana awo kuyamwa ndikuwayambitsa zakudya zina pa mwezi wa chisanu ndi chimodzi amakumana nazo. Kafukufukuyi achitikira pa chipatala chino cha Limbe.

Mukupemphedwa kuti mulowe ndikutenga nawo mbali mukafukufukuyu ngati mukhale wosangalatsidwa naye poti inu ndi mmodzi wa amayi amene mukukwanilitsa zoyenereza anthu kulowa nawo mukafukufukuyi.

Zotsatira za kafukufukuyu zikhoza kuzathandiza kupeza njira zimene boma ndi mabungwe ena okhuzidwa angatsatire kuti azathane ndi mavuto amene angapezeke kudzera mu zokambiranazi. Nkutheka kuti mwina inuyo simuwona phindu lenileni kuchokera mu kutenga gawo kwanu, koma dziwani kuti anthu ambiri, makamaka amayi atha kudzathandizika patsogolo pano chifukwa cha zotsatila za kafukufuku amene inu munatengako nawo mbali.

Palibe choopsya chinachilichonse kwaonse otenga nawo mbali mukafukufukuyu.

Mukalowa kafukufukuyi, mudzafunsidwa mafunso wokhudza zimene inu munazona kapena munadutsamo mutapanga chisankho chosiya kuyamwitsa msanga. Muyenera kuyankha mafunsowa momasuka komanso mwachilungamo mogwilizana ndi zimene inu munazona kapena zinakuchitikirani.

Zokambilanazi zikuyembekezeka kutenga nthawi yokwanira pafupi fupi ola limodzi. Nthawiyi ikhoza kutalikilapo kapena kufupikilapo pang'ono kutengera ndi zochitika zina mkati mwa zokambilanazi.

Muli ndi ufulu kusankha kulowa kapena kukana kulowa nawo mukafukufukuyi, komanso dziwani kuti ndi ufulu wanu kutuluka mukafukufuku nthawi ina iliyonse yimene mungafune kutero ndipo simudzalandira chilango chilichonse. Kulowa mukafukufuku ndikozipeleka nokha, sikokakamiza ayi.

Ndizakhala ndikulemba mayankho amene mukhale mukundipatsa pa zokambilanazi. Pofuna kusunga chinsinsi komanso kuti muthe kumasuka pa nthawi ya mafunsoyi tikhala tili awiri tokha mu chipinda chapaderachi komanso pa mapepala amafunso sipalembedwa dzina lanu. m'malo mwake tigwilitsa ntchito nambala basi. Dzina lanu silidzapatsidwa kwa munthu wina aliyense. Kalata ya chilolezo idzasungidwa mosiyana ndi mapepala a mayankho enawo ndipo zonsezi zizakhala zotsekeledwa mumakabati okhoma bwino nthawi zonse. Ndiyekhayo wopangitsa kafukufuku ndiwomuyang'anira wake amene akakhale ndi mwayi woona zonse zamukafukufukuyi. Ndikukutsimikidzilani kuti zokambilana zonse zizagwilitsidwa ntchito za kafukufuku zokha basi ndi cholinga choti

zotsatila zizathe kuthandizila mfundo zina za kayendetsedwe kabwino ka ndondomeko yokhuza m`mene amayi amene ali ndikachilombo angapewele kupatsila ana awo matendawa.

Mwaichi ndikhala wokondwa komanso wothokoza ngati mungandilole kuti ndikambilane nanu mafunso okhuza nkhaniyi.

Ngati muli ndi mafunso ena apadera mukhoza kufunsa kudzera pa ma adiresi ali pa chikalachi.

Mukupemphedwa kusaina m`musimu ngati ndamvetsetsa zonse takambilanazi ndipo mwapanga chisankho chotenga nawo mbali mu kafukufukuyi.

CHILOLEZO

Ine-----ndamvetsetsa zonse zokhuza kafukufukuyu zomwe zili m`chikalatachi ndipo ndikuvomera kutenga nawo mbali mu kafukufuku ameneyu. Ndapanga chisankho chimenechi mwa kufuna kwanga, popanda kundiumiliza.

Posaina wotenga mbali-----Tsiku-----

Dzina la wopangitsa kafukufuku-----Tsiku-----

---Posaina wopangitsa kafukufuku-----Tsiku-----

ZIKOMO KWAMBIRI POLORA KUTENGA NAWO MBALI MU KAFUKUFUKUYI

APPENDIX 5

University of Malawi
Kamuzu College of Nursing
Private Bag 1
LILONGWE.

12th May, 2009

The Chairperson
Research and Publications Committee
Kamuzu College of Nursing
Private Bag 1
LILONGWE.

Dear Sir/Madam,

**APPLICATION FOR PERMISSION TO CONDUCT A STUDY
AT LIMBE HEALTH CENTRE**

The purpose of my writing is to request your office to grant me clearance to undertake the study. I am a second year student at Kamuzu College of Nursing pursuing a Bachelor of Science Degree in Nursing (Post basic).

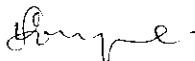
In partial fulfillment of the requirements of the degree program, I am required to carry out a research project. The title of my research is "Experiences of HIV positive mothers who stop breastfeeding at six months."

There are no risks associated with this study for the participants and all ethical considerations will be observed to ensure that there is no violation of the rights of the subjects throughout the study.

The proposal for the study is enclosed for your approval.

Your consideration will be greatly appreciated.

Yours sincerely,



Wezi Longwe Mwenda (Mrs.)

APPENDIX 6

FIRST APPROVAL CERTIFICATE FROM RPC BEFORE CORRECTIONS WERE MADE IN THE PROPOSAL.



University of Malawi
Kamuzu College of Nursing

RESEARCH AND PUBLICATIONS COMMITTEE

APPROVAL CERTIFICATE

TITLE: Experiences of HIV positive mothers who stop breast feeding at six months

INVESTIGATOR(S): Mwenda Wezi Hilda Mrs

YEAR OF STUDY: Mature year II Bsc

REVIEW DATE: 22nd / July, 2009

DECISION OF THE COMMITTEE: Approved with minor corrections

SIGNATURE:  DATE: 22/07/09
DEAN OF POSTGRADUATE STUDIES AND RESEARCH

CC: supervisor:

DECLARATION OF INVESTIGATOR(S)

I/We fully understand the conditions under which I am/we are authorized to carry out the above mentioned research and I/We guarantee to ensure compliance with these conditions. In case of any departure from the research procedure as approved, I/We will resubmit the proposal to the committee.

DATE: 29-07-09 SIGNATURE(S): 

APPENDIX 7

Second and last approval certificate from RPC after corrections were made in the proposal.



University of Malawi

KAMUZU COLLEGE OF NURSING

RESEARCH AND PUBLICATIONS COMMITTEE

APPROVAL CERTIFICATE

TITLE: **EXPERIENCES OF HIV POSITIVE MOTHERS WHO STOP BREAST FEEDING AT SIX MONTHS AT LIMBE CLINIC.**

INVESTIGATOR(S): MRS WEZI LONGWE MWENDA

YEAR OF STUDY: MATURE ENTRY: BSc IN NURSING

YEAR II

REVIEW DATE: 22ND July 2009

DECISION OF THE COMMITTEE: **APPROVED**

SIGNATURE: *[Signature]*

DATE: 23/11/09

DEAN OF POSTGRADUATE STUDIES AND RESEARCH

CC: supervisor: DR. B.N. NYASULU

DECLARATION OF INVESTIGATOR(S)

I/WE fully understand the conditions which I am/we authorized to carry out the above mentioned research and I/we guarantee to ensure compliance with these conditions. In case of any departure from the research procedure as approved, I/We will resubmit the proposal to the committee.

DATE: 23rd November 2009 SIGNATURE(S): *[Signature]*

APPENDIX 8

LETTER TO BLANTYRE DHO AND AN APPROVAL
NOTE FROM THE DHO.

University of Malawi
Kamuzu College of Nursing
Private Bag 1
LILONGWE.

12th May, 2009

The District Health Officer
Blantyre District Health Office
P.O. Box
BLANTYRE.

Dear Sir/Madam,

PERMISSION TO CONDUCT A STUDY AT LIMBE HEALTH CENTRE

I am a mature year two student pursuing a Bachelor of Science Degree in Health Services Management at Kamuzu College of Nursing. In partial fulfillment of this award, I am expected to conduct a research study, hence the request.

The aim of this letter is to seek your permission to interview some mothers at Limbe Health Centre in relation to a research topic entitled "Experiences of HIV positive mothers who stop breastfeeding at six months." The mothers who meet this criteria will be asked questions related to their experiences following the abrupt cessation of breast feeding.

I believe that the results of the study will help government, NGOs and other stakeholders to review their policies and guidelines in relation to PMTCT programmes. The results may act as a basis for further research investigations on the matter.

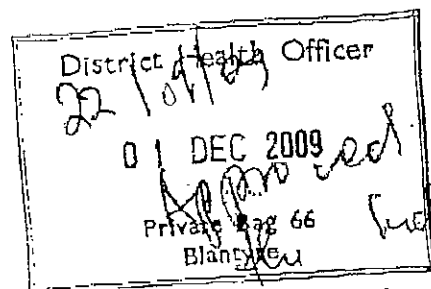
I propose to carry out the study between July and August, 2009.

Your consideration will be greatly appreciated.

Yours sincerely,

Wenzi Longwe Mwenda

Wenzi Longwe Mwenda (Mrs.)



see

exchange

Limbe file

file

Wenzi Longwe Mwenda: Experiences Of HIV Positive Mothers Who Stop Breastfeeding At Six Months.

APPENDIX 9

University of Malawi
Kamuzu College of Nursing
Private Bag 1
LILONGWE.

12th May, 2009

The in-Charge
Limbe Health Centre
P.O. Box
BLANTYRE.

Dear Sir/Madam,

PERMISSION TO CONDUCT A STUDY AT LIMBE HEALTH CENTRE

The aim of this letter is to seek your permission to interview some mothers who stopped breastfeeding at six months at your clinic. I am a mature year two student pursuing a Bachelor of Science Degree in Health Services Management at Kamuzu College of Nursing. In partial fulfillment of this award, I am expected to conduct a research study, hence the request.

My research topic is entitled "Experiences of HIV positive mothers who stop breastfeeding at six months." These mothers will be asked questions in relation to the subject above.

Looking forward to your favourable consideration.

Yours sincerely,



Wezi Longwe Mwenda (Mrs.)