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College of Medicine

Early Breastfeeding Cessation Challenges: A Cross Sectional Study in PMTCT Program in Lilongwe Urban

By

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Certificate of Approval

The thesis of Wezi Msungama has been approved the thesis Examination Committee.

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DECLARATION

I, Wezi Msungama, hereby declare that *Early Breastfeeding Cessation Challenges: A Cross Sectional Study in PMTCT Program in Lilongwe Urban,* is my own work, and has not been submitted for any degree or examination at the University of Malawi or any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete reference.

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Date 20th December 2007

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ABSTRACT

Background: Exclusive breastfeeding followed by early cessation significantly lowers the MTCT. However, this is a deviation from the normal infant feeding practice in Malawi.

Objectives: (1) to explore the experiences of HIV positive mothers with children aged seven months and above on early breastfeeding cessation. (2) to explore perceptions of key decision makers on infant feeding in the community on early breastfeeding cessation (3) to identify cultural barriers to early breast feeding cessation.

Methodology: Sixteen in depth interviews for HIV positive mothers in PMTCT program in Lilongwe urban; and four FGDs for key decision makers on infant feeding were conducted. Socio-demographic data was collected on all the participants. Nvivo was used to analyze qualitative data.

Results: The age range of mothers interviewed was 22 to 38 years. 75% were not working and depended on their spouses economically and 19% had no formal education. The following factors were found to be hindering mothers in the PMTC program to stop breastfeeding at six months: Low socio-economic and educational level, new concept of early breastfeeding cessation, food insecurity, fear of being found out to be HIV positive, stigma and lack of knowledge on PMTCT in the community.

Conclusion: Broader aspects need to be considered if early breastfeeding cessation is to be successful as an infant feeding option in PMTCT program in Malawi.

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LIST OF ABBREVIATIONS

AIDS	=	Acquired Immune Deficiency Syndrome
ANC	=	Antenatal Care
ARV	=	Antiretroviral
A/25	=	Area 25
BF	=	Breastfeeding
CAB	=	Community Advisory Board
CBO	=	Community Based Organization
CHGA	=	Commission on HIV/AIDS and Governance in Africa
CTA	=	Call To Action
COMREC	=	College of Medicine Research Ethics and Committee
DHS	=	Demographic and Health Survey
FIDETP	=	Forgarty Infectious Disease Epidemiology Training Program
FGD	=	Focus Group Discussions
HIV	=	Human Immune Deficiency Virus
IDI	=	In-depth interview
KW	=	Kawale
KWF	=	Kawale Female
KWM	=	Kawale Male
MOH	=	Ministry of Health
MTCT	=	Mother To Child Transmission

NAC	=	National AIDS Commission
NVP	=	Nevirapine
PMTCT	=	Prevention of Mother To Child Transmission
UNC	=	University of North Carolina
UNICEF	=	United Nation Children's Fund
VCT	=	Voluntary Counseling and Testing
WHO	=	World Health Organization
WFP	=	World Food Program

CHAPTER 1 BACKGROUND

1.1 HIV and Mother to Child Transmission

The HIV pandemic continues to threaten lives and is one of the most serious health problems in the world. Child survival, especially in Africa, has greatly been affected by this pandemic. In 2004 alone an estimate of 640,000 children acquired HIV and 51,000 children died of AIDS in Africa (UNICEF, WHO, 2004). Infants are predominantly infected through mother to child transmission (MTCT), which can occur during pregnancy, delivery or breastfeeding (UNAIDS/UNICEF/WHO, 1998). MTCT in Africa is severe due to high prevalence rates of HIV infection among women of reproductive age, large total population of women of reproductive age, high birth rates and lack of effective MTCT interventions (Preble and Piwoz, 2001)

In Malawi it is estimated that 1 to 2 percent of children aged between 0-14 years are infected with HIV. Approximately 90% of the infected children acquire the virus through MTCT. In absence of any intervention to prevent MTCT, an estimated 25 to 35 % of HIV infected untreated mothers will pass the virus to their infants (Piwoz E, Huffman SL, Lusk D et al, 2001). High prevalence of HIV in antenatal mothers in Malawi, estimated at 19.8% nationally (HIV Sentinel Surveillance report, 2003) is postulated to fuel the current pediatric HIV infection. In addition, the high fertility rate in Malawi, estimated at 6.0 (DHS, 2004) implies that a large number of infants

could become HIV-infected if current efforts at prevention of MTCT are not increased.

1.2 Breastfeeding and Mother to Child Transmission

Breastfeeding provides optimal nutrition for infants and it contains a lot of maternal antibodies essential for protection against many childhood infections. However, HIV is also present in breast milk in both free and intra cellular form. The amount of HIV in breast milk is influenced by maternal viral load, stage of HIV disease and any prevailing breast pathology. On average 15% of babies born to HIV infected mothers will become infected through sustained breastfeeding (Preble EA & Piwoz EG, 2001). Recent studies have shown that the risk of mother to child transmission through breast milk depends on a number of factors namely breastfeeding duration, pattern of breastfeeding the baby, breast health, maternal viral load, maternal nutrition and maternal nutrition status (Coutsoudis A, Pillary K, Kuhnn L, et al, 2001). WHO recommends that breastfeeding should be avoided in HIV positive mothers when replacement feeding is acceptable, feasible, affordable, sustainable and safe (UNICEF/WHO, 2004). In most developing countries breastfeeding is the normal, safest and culturally acceptable method of infant feeding. In areas where breastfeeding is the norm, HIV transmission through breastfeeding accounts for more than one third of all transmission (Ndauti R, Mbori-Ngocha D, Richardson B, et al, 2000). Breastfeeding offers protection against infection, malnutrition and premature death. Any deviation from breastfeeding may result in increased infant mortality and stigmatization. When breast milk substitutes are used, infants are five times more

likely to have bacterial infection than breastfed infants even when the hygiene is good. Where the hygiene is poor, artificially fed infants are 20 times more likely to die from diarrhea diseases than breastfed infants (SAFAIDS, 2004).

Furthermore, WHO recommendations emphasizes that breastfeeding should be supported and promoted in all populations irrespective of HIV infection rates; there should be improved access to HIV counseling and testing and that HIV positive women should be fully counseled about the benefits of breastfeeding, the risk of HIV transmission through breast milk and the risk and possible advantages associated with other methods of infant feeding (WHO, 2000). In Malawi the majority of women, whether infected or not, choose to breastfeed their infants for a variety of reasons (Health workers handbook, 2002).

1.3 Exclusive Breastfeeding and Early Breastfeeding Cessation

Promotion of exclusive breastfeeding has been central to improving child health and reduction of infant mortality rate. Exclusively breastfed babies have significantly lower rates of HIV transmission at six months and at 15 months compared to infants who are partially breastfed and receive other liquids or food in early infancy (Coutsoudis A, Pillary K, Kuhnn L, et al, 2001). Despite the known and proven benefits, the prevalence of exclusive breastfeeding in many parts of the world is low. In Sub Saharan Africa, only 33% of the children under the age of three months are exclusively breast-fed. There are many reasons for this including peer pressure,

medical advice and economical consideration (www.planintrenational.org). Yeo et al (2005) in a study in Cote d' Ivore also found that the majority of women regarded breastfeeding as the appropriate method of infant feeding, although the idea of exclusive breastfeeding was not well accepted.

In a study of infants born to HIV infected women in South Africa, it was found that HIV infection was detected at six months in identical proportion of exclusively breastfed infants (19%) and never breastfed infants (19%) and those who received mixed feeding had higher rates of infection (Coutsoudis A, Pillary K, Kuhnn L, et al, 2001).

An anthropological study conducted in Tanzania underscores additional dilemmas relating to implementing infant feeding options. Findings suggest HIV related stigma and fear of rejection are major factors influencing infant feeding behaviors. Women often breast feed despite their knowledge of the risk of HIV transmission. The cost of not breastfeeding and associated rejection of close kins and neighbors represent a greater burden (Leshabari SC, 2004).

Furthermore, in a study in Kenya to determine the correlates of prolonged breastfeeding (defined as breastfeeding beyond 7 months) among HIV infected women, those who chose to breastfeed were encouraged to exclusively breastfeed and stop rapidly at 6 months. Among 292 women who were followed for one year, 205

(69%) elected to breastfeed at enrollment. The median planned duration of breastfeeding was 3 to 6 months but the median observed duration was actually about 12 months. Only 27% of the breastfeeding mothers stopped at six months or less (Wairua WG, Wamalawa D, Mbori-Ngacha D, et al, 2004).

In Malawi, nearly all of women initiate breastfeeding soon after birth. Findings from the Malawi DHS (2004) indicates that the mean age for introducing solids is 4.3 months and the median age of breastfeeding is 23.2 months. Exclusively breastfeeding followed by early cessation at six months is a deviation from the normal practice, as such it is important to understand problems and challenges that the HIV positive mothers face.

1.4 Culture and Early Breastfeeding Cessation

Infant feeding practices are linked directly to mother's social, cultural and economical status (Titus, 2004). A number of selected studies that were presented at the 2004 World AIDS conference in Bangkok focused on cultural and community related infant feeding challenges faced by HIV positive mothers to their cultural and social back ground and their families. These studies identified several issues that affect early cessation of breastfeeding such as unwillingness to disclose HIV status to one's partner or other family member(s); pressure from mothers in-law to young mothers to breastfeed their children and introduce other food early; lack of community support for either exclusive breastfeeding or replacement feeding options (neither being

culturally unacceptable and both potentially seen as an indicator of HIV positive status); fear of discrimination, rejection and physical abuse by family and community members, should their status become known (XII World Aids Conference,2004).

A study in Kenya, which was aimed at determining the correlates of prolonged breastfeeding beyond seven months among HIV positive women, found that 73% continued to breastfeed beyond six months. Prolonged breastfeeding was associated with lower education, having had previous infant and unemployment. There was no correlation of duration of breastfeeding with marital status, maternal age, disclosure of status, social economic status and maternal CD4 count (Wariua WG, Wamalawa D, mbori-Ngacha D, et al, 2004). However, another study in Kenya found out that partner notification in VCT and couple counseling increased uptake of intervention to prevent mother to child transmission (Farghur C, Kiarie JN, Richardson BA, et al, 2004).

In Malawi a study was done to determine antenatal attendees knowledge and experience towards selected aspects of prevention of mother to child transmission of HIV (Tadesse E and Muula AS, 2004). The study found that antenatal mothers consider several factors before making decisions on HIV testing. The factors were similar with those found by Lindgren T, Rankin SH, Rankin WW, et al (2005) in a study looking at socio-cultural factors and barriers to prevention among Malawian women. These factors include women's roles, men's role, gender/power relation and

disempowerment. These results may also apply to postnatal mothers as they make decisions on infant feeding depending on their HIV status.

There are several studies that have been done in Malawi on acceptability of VCT among women attending antenatal clinics in Malawi, which have indicated high acceptability of VCT (National AIDS Research and best practice conference, April 2004). However, there has not been much research done on prevention of mother to child transmission postnatally let alone on early breastfeeding cessation in Malawi. The studies done in other countries cannot be applied to Malawi due to some cultural differences and differences in PMTCT policies. As such it is important to conduct this study and compare with the findings form other countries.

1.5 Justification of the Study

The current WHO recommendations are that HIV positive mothers should exclusively breastfeed their babies and stop at six months if breastfeeding substitutes are not feasible and safe. Women in PMTCT program are counseled on infant feeding options of which exclusive breastfeeding followed by early cessation is one of them. However it seems that a lot of women are having problems in stopping breastfeeding at the advocated age of six months. This study wants to find out from women the challenges that they face in early breastfeeding cessation. Data from Malawi DHS indicate that the median age for stopping breastfeeding in Malawi is 23.2 months.

The cultural system in Malawi like most of the African countries evolves around a kinship system with most decisions like stopping breastfeeding still being influenced strongly by the kinsmen and various decision makers outside the nuclear family. The study also intends to find out from key decision makers like men, elderly women, traditional birth attendants and local counselors what they think can be the challenges in early breastfeeding cessation. Once these are known, they will assist in modifying and strengthening the information, education and communication materials used in PMTCT programs. The findings will also help in informing policies that will target the community on PMTCT through breastfeeding.

CHAPTER 2 OBJECTIVES

2.1 Broad Objective

To determine the challenges of early breastfeeding cessation in HIV positive women attending PMTCT program with children aged seven months and above.

2.2 Specific Objectives

1. To explore the experiences of HIV positive women with children aged seven months and above on early breastfeeding cessation.
2. To explore perception of key decision makers on infant feeding issues in the community (i.e. women above 45 years, traditional birth attendants, counselors (anankungwi) and married men).
3. To identify cultural barriers to early breast feeding cessation among HIV-infected women.

CHAPTER 3 METHODOLOGY

3.1 Research Design

A cross sectional study was conducted using qualitative research methods to acquire in-depth information on challenges of early breastfeeding cessation. The main tools that were used were in-depth interviews and focus group discussions.

3.2 Setting

This study was conducted at two PMTCT sites in Lilongwe urban, namely Area 25 and Kawale Health Centers. There are four public health facilities that provide PMTCT services in Lilongwe urban and these are Bwaila Hospital, Area 25 Health Center, Area 18 Health Center and Kawale Health Center. These are well-established PMTCT sites and are run by University of North Carolina (UNC) Project, which is a research project, working in collaboration with Kamuzu Central Hospital and the Ministry of Health and Population. The two sites were chosen because they are at opposite ends of the PMTCT coverage area, have good follow up systems and well established support groups for HIV positive mothers. In addition the two sites provide 40% of the PMTCT service in Lilongwe. It is estimated that about 25,000 women receive PMTCT service from the four listed health facilities per annum.

3. 3Study Population

There were two study populations for this study. The first population was that of HIV positive women with children above seven months of age and in PMTCT program. These are the women who are expected to have stopped breastfeeding at six months of babies' age. The second study population was the key decision makers on infant feeding in the community and these are elderly women above forty-five years, traditional birth attendants, local counselors and married men, from the same community. Traditionally views from persons in the second population tend to have a major influence on the behavior, practices and attitude of persons in the first study population. Men are the decision makers in the home and are the breadwinners as such they have a lot of influence on what is happening in the family hence the need to know their beliefs on the suggested breastfeeding changes for HIV infected women.

3.4 Sampling

Purposive and convenient sampling methods were used to select HIV positive women with children above seven months of age and elderly women. In this study participants were chosen in such a way as to ensure that the sample covered a full range of possible characteristics of PMTCT attendants. Participants were selected as they came for their follow up visits and through HIV positive mothers in PMTCT program support groups that are held every month at each clinic. A total of sixteen in-depth interviews of HIV positive mothers with infants above seven months of age

were conducted. Eight in-depth interviews (IDI) were conducted at each study site. Breastfeeding women below 18 years were not be eligible since legally they are not allowed to provide consent in Malawi unless legally married for which it was difficult to verify.

The elderly women, traditional birth attendants, local counselors and men, who participated in the focus group discussions (FGD) were identified by the Community Advisory Board (CAB) members for UNC Project. The CAB members act as a link between UNC Project and the community and they live in the communities where participants come from. They purposively selected participants through house to house. A total of four FGD were conducted with key decision makers on infant feeding and these were elderly women above forty-five years, local counselors, traditional birth attendants and married men. Two of the focus group discussions comprised of elderly women above forty-five years, traditional birth attendants and local counselors, volunteers in CBOs. The other two were for married men only. In order to get rich data, the married men were also in two categories. The first one being of younger married men aged 22-45 and the other being elderly men aged 45 and above. Each FGD comprised of 8-10 participants. The number of 8-10 participants is sufficient to stimulate good but manageable discussions. Moderators for each FGD were of the same gender as participants.

3.5 Data Collection

Data for this study was collected through in-depth interviews for the first study population and focus group discussions for the second study population. A research team consisting of the principal investigator, 3 research assistants (2 females and 1 male) and one data entry clerk was assembled to conduct the study. Training on qualitative research was conducted for the research assistant

Question guides first developed in English (appendix 3 and 4 for in-depth interview and FGD respectively) and translated into Chichewa (appendix 5 and 6 for in-depth interview and FGD respectively) were pre-tested on PMTCT study staff and adjusted accordingly before being administered to study respondents. Most of the questions were open ended to capture as many diverse opinions as possible. Each in-depth interview lasted approximately 1 hour. A brief profile comprising of socio-demographic data (appendix 1) on each participant was collected to help in coming up with the attributes during data analysis.

Four FGDs were conducted after the in-depth interviews. Two of the FGD (one from each site) were for women 45 years and above. There were 8 participants for Kawale and 10 participants for Area 25 and these were selected house to house by CAB members. The two men FGD (one for younger men 20-45 years and the other for those over 45 years). Eight participants were selected from Area 25 for the under 45 year group and ten from Kawale for the over 45 year group. Each FGD was

conducted at the chief's house right in the community to ensure maximum participation and avoid transportation difficulties. There were two facilitators for each FGD; the moderator of the same gender as participants led the discussion by asking participants to respond to open-ended questions. The other took detailed notes of the discussion. A tape recorder was used to record all the discussions. This helped to ensure accurate data and facilitate analysis.

3.6 Data Analysis

Data analysis started concurrently with data collection. After each session of the in-depth interviews and FGD, the tape recordings were transcribed. Then all the transcribed notes from the tape recordings, the note taker and debriefings were expanded into more narratives and translated into English. The translated transcripts were then entered into computer.

Nvivo version 2.0 software package was used to analyse the qualitative data. Two projects were formulated in Nvivo, one for the in-depth interviews and the other one for the FGDs. Using the interview guide, two code books for each project were developed to come up with the tree nodes and children nodes. Then all the transcripts were coded using the code book. Summaries from all the codes were generated and these were closely read to identify relationships in the discourses and emerging theme across all the sets of the interviews and FGDs.

Demographic data was analysed in Excel software package.

3.7 Limitations

HIV positive mothers from two PMTCT sites in Lilongwe urban were included in this study. It is important to note that these women could not probably be representative of all women in the PMTCT program in Malawi but for the urban with at least primary schooling. Most of them were financially insecure and of lower levels of education. As such, since the majority of women in the country fall under this category, the findings could be applied to most settings in Malawi.

3.8 Ethical Consideration

Ethical approval was granted by the College of Medicine Research and Ethics Committee. Permission was also sought from Lilongwe District Health Office and UNC Project to get clearance for conducting the study at the mentioned health facilities in the district.

Before asking any study questions participant were informed about the purpose of the study, methods and procedure of data collection and benefits of the study. This helped the participants to have a clear picture of what is happening and the benefits and possible risks of the study. This information was provided in Chichewa for easy understanding. Taking into consideration the low literacy level of Malawian women

which is estimated at 49% (DHS, 2000), the consent form for the study was read to the participants and they either wrote their name or put a thumb print depending on their literacy level. If the participants know what is going on, they voluntarily accept to participate in the study. It was also explained to the participants that since participation in the study is voluntary, those wishing to withdraw, could do so at any time.

CHAPTER 4 RESULTS

The study included two categories of study participants. First category was for HIV positive mothers in PMTCT program and the second for key decision makers on infant feeding in the community. For the first category, a total of sixteen in-depth interviews were conducted while in the other category, four FGDs were conducted each comprising 8 - 10 people. Two of these focus groups were for women and two were for men. In total 36 people participated in the FGDs. Data for this study was collected within a period of one month from 12 December 2006 to 14 January 2007.

4.1 Demographic characteristics of participants

The table below shows findings on demographic characteristics of participants:

Table: 1 Demographic Characteristic of Respondents.

Demographic characteristic	**In-depth interviews(n=16)**	**Focus Group Discussions**	
		Males (n=18)	**Females(n=18)**
Age in years (mean)	26.6	49.6	50.8
Educational attainment:			
None	3 (18.8%)	1(5.6%)	3 (16.7%)
Primary	8 (50%)	9 (50%)	11(61.1%)
Secondary	5 (31.3%)	8 (44.4%)	4 (22.2%)
Marital status:			
Married	15 (93.8%)	15 (83.3%)	10 (55.6%)
Divorced	1 (6.2%)	0	4(22.2%)
Widow	0	3(16.7%)	4(22.2%)
Occupation:			
Working	4 (25%)	14 (77.8%)	16 (88.9%)
not working	12 (75%)	4(22.2%)	2 (11.1%)

4.1.1 Age Distribution

The average age of mothers in PMTCT program who participated in the in-depth interviews was 25.4 years for those at Area 25 and 28.0 years for those at Kawale. The youngest mother was 22 and the oldest was 38.

For the focus group discussions, there were age variations especially in the male groups. This was done purposively in order to get views from different age categories. The mean age for males from Kawale was 60.1 years and form Area 25 was 32.5 years. This was done purposively to get views from younger married men as well as older married men. The overall mean age for men was 49.6 years. For females, the mean age for those at Area 25 was 46.6 years while at Kawale, was 48.6 years. The overall mean age for the women was 50.8 years.

4.1.2 Education Attainment

Most women in IDI (50%) had primary education while 31.3% had secondary education and 18.8% had no formal education.

These findings were not very different from the FGDs findings where 55.6% had primary education, 33.3% had secondary education and 11.1% had no education.

4.1.3. Occupation

For the mothers in the IDI, only 25% were working while 75% were housewives and depended on their husband for household income.

In the FGDs 83.3% were working and only 16.7 were not working. Their occupation included any volunteer work, small scale businessmen/women, traditional healers, traditional birth attendants, local leaders, teachers and retired nurses.

4.2 Qualitative Findings

Participants from both study populations talked openly about issues surrounding HIV in relation to mother to child transmission, what HIV positive mothers go through as they are stopping breastfeeding early and also some factors contributing to failure to stop breastfeeding at six months. The findings have been presented under the following themes: knowledge on PMTCT, status disclosure, experiences, barriers, opinions and roles in prevention of mother to child transmission.

4.2.1 Knowledge of PMTCT

UNC Project is a major provider of PMTCT services in Lilongwe urban. All the PMTCT services in the public urban health centres of Lilongwe are provided by UNC project under a program known as Call to Action (CTA) and in vernacular it is known

as *'ndondomeko'*. The name *'ndondomeko'* was used during data collection for easy communication and understanding.

Mothers who participated in the IDI were asked to briefly explain what they know about CTA program *(ndondomeko*). 62.5% of the mothers were able to briefly explain some activities and objectives of PMTCT program.

"It is the group which teaches on how we can prevent the virus; How we can prevent our baby from getting the virus during birth and when breastfeeding; Also on how we can reduce multiplication of the virus in our bodies through the use of condoms when having sex. They give the drug which reduces transmission of HIV to the infant. The name of the drug is Nevirapine. It is given during antenatal and we are supposed to take it during labor." (KW/03,IDI)

Three mothers out of 16 (18.8%) could not clearly explain the activities of the PMTCT program while another 18.8% expressed some ignorance even though they joined the PMTCT program. Below is what one participant said showing lack of knowledge:

"What I know is that whoever is enrolled in this program is HIV positive but I do not know the details of the program. When I visit the CTA Clinic, I enter that room-[pointed at reception room of CTA clinic], am advised on caring for the child. They also question me on the number of months am suppose to breastfeed the child. I tell them that a child is supposed to be breastfed for six months. Therefore they question

me why I have not yet stopped breastfeeding my child. I tell them that this is a new phenomenon (zachilendo) to me because I have never done it before. That is why I have not yet stopped breastfeeding my child. And they just say 'ok' (chabwino). Last month I did not report on the appointment date, I came after the date, but they were suppose to collect blood specimen from my child for the second time to check his HIV status." (25/01,IDI)

The knowledge of PMTCT is quite different in the key decision makers' category where the majority expressed lack of knowledge and just a few were able to explain what PMTCT program is about. The majority said that it is a new concept and they do not know much about it. This is what one said:

"We have stopped bearing children so we don't know about these issues. This question can be better answered by our friends who are still bearing children."(KWF/006, FGD) [The majority of other participants in the group murmured in agreement some nodded their heads]

"We just hear that at the hospital they treat pregnant women to see if they have AIDS and that these days a baby can be protected from the virus but what exactly happens there we don't know"(KWM/004 FGD)

This was further illustrated by a hot debate in all the FGDs on whether HIV positive mother can have an HIV negative baby. The majority believe that it is not possible for HIV positive mother to have an HIV negative baby. Here are some examples of what they said:

"The baby already gets the virus from the mother while she is pregnant so if we are saying that the child should stop breastfeeding at six months it is just to protect the child so that he should not be getting more virus because of breastfeeding. But the mother and father have already transmitted the virus to the baby. But for the child to grow health that is why they say that we should stop breastfeeding the baby at six months or 3 month. If we say that the baby does not have the virus then we are lying because by the time the baby is born, the mother and father have already passed the virus to the baby because the baby has been made by the mother and father."(KWF/004, FGD)

"Some of us we do not understand how a baby could not be infected with HIV while the mother is HIV positive. Considering that there is flow of blood between the mother and the baby where supply of food takes place. So how come there are chances that the baby can not be infected with the virus as there is constant flow of blood even during child birth, there is cutting of umbilical cord, does this not show that there is flow of blood between mother and baby? So to me I do not understand that a baby can born HIV free." (25F/007, FGD)

4.3 Status Disclosure

4.3.1 Persons Disclosed Status To

Status disclosure to the spouse was 100% (n=16) among mothers in the in-depth interviews. All mothers said they disclosed the status to their husband. Some

participants also disclosed to other people apart from the husband, 12.5% (2 out of 16) to their mother; 12.5% to sister; 12.5% to close friend; 6.25% (1 out of 16) to in-law; 6.25% to elder child:

4.3.2 Reactions after Disclosure

Women in IDI received different reactions from the persons that they disclosed their status to. Fourteen mothers (87.5%) said they received positive reactions and were encouraged by those people whom they disclosed their status to:

"The day I was tested at ANC is the same day I disclosed my HIV status to my husband He also went for testing and he was also found positive. So we agreed that we should live normally like before we knew we were positive. I also explained to him that I had enrolled in CTA program where advise is given on how I can care for myself, up to now we are living normally we do not have problems." (25/05, IDI).

"My husband told me not to worry, it happens. The most important thing is to avoid thinking about it (maganizo). While my friend also encouraged me and told me that it happens. On her part, she does not know her HIV status. She further encouraged me that it is good that I know my status. My mother at first, she was worried (kukhumudwa) then afterwards, she has been encouraging me, she advised me to be eating nutritious foods and further said I should stop breastfeeding the baby early. She also advised me not to conceive again in order to maintain my immunity." (25/02, IDI).

"At first they were angry especially my mother as she thought that the baby will not have good health. But upon seeing that my child is growing well, she accepted. Another person is my child who encourages me to take the drugs every time after I disclosed my status because my immunity was also low. My child went for testing and was found to be HIV negative. My husband is also receiving ARV and we encourage each other." (KW/04,IDI).

These findings were similar to those from the FGDs where the participants said that they would encourage the mother who has disclosed her HIV positive results and has joined CTA program so that she should not have worries:

"Yes this is depressing issue (zokhumudwitsa) but you can not show it to the child that you are also affected as this may hinder you from helping the child. You have to encourage the child, advice spiritually and nutritionally, helping her to forget everything so that she should not have worries (nkhawa) I cannot do otherwise as the problem is already at hand."(25F/006, FGD)

"Encourage the child if she has been found HIV positive and advise her to adhere to all hospital advice. She should follow all hospital advice so that her life may prolong after being counseled at the hospital." (KWM/004, FGD)

In the male FGD the majority said that if the woman is going for an HIV test, she should inform her husband first and even before she joins the PMTCT programs to avoid negative reactions.

"The wife is supposed to inform the husband before joining the program. He should give her an OK, not just joining the program without informing the husband first."(KWM/008, FGD)

The other 12.5% (2 out of 16) of HIV positive mothers reported that they received negative reactions from their husbands after disclosing the status:

"At first he was refusing that he is not the one who brought the virus in the family ……. In the early days he was very angry and I was also worried to the extent that I wanted to commit suicide. Thanks to CTA program, they were encouraging me every time I visited the clinic. At first I thought am the only one infected but later when I visted the clinic, I met many infected women, so this also encouraged me."(25/06, IDI)

4.3.2 Influence of HIV Status Disclosure on Early Cessation

Thirteen out of sixteen (81%) mothers from IDI indicated that HIV status disclosure can help in early breastfeeding cessation. Some said it is good to disclose status because people around will know the reasons why you are stopping breastfeeding

early, and they will encourage and support you as you are ceasing the breastfeeding and one said it can prevent being chased out by your husband since he knows what is happening:

"Yes disclosure of status can help because in our culture we do not breastfeed for six months only. So it is good to disclose for them to know the reasons why you are stopping breastfeeding. With this there won't be any queries in the family and they can't chase you away from the family." (KW/08, IDI)

"It helps because when you stop breastfeeding the child, people around are not surprised. But if you have not disclosed, they become suspicious and wonder why you have stopped breastfeeding the child early."(25/07, IDI)

One out of 16 (6.25%) also indicated that status disclosure can be an encouragement to other people to see that there is no harm in early breastfeeding cessation:

"The growth and health of the child encourages and can be like an example of those who breastfeed their baby for six months only. Other people can see that there is no harm to early breastfeeding cessation. Some women say they cannot stop breastfeeding early as they are poor. But after being advised and see health of the babies who breastfeed for six months only, knowing the status of their mothers they can be encouraged to participate in CTA program if we disclose our status to them. I even encourage those who say that they have nothing to feed the baby on how they

can stop breastfeeding their babies. There are some who have never gone for testing and they get surprised when they hear that I stopped breastfeeding my baby."(KW/04, IDI)

Three of the 16 mothers (18.75%) expressed that disclosure of one status cannot help in early cessation because the moment you stop breastfeeding people already start suspecting something:

"On my part I felt that stopping a child to breastfeed is not good because if I stop to breastfeed the child early people will start questioning me why I have stopped to breastfeed the child. So I will not have an answer. Most people these days know that when somebody has stopped breastfeeding a child early then the person is HIV positive. This is why HIV positive mothers continue breastfeeding their babies."(25/01, IDI)

4.4 Experiences during Early Breastfeeding Cessation

Half of the mothers (50%) from the IDI explained that they were able to stop breastfeeding at six months of infants' age. Even though they managed to stop breastfeeding at this age, there were some problems that they faced. The most commonly mentioned problems were that the baby cried a lot, baby refused other food, lack of food and money to buy the necessary food for the infant. Others problems were breast engorgement and feeling like not loving the child. Here is what some women said:

"It wasn't easy to stop breastfeeding the baby, the baby was crying a lot, refusing other food and sometimes even looked sick."(KW/02, IDI)

"The baby felt unloved as I was not giving her breast milk. The baby didn't like other food, had no appetite, suffered from diarrhea as was not used to other foods. Yes, that was last year when we had hunger crisis, it was difficult to get maize. Infant was just crying."(KW/0,4 IDI)

"I had no money to buy milk, the baby got sick, it was also difficult to get the right food" (KW/07,IDI)

"I had no food but this did not stop me from stopping breastfeeding my baby apart from this there was no other problem because I cannot fail to stop breastfeeding my baby due to fearing my neighbors that they will know that am HIV positive, all I want is good health of my child."(25/03, IDI)

The other 50% indicated that they were still breastfeeding their babies. They had different reasons for this and some of them said:

"My husband is very supportive he asks me why I have not stopped breastfeeding the baby up to now. So I explained to him that I feel it is a new thing (zachilendo) to me. I

think may be the child will be malnourished. In addition people will know that am HIV positive when I stop breastfeeding the child."(25/01, IDI)

"I cannot afford to buy milk but sometimes I do buy the milk only that my baby refuses the milk but accepts Porridge. I feel the child might develop malnutrition if not feed on milk."(25/02,IDI)

"The problem which I have is that I do not have money thus why I have not stopped breastfeeding my baby. I do not have any other problem apart from this money issue because if people noticed that I have stopped breast feeding my baby then they will think am pregnant."(25/04, IDI)

The key decision makers were asked the problems that can be faced when the mother is stopping breastfeeding at six months. They also mentioned similar problem as those that were faces by the mothers in the PMTCT program. Problems like lack of food, money, baby crying and becoming malnourished, and some maternal conditions were also mentioned:

"We must say it here that it's a general problem when it comes to food availability, especially for young children. In the first place, food for these young ones is very expensive, and we are very poor here in Malawi. To feed the child up to maybe two

years is not a joke. Sometimes you go ask for food elsewhere, and you get despised, humiliated." (KWM/007, FGD)

"The child gets malnourished, the face doesn't look well, his blood is not strong, and they say that the child has kwashiorkor, he is always weak because he is not getting enough milk. This is just done because of illness and the issue of HIV that is why the child is stopped breast feeding early, but what is needed is that the child should be breastfeeding adequately; he is healthy and walks quickly. But because of this HIV they stop breastfeeding early because what else can they do."(KWF/013, FGD)

4.5 Barriers to Early Breastfeeding Cessation

4.5.1Cultural Barriers

From the data that was collected in both categories of this study, it seems that there are no cultural or traditional practices that may hinder early breastfeeding cessation. Mostly people mentioned that early breastfeeding cessation is associated with pregnancy. When a woman is pregnant, she stops breastfeeding the other sibling:

"The problem is our culture because we associate stopping BF with pregnancy it is either the mother is pregnant or anticipating pregnancy. So if the mother stopped breastfeeding the child, she may also become pregnant. It is difficult to take care of the child while pregnant as a result you may loose one thing either the pregnancy or

the life of the child. Because if you are pregnant while the other child is still small, you loose interest in taking care of the child."(25F/003, IDI)

"I have not heard of any well defined social or cultural beliefs, but there is just fear that the child may become malnourished if she stopped breastfeeding early because of lack of proper foods."(25M/005, IDI)

4.5.2 Peer Pressure from Community

What happens in the community or what people in the community say may hinder HIV positive women to stop breastfeeding their babies early. Women may feel that they are being stigmatized by other people. Some women need to have strong will in order to stand up to the pressure from the community:

"When people asked me I only said that that its my choice to stop breastfeeding my child as I can chose to stop breastfeeding my child or not. I can chose not to breastfeed my child immediately after birth as it is my freedom, so I chose to breast feed my child for six months only that is why I stopped. So when people were asking me why I stopped breastfeeding, I was saying it is my choice. To some I was saying the baby started denying breast milk on her own that is why I stopped breastfeeding her."(KW/02,IDI)

"They ask many questions like are you pregnant or do you have the virus?"(KW/07,

IDI)

"Everybody in the community says that stopping breastfeeding the child early means that the mother is HIV positive. But this cannot hinder someone from stopping to breastfeed her child."(25/03,IDI)

"They question that there must be something. May be the mother is pregnant because culturally people believe that if a child stops breastfeeding, then the mother is pregnant because pregnant women do not breastfeed. But these days people listen to radio and through the radio, they learn that HIV positive mothers are advised to stop breastfeeding at six months. Therefore, the neighbors question why you have stopped breastfeeding the child and they know that the person is HIV positive. They do not even say that you have HIV but AIDS. So they ask while knowing the truth."(25/02, IDI)

What the participants in the in-depth interviews said concurred with the FGDs who agreed that that early cessation is associated with being HIV positive and this may lead to being stigmatized.

"The government tells us to breastfeed our children up to the age of two years, therefore if a child stops breastfeeding at six months and you have not disclosed your HIV status, the neighbors wonder why the mother has stopped BF the child at six months, then they conclude that the mother has AIDS. As you know a lot of people do

not understand the issue of HIV/AIDS. Few people do understand and do not discriminate. In this case neighbors may tell each other to stop visiting the house of that mother who is suspected to have AIDS ' YOU MAY CONTRACT (MUKATENGA) AIDS. Even telling kids not to play with such and such a child because it has AIDS. There are so many things which HIV positive mothers experience just because they have stopped bf their child early at six months."(25F/004, FGD)

"The problems that a mother can face is that most people laugh, they would say hey that stopped breastfeeding her baby she has AIDS. Or even if some children would like to play at that house they would be told not to. So those people would be very miserable and that is why most people would just continue to breastfeed."(KWF/009, FGD)

4.5.3 Husband Say/ Power

It was noted that the husband has to be notified before breastfeeding cessation takes place. However 75% of the mothers said that the husband has no power over the decision of stopping breastfeeding early or not:

"I think the woman is the one who decides to stop breastfeeding the baby because she is the one who breastfeeds. The husband has the role to encourage the woman. However even if the husband may say that the child should stop breastfeeding but if the woman does not want, she can continue breastfeeding the baby especially when the husband is not around."(25/06, IDI)

"The woman has more power. Because she is the one who breastfeed and knows the baby's life more than the husband." (KW/07,IDI)

When asked what influence spouse had on their decision to implement early breastfeeding cessation, 25% said that the husband has the power to influence the decision of early breastfeeding cessation:

"A mother may think of stopping breastfeeding a baby but the husband may say no, the baby should continue breastfeeding, and then the mother continues until when the child grows a little older and can easily stop breastfeeding even without the father's consent."(25/08,IDI)

From the focus group discussion both men and women agreed that the mother has more power over stopping breastfeeding early or not however the husband should know about early cessation in advance as there is need for budgeting for the baby's food and planning to avoid another pregnancy:

"In our culture (ngoni), a woman cannot just stop breastfeeding without informing the husband. It will be as if she is hiding something."(KWM/007, FGD)

"I should think the woman should tell her husband all about her program, what she intends to do, so that they budget together what they should do to make sure the child has food throughout, because these types of foods are expensive."(25M/003, FGD)

4.6Opinions

4.6.1 Adequacy of Information Given

All mothers in the in-depth interviews expressed that the information that they are given is enough to assist them to stop breastfeeding early. However only 12.5%(2 out of 16) of the mothers were able to correctly say the some points in the process of early cessation like expressing breast milk in the cup and let the baby feed from the cup. 87.5% of the mothers could not correctly say the process of early cessation and they practiced mixed feeding as opposed to abrupt cessation which is recommended:

"The advice which is given is that when you are about to stop breastfeeding the baby, we need to stop breastfeeding the baby frequently; we may just breastfeed in the morning and evening. This will make the baby to adjust. In between the breast feeds, the baby is given porridge" (KW/02, IDI)

"They say that the child should stop breastfeeding at six months. Put the baby to breastfeeding once a while at the same time introduce porridge to the baby. You also

need to start feeding expressed breast milk from a cup. The baby will get used to feeding from the cup. When the child stops breast feeding, give it porridge mixed with various food nutrients so that the child should be malnourished. Breastfeeding a baby once in a while means putting a baby to breastfeeding in the morning and in the evening and in between giving it porridge for one week before he/she completely stops breastfeeding." (25/05,IDI)

4.6.2 Possibility of Early Breastfeeding Cessation

Some of key decision makers in FGDs stated that it is possible to stop breastfeeding the baby at six months but with good reasons for doing this:

25F: (Chorus response). It is possible to stop breastfeeding at six months. However……..

"If we think of our Malawian culture, stopping breastfeeding a child at six months is like punishing the baby. However it is good that there is an intervention (chithandizo) that is being given to the child. Therefore we need to follow this advice of stopping breastfeeding the child at six months of age. In addition, when the child stops breastfeeding at six months, it is started on other foods like porridge, fruits, milk or whatever food is available. Whatever food we may give to our child will make it grow healthy."(25F/002, FGD)

"If there is a good reason, then it is possible. Sometimes it happens that the child is born is born alive while the mother dies while giving birth. In most circumstances this child grows well just like any other child. So this is possible too. So long as the husband is let known of the issue at hand and the fact that breastfeeding will be stopped at six months because of HIV, so that preparations for extra feeding after six months should be done in advance. For those people outside the family who may be curious and question the cessation, they can simply be told that it's 'our decision' as a family, and we are happy about it."(KWM/009, FGD)

There were also some who said that it is not possible to stop breastfeeding at six months:

"I still think it's impossible. (All laughed).Because of our beliefs. Here in Malawi, our culture does not allow us wean the child within such a short period of time. You would be told it's the White people who do that, not us Moreover most people cannot afford to buy food for the baby."(25M/007, FGD)

4.6.3 Promotion of Breastfeeding Cessation

Respondents from in depth interview and FGDs expressed different opinions on how CTA program and early breastfeeding cessation can be promoted. Most of them stressed on continuous counseling of women, broadcasting HIV messages and providing food for the baby during cessation period:

"There is need to continue counseling the women, the doctors should continue encouraging the mothers, those women with HIV should not continue bearing more children; Women should disclose their status to the husband for them to assist each other; Positive women should also share the message to friends relatives and neighbors. Also the message on early cessation should be spread everywhere, if you can have CTA program on the radio explaining the benefits of it. Stigma and discrimination are being prevented as AIDS message is being given. People infected with HIV are of good health than before."(KW/04, IDI)

"It *is really happening that the children are not well taken care of when they stop breastfeeding at six months, what I may say is that government should be supplying food supplements to these children when they stop breastfeeding. Because we may stop breastfeeding the child at six months but the child may be hungry most of the times as the parents may not have food to give to the child. This child may develop other conditions. (25F/006, FGD)*

CAHPTER 5 DISCUSSION

Early breastfeeding cessation is a new practice in Malawi. Society tends to attribute all kinds of reasons which are not always true to this practice. If a woman stops breastfeeding early, her community suspects that she is pregnant or she is HIV positive. Because of fear of being suspected to be HIV positive which is associated with stigma, most mothers in PMTCT fail to stop breastfeeding their infants early. This is a challenge to PMTCT program which advocates exclusive breastfeeding followed by early abrupt weaning for HIV positive mothers in Sub Saharan Africa (Coutsoudis A, 2005).

This study identified a number of broad issues associated with early breastfeeding cessation and abrupt weaning which include the following:

5.1 Low Socioeconomic Status as a Barrier to Early Breastfeeding Cessation

Inn this study, all the participants in the IDI were married except for one who was divorced. Only 25% of these mothers were working or doing small-scale business and the rest were housewives. This shows that 75% of these mothers depend on other people economically. In Malawi where most families live quite close to the poverty line, there is hardly enough resource to feed the whole household let alone extra resources to purchase special food (e.g high protein diet like egg and milk) for a baby

who has been weaned early. This is further compounded when a mother has to fully depend on the spouse to provide this extra resource. Thus it easier for a mother to avoid early cessation especially if she belongs to a low socio-economic status. Our study results indicated that some women failed to stop breastfeeding at six months due to lack of food. The key decision makers in the community also stated that lack of food is one of the major problems that mothers face when weaning their babies either at six months or later. Piwoz E,Huffman SL, Lusk D, et al, 2001 also found that poverty and food insecurity are the major contributors to difficulties in choosing infant feeding option in HIV positive mothers. Similar results were also found in Uganda where women in low income group and those without meaningful source of income depended on their spouse and families for support and this had an effect on the decision they made on care of the children including cessation of breastfeeding (Bunjo NL,2002).

5.2 Educational Level as a Challenge to Early Cessation

The literacy level in Malawi is very low particularly among women, estimated at 49% (Malawi DHS 2004). Literacy level is directly related to comprehension of issues and perception of risk. The results from this study also indicate that there is a relationship between level of education and early breastfeeding cessation. Mothers who had no education at all or a few years of primary education were more likely not to stop breastfeeding at six months of infant's age. It can be argued that the less educated mothers had poor comprehension of issues pertaining to prevention of mother to child

transmission and they failed to perceive the risk associated with prolonged breastfeeding in light of HIV/AIDS. In view of the homogeneity of the study population in regards to socioeconomic status it was difficult to tease out the any confounding of education and income in relation to breastfeeding cessation. However it is interesting to note that one participant (#25/01) who had no education, but all the financial support from her husband failed to stop breastfeeding at six months because early breastfeeding cessation is new to her. This thus lays more credence of failure to fully understand the issues discussed during her PMTCT program visits and perceive the risk of transmitting the virus to the infant with prolonged feeding rather than an ability to pay for breast feeding substitutes. These findings are similar to those found in Uganda where educational levels positively influenced knowledge about MTCT (Bunjo NL, 2002).

The findings also indicated that most mothers failed to briefly explain what happens at PMTCT program, the objectives of PMTCT program and the process of early cessation. This could also be related to low educational status leading to poor comprehension of issues. Similar observations were made in Kenya where prolonged breastfeeding was associated with lower education, having had previous infant and unemployment (Wariua WG, Wamalawa D, Mbori-Ngocha D et al, 2004).

5.3 Status Disclosure and Early Cessation

This study's findings indicated that early breastfeeding cessation may not be directly related to disclosure of status. In this study all HIV positive mothers disclosed their status to their spouses and others even disclosed to other family members and friends. Although all the mothers disclosed their status, not all stopped breastfeeding their babies at six months. This means that there may be other confounders related to status disclosure and early breastfeeding cessation like the spouse knowing his HIV status and/or spouse being involved in earlier decision to get mother enrolled in the PMTCT program. Several anecdotal reports describes husbands being very cooperative on learning of their spouses HIV status because of they secretly having tested positive earlier and have not been bold enough to disclose their results to their wives. Contrary, there have also been reports of husbands who have violently reacted on knowing the status of their spouses. This was the experience of two of the participants who took part in the in-depth interview. This makes some women suffer psychological problems and hinder them in taking safe measures in their lives.

Hence, status disclosure can indirectly have an impact in early cessation because in Malawian society most mothers depend on their spouse for economic support without which it would be difficult to find supplementary food for the baby. Culturally men are the decision makers in the home; also the elders in the community are the source of knowledge. So if the mother wants to adhere to PMTCT strategy then she has to disclose her status to other family members so that she is able to stop breastfeeding at six months and get support from them. A study conducted in Zimbambwe also found

that a woman's disclosure of HIV status is a critical component of PMTCT. That study, noted that HIV infected mothers in PMTCT program who disclosed their status to their partners were able to fully participate in interventions to reduce MTCT including early cessation (Marangwanda C, Maulana M, Stranix L, et al, 2004). In another study in Uganda, looking at views of HIV infected mothers on early cessation of breastfeeding, it was found out that disclosure of status to spouses, and involvement of the husbands played a great role in the success of early breastfeeding cessation (Bunjo NL, 2002)

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5.4 Early Breastfeeding Cessation and Stigmatization

HIV positive mothers face a lot of dilemmas in following the PMTCT strategy. This is mostly due to stigma and discrimination that is associated with HIV and AIDS. For HIV positive women to stop abruptly breastfeeding their babies at six months, they have to be strong and very determined so that they are able to withstand community pressure. Early breastfeeding cessation already is associated with HIV and many mothers fearing to be known that they are positive, they continue to breastfeed their babies even after six months thus increasing the risk of HIV infection. This was demonstrated in what some women said that they stopped breastfeeding their babies and found some excuses to tell people when they asked. There were also other mothers who failed to stop breastfeeding because they did not know what to tell people why they are not breastfeeding and feared being stigmatized.

In the communities there is also high unmet need for HIV and AIDS education and especially on HIV transmission to children. This was demonstrated through lack of knowledge on mother to child transmission among married men and elderly women who took part in this study. This is a major set back in the PMTCT program as these elderly people and the husbands play a major role in influencing the decision on infant feeding. Lack of knowledge on MTCT and PMTCT in the community can also fuel the stigma that is associated with early cessation. If communities do not understand the mechanism of MTCT, this might lead to skepticism about the effectiveness of the prevention programs (Nyblade L, Field ML, 2001)

5.5 PMTCT Program Gaps and Early Breastfeeding Cessation

Early cessation can be promoted if the service provision responds to the need of the people. The counseling on infant feeding should be continuous and individualized (Piwoz E, Huffman SL, LuskD, et al 2001). From the findings, participants indicated that continuous counseling should be done so as to promote early breastfeeding cessation. Continuous counseling is very crucial in this setting as at the same time mothers would be reminded and encouraged as needed. However several studies have shown that uptake of PMTCT at initial stage is very high but the number of women coming for the follow up visits reduces dramatically after 3 months post delivery. Thus the crucial time for educating and encouraging the mothers about early breastfeeding cessation is missed. This is another of the big challenges for PMTCT program since continuous counseling is needed for the women so that they are able to

make appropriate infant feeding choices. A study done in Thyolo District, in rural Malawi found that the loss to follow up of mothers in PMTCT program is more that three quarters by 6 months post natal (Manzi M, Zacharia R, Teck R, et al, 2005). The commission on HIV/AIDS and Governance in Africa(CHGA) describes this pattern as the 'cascade' effect whereby the clients' use of the services from the initial contact , through counseling, testing, returning to collect results, receiving treatment, and receiving infant treatment counseling ,declines at each step of the process. The same pattern was also observed by a study looking at follow up of clients in PMTCT in Lilongwe where the number of women coming for their follow up visit kept declining (Chinkonde J, 2006, unpublished report). Some of the reasons that could lead to low uptake of PMTCT services may include denial of HIV positive results, opposition from spouses, and women's fear of disclosure of HIV status to the partner.

CHAPTER 6 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Programs in prevention of mother to child transmission of HIV play a great role in improving child survival in this era of HIV. In Malawi breastfeeding is the norm and it provides nutrition and barrier to other infections, yet breast milk is also an important route for mother to child transmission of HIV. Exclusive breastfeeding followed by early cessation is one way of minimizing mother to child transmission. This study has shown that early breastfeeding cessation continues to be a challenge to most mothers in PMTCT program in Lilongwe urban.

There are several factors that hinder mothers in PMTCT program from stopping breastfeeding their babies at six months. These include lack of food to feed the baby after weaning, due to lack of financial resources to purchase breast milk substitutes, fear of stigmatization by the community. Low levels of education in HIV positive mothers also act as a barrier to early breastfeeding cessation because the mothers fail to comprehend issues pertaining to PMTCT and identify the risk of continuing breastfeeding.

Early breastfeeding cessation has shown to greatly reduce the HIV transmission rate from mother to the child. However this option seems to have other factors that may make it not to be successful. It is therefore important that the government should put in place more proactive strategies considering the challenges to early breastfeeding

cessation in low socio-economic environment. Hence broader aspects need to be considered if early breastfeeding is to be promoted among HIV infected mothers in Malawi.

6.2 Recommendations

Understanding challenges to early breastfeeding cessation in low socio-economical environments is critical to the development of effective counseling strategy. There is a need for government to critically re-examine its policy of breast feeding cessation at 6 months in this community where breast milk alternatives are well beyond the reach of many women. An approach which extends breast feeding to a later age in life when child is able to partake in food served for the rest of the family may be a more realistic approach than the current abruption cessation at 6 months.

PMTCT programs should involve the entire community through education and mobilization that extend beyond the pregnant woman. To this regard, the government should consider more proactive strategies to educate the public about the problem of MTCT and that there are ways on how this can be reduced. This will encourage the community to accept those who are HIV positive and will facilitate the prevention of infant infection through prolonged breastfeeding.

Reducing fear and stigma is seen as crucial in strengthening social support. Elderly women, traditional birth attendants, local counselors are highly trusted and may be

consulted on decisions related to HIV. These people need basic training in HIV and infant feeding so that they are able to provide information and counseling to mothers.

It is also important to have skilled counselors to provide guidance and help to HIV infected women to make appropriate infant feeding decision and adhere to it. The PMTCT guidelines should involve counselors training on how to facilitate male involvement and how to deal with the existing barriers in early cessation.

Lastly, for the PMTCT program to be successful in its current form of abrupt cessation of breast feeding at 6 months there is need for the government to put in place strategy to ensure good health of the infants after early breastfeeding cessation. Most mothers cannot afford nutritious food for the infant as such, there is need for food supplementation for these infants so that they continue to grow health.

6.3 Areas for further research

HIV infection will remain in our population for a long time to come. Likewise for our nation to continue to survive, the older population will have to be replaced by children being born. There is need therefore for further exploration of issues around HIV infection, pregnancy and the new born. This study has only explored a few of the issues around these topics. Other issues that need further research include:

- Perception, Attitudes, Practices and Knowledge regarding Mother to Child transmission in Malawi.
- Attitudes and Practices of infant feeding in Malawi.

- Perceptions and stigma associated with not breastfeeding.
- Impact of early breastfeeding cessation on survival of HIV negative infants

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APPENDICES

Appendix 1: Socio-demographic data (for women in PMTCT Program)

Participant ID ---------- Date of interview……..

Investigator ID ---------- Place of interview……

Date ----------

1. How old are you? ---------- How old is your baby --------

months

2. Are you?

- 1= Married 4= Single
- 2= Divorced 5= Separated
- 3= Widow

3. What is the level of education that you attained?

- 1= No education
- 2= Primary school
- 3= Secondary school
- 4= Tertiary education

4. Occupation

Apart from your household work, are you currently working?

- 1= No
- 2= Yes (specify)…….

5. Is your husband currently working?

- 1= No

- 2= Yes (specify)…….

6. What is the level of education of your husband?

- 1= No education
- 2= Primary school
- 3= Secondary school
- 4= Tertiary education

7. Which of the following people provide you with financial support?

- 1= Self
- 2= Husband/ boyfriend/fiancée
- 3= Parents
- 4= Grand parents
- 5= Other family members
- 6= Friends

8. Who gave you advice on how to feed your baby?

- 1= Nurse
- 2= Husband
- 3= Other family members
- 4= Friends
- 5= Other(specify)…….

Appendix 2: Socio-demographic data (for key decision makers)

Participant ID ---------- Date of interview……..

Investigator ID ---------- Place of interview……

1. How old are you? ----------

2. Are you?

- 1= Married 4= Single
- 2= Divorced 5= Separated
- 3= Widow

3. What is the level of education that you attained?

- 1= No education
- 2= Primary school
- 3= Secondary school
- 4= Tertiary education

4. Occupation

Are you currently working?

- 1= No
- 2= Yes (specify)…….

5. Is your spouse working?

- 1= No
- 2= Yes (specify)…….

6. Where do women get the message on how to feed the baby?

- 1= Nurse/ health worker

- 2= Husband
- 3= Other family members(specify)……
- 4= Friends
- 5= Other(specify)…….

Appendix 3: Question guide for in-depth interviews

(FOR WOMEN WITH INFANTS MORE THAN SEVEN MONTHS)

Clinic code…… Place of interview…….

Code of interviewer…… Date of interview…….

Starting time…….. Ending time…….

1**. Explore knowledge on PMTCT**

-What do you know about PMTCT program?

-What are the objectives of PMTCT program?

-Where did you learn about PMTCT?

-Have you discussed with anyone that you joined this program?

2**. Find out if the client disclosed her HIV status to her spouse or any relative?**

-Did you disclose your HIV status to your spouse or any relative?

-What was the reaction of those that you disclosed your status to?

-Do you think disclosure of status may influence early cessation? In what way?

3. **Experiences of early breastfeeding cessation**

-Were you able to successfully stop breastfeeding at six months? If not successful what were the reasons?

-What problems did you meet when you were stopping breastfeeding?

-Who influenced your decision to stop or not to stop breastfeeding at six months?

-Did you receive any support from your- spouse?

- Family?

- Community?

- Health workers? (Probe)

4. **Barriers to early breastfeeding cessation**

-What are some of the traditional / cultural practices that may hinder early breastfeeding cessation? (probe).

-Do husbands have any role in decisions to stop breast feeding? Who is influential when making such decisions?

-What do people in the community/ your family say when you do not breast feed? (Probe) (Probe for some concrete case examples here. Real stories, positive or negative on what people say. These perceptions may either reinforce or destroy peoples confidence to decide to breastfeed or not.).

-Do people have the means/ wherewithal to support the child after early weaning?

4. Opinions on messages on early cessation

-In your opinion do you think that you get enough information from the health workers on how to stop breastfeeding at six months? Why health workers only?

(Briefly explain what you are told to do in early cessation)

-Where else do you get the information on early breastfeeding cessation? Is the information adequate?

5. **How can early breast feeding cessation be promoted in HIV positive women?**

-What should be done to promote early breastfeeding cessation in HIV positive mothers?

Appendix 4: Question guide for focus group discussion

(FOR ELDERLY WOMEN, LOCAL COUNSELLORS, TBAs AND MARRIED MEN)

Clinic code…… Place of interview…….

Code of interviewer…… Date of interview……..

Starting time…….. Ending time……

1. Knowledge on PMTCT

-What do you know about prevention of mother to child transmission program?

-Where did you learn about mother to child transmission?

-What would be your reaction if you knew that your daughter (or wife for men) has joined the PMTCT program?

2. Opinions on early breastfeeding cessation

Exclusive breastfeeding followed by early breastfeeding cessation is one mode of prevention of mother to child transmission on HIV and is practiced here in Malawi.

-How long do you think a woman should breastfeed her baby?

-Do you think it is possible to stop breastfeeding at six months? *Explain.*

-What problems do you think a woman can encounter when stopping breastfeeding at six months? *Probe*

3. Roles in prevention of mother to child transmission

-What do you think are your roles towards prevention of mother to child transmission of HIV?

-Do you see mother to child transmission of HIV as a problem?

-Do you view early breastfeeding cessation as one way of reducing mother to child transmission?

-What do you think are the benefits of early breastfeeding cessation?

How can early breast feeding cessation be promoted in HIV positive women?

-What do you think should be done to improve the way PMTCT is provided?

4. Socio- cultural barriers

-What could be the socio-cultural barriers to early breastfeeding cessation? *(Probe more)*

-(For men) If they do notice that breastfeeding cessation has occurred before discussion what would be your reactions?

- What kinds of things do think a woman should share with the husband before stopping breastfeeding?

Appendix 5: Question guide for in-depth interviews (chichewa version)

Clinic code…… Place of interview…….

Code of interviewer…… Date of interview ……..

Starting time…….. Ending time……

1. Explore knowledge on PMTCT

-Kodi mukudziwa chiani za pulogalamu ya ndondomeko (pologlamu yochepetsa mpata wopatsila tizilomba ta HIV kuchokela kwa mayi kupita kwa mwana)?

-Kodi cholinga cha ndondomeko ndichiani?

-Kodi munamvera kuti za pologalamu ya ndondomeko?

-Kodi munakambilanapo ndi wina aliyense kuti munalowa mu ndondomeko?

2. Find out if the client disclosed her status to her spouse or relative

-Kodi munauzapo amuna anu kapena wachibale wina aliyense zoti muli ndi kachirombo ka HIV?

-Kodi amene munawauza analandila bwanji za uthenga wa m'mene mulili muthupi mwanu?

-Kodi mukuganiza kuti kuulula kuti munthu uli ndi kachirombo ka HIV kungathandize kusiya kuyamwitsa mwana pa miyezi isanu ndi umodzi? *Munjira yanji?*

3. Expriences of early breastfeeding cessation

-Kodi munakwanitsa bwinobwino kusiya kuyamwitsa mwana pa miyezi isanu ndi umodzi?*Ngati sumunakwanitse zovuta zake zinali zotani?*

-Ndizovuta zanji zimene munakumanazo pamene mumasiya kuyamwitsa mwana?

-Amene analimbikitsa chiganizo chanu ndi ndani chakusiya kapena kusasiya kuyamwitsa mwana pa miyezi isanu ndi umodzi?

-Kodi munalandila chithandizo/chilimbikitso kuchokera kwa:- amuna anu

- a kubanja kwanu
- anthu aku dera kwanu
- ogwira ntchitoya za umoyo? (probe)

4. Barriers to early breastfeeding cessation

-Kodi ndi miyambo iti imene ingalepheletse kusiya kuyamwitsa mwana msanga?

-Kodi anthu aku dera lomwe mumachokera amati chiani mukamapanda munthu akasiya kuyamwitsa mwana msanga?(probe for some concrete case examples here. Real stories, positive or negative on what people say. These perceptions may either reinforce or destroy peoples confidence to decide to breastfeed or not.).

-Kodi azibambo/ amuna anu ali ndi mphamvu ina iliyonse pa chiganizo chosiya kuyamwita mwana pa miyezi six?

-Ali ndi mphavu ndani popanga chiganizo chosiya kuyamwitsa mwana?

-Kodi mumapeza bwanji chithandizo/ chisamaliro cha mwana akasiya kuyamwa kuti akhalebe wa thanzi?

5. Opinions on messages on early cessation

-Mumaganizo anu, kodi mumaona kuti azaumoyo amapeleka uthenga okwanila wam'mene mungasiyile kuyamwitsa ana pa miyezi isanu ndi umodzi?

(Mwachidule lonogosolani m'mene anakuuzilani zoti muchite posiya kuyamwitsa ana)

- Ndikuti kwina komwe mumapeza uthenga wa kusiya kuyamwitsa Mwana pa miyezi isanu ndi umodzi? Kodi mukuona kuti uthenga wu ndiokwanira?

6 How can early breast feeding cessation be promoted in HIV positive women?

-.Kodi kusiya kuyamwitsa ana msanga kwa azimayi amene ali ndi tizilombo ta HIV kungapite bwanji mtsogolo?

-Kodi ndi chiyani chomwe chingachitike kuti tipitse patsogolo ntchito yosiya mnsanga kuyamwitsa ana mwa azimayi amene ali ndi tidzirombo ta HIV?

-Mukuganiza kuti pangachitike chiani kuti tipititse patsigolo pologalamu ya ndondomeko?

Appendix 6: Question guide for FGD (Chichewa version)

(For key decision makers on infant feeding in the community)

Clinic code…… Place of interview…….

Code of interviewer…… Date of interview……..

Starting time…….. Ending time……

1. **Knowledge on PMTCT**

   Kodi mumadziwa chiani za pologalamu ya ndondomeko (pologalamu yochepetsa mpata wopastila tidzirombo ta HIV kuchokela kwa mayi kupita kwa mwana)

   -Kodi manaphunzira kuti za kupatsila tidzirombo ta HIV kuchokera kwa mayi kupita kwa mwana?

   -Kodi mungamve bwanji mutadziwa kuti mwana wanu *(kapena mkazi wanu kwa azibambo)* analowa mu pologalamu ya ndondomeko?

2. **Opinions on early breastfeeding cessation**

Kuyamwitsa mwa kathithi mosatizidwa ndi kusiya kuyamwitsa mwana msanga nsanga ndi njira imodzi yopewera kufalikira kwa tidzirombo ta HIV kuchokera kwa mayi kupita kwana ndipo imachitika m'Malawi muno.

Kodi mukuona ngati ndizotheka kusiya kuyamwitsa mwana pa miyezi isanu ndi umodzi? *(longosolani*)

-Ndi mavuto anji amene mukuganiza kuti azimayi angakumane nawo pamene akusiya kuyamwitsa pa miyezi isanu ndi umodzi? *(probe*)

3. **Roles in prevention of mother to child transmittion**

Kodi mukuganiza kuti udindo wanu ndiotani pa nkhani yochepetsa mpata wopatsila tidzilombo ta HIV kuchokela kwa mayi kupita kwa mwana?

-Kodi mumaona kuti kusiya kuyamwitsa mwana msanga ngati njira imodzi yochepetsera mpatawopatsira tidzirombo ta HIV kuchokera kwa mayi kupita kwa mwana.

-Kodi mukuganiza kuti ubwino wosiya msanga kuyamwitsa mwana ndi chiani?

- Kodi mukuona ngati kusiya kuyamwitsa mwana msanga kungapite bwanji patsogolo kwa azimayi amene ali ndi tidzirombo ta HIV?

4. **Socio- cultural Barriers**

-Kodi ndi miyamdbo iti imene ingalepheletse kitu mwana asiye kuyamwa msanga?

-(***For men***)Mutazindikila kuti mwana wasiyisidwa kuyamwa musanakambilane ndi akazi anu mungamve bwanji?

_ Kodi ndi zinthu ziti zomwe mzimayi akuyenela kukambilana ndi amuna ake asanasiye kuyamwitsa mwana?

Appendix 7: Consent form (English version)

Things to know about this study

My name is Wezi Msungama, I am a student at College Of Medicine in Blantyre, pursuing a Masters in Public Health. To fulfill the academic requirement for the award of my degree, I am expected to conduct a research study.

Before you decide to join this study, you need to know the purpose, the benefits and possible risks of the study. You can decide whether to join the study or not. If you agree to take part in this study you will be asked to sign this consent form or make your mark.

What is the study all about?

Mothers who are HIV positive are counseled to exclusively breastfeed their babies and to stop breastfeeding at six months in order to reduce chances of transmitting HIV to the baby. In Malawi breastfeeding is the norm and under normal circumstances women breastfeed for as long as two years. This study wants to explore the challenges that women face during early breastfeeding cessation

The findings will help in answering some questions that will help in developing appropriate policies and IEC materials targeting women in PMTCT programs and in the community.

What will happen if you join this study

If you decide to take part in this study you will be one of approximately 80 people who will be interviewed in eight focus group discussions. Each focus group discussion will comprise of about 8-10 people and will take approximately 60-90 minutes. A tape recorder will be used to record all the interviews to come up with themes and in analysis.

Risks to you

There are no known risks for participating in this study. However, if your friends know that you are participating because of your HIV status, it may cause some discomforts to you.

Potential benefits

You will not directly benefit from this study. But what we will learn will help in coming up with solutions on the challenges that women face in early breastfeeding cessation.

Confidentiality

All the information that will be collected from this study will be kept confidential as required by law. All those taking part in this study will be identified by numbers only. Your name will not be written anywhere. All the records will be kept in a lockable drawer and will be accessible to study staff only.

Reimbursement

You will be given a packet of sugar and soap as a token of appreciation for taking part in this study. There is no cost for you for participating in this study.

STATEMENT OF CONSENT

The study has been explained to me and all my questions have been answered.

- ❑ I agree to take part
- ❑ I do not agree to take part

_____	_____	_____
Name of participant	Signature of participant	Date
_____	_____	_____
Name of Investigator	Signature of Investigator	Date

If the participant is illiterate, she should put her right thumb print and write her name below. Witness is required for the consenting in this case.

Name of participant_____

_____	_____	_____
Name of witness	Signature of witness	Date

Appendix 8: Consent form (chichewa version)

Kalata Ya Chivomerezo

Zoyenera kudziwa za Kafukuku ameneyu

Kakukufukuyu akupangidwa ndi mmodzi mwa ophunzira za umoyo pa sukulu ya zaukachengedewa za udokotala ku College of Medicine ku Blantyre. Pokwaniritsa zofunikira pamaphunziro a ukachechedewo akuyenela kupanga kafukufuku.

Musanaganizile kutenga nawo mbali pakafukufukuyu, mukuyenela kudziwa cholinga, ubwino wake ndi zovuta za kafukufuku. Mukhonza kusankha kutenga nawo mbali kapena ayi. Mukavora kusankha kutenga nawo mbali, muzapemphedwa kusaina kalata ya chivomerezo kapena kuika chizindikilo chanu.

Kodi kafukufukuyu ndi wachani ?

Amayi amene ali ndi tizilombo ta HIV amapatsidwa uphungu woyamwitsa ana awo mwakathithi ndi kusiyatu kuyamwitsa pa miyezi isanu ndi umodzi ndi cholinga chochepetsa mpata wopatsira ana awo tizilombo to HIV. Ku Malawi kuno kuyamwitsa ana ndichikhalidwe ndipopa chikhalidwechi amayi amayenera kuyamwitsa kufikira zaka ziwiri. Kafukufukuyu akufuna kupeza zovuta zomwe amayi amakumana nazo panthawi yomwe akusiya kuyamwitsa ana msanga.

Zotsatila za kafukufuku amaneyu zizathandiza kuyankha ena mwa mafunso omwe azathandize kupititsa patsogolo malamulu ovonelezeka ndi zipangizo zophunzitsira a zimayi amene ali ku ndondomeko (pologamu yomwe imaona za kuchepetsa mpata wopatsila tizilombo ta HIV kuchokela kwa nayi kupita kwa mwana) ndi m'mader aosiyansiyana.

Kudzachitika chiani mukatenga nawo mbali mukafukufuku ?

Ngati mwaganiza aotenga nawo mbali mukafukufuku mudzakhala m'modzi mwa anthu pafupifupi makumi asanu ndi atatu (80) amene adzafunsidwe mafunso mamagulu 8 adzokambilana. Gulu lazokambilana lilonse lidzakhala ndi anthu pakati pa 8 ndi 10 ndipo lidzatenga nthawi pafupifupi ola kapenaola ndi theka. Chojambulira mawu chidzagwritsidwa ntchito potolela mfundo ndikupeza mutu wa zokambilana.

Zovuta kwa inu

Palibe zovuta zodziwika pakutenga nawo mbali mukafukufukuyu, komabe anzanu atazindikira kuti zakutenga nawo mbali kwanu chifikwa choti muli ndi kachilombo ka HIV zikhonza kukupangitsani kutimusowe mtendere.

Phindu lanu

Mukhonza osapeza phindu lenileni kuchokera mu kafukufuku. Koma zomwe tidzaphunzile zidzatithandiza kupeza njira pa zovuta zomwe amayi omwe akusiya kuyamwitsa ana mwansanga amakumana nazo.

Chinsinsi

Mfundo zones zomwe zidzatoleledwe mukafukufuku zidzasungidwa mwa chinsinsi monga mwa lamulo. Otenga nawo mbali onse adzadziwika ndi nambala basi. Dzina lanu silidzalembedwa paliponse. Zolembedwa zones zizakhomeledwa mu dilowa ndipo zizaonedwa ndi ogwila ntchito mukafukufuku okha basi.

Malipiro/zokubwenzerani

Mudzapatsidwa paketi ya sugar ndi sopo ngati chithokozo pakutenga nawo mbali kwanu mukafukufukuyu. Palibe chimene mukuyenela kulipira mukafukuukuyu.

MAU A CHIVOMELEZO

Kafukufuku walongosoledwa kwa ine ndipo mafunso anga aykhidwa.

- Ndikuvomera kutenga nawo mbali
- Sindikuvomela kutenga mbali

_____	_____	_____
Dzina la otenga mbali	Chizindikilo cha otenga mbali	date
_____	_____	_____
Dzina la ofufuza	Chizindikilo cha ofufuza	Date

Appendix 9: Budget for the study

Item	MK
Training of research personnel	
3 persons *2 days *K1000/day	6,000
Refreshment* 2 days	1,500
Sub total	7500
Data collection	
3 persons * 15 days *K2000/ day	90000
Fuel @k1000/day	15000
Compensation for participants@ K200/participant	12400
Sub total	117400
Data collection aids	
Tape recorder @ K10000each * 3	30000
Blank tapes @K150 each *20	3000
Carrier bags @200 each *4	1200
batteries @ K200 * 20	4000
Sub total	38200
Stationery	
reams of paper @ K750*3	2250
Arch lever files @350 *1	350
Note pads @350 *10	3500
Pens @ 400 / unit	400
pencils 100/ unit	100
memory stick @k10000	10000
Sub total	16600
Supervision and coordination	
1 field coordinator@ K2000/ day *15 days	30000
Data entry	
1 data entry clerk @ K2000/ day * 10 days	20000
Grand Total	**229700**