UNIVERSITY OF MALAWI

College of Medicine

Factors Contributing to the Low Uptake of PMTCT Services in Blantyre and Balaka Rural.

By

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CERTIFICATE OF APPROVAL

The Thesis of Julliet Charity Yauka Nyasulu is approved by the Thesis Examination Committee

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DECLARATION

I Julliet Charity Yauka Nyasulu hereby declare that this thesis is my original work and has not been presented for any other awards at the University of Malawi or any other University.

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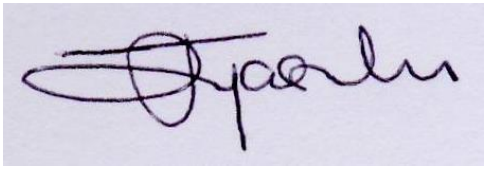

Signature

Date 15th December 2007

DEDICATION

I dedicate this work to my loving parents Simon Yauka Kumwenda and Lyness Nyabongololo Gondwe, who taught me the beauty of education.

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ABSTRACT

Introduction: Malawi is one of the 10 countries most affected by HIV/AIDS pandemic worldwide. In response to this the Malawi government in collaboration with other partners like GOAL Malawi, has established the Prevention of Mother to Child transmission programme (PMTCT). Low uptake of PMTCT services is one of the biggest challenges the programme faces.

Study Objectives: To establish factors contributing to low PMTCT service uptake by women in Blantyre and Balaka Rural.

Methodology : This was a cross sectional qualitative study conducted at 7 selected health sectors in Blantyre and Balaka Districts. Data were generated from 83 subjects through in–depth interviews and focus group discussions. Qualitative data were analyzed manually and SPSS was used to analyse quantitative data.

Results: The study confirmed that there was low uptake of PMTCT services by mothers in the study areas. The main barriers for low uptake of the services identified include stigma and discrimination, opposition from male partners, women's fear of disclosure of HIV status, and cost of infant feeds. The study also established big knowledge gaps among PMTCT providers.

Conclusions and Recommendations: In order to promote uptake of PMTCT services by mothers, there is need to involve men since they play a significant role in decision making in Malawi. Raising awareness of the programme among the community will promote community involvement and support of the mothers on the PMTCT programme. Training of health workers and simplifying the counseling content in protocols for easy reference may improve the quality of counseling given by the PMTCT providers.

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ACRONYMS

AIDS	-	Acquired Immune Deficiency Syndrome
ANC	-	Ante Natal Care
APPLE	-	AIDS Prevention Positive Living and Empowerment
ARV	-	Anti Retroviral
CHAM	-	Christian Health Association of Malawi
DHO	-	District Health Office
FGD	-	Focus Group Discussions
HBC	-	Home Based Care volunteer
HIV	-	Human Immunodeficiency Virus
HSA	-	Health Surveillance Assistant
IEC	-	Information, Education and Communication
MHDS	-	Malawi Health Demographic Survey
MoHP	-	Ministry of Health and Population
BFHI	-	Baby Friendly Hospital Initiative
MTCT	-	Mother to Child Transmission
M2M2B	-	Mother to Mother to Be
NGO	-	Non-Governmental Organization
PLWA	-	People Living with AIDS
PMTCT	-	Prevention of Mother to Child Transmission
STD	-	Sexually Transmitted Disease
TBA	-	Traditional Birth Attendant
VCT	-	Voluntary Counseling and Testing
WHO	-	World Health Organization

CHAPTER 1 INTRODUCTION

Mother to Child Transmission (MTCT) of Human Immunodeficiency Virus (HIV) may occur during pregnancy, labor and delivery or after birth while breast feeding. Prevention of Mother to Child Transmission (PMTCT) of HIV infection can involve anyone or all of the following options, use of antiretroviral drugs by the mother during pregnancy and breastfeeding, deciding not to breastfeed the baby or deciding to deliver the baby by caesarian section (Stringer 2005). Breast-feeding is almost universal in Malawi and although replacement feeding is the most suitable way of eliminating breast-feeding associated HIV infection is considered not feasible because of cost associated with it (Zulu 2006).

The Joint WHO and UN report shows that without any intervention, 27-30% of babies born to HIV infected mothers will acquire the virus; transmission during pregnancy is estimated at 5-10%. During labor and delivery, the transmission rate is 10-20% while during breastfeeding; the rate is also at 10-20%. In the same report, it is also indicated that among all babies who are infected with HIV, 21% got the virus from their mothers during pregnancy, 65% during labor and delivery while 14% got the virus through breastfeeding (WHO/UNIADS/UNICEFUNFPA 2003).

GOAL Malawi is an Irish Non Governmental Organization implementing a comprehensive Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) programme in rural Blantyre and Balaka districts funded by the European Union since 2004. The aim of this programme is to slow the spread of

HIV/AIDS and to mitigate its impact by reducing HIV infection among target communities. The programme endeavors to strengthen existing health systems and make the community have more access to Prevention of Mother to Child Transmission (PMTCT) services. The organization supports the programme by training PMTCT health providers and promotion of access to the services through establishment of support groups at community level. Low uptake of PMTCT services is one of the biggest challenges the programme meets (GOAL Malawi 2005).

1.1 Literature review

The joint UNAIDS epidemic report indicates that about 39.5 million people were living with HIV/AIDS (PLWHAs) worldwide by the end of the year 2006. Of the PLWHAs, 24.7 million are in the Sub-Saharan region. Among HIV positive children, more than 90% also come from the Sub Saharan region (UNIAIDS/WHO, 2006). Each year, close to 600,000 children are infected with the HIV virus from their mothers worldwide, with the majority in developing countries. Estimates show that 1.2% of the children 0-4 years are HIV positive and 90% of them have acquired the infection from their mothers. Among all the HIV positive babies, 65% are infected during labor and delivery WHO/UNIADS/UNICEFUNFPA (2003).

The prevalence of HIV in Malawi is estimated at 14% among the reproductive age group of 15-49 years. Mother to Child transmission is the second most common mode of transmission of HIV in Malawi. Increasing numbers of children have HIV infection, especially in the countries hardest hit by the pandemic. In 2006, an estimated 2.3 million

children under 15years of age were living with HIV/AIDS, a total of 530 000 were newly infected, and 380 000 died. By far, the main source of HIV infection in young children is MTCT (Joint United Nations Programme on HIV/AIDS, 2006).

The HIV virus may be transmitted during pregnancy, labor and delivery, or by breastfeeding. HIV/AIDS transmitted through mother to child has been estimated to account for about 8% of deaths in children fewer than five years of age in sub-Saharan Africa. In areas where the prevalence of HIV in pregnant women exceeded 35%, the contribution of HIV/AIDS to childhood mortality was as high as 42% (Ministry of Health December 2005) In the sub-Saharan Africa and other regions with high HIV prevalence, about one in three children born to mothers with HIV become infected (Brocklehurst, 2002) by contrast, mother to child transmission of HIV in developed countries has been reduced to less than 5% through antenatal HIV testing and antiretroviral therapy (Bulterys and Fowler, 2000).

“Every year in Malawi 30,000 children are born that are infected with the HIV virus. A large part of these infections can be prevented. Almost all of these infections could be prevented and mortality markedly reduced by the delivery of a comprehensive package of prevention and care interventions. The current coverage and uptake of services to prevent the transmission of HIV infection in most resource limited settings, including those with a high burden of HIV infection, is still too low to have a meaningful impact on the epidemic among children." (Joint Mission for PMTCT and Pediatric Treatment, Malawi, Oct 2005)

Inadequate PMTCT service providing facilities has also proved to be a major challenge to PMTCT uptake (Ministry of Health December 2005),For instance in Nkhotakota district, PMTCT is offered in two health facilities which are not adequate to serve the rural population. People still have to travel on foot to reach the nearest health centre which can be as far as 30km away. Many areas are impassable during the rainy season making it impossible for patients and health personnel to reach them (UNICEF/WHO 2006).

The PMTCT pilot programme by Zimba et al (2004) showed that 46% of the HIV mothers received Nevirapine. Even though this programme designed an intensive follow up system for the mothers, keeping the HIV positive mothers in the programme was their greatest challenge. Similarly, a study conducted in Uganda by Bajunirwe and Mizoora revealed that the strongest predictor of willingness to accept an HIV test and join the PMTCT programme was the woman's perception that her husband would approve of her testing for HIV. Women who thought their husbands would approve were almost six times more likely to report a willingness to be tested compared to those who thought their husbands could not approve. In some circumstances where women have consented to an HIV test without the husband's approval, the women suffered domestic violence (Bajunirwe and Mizoora 2005).

Another study done by Krah on barriers to PMTCT uptake done in South Africa showed adequate awareness and appreciation of the benefits of VCT by both providers and the community. Providers' and the community's views were similar. However, a few gaps in

the knowledge of the community members were exhibited about the perceived disadvantages of VCT. A number of varied and complex factors were identified as barriers to the acceptance and uptake of VCT. The study concluded that a vigorous and innovative information, education and communication (IEC) drive with accurate, consistent and culturally appropriate messages is required to reduce the community-related barriers to uptake of VCT, in addition to couple counseling. These will positively impact on the uptake of VCT during the scaling-up of PMTCT and increase its cost-effectiveness (Krah 2004)

Current infant feeding recommendations by WHO and UNICEF for mothers who are HIV positive indicate replacement feeding where it is feasible, safe, and acceptable; of which if these conditions are not met, which is difficult to achieve in developing countries settings; then exclusive breastfeeding is recommended (WHO, UNICEF 2003). However, in Malawi the norm for infant feeding in most communities is mixed feeding and not exclusive breastfeeding (NSO 2004). A number of studies as highlighted by Chopra have found out that mixed-fed infants are at a greater risk of acquiring HIV than those breastfed exclusively. Infants up to 3 months of age given both breast milk and other foods have 24.1% risk, while those exclusively breastfed have 14.6% risk and non-breastfed infants have 18.8% risk. In the context of HIV/AIDS then, being just breastfed or exclusively breastfed can mean either life or death for an infant (Chopra et al 2002).

When an HIV-positive mother chooses not to breastfeed or stop breast feeding later, they should be provided with specific guidance and support for at least the first two years of

the child's life. It is recommended that government policy makers should either subsidize or provide free infant feeds for HIV-positive mothers (WHO, UNICEF 2003). The greatest challenge for this recommendation is that most governments like Malawi cannot afford the policy making it difficult to implement PMTCT programme.

The ministry of Health (MoH) monitoring and evaluation report states that the Ministry's 5 year scale up plan (2006-2010) has set a target of 75% coverage of pregnant women with a comprehensive package of PMTCT services. According to a report of a countrywide survey of HIV and AIDS services in government facilities in 2004, it was estimated that only 2.3% of pregnant women who were HIV+ received Nevirapine. The main explanation to these findings was unavailability of the PMTCT services as only 7% of the health facilities with Antenatal Clinic (ANC) were providing the services by then (Ministry of Health December 2005).

1.2 Statement of the Problem

Since 2004, the Ministry of Health, Christian Health Association of Malawi (CHAM) and other non-governmental organizations like GOAL Malawi support the implementation of the PMTCT role out plans. Regardless of all these efforts, PMTCT services uptake by pregnant mothers has been poor. Only 10-20% of HIV positive pregnant mothers in the Goal health centres deliver at the health facilities to receive for PMTCT (GOAL Malawi annual report 2005). This study will therefore determine barriers to utilisation of PMTCT services and make recommendations on how to improve the services in these health centres.

1.3 Study Justification

Nevirapine reduces the risk of Mother to child HIV transmission (Bulterys and Fowler 2000). The Voluntary Counselling and Testing (VCT) and PMTCT role out plans for the Malawi government is expected to reduce the HIV infection rates at all levels. The results from this study may help inform policy on what the barriers to uptake of PMTCT services are and how to address them. As GOAL Malawi is expanding to Nsanje district and other health facilities in Blantyre and Balaka, the study results may be used to reduce such barriers in the new working areas.

The results will be submitted to the College of Medicine as a dissertation. The results may also be submitted in a peer reviewed journal for publication. An abstract will be submitted for presentation at the College of Medicine research dissemination day.

CHAPTER 2 - STUDY OBJECTIVES

2.1 Broad Objective

The main objective of the study was to establish factors contributing to low uptake of PMTCT services in Blantyre and Balaka Rural areas.

2.2 Specific objectives

1. Identify knowledge of mothers and communities on the available PMTCT services at their health facilities
2. Establish the role of the spouses/husbands in accessing PMTCT services
3. Identify barriers to women's uptake of PMTCT services
4. Explain what can be done to address the barriers to PMTCT uptake.
5. To establish knowledge on PMTCT among PMTCT health providers

CHAPTER 3 METHODOLOGY

3.1 Study Design

This was a quantitative and qualitative cross sectional study conducted in Mdeka, Mlambe, Chileka and Lundu health centers in Blantyre and Kankao, Chiyendausiku and Phalula Health Centers in Balaka district. GOAL Malawi works in the seven health centers of the two districts. Triangulation strategy was used to enhance trustworthiness of elicited data. Qualitative design was used to better understand the direction of causality of low PMTCT uptake. The study involved multiple data sources and perspectives to reduce the chance of systematic bias. Use of both qualitative and quantitative methods allows immediate crosschecking and replication of results.

3.2 The target population

Mothers, men and key informants from the communities of Mdeka, Kankao and PMTCT providers from the seven health facilities supported by GOAL namely; Blantyre (Mlambe hospital, Mdeka, Chileka and Lundu health centers) and Balaka (Balaka district hospital, Chiyendausiku, Kankao and Phalula health centers).

3.3 Sampling

3.3.1 Description of the sample

6 Focus Group Discussions (FGDs) from Blantyre and Balaka of

- 6-10 men either married or in union with women in the child bearing age.
- 6-10 key informants from the health facility catchment areas were selected for a FGD e.g. 1-2 representatives in each category of Traditional Birth Attendants,

Initiation counselors, Group village heads and religious leaders and other community key leaders

- 6-10 mothers from the community in their reproductive age group either married or in union with men.

In depth Interviews of

- Self administered questionnaires with 16 nurses trained as PMTCT providers from the following 7 GOAL supported health facilities: Blantyre (10) (Chileka, Mdeka, Lundu and Mlambe) and Balaka (6) (Balaka district hospital and Kankao, Phalula and Chiyendausiku health centers)
- 10 women who delivered at Mdeka (5) and Kankao (5) health centers and received Nevirapine. These women were identified from PMTCT support groups set up by GOAL Malawi in its catchment area communities.
- 10 mothers who tested HIV positive at Mdeka (5) and Kankao (5) health centers before delivery but declined the PMTCT services and did not deliver at the health facility.

3.3.2 Sampling/selection of study participants

- Purposeful sampling was used for selection of health centres as Mdeka and Kankao health centres were the first facilities to establish PMTCT services in GOAL Malawi catchment areas.
- All nurses trained as PMTCT providers in GOAL Malawi supported health facilities in Blantyre and Balaka were purposefully selected for in-depth interviews.

- 16 health PMTCT providers completed the self administered questionnaires.
- PMTCT up takers were members of the PMTCT community support group called Mother to Mother to Be (M2M2B). These groups were composed of mothers who joined the PMTCT programme and formed a community PMTCT support group (M2M2B) with assistance from GOAL Malawi. GOAL trained the group members in PMTCT advocacy at community level.
- PMTCT non up takers were those mothers who received a PMTCT motivational talk and tested HIV positive, got registered into the PMTCT programme but did not come to deliver at the health facility. PMTCT register book was used and these mothers were followed up in their homes secretly by health surveillance assistants (HSAs) and asked to come to health centre to ensure privacy and confidentiality. The PMTCT provider assigned with the questionnaires at the health centre asked for their consent and all the 10 mothers gave consent to respond to the questionnaire. Registration of those who declined the PMTCT services started in December 2006, consent and in-depth interviews was done from 14th - 19th February in both districts.

- Convenient sampling was used to select participants for Focus Group Discussions (FGDs) from near by villages from the health centre. The selection was done by the principle investigator with the assistance of a youth volunteer a day before the discussions. Ten participants per FGD were then booked for a focus group discussions at the health centre to be conducted the next day. Between 6 to 10 FGD participants turned up per FGD.

3.4 Data collection

Data were collected to explore issues around demand for PMTCT services, specifically looking at acceptability by local communities, perceived quality of PMTCT services, health beliefs (facilitating), and infant feeding practices, incentives and support systems.

3.4.1 Triangulation of data

In order to establish trustworthiness and validity of results different sources of data were chosen. Both qualitative and quantitative approaches were used which includes in-depth interviews of PMTCT providers and mothers on the PMTCT programme and Focus group discussions for key leaders, reproductive aged men and women. Throughout the data collection process and analysis there was consistence in the findings from the five different sources of information.

3.4.2 Researcher as enumerator

The researcher participated fully during the data collection process by co facilitating Focus Group discussions and conducting or observing in-depth interviews. This has had a positive bearing on the reliability of the results in that, the researcher was well acquainted with the study objectives and ensured that respondents had understood well the interview questions in the light of the objectives of the study. However, the PMTCT non up takers were not free to neither be interviewed nor their interview to be observed by others rather than the health facility PMTCT providers themselves. As a result of this 2 community

health nurses PMTCT providers in Kankao and Mdeka health centers were trained and conducted the in depth interviews with the PMTCT non up takers.

3.4.3 Data Collection tools

Data were collected from health workers, PMTCT up takers and PMTCT non up takers through in depth interviews using a designed questionnaires adapted from MHDS questionnaire (National Statistical Office Malawi 2004); Medsins Sans Frontiers (MSF) PMTCT Monitoring and evaluation tools (MSF 2002) and GOAL Malawi HIV/AIDS programme baseline survey (GOAL Malawi 2005) . The question guide for the FGDs was developed by the researcher.

3.4.4 Preparation for data collection.

Permission was sought from the District Health Officers and District Commissioners from Blantyre and Balaka districts to conduct the study. Four data collectors were hired and trained for two days. The data collectors were familiar with data collection as they participated in the comprehensive programme evaluation survey of the same GOAL Malawi HIV/AIDS programme. At the time of their training, the data collectors already had previous experience in conducting FGDs and in-depth interviews. The data collectors practiced on the questionnaires by pairing up and interviewing each other followed by a critique. This exercise promoted familiarization to the tools by the data collectors and improvement of their skills in collecting qualitative data.

Two health workers from the health facilities were oriented on how to conduct an in-depth interview with PMTCT non up takers for half a day.

3.4.5 Administration of questionnaires

FGDs for men, women and key leaders, in depth interviews for PMTCT up takers and PMTCT service providers were conducted between 11th to 16th December 2006 by trained data collectors and the researcher herself. In-depth interviews for PMTCT non up takers were administered by the PMTCT service providers between14-19th February at the health facilities after booking appointments with the mothers through the HSAs to promote confidentiality. The two community nurses were oriented on conducting the in-depth interviews questionnaires to PMTCT non up takers.

The health worker questionnaire was self administered. The questionnaire was distributed a day before the other interviews and submitted the next day when FGDs and PMTCT uptake in-depth interviews took place. Verification for the responses to the questionnaires was done when collecting the questionnaires.

Interviews with PMTCT up takers and Focus group discussions with women, men and key leaders were done at the health facility. Women who declined to join PMTCT programme did not want to be interviewed by anyone else apart from the PMTCT provider to ensure privacy and confidentiality. Demographic data for FGD participants using the attached form was collected on the same day of FGDs. Drinks and snacks were served during the FGDs which took an average time of 1 hour 30 minutes each.

3.4.6 Data handling

Questionnaires were checked on spot at the end of each interview, in case some questions had been omitted. At the end of the day, the questionnaires were re-checked for inconsistencies. In case of such occurring, the researcher went back to the respondent to seek clarity in order to validate the data. All extra notes from the in-depth interviews were stapled to the specific questionnaire and each FGD notes were written in separate notebooks.

Note taking for Focus group discussions was done by one of the data collectors and the researcher was sitting in the discussions to assist the facilitator and observe the trend of issues and themes generating from the discussions. After the FGDs, the researcher typed comprehensive write-ups from the hard copy field notes for each on the 6 FGDs.

3.5 Analysis

3.5.1 Qualitative

Manual qualitative data analysis was ongoing throughout the data collection period. Emergent concepts and themes were identified in the early stages of data generation and after data collection codes have been used to identify common themes and salient issues.

3.5.2 Quantitative data

Quantitative data on participants demographic characteristics, health workers knowledge on the risk of MTCT of the IV virus and others were analysed using SPSS version 12.0.1 and presented in summary tables and graphs consisting of key outcomes broken down.

3.6 Study Limitations

3.6.1 Researcher not taking part in in-depth interviews with women who did not utilise PMTCT services.

Women who declined to join PMTCT programme did not want to be interviewed by anyone else apart from the PMTCT provider to ensure privacy and confidentiality. This meant the researcher could neither observe nor conduct the in-depth interviews. In order to ensure high quality data, two community health nurses PMTCT providers were oriented on conducting the in-depth interviews using the designed question guide. Issues of probing were emphasised during the orientation.

3.6.2 Tape recording was not done

The investigator did not include tape recording during the FGD due to insufficient funds for the study. The note takers were however properly trained on expansion of field notes soon after the FGD. A debriefing session was conducted on daily basis by the investigator and field workers in order to elicit information from all FGS and in-depth interviews conducted on that day from the various section of the question guide.

3.6.3 Time spent in the community

Data was collected in 4 days: one day per site for In-depth interviews for health workers and the second day for in-depth interviews for PMTCT up takers and FGDs. This was a limitation to the study since the more the time spent in the community, the better the quality of data. (Rao, V and Woolcock, M. 2003) recommends a minimum of 1 week in the community for a better understanding of qualitative data being collected.

3.6.4 Sampling

Not all participants booked for focus group discussions turned up for the discussions. The demographic data of those collected was not known as a result there may be systematic differences between those who participated and those who did not participate. In case the characteristics were different, it would be difficult to draw inference about a wider population (Campbell & Machin 1999).

3.7 Ethical Considerations

Verbal consent was sought from participants. Permission to conduct the study was sought from the heads of the facilities. A waiver for ethical approval was obtained from College of Medicine Research and Ethics Committee (COMREC) since this was an evaluation of an ongoing program implemented by GOAL Malawi..

CHAPTER 4 STUDY RESULTS

The presentation of results will be done in two sections. The first section will describe findings from in-depth interviews whilst the second part will focus on results from Focus group discussions (FGDs).

Table 1: Description of the study population

		Balaka		Blantyre		Total
		Male	**Female**	**Male**	**Female**	
FGD	Key leaders	**3**	**3**	**4**	**3**	**13**
	Women	**-**	**7**	**-**	**11**	**18**
	Men	**8**	**-**	**8**	**-**	**16**
Health workers		**1**	**5**	**1**	**9**	**16**
PMTCT uptakes (Mothers)		**-**	**5**	**-**	**5**	**10**
PMTCT Decliners (Mothers)		**-**	**5**	**-**	**5**	**10**
Total		12	25	13	33	83

In the study a total of 83 participants were involved through conducting Focus group discussions and in-depth interviews. In-depth interviews involved 10 mothers on PMTCT programme (5 per district), 10 mothers HIV+ve but declined to enroll for PMTCT services (5 per district) and 16 PMTCT service providers (10 from Blantyre) and (6 from Balaka) had self administered questionnaires. Focus group discussions had 49

participants of whom 13 were key leaders, 18 women and 16 men from Blantyre and Balaka. Average age for the participants was 45 years with an age range of 21-60 years.

4.1 RESULTS FROM IN-DEPTH INTERVIEWS

4.1.1 In-depth interviews with mothers

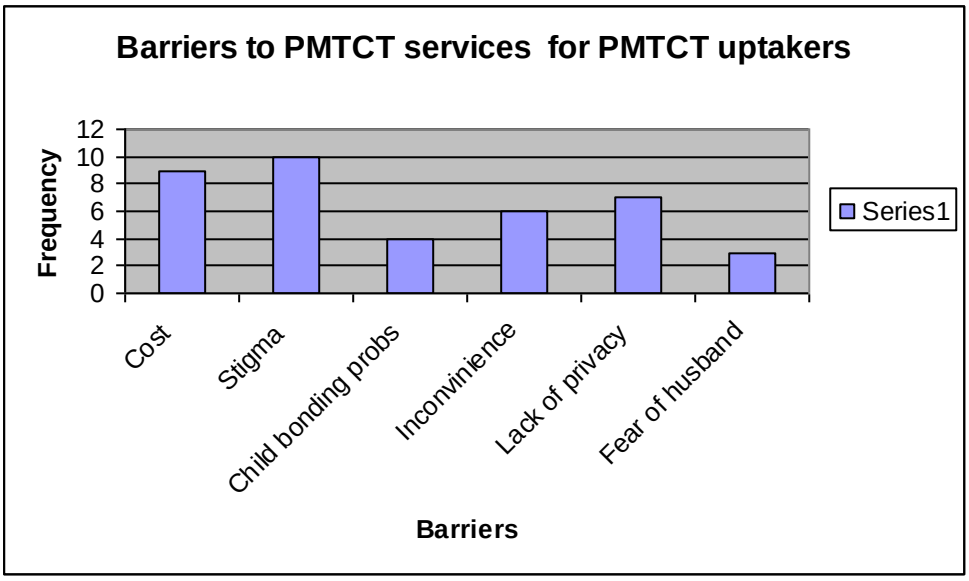
Table 2 describes the different characteristics of the mothers who joined the PMTCT services and those who declined to join the services. The mean age of interviewed mothers was 26 years both for PMTCT up takers and non up takers. All mothers who joined PMTCT services knew MTCT can take place and 3 out of 10 mothers who declined the services did not know MTCT can take place. It is important to note that 9 out of 10 PMTCT up-takers felt the health facility had respect for confidentiality whilst only 4 out of 10 non up-takers felt the health facility had respect for confidentiality. The table also shows that only 1 out of 10 PMTCT up-takers was staying with her partner whilst 6 out of 10 non up-takers were staying with their partners. It is important to note that 8 of the PMTCT uptakers mentioned that their marriage divorces were due to the fact that they joined the PMTCT programme. The table also shows that 9 out of 10 PMTCT up takers felt confidentiality at the health facility was respected whilst only 3 out of 10 non up takers felt the health facility had respect for confidentiality.

Table 2 Characteristics of mothers who joined PMTCT services and those who declined the service

Characteristic	PMTCT up takers	PMTCT decliners
Mean Age	26	26
Educational level		
Standard 5 and below	10	0
Standard 5 and above	0	10
Confidentiality		
Felt health facility respected confidentiality	9	4
Felt health facility did not respect confidentiality	1	6
Knowledge of MTCT		
Knew/believed MTCT can take place	10	7
Never Knew/believed MTCT can take place	0	3
Marital status		
Staying with a partner	1	4
Not staying with a partner	9	6
Average number of visits to ANC		
1-2 visits	4	6
3.4 visits	6	4
Confidentiality		
Felt health facility respected confidentiality	9	3
Felt health facility did not respect confidentiality	1	7

Mothers who joined PMTCT programme were asked on the challenges they meet as PMTCT service up takers. This question was posed for an individual's lived experience. It is important to note that this question had multiple answers.

Figure 1 : Barriers to PMTCT uptake by PMTCT up takers



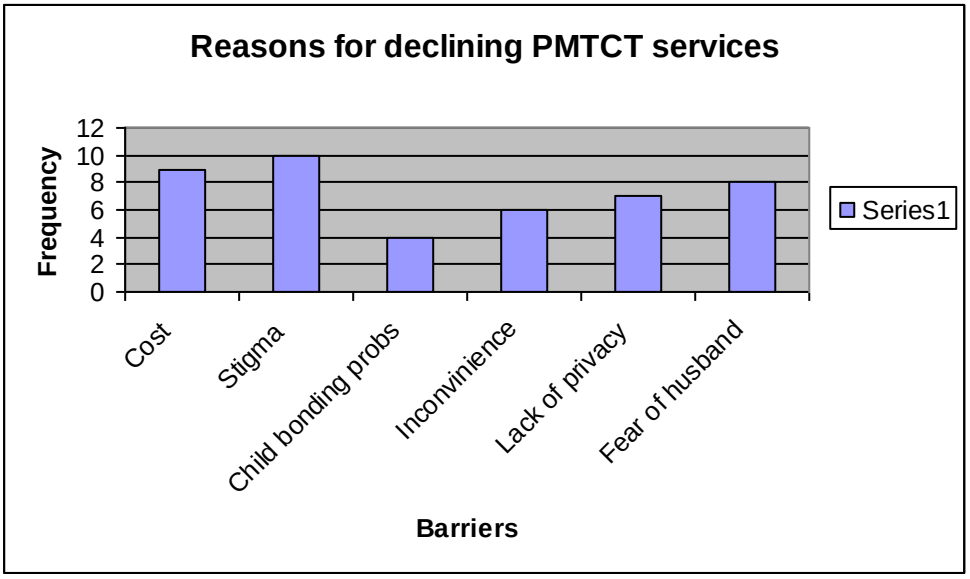
As observed in figure 1, the most commonly cited challenge by all mothers was Stigma and discrimination. Even if the spouse or husband is supportive, relatives can also stigmatize an HIV+ve woman.

''The greatest problem is stigma and discrimination. One day I went for a funeral and we were given nsima for five people but all the women left because they were afraid to contract the HIV virus from me. My relatives did not allow me to touch their kitchen utensils so that they don't contract the virus. But am not worried because my husband is very supportive'' (woman in-depth interview Kankao)

On the other hand some mothers reported some abuse by their spouses after they learnt of their HIV +ve status. 4 out of the 10 PMTCT up takers who were interviewed reported divorce due to their HIV status.

''I told my husband of my HIV status and asked him to go for testing but he totally refused and was not happy that I joined the PMTCT programme. After delivery of my baby the doctors assisted me very well and both the baby and I receive Orofin (meaning Nevirapine) but my husband started to go out with another girl. After a month, he decided to divorce me and went for another woman. I have never received any support from my husband from the time he knew of my HIV status. Now am struggling to bring up my 3 children the baby inclusive'' (woman in-depth interviews Mdeka).

Figure 2: Reasons for declining participating in the PMTCT services by PMTCT non up takers



Those mothers who were HIV +ve but did not join the PMTCT programme were asked on the reasons for refusing to join the PMTCT program. All the 10 PMTCT non up takers mentioned stigma and discrimination against those who are HIV positive as the greatest barrier to PMTCT uptake. The second commonest reason mentioned by 8 out of

the 10 mothers was fear of their husbands. The mothers said that their husbands did not allow them to join the PMTCT programme as a result the HIV positive women chose not to deliver at the hospital as a confirmation to their spouses that they did not join the programme. It is also important to note that this question had multiple answers.

"I was afraid because my husband does not want us to get tested for HIV. Even now if he learns that I came here to have an HIV/AIDS related interview with you I will be in problems. I therefore deliberately had my delivery at home so that my husband should be sure that I have not taken Nevirapine. I would have lost my marriage! I was in a confused state. I did not know what to do." (Woman in-depth interviews Kankao).

"My husband did not like to know our HIV status. When I told him that I was HIV positive, our family broke-up for months. Up to now he does not want to talk about this issue and I decided to deliver my child at home. He says he does not want our family to be known to be HIV positive and be stigmatised for that"(woman in-depth interviews Mdeka).

In addition to fear of spouse, stigma and discrimination, two women said were afraid of witchcraft. They felt if people knew that they were HIV positive, they would bewitch them so that the community would think their sicknesses were due the HIV/AIDS.

"In our family witchcraft is very common. If some members learnt that I was HIV positive, they will get their way through and bewitch me so that in the end they say I died of HIV" (woman in-depth interviews Mdeka PMTCT non up taker).

4.1.2 Indepth Interviews with Health workers

16 PMTCT service providers with an average age of 31 participated of whom one was a registered nurse, 2 were Community health nurses and 13 were enrolled nurse midwives or nurse technician midwives. 10 of the PMTCT service providers were from Blantyre whilst 6 were from Balaka.Data from health workers from the 7 health centres showed that all the 16 health workers were trained in PMTCT and their facilities were providing PMTCT services apart from Chiyendausiku in Balaka which provided PMTCT antenatal services and the women were referred to Balaka district hospital for delivery.

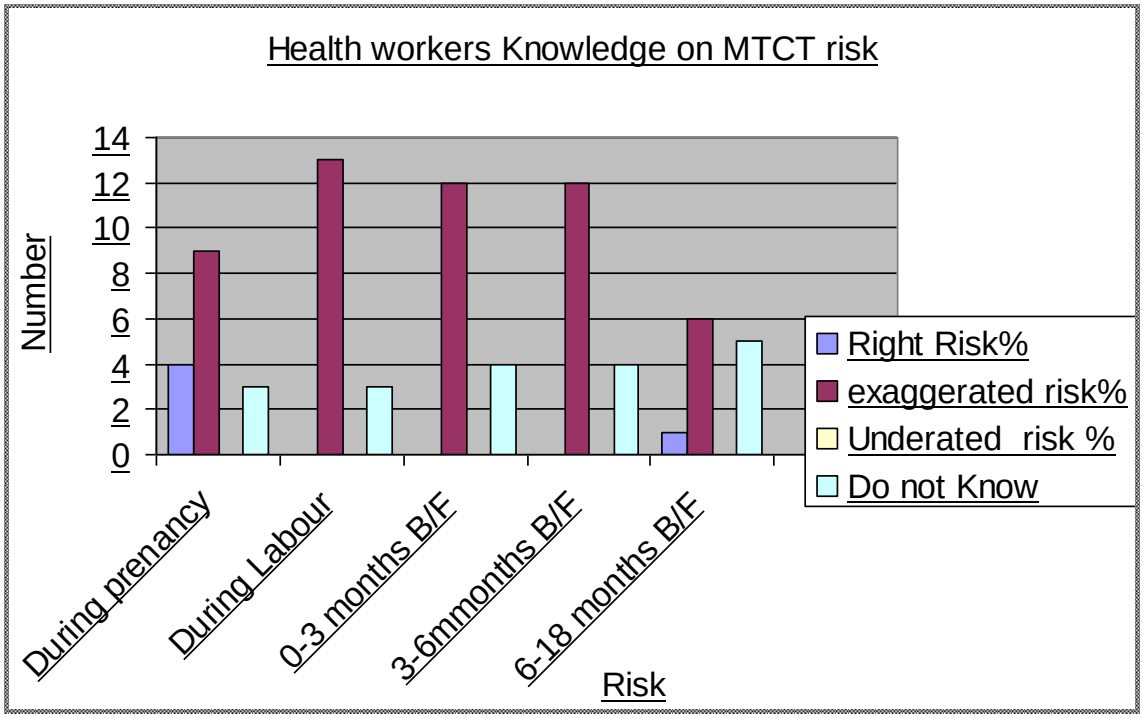
Barriers to PMTCT uptake as perceived by health workers

When health workers were asked what they perceived to be barriers to PMTCT uptake, fear of husbands/spouse related problems, was mentioned by all health workers. Due to shortage of trained nurses in VCT, mothers who report at night in the labor ward whilst in labor are not tested hence denied the opportunity of accessing Nevirapine in case they are HIV+ve. The other most commonly mentioned factors were stigma and discrimination, inability to source infant foods and lack of knowledge in PMTCT. Shortage of health workers was another challenge which leads to mothers taking too long to go through VCT and health workers spending too little time on counseling the mothers.

"We do have critical shortage of staff especially in health centres. Imagine I am the only PMTCT provider at this health centre and I am supposed to be at the health facility 2 weeks of every month as my post is at Chilomoni health centre. I do not have time to provide proper counseling to the mothers" (PMTCT provider Lundu health centre).

Knowledge of health workers on the risk of MTCT of HIV

Figure 3: Summary of risks of MTCT of HIV as perceived by the PMTCT service providers



Health workers were asked on their opinions on the risk of MTCT during pregnancy, labour, and 3-18 months of breastfeeding age categories. These risks were then compared to the known risks according to (WHO/UNIADS/UNICEF/UNFPA 2003) at each stage and then rated as whether right, exaggerated, underrated or if the respondent did not

know. There is need to note that each respondent was required to give 5 responses on this question. Exaggerated or overrated risk was the highest seconded by those who did not know, none of the health workers underrated the risk and only 7.5% of responses were right. Exaggeration and not knowing the transmission risk is a clear indication of knowledge gaps among the health workers.

4.2 RESULTS FROM FOCUS GROUP DISCUSSIONS

The following are themes and sub themes generated from the FGDS

4.2.1 Knowledge on MTCT of HIV

The majority of participants both in in-depth interviews and FGDs knew that MTCT of HIV can take place. The most commonly cited way of transmission was the mixing of the mothers and baby's blood especially during delivery. The respondents also agreed to the fact that MTCT of HIV takes place in their communities

''Yes the mother can transmit the disease to the baby because during delivery the woman's blood is mixed with that of the baby. There is a lot of mother to child transmission taking place in our community'' (No 4 Women's FGD Mdeka)

How ever some of the respondents felt MTCT cannot take place. *''Yes I hear on the radio that an HIV positive mother can pass the virus to the baby but I do not believe this I feel it is not possible'' (No3 Kankao Key leader FGD)*

The majority of respondents from the 6 Focus Group Discussions (FGDs) were not knowledgeable of the PMTCT services available at the health facilities as a result non of them was sure of the quality. Some respondents were actually asking the facilitator from GOAL Malawi to assist with the establishment of the PMTCT programme at the centre. The respondents felt the main contributing factor for lack of publicity of the available PMTCT services was the secrecy surrounding the HIV/AIDS issue under the guise of maintaining confidentiality of ones HIV status.

> *''The services are not available in Kankao health centre but we do hear about it on the radio that in Mwanza they do give HIV+ mothers Orofin (meaning Nevirapine) to protect the unborn baby from contracting the virus. What we can ask for from GOAL Malawi is that you assist us in establishing the services for our women. The problem is that even if they start offering the services here women are too secretive to tell someone of their HIV status.'' (N01 Male FGD Kankao)*

> *''No if the woman has the virus then this innocent baby is at risk of contracting the virus from the baby. But we need this Nevirapine to provided at Mdeka health centre'' (No3 Mdeka key leaders FGD)*

The main contributing factor attributed to men's lack of knowledge on PMTCT services at the health centres was the fact that the clinics are not men friendly. Participants pointed

out on the unfriendliness of the health facilities to men. They indicated that men are in most cases not welcome to be part of women related services.

''The main problem is that the health facility is mainly accessed by women hence men do not feel welcome whenever they join their wives to the health centre'' (No 4 Mdeka Male FGD).

4.2.2 Decision making for PMTCT by mothers

All FGD participants (including women) felt the woman should not make a decision on her own without consulting the spouse (husband). The respondents cited the significant role the husband had in deciding whether the woman accesses PMTCT services or not. The commonly mentioned consequence of the woman making own decision was divorce.

> *''The man is the head of the family a woman cannot just go for a test without prior informing the husband! If a woman is really submissive she has to talk to the husband about it and men cannot refuse for it is for the better mate of their unborn baby. The problem is that if the woman goes on her own and the husband finds out the marriage will end into divorce'' (No 2 Kankao male FGD).*

A woman's positive HIV status was interpreted that the spouse too is HIV positive. The HIV positive status was looked at as a shameful thing to know.

> *''If a woman breaks the news to me that she is HIV positive ndiye kuti andiyalutsa! (Has brought shame on me) Usually in such circumstances the man*

starts selling livestock and all his investments then that's the end of marriage!'' (No 7 Mdeka male FGD)

When the participants were asked on what the government can do to promote PMTCT accessibility by mothers, involvement of husbands was the most commonly cited action. However some few women felt that even though the community looks at husbands as decision makers women can still exercise their rights and go for PMTCT on their own.

4.2.3 Barriers and incentives to PMTCT uptake

4.2.3.1 Cultural practices related to breastfeeding

Majority of participants understood the general risk of MTCT of HIV during breastfeeding. They felt milk production is from the mother's blood and may have the HIV virus if the mother is infected. The most dangerous period narrated during the FGDs was teething period when the baby can bite the mother's breast exposing itself to infected blood.

''Breast milk is produced from the mother's blood and if HIV infected the milk can contain the virus. The other problem is that if you continue breastfeeding the child to the teething age, they bite their mother's breast and be exposed to infected blood. But for those who do not know much may think this woman just wants to kill the baby if she stops breast feeding''.

However the greatest challenge which emerged in all FGDs was acceptability of early replacement feeding by the community. It was noted that early cessation of breastfeeding was associated with mother being pregnant, lack of care and love for the baby or HIV/AIDS.

''If the woman stops breastfeeding it is fellow women who start back biting her. In actual sense the village people cannot allow a woman not to breast feed. They can talk of many things like: the woman

Wants the child to die

Is a witch (akufuna a khwimire mwanayo akafa)

Has HIV virus (Ali ndi kachirombo)''

(No6 Mdeka key leader FGD)

4.2.3.2 Cost related factors

In addition to acceptability of replacement feeding by the community the majority of the participants also pointed out the financial implications the PMTCT programme has. The participants felt the community cannot afford neither replacement feeding nor exclusive breastfeeding for six moths then abrupt weaning as per health workers counselling advise. The main concern of the participants was the fact that milk is very expensive. They would rather spend their little resources on their basic needs than buying infant feeds.

''The most difficult part is where to find money to buy baby milk as is very expensive. If we fail to manage buy flour for nsima how can you afford the milk? The child will end up malnourished and may die!'' (No 5 Kankao male FGD)

However the minority especially women felt that PMTCT was worth it as they have seen children being protected from contracting HIV virus from the mothers through following PMTCT counselling.

‘‘That’s the most important point! (In response to a participant who stressed the importance of following health worker’s advice) I have my brother in law who lost 2 children due to HIV but after they joined PMTCT at Queens and followed counseling advise, now he has two healthy children’’ (No8 Female FGD Mdeka).

4.2.3 3 Stigma and discrimination

Most respondents from all FGDs mentioned that it was difficult for people not to know that the woman is HIV positive if she decides to join the PMTCT programme. Joining of PMTCT M2M2B groups and replacement feeding in the communities was associated with an HIV positive status. Community knowledge of the woman’s HIV +ve status, predisposes the woman to stigma and discrimination.

‘‘For someone like me the community may not know that I am HIV positive. But for a woman on PMTCT programme everyone will know especially if she does not breastfeed the baby and joins GOAL Malawi support groups. The woman can be scolded by people (kutonzedwa ndikunenedwa) if found HIV+. The greatest challenge in this community is stigma and discrimination as a result people get discouraged’’ (No6 Kankao female FGD).

4.2.3 .4 VCT centre related problems

The respondents raised problems related to VCT services, which discourage women from joining the PMTCT services. The commonly cited problems from mainly female FGD members were: lack of confidentiality of ones HIV status by health workers, long waiting time for VCT services and irregular availability of VCT reagents.

"The health centre staff should have respect and have privacy. There are many reasons for that just to mention a few: Some people say that the VCT counselors at the health centre reveal people's HIV status. Sometimes forty women have to be tested for HIV at the same time by one counselor as a result they have to wait for a long time. The government and GOAL Malawi should try to train more people as VCT counselors'' (No 8 Mdeka female FGD)

4.2.5 What to be done to attract women to join PMTCT programme

4.2.5.1 Prolonged breastfeeding period

The majority of participants both in Focus group discussions and in-depth interviews felt that there would be no problem if the PMTCT programme could allow mothers to still breastfeed their babies up to 1 year or more. The participants stated that breast-feeding for 6 months and abrupt weaning or total replacement had cost implications and were also associated with stigma and discrimination. The explanation given was that replacement feeding or early abrupt weaning is not accepted in the 'Malawi culture'.

4.2.5.2 PMTCT community sensitizations

Almost all participants in the six focus group discussions were not aware of the PMTCT services provided at the health facilities. After the participants were briefed on the existence of the services, they felt that the services lack community sensitisations. The participants felt community sensitisations through the chiefs will promote community and spousal support.

4.2.5.3 Male involvement

Most participants made an observation that men are not involved in delivering the PMTCT services. The main reasons cited by participants were: health centres not friendly to men and lack of knowledge of such services by men. Most male participants felt that they need to be properly informed, educated and sensitised on PMTCT services.

4.2.5.4 Provision of supplementary feeds for replacement feeding

The majority of participants also stated that providing mothers on the PMTCT programme with infant feeds could attract mothers to PMTCT services. If you have to decide for PMTCT you have to manage to buy the expensive infant feeds, which is in most cases not affordable at community level. The participants said that most mothers may not take part on PMTCT services due to lack of resources as such provision of infant feeds could encourage mothers.

5.0 DISCUSSION

5.1 Discussion of results

The aim of this study was to establish the factors contributing to low uptake of PMTCT services in GOAL Malawi PMTCT programme implementing areas. The results from this study showed consistency in findings from in-depth interviews for health workers and mothers as well as from Focus group discussions. In this section Triangulation of the 6 different data sources Men, women, key leaders, PMTCT up takers, PMTCT non up takers and PMTCT service providers) will be reflected.

5.1.1 Opposition from male partners

The study showed to some extent that women do not have powers to decide on their own to join the PMTCT programme and that the male partners are the decision makers. Mothers therefore fail to join the PMTCT programme because of opposition from their male partners. Opposition from male partners was attributed to lack of involvement of male partners in delivery of the PMTCT programme. Without the knowledge and support of their spouses, women may rarely be able to follow advice about feeding practices or avoid falling pregnant again. However, as lessons from family planning programmes have shown, the highest uptake of services is achieved where male partners approve and give support for services (Abdula et al 2004). A study conducted by Malawi Human Rights Commission revealed how Malawian culture infringes on the reproductive health rights of women and girls by dictating their role to be of lower profile and make them

unable to make their own decisions (MHRC 2005). Even though there are efforts to empower women in Malawi, cultural values seem to supersede.

Due to the opposition from male partners this study has also established horrendous family break ups when women decide to join the PMTCT programme. As much as the programme aims at protecting the unborn child from contracting the HIV virus from their mothers, family break ups in this study have proved to have more devastating consequences socially, psychologically, economically and culturally. The study has also established that those mothers who are HIV positive experience domestic violence mainly from their spouses for example being chased out of their homes. In circumstances where women have consented to an HIV test without the husband's approval, the women most of the times suffered domestic violence (Bajunirwe and Mizoora 2005)

5.1.2 Stigma and Discrimination

Factors associated with stigma and discrimination against those with HIV/AIDs has been found to be the greatest barrier to PMTCT uptake in this study. The challenge is the lack of confidentiality of one's HIV status in delivery of PMTCT programme. Due to stigma the following issues arise reducing PMTCT uptake:

HIV +ve mothers will try to make sure that the community does not know of their HIV+ve status by not taking Nevirapine or not following the feeding option counsel for the recommendation for early cessation of breastfeeding for HIV-infected mothers conflicts with the Malawian cultural norm of breastfeeding for up to 1-2 years. Similarly in a PMTCT study done by Combs Thorsen findings showed that the women in the study

had an overwhelming fear of being associated with immoral behavior due to HIV being linked to promiscuity, infidelity, and prostitution. As such, they feared that their family would not care for or love them. They also feared that friends would severe all ties and gossip about them Combs Thorsen (2006).

5.1.3 Knowledge of health workers on risk of MTCT of HIV

The results clearly indicate the knowledge gaps among PMTCT service providers on the risk of Mother to Child Transmission of HIV despite the fact that they went through a14 day PMTCT provider's course. The next questions one should ask is "what do the providers tell the mothers during the PMTCT counseling sessions" or "what is the PMTCT providers course content?" Counselors need a deep understanding of the social issues and the household situation, as well as the ability to explain complex scientific concepts on risk in a way that is understood by women who do not ordinarily think in these terms (Coutsoudis 2001). Exaggeration of risk of transmission by health workers may scare mothers leading to low uptake. Health workers perception of risk to the infant of contracting HIV from breastfeeding can affect attitudes and counseling messages of the health workers. As key gatekeepers in influencing mothers' decisions on infant feeding (Seidel 2000), health workers can help to reduce rates of postnatal transmission of HIV and increase child survival by providing HIV-infected mothers with accurate information on infant feeding that captures the risks and benefits of different feeding options (Piwoz et al 2006). Consistent to these findings, Piwoz et al concluded uncertainty in estimation of risk among PMTCT counselors but in this study all the health workers did not undergo a formal PMTCT training. Chopra in a study done in South

Africa also found that there are still gaps in the knowledge of health workers, many of whom are not comfortable counseling women experiencing infant feeding difficulties (Chopra 2002).

5.1.4 Shortage of health workers

In addition to knowledge gap among the health workers, the study has also established lack of time spent by health workers for counseling the mother due to shortage of staff as another challenge. In all the 7 GOAL supported health centers, there is an average of two PMTCT providers per health centre to carter for both day and night shifts. In addition to provision of PMTCT services, they are also responsible for several other activities at the facility. This leads to long ques by antenatal mothers getting VCT services and inability for PMTCT providers spending enough time with the mothers. The WHO guidelines for decision makers on HIV and infant feeding included allocation of staff time for counseling and supporting all mothers with regard to infant feeding as one of the items that should be budgeted for to meet needs (WHO 2003). Health workers need to assess an individual mother's circumstances to ascertain what is most feasible and safe for her. Time is required to explain the factors that increase the risk of breastfeeding transmission of HIV or of morbidity from replacement feeds, and to give suggestions to reduce these risks (WHO 2000).

5.1.5 Cultural practices related to breastfeeding

The cultural norms from the study sites was for a mother to mix feed a child for a minimum of 18 months, early cessation was associated with lack of love for the baby by

the mothers as it increases the risk of sickness and death. The PMTCT recommendation of replacement feeding or exclusive breast feeding with early cessation poses a big challenge for the mothers. This finding is consistent with several other studies. Of concern is the fact that, although exclusive breastfeeding is deemed the ideal practice for infants up to about six months of age, even in the general population exclusive breastfeeding is practiced rarely, with only 6% in Mangochi (Kamudoni 2005).

5.1.6 Cost related barriers

The study also established that whether the mother chooses replacement feeding or exclusive breast feeding with early cessation there is a cost attached to it. Unless the PMTCT programme recommends prolonged breastfeeding, or provide free infant feeds, most mothers cannot afford. The WHO infant feeding guidelines recommends that for the entire period that bottle feeding will take place infant milk must be accessible and affordable, and it must be possible to prepare it safely with clean water and utensils. These guidelines highlight that this is almost impossible in most sub-Saharan countries including Malawi where there is extreme poverty. In developing countries, an infant that is breastfed - even just a little - is more than twice as likely to survive its first year as one that isn't breastfed at all (WHO/UNICEF 2003)..

5.1.7 Incentives to PMTCT uptake

Most participants felt that male involvement is the best way forward to promotion of PMTCT services. GOAL Malawi in coordination with Mlambe tried to initiate PMTCT Male championship but the results have been disappointing so far. The study also

revealed that community members from the study sites were not aware of the existence of the PMTCT programme in their health centers and what the programme entails. Even though GOAL Malawi established some M2M2B support groups, they seem not to do much sensitization at community level. For such a programme to excel there is need for community support. Similarly in a study done in South Africa Durban, one of the recommendations was community involvement so that the community and households must be accepting of the fact that a woman doesn't breastfeed her child (Chopra, 2002).

It was also found that PMTCT services are not male friendly. A spouse would feel out of place if he decides to join the wife to the health centers. Making the services male friendly would act as incentives for men to support their women to join the PMTCT programme. In line with this GOAL Malawi plans to implement a new design of a male championship programme adopted from Mwanza district hospital. The new male championship programme design aims at making PMTCT services male friendly and promote male involvement. Without the knowledge and support of their spouses, women are rarely able to follow advice about feeding practices or avoid falling pregnant again. This finding is consistent with findings from other studies done in Malawi and elsewhere WHO (2004).

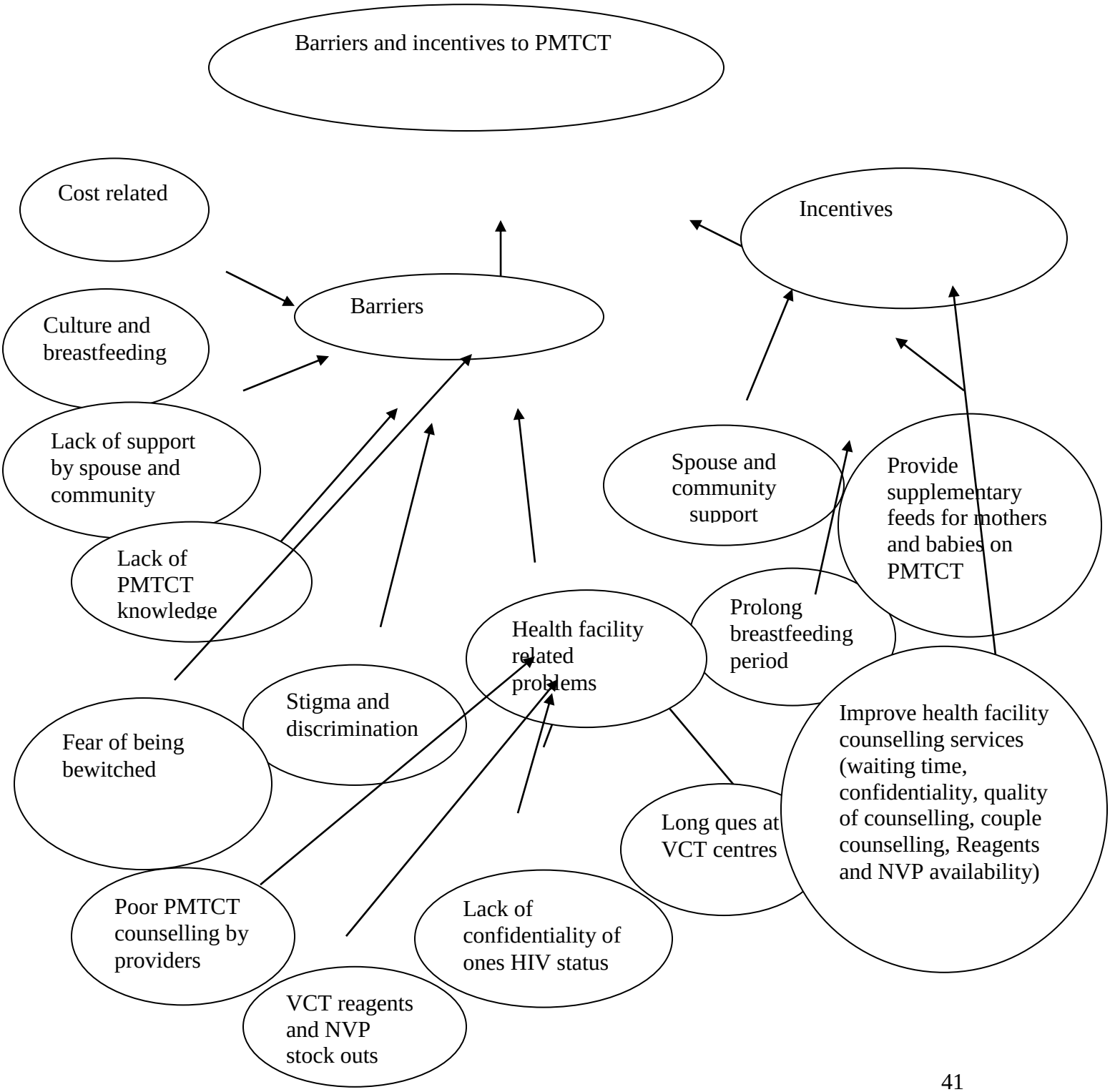
CHAPTER 6 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusions

The government and other stakeholders like GOAL Malawi are trying to establish PMTCT programme in the existing health structures in order to reduce Mother to Child Transmission of HIV. This study has confirmed the low uptake of PMTCT services by he mothers. The main reasons for low uptake of the services identified include stigma and discrimination, opposition from male partners, women's fear of disclosure of HIV status to their partner – and fear of being 'found out' if taking drugs or not breastfeeding, cost of infant feeds, concern about taking drugs in pregnancy, not returning for checkups in the month before delivery, and delivering at home before treatment can be given. The WHO recommendation of replacement feeding or early rapid cessation has proved to be contradictory to Malawian culture according to findings from this study. Therefore, in order to win the battle the cultural values on breastfeeding have to be challenged or the duration of breastfeeding recommendations should be prolonged.

In Synthesizing the discussions from this study this appears to be the interrelationship between the various factors to low PMTCT uptake

Figure 4: Barriers and incentives to PMTCT uptake



The illustration above is the clear indication of the interrelated factors to PMTCT uptake. In order to promote accessibility of PMTCT services by mothers, there is need for a holistic approach to solving the problem. It is interesting to note that on incentives apart from spouse and community involvement in the PMTCT programme the rest of the incentives are to be provided by the PMTCT service providers. It is necessary to involve men at the point of HIV testing through couple testing since they play a significant role in decision making process in Malawi. Raising awareness of the programme among the community will promote community involvement and support of the mothers on the PMTCT programme. Training of health workers and simplifying the counseling content in protocols for easy reference can improve the quality of counseling given by the PMTCT providers.

6.2 Recommendations

In view of the above findings therefore, the following recommendations are put forward:

1. There is need to promote involvement of the male partner and the wider family in the MTCT programme. Couple HIV counseling and testing would be a way to greater involve men. A criticism of MTCT services is that they are too female focused, which may be understandable given that most of these services are linked to antenatal clinics. However, as lessons from family planning programmes have shown, the highest uptake of services is achieved where male partners approve and give support for services.
2. Need to establish Father to father to be (F2F2B) support groups in order to promote male involvement and PMTCT support by males.

3. To achieve a high success rate, PMTCT programmes service providers must have well-trained, supportive staff who take great care to ensure confidentiality. A protocol should be developed on the type of information to give during counseling including the risk and feeding options. This should be accompanied with monitoring and evaluation of the quality of counseling given to the mothers by the providers.
4. Ensuring confidentiality and providing services in such a way that it is impossible to tell whether the individual is part of a PMTCT programme would address a key obstacle to utilizing available services: fear of being discriminated against by health workers, the community, by family members and partners is an obstacle to entering PMTCT programmes.
5. There is need to intensify education of mothers and their spouses on infant feeding practices in order to address the low adherence to recommended breastfeeding practices. There are strong cultural barriers to the recommended feeding strategies: Exclusive breast feeding and rapid cessation or total replacement feeding.
6. Involving the family and community is key factor to both designing appropriate service delivery, as well as increase demand for services. GOAL Malawi PMTCT programmes already do this through activities such as mother to Mother to Be (M2M2B) community support groups. Key leaders will also be oriented on the PMTRCT programme in the next phase. These activities need to be further integrated into PMTCT activities and scaled up.

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APPENDIX 1

Health worker Self Administering interview questionnaire

UNIVERSITY OF MALAWI

GOAL MALAWI HIV/AIDS PROGRAMME

A. <u>INSTRUMENT I: PMTCT UPTAKE BARRIERS AND INCENTIVES – HEALTH WORKER</u>

DECEMBER 2006

1. **QUESTIONNAIRE IDENTIFICATION NUMBER** |___|___|___|
2. **DISTRICT** O Blantyre O Balaka
3. **FACILITY NAME**

   _____

4. **Health Centre type:** O Ministry of health O CHAM
5. **JOB TITLE OF THE RESPONDENT:**

   _____

6. DATE OF INTERVIEW: _____/_____/____

Introduction: "My name is Juliet Nyasulu; I'm working for the GOAL Malawi. GOAL is implementing an HIV/AIDS programme in your area through the community of Kankao/Mdeka health centres. We're interviewing women from this community to

collect more information which can assist GOAL and the government of Malawi to better implement the HIV/AIDS programmes.

Confidentiality and consent: "I'm going to ask you some very personal questions that some people find difficult to answer. Your answers are completely confidential. Your name will not be written on this form, and will never be used in connection with any of the information you tell me. You do not have to answer any questions that you do not want to answer, and you may end this interview at any time you want to. However, your honest answers to these questions will help us better understand what people think, say and do about certain kinds of behaviors. Can I go ahead? We would greatly appreciate your help in responding to this survey. The interview will take about 20-30 minutes. Are you willing to participate?"

1. Demographic information

No.	Questions and filters	CODING CATEGORIES	Skip to
1.	Sex of respondent	• M/F	
2.	What is your current technical qualification	• Clinical Officer • Registered Nurse • Enrolled Nurse/midwife • Community Nurse • Trained Midwife • Others (specify)	
3.	In what year did you start working in your current position in this facility?		

2. What are some of the challenges you face when providing health care services (Put a letter indicating the degree of challenge for each item)?

4.	Lack of time Patients unable to pay fees	A=Not a challenge B=Minor Challenge	

	Lack of patient education Patients non-compliance Lack of hospital resources Lack of personnel Lack of teamwork Lack of training Others specify	C=Major Challenge D=Not applicable For example if Lack of time is a minor challenge then it should show Lack of time (B)	

3. PMTCT and Reproductive health services

5.	Does your health facility offer PMTCT services?	• Yes • No	
6.	Do you think all pregnant women should be encouraged to go for VCT	• Agree • Disagree • Don't know	
7.	**How does the clinic ensure that client confidentiality is maintained?**	• Don't know • Client records are locked up • The importance of confidentiality is discussed during a staff meeting • Other, Please specify	
8.	Do you personally provide Prevention	• Yes	

	of Mother-to-Child Transmission (PMTCT) support services:	• NO	
9.	In your opinion what is the risk of mother to child transmission during the following times in percentage?	• During pregnancy = • During labor = • During the first 3 moths of breast feeding = • During the first 6 months of breastfeeding = • Breastfeeding from 6 to 18 months =	
10.	**If you provide PMTCT services, how many clients on average per month do you serve?**		
11.	**What is the most common feeding option do mothers on PMTCT programme chose**	• B/Feeding • Replacement feeding • Mixed feeding • Others	
12.	The PMTCT uptake for mothers is good	• Strongly • Agree • Disagree • Don't know	

13.	What challenges or problems do mothers meet in making the decision to join the PMTCT programme

14.	What challenges or problems are the women meeting whilst in the PMTCT programme

15.	What reasons do mothers give for not accessing the PMTCT Services (Please explain in details)

16.	What should be done to promote accessibility of the services to the mothers? (Please explain in details)

APPENDIX 2 MOTHERS' IN-DEPTH INTERVIEW QUESTIONNAIRE

GOAL MALAWI HIV/AIDS PROGRAMME

B. INSTRUMENT I: PMTCT UPTAKE BARRIERS AND INCENTIVES - MOTHERS

DECEMBER 2006

QUESTIONNAIRE IDENTIFICATION NUMBER |___|___|___|

DISTRICT_____

NAME OF HEALTH CENTRE _____

VILLAGE_____

Date of interview……

Introduction: "My name is Juliet Nyasulu; I'm working for the GOAL Malawi. GOAL is implementing an HIV/AIDS programme in your area through the community of Kankao/Mdeka health centers. We're interviewing women from this community to collect more information which can assist GOAL and the government of Malawi to better implement the HIV/AIDS programmes.

Confidentiality and consent: "I'm going to ask you some very personal questions that some people find difficult to answer. Your answers are completely confidential. Your name will not be written on this form, and will never be used in connection with any of the information you tell me. You do not have to answer any questions that you do not want to answer, and you may end this interview at any time you want to. However, your

honest answers to these questions will help us better understand what people think, say and do about certain kinds of behaviors. Can I go ahead? We would greatly appreciate your help in responding to this survey. The interview will take about 20-30 minutes. Are you willing to participate?"

Demographic information

No.	Questions and filters	CODING CATEGORIES	Skip to
17	How old are you		
18	Please state your level of education	• NEVER WENT TO SCHOOL • STD 1-5 • STD 5-8 • SECONDARYYY SCHOOL • TERTIALLY LEVEL	
19	What is your marital status	• MARRIED OR LIVING WITH A PARTNER • SINGLE • DIVORCED • WIDOWED • OTHER S SPECIFY	
20	What is your occupation	• TEACHER • NURSE • FARMER • HOUSEWIFE • OTHERS SPECIFY	

4. Antenatal Care (ANC)

No.	Questions and filters	CODING CATEGORIES	Skip to
21	During your pregnancy, did you attend Antenatal care (ANC)	• YES • NO	
22	Did you decide on your own to start ANC or someone had to decide for you?	• MYSELF • DECIDED WITH SOMEONE ELSE • SOMEONE ELSE DECIDED	
23	If someone else; could you tell me who helped you decide?	• HUSBAND OR PARTNER • RELATIVE FROM HUSBAND SIDE • OTHER FEMALE RELATIVE • FRIEND • OTHER (SPECIFY)	
24	How many visits did you make all together	• ONCE • TWICE • THREE TIMES • FOUR TIMES OR MORE	

25	Were there any difficulties in attending regularly from problems like money, transport or getting off work?	• YES • NO	
26	If yes what are these difficulties	• MONEY • TRANSPORT • GETTING OFF WORK • LONG WALKING DISTANCE • OTHER (SPECIFY)	

5. Knowledge about Mother to Child Transmission (MTCT) of HIV: A lot of people are talking about HIV/AIDS these days. I would like to ask you these questions

27.	Can a mother who is HIV positive and healthy transmit the virus to the baby?	• YES • NO	
28.	*If yes* Can the virus pass from mother to the baby During pregnancy During labour and delivery	• YES /NO • YES/NO • YES/NO	

	During breastfeeding		
29.	Are there ways in which this transmission can be prevented?	• YES • NO	
30.	If yes which ones	• Taking Nevirapine by the mother and baby • Exclusive B/Feeding then abrupt weaning at 6 moths • Replacement feeding • Others (specify)	

6. Thinking about the care received at the health facility

31.	Were you offered special information (counselling) about HIV/AIDS at your first ANC visit?	• YES • NO .	

32.	Did you feel that your confidentiality was respected?	• YES/NO	
33.	What did you like about the counseling?		
34.	What did you not like about the counseling?		
35.	Were you offered an HIV test during During ANC During labour After delivery	• YES/NO • YES/NO • YES/NO	
36.	Did you decide to get an HIV test?	• YES/NO	
37.	Did you decide on your own to get an HIV test?	• YES/NO	
38.	If someone else could you tell me who helped you decide?	• HUSBAND OR PARTNER • RELATIVE FROM HUSBAND SIDE • OTHER FEMALE RELATIVE • FRIEND • OTHER (SPECIFY	

39.	Would you mind telling me about your HIV status?	• YES/NO	

7. Knowledge and accessibility to PMTCT services (This part in more qualitative and questions 36-46 requires probing and the write up to be done on a separate sheets).

40.	Have you ever heard of PMTCT services	• YES/NO	
41.	Dof you have available PMTCT services in the nearest health facility?	• YES/NO	
42.	*If HIV+ :* did you take Nevirapine (Show her a sample of the tablet) *If no skip to question 38*	• YES/NO	
	If yes to question 26		
43.	At what pregnancy stage were you given the drug	• 8 months • Before 8 months • During labour • Other (specify)	
44.	At what pregnancy stage did you drink the drug	• 8 months • Before 8 months • During labour • Others (specify	
45.	Did your baby receive the Nevirapine	YES/NO	

	syrup?		
46.	At what age did your baby receive the Nevirapine syrup?	• Within 72hrs after birth • Others specify	
47.	What feeding option did you chose for your baby?	• Breast feeding • Replacement feeding • Mixed feeding • Others (Specify)	
48.	Are you having problems with the your choice of feeding option	YES/NO	
49.	If Yes to 32 what are they?	• Cost • Convenience • Stigma and discrimination • Bonding with the child • Others specify	
50.	Do other women on the programme have problems with the feeding options of their choice?	YES/NO	
51.	If Yes to 34 what are they?	• Cost	

		• Convenience • Stigma and discrimination • Bonding with the child • Others specify	
52.	Why did you decide to take Nevirapine?		
53.	What challenges or problems did you meet in making the decision to join the PMTCT programme		
54.	What challenges or problems are you meeting whilst in the PMTCT programme		
55.	Have you ever thought of dropping or regretted for joining the PMTCT programme?	YES/NO	
56.	Why or why not		
57.	Other women decline to opt for PMTCT services after being well informed on the positive HIV status. Why do you think that happens?		
58.	What should be done to promote accessibility of the services to such women (in question 37)		

	If no to question 26		
59.	Why did you decline to take up the programme?		
60.	Have you ever regretted and felt you would have joined the programme?		
61.	Why or why not?		

APPENDIX 3 : FOCUS GROUP DISCUSSIONS QUESTION GUIDE

GOAL MALAWI HIV/AIDS PROGRAMME

TOPIC GUIDE FOR FOCUS GROUP DISCUSIONS

DECEMBER 2006

FGD IDENTIFICATION NUMBER |___|___|___|

DISTRICT O Blantyre O Balaka

FACILITY NAME

_____

Health Centre type: O Ministry of health O CHAM

JOB TITLE OF THE RESPONDENT:

_____

DATE OF INTERVIEW: _____/_____/____

Introduction: "My name is Juliet Nyasulu; I'm working for the GOAL Malawi. GOAL is implementing an HIV/AIDS programme in your area through the community of Kankao/Mdeka health centers. We're interviewing women from this community to collect more information which can assist GOAL and the government of Malawi to better implement the HIV/AIDS programmes.

Confidentiality and consent: "I'm going to ask you some very personal questions that some people find difficult to answer. Your answers are completely confidential. Your name will not be written on this form, and will never be used in connection with any of the information you tell me. You do not have to answer any questions that you do not want to answer, and you may end this interview at any time you want to. However, your honest answers to these questions will help us better understand what people think, say and do about certain kinds of behaviors. Can I go ahead? We would greatly appreciate your help in responding to this survey. The interview will take about 20-30 minutes. Are you willing to participate?"

[redacted]

Conduct a warm up session of the discussion

A. Introduce each and take the particulars of the participants using the designed form and introduce the facilitator, note taker and self-introduction of participants.
B. Purpose of the FGD
C. Explain and reassure the group on confidentiality
D. Get consent from the group

1 Knowledge about Mother to Child Transmission (MTCT)

E. Many people talk about HIV/AIDS nowadays, is it possible for and HIV+ mother to transmit the virus to her baby?
F. If yes to A; how can she transmit the virus to the baby?
G. Is MTCT taking place in your community currently?

2. ***Prevention of mother to child transmission (PMTCT) of HIV services: availability and quality***

    A. How can a baby be protected from getting the HIV virus from an infected mother?

    B. Is it possible to prevent MTCT of the ~HIV virus? If yes how?

    C. Does your health center provide PMTC services

    D. How does the community look at the quality of PMTCT services at your health center

3. ***Prevention of mother to child transmission (PMTCT) of HIV services : accessibility***

    A. Do mothers from the community receive PMTCT services at Kankao/Kwitanda health center

    B. For a mother to join the PMTCT programme she has to have an HIV test and if positive gets registered into the programme. Who makes a decision for a mother to join the PMTCT programme?

    C. In your community whom do you think is supposed to make a decision for a mother to join the PMTCT programme?

4. ***Prevention of mother to child transmission (PMTCT) of HIV services –social support***

    A. What are the roles and responsibilities of a spouse (husband) in PMTCT?

    B. Usually in PMTCT a mother is supposed to either breastfeed the child exclusively for only 6 moths or not breastfeed at all. How does your community look at this?

5. ***Prevention of mother to child transmission (PMTCT) of HIV: barriers and incentives***

   A. What are the challenges or problems faced by mothers who decide to register for PMTCT programme?

   B. What should be done by the community to promote accessibility of PMTCT services by mothers

   C. What should be done by the government to promote accessibility of PMTCT services by mothers

   D. What should be done by the health providers to promote accessibility of PMTCT services by mothers

Appendix 4 : Focus Group Discussions demographic data for participants

NO	Age	Religion	Educational level	Marital status
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				
11.				
12.				