

**Influences of HIV on Exclusive Breastfeeding: An Exploration of
Community-based Peer Support in Rural Malawi**



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DECLARATION

I, Agatha Kapatuka Bula, confirm that the work presented in this thesis is my own.

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ABSTRACT

Exclusive breastfeeding (EBF) for 6 months is recommended as the most cost-effective public health intervention to improve child survival particularly in Sub-Saharan Africa and is central to achieving Millennium Development Goal number 4 for child health. However, despite the benefits of EBF to infants and mothers, the rates continue to decrease as the age of the infant increases in an African cultural context including Malawi. There is increasing literature on the effectiveness of community-based peer counselling on EBF promotion in resource-poor settings but its effectiveness in the context of HIV and experiences of HIV positive women with the intervention remains a gap.

The purpose of this thesis was to explore determinants of EBF using MaiMwana infant feeding peer-counselling intervention conducted in Mchinji, Malawi as a case study. Specifically, in this study I explored the effectiveness of the intervention to help HIV positive women to overcome the barriers and examine people's experiences and perceptions towards the intervention with respect to HIV and poverty. I adopted qualitative in-depth interviews with 39 informants, including breastfeeding mothers, peer counsellors and key informants who were purposely selected. The data was analysed using a framework approach.

I found that despite having good knowledge, women from rural communities face considerable challenges while practicing EBF. Cultural beliefs, economic constraints, lack of power and support, and fear of transmitting the virus to their infants were cited as major barriers that prevented them from practicing EBF. Overall, the findings from this study suggest that peer counsellors are well accepted by service-users and other community members as they positively viewed their frequent visits as providing additional support, reinforcing infant feeding messages and provide psychological support to women resulting in improved EBF rates. Furthermore, the presence of peer counsellors was viewed as "bringing services at their door step" which reduced time and cost to travel to the health facility.

Nevertheless, the findings suggest that voluntary work in resource-poor settings presents considerable challenges such as: poor motivation due to lack of incentives, overworking, lack of knowledge and time to handle HIV positive cases and poor supervision. In order to effectively promote EBF in resource-poor settings, public health programme designers and implementers need to consider these barriers so as to design community-based interventions that suit the local context and create an enabling environment.

GLOSSARY OF TERMS

AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ARV	Antiretroviral
ART	Antiretroviral therapy
BSS	Behavioural Surveillance Survey
BFHI	Baby Friendly Hospital Initiative
BF	Breastfeeding
CD4	Cluster of differentiation 4
CDC	Centre for Disease Control
CHAM	Christian Health Association of Malawi
CHW	Community Health Worker
CBI	Community-based Interventions
CPT	Co-trimoxazole Prophylaxis Therapy
CRCT	Cluster Randomized Controlled Trial
DEHO	District Environmental Health Officer
DFID	Department for International Development
DHO	District Health Office
EBF	Exclusive Breastfeeding
ERF	Exclusive Replacement Feeding
FGD	Focus Group Discussions
FPAM	Family Planning Association of Malawi
GBV	Gender-Based Violence
GDP	Gross Domestic Product
GoM	Government of Malawi
HDI	Human Development Index
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HSA _s	Health Surveillance Assistants
HCW _s	Health Care Workers
HTC	HIV Testing and Counselling
IDI	In-depth Interview

IMR	Infant Mortality Rate
IYCF	Infant and Young Child Feeding
MDG	Millennium Development Goals
MDHS	Malawi Demographics and Health Survey
MDICP	Malawi Diffusion and Ideational Change Project
MHRC	Malawi Human Rights Commission
MLSFH	Malawi Longitudinal Study of Family and Health
MMR	Maternal Mortality Ratio
MNMC	Malawi Nurses and Midwives Council
MoH	Ministry of Health
MoHP	Ministry of Health and Population
MPH	Masters of Public Health
MTCT	Mother-to-child transmission of HIV
NAC	National AIDS Commission
NGO	Non-Governmental Organization
NHSRC	National Health Sciences Research Committee
NRU	Nutritional Rehabilitation Unit
NSO	National Statistical Office
PBC	Perceived Behaviour Control
PCN	Postnatal Care
PMTCT	Prevention of Mother-to-Child Transmission of HIV
PI	Principal Investigator
RA	Research Assistant
RCT	Randomized Controlled Trial
SHCWs	Skilled Health Care Workers
SIDA	Swedish International Development Authority
SLA	Service Level Agreement
SSA	sub-Saharan Africa
STI	Sexually Transmitted Infections
TBA	Traditional Birth Attendant
TB	Tuberculosis
TPB	Theory of Planned Behaviour
UCL	University College of London
UNAIDS	Joint United Nations Program on HIV and AIDS

UNGASS	United Nations General Assembly Special Session
UNICEF	United Nation Children’s Fund
UNC	University of North Carolina Project
USA	United States of America
USAID	United States Agency for the International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

1.1. Summary

In this doctoral thesis I focus on exclusive breastfeeding (EBF) practices for the first 6 months of life—considered as a key strategy to promote nutrition and child survival in resource-poor settings. Scientific evidence demonstrates that EBF contributes to reduced infant morbidity and mortality due to diarrhoea, respiratory infections and other infectious diseases (Coutsoudis et al., 2001; Jones et al., 2003; Kramer and Kakuma, 2012). Although the health benefits of EBF are widely known, it is well documented in the literature that EBF rates remain globally whereby less than 40% of infants under the age of 6 months are exclusively breastfed (UNICEF, 2012). In the developing world including sub-Saharan Africa (SSA) approximately 38% of infants are exclusively breastfed for 6 months (UNICEF, 2012). Yet, in most countries located in SSA including Malawi breastfeeding is dominant. This clearly indicates that it is not enough to help women to initiate breastfeeding as it is the case with the Baby Friendly Hospital Initiative (BFHI). Lack of support at community level, may be one important barrier for women to practice EBF for the recommended 6 months period but often remains neglected. I therefore, argue that breastfeeding mothers need on-going support in order for them to maintain EBF behaviour at community level where mixed feeding is dominant, cultural beliefs conflict with hospital advice and women have less power to make their own decision on how to feed their infants.

For this study, I have elected to move beyond hospital promotion of EBF to understand in more depth why women do not manage to practice EBF for the recommended 6 months period despite being supported in the maternity and at community level. The thesis emanates from a case-study of the MaiMwana infant feeding peer counselling intervention which took place in Mchinji district, rural Malawi (Lewycka et al., 2010). The main aim for conducting this PhD study was to explore rural women's experiences with EBF behaviour and community-based intervention, focusing on how the programme worked and the complexity of conducting home-based peer support in the context of HIV and poverty. I believe that the findings presented here have retained its relevance because the results of the MaiMwana community-based intervention were not available while doing my work and were published in the final stages of my analysis. Before summarizing the rationale and outlining the objectives of my thesis, I start this introduction chapter by giving an overview of what

inspired me to conduct a study on determinants of exclusive breastfeeding and experiences with community-based promotion of exclusive breastfeeding using peer counsellors in rural Malawi, especially in light of HIV and poverty. Finally, I present an overview of the thesis.

1.2. The journey through my doctoral thesis

As noted by Burgess (2000), the gaps observed in the literature review done by a researcher and also familiarity with the social setting of the study area constitutes the real start of a particular research problem. For me, a combination of my professional background in nursing and midwifery and my previous work experience, coupled with the literature review constitutes the inspiration to conduct this present study as part of my PhD.

Prior to starting my PhD, I worked for over 7 years with the University of North Carolina (UNC) project¹ in Lilongwe, Malawi. I also worked as a trainer and a supervisor of HIV counsellors (who were not medical personnel) for the Malawi Longitudinal Study of Family and Health (MLSFH) third and fourth waves (2004; 2006)² (Anglewicz et al., 2009). During this period, HIV positive mothers who were routinely asked whether they were practicing EBF at each study visit would report to have successfully practiced EBF without any problems. At first, I believed in what they said to me and thought EBF was a simple behaviour that every woman would easily perform. However, as time went on, I witnessed many children below the age of 6 months being diagnosed with HIV and malnutrition, yet their mothers reported consistent EBF at every study visit. Additionally, my own personal experience on breastfeeding as a Malawian mother alerted me that it is not an easy option for women in the country to practice EBF beyond 3-4 months without introducing supplementary feeds. Further, having given birth in this same community, I also experienced pressure to conform to the customary remedies of giving traditional medicines to my own baby during the first month. I also learnt that most Malawian women experienced the same pressure to give traditional medicines while attempting to breastfeed their own babies exclusively for 6 months. According to tradition, the idea behind this practice is to strengthen the baby and protect him/her from childhood illnesses mainly associated with magic. As a working mother,

¹ The UNC Project is collaboration between the University of North Carolina in Chapel Hill and the Malawi Ministry of Health. It is a centre of excellence for conducting both HIV/AIDS biomedical clinical trials and social sciences research in sub-Saharan Africa.

² Longitudinal surveys that examines the role of social networks in changing attitudes and behaviour regarding family size, family planning, and AIDS in rural Malawi (see <http://malawi.pop.upenn.edu/>)

I also remember that I had to introduce my child to milk formula at 3 months of age because I was expected to go back to work. Again, the vast majority of women in Malawi fail to practice EBF for 6 months as recommended because they are culturally expected to start giving maize porridge at 3 or 4 months. Due to these insights, I eventually started questioning whether these study participants were managing to practice EBF as recommended.

Over the years I spent working in Malawi, I was also concerned with the quality of counselling provided to HIV positive women present at the study clinic considering the complexity of counselling HIV positive women to practice EBF for 6 months³. Later on I learnt that nurses and HIV counsellors providing Prevention of Mother-to-Child Transmission of HIV (PMTCT) services in Malawi as elsewhere in high HIV-prevalence countries of SSA were continuously confronted with enormous challenges while implementing the World Health Organization infant feeding guidelines (Leshabari et al., 2007a; Ferguson et al., 2009). These guidelines encourage health workers to impart information to women and allow them to make informed choices whether to exclusively breastfeed or completely avoid breastfeeding (WHO, 2006a; 2010a). The challenges to implementing these guidelines were mainly due to poverty and the deep rooted socio-cultural beliefs and practices that support breastfeeding and mixed feeding but often remain unrecognized.

In 2007 I enrolled in Master of Public Health (MPH) programme at the University of Sheffield where my research topic was “*Knowledge, attitude and practices towards exclusive breastfeeding among HIV positive women in Lilongwe, Malawi*” (Bula, 2009). Through this research, I learnt that despite the numerous motivating factors for HIV positive women to choose EBF, HIV positive women in Malawi face numerous challenges while practicing EBF. Some of these challenges include: lack of power and control over infant feeding, inadequate counselling and support to practice EBF, stigma associated with HIV status, and expectation to go back to work within three months after giving birth (Bula, 2009). However, since this study was conducted in an urban setting, these anecdotal findings made me to realize the need to understand more deeply into the challenges faced by women in rural Malawi who have access to limited resources, have low socio-economic status and are highly

³ The Malawi Government HIV Counselling and Testing Guidelines (HTC) (2003) recommend an average of 8 clients per one counsellor in a day.

dependent on men, and how they are supported to deal with the problems. Being a novice researcher, I became motivated to do this study as part of my PhD.

I then embarked on reading a substantive number of articles related to breastfeeding promotion. The literature highlighted that in Malawi and other countries located in sub-Saharan Africa the key focus of promoting exclusive breastfeeding is through the Baby Friendly Hospital Initiative (BFHI) in maternity facilities despite severe shortages of skilled health care workers (SHCWs). However, it was clear in the literature that such interventions do not take into considerations the cultural and the social environment in which women perform the intended behaviour (Bezner-kerr et al., 2007; Fjeld et al., 2008; Østergaard and Bula, 2010; Arts et al., 2011). This literature search further uncovered community-based intervention studies conducted in Bangladesh, India, Ghana, Burkina Faso, Uganda, South Africa, Tanzania that used peer counsellors to promote EBF which attracted my attention (Morrow et al., 1999; Haider et al., 2000; Bhandari et al., 2003; WHO, 2003a; Aidam et al., 2005; Bland et al., 2008; Tylleskar et al., 2011). Evidence from these interventions indicates that interventions targeting the whole community are more effective and reliable in promoting the rates of EBF in developing countries even in countries located in SSA.

Through the review of this literature, I became aware that the community-based intervention by MaiMwana project which used peer counsellors with the aim of promoting maternal and infant health including EBF in rural Malawi was a remarkable intervention (Lewycka et al., 2010). Insights from this project provided me with an opportunity to have a clear picture of what is on the ground. On reflection, I realize that the MaiMwana community-based intervention did not investigate experiences of HIV positive mothers with the visit who were hiding their HIV status from their family members and peer counsellors and thus not receiving the support they needed; and also the challenges faced when counselling HIV positive mothers who disclosed their status to peer counsellors during the visit. In a face-to-face discussion with Dr. Sonia Lewycka, one of the MaiMwana Project investigators she agreed that my proposal to explore whether the intervention was useful in the promotion of EBF among HIV positive women and also in exploring experiences of counsellors and attitudes of stakeholders would be a beneficial adjunct study. The MaiMwana community-based intervention therefore, constitutes my case study, which has been investigated throughout this thesis.

1.3. A brief background to the MaiMwana community-based intervention

The MaiMwana project is a registered charitable trust established in 2003 as collaboration between the Department of Paediatrics at Kamuzu Central Hospital, Mchinji District Hospital and the University College London (UCL), Centre for International Health and Development. This project was funded by Saving Newborn lives; UK government through its Department for International Development (DFID); the Wellcome Trust; National AIDS Commission (NAC) and UNICEF, Malawi. The intervention was implemented in Mchinji district through women's groups and home-based health education by peer counsellors with the ultimate goal of promoting maternal and infant health in hard-to-reach communities with high HIV prevalence rate and lack of resources (Lewycka et al., 2010)⁴.

The work of MaiMwana can be located firmly to the previous successful studies on community-based interventions conducted in Bolivia and India (O'Rourke et al., 1998; Manandhar et al., 2004). The Warmi project was conducted in remote hilly areas of Bolivia (O'Rourke et al., 1998). Over a period of three years, this intervention achieved a 60% reduction in perinatal death. Similarly, the MIRA Makwanpur project involved a cluster-randomised controlled trial of such an intervention in rural area in Nepal (Manandhar et al., 2004). MaiMwana project decided to design a similar trial to test the intervention to assess its effectiveness in a high HIV prevalence area. It aimed to reduce maternal and infant mortality in the district through community-based health promotion interventions, health service strengthening and research. Additionally the project has been taking a lead in scaling up PMTCT activities in the district since 2004 and is well known in as far as male involvement is concerned. The intervention was a five-year (2005-2010) community-based cluster Randomized Controlled Trial (RCT designed to:

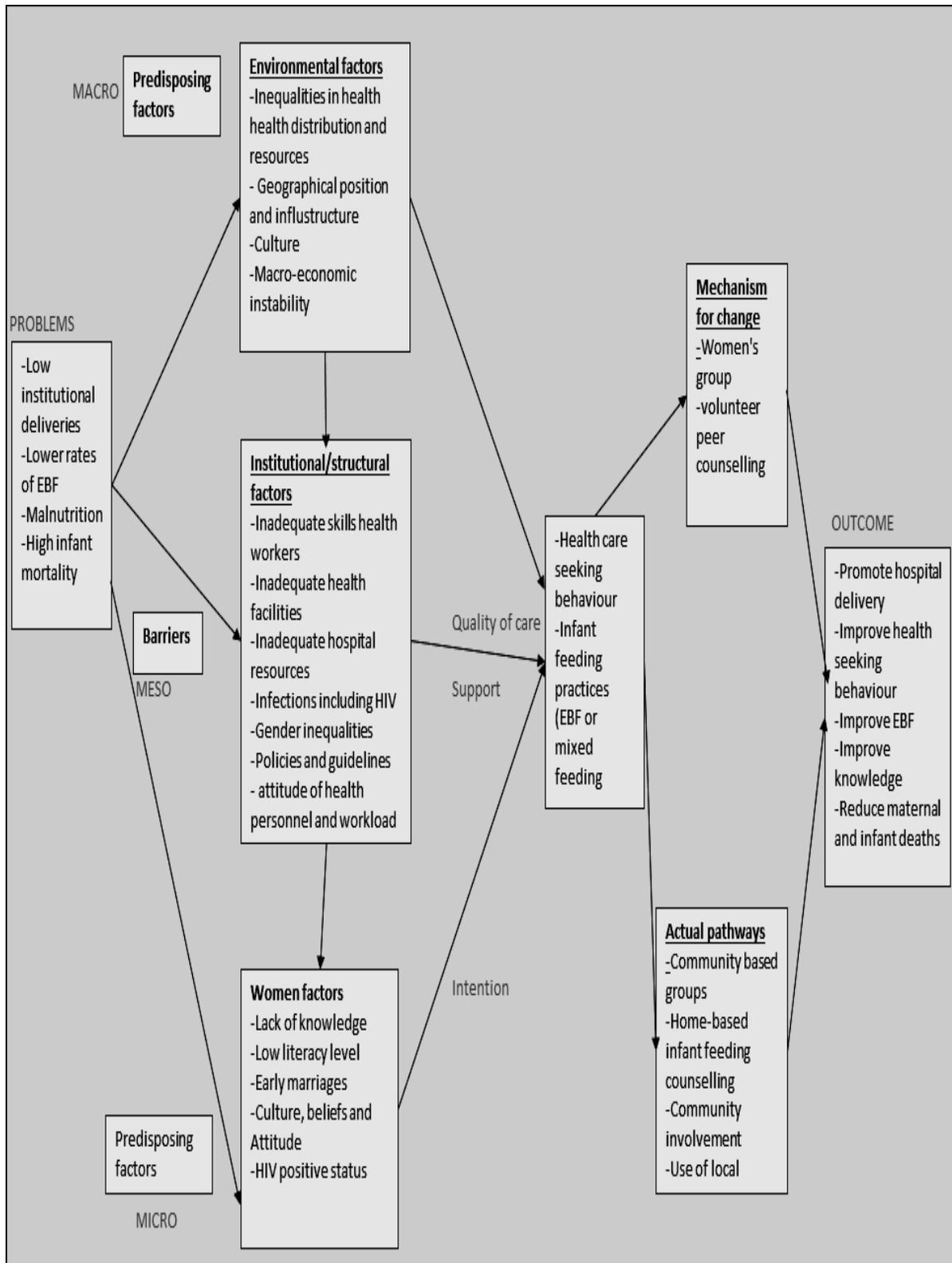
- Assess the impact of a community mobilization intervention through women groups on home care, health care seeking behaviour and maternal and infant mortality in the rural community.
- Assess the impact of volunteer-led infant feeding and care support on the rates of EBF and uptake of HIV prevention services (Lewycka et al., 2010).

⁴Trial number: ISRCTN06477126 and NHSRC number: Med/4/36/1/167

1.3.1. Factors influencing the MaiMwana community-based intervention

At baseline, Lewycka et al. (2010) observed that despite high antenatal care (ANC) attendance among women in the clusters where the intervention was implemented estimated at 91.2% at baseline, only about one-third (36.1%) of them delivered in a health facility and one quarter (25.0%) attended postnatal care (PNC) within 42 days of delivery. Given the fact that the majority of women give birth outside the hospital, it was recognized that the health system would not be able to provide immediate benefit to those who delivery outside the hospital. Furthermore, as in many parts of the country, the district was experiencing increased maternal and infant deaths. The fact that the government of Malawi have had challenges to cope with the situation due to shortage of health personnel and lack of resources, the project intensified community participatory and the need to work with volunteers in order to provide policy-relevant answers to promote maternal and child health. Figure 1-1 summarises the key drivers that prompted MaiMwana investigators to come up with the interventions to improve maternal and child health in rural Malawi

Figure 1-1: Theoretical perspective behind the MaiMwana Intervention and intended outcome



A total of 48 clusters were randomly assigned equally to either one of the following interventions: Women's' group plus volunteer peer counselling, women's group only, volunteer peer counselling only, or no intervention.

1.3.2. Women's group intervention

Women's group intervention was implemented in 24 clusters with a total population of 72,129 at baseline. Twelve of these clusters received women's groups as the only intervention while the other 12 clusters received both the women's group intervention and the volunteer infant care counselling intervention. The women's group was designed to assess the impact of the groups on maternal, perinatal, neonatal and infant mortality (Lewycka et al., 2010). The aim was to building the capacity of the communities and empower them to take control of maternal and child health issues affecting them and employ social networks in the community as "the agent for behavioural change". The women group employed and trained local female facilitators which were divided into 24 clusters, one in each cluster. These facilitators invited all women of bearing age in their allocated clusters to attend meetings to identify problems that affect maternal and child health and come up with locally feasible strategies on how they can be prevented and managed at community level. Women in the control clusters did not received any support in their homes but were rather encouraged to continue with their monthly hospital appointments where they also received infant feeding counselling. Furthermore, the group considered the influence of naturally existing resources of social and community support to promote implementation of the strategies identified. Thus, men and community members were included during the meetings and used locally available resources. MaiMwana project only provided support and guidance.

1.3.3. Volunteer peer counsellor intervention

The volunteer peer counselling intervention recruited local women commonly known as "MaiMwana volunteers" to visit and support women in their homes from pregnancy until the child is 6 months old. The intervention aimed at providing health education to raise awareness, change the attitude and build self-efficacy of mothers in relation to EBF. The project select 72 female volunteer peer counsellors aged between 23-50 years with previous breastfeeding experience. Peer counsellors working for this programme received three types of training: initial, on-the-job and refresher training sessions. The initial training consisted of

classroom lessons and a practical component and lasted for a period of five days. Peer counsellors were chosen because of their familiarity with the clusters and their acceptance within their communities as trusted and reliable sources of information. MaiMwana project collaborated with traditional leaders such as chiefs and other influential people from the community where the intervention was taking place in the selection procedures of peer counsellors to be engaged in these activities. The aim was to make sure that the community is able to select individuals who they felt were responsible enough to do the work on their behalf rather than making selections for them. Before selection of volunteers, the project team organized meeting with community leaders and briefed them about the aims and objectives of the project that is to help promote maternal, neonatal and infant health in the community and promote health-seeking behaviour among women including exclusive breastfeeding. They also briefed them about what is expected from them and the selection criteria of volunteers. Volunteers were selected based on whether they can read and write the local language, have given birth before regardless of their age and reside in the selected clusters. All the volunteer peer counsellors were women and the majority were un-employed. According to the project plan, they used locally available resources in order to implement the intervention. This means that the project did not pay salaries or stipend to these volunteers for the services rendered. MaiMwana volunteers rather received few incentives in the form of allowances for the training, transport refund given at seminars and bicycles to use for transportation and also received some incentives in kind. Further information about MaiMwana project is available on the project website (www.maimwana.org).

The MaiMwana intervention has significantly led to 30% reduction in neonatal mortality and maternal mortality ratio was reduced by 52% overall. Additionally, through the intervention, exclusive breastfeeding rates increased more than two times and brought about changes in health-care seeking behaviour that significantly led to a reduction of both neonatal and maternal morbidity within the intervention areas (Lewycka et al., 2013). However, the researchers found that the effect on EBF rates was only significant in areas with women's group intervention after stratification.

1.4. Rationale for this doctoral thesis, main aim and objectives

Despite high levels of HIV and high HIV prevalence rates in Malawi estimated at 10.6% (Malawi Demographic and Health Survey (MDHS), 2010), like other community based

interventions conducted in resource poor settings, the MaiMwana intervention focused on all pregnant women regardless of their HIV status and used local women to work as volunteers (Morrow et al., 1999; Haider et al., 2000; Bhandari et al., 2003; WHO, 2003a; Aidam et al., 2005; Bland et al., 2008; Tylleskar et al., 2011), (Morrow et al., 1999; Haider et al., 2000; Bhandari et al., 2003; WHO, 2003a; Aidam et al., 2005; Bland et al., 2008; Tylleskar et al., 2011). Because of this, the experiences of HIV positive women who were visited at home and the needs of peer counsellors who were expected to provide infant feeding counselling and support to women during home visits, were not fully explored.

It therefore, became clear to me that there is a gap between the theory and the personal experiences of peer counsellors regarding visiting HIV positive women—let alone experiences of HIV positive women who were visited at home considering that their needs and cultural values were not taken into consideration when designing such interventions. It was also noted that the MaiMwana intervention was designed by researchers from western countries with limited knowledge and experience of the local cultural context, potentially not truly reflecting the values of an African society. It must be emphasized that failure to know whether the intervention had an impact on EBF practices among HIV positive women creates a critical gap in effective public health programming, leading to huge limitations not only in reducing HIV transmission to infants but also reducing infant mortality and achieve Millennium Development Goal (MDG) number 4. This thesis is thus, conducted to address the current knowledge gaps.

As already described above, the MaiMwana intervention used women from the same communities to work as peer counsellors and some may happen to be related to the clients enrolled into the programme. Additionally, it is clear in the literature that some HIV positive in Malawi do not disclose their HIV status to some of the significant others who are known to play a role in infant feeding; and some do not feel comfortable to disclose their HIV status to counsellors coming from the same community (Angotti et al., (2009). It is therefore, necessary to understand how peer counsellors working with MaiMwana intervention who were blinded to maternal HIV status identify HIV positive women and provide the right counselling and support while maintaining confidentiality. The fact that these peer counsellors received a short training, it was equally important to explore the value and quality of counselling offered to women especially those with HIV; this would likely be helpful to improve the type of training offered to peer counsellors more especially on how to assist HIV

positive women. There is also lack of evidence about the challenges faced by peer counsellors while performing their work in rural settings with high levels of poverty and HIV and reactions of clients' partners and significant others following the visit. It was therefore, important to explore these challenges in order to identify better ways likely to influence the effectiveness and sustainability of the programme within the local context.

This research study was designed as a qualitative exploratory study. The main aim was to gain deeper insights and understandings on issues and factors that influence exclusive breastfeeding from participants' perspective. Particularly, I sought to determine whether home-based peer support assisted women to overcome barriers—taking into considerations the experiences, ideas and opinions of HIV positive women and peer counsellors as a central point of focus. It is important to recognise that HIV-infected pregnant women are faced with a dilemma: to choose EBF immediately after being diagnosed with HIV because they cannot afford infant formulas without consulting significant others, at the same time think of how to maintain exclusive breastfeeding in communities where mixed feeding is common and protect their infant from contracting HIV through breast milk. A number of policy implications to improve the working conditions of peer counsellors are identified in this thesis. The research project sought to increase reflections on the challenges faced by peer counsellors, to improve the type of training offered to them so that they are provided with more information and support to effectively counsel HIV-positive mothers at community level. Others seek to mitigate the disadvantages of using unpaid peer counsellors, who rely on farming economically, by considering giving them some allowances for the work done with their organizations. The three main research questions being addressed throughout this doctoral thesis were as follows:

- What factors promote or hinder the intention and ability of mothers including those with HIV to practice EBF for the first 6 months of life in rural Malawi?
- To what extent did the MaiMwana community-based peer counselling assist mothers in rural Malawi to overcome the barriers and manage to practice EBF for the recommended 6 months period?

- How did women, peer counsellors and community members perceive community-based peer counselling to promote EBF in light of the HIV epidemic and high levels of poverty?

The specific objectives for this study were as follows:

- To explore factors that could influence women's intention and ability to practice exclusive breastfeeding for the first 6 months of the infant's life.
- To explore experiences and attitudes of HIV positive women toward exclusive breastfeeding and home-based peer support.
- To examine experiences and accounts of peer counsellors with home-based peer support in the context of HIV.
- To explore perceptions and involvement of other support networks on exclusive breastfeeding and home-based peer support to promote EBF.

1.5. My role as a candidate in this thesis

As a principal investigator I designed the study and developed the study protocol, decided on the sample size, sought ethics approvals and coordinated the translation of data collection tools. Additionally, I trained the research assistant on the study conduct, recruitment procedures, consenting process, data collection, management and analysis. In total I conducted 25 semi-structured interviews (out of 39) while the research assistant conducted the remaining 14 interviews. I was also responsible for checking the quality of the transcripts, data management and analysis using NVivo 10.0 software.

1.6. Structure of the thesis

This thesis is structured over 11 chapters. Chapter 2 explores the background literature on the health benefits of EBF and the risks of HIV, including the changes in the World Health Organization infant feeding guidelines for HIV positive women with special emphasis to sub-Saharan Africa. I conclude the chapter by providing an account of EBF rates globally and end with the importance of accurate reporting of EBF rates in the context of HIV. Chapter 3 follows with an overview of the history, economy and the health care delivery system in Malawi with special emphasis to women and children. The chapter further examines the

current HIV/AIDS pandemic in the country with a particular focus on the implications for women and children. A description of an ambitious and multifaceted approach (option B+) which Malawi has adopted to prevent mother-to-child transmission of HIV (MTCT) in the country is included in this chapter and further an explanation is provided on the advantages of such guidelines in the country and other countries in SSA where almost all HIV positive women breastfeed. Chapters 4 and 5 comprise the literature related to hospital-based versus community-based promotion of EBF behaviour. Chapter 4 mainly explores factors that affect breastfeeding among HIV positive women paying attention to the individual, community and hospital settings. Chapter 5 constitutes the literature related to exclusive breastfeeding promotion at community level and discusses the evidence on the value of using peer counsellors, which has mainly been conducted in the developed world. The chapter reviews available evidence related to community-based promotion on EBF, with special emphasis on interventions conducted in the sub-Saharan Africa and considers the practical aspects of implementing such interventions in the context of poverty and HIV. The chapter concludes with the results of MaiMwana interventions, which formed the central case study of this doctoral thesis.

Chapter 6 sets out a description of the research design, philosophical underpinning of the study, planned methods and sampling. I then explain implementation process and data analysis. This chapter concludes by discussing ethical and methodological issues illuminated by the experience of conducting a sensitive study in developing countries. Chapter 7 presents results arising from the general knowledge of respondents about exclusive breastfeeding and how mothers practice EBF in the cultural context. The chapter further presents promoting factors and barriers. Chapter 8 discusses the findings in the context of experiences with home visiting and looks at people's attitudes towards peer counselling versus hospital counselling. Chapter 9 focuses on experiences with community-based intervention in the context of HIV and people's views on the importance of using peer counsellors to visit HIV positive women and the challenges this may present. Chapter 10 discusses the findings comparing and synthesizing responses from the three study groups and relates the analysis to the wider substantive and theoretical literature. This thesis ends with chapter 11 which covers conclusion, study implications and makes suggestions for further research.

CHAPTER 2: BACKGROUND: EXCLUSIVE BREASTFEEDING AND HIV EPIDEMIC

2.1. Introduction

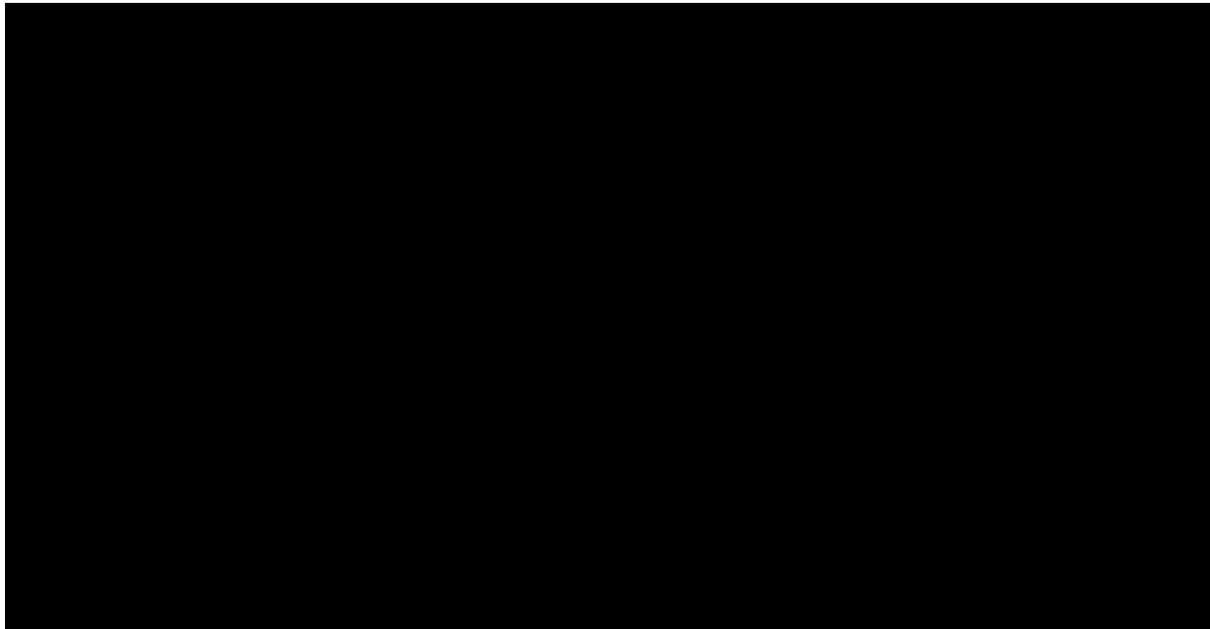
In this chapter I presents a detailed overview of the importance of exclusive breastfeeding. The aim is to highlight the importance of supporting women at community level to promote EBF. This is followed by a review of the magnitude of HIV in sub-Saharan Africa and the risks of MTCT during breastfeeding period. I continue the chapter by providing an overview of infant feeding guidelines for HIV positive women and the challenges of implementing such guidelines in sub-Saharan Africa where HIV prevalence is high. Finally, I summarise the rates of EBF globally and methodological consideration in measuring EBF rates in the context of HIV.

2.2. The relevance of exclusive breastfeeding and child survival

Despite remarkable progress made in reducing child morbidity and mortality worldwide, in 2013 approximately 6.3 million children worldwide under the age of 5 died- a decrease from 7.6 million in 2010 (UNICEF, 2012; World Bank, 2012; Liu et al., 2014). When compared to other regions, the rates of these deaths continue to be concentrated in sub-Saharan African (SSA) countries (about 49.6%) where one in eight children dies before his or her fifth birthday, followed by South East Asia—making SSA the region well known across the world in terms of infant mortality (WHO/UNICEF, 2010a; World Bank, 2012). In 2010, it was estimated that 70% of deaths of children under age 5 occurred in the first year of life, and half of these occurred in the first month of life (World Bank, 2012). According to the Countdown to 2015 Decade Report (2000-2010), around 41% of these deaths were associated with preventable causes such as diarrheal diseases, malnutrition, acute respiratory infections and other infectious diseases including HIV (WHO/UNICEF, 2010a). In particular, under-nutrition, which encompasses stunting, wasting, and deficiencies of essential vitamins and minerals was the most common cause of under-five mortality which accounted for almost one-third of these under-five deaths in SSA (Black et al., 2008; UNICEF, 2012). Poor nutrition among infants has inadvertently slowed down the progress towards MDGs in many countries located in sub-Saharan Africa (United Nations, 2014). The 2014 MDG report demonstrated that the number of stunted children increased alarmingly by one third, from 44

million to 58 million between 1990 and 2012 in sub-Saharan Africa (United Nations, 2014). Figure 2-1 depicts the causes of infant mortality globally in 2010.

Figure 2-1: Global distribution of deaths among children under the age of 5 by cause: 2010



Source: UNICEF, 2012, p. 15

In the context of Malawi and other countries located in SSA such as South Africa, Mozambique and Zimbabwe with high HIV prevalence rate, HIV is estimated to have attributed to about 10-28% of the under-five mortality in 2010 compared to 3% in the rest of the world (UNICEF, 2012). Among these countries, South Africa had the highest mortality rates while Mozambique had the lowest estimates attributable to HIV (10%).

In cognizance of the main causes of under-five mortality, at the United Nations General Assembly Special Session (UNGASS) declaration of commitment meeting in 2001, members present at the meeting endorsed exclusive breastfeeding (EBF) for the first 6 months of life as the safest and most cost-effective way of feeding infants worldwide (United Nations, 2001). The World Health Organization (WHO) has defined exclusive breastfeeding (EBF) as “feeding the baby with absolutely breast milk, and no other additional liquids (including water) or solids (with exception of prescribed drops or syrup consisting of vitamins, mineral supplements or medicine is allowed) during the first 6 months of the infant life” (WHO, 1991). The intervention is regarded as imperative for infant survival and to achieve MDG number 4 by 2015 in resource-limited settings particularly in sub-Saharan Africa where poor

and sub-optimal breastfeeding practices result into child malnutrition and mortality (WHO Collaborative Study Team, 2000a; WHO/UNICEF/UNAIDS, 2008a). The global Strategy for Infant and Young Child Feeding (IYCF) Strategy (2002) co-developed by the World Health Organization and UNICEF with broad participation of governments and other stakeholders further recommend EBF for the first 6 months as a global health goal to ensure optimal health and development of infants and improve child survival (WHO/UNICEF, 2003). However, despite these efforts, the rates of EBF remain low worldwide. To better understand why exclusive breastfeeding is highly recommended and promoted, section 2.3 describes its benefits to the baby and the mother.

2.3. Understanding the health benefits of exclusive breastfeeding

The myriad short and long term health benefits of exclusive breastfeeding to both the infant and the mother have substantially been documented in the scientific literature (Coutsoudis, 2000; Kalanda et al., 2006; Kramer, 2010; Kramer and Kakuma, 2012). In respect to infant growth, breast milk contains all essential nutrients, including vitamins and minerals required for the development of the infant (WHO, 1990; Cushing et al., 1998; Butte et al., 2002). Available evidence indicates that human milk contains special anti-infection agents that stimulate the immune system of newborn babies. Ultimately, infants who are exclusively breastfed for 6 months are protected against common childhood infectious diseases such as pneumonia, diarrhoea, otitis media, acute respiratory tract infections and HIV and eventually, experience lower morbidity and mortality than those who are partially breastfed (Hanson, 1999; Kramer et al., 2000; American Academy of Paediatrics, 2012; Kramer and Kakuma, 2012). In addition, EBF prevents childhood obesity in over-fed babies and against wasting in under-fed babies even under conditions in which low quality weaning foods are present (Coutsoudis, 2000; Hummel et al., 2009).

It has been documented in the literature that exclusive breastfeeding is beneficial in both resource-poor settings like SSA and industrialized countries (Palmer, 2009; American Academy of Paediatrics, 2012). With regard to developing countries, in a cohort study of 1,677 infants conducted in the slums of Dhaka from 1993-1995, Arifeen et al. (2001) found that the relative risk of mortality due to diarrhoea and acute respiratory infections in the first 6 months was two-fold lower in the group of infants who were exclusively breastfed than those who were partially or not breastfed. Similarly, in a clinical trial conducted in Malawi

from 2000 to 2003, Taha et al. (2006) found that EBF was associated with a reduction in mortality and morbidity of approximately 60% among children. In the developed world, a large randomized trial in Belarus revealed that infants who were randomized to a breastfeeding promotion intervention and who were breastfed exclusively and for a longer duration grew more rapidly in the first six to nine months. Additionally, these children who were exclusively breastfed had significantly reduced episodes of one or more gastrointestinal infection compared to those who were born and followed at control sites (Kramer et al, 2000). Furthermore, in the large-scale millennium cohort study conducted in the United Kingdom from 2000 to 2002, Quigley et al. (2007) found that 53% of diarrhoea cases admitted in hospitals could have been prevented each month if women had practiced EBF. Black et al. (2008) further reported that high coverage of EBF for 6 months followed by complementary feeding for 2 years have the potential to prevent 1.4 million deaths and 10% of disease burden every year among children under five years globally.

In addition to the health and nutritional benefits of breastfeeding to the infant, breastfeeding has several benefits for the mother. The short-term health benefits include decreased maternal blood loss after delivery through the action of oxytocin that aids in rapid uterine involution (Heinig and Dewey, 1996). It is also known that women who practice EBF experience delayed resumption of menses, which significantly supports pregnancy spacing during the period of lactation amenorrhea (a natural family planning method) and also promote good bonding with the infant (Heinig and Dewey, 1996). Furthermore, EBF decreases the risks of developing breast and ovarian cancer in the long-term (Whittemore et al., 1992; Labbok, 2001), reduce the risks of cardiovascular disease (Schwarz et al., (2009) and is associated with lower level of postpartum depression (Dennis and McQueen, 2009). Besides, EBF also provides economic benefits as it costs nothing to the mother and is always at the right temperature (Baumslag and Dia, 1995).

Despite the overwhelming health benefits offered by EBF to the baby as well as the mother, a myriad of challenges remain in protecting, promoting and supporting breastfeeding in the era of poverty and HIV (Humphrey and Illiff, 2001; Kuhn et al., 2004). In fact, the discovery of Human Immunodeficiency Virus (HIV) in samples of breast milk from HIV-positive mothers still remains a major public health threat to breastfeeding as a fundamental protection of child survival (Thiry et al., 1985; Van de Perre et al., 1988; Van de Perre, 2000). Subsequently, the

recognition that HIV positive mothers can transmit HIV to their babies through breast milk further created a dilemma throughout the public health community on how to protect, promote and support breastfeeding, especially in SSA where breastfeeding is essential for child survival (Centre for Disease Control and Prevention, 1985; Nduati et al., 1995; UNAIDS, 2009; WHO/UNICEF, 2003b; Kuhn et al., 2004). The following section provides an overview of the magnitude of HIV from a global perspective with a particular focus on SSA and also how this affects infant feeding.

2.4. Overview of the global HIV epidemiology

HIV/AIDS continues to be among the greatest health problems faced around the world. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) global epidemiological data on HIV/AIDS, 35 million people were estimated to be living with HIV globally in 2013 (UNAIDS, 2014). The burden of the epidemic continues to vary considerably between countries and regions. Sub-Saharan Africa endures devastating consequences of the HIV/AIDS epidemic with an estimated 24.7 million people living with HIV by 2013. In 2013, an estimated 2.1 million people became newly infected with HIV globally, down from 3.4 million in 2001. Of all the people who were newly infected, 1.5 million occurred in sub-Saharan Africa and heterosexual contact remains the principal mode of HIV transmission among adults (UNAIDS, 2014).

At the end of 2013, an estimated 240 000 children under the age of 15 years worldwide were newly infected with HIV (UNAIDS, 2014). When compared to other regions of the world, an estimated 90% of all new HIV infections among children occurred in sub-Saharan Africa. This is partly attributed to the fact that HIV prevalence among women of reproductive age (15 to 45 years) is higher than men accounting for approximately 58% of the total number of people living with HIV in sub-Saharan Africa and high fertility rate (UNAIDS, 2014).

Available official data indicate that more than 90% of children living with HIV contract the virus through mother-to-child transmission (MTCT) (UNAIDS, 2011). In the absence of any specific interventions to reduce the risk of HIV transmission like the antiretroviral (ARVs) medicine, it is estimated that 10 to 20 percent of the transmission will occur during pregnancy while labour and delivery account for another 10 to 20 percent. Finally, 5 to 20 percent of

infants become infected from their HIV infected mothers who practice customary breastfeeding, which involves breastfeeding combined with other complementary liquids or solids for the first 6 months and prolonged breastfeeding up to 2 years (table 2-1 below) (De Cock et al., 2000). There is evidence that children who contract HIV through mother-to-child transmission (MTCT) are at a higher risk for opportunistic infections including infection of the central nervous system and without appropriate care and treatment 50% of newly infected children will die before their second birthday (Mueller, 1994; WHO, 2007).

Table 2-1: The risks of MTCT of HIV

Breastfeeding Duration Stage of Pregnancy	Rate of HIV transmission without intervention			
	No Breastfeeding	Breastfeeding to 6 months	Breastfeeding to 2 years	Cumulative Risk of Transmission
In utero / antenatal (during pregnancy)	5 to 10%	5 to 10%	5 to 10%	5-10%
Intrapartum (labour & delivery)	10 to 20%	10 to 20%	10 to 20%	10-20%
Postnatal (breastfeeding)	0%	5% to 15%	10% to 20%	0-20%
Cumulative Risk of Transmission	15% to 30%	20% to 45%	25% to 50%	15-50%

Source: De Cock et al., 2000, p. 1176

2.5. Breastfeeding and the risks of mother-to-child transmission of HIV during postnatal period

Breastfeeding accounts for more than one third of all HIV infections that occur to babies born from HIV infected mothers (table 2.1) (De Cock et al., 2000). This accounts for the larger part of the estimated disparities in the risks of MTCT between developed and developing countries. A number of factors related to the mother and the infant were outlined in the literature as influencing the risks of MTCT during postnatal period (Miotti et al., 1999; Newell, 2001; Mbori-Ngacha et al., 2001; Fowler et al., 2008). Newell report that mothers who are recently infected with HIV have a high HIV plasma viral load and are very infectious and therefore, the risks of transmitting the virus through breastfeeding are extremely high

(Newell, 2004). In support of this, Mbori-Ngacha et al. (2001) found that women who become HIV infected during postnatal period, the risks of MTCT through breast milk may rise to twice as high as those of a woman whose infection is already established (29% vs. 15%) because of high viral load associated with recent HIV infections. In addition, mothers who are diagnosed with a low CD4 cell count of less than 200 or have full-blown AIDS have high chances of transmitting the virus to their babies (European Collaborative Studies, 2001). In support of this, in a study conducted in Zambia, Kuhn et al. (2007) found that 86% of early transmission of HIV to the infant occurred among women who had a low CD4 count.

Additionally, breastfeeding duration appears to be one of the major significant determinants of MTCT during the postnatal period. In SSA where breastfeeding is the predominant form of infant feeding, the longer the HIV infected mother breastfeeds the greater the additional risks of MTCT through breast milk (WHO/UNICEF, 2003b). In one study conducted in Malawi, Miotti et al. (1999) found that 47% of 672 children were infected with HIV through breastfeeding and the risk of transmission was found to increase with age and duration of breastfeeding (cumulative risk of 3.5% at one month, 7% at 5 months and 10.3% at 23 months).

Breast conditions such as mastitis (OR=2.7, CI 95 percent 1.1-6.7), and cracked and bloody nipples (OR=2.3, CI 95 percent 1.1-5.0) significantly increase the risks of MTCT during the breastfeeding period (Embree et al., 2000). Also demonstrative of increased risks were the modes of infant feeding. Mixed feeding that involves feeding the infant with foods or liquids alongside with intermittent breastfeeding during the first 6 months of life has been associated with increased risks of HIV transmission to the baby (Coutsoudis et al., 2001; 2008; Piwoz and Humphrey, 2005; Coovadia et al., 2007; Fowler et al., 2008). With regard to this, the mucosae of the gastrointestinal tract of the infant are only capable to digest and absorb substances found in breast milk that are essential for the first 6 months of life. Therefore, if the infant is given complementary feeds before 6 months of age it may cause inflammation reaction and damage to the lining of the baby's mouth, respiratory, gastrointestinal and urinary tract, which provide initial mucosal immune response to all infections—making it easy for HIV and other infections to penetrate the baby's defence (Newell, 2004). In support of this evidence, a study conducted in South Africa by Coutisoudis et al. (2001) established that infants who were fed on solids foods in addition to breast milk during the first 6 months were 10 times more likely to acquire HIV from their mothers than those who were fed on

breast milk only. Additionally, a study carried out in Zimbabwe by Iliff et al. (2005) demonstrated four-fold increased risk of postnatal infant HIV infection among babies who were mixed fed by 4 months compared to those who were exclusively breastfed. Furthermore, Kuhn et al. (2007) in their study conducted between 2001 and 2004 in Lusaka, Zambia found that EBF for 6 months was associated with a substantially decreased HIV transmission among babies who were breastfed exclusively compared with those who were given other foods before 6 months elapsed (4% versus 10.1%).

2.6. A review of the global infant feeding guidelines for preventing MTCT during the postnatal period

The need to control vertical HIV transmission through breast milk especially in resource-poor settings like SSA has been a worrying issue. A number of organizations such as the World Health Organization (WHO), the Joint Programme on HIV/AIDS (UNAIDS) and United Nation Children Funds (UNICEF) have been jointly working together to formulate a series of global infant feeding guidelines with the goal of reducing the spread of HIV among children (WHO, 1998a; 2001; 2003b; 2010b). As a result, these health experts developed these infant-feeding guidelines employing the concept of HIV-free survival. This reflects the public health principle of babies staying free from contracting HIV through breastfeeding while at the same time reducing the risks of child mortality and morbidity due to malnutrition especially in SSA where the disease burden is exacerbated by pandemics such as HIV and AIDS, and limited access to clean water and sanitation (Rollins et al., 1999).

Before the discovery of HIV in breast milk in 1985, the World Health Organization had been promoting exclusive breastfeeding for the first 6 months as the most appropriate way of feeding the infant globally and reducing infant mortality because of its nutritional superiority over commercial formula (WHO/UNICEF, 2003b). By the time EBF was being promoted, the probability of mother-to-child transmission of HIV through breast milk was still undefined. Later reports from studies conducted in Australia by Thiry et al. (1985); Rwanda by Van de Perre et al. (1988) and Nairobi Kenya by Nduati et al. (1995), supported the idea that HIV was detectable in human milk of HIV infected mothers and could be transmitted to their infants through breast milk.

Later on, studies conducted in Europe proved that complete avoidance of breastfeeding from birth reduces the risks of HIV transmission through breast milk to less than 2% (European collaborative studies, 2001; WHO, 2006c). In view of such protective effects of exclusive replacement feeding against HIV, international guidelines endorsed replacement feeding as the best way of feeding infants born from HIV positive mothers. However, it was found to be easier for HIV positive women from high income countries to adhere to completely avoid breastfeeding because of availability of uncontaminated nutritionally adequate breast milk substitutes combined with antiretroviral therapy (ART) and have access to safe water (Piwoz and Ross, 2005; WHO, 2006b; 2010b). Furthermore, in these high-income countries it was common and culturally acceptable for women not to breastfeed even before it became clear that HIV could be transmitted through breastfeeding and also practically safer (Carter, 1995).

Nevertheless, it was noted that in sub-Saharan Africa where HIV prevalence is a major public health problem women could not afford to buy infant formulas and breastfeeding was normative. As a result, the 1992 World Health Organization infant feeding guidelines recommended that in countries where infectious diseases and malnutrition are the main causes of infant mortality like the sub-Saharan region, all women should be encouraged to breastfeed exclusively for 6 months (WHO, 1992). In 1998, the World Health Organization in conjunction with the UNAIDS and UNICEF published new infant feeding guidelines for HIV positive mothers which emphasized that all women should make their own informed choices about feeding their infants according to their individual situation and to be fully counselled and supported with their chosen infant feeding methods (WHO/UNICEF, 1998). These guidelines recommended a selection of infant feeding options for HIV positive women who choose exclusive replacement feeding (not giving the infant any breast milk from birth), which included home modified animal milk or commercial infant formula as the most appropriate way of feeding the infant and reduce the risks of transmitting the virus to babies born from HIV infected women (De Wagt and Clark, 2004).

In recognition that infant formula was too expensive for many HIV positive mothers in resource-poor settings and that all women opted for breastfeeding despite the dangers of HIV transmission, UNICEF started supporting MTCT programmes in 1998. This included the distribution of infant formulas to HIV positive mothers in some countries including 8 countries located in Africa such as: Benin, Burundi, Cote d'Ivoire, Kenya, Nigeria, Rwanda, Uganda and Zambia between 1999 to 2002 (De Wagt and Clark, 2004). Botswana and South

Africa decided to use their own resources to purchase the infant formula. However, this was criticized as acting against informed choices. For instance, Coutsooudis et al., (2002) found that some health workers in Rwanda and Botswana had started promoting infant formula as the best option for HIV positive women. Furthermore, it was noted that availability of free formula influenced some women to choose infant formula as a way of feeding their infants even in places where this option was inappropriate to her living conditions.

Later the programme faced several challenges. Inadequate distribution of infant formulas to PMTCT clinics was one of the problems faced by the programme. Due to this problem, about 40% of mothers in Botswana and South Africa received insufficient amount of the formulas to meet the demand of their babies because the milk did not reach the intended places on time due to lack of transport (De Wagt and Clark, 2004). A trial conducted in Kenya by Nduati et al. (2000) reported poor compliance among women who were randomized to either breastfeeding or formula milk. Women who were assigned to infant formula in this trial reported that they experienced pressure from the community, family, or spouse to breastfeed (Nduati et al., 2000). As a result, some women gave fewer feeds or over diluted the formula to meet the infant demand while others combine infant formula with breastfeeding. Furthermore, it was noted that some women were stigmatized or their relatives demanded to know the reason why they were not breastfeeding. A similar experience was also reported in among women who were interviewed in a formative study conducted as part of the Breastfeeding, Antiretroviral and Nutrition study (BAN study) in Lilongwe, Malawi which involved HIV positive mothers with undisclosed HIV status (Corneli et al., 2007). In one arm of the BAN study some infants were given nutritional supplement in the form of peanut butter which was locally called “Chiponde cha Mwana”. The researchers found that some mothers living in food insecure household reported to have experienced pressure to share the infant supplement with other family members and neighbours (Corneli et al., 2007).

In 2001, the World Health Organization reviewed the existing infant feeding guidelines based on emerging scientific evidence that HIV positive mothers can pass on the virus to their infants through breast milk as compared to replacement feeding (WHO, 2001). Essentially, the consultation was aware of the possible benefits of EBF through the research undertaken in Durban, South Africa by Coutsooudis et al. (1999). This study showed that the risk of vertical transmission of HIV-1 associated with EBF was significantly lower than that associated with mixed feeding (Coutsooudis, 1999; WHO, 2001).

Since then, several other studies conducted in SSA where HIV is a major public health problem further demonstrated strong scientific evidence that EBF for 6 months can significantly reduce postnatal HIV transmission and other infectious diseases during the first 6 months and the serious risks of malnutrition, gastrointestinal infections and other infectious diseases associated with limiting breastfeeding (Coutsoudis et al., 2001; De Cock et al., 2000; Illif et al., 2005; Kuhn et al., 2007). For example, Nduati et al. (2000) highlighted the results of a randomized clinical trial in Kenya which found that the use of breast milk substitute during the first 6 months was associated with decreased HIV transmission by 44% but also with significant increased risks of death of 3.9% as compared to 1.0% risks among the group which was exclusive breastfed. Notably, in a review by Ross and Labbok (2004), breastfeeding by HIV positive mothers was found to increase HIV-free survival by 32 per 1000 live births during the first 6 months of life as compared to replacement feeding and the risks of death from mixed feeding and replacement feeding exceeded the risks of MTCT through exclusive breastfeeding.

It also became clear that no single option can be universally applicable globally as it was initially assumed and that every option needs to take into consideration the local context of infant feeding and the circumstances of the individual mother in the decision-making process (WHO, 2001; 2006c; Piwoz and Ross, 2005; Coutisoudis et al., 2008). The WHO (2001) infant feeding guidelines supported breastfeeding but also strongly acknowledged replacement feeding as the most effective way of feeding infants born from HIV positive mothers. Therefore, the difficulty lies in determining the contexts in which breastfeeding and/or replacement feeding are most appropriate. The guidelines introduced the criteria for health care workers calling for replacement of breast milk only in situations in which it was *Acceptable, Feasible, Affordable, Sustainable and Safe (AFASS)* explained in table 2-2 below which read:

‘When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), avoidance of all breastfeeding by HIV-positive mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life. To minimize HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman’s situation and the risks of replacement feeding’ (WHO, 2001).

Table 2-2: The World Health Organization criteria for assessing appropriateness of formula feeding in low-income settings

ACCEPTABLE	The mother perceived no problem in formula feeding. Potential problems may be cultural, social or due to fear of stigma and discrimination.
FEASIBLE	The mother (or family) has adequate time, knowledge, skills, resources and support to correctly feed the infant up to 12 hours in 24 hours.
AFFORDABLE	The mother and family, with community or health system support if necessary, can pay the cost of formula feeding without harming the health and nutrition status of the family.
SUSTAINABLE	Availability of continuous and uninterrupted supply and distribution of all ingredients needed for safe formula feeding for up to one year of age or longer.
SAFE	Formula milk is correctly and hygienically prepared and stored, and fed preferably by cup.

Source: Adapted from WHO, 2003b, p. 13

Through the new guidelines, health care workers were advised to provide specific guidance and support to women to help them make the best infant feeding choices after receiving counselling on the risks and benefits of various options (WHO, 2001). The implications of the 2001 recommendations were that HIV-infected mothers from high-income settings would completely avoid breastfeeding because they would afford and safely practice replacement feeding. Eventually, HIV transmission has been reduced to less than 2% in the developed world as a result of ARV prophylaxis during pregnancy and labour, elective caesarean section, and complete avoidance of breastfeeding. Similarly, studies conducted in sub-Saharan Africa have also demonstrated low postnatal HIV transmission among women taking ARVs during the breastfeeding period (Kilewo et al., 2008; Chasela et al., 2009; 2010).

As a result of these considerations, the WHO (2006c) infant feeding guidelines endorsed EBF as the first choice of infant feeding method for HIV positive mothers. Additionally, the 2010 infant feeding guideline also emphasized and supported the idea that breastfeeding should continue unless the AFASS criteria are met and advocated a public health approach rather than an individualized approach (WHO, 2010b). It specified that countries should advocate

for one single infant feeding method to all mothers—either EBF or replacement feeding based on environmental, individual, household and health services conditions instead of relying on individual health care workers to counsel women to make an informed decision. Furthermore, such guidelines encourage decision makers for each country to balance PMTCT with meeting infants’ nutrition needs and prevent other common causes of child mortality. Additionally, the WHO introduced new guidelines for treating HIV positive women (WHO, 2010b). The guidelines were formulated in response to recent evidence that demonstrated that administration of ARVs to all HIV positive mothers with CD4 count less than 350 and throughout the breastfeeding period or providing prolonged ARVs to women with CD4 count greater than 350 can significantly reduce postnatal transmission of HIV. The first two options (option A and B) in the guidelines recommends two short term antiretroviral treatments for HIV positive women not eligible to start treatment for their own health as determined by their levels of CD4 count (table 2-3) (WHO, 2010b). The third option, option B+ which is currently being implemented in Malawi entailed initiating all HIV-infected pregnant and breastfeeding mothers on ART treatment regardless of their CD4 count levels. All these changes in the infant feeding guidelines and ART for PMTCT aimed at reducing HIV transmission to babies through breastfeeding and reduce infant mortality.

Table 2-3: Guidelines for antiretroviral therapy for PMTCT

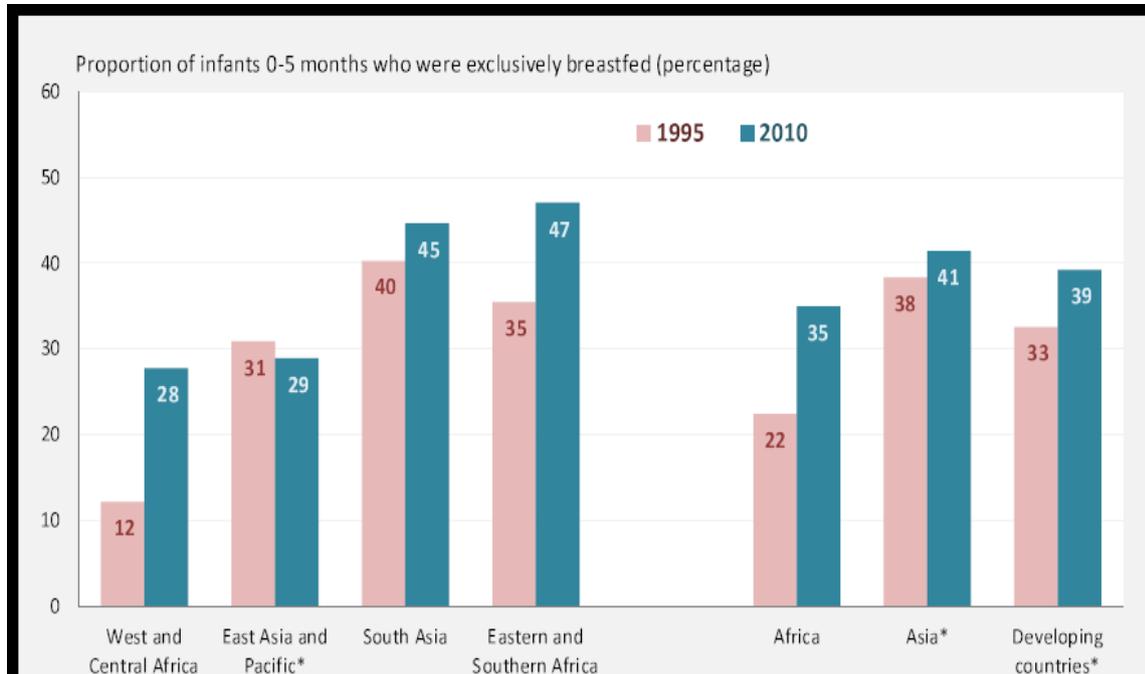
	Woman receives:		Infant receives:
	Treatment (for CD4 count ≤350 cells/mm ³)	Prophylaxis (for CD4 count >350 cells/mm ³)	
Option A^a	Triple ARVs starting as soon as diagnosed, continued for life	<i>Antepartum:</i> AZT starting as early as 14 weeks gestation <i>Intrapartum:</i> at onset of labour, sdNVP and first dose of AZT/3TC <i>Postpartum:</i> daily AZT/3TC through 7 days postpartum	Daily NVP from birth through 1 week beyond complete cessation of breastfeeding; or, if not breastfeeding or if mother is on treatment, through age 4–6 weeks
Option B^a	<i>Same initial ARVs for both^b:</i>		Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method
	Triple ARVs starting as soon as diagnosed, continued for life	Triple ARVs starting as early as 14 weeks gestation and continued intrapartum and through childbirth if not breastfeeding or until 1 week after cessation of all breastfeeding	
Option B+	<i>Same for treatment and prophylaxis^b:</i>		Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method
	Regardless of CD4 count, triple ARVs starting as soon as diagnosed, ^c continued for life		

Source: World Health Organization, 2010c, p. 5

2.7. Exclusive breastfeeding Trends: A global picture

Despite protective effects of breastfeeding against HIV, the rates remain low globally. Figure 2-2 denotes significant increase of EBF rates in all regions including developing countries with the West and Central Africa demonstrating the highest increase of EBF from 12% in 1995 to 28% in 2010 (UNICEF, 2012; Cai et al., 2012)⁵. Figure 2-2 further shows a remarkable increase on EBF rate in the Eastern and Southern Africa where 47% of infants were exclusively breastfed up to 6 months in 2010 as compared to 35% in 1995 (UNICEF, 2012). Nevertheless, despite such increase in EBF rates, globally, no more than 40% of infants are exclusively breastfed for 6 months and significant ratio disparities exist between regions across the world and among countries on the duration of EBF (Cai et al., 2012; UNICEF, 2012). Evidence from the data presented in figure 2-2 has consistently demonstrated that 39% of infants were exclusively breastfed in developing countries in 2010, an increase from 33% in 1995 (Cai et al., 2012). Additionally, as will be discussed below, reliability of measures of exclusive breastfeeding should be viewed critically.

Figure 2-2: Trends of exclusive breastfeeding by region 1995-2010



Source: Cai et al., 2012, p. 4

⁵ United Nations Children's Fund (UNICEF) maintains a global database of internationally comparable indicators for monitoring infant and young child feeding practices. This database contains data from 440 national household surveys for 140 countries and is updated annually. This database is used to report annual levels of breastfeeding at global, regional and country level.

Interestingly, trends in EBF differ in countries located in SSA including countries with extreme high HIV prevalence rates. On the other hand, it is plausible that the differences in EBF across regions and countries could largely be related to socio-cultural, environmental and economic factors that exist in different countries and stigma attached to replacement feeding or breastfeeding. For instance, in Western countries women are free to give their infants' formula while if a woman in SSA decides not to breastfeed it is normally associated with HIV. Similarly, in South Africa 61% of mothers initiate breastfeeding within one hour of a child's birth but only 7% of infants were exclusively breastfed at 6 months because women are free to choose between infant formula and breastfeeding (South Africa DHS, 2003). In Mozambique 37% of children are reported to be exclusively breastfed for 6 months as compared with 80% in Rwanda (Mukuria et al., 2006; Arts, 2011).

Although the rates of EBF have been increasing for the past two decades across the world, empirical evidence shows that exclusive breastfeeding is not a common infant feeding practice in an African cultural context including Malawi where mixed feeding is a norm. This clearly indicates that mixed feeding is still common even among HIV positive women. For example, a randomized clinical trial conducted in Nairobi, Kenya demonstrated that many of the HIV positive women who were randomized to infant formula only and those in EBF group ended up with mixed feeding (Nduati et al., 2000). Similar findings were reflected in other trials conducted in South Africa. De Cock et al. (2000) and Doherty et al. (2006) found that many HIV positive women, who were randomized to EBF during the first 6 months of the infant life, introduced other feeds before 6 months elapsed despite intensive counselling. This is of concern considering the risks of MTCT and infant mortality and morbidity due to mixed feeding. Given the greater risk of infection and higher infant mortality rate in developing countries, this increase certainly falls far short of the WHO's desired worldwide public health recommended target of 90% "universal coverage" of EBF for the first 6 months of the infant life (Jones et al., 2003). Thus, it is useful to explore ways of promoting and support EBF behaviour which was the main focus of this thesis, which could lead to significant improvement in child survival and development.

2.8. Methodological considerations and limitations in measuring EBF rates in the context of HIV

Reliable documentation of EBF practices during the first 6 months of life is essential to inform policy-makers to correctly estimate postnatal risks of HIV attributable to infant feeding pattern. Although clear measurements exist, they are not always uniformly applied across the world (Thakwalakwa et al., 2012; Greiner, 2014). While this data is useful to estimate the rates of exclusive breastfeeding, few studies have applied strict definition of EBF between countries or within a country due to different methodology used to measure EBF rates. The 24-hour recall is the most widely used method to estimate EBF rates globally. In 24-hour recall methodology, all mothers with children less than 24 months of age would be asked the current age of the child and the kind of food given during the previous 24 hours. This may not give the real picture of EBF rates and such discrepancies may overestimate the number of babies being exclusively fed, as they are likely to include babies who did not receive formula milk but may have received water or solids. For instance, in a review of nationally representative surveys that collected data on breastfeeding rates in 94 developing countries Lauer et al. (2004) argued that 24-hour recall will not always represent a true exposure status. However, breastfeeding data in many countries is collected based on using 24-hour history, where most often people tends to always want to say the right thing instead of reporting the real practice or find it difficult to recall the real practice.

Again, other studies have identified inaccuracies and inconsistencies in reporting the current EBF rates often using 24-hour recall methodology and long-term recall (WHO, 1991; Hector, 2011). Some researchers have further questioned the validity of data on EBF based on either 24-hour recall or 48-hour recall as this fail to take into account the possibility that many women would give their infants some food or drinks in the early days (Piwoz, et al., 1995; Bland et al., 2003). For example, in a prospective analysis published in 2000, Piwoz et al. (1995) compared the difference between data from 24-hour recall and those from mothers' daily records. Through this analysis, they found that 24-hour recall overestimated exclusive breastfeeding rates by an absolute magnitude of about 40% at both two and four months of age (92% versus 51% at two months, and 73% versus 30% at four months of age). The most common reason for misclassification was the consumption of water or water-based drinks. The study demonstrated that about 30% of infants classified as 'exclusive' or 'predominant'

received some solid-food supplements; it appears there is a significant tendency to under-report small quantity items administered in addition to breast milk. In another study which was conducted in South Africa by Bland et al. (2003), 31% of infants were classified as being given breast milk only based on 48 hour recall at 6 weeks while when cumulative assessment was done the estimate dropped to 10%.

2.9. Conclusion

In this chapter I have described the importance of exclusive breastfeeding to both the baby and the mother to highlight why it is important to promote the behaviour. From this chapter it is established that the rates of EBF remain low even in SSA where breastfeeding is socially normative despite the high rates of HIV. The information presented here also included the HIV epidemiology and why it is a major problem in sub-Saharan Africa considering the percentage of children who acquire new HIV infection through MTCT and the challenges faced in the region to reduce the risks of MTCT during postnatal period due to poverty and culture that support mixed feeding. The information provided here is useful to understand why women in sub-Saharan region need to be supported to practice EBF and underpins the rationale for this study. The next chapter explores HIV situation in Malawi and infant feeding practices and the challenges faced while implementing the WHO guidelines.

CHAPTER 3: HIV AND INFANT FEEDING IN THE MALAWIAN CONTEXT

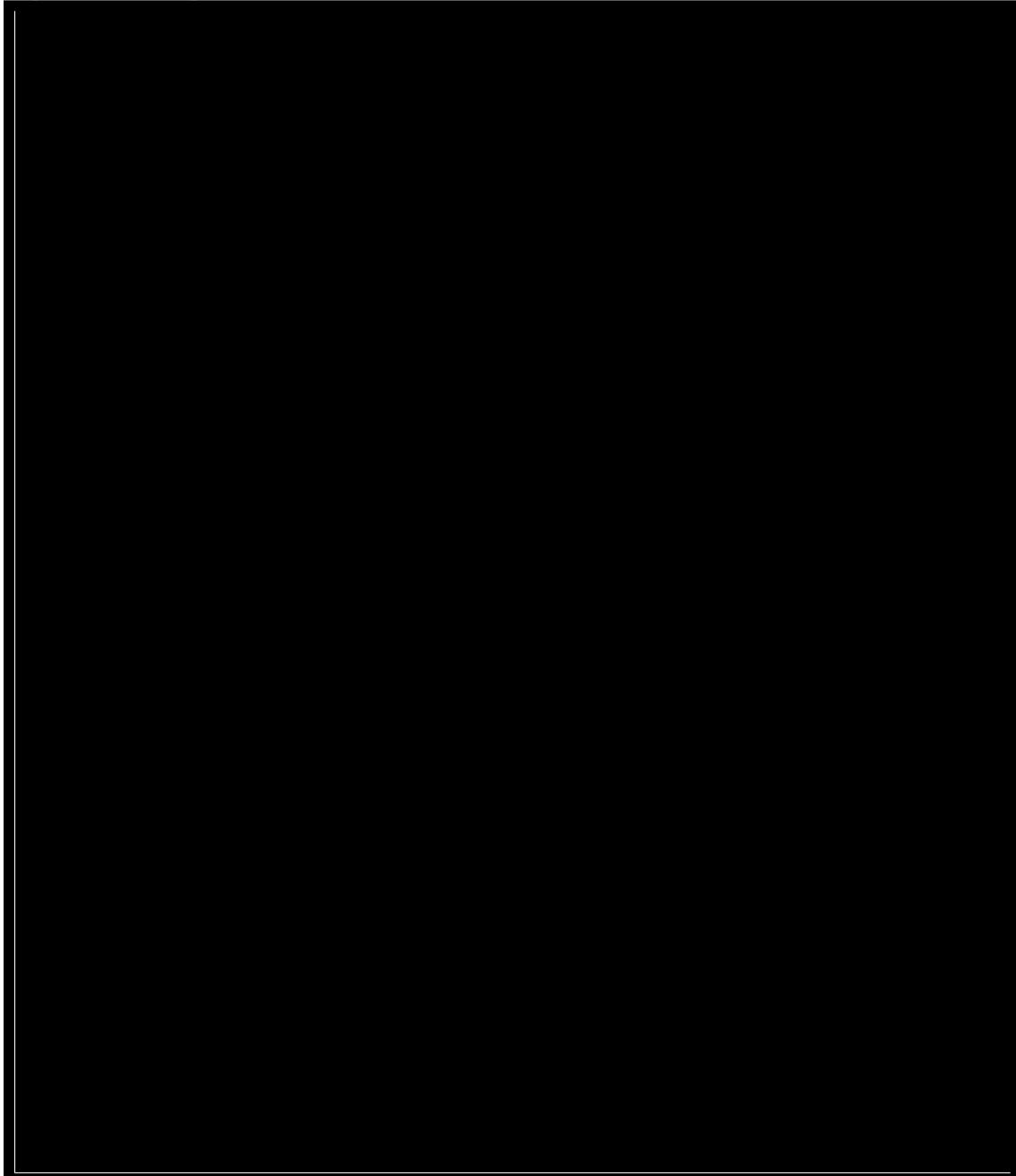
3.1. Introduction

Having looked at the global HIV situation, presented the risks of MTCT during breastfeeding period and global rates of exclusive breastfeeding in the previous chapter, I now provide an overview of the context of my study in order to comprehend the importance of promoting EBF among HIV positive women in Malawi. First I provide an overview of the economy and HIV epidemic in Malawi. More specifically, I set out the magnitude of HIV among women and children. Secondly, socio-cultural issues surrounding infant feeding decision-making is an important indicator that determines infant feeding methods in the country. This is further explained in this section in order to highlight the challenges faced by the country while implementing the WHO infant feeding guidelines for HIV positive women.

3.2. Geographical position, history and politics

Malawi is a small poor landlocked country situated in the sub-Saharan region. It is bordered by the People's Republic of Mozambique to the East and South, Republic of Zambia to the West and United Republic of Tanzania to the North (MDHS, 2010). The country has a total area of approximately 118,484 square kilometres, of which 94, 276 square kilometres is land. The remaining 475 square kilometres is mostly covered by Lake Malawi. The country has three administrative regions comprising the Northern, Central and Southern regions. The country is further divided into a total of 28 districts of which 6 districts are in the Northern Region, 9 are in the Central Region and 13 are in the Southern Region. Chichewa is the national language spoken throughout the country (MDHS, 2010). Figure 3-1 shows a map of Malawi and its location within Africa.

Figure 3-1: Map of Malawi



According to statistics, the population of Malawi was estimated at 13,187,632 in 2008 (National Statistical Office (NSO), 2008). The population comprises 49% males and 51% females of which 42.2% are in the reproductive age bracket of between 15-49 years. Childbearing starts quite early with a mean age at first childbirth reported at 19 years. At the same time, childbearing and nurturing is regarded as a woman's prime responsibility in both patriarchal and matriarchal social systems (MDHS, 2004). This has resulted in high fertility rate estimated at an average of 6.0 in the country.

Malawi got independence in July 1964 after being a British protectorate from 1891 to 1964 and gained the status of republic in 1966 (MDHS, 2004). In 1994 the country adopted a multiparty system after being ruled by one party system for 30 years (MDHS, 2004). The main political transition to the multiparty system was seen by the changes in the constitution, which led to the launch of the Poverty Alleviation Programme aiming at empowering the poor and improving their livelihoods. The health sector was identified as one key sector for poverty reduction. This political transition led to formulation of the national health policy with the main objective of creating equal opportunity for all in accessing health care programmes (World Bank, 2006). Free primary school education was introduced during the same period that has been marked by an increase in literacy level especially among females from 49% in 2000 to 67.6% in 2010 (World Bank, 2009b; MDHS, 2010).

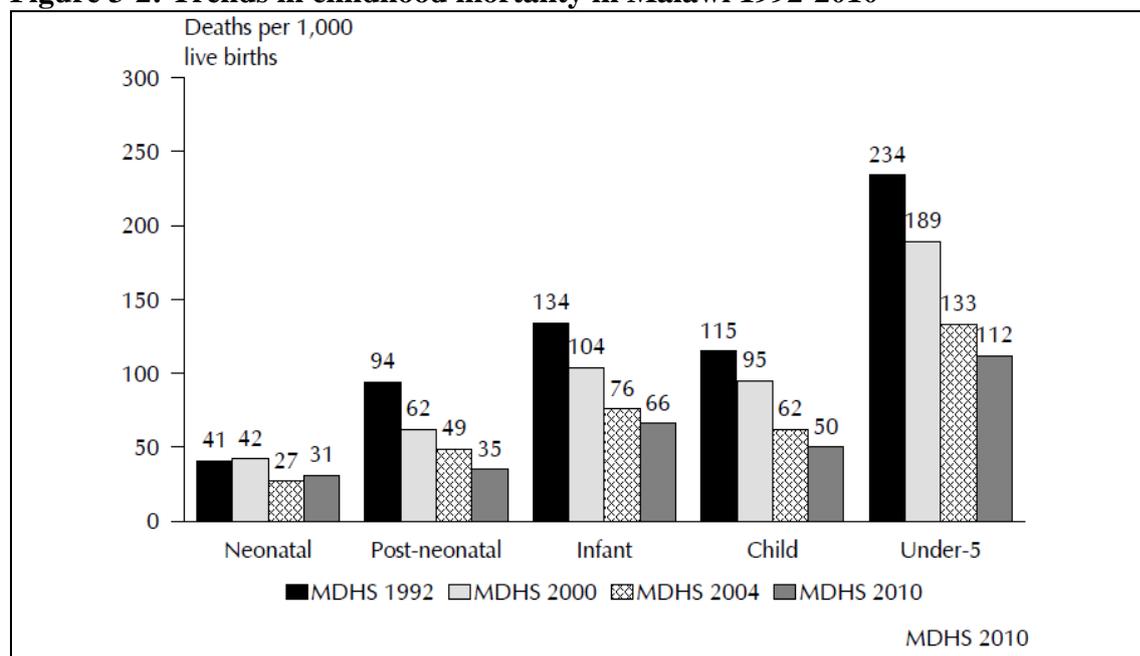
In Malawi, the majority of women do not complete secondary education due to high dropout in school because of teenage pregnancies and early marriages. For instance, according to the 2011 Welfare Monitoring Survey, 38% of girls aged between 14-19 were not in school as compared to 5% of males because they were married (National Statistical Office (NSO), 2012; p. 47). Women's lower education levels are related to lower work force participation and decreased earnings because the majority of them cannot be employed in gainful employment and often end up working in family farms or in the informal sector and spend less time on income generating activities. Such work is often unrecognized as employment by women and men themselves and they are mostly unremunerated (MDHS, 2010). Given this situation, it is perhaps no surprise that there is increased economic dependence among women to men, creating unequal power relations between men and women and ceding of women's autonomy; and lack of control over their sexual and reproductive rights including infant feeding practices.

3.3. Socio-economic situation and the impact on maternal and child health

Evidence points to a significant decline in maternal and child mortality in Malawi and is rated to be on track in as far as achieving MDGs number 4 of reducing under-five mortality rate (Countdown 2015 Decade Report, 2000-2010). However, despite such commendable improvements, the basic health indicators in Malawi are amongst the worst globally. For instance, data presented in figure 3-2 below shows that infant mortality rate has decreased

from 134 in 1992 to 66 in 2010 and under-five mortality rate has decreased from 234 to 112 live births in 2010 (MDHS, 2010). The majority of these children die due to preventable causes such as malnutrition, diarrhoea, respiratory tract infections, malaria and HIV. Consequently, when malnutrition present in a child with HIV infection, it can precipitate death. For instance, the 2006 country UNICEF report demonstrated that between 25 and 50 percent of malnourished children admitted in Nutritional Rehabilitation Units (NRU) for malnourished children in the country were HIV-positive (UNICEF, 2007).

Figure 3-2: Trends in childhood mortality in Malawi 1992-2010



Source: MDHS, 2010, p. 97

Maternal mortality ratio continues to be one of the highest globally estimated at 675 per 100,000 live births (MDHS, 2010). The high maternal and infant mortality in Malawi is mainly compounded by preventable causes such as high burden of diseases mainly Malaria and the HIV/AIDS pandemic, along with grinding poverty, food insecurity and the chronically under staffed health facilities that have adversely affected the quality of health services in the country (MDHS, 2010; National AIDS commission (NAC)/Government of Malawi (GoM), 2008).

Malawi is ranked 171 out of 187 countries on the Human Development Index (HDI), reflecting the country's human development challenges (World Bank, 2012). Approximately 65% of the country's total population is defined as living below the poverty line (below \$1

per person per day) and unable to meet their daily consumption needs; the rural area which comprises 80% of the total population being significantly poorer than the urban areas (African Development Bank Group, 2011). Poverty levels in Malawi are exacerbated by epidemic disease and food insecurity as the economy is predominantly dependent on rain-fed agriculture. As a result, any fall in the agricultural output due to climate change or severe drought and high cost in farm inputs leaves the majority of the population with inadequate food.

3.4. The health care delivery system

The government through its Ministry of Health and Population (MoHP) provides 60% of modern health care services including maternal and child health services offered free-of-charge at point of care (MoHP, 2007a). Private facilities run by the Christian Health Association of Malawi (CHAM) are responsible for 37% of the health facilities while the private-for-profit facilities and the Ministry of Local Government provides the remaining 3% of the services (Zere et al., 2007). CHAM hospitals demand a subsidized user-fee for some maternal and child health care such as ANC, Under-five, labour and birth at the point of care through the Service Level Agreement between the MoHP and CHAM, (MoHP, 2007a). The MoHP also has the overall responsibility for developing policies, planning strategies and programmes and ensuring provision of quality health services to the population (Government of Malawi, 2002).

The health service delivery system in the country consists of primary, secondary and tertiary care. Provision of health care is mainly through primary health care with the main focus on preventive intervention where approaches and strategies are mainly routed in the community (Zere et al., 2007). At this level, services are mainly provided through community-based outreach programmes, rural hospitals, health centres, health posts, outreach clinics and community initiatives such as drug revolving funds. District hospitals and CHAM hospitals provide secondary care (Ministry of Health and Population, (MoHP), 1999). Most districts have one district hospital owned by the government. Central hospitals provide tertiary care, which is similar to those at secondary level except for specialist surgical and medical interventions.

Despite efforts to improve maternal and infant mortality and promote the health seeking behaviour of people, the country still faces challenges in the distribution of skilled health care workers across the health facilities in the country. The World Health Organization (2008) estimated that there were only 266 doctors in the country making a rate of less than 1 doctor per 10,000 populations. The majority of skilled HCWs in Malawi prefer to work in health facilities located in the urban areas despite the fact that the majority of the population resides in the rural communities (MoHP, 1999). Furthermore, many health professionals are reluctant to work in these remote places due to poor working conditions and poor access to social services. It is not surprising, therefore, that many of them work outside their salaried work to supplement their income while others leave the country for greener pastures due to low salaries (Muula and Maseko, 2005).

Variations also exist in the distribution of available resources with more resources being allocated at secondary and tertiary care “top to bottom approach” that is favouring the medical model rather than the community level where illnesses mainly originate (Walley, 2006). This is mainly because the GoM mainly relies on donor funding in the financing of the health sector. There are also different multilateral, bilateral and non-governmental organizations that are operating on different activities and programmes in the health sector (WHO, 2004).⁶ The preference and power of donors and available organizations have resulted in health-policy making being more internationalized, and less co-ordinated, which has greatly affected the government effort to promote equal access to care. As a result, access to health care services remains a challenge whereby only 54% of the population is estimated to have access to formal health care services within a 5 kilometre radius (Mtonya et al., 2005). Consequently, many patients including pregnant women especially in rural Malawi travel long distances to reach a health facility to access care and treatment. Therefore, despite health care services being provided free-of-charge at the point of delivery, there are indirect costs incurred by the rural population to reach a nearest health facility in the form of transport. Furthermore, the quality of care is compromised due to shortage of skilled health care workers and lack of resources. As such, the country has for a long time relied on

⁶ The Global Fund is the main provider of funds to fight against HIV/AIDS, Malaria and tuberculosis alongside with other actors such as DFID, UNAIDS. As a result, the country cannot use the money from Global Fund to implement other activities apart from the activities outlined in the agreement.

traditional birth attendants (TBAs)⁷ to assist women giving birth at home due to a number of reasons including lack of transport to reach the nearest health facility (Mtonya et al., 2005). In 2008 there were about 5,000 TBAs in the country providing maternal health services in hard-to-reach places and only 2000 had received formal training that negatively affect management and referral of women to the health facility (Bisika, 2008). On a more positive note, a study conducted in the country by Hamela et al. (2014) demonstrated that with proper training and provision of birth kits to TBAs resulted into increased the number of pregnant women referred to the hospital and safe deliveries with improved infection control practices.

In October 2007, the Malawi Ministry of Health revised the Road Map to Combat Maternal and Infant Health Problems in which the major goal was to reduce maternal mortality ratio (MMR) by three-quarters and infant mortality by two thirds and attain MDGs 4 and 5 by 2015 (MoHP, 2007b). The Road Map also aimed at training of nurses and midwives and strengthening the individual, families and community capacity to improve maternal and neonatal health. The Road Map recognized several factors contributing to Malawi's high MMR, which include: shortage of staff and weak human resource management, limited and delay in utilization of maternal health care services, weak referral systems, weak community participation and involvement, poor uptake of exclusive breastfeeding and early introduction of food to babies.

Likewise, through the Road Map, the need to review and redefine the role of TBAs in the provision of maternal and child health care services including EBF and ensure timely introduction of complementary foods were identified as crucial ways to meet the intended goal of reducing infant and maternal mortality (MoHP, 2007b). Subsequently, in line with the WHO guidelines, in 2007 the country issued a policy stopping TBAs from providing care to women during pregnancy and delivery in order to promote total utilization of skilled maternal health care, and only allowed them to counsel and motivate women for timely utilization of maternal health care services. The other factor for banning them from practice was to promote women's access to HIV counselling and testing services and also to receive antiretroviral viral drugs for PMTCT if HIV positive and reduce the chances of MTCT. Notwithstanding this effort, some evidence demonstrates that despite the ban, TBAs are still

⁷ TBAs are local women who do not have any formal professional training but draw their own experience to help women deliver in the rural communities.

functioning in many parts of the country as a good number of women give birth in the community with the TBA (Nove, 2011; Lippmann et al., 2013). Moreover, this job is a source of income for the TBAs making it difficult for them to completely stop the role but rather continued practicing in secret due to fear of being fined. Though the Government completely banned them from conducting deliveries, some of them expressed willingness to work with the government and administer ARVs to labouring women (Lippmann et al., 2013).

Apart from earning a living, it is clear in the literature that women in the rural area prefer to be assisted by the TBA during child bearing due to several reasons. In some studies conducted in different parts of Malawi women reported that TBAs are available within the hard-to-reach places and as such they do not need to use transport to reach the health facility (Seljeskog et al., 2006; Bisika, 2008; Kumbani et al., 2013). Some reported that TBAs treat them with respect and dignity as compared to the treatment they receive at the hospital (Seljeskog et al., 2006; Bisika, 2008; Nyirenda et al., 2014).⁸ Furthermore, women complain of lack of attention by health care workers due to workload and shortage of midwives that in most cases they depend on the female guardian to provide some nursing care and in some cases some of them give birth alone despite being at the hospital. Consequently, women who deliver with the TBA do not tell the truth to the health care worker on the place of delivery. Instead, some would report that they delivered on their way to the hospital in order to protect the TBA. For instance, the current Malawi DHS (2010) demonstrated that approximately 24% of deliveries occurred outside the hospital and only 14% reported to have been assisted by the TBAs while the remaining 10% reported to have delivered on their way to the hospital. In 2010, the late President of Malawi, Professor Bingu wa Mutharika lifted the ban on his return from the UN Summit on Millennium Development Goals in New York because the government felt that it was better to train TBAs rather than to completely ban them from practicing (Nove, 2011). As of late, the government of Malawi still do not allow TBAs to attend births.

Through the Emergency Human Resource Programme, Malawi as a country embraced the idea of short-term training of non-medical personnel. For instance, one of the solutions which were suggested to address the problem of shortage of health personnel was training of

⁸ There have been several complaints in the country about the attitude of nurses towards patients. In some cases some of the issues remain unreported to the relevant officials due to the lack of knowledge on the patient bill of right—that is to be treated with respect.

auxiliary nurses who received bedside training for a period of one year under a qualified nurse. The aim was to allow them to provide some basic nursing care to patients in the hospital as well as maternity ward in order to relieve the workload from the nurses and midwives in the country. However, the programme was abolished due to fear mainly by the Malawi Nurses and Midwives Council (MNMC) that the quality of nursing care provided to patients would be compromised (Muula, 2006). The other concern was that these auxiliary nurses were assigned some nursing care to patients by qualified nurses that were beyond their qualification and scope of practice.

3.5. HIV epidemiology among the general population and gender inequalities

Even though Malawi has halted and reversed the spread of HIV/AIDS since a significant increase in 1999, it is among the group of sub-Saharan countries with the worst HIV prevalence rate in the world. The recent MDHS results show that an estimated 930,000 Malawians were HIV positive which was equivalent to 10.6% among persons aged 15-49 (MDH, 2010). In Malawi, the primary mode of HIV transmission is largely through heterosexual contact, accounting for 90% of all new infections that occurred in the country. The (2010) MDHS demonstrated that 80% of new HIV infections occurred among partners in stable relationships within the general population mainly driven by concurrent and multiple partnerships.

The distribution of HIV in Malawi is by no means unequal between regions, urban and rural settings, gender and age groups. The epidemiological trend is disproportionately high among women estimated at 12.9%, compared to 8.1% among men, and the prevalence was still lowest at age 15-19 (MDHS, 2010). With regard to geographical location, HIV prevalence is highest in the Southern Region estimated at 14.5% (females 17.6%, males 11.0%), in the Central Region is 7.6% (female 9.0%, males 6.2%), and is lowest in the Northern Region at 6.6% (female 8.2%, males 4.8%). HIV prevalence continues to be significantly higher among those people living in the urban areas 17.4% compared to those in the rural areas 8.9% (MDHS, 2010). For women, HIV prevalence was highest among those aged 35-39 (23.8%), which is six times the prevalence of women age 15-19 (4.2%) (MDHS, 2010). Similarly, HIV prevalence among pregnant women has tremendously declined from 16.9% in 2001 to 10.6% in 2010 (MoH/GoM, 2011b).

3.5.1. Social drivers of HIV infection among women in Malawi

The higher epidemiological susceptibility for HIV infection among women in the country is not due to their own risk behaviour but, it is deep-rooted to other key issues such as poverty, cultural and gender inequalities that exist between men and women in the country (Ghosh and Kalipeni, 2005). These factors have resulted into the construction of socio-cultural norms that place women in unequal relations to men, thereby limiting their ability to mitigate the risks of HIV acquisition. For instance, there is constant evidence that greater proportion of women and young girls in the rural communities are kept out of school due to poverty and early marriage that diminishes women's ability to refuse sex or to negotiate condom use (Susser and Stein, 2000). Poverty may also lead to increased migration of men both within the country from rural to urban areas and to neighbouring countries in search of work. Migration is a well-established risk factor for HIV for both women and men. This eventually exposes men in close proximity to high risk sexual networks and the majority of them return back to their families while infected with the virus or when they fall sick (MDHS, 2010).

More striking is the culture of silence surrounding sexual and reproductive health in the country which undermine women from exercising their social and legal rights. As a result, women have limited opportunities to enforce HIV prevention measures like condom use from their male counterparts due to fear of violence and abandonment (Kalipeni et al., 2004). In addition, Msapato et al. (1990) pointed out that people perceive that condoms use impede sexual pleasure (cited by Kalipeni et al., 2004). Further, due to such cultural prescribed and gender roles, women are subordinate to their male partners and are not expected to demand safer sex such as through condoms use, which is the best available effective protection against heterosexual HIV transmission. Consequently, if women demand condom use, this may lead to gender-based violence (GBV) and confrontation as condoms are usually associated with promiscuous behaviour.

It is also evident that women especially in some districts in the Southern Region of Malawi and partly in other districts across the country like Mchinji are subjected to cultural beliefs related to sexual cleansing and wife inheritance if the husband dies (Chikaphupha et al., 2011). In one qualitative participatory approach which was conducted in Mchinji district it was found that in some cultures chiefs were being given young women to have sex with when they had gone to any function where they spent a night (Chikaphupha et al., 2011). This

practice was conducted as a token of thanks given to the chief by the host chief for attending the function. These cultural practices however, degrade women's power over their sexual choices, which contribute to the spread of HIV among women (Chikaphupha et al., 2011).

In Malawi, vulnerability due to AIDS has also increased with children especially young girls living in households with chronically ill parents or having lost one of their guardians due to AIDS. This entails that these orphans and vulnerable children have been left without proper care and support which expose them to the risk of abuse and exploitation that may ultimately push them into the HIV and poverty vicious cycle (MDHS, 2010). In this regard, some young girls who head households sell sex for money as a survival strategy for themselves and their own siblings in the absence of their parents and the majority of them do not negotiate condom use. Such behaviour increase the vulnerability to contract HIV and unwanted pregnancy among young girls resulting to premature death due to obstetric complications or AIDS. For instance, the Behavioural Surveillance Survey (BSS) conducted in the country in 2013-2014 by the National Statistical Office (NSO) demonstrated a slight decrease in HIV prevalence rate among female sex workers 62.2% from 70.7% in 2006 which remained highest as compared to the national HIV prevalence of 10% (NSO, 2006; 2014; MDHS, 2010). Furthermore, the high HIV prevalence rate was also reported in a study conducted among sex workers by Family Planning association of Malawi (FPAM) in 2011. In this study it was found that 23% of the sex workers self-reported to have HIV compared to the national prevalence of 10.6% (Chizimba and Malera, 2011).

3.6. The magnitude of HIV among children

According to the recent MDHS (2010), approximately 93,000 children under 15 years are currently living with HIV in the country. The vast majority of them contract the virus through mother-to-child transmission of HIV (MTCT). Despite being largely preventable, MTCT remains the second mode of HIV transmission after unprotected sex, accounting for 30% of all new infections in the country. In the absence of any intervention, approximately 30,000 babies will be born with HIV in the country every year and most of these infected children are vulnerable to acute malnutrition and hence have low resistance to infections (MoHP, 2008). For instance, in 2006, between 20-50% of infants who were admitted in the nutrition clinics across the country were diagnosed with HIV (UNICEF, 2007a). Furthermore,

undernourished babies who survive through infancy often suffer from recurring infections, which eventually affects their growth often with irreversible damage to their future physical and mental wellbeing. Consequently, the majority dies before the age of two years due to malnutrition and lack of treatment and care (NSO, 2008). HIV is estimated to contribute to about 13% of the under-five mortality that occurred in the country in 2010 (UNICEF, 2012). Due to this, international and national organizations started implementing the PMTCT programme to reduce HIV epidemic among children in Malawi.

3.7. The PMTCT programme in Malawi

Malawi as other countries in sub-Saharan Africa with high rates of HIV embraced the WHO guidelines and piloted the PMTCT programme in 2001, which was officially launched in 2003 (Moses et al., 2008). The main goal was to reduce the risks of MTCT of HIV. The implementation of PMTCT services in the country began in a few pilot projects where individual projects used different models, which presented challenges for the government to monitor and evaluate its effectiveness. Subsequently, in 2003 the government of Malawi developed the national HIV/AIDS policy and the Malawi PMTCT guidelines through the National AIDS Commission which were introduced into the health care system to guide health workers in planning, implementing and evaluating PMTCT services (NAC, 2003). The goal was to prevent further spread of HIV infections and mitigating the impact on socio-economic status of individuals, the community and the nation as a whole. The four main intervention strategies outlined in the policy to reduce the spread of HIV include: 1) Information, education and communication to promote health behaviour change; 2) Prevention of mother-to-child transmission of HIV (PMTCT); 3) Treatment of sexually transmitted infections; 4) Monitoring and evaluation. The PMTCT programme in Malawi is fully integrated into the already existing maternal and child health care delivery system in order to take advantage of the high antenatal attendance rate of 91% (Moses et al., 2008). The Department of Nutrition, HIV and AIDS was established in 2004 in the country to provide policy and technical guidance on nutrition in order to improve nutritional status of the general population especially among children (MoH/GoM, 2007).

Since the introduction of the PMTCT programme in 2002, the initial approach to test pregnant women in the country was the “opt in” strategy. Following this approach, all

pregnant women attending their initial ANC were given a general talk on maternal and child health followed by a motivation talk on the importance of HIV testing and PMTCT (MoH, 2003). Women were then given more detailed information about PMTCT in small clusters of 5-8 in a private room and encouraged to undergo voluntary HIV counselling and testing. Those willing to be tested were counselled individually and a whole blood sample was taken for ELISA test and asked to return for their results after one week. Those who tested HIV positive were then enrolled into the PMTCT program. The problem with this strategy was that many women were not returning back for their results and acceptance rate for HIV testing was just about 45% (Moses et al., 2008).

As many other countries in SSA, in 2005 the Malawi Ministry of Health in collaboration with the National AIDS Commission (NAC) adopted the “opt out” strategy (provider initiated) and Rapid HIV testing was introduced in all ANC as part of the HIV policy. Later in 2007, HIV testing was offered routinely to all pregnant women attending ANC. The aim for adopting these changes was to ensure that all pregnant women benefit from the PMTCT package services available in the country that comprises of: a) routine offer of quality HIV counselling and testing to all pregnant women; b) comprehensive and obstetric health care; c) antiretroviral drugs for PMTCT; d) safe infant feeding counselling and support and follow-up. By the year 2004, there were only 40 PMTCT sites in the country. In 2006, UNICEF contributed to the national expansion by providing technical and financial support to 28 districts to develop a five-year PMTCT scale-up plan (UNICEF, 2007a). As of June 2011, the number of sites providing PMTCT services in Malawi increased to 544, up from 119 sites in 2006 and managed to offer HIV testing and counselling to 73% of the target and 54% coverage of the estimated pregnancies in the population (GoM/MoH, 2012).

During the period of 2002 to 2011, only women with a CD4 count of less than 350 in Malawi and other countries in SSA were eligible to start ARVs while all other women were offered single-dose Nevirapine tablet to take during labour while all infants born to these HIV positive women were given single dose Nevirapine syrup within 72 hours of birth. The country, through the PMTCT/ART Technical Working Group (TWG) with growing political support and the Department of HIV and AIDS of the MoHP, revised the old PMTCT guidelines (2008) into integrated guidelines on clinical management of HIV in children and adults. This was done in response to the UNAIDS: *“Getting to 2010-2015– zero new infections, zero AIDS related deaths, and zero discrimination against HIV infected persons.”*

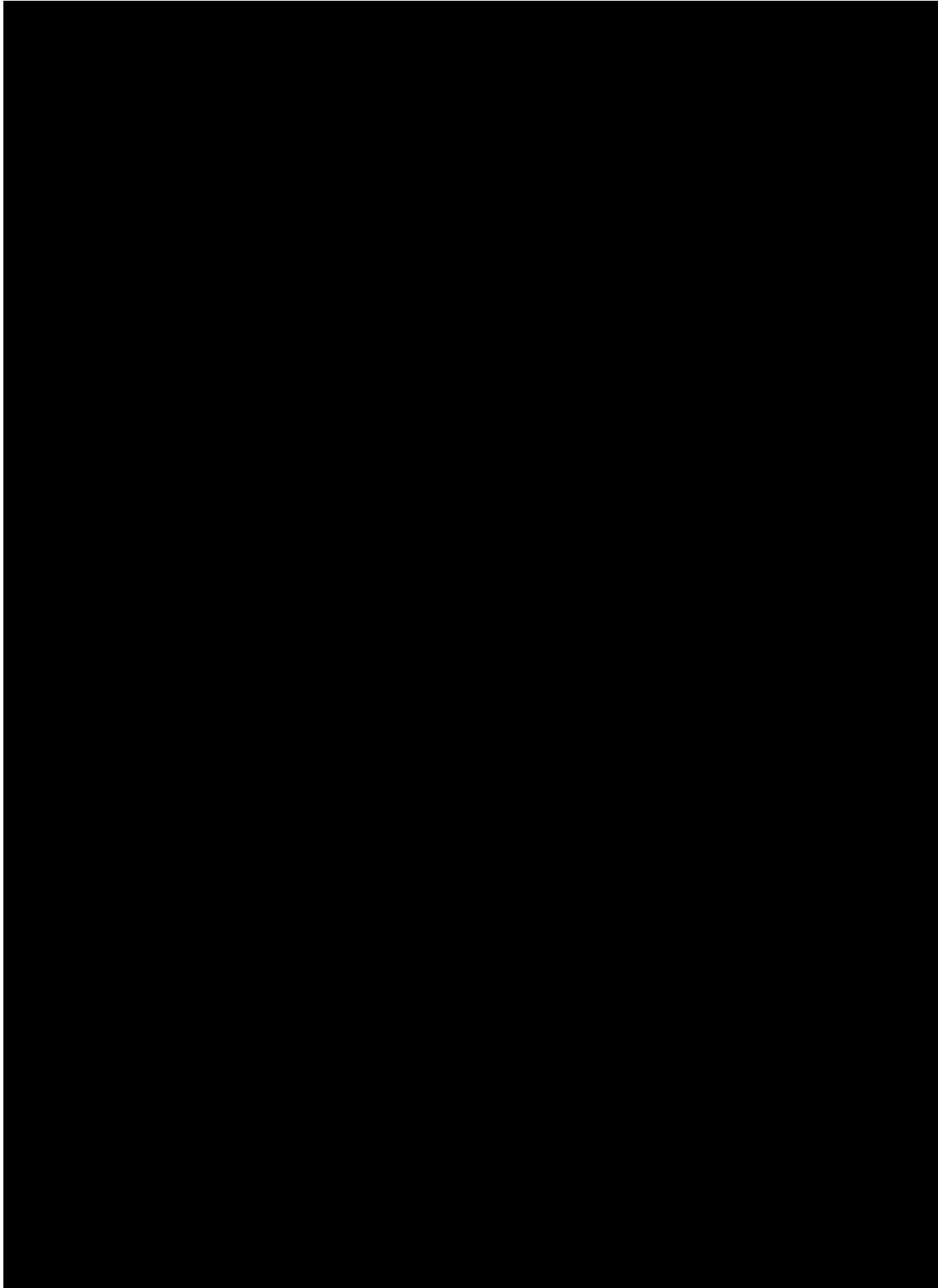
The new guidelines further incorporate the recent WHO antiretroviral guidelines on treating pregnant women and preventing infections in infants explained in the previous chapter (WHO, 2010c; MoH/GoM, 2011a; Schouten et al., 2011). Malawi is therefore, among the three first countries in SSA which adopted the WHO (2010) test-and-treat programme known as (option B+) already explained in the previous chapter. Other countries include: Cote d'Ivoire and Rwanda (MoH/GoM, 2011a). The guidelines further emphasize the importance of prioritizing and providing lifelong antiretroviral therapy to all HIV infected pregnant women eligible for the treatment for their own health (CD4 count <350 cells/ mm^3 or present with WHO stage 3 or 4 disease).

Following option B+ guidelines, women who test HIV negative during antenatal period are retested every three months until the child stops breastfeeding. The aim is to rule out early infection and prevent further spread of HIV from infected mothers to their infants and provide essential antiretroviral treatment to women who test HIV positive regardless of their level of immunity (CD4 count). The Government of Malawi decided not to continue to make CD4 count the trigger for HIV positive pregnant women to start ARVs but rather to pursue a more universal public health approach because of scarcity of CD4 count machines in many health facilities in the country (MoH/GoM, 2011a; Wettstein et al., 2012). The guidelines further recommend that ARV prophylaxis be started from as early as 14 weeks gestation (second trimester) or as soon as possible when women present later in pregnancy, labour or during delivery. There are also other known health benefits related to the implementation of option B+ approach (Hargrove et al., 2010; Cohen et al., 2011) which include:

- Protection against mother-to-child transmission of HIV among those women who become pregnant again in future given the high fertility rate in Malawi.
- Reducing HIV transmission to sexual partners, especially for sero-discordant couples.
- Preventing drug resistance due to stopping and restarting of ARV drugs among HIV positive women with subsequent pregnancies or if they require treatment for their own health in future and also as part of an effort to keep mothers alive to enable them to continue breastfeeding safely.

Figure 3-3 presents a flowchart of this new routine assessment of child exposure to HIV being implemented in the country.

Figure 3-3: Flowchart for routine ascertainment of HIV exposure/infection status in children under 24 months

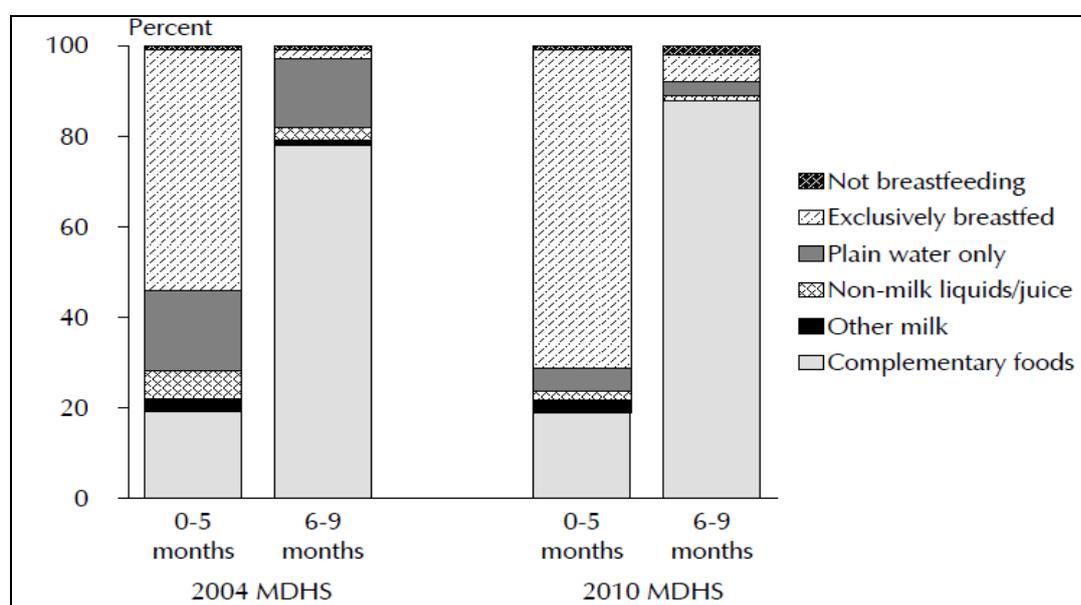


Source: Ministry of Health, Malawi (GoM/MoH), 2011, p. 16

3.8. Exclusive breastfeeding practices among HIV positive women in Malawi

In Malawi, like other developing countries across the world, breastfeeding is universally practiced whereby 98 percent of mothers initiate breastfeeding soon after birth and is often prolonged beyond 23-24 months of the infant age (MDHS, 2010). The MDHS (2010) demonstrated an increase in EBF rates from 53.3% in 2004 to 73.3% (figure 3-4). It is further estimated that the median duration of EBF is 3.7 months, which falls short of the WHO as well as the MoHP recommendations that all mothers in Malawi practice EBF for 6 months.

Figure 3-4: Exclusive breastfeeding rates in Malawi, 2004-2010



Source: MDHS, 2010, p. 138

On a more positive note, a study conducted in rural Malawi by Thakwalakwa et al. (2014) found that exclusive breastfeeding was acceptable among women receiving ART (97%). Nonetheless, a number of other studies conducted in some parts of the country have reported lower prevalence of EBF for 6 months as compared to the 2004 and 2010 MDHS estimates (Kalanda et al., 2006; Bezner-Kerr et al., 2007; Kamudoni et al., 2007). For instance, a study conducted in Chikwawa district Kalanda et al. (2006) found that only 13.3% of mothers practiced EBF by 4 months and only 1.5% breastfeed exclusively up to 6 months. Similarly, Bezner-Kerr et al. (2007) in their study conducted in the northern part of the country reported that 65% of women gave their babies food supplements in the form of water, tea, maize porridge, gripe water and traditional drugs in addition to breast milk even during the first week of life and only 4% breastfeed exclusively for 6 months. Similarly, Kamudoni et al.

(2007) in their study conducted in Mangochi district in the southern part of the country found that EBF rates were as low as 4.7% among women in the rural and 46.8% among those from semi urban areas at 4 months. These studies further found that mothers were also giving their infants food supplementation (mostly water, maize-based porridges, and herbal water) within the first 2 weeks after birth as part of the traditional practice, a stage when it is recommended that the child be exclusively breastfed. This clearly indicates that the majority of women including those with HIV do not practice EBF for 6 months. In the context of HIV/AIDS, This is worrisome as evidence in section 2.5 demonstrated that mixed feeding is associated with increased risk of MTCT of HIV (Coutsoudis et al., 2001).

It is further noted by other researchers that the complementary feeding, usually maize porridge, given to infants in Malawi before the end of 6 months is mostly inadequate and inappropriate mainly due to poor nutritive quality of food available in the country due to poverty and lack of knowledge and skills of care givers (Gibson et al., 1998; Hotz and Gibson, 2001). As a result, malnutrition among Malawian children who constitute a greater part of the population has remained virtually an endemic major public health and developmental challenge since 1992 (MDHS, 2010). For instance, the most recent Malawi Demographic and Health Survey report demonstrates a slight change in children's nutrition status whereby 47.1% of children under the age of five were still classified as stunted (chronic malnutrition) as compared to 53% in 2004, while wasting has decreased from 6 to 4% since 2004 (MDHS, 2004; 2010). 17 percent of these cases involve children under the age of 6 months. The report further estimated that children in the rural areas are more likely to be stunted (48%) than in the urban area 40.7%. This is mainly attributed to inappropriate infant feeding practices coupled with poverty, making it difficult for many infants to resist widespread infectious diseases in the country.

Subsequently, EBF for 6 months is identified as one of the high impact interventions in the country in order to achieve the Malawi Development Strategy and Millennium Development Goals number four: reduce child mortality (Strategic plan for Child Survival for Malawi, 2008-2012, p. 38). To minimize these challenges and also considering the enormous benefits of exclusive breastfeeding to both the baby and the mother and the protective effect against HIV among children born from HIV positive mothers, it was seen as important to promote EBF behaviour among all mothers regardless of their sero-status. The key focus of promoting EBF behaviour in the country is through the Baby Friendly Hospital Initiative (BFHI) in the

maternity services since 1993 as a means to reduce the high prevalence of malnutrition among children and to improve child survival rates. This was done because women in Malawi are poor, HIV positive women would find it difficult to make an informed choice on infant feeding method and maintain the chosen method. As such the country started using the WHO infant feeding guidelines for HIV positive women (2003), the Malawi National HIV Policy (2003) and the Malawi PMTCT guidelines (2003) with support from UNICEF and the World Health organization. Later in 2004 the department of nutrition, HIV and AIDS was set up to provide policy and technical guidance on nutrition in order to improve nutrition status of the general population especially among children. EBF is now promoted following the World Health Organization infant feeding guidelines (2010), the revised Infant Nutrition Policy for Malawi (2008-2013) and the (2011) guidelines on clinical management of HIV in children and adults for the country.

3.9. Conclusion

In this chapter contextual factors related to Malawi that are central for this thesis have been discussed. In summary, Malawi continues to register high maternal and infant mortality late due to poverty, food insecurity high burden of diseases such as Malaria and HIV/AIDS pandemic and the chronically under staffed health facilities. The HIV epidemic among women and children in the face of poverty in Malawi remain vital on why health care workers find it difficult to implement international and national infant feeding guidelines and policies that promote individual informed choices. Otherwise they just encourage HIV positive women in the country to practice EBF despite evidence that replacement feeding can reduce MTCT. Promotion of EBF is thus, done to reduce infant mortality mainly caused by infant malnutrition in the country and also infectious diseases. Otherwise if women are advised not to breastfeed, there will thus be more children dying due to malnutrition and other communicable diseases. The discrepancies between the global infant feeding guidelines, the socio-economic context and culture in sub-Saharan Africa may remain central and set the scene for the next chapter, which present the literature related to hospital-based promotion of EBF and the challenges faced by poor women in SSA.

LITERATURE REVIEW

CHAPTER 4: HOSPITAL-BASED PROMOTION OF EXCLUSIVE BREASTFEEDING

4.1. Introduction

In this chapter I present an empirical literature review which I conducted before conducting the study and throughout the study period. The literature search focused on the quantitative and qualitative studies that have been conducted relating to factors that affect EBF practices among breastfeeding mothers. Firstly, I focus on the effects of the Baby Friendly Hospital Initiative (BFHI), designed to increase breastfeeding rates worldwide and provide an overview of the behaviour change theories behind infant feeding guidelines for HIV positive women. Secondly, I critically explore how infant feeding guidelines for HIV positive mothers framed under the discourse of “informed choice” through the BFHI conflicts with the “local context” and “culture” in Malawi and other countries located in sub-Saharan Africa where breastfeeding is predominant and exclusive breastfeeding is not a common practice. The intention is to highlight individual, environmental and institutional determinants of breastfeeding, the challenges faced in implementing infant feeding guidelines among poor women who are also expected to follow cultural norms of giving their babies other food or liquid even during the first week of life.

To identify empirical evidence, the databases such as PubMed, EBSCO Host, OVID online, were searched for published English articles from 1990 to 2014 as it was felt that earlier studies before the launch of the Baby Friendly Hospital Initiative would be less relevant. In addition, a Google scholar search of non-peer reviewed reports related to infant feeding guidelines and review of non-peer reviewed international and national policies and reports related to EBF and HIV was done. These databases were searched for the key words: exclusive breastfeeding, breastfeeding, HIV, sub-Saharan Africa, stigma, culture and breastfeeding support, using Boolean operators to combine terms. This was done to understand the challenges faced by HIV positive women in resource-constraints settings while following the WHO infant feeding guidelines being implemented mostly in hospitals which are categorised as Baby Friendly.

4.2. The Baby friendly Hospital Initiative

In the 1990s, members at the WHO/UNICEF policy makers' meeting on breastfeeding in Florence, Italy produced and adopted the Innocenti Declaration that focused on hospital and health services in the Protection, Promotion and Support of Breastfeeding. This was a Global Initiative, co-sponsored by the United States Agency for International Development (USAID) and the Swedish International Development Authority (SIDA) (WHO, 1990). The declaration states that:

“As a global goal for optimal maternal and child health and nutrition, all women should be able to practice breastfeeding and all babies should be fed exclusively on breast milk from birth to 4-6 months of age. Thereafter, children should continue to be breastfed while receiving appropriate complementary foods for up to two years or beyond” (WHO, 1990).

The declaration established four targets; that is all governments were to have achieved the following by 1995:

1. Appointed a national breastfeeding coordinator and established a multisectoral national breastfeeding committee.
2. Ensured that every facility providing maternity services fully practices all ten of the ‘Ten Steps to Successful Breastfeeding’ set out in the joint WHO/UNICEF statement.
3. Taken action to give effect to the principles of the International Code of Marketing of Breast-milk Substitutes.
4. Enacted imaginative legislation protecting the breastfeeding rights of working women and established means for its enforcement.

Thereafter, initiatives have been implemented to increase the rates and duration of EBF because of the numerous health benefits to the infant as well as the mother explained in chapter 2. The Baby Friendly Hospital Initiative (BFHI) is the best known example of such widely adopted multi-faceted global intervention which was jointly launched in 1992 by the World Health Organization and the United Nations Children's Fund, following the adoption of the 1990 Innocenti Declaration (WHO, 1998). The BFHI aimed at ‘Protecting, Promoting

and Supporting Breast-feeding through education of health care workers (HCWs) and through implementation of the second target of the Innocenti declaration: “Ten Steps to Successful Breastfeeding” (table 4-1) (WHO, 1998).

Table 4-1: BFHI Ten Steps to successful breastfeeding

1	Have a written breastfeeding policy that is routinely communicated to all health care staff.
2	Train all health care staff in skills necessary to implement this policy.
3	Inform all pregnant women about the benefits and management of breastfeeding.
4	Help mothers initiate breastfeeding within half an hour of birth.
5	Show mothers how to breastfeed, and how to maintain lactation even if they should be separated from their infants.
6	Give newborn infants no food or drink other than breast milk, unless medically indicated.
7	Practise rooming-in - that is, allow mothers and infants to remain together - 24 hours a day.
8	Encourage breastfeeding on demand
9	Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.
10	Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.

Source: WHO, 1998, p. 5

The BFHI is intended to give everybody the best start in life by ensuring that breastfeeding is promoted as a norm in all maternity units. It sets out the gold standard interventions mainly focusing on hospitals with the presumption that most women will give birth in health facilities (Perez-Escamilla, 2007). Over the past 15 years since the launch of the BFHI, more than 20,000 hospitals in 156 countries around the world have been designated as ‘Baby Friendly’ (WHO, 2009).

4.3. The impact of BFHI on breastfeeding and exclusive breastfeeding

The advent and scale-up of the BFHI have had a direct impact on breastfeeding initiation and including breastfeeding at hospital level worldwide (see chapter 2) (WHO, 1998; Perez-Escamilla, 2007; Bartington et al., 2006). This is also reflected by a significant decline in under-five mortality by an estimated rate of 90 deaths per live births in 1990 to 48 deaths per 1000 live births in 2012 (The WHO (2014) world health Statistics data (p. 13) (see section 2.2).

Kramer et al. carried out a large cluster randomized trial called “The Promotion of Breastfeeding Intervention Trial (PROBIT)” with 17046 mother-infant pairs in 31 maternity hospitals and polyclinics in the republic of Belarus to evaluate the effectiveness of the BFHI (Kramer et al., 2001). In this trial, Kramer et al. assigned 16 sites to receive an experimental intervention modelled on the BFHI launched by the WHO/UNICEF while 15 sites were assigned to the control intervention of continuing usual infant feeding practices and policies. The researchers found increased rates of EBF and decreased risk of gastrointestinal tract infection in the first year of life among infants of mothers assigned to follow BFHI policies as compared with those giving birth at control hospitals (19.7% vs 11.4%; adjusted odds ratio [OR], 0.47) (Kramer et al., 2001). Similarly, a study conducted in Switzerland, Merten et al. concluded that the BFHI was associated with significantly longer duration of breastfeeding among those who had given birth in a baby-friendly hospital that showed good compliance with the Ten Steps to Successful Breastfeeding as compared to those who had given birth in a baby-friendly facility without good compliance (Merten et al., 2005). In Malawi the BFHI was implemented in 1993 in response to the low rates of EBF for the first 6 months reported at 3% among all mothers delivering in health facilities across the country (MDHS 1992). Another study conducted in the country by Vaahtera et al. also reported extremely low rates of EBF at 4 months estimated at 0% (Vaahtera et al., 2001). However, with the introduction of BFHI the rate of EBF has risen tremendously from 3% in 1992 to 73.3% in 2010 (MDHS, 2010). The irony here in public health terms is that while health planners assume that people’s faulty cultural beliefs and practices lie at the root of their behaviours, the more substantial evidence suggests that issues of medicalization and institutionalisation of birth had a big negative impact on breastfeeding rates that BFHI then had to seek to correct. In effect it is addressing some of the unhelpful cultural norms of modern hospital-based medicine.

On the other hand, a series of studies have generally reported that BFHI being a hospital-based strategy, concentrated on hospital policies and guidelines to promote breastfeeding and EBF in the maternity ward (steps 1 to 9) where individual mothers stay for a short period of time after delivery (Perez-Escamilla, 2007; Saadeh and Casanovas, 2009). This is considered as unfortunate due to a number of reasons. For instance, as already described in chapter 2, in Malawi and other countries located in SSA, a large proportion of pregnant women deliver outside the hospital—either at home or at the TBA’s home and this is higher in the rural areas where poverty levels are high among women. It is therefore, recognized in the literature that under such circumstances, it became difficult to encourage all women to initiate breastfeeding through BFHI within the first hour of the infant birth (step 4 of the BFHI) (Perez-Escamilla, 2007). On the other hand, although these women deliver at the hospital, not all manage to practice EBF for 6 months despite initiating the behaviour within the first hour after giving birth. Van Esterick, (1989) previously observed that most research conducted in this area has been to identify and minimize barriers to initiation and maintenance of breastfeeding behaviour with the ultimate aim being to find ways of changing individual women’s behaviour in order to increase exclusive breastfeeding rates. Maintaining this on the other hand, requires knowledge, familiarity and practice. Murphy, (2003) further argued that such rigid guidelines conflict with the concept of breastfeeding being an adaptive process where individuals benefit from their own experience or that of others outside the institutional environment. Fletcher et al., (2008) further argued little consideration is taken about the harm which these guidelines may cause to HIV positive women who struggle to provide nutrition to their babies while dealing with the challenges related to living with HIV.

4.4. BFHI and EBF promotion in the era of HIV: Expert and culture at a distance

The high HIV prevalence especially in sub-Saharan Africa was a major concern in the implementation of the BFHI steps. Later in 2014 the BFHI steps were revised by the WHO and UNICEF to take into considerations the needs of HIV positive women and incorporate the changes on the WHO infant feeding guidelines in the context of HIV (WHO, 2010). The revised BFHI integrate the care of pregnant women and mothers in the context of HIV and training of health care workers. It strongly encourages health care workers to provide scientific information to HIV positive women so that they can weigh up the risks of MTCT through breastfeeding with the risks of formula feeding and make an “informed choice”

whether to exclusively breastfeed or exclusively formula feed (WHO, 2010). Table 4-2 illustrates the BFHI 10 steps that takes into consideration the needs for HIV positive women and how to support those who decide not to breastfeed.

Table 4-2: BFHI Ten Steps to successful breastfeeding in the context of HIV

	Guidance on applying the “ten steps” in facilities with high HIV prevalence
Step 1:	Expand the policy to focus on the infant feeding including guidance on the provision of support for HIV positive mothers and infants.
Step 2:	Ensure that the training include information on infant feeding options for HIV-positive women and how to support them.
Step 3:	Where voluntary counselling for HIV and PMTCT is available, counsel all pregnant women on the benefits of knowing their HIV status so that, if they are HIV positive, they can make informed decision on infant feeding, considering the risks and benefits of all options. Counsel HIV positive mothers on various infant feeding options available to them and how to select options that are acceptable, feasible, affordable, sustainable and safe. Promote breast feeding for women who are HIV negative or of unknown status.
Step 4:	Place all babies in skin-to-skin contact with their mothers immediately following birth for at least an hour. Encourage mothers who have chosen breastfeeding to recognize when their babies are ready to breastfeed, offering help if needed. Offer mothers who are HIV positive and have chosen not to breastfeed help in keeping their infants from accessing the breast.
Step 5:	Show mothers who have chosen to replacement feed how to prepare and give other feeds, as well as to maintain optimal practices and dry up of their breast milk while maintaining breast health.
Step 6:	Counsel HIV positive mothers on the importance of feeding their babies exclusively by the option they have chosen (breastfeeding or replacement feeding) and the risks of mixed feeding (that is, giving both the breast and replacement feeds).
Step 7:	Protect the privacy and confidentiality of the mother’s HIV status by providing the same routine care to all mothers and babies, including rooming in.
Step 8:	Address the individual needs of mothers and infants who are not breastfeeding, encouraging replacement feeding at least 8 times a day.
Step 9:	Apply this step to both breastfeeding and non-breastfeeding infants.
Step 10:	Provide ongoing support from the hospital or clinic and foster community support for HIV positive mothers to help them maintain the feeding method of their choices and avoid mixed feeding. Offer infant feeding counselling and support, particularly at key points when feeding decisions may be reconsidered such as the time of early infant diagnosis and at six months of age. If HIV positive mothers are breastfeeding, counsel them to exclusively breastfeed for the first 6 months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe to them and their infant at that time.

Source: WHO, 2009, p. 28

Available evidence has shown that health workers face challenges to implement the revised BFHI ten steps in resource-poor settings with high rates of HIV (Leshabari et al., 2007a; Ferguson et al., (2009; Laar et al., 2009; Koricho et al., 2010). Firstly, the few health workers available in these resource-constrained settings who for a long time have not been able to provide the basic patient care are now involved in dealing with the HIV crisis and are expected to assess AFASS criteria and support HIV infected poor mothers with the chosen infant feeding methods. Secondly, implementation of option B+ in Malawi and other countries in sub-Saharan Africa discussed in chapter 3 has also increased the workload for the health workers. As a result, health workers have struggled to implement such guidelines in the face of severe poverty and food insecurity and cultural practices that support mixed feeding. For instance, Ferguson et al. (2009) conducted an evaluation study in Malawi as part of the Breastfeeding, Antiretroviral and Nutrition Study (BAN). In this study they found that nurses drew attention to the high patient-to-nurse ratio as one of the major barriers to assess AFASS criteria and implement the infant feeding guidelines. They also found that nurses reported that women who choose replacement feeding failed to understand the complex information provided to them by health care workers and argued that they lack knowledge on the right amount of formula to be given to the child (Ferguson et al., 2009).

Koricho et al. (2010) in their qualitative study further found that because of poverty, counsellors tend to forget the aspect of informed choice and AFASS assessment and ended up giving advice to women to practice EBF because they could not afford to buy the formula. Leshabari and colleagues conducted a qualitative study in PMTCT sites in Zambia involving nurse counsellors to develop locally relevant, objective and standard tools to help HCWs assessing a mother's circumstances when providing counselling on available infant feeding options in SSA, thereby supporting them in making an informed choice (Leshabari et al., 2007b). This study further explored infant feeding decision-making process. This study found that counsellors experienced stress and frustration, felt inadequate in their ability to counsel mothers and that women tended not to trust them. Furthermore, it was noted that women chose breastfeeding because they did not want to violate the rules of being a "good mother" by choosing infant formula (Leshabari et al., 2007b).

In another study conducted by Laar et al. in Ghana they found that the PMTCT Managers of maternities which were Baby Friendly Hospital Initiative compliant influenced them to encourage women to initiate breastfeeding within the first 30 minutes after birth and to avoid displaying infant formula in these facilities. Moreover, HIV positive women did not opt for infant formula even if they could afford it due to fear of being asked by people around them the reasons why they were not breastfeeding as normatively every woman in these communities does breastfeed (Laar et al., 2009).

Considering the challenges of allowing women to make an informed choice in SSA, Adegbehinbe et al. conducted a survey with 57 experts involved in PMTCT programmes in five English speaking SSA countries (Nigeria, South Africa, Malawi, Kenya and Namibia) in 2012 to develop and validate the AFASS assessment tool that could be used for infant feeding counselling. Based on the findings from the expert panel that differed in many aspects of the WHO (2010) guidelines, it was conformed that the revised AFASS tool, which advocates for a public health rather than the WHO (2010) individualized approach, should be used. However, the team advocated that the tool should be tested by providers of infant feeding advice with the aim of adoption into routine PMTCT programmes in SSA (Adegbehinbe et al., 2012).

4.5. Informed choice and intention of HIV positive women to breastfeed

Ajzen's Theory of Planned Behaviour (TPB) proposed individual intention as the main influence of a given behaviour and that if individuals have a favourable attitude they are more likely to perform the desired behaviour (Ajzen, 1985, 1988; 1991). Maternal intention exerts an independent influence on breastfeeding. Further, mothers feel pressure to breastfeed because of their intention and desire to maintain the mother-infant bond which further complicates choices of HIV positive women who can afford infant formula (Crossley, 2009; Lee and Furedi, 2005). The findings from a longitudinal, descriptive and correlation study of 110 HIV-positive mothers that was conducted at Queen Elizabeth Central Hospital in Blantyre Malawi by Kafulafula et al. (2013) confirms the opinion that maternal intentions do affect exclusive breastfeeding behaviour. This study concluded that high EBF prenatal intentions as suggested by Ajzen (1985; 1991) among HIV-positive mothers was positively associated with long duration of EBF which conforms with the theory that breastfeeding intentions are the principal predictors of breastfeeding behaviours. In addition, breastfeeding

is highly promoted in many hospitals in the country as the best option for feeding babies, which may also influence the intention of HIV positive women to choose EBF (Blystad and Moland, 2009). Consequently, despite the knowledge about the dangers of transmitting the HIV virus to their babies through breastfeeding and about alternative infant feeding choices offered to them by the health providers, many mothers initiate EBF soon after birth. This is because these mothers would not want to break this natural bond brought about by breastfeeding by choosing infant formula (Blystad and Moland, 2009). In a case study of her own experience Crossley (2009) further reported that she had strong intention and desire to breastfeed due to the notion of the “infant-mother bond” and she wanted to connect motherhood “the right way” through breastfeeding. Therefore, many women would want to maintain their identities as good, responsible mothers who follow their obligation at home and the expert expectation of the health professionals at the same time minimize the risk of MTCT of HIV to the child as they are held accountable for the health of the babies.

Doherty et al. in their longitudinal qualitative study conducted in 3 sites in South Africa found that the reasoning behind women’s exclusive breastfeeding choices was related to their knowledge on the benefits of practicing EBF and the desire to protect their babies from contracting HIV; and the entrenched knowledge that “breast milk is best” (Doherty et al., 2006). This association was also found in another study conducted by Levy et al. in Lilongwe Malawi, which also found that HIV positive women choose EBF because of the same feelings that “breast milk is best for the baby” (Levy et al., 2010). The study further found that HIV positive women expressed the feeling that exclusive breastfeeding is natural and that infant formula is not good for the baby. The findings also demonstrated that mothers’ intention to choose EBF and ability to breastfeed for 6 months was related to women’s pre-existing views on breastfeeding, the quality of the counselling they received, and their understanding of the medical-scientific information including how infant feeding practices and prophylaxis therapies each can reduce the risk of MTCT.

4.6. Knowledge of HIV positive mothers and EBF practices

Several studies conducted in Africa have documented the importance of women’s knowledge as a predictor of breastfeeding behaviour. For instance, studies conducted in Malawi and Mozambique found that due to lack of more detailed knowledge most women started introducing other foods including water, traditional medicine and porridge to their babies

before six months elapsed (Bezner-ker et al., 2007; Arts et al., 2011). Chopra et al., (2009) in their study found that infant feeding is given little attention in many PMTCT facilities. In addition, some women in Mozambique believed that breast milk alone is not enough to meet the nutritional demands of the baby and make the baby grow health (Arts et al., 2011). Similarly in Zambia Fjeld et al. (2008) found that because of the misconceptions that breast milk contains insufficient water women perceived that giving of water, other fluids and meal-meal porridge as the best way to feed their babies. While awareness of the benefits of breastfeeding may be high, more detailed knowledge about the issues surrounding breastfeeding or mixed feeding may be lacking on some women.

On a particular note, is the mother's knowledge on breastfeeding in the context of HIV and the changes which have been taking place on global infant feeding guidelines since early 1990s discussed in chapter 2 (WHO, 1998; 2001; 2006; 2010b). These changes in the international guidelines made breastfeeding in the context of HIV to be more complex and greatly affected women as well as HCWs in sub-Saharan Africa with the largest burden of HIV infection and where health workers are scarce. Fletcher et al. (2008) argues that due to the extreme shortage of skilled health care workers in most maternities in SSA and extreme poverty, nurses and midwives fail to provide the necessary information and support to HIV positive women to enable them make an informed choice on infant feeding methods. For instance, in a study conducted in South Africa by Seidel et a. (2000) with 11 HIV positive women they found that at no time was any of these women informed during their pregnancy, or even immediately after, of the risks of HIV transmission through breastfeeding, despite the fact that in South Africa the AFASS criteria are more likely to be fulfilled than in most of SSA. Consequently, the majority of them choose exclusive breastfeeding as opposed to replacement feeding. However, the study found that due to lack of knowledge on EBF the majority of them fail to maintain exclusive breastfeeding for the recommended 6-months period, which as discussed in chapter 2 increases the risks of transmitting the virus to their babies. Similarly, through an observation study of counsellors conducted in South Africa, Chopra et al., (2005) found that the majority of HIV positive women who choose exclusive breastfeeding were not confident on how to do it. In this study, it was observed that these women were not well informed by the counsellors during the counselling session and the researchers expressed the need to pay more attention to the counselling provided to women in order to achieve optimal infant feeding.

Although women may be aware of the risks of HIV transmission in breast milk, inadequate quality of information as well as the policy changes described in chapter 2 (WHO, 2010) mean that health messages can cause confusion and concern. In a qualitative study conducted in Lilongwe Malawi by Østergaard and Bula (2010) interviewing HIV positive mothers to explore factors that motivate or hinder them to do so, it was found that HIV positive women are generally left confused because they were not well informed on the changes in the infant feeding guideline. The researchers found that women who attend the PMTCT programme struggle with the conflicting messages surrounding lactation and HIV which on one hand they are told that “breast is the best” while on the other hand they understand that an HIV positive mother risks transmitting HIV when she breastfeeds her new-born. Consequently, women in this study were uncertain on whether practicing EBF for 6 months would protect their infants from contracting the virus or rather increasing the risks of transmitting the HIV virus to the baby. Furthermore, the majority of them reported to have opted for EBF due to lack of information on the available infant feeding options which according to their own views were often not explained to them by the health care workers (Østergaard and Bula, 2010).

According to the BFHI, the dominant approach to achieving such guidelines has been to educate and support women to start and continue with EBF rather than understanding behaviour change process from a broader perspective. The implicit assumption behind such policies and guidelines was that if individual mothers and babies are provided with information and a good start with breastfeeding while in the hospital this will increase the probability of EBF for 6 months. Baumslag and Dia. (1995) further affirmed that when a woman is pregnant there is a natural genetic connection between the mother and the unborn baby that needs to continue after delivery and breastfeeding provides such a powerful connection. In one study conducted in Cambodia, Hernández et al. (2010) found that women who opted for breastfeeding understand it as an act that goes beyond the biological and consider it as a natural process. Under such concepts, BFHI guidelines viewed breastfeeding as a public health issue, which is supposed to start naturally, rather than a social behaviour that is deeply rooted in culture. However, human culture and biology are deeply inter-twined.

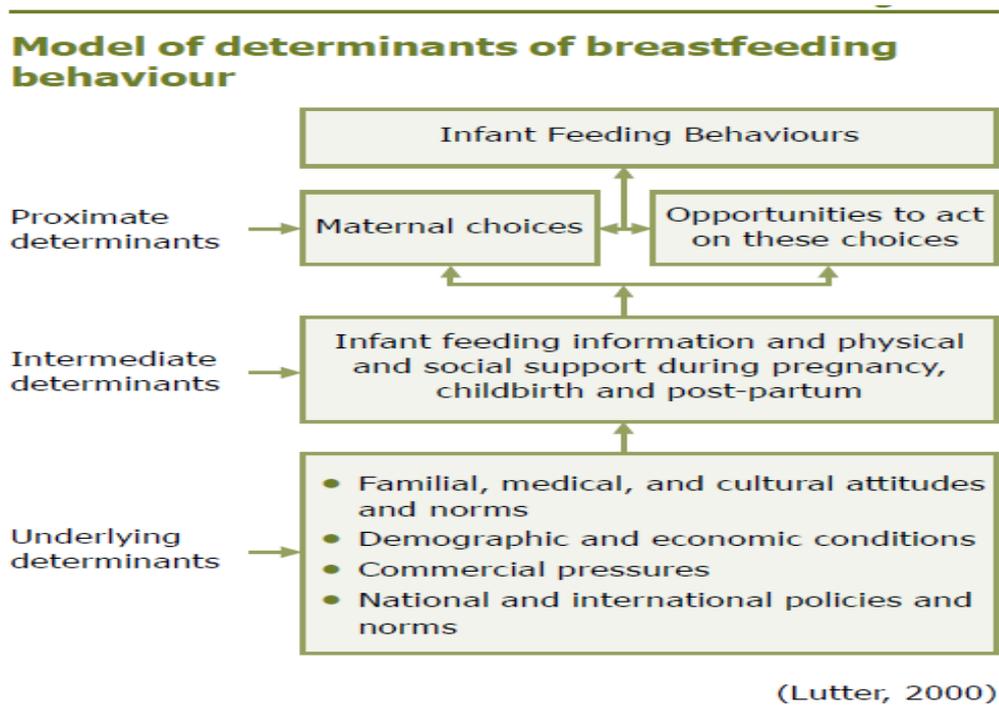
There is also a concern by women that due to high fertility rate, limited time and resources, midwives may spend less time with individual women (Østergaard and Bula, 2010). The PMTCT guidelines in the country allows health care workers to provide group counselling to HIV positive women attending PMTCT instead of the desired individual client-centred counselling, to address individualized problems (MoH, 2008). In many clinics in the country, HIV positive women form mother-to-mother support groups where they meet and share their experiences, and also discuss better ways to overcome the barriers and manage to practice EBF. Hoddinott et al. (2000) highlighted that client-centred counselling influences health care worker to ask women open questions about experience, values, priorities and goals and discuss how the chosen infant feeding method will fit into their family life. Some studies have shown that such individualized client-centred counselling provided by HCWs that meet the women's demand increases confidence among mothers to practice breastfeeding (Sheehan et al., 2010; Hoddinott et al., 2000; 2012) but client centred approaches could be used in an individualised or a group approach.

Arguably, such circumstances where all women with HIV are counselled in a group might alternatively benefit from being able to share experiences without fear of stigma. For instance, in a study conducted in Zimbabwe, Chandisewera et al., (2007) reported increased HIV testing among women who received group counselling from 65% to 99.9% probably due to the fact that the majority of them were less fearful of participating in HIV testing. Similarly, in another study conducted in Lusaka Zambia Kuhn et al., (2007) found that more than 80% of women who participated in mother-to-mother support groups managed to practice EBF. In Østergaard and Bula's study in Malawi however it was found that even though such group counselling could benefit HIV-infected mothers, some of them did not feel comfortable to talk about the unique challenges that were hindering them to practice EBF in the presence of other people. This was because the majority of them would not feel comfortable to tell the HCW that they failed to practice EBF due to fear of accused as failing to follow the hospital advice by the HCW as well as their fellow mothers present during the discussion (Østergaard and Bula, 2010).

4.7. Determinants of exclusive breastfeeding among HIV positive women in SSA

While the BFHI ten steps have been promoted to improve the rates of exclusive breastfeeding globally, implementation of the BFHI and other programmes to support exclusive breastfeeding however, have faced some limitations especially in poor-settings like SSA with high rate of HIV. Through such infant policies and guidelines for HIV-infected mothers framed under the discourse of “informed choice” which target the individual mother, policy makers consider breastfeeding as a natural biological behaviour that every mother is capable to perform after giving birth (Baumslag and Dia, 1995; Diclemente et al., 2009). Such policies policymakers tacitly posit the individual mother as the key decision maker, responsible for her own health. This section therefore, discusses the enormous gap between such infant feeding guidelines and policies and socio-cultural norms in resource-poor settings like Malawi alongside with other countries in SSA where mixed feeding is predominant. The spectrum of breastfeeding determinants is, therefore, captured better in Lutter’s model (figure 4-1). Lutter’s model categorises these determinants into three groups: proximate determinants (that include maternal choices and opportunities to act on the choices); intermediate determinants (that include infant feeding information and social support) and finally underlying determinants (familial, medical and cultural attitudes and norms, economic conditions) and how they affect breastfeeding behaviour. Proximate determinants are those that are directly related to the mother while intermediate and underlying determinants are the external forces which affect breastfeeding behaviour (Lutter, 2000). These are discussed in this section in relation to HIV.

Figure 4-1: Models of breastfeeding behaviour



4.7.1. Power and control over infant feeding among women in resource-poor settings

Using Lutter’s model (figure 4-1), although maternal intention coupled with knowledge are considered as the main predictors of breastfeeding (proximate determinants), other studies have shown that breastfeeding as health behaviour is also affected by other variables such as culture, education level, past experience, ethnicity and social economic status which are not taken into account in the way it is promoted through the BFHI. Deborah McCarter-Spaulling (2009) argues that, in most cases however, there may be a conflict between the individual attitude and the multiple factors that affect breastfeeding behaviour. She indicated that:

“Breastfeeding: best for mom and best for baby. So simple and natural. ...it is as complicated as any other relationship: a dance between two (or more) individuals, each bringing his or her uniqueness to the “table,” or in this case, the breast. Sometimes the dance is flowing and graceful, and sometimes it is clumsy and awkward. And no relationship develops in isolation; there are always external forces that act on it to influence the course of events.” (p. 218).

The above quotation by Deborah McCarter-Spauling, (2009) clearly demonstrates that infant feeding in many societies, especially those in SSA do not only concern mothers but rather rely much on the guidance, advice and support they receive from significant others such as the spouse, mother-in-law as well as the health personnel as well as a wider social norms. In this case, women more especially those with HIV are therefore, faced with a conflict between technical advice from health professionals and lay advisers such as family members and neighbours as everyone will give different options and rules on what they think is the best way of feeding the infant (Bezner-kerr et al., 2008; Maher, 1992). However, the BFHI intervention mainly focused on changing the intention of mothers who were considered to have the power to decide on how to feed their infants. Murphy, (2003) considered such breastfeeding promotion and support which concentrate on the individual mother as the agent for change. From a scientific point of view, this is considered as just verbal encouragement mainly in resource-poor settings due to lack of human and material resources to enable the woman to practice exclusive breastfeeding for the recommended period (p. 207).

For an individual woman to successfully practice EBF requires her informed decision coupled with the ability to implement the chosen behaviour and the determination to overcome numerous structural barriers which she faces within the community, such as social networks which may obstruct her intention to practice EBF (WHO, 2003a). Evidence also demonstrates that women in Malawi and other countries in SSA are also supported by their relatives, friends and family members who even accompany them to the hospital when the woman goes to give birth and also in the community to feed their babies (Guay and Ruff, 2001; Bezner-Kerr et al., 2008; Fletcher et al, 2008). If significant others such as the spouse, relatives, friends or doctor see performing the behaviour as positive and support it and if the individual is motivated to meet the expectations of significant others, then a positive behaviour change is expected from that individual. The importance of family and social network support is particularly significant in SSA but arguably universal; for instance, in a study conducted in Cambodia, breastfeeding mothers reported to have immediately received support from elderly women on the care of the new-born, usually a family member like the grandmother or the mother-in-law (Henandez and Vasquez, 2010). However, health education on breastfeeding in many countries is often done at the antenatal, postnatal and labour ward following the BFHI steps already explained above which only target the woman without involving significant others. This in the end negatively affects involvement of

significant others including the partner or others who support the woman in the community. Subsequently, women are always at the receiving end of mixed messages from the hospital and the community. Given the powerful discourse related to what they are expected to do while in the community, it become problematic for them to assert their own control over infant feeding and act against culture.

Some studies conducted in sub-Saharan Africa also found that other women believe or they are advised by elder women that if they breastfeed exclusively for a longer period of time the child will become accustomed to the breast milk and that will make it difficult for the child to accept complementary food after 6 months elapses (Hernandez and Vasquez, 2010; Levy et al., 2010). As a result, such women fail to comply to the expert rules of infant feeding specified by health professional and start giving the infant other foods or fluids before six months elapses because older people are always trusted and are believed to have expert knowledge based on their own personal experience. Consequently, due to lack of continuous support from the health professional to continue practicing EBF at community level, many women fail to exercise their autonomy to challenge such lay advice and conform to the traditional remedies. In fact, mothers are granted formal autonomy in this model of health promotion, which is thought to be free of coercion, to make choices on behalf of their babies, ensuring their present and future health welfare. An HIV positive mother may have knowledge about the benefits and dangers of breastfeeding while having HIV and is believed to use the technical expertise from health professionals, given while at the hospital, to make an individualized informed choice on how their babies will be fed. However, many studies reported that such easy endorsement becomes complex when women are discharged from the hospital after giving birth and go back to the community (Bezner-Kerr et al., 2008; Chopra and Rollins, 2008; Doherty et al., 2006). In one study conducted in Malawi by Bezner Kerr et al., (2007) it was found that women experienced direct pressure from family members especially grandmothers who pressurize them to follow some set of traditional rules and cultural practices. In that study it was found that women were advised by their grandmothers to give their babies Mzuwula (a type of herbal infusion), and Dawale (another herbal infusion), water and porridge soon after birth and before 6 months elapsed (Bezner-Kerr et al., 2007). Further in the same study by Bezner-Kerr and colleagues, (2008) provided evidence that paternal grandmothers are actively involved in early childcare and are key decision-makers in deciding when to introduce complementary feeds to the infants.

Understandably, in sub-Saharan Africa, the question of status of women is very important because of what is expected from them by the society. Consequently, in this society where breastfeeding is a norm, the public witnessing of breastfeeding serves as an identity marker for the social standard of the woman and if any of them is seen not breastfeeding, the individual is condemned as being irresponsible. Furthermore, in most of the countries in this region, the increased prevalence of HIV among women of childbearing age and the knowledge that mothers who are infected with HIV can transmit the virus to their babies through breast milk places a major burden on mothers to make a critical choice regarding infant feeding. The pressure to introduce other foods in sub-Saharan Africa may become irresistible among first time mothers, as they are always considered as inexperienced mothers who need to be monitored, unlike those women who have given birth and breastfed their babies before (Thairu et al., 2005; Doherty et al., 2006; Bezner-Kerr et al., 2007). Even if these young mothers disagreed with such traditional ways of feeding the baby and follow expert advice from health professionals, family members, especially their mothers and mother in-laws, hold more power and may over-ride the young mothers' decisions to feed their infants on breast milk exclusively for 6 months (Bezner-Kerr et al., 2007). In one qualitative interview study within a prospective cohort of 650 HIV-positive mothers, Doherty et al. (2006) purposively selected a subsample of 40 women for in-depth interviews. They found that HIV-positive mothers in this study—who were predominantly young, single and unemployed—were struggling to protect their decision-making autonomy due to fear of disclosure of their HIV status if they refuse to follow the family and community norms that encourage breastfeeding but with early introduction of fluids and foods (Doherty et al., 2006).

As previously discussed, the WHO guidelines advocate that HIV positive women should make informed choices and that they should be supported while in the hospital on the chosen method, either to exclusively breastfeed or exclusively formula feed (WHO, 2010b). However, the evidence suggests that the decision on how to feed the infant is a social rather than an individual decision and social relations surrounding infant feeding coupled with hospital advice plays a major role in the woman's ability to choose and adhere to her choice to practice EBF for 6 months. Additionally, culturally women in the sub-Saharan region have less power to control their reproductive health life and often are not the core decision makers' in reproductive health issues, including issues concerning the feeding of their own infants. It was further clear in the literature that in these settings such decisions are mainly made by their partner, their mother in-law, their own mothers as well as older women based on their

previous experience and traditional role to provide practical advice to young women (Maher, 1992; Bezner-Kerr et al., 2008). One good example is the qualitative study conducted by Leshabari et al. (2007) with HIV positive mothers attending the PMTCT clinic in Kilimanjaro Tanzania. The findings from this study demonstrates a gap between intentions and infant feeding practice in a context where the social expectations to breastfeed are high, and where significant others and neighbours are part of the decision-making team surrounding infant feeding yet HIV positive women are expected to make an informed decision without involving them. The study therefore, highlights the pressure between the competing concerns of the medical and social risks involved in the choice of infant feeding method, and documents that the feeding options may be difficult to adhere to, whether a mother chooses exclusive breastfeeding or replacement feeding. Therefore, the ability to adhere to the chosen method depends on societal norms and the unique challenges women need to overcome when they go back to the community (WHO, 2010b). However, PMTCT programmes are grounded on the notion that changing the mother's behaviour is the key to health promotion, assuming that once the mother is educated she will act according to the information given.

At the same time, mothers increasingly look for expert guidance and support from HCWs to minimize transmitting HIV to their children (Lee, 2008). The decision of some HIV positive women to practice EBF is influenced by the respect that women have towards health care workers (HCW) and the concept that "health professionals are always right". In fact, HCWs who in most cases do not explain other infant feeding options and mostly promote EBF to these economically disadvantaged women are believed by women to provide scientifically sound, trust-worthy knowledge to clients. However, policy-makers and health workers face many challenges in adapting and implementing infant feeding guidelines for HIV positive women. The findings from a qualitative study conducted in Lilongwe Malawi by Chinkonde et al. (2010) is one example that illuminated the challenges due to the gap between the WHO guidelines and cultural beliefs and the actual practice. In this study, researchers conducted in-depth interviews with policy-makers and providers of interventions to prevent mother-to-child transmission (PMTCT) of HIV to explore the challenges faced in adapting and implementing these guidelines. This study found that health workers found it difficult to advise women to wean onto a mixed diet (breastfeeding and giving of other foods) after six months because they were worried that they would lose the trust of the PMTCT clients and the population at large who were initially advised to completely stop breastfeeding soon after 6 months, and they feared that continued breastfeeding was unsafe. The researchers

recommended that policy-makers should ensure that consensus is carefully considered and that comprehensive perspectives are incorporated when adapting the global guidelines.

In many communities the pleasure arising from the good infant-mother bond created through breastfeeding is one major factor that helps women to continue breastfeeding their infants exclusively. In one mixed method study Lee and Furedi (2005) identified and examined the way in which women are increasingly being inculcated with a strong cultural expectation to breastfeed and how the connection of being a good or successful mother has a very strong influence on some women. Mothers who failed to breastfeed in the process experienced feelings of guilty, failure and uncertainty, and one in every 10 women experienced a strong sense of marginalization and despair (Lee and Furedi, 2005).

Additionally, in the context of HIV the symbolism of breastfeeding and mother's milk seem to be changing from a substance that is celebrated as a "passport to life" to a "substance that threatens the life of the infant" (Moland, 2004; Blystad and Moland, 2009). For example findings from qualitative studies conducted in South Africa and Ethiopia indicated that women who were HIV positive together with the surrounding community considered breast milk of HIV positive mothers as 'bad—contaminated with HIV—and not good for the infant' (Koricho et al., 2010; Seidel et al., 2000) Furthermore, HIV positive women who were breastfeeding were blamed as "bad mothers" by the surrounding community because they were not only considered as breastfeeding but also 'breast poisoning' their infants. At the same time, during interviews with HIV positive women who were on ARVs for their own health in Lilongwe Malawi (Bula, 2009 unpublished dissertation) women reported that they felt that the drugs were 'too strong and poisonous' to be passed on to the infant through breast milk due to the side effects which they themselves experienced while taking the medication. As a result, women from these studies resorted to harmful practices of reducing the number of times of feeding the infant with breast milk and introducing other feeds to reduce the amount of HIV and ARV drugs passed on to the infant through breast milk and to maintain their dignity as "good and caring mothers" in their society by continuing to breastfeed.

4.7.2. Poverty and the feeling of insufficient milk production

Poverty is also seen as an important barrier that makes it hard for many poor African women to choose and practice EBF for six months. Apart from caring for the child and practising EBF, HIV positive women are expected to do their daily house chores and generate some form of income from farming and work a few weeks post-delivery, which is not compatible with EBF and their health, exposing them to mixed feeding (Fletcher et al., 2008; Doherty et al. 2006). Some women may need to leave the baby with care givers just a few weeks post-delivery in search of jobs or generating an income (Moland et al., 2010). Therefore, for them to manage to practice exclusive breastfeeding (which demands that a child should at least breastfeed for not less than 8 times in a day and be breastfed on demand) requires individual maternal judgment and feelings towards the behaviour and the cost in terms of time and energy as she is expected to balance her baby's needs with other maternal obligations both at home and field work before 6 months elapses. Moreover, if the child becomes infected, HIV positive women are blamed for not taking responsibility to protect them. Ryan (1976) argued that such "victim blaming" mostly ignores the constraints that individuals face.

Furthermore, the cost of infant formula is often beyond the means of poor families. Even if made available for free, simply providing access to infant formula is not equivalent to providing safe alternatives to breastfeeding. Women in developing countries are left struggling on how to safely use it due to lack of clean water and bottle and fuel to prepare the feeds, increasing the risks of mixed feeding (De Wagt and Clark, 2004). Mothers who opt for infant formula are also required to provide the feeds to the infant in the night and may find it extremely difficult in making up infant formula with no electricity, running water and refrigeration in these poor countries. Because of low socio-economic status of many women in sub-Saharan Africa and the knowledge about the dangers of replacement feeding, health care workers recommend exclusive breastfeeding among all women regardless of HIV status and most often the other infant feeding methods are not mentioned to allow the woman to make an informed decision (Leshabari et al., 2006). Therefore, the majority of HIV positive women are left with little or no options regarding informed choice and lack knowledge on infant feeding options because alternatives to breastfeeding are not acceptable, feasible, affordable, sustainable and safe (AFASS) for many HIV infected women (WHO, 2010b).

Lastly, poverty also creates a situation where women have no choice on what to eat and eat what is available regardless of nutrition content. Hence this inadequate nutritional intake is commonly associated with “low milk production” by women themselves in these low-income settings. Despite the knowledge that milk can still be produced in extreme hunger, the majority of women believe that shortage of food is the main contributing factor for low milk production. Findings from qualitative studies suggest that breast milk alone is perceived by the majority of mothers, including HIV-infected mothers, to be an inadequate nutrition for infant weight gain and growth. As a result, semi-solid foods and other liquids were given to infants prematurely in order to complement breastfeeding (Fjeld et al., 2008; Leshabari et al., 2006; Lunney et al., 2008; Østergaard and Bula, 2010). Considering the physiological needs for milk production, the more the baby suckles the more breast milk will be produced (Henderson and Macdonald, 2004).

4.7.3. The role of social stigma: Experiences of HIV positive mothers

Evidence demonstrates that choosing replacement feeding would look abnormal. Woman who opt for replacement feeding are highly stigmatized in many cultures in sub-Saharan Africa where breastfeeding is normative, because she is acting outside the local norm and is suspected to be HIV positive (Koricho et al., 2010; Thorsten et al., 2008). The situation becomes difficult for women who give birth in the “Baby Friendly Hospital Initiative” units where all women are expected to put the baby to the breast within 30 minutes after birth and are encouraged to continue with exclusive breastfeeding. In fact, several breastfeeding messages (including pictures) are written everywhere in the maternities even outside which encourage women to initiate breastfeeding and continue with EBF for 6 months and also the advantages of performing BF behaviour (see figure 4-3).

Figure 4-2: An example of information about the advantages of feeding babies with breast milk only (photo taken from one of the hospitals in Malawi)



In most of these BFHI units women are mostly not allowed to bring in bottles or any food and posters that encourage breastfeeding are pasted everywhere even at the entrance. Therefore, in most circumstances if an HIV positive woman opts for replacement feeding she is expected to explain to the nurse why she is bringing infant formula onto the ward and the reasons for not breastfeeding (Thairu et al., 2005). In a study conducted by Doherty et al. (2006) in South Africa where the government distribute free infant formula to HIV positive women, one HIV positive woman who opted for replacement feeding complained that other people in their society would laugh at her when they see her coming back from the hospital with tins of milk and even said that she has HIV. Additionally, most of the postnatal wards are just an open space and it also becomes hard for HIV positive women to choose formula feeding as other

women and relatives would wonder why she is not breastfeeding. In the same study conducted in South Africa, one HIV positive woman who was also not breastfeeding found it hard to formula feed in the ward (Doherty et al., 2006). She ended up covering herself and adopting breastfeeding position while bottle-feeding her baby. When she was caught by the midwife, an explanation was demanded as to why she was bottle feeding instead of breastfeeding.

Based on the same formative study which was conducted in Lilongwe, Malawi as part of the BAN study explained in chapter 1, the infant peanut butter supplement which was given to HIV positive women was named “Nutrition for Breastfeeding mothers” to minimize any form of stigma (Corneli et al., 2007). In such cases, women opt for EBF because they did not want their HIV status to be known to others. Moreover, replacement feeding poses risks to child survival because women who opt for replacement feeding are highly stigmatized in many cultures, which greatly affects compliance to the chosen method (Thorsten et al., 2008).

Just like replacement feeding, exclusive breastfeeding for 6 months is equally associated with HIV positive status in high HIV prevalence areas especially if no good and legitimate explanation is given for not giving the child complementary feeds to the infant at 3 to 4 months as per common practices (Doherty et al., 2006). As the knowledge that exclusive breastfeeding for 6 months is the most effective way to prevent HIV transmission through breastfeeding is now disseminated in the community, women who continue to breastfeed their infant exclusively beyond 3-4 months are closely monitored and a confirmation about their HIV positive status is done when they completely wean their infants at 6 months (Doherty et al., 2006; Østergaard and Bula, 2010).

The difficulties faced when HIV positive women decide to wean their babies at 6 months is greater in most sub-Saharan African countries where breastfeeding in public is not an issue. Østergaard and Bula (2010) study in Malawi women complained of the challenges they faced if a child was crying in the public transport or in front of other people during social gatherings like church, funerals or weddings. Under such circumstances fellow passengers or surrounding people start insulting them and demand the reason why they are not breastfeeding their babies in an effort to quiet the infant (Fletcher et al., 2008; Østergaard and Bula, 2010). The issue is that women can only keep secret their HIV status during the first 3-

4 months of the infant age but beyond that people tend to wonder why they are not giving other food as culturally practiced (Fjeld et al., 2008; Østergaard and Bula, 2010). These suspicions have greatly complicated exclusive breastfeeding adherence among women who decided to keep confidentiality of their HIV status to their partners and close relatives such as their mothers and mother in-laws.

4.8. Conclusion

This chapter described determinants of breastfeeding and how these affect EBF promotion through the Baby Friendly Hospital Initiative and highlighted the challenges of implementing such initiatives in sub-Saharan region with high rates of HIV, where many births still take place outside the hospital and some people find it difficult to access care. The BFHI concept is no longer limited to the ten steps in maternities but rather has been modified to include infant feeding guidelines for HIV positive women as seen in the second column of table 8, but considerable challenges still exist.

Understanding the challenges which HIV positive women face while practicing EBF especially when they go back to the community would help policy makers and programme implementers to value the need to support women in the community. Equally important is the notion that despite breastfeeding being considered as a natural behaviour that every mother can perform and the fact that BF is dominant in SSA women still need support to initiate and maintain the behaviour. The main challenge in the BFHI approach lies on the quality of counselling offered to women on infant feeding, as well as social support especially in the community due to shortage of health personnel. Hence, the need for shifting roles and involving the community in health care delivery at community level in order to make services available and accessible in hard to reach places and reduce the inequalities. The next chapter introduces the evidence on community-based exclusive breastfeeding support and its potential value in supporting women in this context.

CHAPTER 5: COMMUNITY-BASED PROMOTION OF EXCLUSIVE BREASTFEEDING: A SHIFT TO THE COMMUNITY PARADIGM

5.1. Introduction

The literature discussed in the previous chapter indicates the limitations of current policies and approaches to promote exclusive breastfeeding at community level. In this chapter I now focus on the literature related to the use of community-based interventions (CBI) to promote exclusive breastfeeding in resource-poor settings in under-served areas with shortage of skilled health care workers. A literature search was conducted using the Internet databases such as PubMed, EBSCO host, BioMed Central and OVID online. The key words: peer counsellors, motivation, incentives, CHWs, volunteers, and developing countries were used in different combinations during the search. In addition, several books and articles related to community-based intervention were reviewed. I begin this chapter by defining the concept of community-based health promotion before assessing the role of peer counsellors in the promotion of EBF at community level. I will then review the evidence related to community-based promotion of EBF using peer counsellors.

5.2. Community-based health promotion

Health was defined by World Health Organization (1946 constitution) as the absence of disease because infectious diseases were considered to be the predominant cause of illness and death at that time. As a result, health promotion interventions mainly focused on the individual self-care, specifically for the preservation of his or her health. However, due to the reduction of these infectious diseases by the mid-1900s, and the realisation that socio-economic conditions also affect susceptibility, health had come to mean more than simply a disease and this perspective, ceased to be on strictly individualized health promotion interventions, shifting to an activity directed towards enabling people to take action.

The Ottawa Charter for health promotion (1986) defined health promotion as the process of enabling people to increase control over and to improve their health, and creating a conducive environment to health in which people are better able to take care of themselves. Green and Kreuter (1991) on the other hand, defined health promotion as a combination of health education and related organizational, economic and environmental supports for behaviour of individuals, groups, or communities conducive to health. The central concern of health

promotion is health behaviour which Gochman (1997) defined as those personal attributes such as beliefs, expectations, motives, values, perceptions, and other cognitive elements; personal characteristics, including affective and emotional state and traits; and overt behaviour patterns, actions, and habits that relate to health maintenance and improvement health. Much as health promotion interventions are directed towards increasing people's control over behaviour, the physical environment can limit people's participation in a society. Community-based interventions are those that target a group of individuals or a geographical community but are not aimed at a single individual. Community-based interventions are designed to modify personal, social and environmental factors which aim to improve people's control and thereby changing the determinants of health behaviour (WHO, 2003a).

5.3. Community involvement and participation

Community participation and community involvement in health are the descriptions given to the important mechanism of facilitating change or health development through interaction with the community. Community participatory approaches became a core part of primary health care strategies since the adoption of the concept of primary health care (PHC) by the World Health Organization (WHO) member countries in 1978 at Alma-Ata (WHO/United Nations, 1978; Tones and Tilford, 2001; Tones and green, 2004). The community can participate in the implementation of an intervention at different levels. Hatch et al (1993), cited by Blumenthal and Diclement, (2004) distinguishes four levels of community participation. At the first level, people consulted by the researchers are often working at the human service agency and living outside the community. However, in this model the community residents are unaware of the research or intervention to be carried out into their community and have no influence on its design. At the second level, the project involves leaders from the community such as chiefs, church leaders and representatives of organizations taking place in the community. Even though the project retains total control of the project in this model, there is passive involvement of the community. At the third level, community leaders are only asked by the project for the endorsement of the project and also hiring of some people often from the same community to work with the project. However, the community members are not involved in the design of the intervention and interpretation of findings. Hatch et al., (1993), refer to this model as community-based but not community involvement". This level of involvement may lead to manipulation of the community since those hired are often influential members of the local cultural systems. The fourth level both

involves and empowers the community in which the community is involved to define the agenda, identify the problem, analyse the contributing factors and help to come up with possible solutions. The major challenge at this level may arise due to the differences between researchers and the community and researchers therefore, may find it challenging to negotiate these differences and built a trustable relationship with the community (Hatch et al., (1993) cited by Blumenthal and Diclement, (2004), pp.13-14).

Community participation has demonstrated an increase in the sustainability, cultural appropriateness and reliability of interventions (Arcury et al., 1999). The more participation there is in a community intervention this may not only improve the quality of the services but also enable the intervention to be more successful (Tones and Tilford, 2001). The purpose of community participation is to strengthen the skills and capabilities of individuals to take action, and the capacity of groups or communities to act collectively to exert control over determinants of health. Thus, if the community itself recognizes it has a felt need and identifies the ways of resolving that need without any external intervention, change will happen more rapidly (Tones and Tilford, 2001). However, a professional-client paradigm is observed in community-based interventions conducted in developing countries, which often take place in minority and disadvantaged communities (Blumenthal and DiClemente, 2004). Under normal circumstances these communities are often powerless and have no control over the intervention. Hence community empowerment is a key component to positive effects.

5.4. Importance of task-shifting to lay community health workers

Shortages of skilled health workers, particularly in underserved areas, have been identified as a key facet of the growing human resource crisis. The World Health Organization estimates that four million health-care workers are needed globally to meet the health-care needs of the world. The late Director-General of the WHO (2006) argued that:

“There is a chronic shortage of well-trained health workers. The shortage is global, but most acutely felt in the countries that need them most. For a variety of reasons, such as the migration, illness or death of health workers, countries are unable to educate and sustain the health workforce that could improve people’s chances of survival and their well-being” (WHO, 2006).

These shortages are driven by a number of pull and push factors in the more resource-constrained countries. The pull factors include: increased demand for health workers in high-income countries, with good remuneration and working conditions while the push factors include; increasing morbidity, mortality and absenteeism rates, coupled with increasing workloads due to the impact of the HIV/AIDS pandemic; and inadequately funded and poorly managed and performing health systems, which lead to deteriorating working conditions in many underserved areas. In this regard, sub-Saharan Africa and East Asia are presently faring the worst. Task-shifting to lay community health workers (LCHW) has been a cornerstone of primary health care since the 1980s due to chronic shortage of trained health professionals (WHO/UNICEF, 1978). Task-shifting defined as the rational delegation of tasks to health-care workers with lower qualifications, has been one of the key strategies for dealing with the shortage of health-care workers.

The WHO study group (1989) defined the lay community health worker as any lay health worker carrying out functions related to health care delivery, trained in some way in the context of intervention; and having no formal professional or para-professional training and working in the communities from which they come (WHO, 2007). Worldwide, community health workers are known by a variety of different titles including, for example, peer counsellors, outreach educator, expert clients, village health worker, health promoter, community helper, community health promoters, community nutrition workers and community health volunteer (Gilroy and Winch, 2006). Lay health workers (LHWs) perform diverse functions related to healthcare delivery.

Peer counsellors—a name that is used most in this thesis, are therefore a type of community-based lay health workers who were involved in the MaiMwana trial to promote exclusive breastfeeding for 6 months (Lewycka et al., 2010). The underlying assumption is that while hospital-based promotion is well known to be effective regarding successful initiation of breastfeeding, the rate of exclusive breastfeeding for 6 months remains low. Peer counsellors reinforce exclusive breastfeeding behaviour in a socially and culturally acceptable contextual setting because they have knowledge about the socio-cultural context in which infant feeding takes place and understand cultural and environmental barriers to breastfeeding in their communities (Nkoki et al., 2010). Moreover, the relationship between peer counsellors and the mothers is mutual and is therefore, believed to reduce the gap separating health professionals and communities and thus mothers will be more confident to accept and take up

key messages (WHO, 2007). Peer counselling in infant feeding seeks to serve three main purposes:

- Informative counselling: strives to give the mother adequate information of different facts in order for them to make a sound judgment.
- Supportive counselling: Aims to help the mother safeguard her choices by recognizing and addressing cultural norms and practices that could act as barriers.
- Preventive counselling: Aims to develop awareness for and confidence of sustaining exclusive infant feeding.

A review of evidence on the relevance of community-based interventions by the World Health Organization illuminated that peer counsellors have the capacity to reach mothers in their real situation which enables them to better conceptualize mothers actual problems in sustaining the behaviour (WHO, 2003a). Furthermore, peer counsellors also provided an opportunity to create a forum to educate family members especially the husband, mother in-laws and grandmothers on what a breastfeeding woman needs and enlist their support in meeting these needs. Moreover, the use of peer counsellors provided accessible EBF counselling among underserved populations in poor countries where most deliveries occur outside the hospital or where access to health care services are limited and health workers are insufficient (WHO/UNICEF/PEPFAR, 2008).

5.5. Evidence related to community-based interventions to promote EBF

Community-based interventions (CBIs) have been conducted mainly in developed and a few developing countries to evaluate whether such interventions would promote exclusive breastfeeding rates (table 5-1). It is important to note that table 5-1 presents community-based interventions results in terms of effectiveness of CBI to improve EBF rates. Of special note was the PROMISE-EBF study, which was conducted in four resource-limited and high HIV prevalence countries in sub-Saharan Africa namely: South Africa, Tanzania, Uganda and Burkina Faso (Bland et al., 2008; Tylleskar et al., 2011). In general the bulk of literature reviewed provided an insight into the correlation between community support using peer counsellors and exclusive breastfeeding practices and the likelihood that the majority of mothers visited in their homes by these peer counsellors adopted the behaviour (Morrow et

al., 1999; Haider et al., 2000; Bhandari et al., 2003). Overall, there is growing recognition that programmes which reach beyond the hospital and use lay health workers (peer counsellors) at community level have a great potential to improve and sustain EBF in both high and low income countries.

Table 5-1: Evidence of community-based intervention to promote EBF

Study design	Subjects and site	Intervention	Outcome
Morrow et al., 1999 Cluster randomized controlled trial	Peri-urban Mexico N=130 Inclusion: all pregnant women	Peer counsellors visited women 3 or 6 times. Group 1: 6 visits during pregnancy, and then 1, 2, 4, 8 weeks postpartum	EBF rates at 6 months: 67% among those visited for 6 months 50% among those visited for 3 months 12% among the control group
Haider et al., 2000 (Cluster randomized controlled trial)	Dhaka Bangladesh N=726 Population: Women aged between 16-35 years with 3 children or less	Peer counsellors conducted up to 15 home visits including 2 in the last trimester, 4 during the first month and every two weeks thereafter up to 5 months	EBF at 3 months: 70% among those visited in their homes 6% among those not visited in their homes
Bhandari et al., 2003 (Cluster randomized controlled trial)	Haryana India N=1115 Population: All infant born within the selected clusters	Used volunteer counsellors and included community monthly meetings and opportunistic visits by community based health worker and traditional birth attendants to promote EBF	At 3 month EBF rates as 79% among the intervention group compared to 48% among the control group while at 6 months 42% of women in the intervention group were still practicing EBF compared to 4% in the control group.
Anderson et., 2005 (Randomized controlled trial)	Hartford Latina low income community N=162 Population: Pregnant women less than 32 weeks gestation	Peer counsellors offered 3 perinatal home visits and 9 postnatal home visits among the intervention group	The intervention increased breastfeeding initiation among those in the intervention group by 91% versus 76% among those in the control group
Aidam et al., 2005 (randomized controlled trial)	Tema Ghana N=136 Population: Pregnant women	One group of women was followed up in their homes by community health workers from perinatal period while another group was followed up from delivery. Health workers made 9 home visits at 1, 2, 4, 6, 8, 12, 16, 20 and 24 weeks postpartum in all groups except the control group.	At 6 months the rates of EBF was estimated at 90% among those who were visited at home from prenatal period compared to 74% among those who were visited at home from postnatal period and 47% among the control group.
Tylleskar et al., 2011 (Multi-country community based cluster randomized controlled trial)	Burkina Faso South Africa Uganda Zambia N=2579 Population: infant pair in all the four countries	Peer counsellors who were offering home-based breastfeeding counselling made the first visit during third trimester then at week 1, 2, 4, 8, 16 and 20 post-delivery. In Uganda and south Africa the visits were conducted at week 1, 4, 7 and 10 post-delivery.	EBF rates were as follow: In Burkina Faso 77% among the intervention group versus 23% among the control group; In Uganda 77% in the intervention versus 24% in the control group while in South Africa the rates were 8% in the intervention versus 4% in the control group.

One community-based randomized controlled study conducted in Mexico City (Morrow et al., 1999) assessed the impact of community-based peer counselling on EBF behaviour among low income women. This study included 2 intervention groups and a control group. The first intervention group received 6 peer counsellor visits starting in early pregnancy and ending at week 8 postpartum while the second intervention group received 3 peer counsellor's visits starting in late pregnancy and ending in week 2 after delivery. The control group received no peer counselling. This community-based intervention had a strong impact on EBF rates at both 2 week and 12 week postpartum. At 3 months, EBF was reported to be 67% among women who were visited 6 times in their homes by the peer counsellors and 50% among those who were visited 3 times compared to 12% among those who were not visited in their homes. This trial also demonstrated a 50% reduction of the cumulative incidence of diarrhoea as a result of the peer counselling intervention.

Similarly, in the state of Haryana India, Bhandari et al., (2003) used cadres of health workers including traditional birth attendants, health and nutrition workers and nurse midwives in the promotion of exclusive breastfeeding. In both the intervention and control communities EBF was estimated at 5% at 4-6 months before the intervention. In the intervention communities, at each counselling contact, the health worker assessed an infant's feeding practices, identified difficulties, and provided information on the benefits of exclusive breastfeeding. At age 3 and 6 months, mothers and infants were visited at home by a member of the study team to ascertain exposure to different counselling sources and trained nutritionists did 24-hour dietary recalls at the 3-month visit. These infants were revisited at age 9 months to ascertain the duration of exclusive breastfeeding and to assess the effect of the complementary feeding intervention. In addition, mothers were asked about diarrhoea in their child in the past 24 hours and the past 7 days. The intervention demonstrated 5-10 fold increase in exclusive breastfeeding rates between 4 months and 6 months of life. At 4 months 69% of infants were exclusively breastfed among those in the intervention group compared to 48% among those who were in the control group and the positive effect remained high up to 6 months 42% versus 4% among the control group. There was also a 50% reduction in babies receiving animal milk in addition to breast milk in the intervention group ($p=0.01$). Furthermore, 7-day diarrhoea prevalence was lower in the intervention than the control communities at 3 months (0.64, 0.44-0.95, $p=0.028$) and 6 months (0.85, 0.72-0.99, p value =0.04).

In another study which was conducted in low-income Latinas in Hartford, USA, where the rates of EBF are very low, Anderson et al., (2005) randomly assigned women to either receive an intensive protocol of prenatal, perinatal, and postnatal peer-counselling visits or conventional breastfeeding support (control group) and were followed through 3 months postpartum. In addition to the routine breastfeeding support and education, women assigned to the peer counselling group were offered 3 prenatal home visits, 9 postpartum home visits, and daily in-hospital visits during postpartum hospitalization, from the assigned peer counsellor. This was in addition to the care received by the control group. In this study it was found that women who were followed up in their homes were 15 times more likely to practice EBF than those who were not visited. The rate of nonexclusive breastfeeding in the control group was significantly higher compared with the intervention group at months 1, 2, and 3, respectively, using the “previous 24 hours” or the “previous week” recall definitions. Furthermore, at 3 months postpartum, 98.6% of mothers were not exclusively breastfeeding their infants since birth in the control group compared with 79.4% in the intervention group. Home visiting was also seen to be effective in places where hospital delivery is uncommon. The authors concluded that breastfeeding peer counselling was a highly efficacious method for promoting EBF among inner-city women in the United States with exceedingly low rates of EBF and strong preference towards feeding formula.

In Dhaka City Bangladesh, where 95% of women deliver outside the hospital and where a community health worker is not routinely available, home visiting was highly associated with the increase in the rates of EBF, initiation of breastfeeding and reduction in giving pre-lacteal feeds among women who were visited in their homes. During the intervention, Haider et al., (2000) randomly assigned 40 adjacent zones to intervention or control groups. These women were enrolled during the last trimester of pregnancy. Women in the intervention group received 15 home-based counselling visits by peer counsellors, with two visits in the last trimester, three early postpartum (within 48 h, on day 5, between days 10 and 14), and fortnightly thereafter until the infant was 5 months old. The prevalence of exclusive breastfeeding at 5 months was 70% for the intervention group and 6% for the control group which did not receive any home visits by the peer counsellors (difference=64%; 95% CI 57%–71%, $p > 0.0001$). Despite difficulties and a strong cultural tradition, peer counsellors had a significant influence in reducing pre-lacteal feeds in the intervention group where only 31% of babies in the intervention group were given pre-lacteal feeds compared with 89% in

the control group ($p < 0.0001$). The authors concluded that the higher frequency of home visits in the study may have contributed to the greater success and the early postpartum contacts were endorsed by mothers who reported that these visits were the most helpful.

5.6. Evidence from sub-Saharan Africa

There have been only a few studies conducted in Africa which found positive results on the effectiveness of community-based intervention to promote EBF. The significant effect on EBF become higher if follow up starts during pregnancy as evidenced from a Randomized Controlled Trial (RCT) conducted in Ghana (Aidam et al., 2005) and the very recently another large-scale study called the PROMISE EBF study (Tylleskar et al., 2011); and recent findings from the MaiMwana trial. The study in Tema, Ghana used health care workers, rather than peer counsellors, to visit women in their homes, randomly assigning women to 2 intervention groups and 1 control group. The first intervention group ($n=43$) received exclusive breastfeeding support during antenatal period, during labour and finally during postnatal period. The second intervention group ($n=44$) received EBF support during perinatal and postnatal period only. The control group ($n=49$) received non breastfeeding support. Results demonstrated that at 6 months postpartum 90% of infants in the first intervention group and 74.4% in the second group were breastfeed exclusively compared to 47.7% among the control group (p value =0.008), assessed using the previous 24-hour indicator.. The results further demonstrated that lactation counselling attributed to 100% increase in EBF rates during the first 6 months (39.5% in the intervention group versus 19.6% in the control group) (Aidam et al., 2005).

The PROMISE-EBF study was a multi-country community-based cluster-randomised behavioural-intervention trial carried out in sub-Saharan African countries namely; Burkina Faso, Uganda, South Africa and Zambia from mid-2006 to mid-2008 to improve the rates of exclusive infant feeding through the assistance of locally recruited community peer supporters (Tylleskar et al., 2011). In South Africa peer supporters were initially paid a monthly stipend of R1000 (\$127, and in the second year of the trial the stipend increased to R1200 (\$152) (Nkoki et al., 2010). The peer counsellors were trained for a period of 1 week using the WHO training materials on breastfeeding counselling and HIV and infant feeding counselling and they were supervised once or twice monthly during the course of the project. In total 2579 mother–infant pairs were assigned to the intervention or control clusters in all

the three countries. All mothers were offered at least five visits, starting with a visit in the third trimester. In Burkina Faso, mothers were scheduled to have home visits during the first week postnatally, and thereafter at weeks 2, 4, 8, 16, and 20. In Uganda and South Africa, home visits were scheduled within the first week and thereafter at weeks 4, 7, and 10.

In general, while the results from the trial indicated that community-based infant feeding counselling delivered by peer counsellors significantly increase the rates of exclusive breastfeeding by two- to three-fold compared with non-intervention communities in Uganda and Bukina Faso, the intervention have failed to show much impact in South Africa. At 12 weeks, in Burkina Faso the rates of EBF between the intervention and control clusters were 77% versus 23% respectively (prevalence ratio 3.27, 95% CI 2.13, 5.03); while in Uganda the rates of EBF were 77% in the intervention versus 24% in the control clusters (prevalence ratio 2.30, CI 2.00, 2.35); finally in South Africa the rates between the intervention and control clusters were 8% versus 4% respectively (prevalence ratio 1.98, CI 1.30, 3.02). One argument for the lower impact on EBF rates in South Africa as stated by the authors is that in South Africa the national programme for prevention of mother-to-child trans-mission of HIV-1 provides free formula to HIV-infected mothers while in Burkina Faso and Uganda EBF is highly recommended to all mothers regardless of HIV status (Tylleskar et al., 2011). Furthermore, the South African Department of Health's routine child health services have a history of promoting commercial infant formula as part of the protein energy malnutrition scheme. Furthermore, it was reported that Burkina Faso had the poorest participants with the lowest education, whereas the participants from South Africa were of higher economic status with the highest education. This means that the impact of community-based peer counselling was more significant in rural Africa, where utilization of health facilities is limited, and in poor countries. These results shed light on the greater need for community-based intervention in poor countries than countries which are much better resourced.

5.7. The results of MaiMwana community-based intervention

The results of the MaiMwana intervention discussed in chapter 1 suggest a significant reduction of MMR (74%), PMR (33%), NMR (41%) and IMR (28) in the women's group intervention while volunteer peer counselling demonstrated a reduction in IMR by 36% and infant morbidity by 42% (Lewycka et al., 2013). Overall, EBF rates increased more than two

times in all the interventions, however, after stratification the effect was only significant in areas with women's group intervention. The results show that women's groups with a community action cycle can improve survival of the newborn babies and mothers in poor communities. In addition, apart from improving infant feeding behaviours volunteer peer counsellors also might have a direct effect on infant mortality (Lewycka et al., 2013). The women's group could have a greater impact probably because the programme did not only target women but also included other people in the community such as men, elderly women and other decision –makers and leaders who are known to influence infant feeding practices in the community while the peer counselling intervention target the woman only.

5.8. How do peer counselling help to address the critical shortage of health personnel in the context of HIV?

Lay counsellors have widely been used in many countries including countries located in the SSA (Callaghan et al., 2010) including Malawi (Landes et al., 2013; Tenthani et al., 2012) to provide HIV care and support. This is due to the fact that HIV counselling and care for people living with HIV/AIDS especially in the Sub-Saharan region is characterized by lack of quality human resource to provide care and support and task-shifting was found to be a cost-effective way for addressing shortage of human resource for health in HIV treatment and care (Callaghan et al. 2010). For example, in 2007, Diginitas International recruited HIV positive clients who were stable on ARVs to work as expert clients (EC) and provide care and support to other HIV positive clients (Landes et al., 2013; Tenthani et al., 2012). ECs work within the health facility to identify patients that require extra care and support within ART and PMTCT clinics and explain to patients the benefits of being on ART based on their personal experience. They also assisted with patient transfer, height, weight and temperatures. Overall, ECs reduced the workload to be carried out by the health personnel within PMTCT and ART clinic (Tenthani et al., 2012). Similarly, in a recent study which was conducted by Centre For Public Health Policy Research and Development (CPHPRD) for Catholic Relief Services (CRS) in Malawi, the majority of the HCWs who are working in health facilities where there are Expert Client Models expressed satisfaction with the work done by this group of people because they were able to provide further counselling to HIV positive women, promote drug adherence and help trace defaulters in ART as well as PMTCT (Catholic Relief Services, 2014, Unpublished report).

Even though the use of peer counsellors seems to be effective in improving maternal and infant health as well as exclusive breastfeeding, most of these reports concentrated on the impact on maternal and infant health generally. Relatively few of these interventions have considered the impact on HIV positive women as well as the welfare of those peer counsellors who are expected to visit both HIV positive and negative women in their homes. Notably, a non-randomized intervention cohort study conducted in South Africa to increase EBF among HIV positive and negative women, suggests that “use of peer counsellors to visit and counsel women in their homes” may significantly increase the rates of EBF practices among HIV positive women: sixty eight percent of HIV positive women were able to practice EBF at 5 months compared to the national rates of 6% despite that infant formulas are made available for free among HIV positive women in the country (Bland et al. 2008). Furthermore, findings from qualitative interviews conducted in South Africa within the PROMISE-EBF study, HIV positive women demonstrated some worries and had a lot of questions on how to feed their babies and the presence of the peer counsellors helped them to get answers to the questions they had (Nkoki et al., 2010).

Given that HIV positive pregnant women are faced with conflicting imperatives, as discussed in chapters 3-4, counselling HIV positive women was perceived to be a difficult task and time consuming (Leshabari et al., 2007a; Ferguson et al., 2009). This was increased further because counsellors were blinded about the women’s status and some women disclosed their status during the counselling session. This impact could be more significant in countries where infant formulas are not available for free for HIV positive women like Malawi because HIV positive women have no other option but comply with EBF to have HIV free babies. Qualitative focus group discussions which were conducted in Mumbai India as part of the PROMISE-EBF trial exploring perceptions of women health facilitators involved in community-based interventions indicated the need for public health programmes involving peer workers to consider perceptions, expectations, and training of peer workers when planning such interventions to be effective (Alcock et., 2009).

5.9. Conclusion

This chapter has explored and discussed available evidence related to community-based intervention in the promotion of exclusive breastfeeding. The literature search identified a number of studies conducted in resource-poor settings, including sub-Saharan Africa which has shown significant impact on EBF rates. Distance to health facilities and shortage of skilled health workers are all situations that make community-based interventions using peer counsellors likely to be more effective in promoting exclusive breastfeeding among women in resource poor settings. Although found to be effective however, the scaling up still remains slow, particularly in the developing countries where EBF is essential for infant survival. The chapter presented in detail the results of the MaiMwana intervention which also demonstrated significant impact on EBF in Malawi. The MaiMwana intervention further highlights the importance of involving the community members such as men and elderly women when implementing such community-based interventions (Lewycka et al., 2013). These are well known to influence infant feeding in the country and suggest that their involvement could help to increase their knowledge on the importance of exclusive breastfeeding (Bezner-kerr et al., 2008). In addition, the review identified that most of the studies conducted in SSA did not consider the consequences of using peer counsellors in high HIV areas.

CHAPTER 6: RESEARCH DESIGN, METHODOLOGY AND METHODS

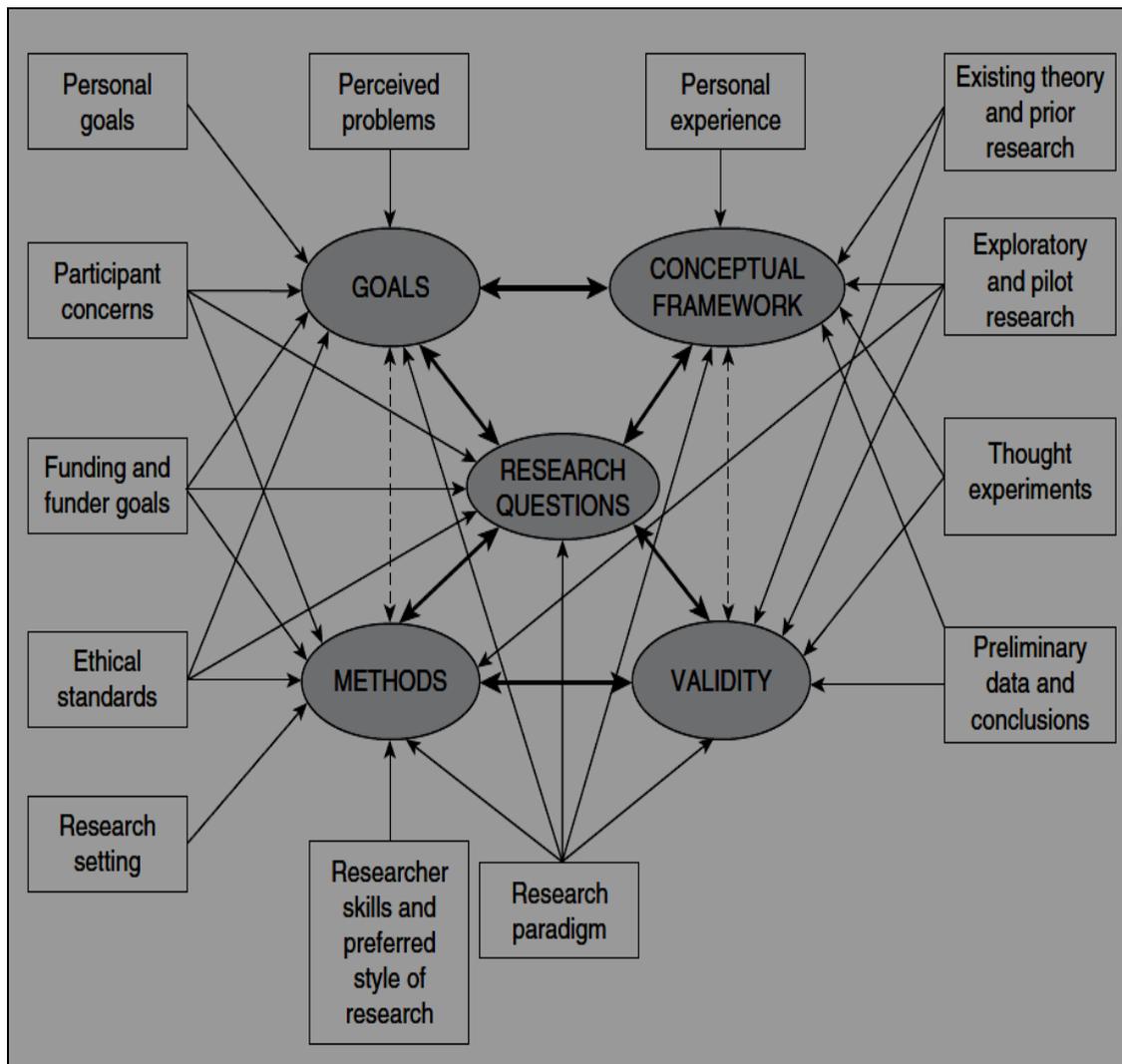
6.1. Introduction

This chapter describes the study design and the general methods used to collect data for this thesis. Crotty (1998) considers that when developing a research project the researcher needs to justify the reasons for choosing specific methodology and methods and systematically document the logical sequence of the approach. The chapter further sets out the justification of the research approach along with an explanation of the methods used for data collection. Lastly, ethical and methodological issues are further presented in this chapter.

6.2. Overview of the research design

To explore factors that affect women to practice EBF and experiences with home-based peer counselling, I selected to use qualitative exploratory case study research design (Yin, (2003). Yin (2009) defines a research design as a logical sequence that connects the empirical data to a study's initial research questions to be answered, and ultimately, to its conclusion (p. 26). My original planned design had involved a mixed methods approach including quantitative re-analysis of the MaiMwana dataset to identify outcomes for HIV positive women and qualitative data collection to understand experiences of different actors in the project. The design was however modified to enable a fuller focus on qualitative methods since I realized that the quantitative analysis of this dataset while partly addressing the research questions, would not capture the real personal experience of participants with the intervention. I used Maxwell's model for contextual factors influencing research design (figure 6-1) to best illuminate factors that underpinned the design and conduct of my study (Maxwell, 1995, p. 7). Maxwell' model comprises of five components which influence one another including: purpose, conceptual framework/context, research questions, methods and validity (Maxwell, 1995).

Figure 6-1: Contextual factors influencing research design



Source: Maxwell, 2005, p. 6

Research questions reflect what the researcher wants to learn by doing the study and is recognized as the main predictor of the research design and methods (Maxwell, 1995). Miles and Huberman (1994) further stress that research questions help the researcher to focus the study on the intended goal and conceptual framework (p. 22). Maxwell (2005) further suggests that assumptions, expectations, beliefs and theories also influence the design of the study. My choice to use qualitative methods in this project was therefore, influenced by the research question, which aimed at exploring the reality of lived experiences (*ontological assumption*) of HIV positive breastfeeding mothers; and to examine experiences with home visit and the significance meaning given to such experience (Yin, 2009). The design and conduct of my study was further influenced by extensive theory of knowledge and personal experiences on how infant feeding is controlled in many communities (*epistemology*) and the

sensitivity of exploring exclusive breastfeeding in the context of HIV (Renzetti and Lee, 1993; Creswell, 2007). The model by Maxwell (1995) guided the conduct of my study in terms of sample selection, site, data collection and analysis process.

I also observed that the gaps I identified from the literature about the topic could best be answered using qualitative methods. Moreover, through *available evidence* I observed that many interventions to promote EBF—mainly through the Baby Friendly Hospital Initiative target the individual woman without involving significant others who are known to be influential in as far as infant feeding is concerned. Considering the gaps between the researchers and the communities in terms of education level, language, understanding of the research process and socio-economic status, I was also interested to find out how the investigators of the MaiMwana intervention from western countries involved the local communities in the design and conduct of the intervention. Qualitative methods further created a framework to analyse themes and concepts derived from the exploration of perceptions of the larger community who were involved in community-based peer counselling to promote EBF. This helped to gain an insight on the nature of the problem and infant feeding decision-making process in a natural setting (Ritchie et al., 2014). Overall, the use of qualitative methods in this study helped to build a complex, holistic picture, and conduct a cross-sectional analysis of words and views across different cases included in the study (Denzin and Lincoln, 2003; Creswell and Plano Clark, 2007; 2011).

Apart from the research question, other factors that were also taken into consideration when designing this present study included: time to collect data, funding, and the dichotomy between western (that is my learning institution) and non-western culture (the study area). I anticipated some potential challenges to gain ethics approval from two ethics committees with diverse beliefs and knowledge on the subject matter, access to the study area, recruitment of study respondents, consenting process and conducting interviews.

6.3. Philosophic underpinnings of qualitative design

Quantitative and qualitative are the two different research methodology of inquiry (Morse and Richards, 2002; Denzin and Lincoln, 2005; Creswell, 2007). In the social sciences community, these two approaches often vary along a number of dimensions in terms of the

paradigms⁹ or worldviews which researchers bring to each approach (Creswell, 2007; Teddlie and Tashakkori, 2009). Denzin and Lincoln (1994) however, argued that these differences are often less apparent in real practice. Creswell (2007) for example, explains that logically both qualitative and quantitative research falls within the process of scientific research which follows a common structure. In both approaches researchers start with a phenomenon or problem that needs to be studied, examine the literature related to the problem, pose questions, gather data, analyse the data to identify patterns and write the report. In some circumstances both quantitative and qualitative data can be collected (mixed method approach), analyzed, and the researcher can integrate the findings, or draws inferences in a single study or within multiple studies in order to incorporate the strengths of both methodologies (Patton, 2002; Burke and Onwuegbuzie, 2004; Creswell and Plano Clark, 2007).

Qualitative research is usually associated with a constructivist paradigm which posts that humans generate knowledge and meaning from an interaction between experiences and ideas and that there is no absolute reality external to human interaction waiting to be discovered (Miller and Brewer, 2003; Yin, 2003; Denzin and Lincoln, 2005). Denzin and Lincoln describe a qualitative approach as one that locates the observer into the world, referring to the approach as “interpretative, naturalistic to the world” focusing on naturalism as a way of inquiry, attempt to make sense of, or interpret, phenomena in terms of the meanings people bring to them (Denzin and Lincoln, 2005, p. 3). Qualitative methodology therefore captures the meaning that participants attach to their lives and circumstances in their natural environment (Speziale and Carpenter, 2011).

Qualitative researchers recognize the importance of the subjects and use perspectives of people to understand what people do in their territories and why, that can be tested and linked to scientific literature (Creswell and Plano Clark, 2007). Creswell (2007) for instance, describes the approach as building patterns, categories and themes from “bottom up” approach (p. 45). Patton, Dahlgren and colleagues describe such a method as having an inductive orientation rather than deductive which allows the qualitative researcher to develop new theories from the data (Patton, 2002; Dahlgren et al., 2007). Denzin and Lincoln (2005)

⁹ Lincoln and Guba (1985), explains a paradigm as a systematic set of beliefs or framework that guides the research process and practice in the field (p.15).

further argued that qualitative researchers seek answers to questions that stress how social experience is created and given meaning. Rubin and Rubin (2012) add that qualitative researchers focus more on what has happened in a specific circumstance (p. 16). Lavender et al. (2004) further concur with this view and highlight that qualitative methods help the researcher to play the role as an active learner who can tell the story from the participants' views rather than an expert who passes judgment on participants. Creswell (2013) also expound that qualitative research is often conducted when the researcher wants to empower individuals to share their stories, hear their voices and minimize the power relations that often exist between a researcher and participants in a study. Besides, the trust that participants develop towards the researcher enables issues to come to light that the researcher may not have expected (Creswell, 2013, p. 48). One advantage of qualitative methodology is that the researcher gets closer to the participants; and the use of open-ended questions and probing gives participants an opportunity to respond in their own words, rather than forcing them to choose from fixed responses. And again, rather than presenting the research in statistical format, qualitative research mostly produces words in the form of comments and statements (Creswell and Plano Clark, 2007).

Qualitative approach is particularly appropriate when information is sought on complex and sensitive phenomena (Renzetti and Lee, 1993; Holloway and Jefferson, 2007). In this context, take the issues of infant feeding in the context of HIV for instance, which was being explored in this study; it is a complex phenomenon that involves deep rooted ideas in the context of biomedical knowledge, power relations, global and national policies. Secondly, such phenomena demanded respondents to discuss their sexual behaviour and disclose their HIV status which under normal circumstances is kept confidential due to the stigma attached to it. In such situation the use of qualitative methods was deemed the most amenable because it allowed the researcher to use various techniques to capture and learn the complexity of the phenomenon from a subjective perspective. Furthermore, this was useful to gain more insight into some of the issues that could not be captured using quantitative methods (Creswell, 1998; Denzin and Lincoln, 2003; Lavender et al., 2004). These include: psychological effects of exclusive breastfeeding while HIV positive and personal effects of home-based peer support. The approach further provided more comprehensive evidence on why HIV positive women often did not manage to practice EBF and further explore their experiences using skills to observe people and record behaviour in their natural setting and address the research problem (Creswell and Plano Clark, 2007). Overall, the use of qualitative methods in this

study helped to build a complex, holistic picture, and conduct a cross-sectional analysis of words and views across different cases included in the study (Denzin and Lincoln, 2003; Creswell and Plano Clark, 2007; 2011).

Qualitative approach has come under criticism as failing to produce results which can be generalized because the findings are mostly based on in-depth study of single or few cases who they feel are information rich on the phenomena under study (Teddlie and Tashakkori, 2003; 2009). In the case of this study, the work was conducted alongside a large scale cluster RCT, which was gathering data on outcomes, but did not consider experiences of HIV positive women who were visited home and those involved in visiting HIV positive mothers.

6.4. Case Study

I used qualitative explanatory case study design to collect and analyse data in this study (Yin, 2003; 2009). Yin (2013) described a case study as an empirical inquiry that investigates a phenomenon of interest (the case) either about individuals, organizations, processes, programmes, neighbourhoods and even events within real world context especially when the boundaries between the phenomenon and context may not be clearly evident (p. 16). In this study, the MaiMwana project home-based peer counselling intervention using different groups of informants which included breastfeeding mothers; both HIV positive and negative, volunteers peer counsellors and key informants constituted my case study (Yin, 2003; 2009; 2013). According to Yin (2013) an explanatory case study is used to explain how and why some sequence of events occurred or did not occur (p. 213). Furthermore, case study approach was chosen because it has the potential to allow participants to present their views and lived experiences in their own opinion (Denzin and Lincoln, 2005; Creswell and Plano Clark, 2007; Yin, 2003; 2009). Consequently, both positive and negative issues about EBF as well as home-based peer support were drawn out to answer the research questions.

Again, a case study design was chosen over other methodology because the aim was not to generate theories grounded in the data as it is the case in grounded theory (Glaser, 1967); nor did I want to explore the cultural theories as in qualitative ethnography (LeCompte and Schensul, 1999); but rather the use of prior theory during the designing phase was the essential element which guided the type of participants to be included in the study and the data to be collected (Yin, 2009). Again, the focus was not on generalization of findings to a

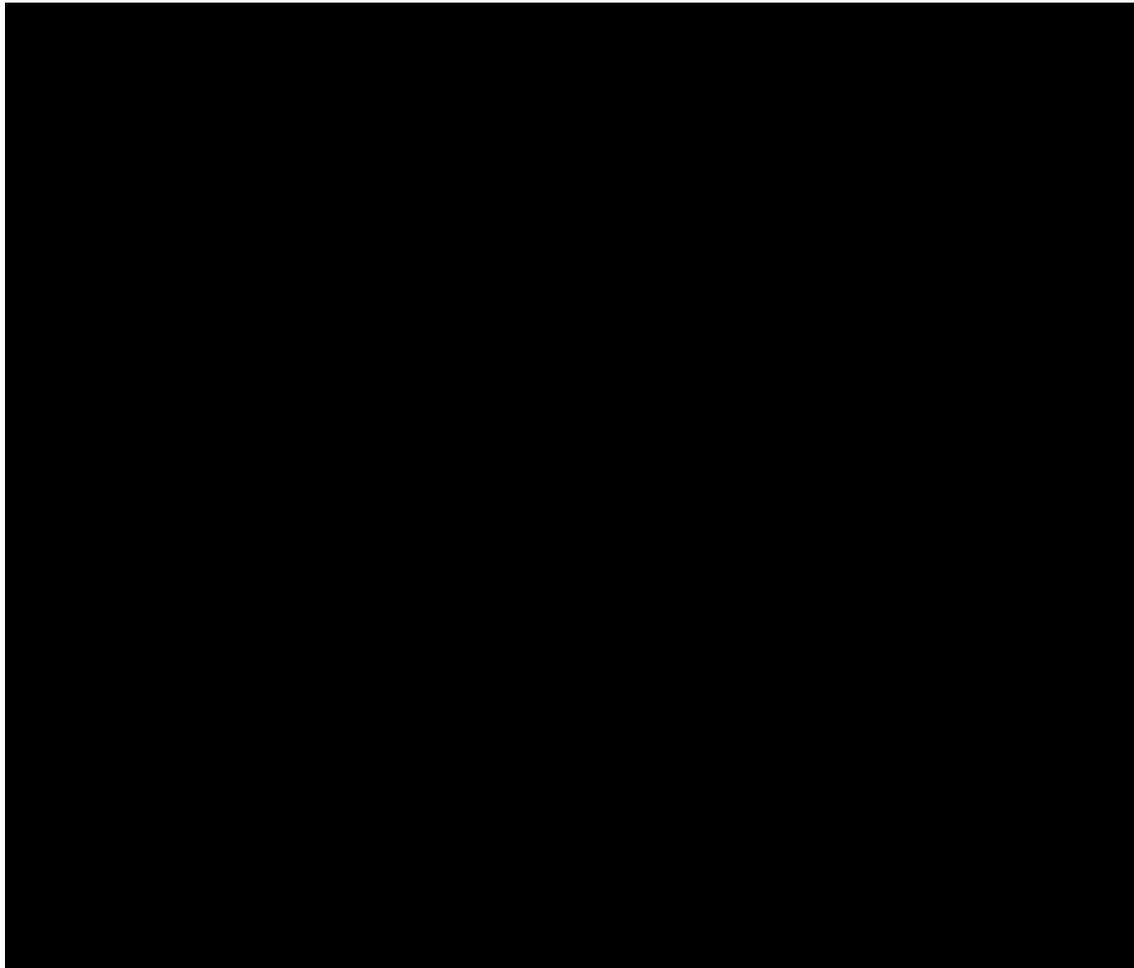
wider population but rather to understand experiences of participants within their natural setting (Creswell, 2007). A case study qualitative approach was therefore, useful for me to explore a phenomenon through one or more cases described above that were knowledgeable with the phenomenon under study and not the whole population (Creswell, 2007). Moreover, an investigation into home-based peer support to promote EBF among HIV positive women forms a significant case study. This in my view is because despite MaiMwana project implementing the intervention in high HIV prevalence areas did not have the opportunity to investigate this phenomenon, despite the numerous challenges attached to infant feeding in the context of HIV (Lewycka et al., 2010). It is also important to note that the use of case study in this study which is sensitive in nature did not involve lengthy participant observation which requires more time (*as it is the case with ethnography*) (LeCompte and Schensul, 1999) but partly observed participants in their natural settings (Yin, 2013). The aim of conducting an explanatory type of case study was to generate a deeper understanding of how and why women especially those with HIV fail to practice EBF despite knowing the dangers of mixed feeding and also to hear their views and perceptions related to home-based peer counselling. This was also intended to ask participants about their individual experiences and feelings with EBF and home-based peer counselling and only observe them during their meetings.

Community-based interventions operate at the community level, family level and individual level. Therefore, case study design further provides an opportunity to connect the influence of cultural factors and the micro-level of social factors or the action of individuals (Yin, 2009). Furthermore, Case study design is also seen to be important to understand why interventions succeeded or failed (Pope and Mays, 2006). In this study it was therefore, desired to understand whether the home-based peer counselling intervention which was being implemented by MaiMwana Project really helped women especially those who were HIV positive to practice EBF for 6 months or not. This was because I considered the complexity of implementing the interventions in communities with deep-rooted hierarchical cultural practices related to infant feeding, high poverty and HIV prevalence among women. The use of case study approach allowed me to understand the lives of individual women included in the study, their stories, as well as social and cultural structures; and organizational performance (Yin, 2009). The use of sub-units in the study provides opportunities for extensive analysis that helped the researcher to generalize findings. In this case, if two or

more respondents support the same broader theory—referred to as analytical generalization by Yin (2009) then the research findings can be generalized on an analytical level.

6.5. Study setting

Figure 6-2: Map of Malawi showing Mchinji district



This study was conducted within the catchment area of the MaiMwana Project already explained in chapter 1 in Mchinji district. Mchinji district lies to the west of Lilongwe, the capital city of Malawi (figure 6-2). The district shares international borders with Zambia to the west and Mozambique to the South west. The district had an estimated population of 456,516 in 2008 (NSO, 2008). The district is divided into 9 Traditional Authorities (TAs): Dambe; Kapondo; Mavwere; Mduwa; Mkanda; Mlonyeni; Nyoka; Simpasi; and Zulu. The district centre is Mchinji Boma where MaiMwana project main office is located. Eighty percent of the population lives in the rural area that is dependent on subsistence farming as the major source of income and employment. This is Similar to the general population in

Malawi (NSO, 2008). The district heavily relies on rain-fed agriculture and the main crops cultivated in the district include: maize, tobacco and groundnuts which attract people from other districts to come and work as casual tenants. About ninety-four percent of the people in the district are Christians and the majority predominantly speaks Chichewa (90%) which is the main language in Malawi. The common type of marriage is patriarchy where the woman moves from her home and stay with the man.

The district has one district hospital which is the only referral hospital and other 15 health facilities scattered across the district. Despite high antenatal attendance in the district only, half of the women give birth at a health facility (MDHS, 2004). This district has seen a rise, in recent years, in the number of women delivering at a health facility because of village bylaws created by leaders whereby pregnant women who deliver home pay a fine. The district Hospital was recognized as a Baby Friendly Hospital Initiative in 2005 and almost all women breastfeed their babies. All the health facilities routinely provide PMTCT service to all antenatal mothers. According to the 2007 antenatal surveillance report, Mchinji had an estimated HIV prevalence of 8.8% (NAC/GoM, 2008).

6.6. Initial exploratory field trip

During the first year of my study time, I embarked on a month long exploratory trip to MaiMwana project Malawi from April through May 2011 prior to data collection. The aim of this trip was examine how the project implemented its intervention, get familiar with their daily activities and ensure that my study design take into account the social and cultural context of the study area. I also took advantage to build relationships with the team as (Lofland et al., 2006) explains why it is important for the researcher to build good relationship with key gate keepers in order to get entry into the field, as gatekeepers tend to often protect the occupants of the strata from intrusion and disturbances. In addition, I attended to some project meetings and interacted with project staff in order to understand their perspectives towards the proposed study.

Later during the visit, I held a series of meetings with the MaiMwana health team to gather some insights on how peer counsellors perform their work and how they support them to work effectively. Some other activities accomplished during the visit included: conducting a series of consultative meetings with various key stakeholders (table 6-1) particularly those

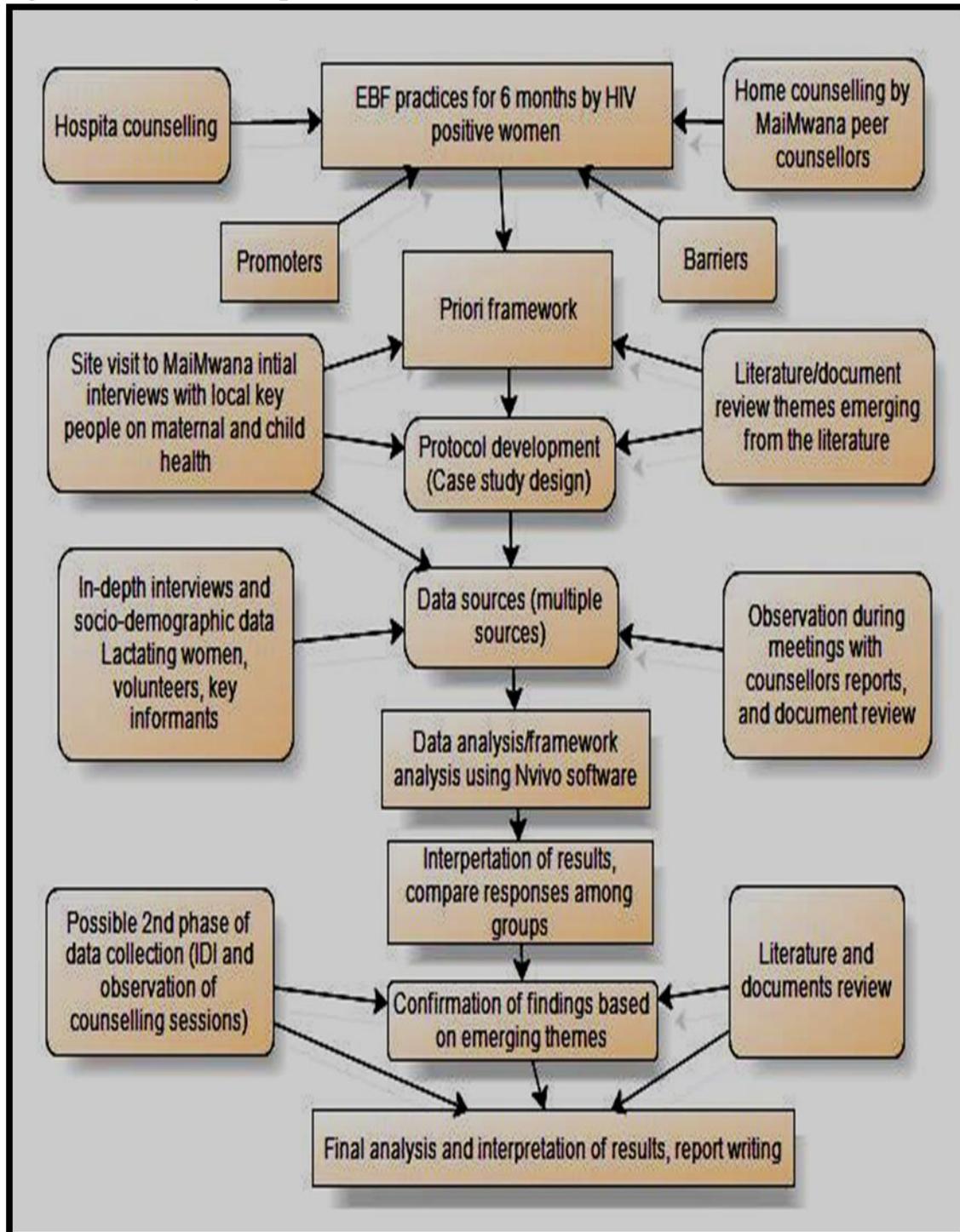
working in the field of maternal and child health to inform them about this study and allowed them to comments or ask questions. I also attended some meetings and workshops related to safe motherhood within the country and further obtained documents, past and current national policy documents and guidelines related to infant feeding from the Malawi Ministry of Health and National AIDS Commission.

Table 6-1: Meetings with key stakeholders

Organization	Number of meetings
Kamuzu College of Nursing	2
MwaiMwana Project	3
World Health Organization	1
Presidential Initiative in Safe Motherhood	2
Midwifery led Maternity Unity (Achikondi Maternity clinic)	1
Nurses and Midwives Council of Malawi	1
Total	10

Information gathered from this visit was paramount to further identify the gaps, plan recruitment procedures and data collection methods and also to avoid duplication of work already done by the project. Additionally, I investigated practical issues related to the conduct of my study in terms of the process of gaining ethics approval and permissions, entry into the field, recruitment of participants, spacing, how to access available project data and identify potential barriers. The meetings with stakeholders created opportunities for them to provide their input on the study design and specific areas to be explored and also helped to refine research questions before commencement of data collection phase. This trip also allowed me to develop the study's working framework (figure 6-3) which furnished guidance on literature search and development of interview guides, and also guided the conduct of my study and selection of appropriate data collection methods.

Figure 6-3: Study conceptual framework



I then obtained permission from MaiMwana Project prior to entering the field because it would have not been appropriate for me to enter into the field and recruit respondents from their catchment area without their permission.

6.7. Entry into the field for data collection

Since lactating mothers were recruited from health facilities, I personally visited the health facilities and convened face-to-face meetings with the clinic managers and other clinic staff especially those responsible for conducting under-five and PMTCT clinics to obtain permission to recruit participants from their clinics. This was also done to inform them about the study in detail, build rapport, get familiar with the routine and practices of the clinic settings for easy recruitment of breastfeeding mothers especially those who were HIV positive, and identify space for conducting interviews. Additionally, considering the sensitivity of the research topic, the clinic staff was informed about the ethical principles guiding my study and the importance of voluntary participation of respondents and confidentiality. After the meetings we agreed on the days to conduct interviews and ensure that these interview dates were scheduled on the same days in a week when these clinics conduct PMTCT activities¹⁰ so that I could easily recruit the required sample of HIV positive women. In the end, I left an information sheet for the staff to read during their own free time.

Since this study included HIV positive women, I anticipated challenges during interviews because some of the questions asked were sensitive and personal. For instance, respondents were asked some questions about their personal experiences being HIV positive, how they contracted HIV, reaction of significant others especially spouse following disclosure of HIV status and personal feelings when breastfeeding while knowing that they might transmit the virus to their babies. Renzetti and Lee (1993) state that collecting such information may cause emotional distress to respondents being studied and this trip was used to learn the referral systems within the clinics.

6.7.1. Recruitment and training of a research assistant

A research assistant was hired in consultation with the MaiMwana project health team to assist with the data collection. The research assistant was a woman in her late 40s and was selected based on the following criteria: a minimum of 12 years of education, prior training in community work, interested in maternal and child health, living within the district where the study was taking place and familiar with maternal and child health activities taking place in the district and MaiMwana Project. The research assistant had previously been trained in

¹⁰ PMTCT clinic is carried out once a week in all the health centres where I conducted interviews with HIV positive women.

Rural Community Development, which included qualitative research methods. She was unemployed and was contracted to assist throughout the data collection period following UNC guidelines of temporary employment. In order to prepare her for the study, I provided a two-day orientation training prior to the start of field work. The training focused on overview of the research protocol and rationale, purpose of the study, research objectives and principles governing my research, how to recruit clients, data collection, management and storage, and issues of confidentiality. In addition, data collection tools were also discussed and how to use the topic guide. The aim was to ensure that we ask questions in the same manner.

6.8. Study population, sampling procedure and rationale for selection

To collect rich information required to address the research question under study, I selected and included a diverse group of respondents with good knowledge and in-depth understanding of the programme to participate in this study (Bryman, 2008). The aim was to explore determinants of EBF behaviour from different perspectives and also to allow them to share their complex stock of knowledge and experiences related to exclusive breastfeeding and community-based interventions in the context of HIV. A total of 39 respondents were purposively selected from the MaiMwana intervention areas to guarantee sufficient number and ensure representation of different study participants. These were categorized into three main groups summarized in table 6-2 below. The interview process will be explained in detail later in this chapter.

Table 6-2: Interviewed study population

Category	Number
Breastfeeding mothers	19
MaiMwana volunteers	8
Key informant	12
Total	39

6.8.1. Category 1: Breastfeeding mothers and recruitment process

This sample included both HIV positive and negative women, either visited or not visited home by the peer counsellors. Selection of women was restricted to only include women who

opted for EBF and coming from the villages within the selected clusters where MaiMwana was conducting the trial. This was confirmed by checking the health passport of either the woman or the infant. Out of 19 women interviewed, 12 were HIV positive while the remaining 7 were HIV negative; while 12¹¹ were visited at home by the peer counsellors while 7 were from the control clusters.

I involved these women in this study to learn their experience with exclusive breastfeeding, the challenges faced and whether home visits by peer counsellors helped them to maintain the behaviour. Inclusion of HIV positive women was useful to explore their coping mechanism—especially to explore whether home-based peer support helped them to cope with the double burden—living with HIV at the same time knowing that they could transmit the virus to their babies through breastfeeding. Furthermore, this was helpful to explore experiences of women with different HIV status and also to identify issues of “spill-over effects”. In this case, HIV negative women or those with unknown HIV status tend to avoid EBF due to fear of transmitting the virus to their babies, firstly, because they may suspect that they can have HIV, and secondly, they fear being labelled as “HIV positive” if they are seen breastfeeding exclusively for a longer period, which is inconsistency with the norms of cultural practice (WHO/UNICEF, 2003b). Again, inclusion of both HIV positive and negative breastfeeding mothers in the sample was to avoid raising suspicion and causing involuntary disclosure of HIV status among women. Interviewing women who were not visited home by the peer counsellors was desired to capture opinions and perceptions of women towards the intervention and compare which groups prefer to be visited or not and the challenges which they faced or anticipated.

Three health facilities namely: Mikundi, Nkhwazi and Guilime were selected and used to recruit breastfeeding mothers who formed the core group of the sample. These sites were selected in consultation with the MaiMwana health team who had information on the performance of the surrounding clusters—that is high or low EBF rates among study clients and all were providing PMTCT services. Among the three, Mikundi and Nkhwazi are government owned where by all health care services are provided for free while Guillime is under Christian Association of Malawi (CHAM) and demand a user-free on some of the services. In addition, the above clinics were conveniently selected in such a way that both

¹¹ This number included both HIV positive and negative women

women coming from intervention and control villages are interviewed. In this case, Mikundi and Guillime were mainly surrounded by clusters from the intervention group while Nkhwazi was surrounded by control clusters. After selection of the health facilities, a list of clusters served by these health facilities was obtained from the MaiMwana health team.

Purposive sampling technique which is sometimes called “judgement sampling” was used to recruit a convenience sample of 19 breastfeeding mothers (Bowling, 2009). Purposive sampling is defined as a deliberately non-probability sampling technique commonly used in qualitative research (Punch, 2005; Bowling, 2002; 2009; 2014; Bryman, 2012). Rather than selecting a statistically representative sample as it is the case with probability sampling, the purpose of using purposive sampling is to select relative a small samples (people or settings) with a particular characteristic but different in terms of key characteristics relevant to answer the research questions that are being posed (Patton, 2002; Flick, 2009; Bryman, 2012). Patton (2002) describes purposive sampling technique as the one in which a researcher decides the purpose he/she wants informants to serve and go out to find those with the desired characteristics or experiences. He further emphasized that in this sampling technique the emphasis is on the quality of information rather than quantity and the aim is not to maximize numbers but to become saturated with information on the subject matter (Patton, 2002, p. 230). Through purposive sampling technique, I selected a relatively small number of breastfeeding mothers who had good experience with exclusive breastfeeding and home based peer support that particularly provided rich first-hand information related to the subject matter (Creswell and Plano Clark, 2007; Creswell, 2009). This technique was useful because I wanted to have a heterogeneous sample (Holloway and Wheeler, 2009), ensuring that both HIV positive and negative women as well as those visited and not visited in their homes were interviewed.

Through purposive sampling, selection of mothers was restricted to only include those who opted for exclusive breastfeeding and coming from the villages within MaiMwana clusters and this was confirm by checking the health passport of either the mother or her baby. This was done because in Malawi people have no specific hospitals where they could go and access treatment and care due to shortage of drugs especially in government-owned health facilities compared to CHAM hospitals. For instance, during the time I was conducting the study many government facilities were experiencing severe shortage of essential drugs which forced the majority of people to seek care and treatment from CHAM hospitals. On the other

hand, due to the user-fee demanded at CHAM hospitals many people prefer to seek free medical care from the government-own health facilities. Furthermore, these mothers were selected based on the distance from their village to the health facility, age and parity.

Purposive sampling technique was also seen to be most appropriate for this study because I anticipated sampling of HIV positive women to be challenging (Renzetti and Lee, 1993). Renzetti and Lee further explain that participants required to participate in studies of sensitive topics tend to hide their status and they may be reluctant to talk about it, even to an independent researcher; and again their records are kept protected. Additionally, in most cases such participants are not willing to get involvement in activities targeting HIV positive people due to fear of being stigmatized by other people in the community if they come to know that they are HIV positive (Renzetti and Lee, 1993, p. 30). Furthermore, through purposive sampling I selected peer counsellors who had experience with conducting home visiting in the context of HIV and expose the major barriers they faced that I believed would be paramount to develop programmes relevant to overcome the same problems beyond the study area (Patton, 2002).

The under-five clinic was used to recruit a diversity of women attending the clinic in terms of age, parity and socio-economic status. However, considering issues of confidentiality surrounding HIV, it was envisaged to be difficult to ensure a balanced sample of HIV positive and negative women. Renzetti and Lee (1993) explain that it is important to use special locations where rare populations tend to congregate as sources of recruitment. Renzetti and Lee (1993) further explains that access of special groups for instance, people living with HIV is often difficult due to the stigma attached to the disease. Therefore, to systematically recruit HIV positive women, the PMTCT clinic (i.e. a more specialized HIV clinic for PMTCT) was also used. The clinic staff who had access to the databases and records of HIV positive women were asked to refer HIV positive women to me for recruitment. Recruitment of HIV positive women in this study therefore did not require HIV testing because all pregnant mothers are routinely tested for HIV during their initial antenatal visit in the country (MoH/GoM, 2011a).

Once the clinic staff identified a potential respondent, they briefly explained the study to them, obtained verbal consent and those willing to participate and met the inclusion criteria were referred to me after they had completed all their activities for that visit. I asked the staff in-charge for a confidential place within the health facility premises with minimal disturbances but this was not guaranteed as disturbances are bound to happen in a public place like a clinic because people are always knocking and seeking help. I made myself available specifically on the clinic days and further explained the study to eligible women in more detail. This second sensitization was done to ensure that women were voluntarily willing to participate in the study after understanding the purpose, advantages, and risks to them and met the eligibility criteria. I then provided study information sheet (appendix 2) to those who were willing to participate. This initial contact with the respondent was crucial for me to develop rapport with clients as Speziale and Carpenter (2007) state that being in contact with participants several times helps the researcher to develop rapport and make participants feel more comfortable in sharing sensitive information. Furthermore, I explained my position as a researcher and further stressed that I had no direct involvement with the MaiMwana Project and the health centre staff. This was done to ensure confidence in women and allow them to freely voice their thoughts during interviews.

Detailed information on infant feeding practices, HIV serostatus and socio-demographic information was collected from all women who accepted to be interviewed to assess whether they were eligible to join the study (Appendix 6). Eligible mothers were then asked if they were able to come for the interview at a later date and whether they felt comfortable to be interviewed within the hospital premises; otherwise I was flexible to conduct the interviews at any other place such as churches or school, where the woman would be comfortable to express herself. Interestingly, all women were comfortable to be interviewed within the hospital premises. Depending on the time available, and the women's preferences, some women were interviewed immediately after reading the information sheet and obtaining written informed consent form from them (appendix 6); otherwise another date was arranged that was convenient to both of us. Some index women were asked if their partners could be interviewed while others were also asked to identify significant others, health professionals and key informants who they felt were influential in the implementation of the programme and infant feeding. None of them was interviewed at her homes owing to ethical concerns about the potential for raising suspicion about their HIV status through a researcher visit.

6.8.2. Category 2: MaiMwana volunteers and recruitment process

Eight peer counsellors and supervisors were interviewed. Interviewing volunteers was important to explore how they identified women to participate in the programme, their general experiences as peer counsellors providing home visits to mothers in resource-poor settings, how they involved the social system members during the counselling sessions and challenges faced. This group further provided information about their training, supervision, their level of knowledge to handle HIV positive women and refer them for care and support. Furthermore, the group provided an insight into characteristics of women who were more challenging during the visit and how the woman's HIV status affected the way they conducted the visits. Considering severe shortage of skilled health care workers in the country, interviewing supervisors also provide opportunity for them to reflect and share their experiences with offering supervisory support to peer counsellors as well as being on full-time job with the government (see appendix 13 for the job description of HSAs).

This group was identified based on their performance whether good or bad, EBF rates in their allocated clusters and their age. In this case, their selection was mainly dependent on consultation with MaiMwana health staff to identify peer counsellors and supervisors who they felt were knowledgeable enough about the project and the subject matter and also their performance. I also took advantage of the quarterly meeting of the volunteers to book and interview some of them who were coming from far.

Once a peer counsellor or supervisor was identified, contact details were obtained from MaiMwana health staff and later I contacted them by phone or through face-to-face by the research assistant to explain the study to them and ask for permission if she/he was willing to participate in the study. For those who expressed interest to be interviewed, they were given the information sheet (appendix 3) by the research assistant at least two days before the scheduled interview day to read and reconsider their decision to participate. Respondents were then reminded about the interview date a day before the scheduled interview date to confirm their participation. The interviews were organized to make sure that their working schedule was not compromised. If respondents preferred to be interviewed in non-working hours special arrangements were made accordingly.

6.8.3. Category 3: Key Informants and recruitment process

Interviews were also conducted with 12 key Informants, comprising of elderly women, male partners, chiefs, traditional birth attendants, health professionals and MaiMwana staff. Involvement of key informants provided broader understanding of infant feeding practices, decision making process, local and potentially culturally constituted dilemmas on EBF, and their involvement in the design and conduct of the MaiMwana intervention. Their inclusion was paramount because they form part of the “decision-making team” in infant feeding choices and practices. This was also useful to gain an insight on how best to involve them during the implementation of similar intervention in future. Renzetti and Lee (1993) emphasize that key informants become highly motivated to participate and provide a positive contribution to the discussion if the researcher recognizes them as having experience and knowledge on the subject matter. Therefore, these interviews were not only used to gain information but rather to empower them to conceptualize strategies that were useful to implement community-based intervention to promote EBF in resource-poor communities.

Key informants were recruited through consultation with MaiMwana staff and through snowball sampling technique (Bryman, 2012, p. 418). Snowball sampling involves selecting a small group of people relevant to the research questions and participants are asked to propose information-rich key informants for interviews (Schensul et al., 1999; Lofland et al., 2006; Bryman, 2012). In the first place, I conducted interviews with breastfeeding mothers—the desired group to practice EBF, concurrently with interviews with peer counsellors and their supervisors. At the end of each interview breastfeeding mothers and the peer counsellors were asked to suggest names of stakeholders who they felt were influential and directly involved in the promotion of infant feeding within the clusters or working in the health facilities where study clients were referred for care and support services. According to Bryman, one advantage of using snowball sampling is that it reveals connectedness of individuals in networks (Bryman, 2012, P. 424). In this study, names of people who were repeatedly mentioned or suggested as being influential in as far as infant feeding decision-making and support were taken note of and contacted for interviews. Hence, interviews with key informants was subject to preliminary findings from the interviews with women and counsellors on who they perceive as being the key determinants of how women practice EBF.

Once identified contact details were obtained from MaiMwana project or through the peer counsellors and then the research assistant visited them to give them study information sheet (appendix 4) and an invitation letter at least two days prior to the interview. Interviews with key informants mainly took place towards the end of data collection in order to involve carefully selected key informants who were knowledgeable enough and frequently mentioned to obtain rich information. Interviews of key informants took place in the community, their work places or at the health facilities that ensured maximum confidentiality.

Male partners on the other hand, were recruited through their female primary partners. In this case, after sensitizing the woman about the study, some of them were asked if their partners escorted them to the clinic and if they were willing to allow them to be interviewed. Interested women were then asked to seek permission from their partners on behalf of the researcher. Those interested were then given study information sheet (appendix 5) and scheduled for interviews depending on their time schedule even during weekends. Special efforts were made to include men who did not report at the clinic in the sampling frame. In this case, women were asked if they would allow their partners to come for an interview at the hospital or any other place convenient to them. If willing they were given information sheet to give to them. All measures were put in place to ensure that the HIV status of the female partners was absolutely not disclosed to the male partners under any circumstances. Interviews for key informants mainly took place after working hours for those who were working so as not to disturb their working schedule.

6.8.4. Inclusion and exclusion criteria into the study and response rate

Respondents with the following criteria were included in the study:

- 18 years and above since this is the legal age for an adult in the country.
- Willing to participate in the interview.
- Able to communicate in Chichewa or in English.
- Coming from the MaiMwana clusters.
- For men, if the partner consent for them to be interviewed.

Respondents with the following criteria were excluded:

- less than 18 years old, did not breastfeed their infants,
- Not willing to provide informed consent

- Coming from outside the MaiMwana clusters.
- For men, if the partner refused consent for them to be interviewed.
- Unable and not capable to provide informed consent and take part in the interview for example, sick, or psychologically unwell.

Overall, response rate was very good. All peer counsellors that were requested to participate did and only 5 breastfeeding mothers (4 HIV negative and 1 HIV positive) did not return for their scheduled interview because the clinics were closed due to shortage of supplies and medicines. It was very difficult to find male participants despite the majority of women promising to bring their partners for interview but did not turn up. One key informant (health worker) was visited twice and I was unable to interview her due to her busy schedule.

6.9. Data collection strategies and logistical matters

Data collection in this study took place over 6 months from January through August 2012 using multiple qualitative data collection techniques. These include:

- Individual face-to-face in-depth interviews,
- Document analysis,
- Indirect observation and field notes.

Creswell (2007) emphasized that triangulation of methods and/or data sources strengthen the research findings. These techniques are discussed further below.

6.9.1. Collection of socio-demographic data

For each respondent, a brief screening interview was conducted before the main interview. The purpose of this initial screening was to make a record of socio-demographic and other characteristics of all respondents and select relevant respondents for interviews. During this initial contact, respondents were asked about their age, marital status, number of children and socio-economic status using demographic questionnaire forms (appendices 6 and 7). The questionnaire also included some question to assess their knowledge about activities being carried out by MaiMwana project. Also at this point, age of the smallest child and infant feeding methods were assessed in order to exclude those who did not breastfeed their infants. The questionnaire included closed-ended questions which were administered face-to-face.

The face-to-face method was chosen because this method has, traditionally, the highest response rate (Creswell, 2003). Also, considering that most breastfeeding mothers were illiterate, it was necessary to read the questions to them in a simplified manner for easy understanding in order to collect the required information from them to answer the research questions (Oppenheim, 1992). Information collected during screening process was then entered into an excel sheet and was later compared with interview responses during analysis.

6.9.2. Conducting in-depth interviews and the use of an interview guide

Data in this study was mainly collected through in-depth interviews. In-depth interview is often described as being “conversation with a purpose” which differentiates them from a normal conversation (Kvale, 1996; Lofland and Lofland, 1995). This method was chosen considering the sensitivity of the topic under study and my interest to learn about people’s experiences and perceptions with exclusive breastfeeding and home-based peer counselling (Mason, 2002). Kvale (1996) and Mason (2002) further described in-depth interviews as the best method to learn about individual perspectives that allows people to talk about their personal feelings, opinions and experiences while the researcher plays a role as an active listener. The aim of using in-depth interviews was to get people to talk about their personal feelings, opinions and experiences in their own words (Kvale, 1996; Burgess, 2000). Lofland et al. explain that group interviews are not suitable when exploring topics of any particular embarrassment (Lofland et al., 2006, p. 20). Therefore, qualitative in-depth interviews were valued as being ideal in giving a human face to the research problem and helped to effectively comprehend the sensitive topic that I was exploring which I envisaged that people might be reluctant to discuss in a group.

In-depth interviews in this study were conducted face-to-face using the local language (Chichewa), a local dialect spoken by all interviewees but respondents were allowed to express themselves in English. The aim was to allow participants express their feelings and experiences in their own language. Two different semi-structured topic guides were developed and used in this study as suggested by Kvale and Brinkman (2009) —one for breastfeeding mothers (appendix 8) and another one for MaiMwana volunteers and key informants (appendix 9). Use of topic interview guides provided a framework around which the interviews could be conducted, particularly because a research assistant was involved to conduct some of the interviews. This approach helps the researcher to ensure that relevant

issues are covered systematically and in a particular order (Ritchie and Lewis, 2003). I originally developed all data collection tools in English and was verified by my supervisors. The guides were later translated into Chichewa (the local language) by a team of nurses from UNC Project, Malawi experienced in exclusive breastfeeding and translation. The team has been doing translations of study materials for a long time and I used to be a member of this translating team before. Accuracy of the translation was verified by performing an independent back-translation from Chichewa to English. This was also done to ensure that the meaning had not been lost during translation. These forms were also reviewed by service-users in Malawi for comments.

Development of the interview guides was guided by questions on the WHO Indicators for Assessing Breast-feeding Practices (1991) and the Wellstart International's Tool Kit for Monitoring and Evaluating Breastfeeding Practices and Programs (1996), which were modified to suit the study context. These interview guides included a list of questions that explored whether women believed that EBF can prevent HIV transmission, whether EBF is socially acceptable, whether they felt it was easy to practice EBF and the advantages and disadvantages of practicing EBF for 6 months. Questions that specifically aimed at identifying factors that acted as "promoters" or barriers to maintain exclusive breastfeeding behaviour were also included. The women's interview guide also included questions on first introduction of food or fluids and the type of food or liquids which the infant was given before 6 months of age, reasons for giving other foods and influential people to give supplementary feeds. The interview guides also included question related to knowledge about MaiMwana project and experience with home visits, reaction of significant others after the visit, referral system and challenges faced during the visit and experiences with visiting HIV positive women.

These pre-specified concepts, which were derived from the literature and personal experience acted as a departure point from which the interview was initiated to collect data. However, questions were changed based on the concepts derived from interviewees' accounts of issues as Rapley (2007) emphasises the importance of 'following the interviewee's talk, to work with them rather than sticking to the pre-determined agenda of the interviewer'. In other words, if a participant brought up another topic that proved to be relevant to the study that was not considered when designing the topic guides, I followed through on the topic with the same interview or with upcoming interviews. We piloted one in-depth interview with one

breastfeeding mother as well as one in-depth interview with one counsellor and key informant for my research assistant to observe the whole interview process and at the end of the interview we had a debriefing meeting. This way we tested that the questions were acceptable and understood clearly and the topic guides were modified accordingly. All respondents were interviewed only once.

During interviews the questions were not asked following the structured format of the topic guides but rather I was guided by the responses coming from each respondent and on-the-spot decision was made about the content and sequence of the interview while taking into consideration that all the major themes which I was interested to explore were addressed (Mason, 2002, p. 67). Therefore, I kept on giving clear guidance to respondents to allow them to provide responses related to the research objects because the majority of them would want to provide as much information as they could to demonstrate that they are knowledgeable enough about the subject matter. Some would want to talk about problems affecting their own health if they are aware that the interviewer is a nurse or a doctor because of the trust they can develop towards health professionals to keep confidentiality of people's sensitive information or hoping that they would get helped with their problems (Pope and Mays, 2006).

While conducting in-depth interviews, several fixed-response questions from the topic guide were followed by open-ended questions to provide context and elicit an explanation structure for the study (Gray, 2007). Open-ended questions in this study were asked in a loosely structured format which resembled a conversation (Gray, 2009; 2013; Ritchie et al., 2014). The advantage of such an instrument design is two-fold: Structured interviews (i.e., those that ask the same verbatim initial questions in the same order to all respondents allowed for a meaningful comparison of responses across respondents; at the same time, open-ended questions, coupled with the opportunity for inductive probing of responses, gave the participants freedom to respond in their own words (Gray, 2009; 2013; Ritchie and Lewis, 2003). On the other hand, closed questions which are often a common feature of questionnaires, can limit the depth of participant response and consequently the quality of data collected (Bowling, 2002). Patton (2002) further asserted that open ended questions allow the interviewer the opportunity to build a conversation within a particular subject area, to assist in facilitating the flow of the interview, to word questions spontaneously and within context, and to establish a conversational style.

Open-ended questions further evoked responses that were meaningful and culturally salient to the respondents, rich and explanatory, some of which I did not anticipate (Gray, 2007). For example, some respondents mentioned that supervisors always accepted any role that is given to them because of monetary issues while in reality they are not capable of doing the work. Furthermore, if I noticed that I could not make sense out of the answer given by the respondent, I asked follow up questions in order to obtain a deeper understanding of the meaning of what she/he said. I also used illustrative example format and iterative probing when conducting these interviews which involved paraphrasing the questions as a way to show neutrality (Patton, 2002). Patton (2002) further describes that use of illustrative examples demonstrates that the interviewer has good knowledge on the subject matter and the main interest is on what that person's experience has really been like on the subject matter. I also left respondents to continue talking about their experiences for some time before I would interrupt them as Mason (2002) explains that too much attention on asking the right questions could easily disrupt respondents. At the end of each interview, respondents were asked whether there was something which they felt was very important for me to know—a technique described by (Ritchie et al., 2014). This was done to assess if there was any new knowledge related to the subject matter.

In order to capture all the details of the discussion, all interviews were audio-recorded with permission from respondents. Pope and Mays explain that recording of interviews has advantage over writing notes, although it is acknowledged that in some circumstances it is better to write notes than to rely on recording alone as the researcher may lose the information if something went wrong during the recording or when the tape recorder develops technical fault in the process (Pope and Mays, 2006). Therefore, written notes were also taken during interviews. I tried as much as possible to minimize writing too many notes as this could interfere with the process of interviewing. The interviews conducted lasted for about 30 minutes and they rarely exceeded 1 hour, except the first few interviews which were kept broad letting participants “tell their stories” and then subsequent interviews were used to obtain more targeted information and fill in the gaps left by the earlier interviews.

6.9.3. Informal observation and reflexive journal

To provide the richness and depth of the data collected, I also collected data through non-participant observation methods in relation to each interview, meetings and also kept a personal reflexive journal. Denzin and Lincoln (2003) state that keeping reflexive journals and field observation notes help the researcher to keep track of the research process and record what was happening outside the interview like non-verbal actions which could not be captured in the recording. For instance, when I went to the health centres to conduct interviews I noticed that there was only one nurse on duty providing all the services at the health facility. According to Fetterman (1998), field observation notes and reflexive journals serve as initial impression and form the back bone of collecting and analyzing the field data. Likewise, Richards (2005) described that every individual's life situation can be turned into qualitative data through recording of those observations (p. 38). Lofland et al. (2006) further explain that every recorded fieldwork detail is worthy of consideration, for it is from the patterned minutiae of daily life that the researcher might generate significant social insight. Patton (2002) further asserted that field notes contains the researcher's own feelings, reactions to the experience and reflection about the personal meaning and significance of what has been observed. Therefore, I made sure to document all non-verbal cues, comments and questions asked during or after each interviews in a diary which were later kept as memos in NVivo software to help remain reflexive of the thoughts and ideas that I was bringing to the study.

I also conducted non-participant observation of 4 four peer counsellors' quarterly meetings which took place in the month of June within the four satellites offices - one in each nodal office (table 6-3). A primary overall aim was to see how peer counsellors performed their duties and also to have some informal conversations and interactions with them and learn their individual experiences with the intervention. I adopted this approach because I could not manage to follow and observe how peer counsellors conducted the visits in the community. In total 65 peer counsellors and 11 supervisors attended these meetings.

Table 6-3: Observation of peer counsellors meetings

Nodal office	Number of observations	Date of observation
Kamwendo	1	02/07/2012
Kapiri	1	05/07/2012
mkanda	1	03/07/2012
WalilANJI	1	04/07/2012

Observation during these meetings complemented interview data. This was vital for me to have a deeper understanding on how the programme is being implemented and also enabled those volunteers who were not interviewed to share their experiences and learn about the challenges which they were facing while volunteering from a group perspective. During these meetings, peer counsellors were also role-playing activities which they carry out during each visit. In this case, peer counsellors developed a hypothetical case of a breastfeeding mother who was visited home. All scenarios depicted what was really happening during each visit. Other volunteers critique the narrative play and I was also able to take note of their strength and weaknesses.

During these meetings, I also learnt about the reporting system and reviewed some of the registers where peer counsellors record their daily activities and visit outcome. I further took advantage of these meetings to ask for consent and collect socio-demographic data from some peer counsellors and their supervisors who were interviewed at a later date and interviewed some of them who were already consented before the meeting. All my study specific activities were carried out at the end of the meeting because I was aware that the primary agenda of their gathering was to attend these meeting without being disturbed. During these meetings, I learned that the project will soon be handed over to the government. Consequently, peer counsellors were concerned whether the government will be able to sustain the programme in the same way as MaiMwana project due to the problems in the country and were concerned whether they will continue receiving their monthly incentives.

I played a role as an overt observer where participants were aware about my presence (Mason, 2002) and I was given a chance to introduce my study to the team members and interact with the majority of them. It was however difficult for me to only play a role as a

passive observer because I used the same vehicle with the MaiMwana team. Instead I helped with some of the logistics and made sure not to be involved in the facilitation of the meetings as this could have abstracted my intended purpose of observing the entire process. Additionally, I attended local meetings and conferences where MaiMwana intervention, safe motherhood or HIV-related issues were discussed to discover how the community interpret the subject matter. While in the field, I also recorded different kinds of information related to my personal reflections of what was happening in the field on daily basis, thinking, personal feelings, experiences and perception which were recorded immediately after returning from the field, which contributed to the background of how people were thinking about the subject matter. Bogdewic (1992) considered reflexive notes as emotional journey of the researcher. After each visit, I held a briefing meeting with the research assistant where she was allowed to ask questions, express her feelings and discussed any problems encountered in the field and ways to deal with them.

All meeting proceeding, observations and conversations were recorded in a notebook in textual form which helped to capture important issues while in the field or soon after returning from the field. Secondly, soon after each interview I used a debriefing form to reflect methodological issues and the major themes that were emerging and whether there were any issues that would require follow-up during subsequent interviews (Appendix 10). These reflection notes acted as a guide on whether new themes were coming out or not, which required further follow up and also to determine whether to continue or stop data collection. Information on the debriefing form was useful during preliminary data analysis because I could not manage to go through each and every transcript at once.

6.9.4. Document and grey literature review

A review of documents related to the MaiMwana intervention, peer counsellors' training manual and training reports as well government policies and guidelines related to infant feeding guidelines for HIV positive women was done in order to gain more insight on how the project was being implemented in relation to the government policies. Additionally, I also accessed some Malawi newspapers and kept track of all discussions related to cultural infant feeding practices in the country and issues related to prevention of MTCT of HIV.

6.10. Data management and transcription process

In this study, different methods were used to collect data and it was equally important to consider how such a huge amount of data was to be systematically organized and stored for easy tracking and analysis. I developed archival numbers prior to data collection and these were later assigned to each respondent and recorded on each study related document. The numbers were generated based on the three categories of the interviewees as follows: LA001 meaning lactating woman number one; and KI001 for key informant number one and then VPC001 for volunteer peer counsellor number one. A master log sheet was also created where actual names and correlating codes of respondents were documented for easy tracking of respondents. To maintain confidentiality of respondents, the master log sheet was stored in the principal investigator's computer and was password protected.

Data collection materials for qualitative interviews such as an interview guide, two consent forms were pre-packed in an envelope and then labelled with the unique archival number generated. Two digital recorders were used simultaneously during the first interviews and one saved as a back-up until I got used to the recording process. The team tape-recorded each other as part of pilot and the first few interviews conducted served as a pilot too. The team analyzed the conduct of these interviews and necessary changes were made to the guide. Soon after returning from the field, all necessary written documents for each interview such as structured notes taken during interviews and expanded field notes were kept in the designated envelope and securely kept in a lockable cabinet. All digital recordings were then transferred on my computer soon after returning from the field and labelled accordingly.

Transcription of tape-recorded interviews was preferably taking place within 7 days after the interview was conducted and field notes were typed immediately after returning from the field. This was done to prevent piling up of tapes and also to easily remember what transpired during the interview. Verbatim responses were transcribed directly from Chichewa into English. Two transcribers from Malawi News Agency (MANA), Boma Lathu department¹² were sub-contracted to assist with the transcription process of some interviews after signing a confidentiality agreement. However, I transcribed as many of the interviews as I could. All

¹² The team working as editors under Malawi Ministry of Information as editors of the only local newspaper produced in the local language and distributed free of charge across the country.

transcribed copies were named using the same unique archival number assigned when conducting the interviews for easy tracking.

A common format was developed which was shared among the team to guide the transcriptions process for uniformity. All non-verbal cues such as lengthy pauses, repeated words such as “uhhms”, “eeh”, “ahhs” were included in the transcripts. In addition, movements, laughter, baby crying or any back ground noise were also added in the transcripts which are useful to make data live when reading transcripts at a later date. If the respondent mentioned a name of a person during the interview, this was replaced with “name withheld” to promote confidentiality. All the comments or explanations were quoted or put in brackets to differentiate whether this was said by respondents or was written by the researcher to describe the meaning of the words, passages or gestures which I wrote (Rubin and Rubin, 2005; 2012). If I could not make sense of some of the words said mainly due to background noise because of crying babies this was indicated as “words unclear” in the transcripts. Some interviews ended were paused several times because we could not cope with the crying of the respondents’ babies. The transcribers were informed about this to make sure that all these are included in the transcription because they add a meaning to the spoken words like determining feelings of the respondent when being interviewed or hesitating to make a comment. I also made a list of the meaning of some medical terms and other common terms to make sure that they are transcribed accurately without changing the meaning of what the respondent said (Pope and Mays, 2006).

To check the quality of the interviews conducted by the research assistant, I read all her transcriptions while listening to the tapes and discussed with her if some questions needed more probing. In addition, I also discussed with the transcribers if some words were omitted or were unclear. I also consulted other research team members if any Chichewa words were unclear because some Chichewa words can have two or more meanings depending on how they have been used in a sentence as well as to identify areas that required further elaboration. Some Chichewa words or phrases were transcribed and typed the way they were spoken by the participant if I saw that if translated I could not capture the real meaning but an explanation of what the words or expression means in English was provided. This process was followed to ensure that content and core meaning of the original text was preserved. A few interviews were checked by an independent translator at intervals to ensure accuracy. To

promote validity of the study, some selected interviews were forwarded to the supervisors at City University to check if there were any ambiguous and unclear sections that required clarifications before I left the field. All typed transcripts and field notes were kept on my computer and all were password protected. The password was only known to me, the research assistant and my supervisors. All the transcripts and expanded field notes were then imported into NVivo 10.0 software for coding and as back-up file. The qualitative data analysis that I used for this thesis is described in the section below.

6.11. The process of data analysis

Preliminary analysis of the data began concurrently with data collection. Speziale and Carpenter (2007) describe these processes as inseparable in qualitative research. In my view, I saw that this was a useful process to determine the amount of data required and to guide the purposive sampling. Data in this study was analyzed by framework analytical approach developed by qualitative researchers in the UK, as a suitable method for managing and analysing applied qualitative policy type research data (Richie and Spencer, 1994). Framework analysis was seen to be most suitable to analyse the data collected in this study because it provide clear steps to follow and produce highly structured output of data summaries. Furthermore, the integrity of the individual respondent account is preserved throughout the analysis (Richie and Spencer, 1994; Pope et al., 2000). Table 6-4 below provides an explanation of four different main categories of questions which are addressed in applied policy research describe by Ritchie and Spencer (1994), and how the questions which were asked in my study fits into the categories.

Table 6-4: Summary of categories of applied policy research questions and how my study questions fit into them

Category	Goal	Example of questions asked in this study
Contextual	Identify the form and nature of what exists.	What was the experience of women with exclusive breastfeeding and home visits?
Diagnosis	Examining the reasons for, and cause of what exists	What factors affected their intention to practice EBF? How were decisions taken to practice EBF?
Evaluative	Appraising the effectiveness of what exist	How did peer counsellors manage to conduct home visits? How did they identify pregnant women? What were the barriers to effectively conduct home visits?
Strategic	Identify new theories, policies, plans or actions	What strategies need to be put in place to promote EBF? What actions are needed to make the programme more effective? How can the programme be improved?

Framework analysis allowed continuous incorporation of emergent concepts emerging out from the data into the framework in which I had pre-designed (Ritchie and Spencer, 1994; Pope and Mays, 2006). Framework approach was also chosen because it provides systematic and visible interconnected stages to the analysis process that allows the researcher to move back and forth between different levels within the data without losing sight of the raw data (Ritchie and Spencer, 1994; Ritchie and Lewis, 2003). This analytical method also helps in making the analysis process explicit as it demonstrates to other people all the stages on how results have been derived from the data and interpretation of experiences of respondents are transparent. This in the end promotes credibility of the study (Ritchie and Lewis, 2003). Ritchie and Spencer (1994) described five stages in framework analysis which were followed to analyse the data collected in this study. These include: familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation.

The first stage in framework analysis is *familiarization* with the data in which the researcher get immersed into the raw data to identify key ideas and recurrent themes and get familiar with the data set (Ritchie and Spencer, 1994; Ritchie and Lewis, 2003). This stage was more useful for me to get familiar and ‘closer’ to the data, and become used to the participants’ words, especially considering that some of the interviews were conducted by the research

assistant. Therefore, I started by listening to the audiotapes and re-reading field notes and transcripts of all interview transcripts while at the same time paying special attention to my study objectives. The aim was to gain richness of the data collected and identify emergent themes and also explore areas that required further probing. This also helped to determine the right sample size that I felt was enough to help me answer the research questions and avoid collecting excess and unnecessary data (Bryman and Burgess, 1994). Ritchie and Lewis, (2003) stress that this stage is important to build the foundation of the structure and that if the foundation is not built properly then the whole structure is likely to “crash to the ground” along the process. All these pre-identified emergent themes and recurrent themes which were coming out of the data, together with any difficulties encountered while conducting the interview, were jotted down on the debriefing form while key issues emerging from the data were written down in my diary.

NVivo qualitative data analysis software version 10.0 was used to organize and store the data into folders for easy retrieval and further conduct the analysis as Ritchie and Lewis (2003) consider analysis as a continuous and iterative process (p. 219). Importing of data into the software commenced immediately when data collection started; thus, the software helped to create a database of all the data collected in this study, which was organized into different folders based on categories of respondents. Additionally, all field notes written in my diary and on the debriefing form (appendix 10) were typed and imported into the software immediately and transcripts were also imported soon after transcription. In addition, any valuable thoughts or comments were also written down in my diary as comments memos, which were later attached to the data in the software. Strauss and Corbin (1990) define memos as “written records of analysis related to the formulation of theory. Charmaz (2006) explains that memo writing can help the process of analysing and conceptualising data by generating ideas to investigate in the field setting, demonstrating connections between categories, discovering gaps in data collection and linking data-gathering with data analysis and report writing. Memo writing also provides the researcher with the opportunity to stop and think about the data which in turn encourages reflexivity.

The second stage is *identification of thematic framework*. This is the core component of the framework analysis method, which aims at identifying recurrent themes or ideas (Ritchie and Lewis, 2003). In this stage, I firstly developed a codebook, which included a list of codes derived from the familiarization stage. Then, a thematic framework or category was

developed through a priori data (Boyatzis, 1998, p. 31). Prior categories were derived from the interview guides that were used during the interviews as well as from the research aim and objectives. Ritchie and Spencer (1994) further state that the researcher should maintain an open mind to include other key themes emerging from the data rather than only relying on the thematic framework which was developed using prior concepts. Therefore, I kept on reading the interview transcripts, debriefing forms and the field notes several times to obtain a sense of the overall data and identify common themes and also to identify codes which were emergent (*data driven techniques*). These were incorporated into the thematic framework developed earlier on using the topic interview guides. For instance, during interviews counsellors repeatedly mentioned that women were asking for incentives from them during the visit. Then I added demand for incentives as a sub-theme emerging from the data.

Major themes referred to as “families of codes” were then identified which were then formulated into a smaller set of themes (children codes) in order to embrace a wider range of context” (Creswell, 1998; Bryman and Burgess, 1994). These were then compiled together in the codebook in hierarchical order. These charts were then grouped into different categories according to interview groups for easy management of the data in order to easily identifying links between categories in the data. Appendix 1.1 presents an example of the study working thematic framework which I developed through this process. Further, as seen from appendix 1.1, I managed to group more than 50 sub themes/nodes into 11 major categories, which made it easier to code and analyse the data. At this early stage I made sure to include as many categories as possible which were then merged as I continued with the data analysis process.

After developing the thematic framework, the next step involved applying the codes to the segments of the data which is called *Indexing*. Indexing involves the analyst to read the data and make judgment about which particular theme or phrase to link to the portion of the raw data (Richards and Morse, 2007, p. 137). I firstly printed the transcripts, read through to identify emerging themes and started the coding process manually using a highlighter. Coffey and Atkinson (1996) describe coding as both a process of reducing data and also expanding, transforming and reconceptualising data. Therefore, using framework analysis the list of tentative codes which I had developed earlier was linked to the text segment of the data within NVivo software. In some cases several codes were applied to some single phrases in the data often referred to as “multi-indexed” depending on the meaning while some bigger portions of the data remained un-coded if they did not relate to the research objectives

(Ritchie and Spencer, 1994). As the process continued, a printed copy of the coded text was printed and reviewed for obvious errors and some that had similar meanings were then merged. This process was done to assure quality data and also reduce the number of codes as too many codes within the thematic analysis can be tiring and time consuming to be applied to the data (Ritchie and Lewis, 2003). In the process of changing the framework, I made sure to save the earlier version for reference purposes at a later stage.

Charting which is the fourth stage, involves building up a picture of the data as a whole or rearranging the data within themes, by considering the range of attitudes and experience for each theme (Ritchie and Spencer, 1994). Charts are useful to examine the data for pattern and connection. There are two ways of creating charts as described by Ritchie and Spencer (1994) which is determined by the type of analysis to be carried out—either thematic (for each theme across all respondents) or by case (for each respondent across all themes). While conducting analysis of my data I adopted an approach whereby charts were drawn up for each key theme which was then linked to the respondents based on the study's three interview categories namely: breastfeeding mothers, MaiMwana volunteers and key informants. This was done in order to clearly see the pattern of experience with the behaviour or views of respondents on a particular theme. For example, in my study I was interested to explore factors that affect exclusive breastfeeding in the rural community. Therefore, one of the key themes charted was to look at barriers to practice EBF for 6 months. Appendices 1.2-1.3 show an example of a chart related to some selected barriers to practice EBF for 6 months.

The final stage in framework analysis, which is known as mapping and interpretation, involves pulling together emergent issues from the data and interpretations to make meanings out of them in a serious manner (Ritchie and Spencer, 1994). Barrett and Wellings (2002) describe this final stage as the crucial one as it involves creating typologies and associations between themes with a view to provide explanation for the findings and whether they are addressing the intended research questions, aim and objectives. In this stage perceptions and experiences were compared and contrasted among respondents based on their characteristics with reference to the themes which were charted. Throughout the analysis process I was taking note of the key pattern of some of the responses which I was getting from respondents. For example, the majority of breastfeeding mothers reported that they were able to practice EBF for six months. However, the most interesting part was that the majority said their peers who come from the same community gave their babies other foods as well as traditional

drugs and gripe water before 6 months elapsed. Whereas, key informants repeatedly reported that it is difficult for many women in the community to practice exclusive breastfeeding and they also gave similar reasons as the ones mentioned by the women themselves.

6.12. Ethical considerations

6.12.1. Ethical approval

Ethical clearance to conduct this study was obtained from the Research Ethics Committee at City University London Ref PhD/11-12/04 (appendix 11) and the National Health Sciences Research Committee in Malawi approval number 955 (appendix 12). The protocol was also reviewed and approved by the MaiMwana project and permission was further sought from the Mchinji District Health Office to conduct the study within the MaiMwana clusters in the district. Further permission was obtained from the clinic manager of each health facility to recruit and interview women.

6.12.2. Voluntary participation and informed consent

Gelling et al. (2011) explain that gaining informed consent from research participants is central to the research process. Parahoo (2006) defines the principle of informed consent as the process of agreeing to take part in a study based on access to all relevant and easily digestible information about what participation means, in particular, in terms of harm and benefits. In this study informed consent process involved giving each interviewee information sheet during the first contact, at least 48 hours before the interview to read and consider their decision to participate and answering any question which they had and check their willingness to participate. The information sheet described the purpose of the study, the procedures followed, risks and benefits of participation, how their data will be used and protected and signing of informed consent forms.

For those who were illiterate, I personally read the Chichewa study information sheets (Appendices 2-5) and explained the study to them in more detail and gave them a minimum of 48 hours to consider their decision to participate. Participants were also informed that they can withdraw their consent to participate at any time during the interview without any problems. However, I faced a dilemma when some respondents opted to be interviewed right

away due to lack of time and distance to come back for the interview. Despite the fact that I was supposed to give them enough time, I made the discretion to conduct the interview based on the reasons given and ensured that I spent enough time to explain the study to them to make sure that they have fully understood the study before participating. Since some respondents were referred to me by the gate keepers, I also ensured that all respondents provided a written informed consent on their own before participation (Ritchie and Lewis, 2003). Consenting process was done in the local language (Chichewa) which both the researchers and the respondents were fluent in.

Written informed consent was obtained from each respondent who participated in this study using the translated informed consent forms. Bryman, (2012) states that allowing participants to sign informed consent forms give respondents the opportunity to be fully informed of the nature of the research and the implications of their participation into the study (p.140). Non-literate respondents were asked to document their informed consent by marking their informed consent form with a thumb-print or other mark in the presence of a literate third-party or impartial witness who was also fluent in the local language. The aim was to ensure that respondents had really understood why they are participating in the study. Two copies of the informed consent were signed and respondents were offered a copy to take home if they wish. I also ensured that the approved versions of the information sheets and informed consent forms were used during consenting process and signed copies were filed in a lockable cabinet with access limited to myself. All respondents were reimbursed at the rate of MK2000 (Malawi Kwacha –equivalent to approximately \$5) for travel costs and inconvenience. The reimbursement policy was in line with the requirements of the National Health Sciences Research Committee in Malawi and in consultation with UNC project who were responsible for providing the funds to be used during data collection.

6.12.3. Confidentiality and anonymity of study participants

In order to maintain confidentiality, before conducting any interview all measures were put in place to make sure that the interviews took place in a private place free of disturbance. Most of the interviews were preferably conducted at the health facilities in a private room in which discussions could not be overhead by others. For those interviews that took place in the community for key informants and peer counsellors, I firstly assessed whether the place was

suitable for the interview; otherwise negotiations were done with the participants to look for another private place within the community that ensured maximum confidentiality.

I also reiterated that participation in the study was voluntary and that any data collected would not be linked to their names; hence other people will not know who participated in this study. Furthermore, respondents were also assured that they will never be identified in any publications or reports related to this study without their consent and that quotes of participants will be highly anonymized. In order to protect confidentiality with respect to HIV status of women, no disclosure was done to partners or significant others—not even to the peer counsellors during data collection period.

In regard to the data collected in this study, all participant information and any other study related information was stored in locked filing cabinets at UNC Project during the time of data collection, then at City University during data analysis until the time the study was completed. The data was eventually archived at City University in areas with limited access. All reports, audiotapes, transcribed notes, study data-collection forms and administrative forms were identified by a coded number to maintain confidentiality. Forms, lists, logbooks, appointment books, and any other listings that link participant identification numbers to other identifying information were kept separately and securely in a lockable cabinet. The research assistant was briefed about the issues of confidentiality governing the study as part of the training and an agreement form to maintain confidentiality was signed. All databases were secured with password-protected access a system which I changed regularly. All personal identifiers were removed from the dataset and were also encrypted. Since inter-country movement of data was involved, all measures were put in place to make sure that the data was secured enough. In this case, during the transfers all the hard copies and other forms were carried in a lockable small suitcase that was carried as my hand luggage. No data was shipped for safety purposes as much of the data was collected through the audio files and measures were put in place to not to left the data unattended.

6.13. Personal reflection on the methodology

This study aimed to explore a sensitive topic which involved exploring into some deeply personal experiences, known to affect every stage of the research process. Therefore, I anticipated potential implications either directly to the participants in the research as well as

effects on the personal life of the researchers while researching a sensitive topic in my own country of origin as a health care worker (Brewer, 1993; Sieber and Stanley, 1988; Sieber, 1992). The study included HIV positive women and some of them may have recently been diagnosed with HIV and may be in a situation of crisis after the diagnosis and at the same time knowing that their babies can contract HIV during breastfeeding. The Social Research Association 'Safety Code of Practice states that:

Researchers should be ready to spot signs that the respondent is becoming upset or angry. Often, the researcher's training means that strong feelings of this kind can be acknowledged and contained, but there may be occasions when it is more sensible to end the discussion and leave. Such a withdrawal should be decisive and quick, offering an appropriate reason (p. 6-7).

Therefore, I made sure to assess any anticipated risks before the interview and no respondent with known psychological problems was included in the interviews. Furthermore, during interviews I avoided prompting respondents to talk about something that could upset them and made sure to keep observing any emotional reactions and wellbeing of the respondents, which were rare during the data collection period. If any unforeseeable risk occurred to any of the respondents, I provided the necessary support and tried to probe the burning issues distressing the respondent. I was mandated, if the distress became intense, to reschedule or terminate the interview and the respondent was referred for further support to a place in which she feels comfortable. For example, one respondent presented with difficulties to express her feeling and did not want to respond to the questions and as a researcher I was able to help with these feelings by talking to the woman to understand what was upsetting her and the interview was stopped immediately. The use of the hospital premises for interviews eased my task to take care of the client who was distressed by referring the respondent to the counsellor on duty within the health facilities where the interview was taking place.

On the other hand, I also anticipated that women might find it difficult to talk about their sexual behaviour and HIV/AIDS because I considered that asking them questions about their HIV status meant that I was actually asking them sensitive issues about their private life (Renzetti and Lee, 1993). Moreover, discussing their personal issues to an "insider researcher" in this case a Malawian, black and speaking same language, at the same time to an "outsider (stranger)" not coming from the study area would cause fear of breach of their

confidentiality. Being a midwife researcher, on the other hand, was also important in such a way that many respondents were open and willing to talk in-depth about their personal life and HIV status even before I asked them. Furthermore, based on previous experience working in similar situations in the country, and how women disclosed their HIV status to me, I saw that people feel more comfortable to talk about their HIV status to someone who is a stranger not coming from the same community and who is there for a limited period of time.

Being an indigenous Malawian, a female and a mother with a substantial knowledge and engagement in PMTCT and the numerous stories of suffering which were shared by participants I was touched with the stories especially from HIV positive women during the interviews. This feeling of discomfort about what is reported by respondents during interviews has previously been reported by other researchers in the literature (Lofland and Lofland, 1995; Etherington, 1996; Ahern, 1999). HIV positive women in my study were narrating their life experiences after being diagnosed with HIV and what they have gone through. Some of the stories were so funny while others were touching. In order to exclude all pre-conception of the subject matter and enhancing empathetic rapport, it is recommended to use bracketing when conducting interviews in order to collect the data in an honest and objective way and also to be neutral (Ahern, 1999). Reflective bracketing refers to the process of identifying and setting aside any preconceived beliefs and opinions that one might have about the phenomenon under investigation and not making judgment while collecting the data (Ahern, 1999). I therefore made sure to avoid subjecting my own judgment on what respondents were telling me during the interview and I tried to convey that their knowledge, feelings, attitudes and experiences are of great importance to my research study.

I was also faced with a challenge on how to separate the role of a researcher and my professional role as a nurse because some of the women required immediate intervention in these under-staffed clinics. Furthermore, the fact that clinic staff introduced me to the clients as a nurse and said that they should feel free to ask questions, many respondents were aware that I was a nurse by profession. Consequently, the majority of them were very open to disclose their HIV status to me and even talked a lot about the problems they faced because of their HIV status. Before each interview, I clarified to participants that the purpose of the visit was to conduct interviews as part of my research study as a student and not help respondent to cope with their situations or provide care. However, throughout the interview process I kept

observing any emotional reactions and wellbeing of the respondents as some may have some ailments that require immediate medical attention.

It was also recognized that collecting data and transcribing interviews on sensitive topics could affect researcher as well as those involved in transcription emotionally that needs to be taken into consideration before conducting any study (Renzetti and Lee, 1993). In this case, conducting interviews especially with HIV positive women involved listening to real stories of suffering. Therefore, I made sure that I conducted all the interviews with HIV positive women and those people who were sub-contracted to help with the transcription process already explained in the transcription process were fully informed about the study before committing to do the transcription. After the transcription I made sure that I spend some time and talk with them individually to understand their feelings after the transcription process. As a counsellor, I was prepared to offer any support to them if need arises.

6.14. Conclusion

In this chapter I have discussed the theoretical perspectives underpinning the design for my study which was qualitative in nature and the value of qualitative methods in allowing respondents to express their feelings and experience in their own words. The methods and steps in how the data for this study was generated were also presented and finally the approach to data analysis was set out. The chapter further highlight ethical considerations informing the design of this study and methodological concern in regard to researching a sensitive topic -in this case HIV and exclusive breastfeeding may pose challenges mainly because of the stigma attached to the disease and its mode of transmission. This means that individuals who are HIV infected may not feel comfortable to talk about their experience in presence of other people. However, their experience with the infection and EBF behaviour need to be explored in order to understand the challenge this may pose to them.

CHAPTER 7.0: RESULTS: INFANT FEEDING CHOICES AND PRACTICES AMONG RURAL WOMEN

7.1. Presentation of the results and overview

The findings will be presented in three chapters. Chapter 7 reports the major themes related to general knowledge about exclusive breastfeeding, determinant of breastfeeding and how women from the rural communities maintain exclusive breastfeeding in the cultural context. As will be discussed in this chapter, the findings from this study demonstrate that women in the rural area especially those with HIV face numerous challenges while maintaining exclusive breastfeeding. These include: lack of power and decision making on infant feeding, lack of support, fear of transmitting the virus to the baby, stigma and poverty. In chapter 8, I present results related to experiences with home-based peer counselling. This chapter highlights the challenges of using poor women who are involved in informal employment to do the work as volunteers. It is clear from this chapter that women in rural communities find it difficult to incorporate voluntary work into their daily household chores and the perceived benefits of volunteering are also discussed. The chapter also highlights the importance of community involvement in the implementation of community-based interventions. Chapter 9 reports findings related to the importance of visiting HIV positive women in their homes and the challenges faced.

Findings from the three interview categories explained in chapter 6: breastfeeding mothers, MaiMwana volunteers and key informants are integrated within the main themes in all the three results chapters to better understand determinants of breastfeeding and how best to develop programmes to promote exclusive breastfeeding. Some illustrated verbatim quotations from respondents have been used to substantiate the findings. In some sections, individual cases are presented in more detail to illustrate particular themes. To maintain confidentiality, unique numbers given to respondents during interviews have been maintained in the quotes instead of names. For instance, LA001 represents breastfeeding mother number 1, KI001 representing key informant number 1 and VPC001 representing peer counsellor number 1. For each quote reported words of respondents are retained with a few corrections made on repetitive words and repeated expressions such as “ums”, “mmmh”. Furthermore, text not relevant to the illustration of a particular theme has been removed (denoted by) while paying particular attention not to change the meaning of what was said by respondents.

Before presenting the findings, I begin by providing an overview of the background and socio-demographic characteristics of all respondents who participated in this study to better understand major themes emerging from the data.

7.2. Socio-demographic characteristics of respondents

Table 7-1 describes demographic details of all the 39 respondents who participated in the study. The age of all respondents ranged from 22-76 years. The mean age of breastfeeding mothers was 31.2 years while for volunteers¹³ was 42.2 years and 44 years for key informants. The parity of breastfeeding mothers and peer counsellors was 1-6 children. The babies' ages of breastfeeding mothers ranged from 6 to 22 months. 9 out of 19 breastfeeding mothers had at least completed primary school while 7 had no any formal education. On the other hand, the majority of peer counsellors had at least attained secondary school education while a few of them attended primary school education. This was consistent with MaiMwana project requirement that for someone to be selected to work as a peer counsellor they should have some form of education. In terms of key informants, the majority had either completed secondary school or had professional qualification. Further, data in table 7.1 illustrates that the sample was primarily dominated by married respondents (n=33). Both peer counsellors and breastfeeding mothers were from lower social economic class and the majority were not involved in any formal employment and relied on their male partners for financial support who also earned their income mainly through farming (n=20). This is very representative of clientele in rural Malawi as many families are poor and depend on farming as the major source of income.

¹³ Volunteers refer to both peer counsellors and their supervisors. Some of the supervisors (HSAs) were males while all peer counsellors were females.

Table 7-1: Demographic characteristics of respondents

Characteristic	L. women (n=19)	Volunteers (n=8)	Key informants N=12)	Total	Percentage
Age in years					
21-25	5	0	1	6	15.4
26-30	3	1	2	6	15.4
31-35	7	1	3	11	28.2
36+	4	6	6	16	41
Sex					
Male	0	3	9	12	30.8
Female	19	5	3	27	69.2
Marital status					
Married	17	7	9	33	84.6
Widow	1	0	2	3	7.7
Separated	1	1	1	3	7.7
Education level					
No formal education	7	0	0	7	17.9
Primary education	9	2	5	16	41
Secondary education	3	6	4	13	33.3
Tertiary education	0	0	3	3	7.7
Occupation					
Farmer	17	4	5	26	66.7
Nurses	0	0	3	3	7.7
Business	2	1	0	3	7.7
HSAS	0	3	0	3	7.7
TBA	0	0	1	1	2.6
Traditional healer	0	0	1	1	2.6
Other	0	0	0	0	0
Parity					
1 to 3	3	1			
2 to 5	12	3			
6+	4	4			

Data in table 7-2 demonstrates that the majority of respondents were from extended families with a mean number of people in a household of 6. Most access treatment and care from the government hospital and the majority of them (n=18) walk or use a bicycle (n=8) to reach the

nearest health facility. All the households (for breastfeeding mothers and peer counsellors) had access to safe drinking water mainly obtained from a borehole or protected well and minority of them had access to tap water. In terms of housing (not included in tables 7-1 and 7-2), the most common type of housing for both breastfeeding mothers and peer counsellors was grass-roofed with mud floor and none of them had access to electricity. On the other hand, the majority of key informants obtained their water from a tap and had iron sheet roofed houses.

Table 7-2: Selected socio-economic indicators of peer counsellors and breastfeeding mothers

Social economic indices	Number	%
Religion		
Christianity	24	100
Moslem	0	0
Number of people living in the house		
Below 5	7	29.2
5 to 9	15	62.5
10 and above	2	8.3
Access to care		
Government health facility	23	95.8
Private clinic	1	4.2
Mode of transport to the nearest health facility		
Walk	16	66.7
Bicycle	8	33.3
Occupation partner		
Farmer	20	83.3
Self-employed	3	12.5
Formal employment	1	4.2
Water source		
Bore hall	18	75
Protected well	2	8.3
Tap	4	16.7

7.3. Knowledge and perceptions about exclusive breastfeeding

All breastfeeding mothers were asked to explain how they fed their youngest infants and reasons for the chosen method. In addition, mothers and counsellors were also asked some questions to assess their perceptions and levels of knowledge about the meaning of exclusive breastfeeding (EBF), what it is involved and their knowledge about EBF and HIV. Living in communities where breastfeeding is normative, without exception, breastfeeding was mentioned by all respondents as the best infant feeding method and all women reported to have ever breastfed. Overall, all demonstrated familiarity with the concept and practice of exclusive breastfeeding as defined by the World Health Organization, (2001) and the most recommendable aspects of it. For example, some breastfeeding mothers explained that:

“It means the child should be given breast milk only for six months without giving the child any supplementary food.” (LA005- age 32- HIV positive- 04/04/2012)

“Mothers should breastfeed their babies for 6 months without giving them any supplementary food like porridge [made from maize flour] and water. During this period the child is too young to be given other foods. ...after six 6 months the child is matured enough to be given other foods.” (LA010- HIV positive- 22/04/2012)

Most breastfeeding mothers further demonstrated positive attitude towards exclusive breastfeeding because of the knowledge that they have related to the health benefits of practicing exclusive breastfeeding. The majority strongly acknowledged that breast milk alone is sufficient to meet nutritional demand of the baby up to 6 months and helps babies to grow healthier and faster. Some mothers also pointed out that breast milk protects the baby from common childhood illnesses as opposed to those babies who are given other foods before 6 months elapses. This, according to their own views, helps the baby not to fall sick regularly. Thus, they all perceived this may eventually reduce hospital visits, which are costly and time consuming as most were of low socio-economic status and travel long distance to reach the nearest health facility:

“Breastfeeding a child exclusively helps to prevent illnesses such as diarrhoea and other diseases that affect young children as a result of early introduction of foods or liquids. Eventually, you have a healthy baby who is not sick regularly.” (LA017- HIV negative– 27/04/2012)

Since breastfeeding is the common form of feeding the infant in Malawi and is culturally acceptable, all breastfeeding mothers generally considered their choice to breastfeed as acting

in line with both the hospital and cultural expectation. They also stated that women show responsibility and love to their baby through breastfeeding. Conversely, some mothers who breastfed their babies felt that they are respected as responsible parents who care for their infants. Most mothers said that it was desired by every woman to be seen breastfeeding and being considered as “a good mother” by the surrounding communities once they see them breastfeeding as articulated by this woman who was HIV positive:

“In our communities when people see you not breastfeeding they may think that you are not a responsible mother who wants your child to die. As a result, every mother would want to be seen as a good and responsible mother.” (LA013- HIV positive- 27/04/2012)

Overall, most mothers expressed concerns that they could be stigmatized if they opted for replacement feeding because the community is aware that replacement feeding is one option for feeding babies born to HIV positive women. When this topic was probed, it was clear that that all women including those who were HIV positive continued with at least some breastfeeding to avoid being suspected as HIV positive by significant others and the surrounding communities:

“People think that you are a bad mother when they see you not breastfeeding your baby even when you decide to wean the baby early. Some think those who are not breastfeeding are HIV positive.” (LA006- age 37- HIV positive- 04/04/12)

One Key informant also reported his views regarding the reason why women choose exclusive breastfeeding:

“Even at our hospital everybody knows that the baby should be put to the breast soon after birth. The woman is actually violating the rights of the child if she does not breastfeed.” (KI002- Traditional Authority- 02/07/2012)

Additionally, all mothers chose exclusive breastfeeding because of economic reasons. They all reported to have managed to practice EBF for 6 months because they perceived it as the most convenient and cheapest method of feeding their babies. During the discussion it was also clear that just like the general population, most mothers were dependent on their partners for financial support. As a result, most of them were concerned that they could not afford to buy infant formula due to poverty as the majority of them earn their daily living through farming. The quote below demonstrates the impact that breastfeeding mothers felt food shortages in most rural communities had on informed choices for infant feeding methods:

“When I was advised to breastfeed for six months, it was a relief to me because I did not have any money to buy food for my baby. You know porridge requires some sugar and I wouldn’t even manage to buy a packet of sugar.” (LA008- HIV positive- 04/04/2012)

Women also considered breastfeeding as a paramount option because the majority of them are not employed and spend much of their time working in their fields. They articulated that the method is easy because it is always readily available and does not require any preparation. This allows the woman to always move around with her baby and have enough time to perform her household work and field work. This also allows them to participate in community activities like funerals, weddings, and meetings while providing adequate nutrition to their babies without being interrupted. One of them explained:

“You can perform your work in the field at the same time breastfeed your baby. If you breastfeed the baby frequently, the child don’t bother you then you have enough time to do your work like farming and also participate in community activities.” (LA013- HIV positive- 27/04/2012)

7.4. Knowledge and understanding of MTCT and infant feeding

During interviews all mothers were well informed about exclusive breastfeeding and MTCT as they demonstrated good knowledge about the risks of transmitting HIV through breast milk. They all reported to have received counselling on MTCT and recommended feeding options for HIV infected mothers during antenatal care, labour and delivery and postnatal services. Most of them strongly believed that once an HIV positive woman breastfeed exclusively as advised at the clinic, the chances of transmitting the virus to the baby are reduced as opposed to giving supplementary foods before 6 months elapsed. Furthermore, those who were HIV positive demonstrated good knowledge that breast conditions such as mastitis, sore nipples and also any sores in the mouth of the infant increase the risks of MTCT because the virus can easily penetrate the gastro-intestinal tract of the baby:

“At the hospital they explained to us that HIV positive mothers can pass on the virus to their babies through breast milk especially when the child has sores in the mouth. We were also told that if we practice exclusive breastfeeding the child will not contract the virus and if we have any breast problems we should stop breastfeeding.” (LA013- HIV positive- 27/04/2012)

The protection that EBF provides against HIV was connected to not breastfeeding beyond six months of the infant's age as the majority of them start developing teeth. The main explanation given by the majority of them was that once the child develops some teeth it bites the mother and some may contract HIV:

“Many babies start developing teeth at 6 months and if the baby happens to bite the teat of the breast it can bleed. If the mother's blood drops into the baby's mouth, and if the baby has some sores in the mouth then the baby can easily contract the virus from the mother.” (LA004- HIV positive-04/04/2012)

The fact that all the 12 HIV positive women were on ARVs, gave hope to them to continue with breastfeeding even beyond 6 months. Most of them explained that if HIV positive mothers and their babies are given ARVs during breastfeeding period the lower the chances of transmitting the virus to the baby during breastfeeding period. Others also attributed prevention of transmitting the virus to their babies during this period to Co-trimoxazole prophylaxis therapy (CPT) given to their babies to prevent chest and respiratory infections. This was evident in some of the HIV positive mother's interviews:

“...When my child was born he was tested and I was told that he is negative. I was also told that my child was given some medicine (ARVs). As of now he takes Bactrium (Co-trimoxazole Prophylaxis Therapy (CPT)). So I am not worried when breastfeeding.” (LA003- HIV positive- 11/04/2012)

Most women demonstrated good knowledge on the importance of preventing re-infection while breastfeeding. One HIV positive mother who I refer to as Mrs Kapoto, who was breastfeeding her baby explained to always use male condoms every time she had sex with her husband in order to prevent re-infections to her and that any new infection increase the risks of transmitting the virus to the baby. She further reported to have been encouraged to follow such advice because her previous children tested negative:

“We always use condoms which I usually collect from here [Meaning the health centre]. I am aware that if I don't protect myself during the time I am breastfeeding I can increase the amount of virus in my body and eventually infect my baby. I have given birth to two girls who are all HIV negative despite breastfeeding them.” (LA006- HIV positive- 04/04/12)

One other interesting theme that emerged was that despite having HIV free babies, just like other mothers who were interviewed she had the desire to practice family planning or go for

permanent sterilization because she was aware that frequent pregnancies while HIV positive would lower her own immunity and eventually develop AIDS. Ultimately, Mrs. Kapoto was worried about the risks if she becomes pregnant again while HIV positive as insisted by her new husband and also due to her previous experience with the last delivery when she lost a lot of blood. Additionally, despite her two children tested HIV negative, she was aware that it was not guaranteed that all her babies will be HIV negative because some may contract the virus during pregnancy, labour and delivery and through breastfeeding. Therefore, she felt that preventing future pregnancies was the only effective way of reducing HIV infection among children and also to remain health:

“My plan is to have tubal ligation because I don’t want to have more children. But my new husband insists that he wants to see his face [meaning he should have his biological children]. You know women lose a lot of blood during labour and delivery. ...for me I fear that may be if I become pregnant again and considering my status I can lose my life while my husband can live longer.” (LA006- HIV positive-04/04/2012)

On the other hand, from our conversation with Mrs Kapoto it was obvious that gender roles and lack of power that women have within the patriarchal society, adversely affected her decision on whether to become pregnant again or not. The strongest reason for her confusion was her desire to maintain her marriage citing increased social and financial dependence and lack of empowerment despite her knowledge that she would put her life in danger if she becomes pregnant again. Mrs Kapoto was aware that her desire not to have more children may not be considered important because in patriarchal marriage women are not expected to express or take part in any decision-making process related to sexual and reproductive health but rather to be submissive and listen to their spouses. She explained how getting marriage complicated her situation:

“Let me be frank with you, being married for the second time is not all that simple. Men will always say why should I care for your children as if they are mine? ...I have no intention to become pregnant again considering my status. I can lose my life while my husband will not be affected and he can live longer.” (LA006-HIV positive-04/04/12)

7.5. Source of information about exclusive breastfeeding

Women were asked about the source of information about exclusive breastfeeding. The majority of them articulated that they have attained knowledge about exclusive breastfeeding through the counselling they receive from the health care worker at the hospital during antenatal, labour and delivery and postnatal period. This was because all of them attended antenatal care and gave birth at the hospitals which are Baby Friendly and where exclusive breastfeeding is highly promoted:

“we are counselled here at the hospital by the midwife that we should breast feed our babies exclusively until they reach 6 months without giving any supplementary food.” (LA013- HIV positive- 27/04/212)

Health providers also explained the reasons why they promoted exclusive breastfeeding:

“Exclusive breastfeeding (EBF) is part of the government policy that encourages all women in the country to practice EBF soon after the child is born until 6 months without giving any food, water or infant formula. ...This policy which is commonly known as “the Baby Friendly Hospital Initiative” was approved to ensure that babies grow healthy in the country. It is a very good programme because women are educated about EBF right from pregnancy, during labour until postnatal period.We also make sure that the woman put the baby to the breast within 30 minutes after delivery while in the hospital.” (KI007- HCW- 31/07/2013)

“We advise women to practice exclusive breastfeeding so that the baby should grow well and that also to protect the child from different infectious diseases like diarrhoea and pneumonia.” (KI003- HCW- 13/06/2012)

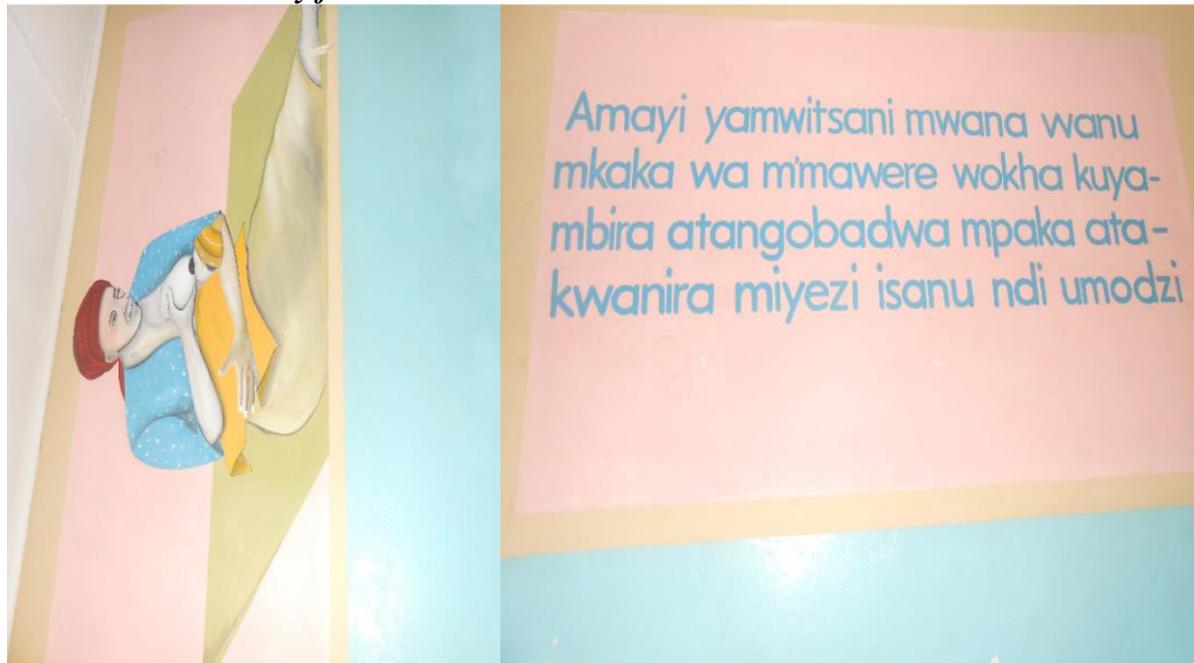
During the time I was collecting data for my study, I reviewed a number of documents including infant feeding policies and guidelines, strategic plan for Malawi¹⁴ and also noticed numerous pictures and messages reinforcing EBF written everywhere within the health facilities especially in the maternity ward. For instance, figure 7-1 below denotes some of the messages taken from one of the maternity entrance. The picture demonstrates how the woman should attach her baby to the breast while the message is written to remind and encourage women to start breastfeeding soon after giving birth and continue with EBF until the child reaches 6 months old.

¹⁴ 2008-2013 Infant and Young Child Nutrition Policy Guidelines for Malawi

2007-2012 National Nutritional Policy and Strategic Plan for Malawi

2008-2012 Five year national strategic plan for accelerated child survival and development

Figure 7-1: Photo: A woman breastfeeding her new born baby and the message encouraging women to initiate breastfeeding soon after birth and continue giving their babies breast milk only for 6 months



A considerable number of women also mentioned their relatives especially their mothers and mother in-laws as important sources of information while a few of them mentioned to have heard about EBF from their friends:

“I heard about EBF from my relatives especially my mother as well as my friends. Most of the times when we are chatting we are able to discuss about the best ways of feeding our children and also share the challenges which we face as women.”
LA005-HIV positive- 04/04/2012)

HIV positive mothers on the other hand, reported to have heard about the importance of exclusive breastfeeding through support groups for HIV breastfeeding mothers taking place in their communities. One of them said:

“We have a support group in our community where we are advised to breastfeed our babies exclusively for six months.” (LA016- HIV positive- 27/04/2012)

Further, interviews with key informants uncovered the role other people in the community play in promoting exclusive breastfeeding in the rural community. For instance, the traditional healer who was interviewed narrated that a lot of women present themselves to him to seek care and treatment for their babies often suffering from continuous diarrhoea and fevers commonly referred to as “Tsempho” in the local language. This means that a lot of

them strongly believe that the infant is sick because one of the parents was promiscuous or someone who was promiscuous held the child while in real sense the child may not be receiving adequate nutrition. He further narrated how he balances the two: that is encouraging women to continue seeking care for their sick children from him at the same making sure that they continue breastfeeding their babies:

“The reason is that they do start off from home having in mind that the child is sick not knowing that it’s due to poor feeding. ...I start by giving the medical to the woman and then advise her to feed the child frequently if it has started eating other feeds. If the child has not yet started eating other foods or porridge I tell them to breastfeed frequently so that the child should become stronger again. So they do continue breastfeeding because of the advice that I give them.” (KI001- traditional healer-11/04/2012”

Health care workers further explained that mothers get additional advice from their relatives especially elderly women on how to feed their babies or if they experience any problem or feeling uncertain or uncomfortable on how to maintain exclusive breastfeeding. In their view, for some who have good knowledge about the importance of exclusive breastfeeding take a role in making sure that the mother is following the advice from the hospital while those with little knowledge would encourage them to strictly follow traditional ways of feeding babies. This is because culturally elderly women have the core responsibility to teach young women on the best ways of feeding young children and protect the future generation and their advice is often considered important (Bezner-Kerr et al., 2008). The following quote from one health care worker describes the role played by significant others to ensure that the woman is following the hospital advice in relation to infant feeding:

“It happens that if one of them is not following the hospital advice, neighbours or elderly women are more less observers. They remind her to follow the hospital advice. We are so encouraged that things are now working well because we actually work in the community and we are able to see what is happening.” (KI004-HCW-04/07/2013)

Women are often given information about exclusive breastfeeding through health education talks given to them every morning when they come to seek medical care at the maternal and child health clinic and through pictorial drawings and messages around the maternities. Every

morning when I arrived at the health centre¹⁵ to conduct the interviews I saw some nurses giving health talks to women and sometimes singing different songs in the local language. Most of these messages are related to pregnancy, family planning and child-care including the importance of exclusive breastfeeding. However, as discussed in chapter 4, infant feeding being a cultural issue, it does not only concern the mother only, but also other members of the family. I also observed that no written information is given to the mothers through leaflets to take home so that they can share with these influential significant others who are often not present at the clinic and not involved when women are being given health education messages on the benefits of EBF. Consequently, some key informants reported that most women eventually forget what they have been told at the hospital when they go back to the community and find it difficult to explain the importance of practicing EBF to significant others mainly their mothers, mother in-laws and partners. Relatives are well known to be the key decision-makers in the country and provide advice to mothers on how to feed the baby (Bezner-kerr et al., 2008).

7.6. Exclusive breastfeeding practices

All breastfeeding mothers were asked how they breastfed their youngest baby from birth until the child reaches 6 months. The aim was to understand whether they managed to breastfeed exclusively for 6 months as they appeared to be well informed. All 19 lactating mothers reported to have breastfed their infants and the majority were seen breastfeeding during the time of the interviews. It is encouraging to note that all of them reported to have initiated breastfeeding within one hour after giving birth because they all delivered within the Baby Friendly Hospital Initiative maternities where all women are encouraged to put the baby to the breast soon after birth:

“I started breastfeeding soon after giving birth and continue until my baby was 6 months old. Then I started giving my child supplementary food during the seventh month.” (LA007- HIV negative- 04/04/2012)

Out of the 19 mothers interviewed, 17 confidently reported to have managed to breastfeed their babies exclusively for 6 months when asked for the first time and only 2 reported that they did not manage. They were further asked follow-up questions on whether they think

¹⁵ Health centres mainly provide primary health care in the country.

other women in their community manage to practice EBF for the recommended 6 months period. This was purposely done because I realised that it might be difficult for women to say to me that they did not breastfeed exclusively, given that they know all the health messages and the fact that they were aware that I was a health professional. Interestingly, the majority of women especially those who reported to have managed to practice EBF for 6 months perceived EBF behaviour to be uncommon among their fellow mothers from the same community. When asked to elaborate further on their responses, they reported to have witnessed their friends giving their babies other foods as well as traditional drugs and gripe water before 6 months elapses:

“They don’t manage to practice EBF for 6 months because most of them buy gripe water when the child is young. Some women give their babies some local medication to facilitate Fontanelle closure.” (LA005- HIV positive- 4/4/2012)

“...Most women in our community complain that the child was crying a lot with hunger or that they went away to do other things and left the child home with other people who eventually gave the child some porridge without their knowledge. Some even ask us why we are only giving breast milk to the child at that age [expected to start giving food at 3-4 months] without giving any food and we are able to answer them.” (LA016- HIV positive-27/04/2012)

It can be argued that it is possible that women reported to have practice EBF while in a real sense they did not manage. Considering the fact that people in a society influence each other’s behaviour (Bandura, 1991), it is questionable that these women who were interviewed would behave differently from their fellow women living in the same community. Those who insisted to have managed to practice EBF for 6 months were further probed to elaborate how they did it and whether they gave any other foods or liquids to the child during the time they were practiced EBF. In asking them how they actually practiced EBF, I hoped to get a good idea whether these women who demonstrated good knowledge on EBF and reported to have managed to practice EBF for 6 months were able to translate the knowledge into practice. Eventually, the number of mothers who still insisted not to give any other food or liquid not even water to their babies until 6 month elapsed declined to only 11 as 6 mothers eventually explained that they had given supplementary foods in the form of water, gripe water or traditional medicines even during the first week of the infant life. Interestingly, some of those women who reported being able to practice EBF did not necessarily perceive the practice of giving some of these liquids such as gripe water and castor-oil to be in conflict with the

concept of exclusive breastfeeding as most of these pre-lacteal feeds are traditionally classified as medicines:

“I managed to practice exclusive breastfeeding until my child was 6 months. (...)I only gave water and castor-oil.” [Oil made from castor-oil beans usually given to babies to stop colic pain] and some traditional medication from the first week.” (LA002- HIV positive- 11/04/2012)

Additionally, interviews with key informants as well as some peer counsellors evokes strong arguments that the majority of mothers in their communities even those who were visited in their homes do not manage to practice EBF for the recommended 6 months period. One health profession reported that they easily identify those babies who are likely to have received complementary feeding earlier because of their slower growth:

“Just looking at the child you really get satisfied that yes this child has not been given any food or liquids since birth. There are other children even if the woman tells us that she is practicing EBF we are able to tell that she is not telling us the truth.” (KI008-HCW-31/07/2013)

7.7. Common complementary foods given and reasons for introduction

Given the culture in Malawi where extended family system is common, respondents were then asked to describe the common food given to their babies and what influenced their decision to do so. Some respondents in this study reported that there is a tension between the role of motherhood and various other roles women play in their communities. In particular, they reported that many women are expected to ensure that they are able to achieve a balance between the care of their babies including breastfeeding as well as caring for the entire family. In many settings, despite the fact that mothers need to spend much of their time caring for their babies including breastfeeding, women in the rural communities are not only involved in domestic work but are expected to generate income for the families through farming. This situation hugely pushes many women to experience psychosocial, mental and emotional problems. However, if a woman tries to concentrate on the care of the child, some partners or family members consider the mother as being lazy. Hence, their low status and socio-economic circumstances mean women struggle to integrate breastfeeding into their daily lives:

“In our community aah, many women do not manage to practice exclusive breastfeeding for 6 month because of different reasons. Sometimes due to household chores or I should say the care they get at home makes some not to manage to practice EBF for 6 months. For example, most women have to breastfeed the child and at the same time go to the field. They don’t breastfeed frequently as required because they have no time. Some men think the woman is lazy if she spends more time with the child instead of cultivating. As a result, women leave the child somewhere within the field for some time without breastfeeding while cultivating and most of the times they wait for the child to cry that’s when they go and breastfeed.” (KI001- Traditonal healer- 11/04/2012)

Although most interviewees were determined to practice EBF for 6 months, culture was seen to play an extremely important role in determining what type of food or liquids to be given to the infant before 6 months elapsed. The majority of them eventually gave their infants some gripe water, milk of magnesium and some herbal infusion such as Mzuwala and Dawale¹⁶ and porridge. In most cases these herbal infusions were given within 7 days after birth. A good explanation related to this is that in most communities in the country there is a cultural taboo that a child should not be taken out of the house before the umbilical cord stump falls off. This normally takes a period of seven days commonly known as “Chikuta” in the local language. After these first seven days, the women are then expected to give some herbal infusions to the baby. The primary reason mentioned by the majority of them was to protect the new born babies who are particularly considered vulnerable to evil spirits and other commonly childhood diseases often characterized by continuous fevers and diarrhoea if other people who may commit adultery hold the new born baby before being protected by these traditional medications. One key informant asserted the reasons why women give these pre-lacteal feed to their babies:

“Most of them give watery porridge mixed with traditional herbs known as Dawale to their babies while others have certain cultural beliefs which they follow like giving the infant some plain water or sometimes add some traditional drugs into the water known as Mzuwala and give it to the baby. These are the common practices in this Chewa tribe [the dominant tribe in the district] whereby women give their children some porridge or water because they believe that breast milk is not enough to meet nutritional demands of the baby.” (KI003- HCW- 13/06/2013)

¹⁶ Mzuwala is herbal infusion made from the leaves of specific tree species found in the area. The infusion is made from crushed leaves mixed with boiled or cold water.

Dawale is herbal infusion made from the roots of a specific tree species found in the area. Sometimes other leaves are crushed and added to the infusion. Sometimes fed to the infant as an infusion or added to porridge to make a very thin porridge.

Traditional medicines were also described by key informants as being given to facilitate Fontanelle closure and also to help the intestines to start functioning properly. One key informant stated that:

“Traditionally, women in our community believe that if they give these traditional medications or some porridge it makes the intestines of the child to start functioning properly and the child does not cry a lot because it is able to digest any food which it is given” (KI003- HCW- 13/06/2012)

Traditional medicines are usually in powdered form made from crushed roots and leaves or uncrushed leaves and roots. As a result, women are advised to soak them in cold water while others boil or add in watery porridge for easy administration to the small baby. As seen from the demographic characteristics above, many women in the rural communities do not have access to clean water as they obtain their water from a bore hole or well. Therefore, giving of these traditional herbs may increase the risks of diarrheal diseases to the infants especially those soaked in cold water which is not boiled at all.

Some women with subsequent children reported to have given other foods to their babies especially gripe water as a routine because they did the same with other children as they found that this was effective in reducing colic pain:

“That’s what I learned with my first pregnancy that if the child is crying with stomach pain we should be giving castor oil or gripe water to relieve stomach pain. So I am used to do that.” (LA002-HIV positive-11/04/2012)

This demonstrates that women may have been accustomed to believe that when the baby is crying a lot then they have to give gripe water, castor oil and some traditional drinks as a routine. The main challenge is that gripe water is mainly sold over the counter, normally at open markets and the effect of extreme heat on gripe water is not known. In addition, each and every one of them decides on the amount to give her baby and the interval is often determined by the behaviour of the baby. This means that those who cry a lot get it more frequent unlike those who cry less. Again, since the gripe water contain some alcohol, when women give their infants alcoholic gripe water. Eventually, the effect of the alcohol would make the child sleep and they would concentrate on their daily work including farming without being disturbed. One interviewee said that the most frequently mentioned reason was

that they gave gripe water to relieve colic pain, which made the child cry a lot especially during the night:

“They say when the child is crying with abdominal pains then gripe water relieves the pain.” (LA012- HIV negative- 27/04/2012)

Since these health centres were close to trading centres, I visited shops to check availability of gripe water. It should also be noted that although non-alcoholic gripe water was available, this was hardly available in the shops because it is expensive and a lot of poor women could not afford to buy it. Hence, most shop owners buy alcoholic gripe water, which is then commonly used by women in Malawi. Through our interaction one shop owner commented that:

“A lot of women from the hospital come to buy gripe water from here [alcoholic one].” (Observation notes, 3/07/2012)

Figure 7-2: Some of the traditional and over-the-counter medicinal supplementary feeds commonly used by women in Malawi



Some respondents reported that women in their community give their babies water and watery porridge especially when the child is 3-4 months old or when the child is crying a lot. Through discussion, there was a common understanding among most respondents on the cultural beliefs especially among older women who still believe that when a child is crying a lot it is a sign of hunger as some women may not produce enough milk to meet the demand of the infant. The reason most commonly reported by most respondents on why they thought that most mothers in their community give their babies some porridge was that the child's crying was taken as a sign of hunger implying that the mother was not producing enough breast milk to satisfy the infant:

“Most of the times they feel that when the child cries a lot then it’s a sign of hunger so they start giving the child some food. In the end the child is malnourished because they don’t know the right amount to give to the child.” (LA011- HIV negative-22/04/2012)

One health worker who was interviewed further expressed her views in terms of promoting EBF among rural women and felt that there was always a conflict between “international policies and cultural practices” on whether breast milk alone is enough to meet the infant’s nutritional demands:

“Many women even me who gave birth long time ago you can agree with me exclusive breastfeeding was not being promoted at that time. Most of the old women therefore, don’t agree with exclusive breastfeeding. They think the woman is wasting her time and also starving the infant without giving any food.” (KI008- HCW-31/07/2012)

Another key informant commented that:

“Most of the time women forget about breastfeeding and if the child is crying a lot they think it’s hungry because they are not producing enough milk and they start giving some porridge. Once they start giving porridge to the child they do forget about breastfeeding because they don’t know the right amount of porridge to give to the child.” (KI001- Traditional healer- 11/04/2012)

7.8. Decision makers to give other foods

Women were asked a series of question to explore who influenced their decision to give the infant complementary feeds. The aim was to gain insights into the social networks that provide social support for infant feeding. In most cases, elderly family members were firmly endorsed by the majority of women as being influential people who made the decision especially young first time mothers to start giving other foods. Theoretically, despite intention being considered as the main predictor of performing a particular behaviour, in real practice these significant others are well known to be the key decision-makers in as far as infant feeding choices and practices are concerned in the country. This is mainly due to gender roles and power imbalance in most societies in the country, which often assumes caring of young children as the main role for the woman while the decision on how to feed the infant rests on older women such as mother in-laws or their own mothers. In addition, these are the very same people who often escort the woman when she goes to the hospital to

give birth. As a result some of them start giving pre-lacteal feeds before the woman is even discharged from the hospital especially those who stay longer into the hospital due to medical complications. Older mothers with subsequent infants on the other hand, reported that they made their own decision on what to give their infants based on their previous experience:

“I just decided on my own to give my child some water before 6 months elapse.”
(LA002- HIV positive- 11/04/2012)

Some of them went on and explained that their friends influenced their decision to start giving the child other foods before six months elapse and some even give them these complementary feeds especially traditional drugs:

Interviewer: Who advised you to give your child some traditional medicine and gripe water?

Respondent: Some of my Friends at home.

Interviewer: So what medicine did you give her?

Respondent: I can't remember and I don't even know the type of medication which I gave my child.” (LA012- HIV negative- 27/04/2012)

Several women often buy traditional medicine from some elderly women who usually sell them along the streets or visit the traditional herbalist. During discussions, the traditional healer who was interviewed stated that he prescribes some of these traditional herbs to be given to the child when women go to seek medical help from them rather than going to the hospital. Within the interviews the most overwhelming reason for seeking traditional medicine was that although bulged or sunken Fontanelle is a common sign of dehydration in children, women in the rural community most often associate this with problems to do with Fontanelle closure commonly known as “Liwombo” in the local language. Instead of going to the hospital for care and treatment, mostly women in the rural community prefer to go to the traditional healer or TBA whereby a confirmation is made that is in line with the woman's thinking. One key informant expressed her views related to this:

“When the child is having continuous diarrhoea we know that it's now the problem to do with the Fontanelle because it becomes sunken and then we are supposed to give the child some traditional drugs.” (KI006- TBA- 18/07/2012)

On a more positive note, despite the fact that provision of traditional medicines is a major source of income for the traditional healers, they also use their knowledge and assess the

infant and take time to give advice to the mother on the importance of frequent breastfeeding when the baby falls sick. The one who was interviewed further reported that if they find that the child has bulging Fontanelle, they just give the traditional medicines which are not very strong to make them happy but in real sense they know that the woman is not breastfeeding her infant. They only do this to maintain their trust and make sure not to lose customers even if they were aware that the problem was due to poor breastfeeding. He narrated that:

“....we give some traditional medicines to make the child become normal again but we know that the main problem is poor breastfeeding. Then I advise them to put the child to the breast frequently. When they are going home we do give them the same advice about frequent breastfeeding otherwise the child will fall sick again.” (KI001-Traditional healer- 11/04/2012)

Some respondents reported to have obtained traditional medicine from the Traditional Birth Attendants (TBA) commonly known as “Azamba” who follow cultural norms and belief. For some, these TBAs were perceived as negative influences that often discourage women, implying that breast milk alone is not enough for the infant and encourage them to start giving other foods to the infant during the first six months. One mother who was breastfeeding and coming from the rural community explained that:

“Some women fail to practice exclusive breastfeeding because the TBAs usually tell them that breastfed only is not enough to meet nutritional needs of the infant up to the age of 6 months. They usually give women some traditional medicines to prevent tetanus and other illnesses. Many women listen to them and they use the herbs or start giving porridge to their infants before the end of 6 months.” (LA019-HIV positive-31/05/2012)

During discussion with one who had been working as a TBA suggested that she no longer conducts deliveries following the ban from the government stopping them from assisting women during labour and delivery. She reported to only assist women with traditional medicines to help some of them conceive, strengthen the pregnancy as well as to protect the baby from evil spirits (most often within the first week of life) and other childhood illnesses, relieve colic pain, and facilitate Fontanelle closure:

“I still give traditional medicines to pregnant women who come to me to seek help. But I no longer conduct deliveries. But people still complain of the distance and they blame the government for telling us to stop conducting deliveries.” (KI006- TBA-18/07/2013)

She further justified her work as being influenced by spiritual powers she acquired from her grandmother (heredity) and also the fact that they are community-based they are more accessible to women in the rural community with poor access to health care services:

“As for traditional medicine there is no way I can stop doing that because for me to start practicing this I had a dream and my mother was performing the same type of work [...] So the government has no powers to stop me from doing that. Many people who live very far from the hospital would still want if we can help them again. Women appreciated the good care that we give them when they come to us for deliver as compare to the hospital.” (KI006- TBA- 18/07/2013)

It was also observed that although the government had banned them from conducting deliveries, most of them still conduct deliveries secretly because this was their only source of income. However, during interview, she reported to only provide traditional medicines to pregnant mothers and their babies due to fear of being blamed and fined if they are known to continue attending birth. Some health care workers further reported to have observed that a significant proportion of women who give birth at the TBA were deliberately not reporting the exact place of delivery and most often report that they delivered on their way to the hospital due to fear of being fined for not following the hospital advice to deliver at the health facility. In addition, the TBA would also be charged with the responsibility of assisting women during delivery to ensure that they adhere to the required standards. As an example, one of the TBA supervisors acknowledged that they see many deliveries being conducted by TBAs during their supervisory visits:

“When we go for area development meeting they report to us the number of women who gave birth outside the hospital but we are not sure whether they really reflect the right numbers or not. The problem is that some people hide when that happens they claim that the woman gave birth accidentally on their way to the hospital though it happened home because they are running away from paying the fine.” (KI004- HCW- 03/07/2012)

7.9. Breastfeeding support and motivation

7.9.1. Support from the hospital

All the mothers who were interviewed attended antenatal care and delivered at the health centre. Women recounted that they managed to practice exclusive breastfeeding because of the counselling messages and support which they receive from the health personnel throughout antenatal period, labour and delivery and postnatal period. Even those women

who experienced low milk production during the first days after birth received support and reassurance from the nurses that helped them to understand that more milk will start coming after a few days and that they should just continue putting the baby to the breast. Some women also acknowledged that they feel motivated to maintain the behaviour because they were visited in their homes and rewarded by someone from the hospital for performing exclusive breastfeeding for 6 months¹⁷ (the issue of home visit is discussed in more depth in chapter 8):

“The gift that I got from the district hospital acted as a motivation to me and other women within my community. The only problem is that they stopped coming otherwise a lot of women were interested to care for their babies and practice exclusive breastfeeding so that they can also be rewarded. I think now they go to another community.” (LA017- HIV negative- 27/04/2012)

Unfortunately, some of the mothers felt that there was less support from the health care workers during postnatal period because they were too busy. In most cases they relied on their guardians most often their own mothers or mother in-law to assist them with breastfeeding while still in the hospital. In some instances, the mother would come alone to the hospital and needed more advice and support on how to breastfeed:

“Most of the times the midwife is too busy helping other women giving birth in the labour ward. As a result, we stay in the postnatal ward with our caretakers who help us to put the baby to the breast. For those who come alone without a guardian you find them struggling alone with no one to assist them with putting the baby to the breast.” (LA014- HIV negative- 27/04/2012)

In addition, women argued that the nurses spend less time with them to educate them about how to maintain EBF when they come for postnatal and under-five care. Most of the times women are counselled in groups and often do not have time to ask them if they were experiencing any problem. In support of this, some of the health care workers reported that because of high fertility in the country, they find it difficult to provide one-on-one counselling to these women. One of them narrated that:

“Considering the fact that there is always shortage of health care workers in these health centres located in the rural community, we find it difficult to provide one to one

¹⁷ The women could not explain properly about who visited her home but it seems there was a programme at Guillime mission hospital where community workers were visiting breastfeeding mothers in the community to make sure that they were breastfeeding exclusively.

support. Otherwise we can't manage to finish all our daily activities. And because there is only one nurse on duty, we make sure to spend much time at the labour ward to assist women rather than the postnatal ward. We just tell women to call us in case they have a problem.” (KI003- HCW- 13/06/2012)

7.9.2. Support from partner and significant others

In most communities local leaders acted as change aides supporting women to spend more time to care for their babies as well as practicing exclusive breastfeeding. One chief commented that as community leaders they are also responsible to sensitize and encourage men in the community to take responsibility and assist the woman in caring for their babies:

“If the child is crying a lot then the woman is not being fair to the child and if other people are around during that time they can even bit the woman for being irresponsible. They will actually ask her whether she is the real mother of the child and whether she is happy to ill-treat the baby. Who actually asked you to become pregnant in the first place? I thought it was your choice with your husband. Why do you ill-treat the baby? The baby has to be breastfeed according. Once the child is full then it will automatically stop on its own and it will actually sleep. You can leave the child somewhere to sleep without any problem and that gives time to the woman to do her household chores.” (KI002- Traditional Authority- 03/07/2012)

Local leaders also have a greater responsibility to sensitize and motivate men during local village meetings to go for Voluntary HIV Testing and Counselling (HTC) with their partners in order to protect the unborn child from contracting HIV. During these visits issues of infant feeding are also discussed and the couple is given an opportunity to choose the infant feeding method they can afford:

“We also involved the chiefs as well as religious leaders so that when having meeting they also explain about the importance of going to the hospital for VCT as a couple and practice exclusive breastfeeding. This has helped a lot of men to know the importance of practicing exclusive breastfeeding for 6 months.” (KI008- HCW- 31/07/2013)

In return, a large proportion of women who were interviewed expressed their feelings that having involvement of their partners in the decision making process on infant feeding methods helped their partners to be supportive during the time they were practicing EBF. Having a supportive partner—who are the decision makers and providers of economic support—considering that many women are not in paid work and were in a patriarchal type of

marriage, appears to be a critical factor determining whether the woman would manage to practice EBF or not. Most women who were interviewed spoke of this as being helpful to them because they were having more time to care for the baby and eventually managed to practice EBF for 6 months. One mother spoke on how her husband encouraged her to continue with exclusive breastfeeding:

“He was always on the forefront encouraging me to just give the child breast milk and I’m sure if I happen to give the child any food he would be angry with me. I also feel probably because the message from MaiMwana talking about exclusive breastfeeding is now everywhere, we can’t say we don’t know.” (LA011- HIV negative- 22/04/2012)

Surprisingly, even if male involvement is highly promoted in Malawi as one way of promoting access to care by pregnant women, during the time I was collecting my data I noted that even if some men escort their wives to the clinic, they are mostly not invited to be part of the discussion because I saw some of them just standing outside the clinic or sitting under a tree while the women was accessing maternal and child health services. When I approached some of them to check whether they have been assisted already or if they needed any help some disclosed that they escorted their wives who were being attended to. In support of this, one respondent described her views related to why men are not participating in childcare:

“The first thing that hinders these men to participate in EBF or any programmes related to infant feeding because of our culture. Culturally caring for kids is usually left for women and men do not take part at all. Secondly, men consider themselves as being too busy than their wives. Lastly, I have noted that many projects coming to our communities mainly focus on the mother and child not men.I have noted that men are not involved in many of these programmes and women sometimes find it difficult to pass on the message to them.” (VPC008- supervisor- /07/2012)

The majority of them mentioned to have received support from their own mothers or mother in law mainly during the first 3-4 months. However as already discussed about these were the common people mentioned as encouraging women to follow traditional way of feeding the infant. In some instance, they would blame the mother if she refuses to follow traditional ways of feeding the baby.

7.10. Conclusion

In this chapter I have explored women's knowledge and how women practice exclusive breastfeeding. I have also explored the factors that influence the breastfeeding behaviour in rural communities. In this study I found that women demonstrated good knowledge about exclusive breastfeeding and were aware about the advantages of practicing EBF mainly because of the support they get at the hospital throughout antenatal period, labour and delivery and breastfeeding period. However, despite having good knowledge and initiation of breastfeeding, and despite initial positive reports, most of them did not manage to practice exclusive breastfeeding as required. Gripe water and traditional herbs mixed with porridge (Mzuwala) were the main supplementary feeds given to babies before 6 months elapsed and some of these are given during the first week following the birth.

The other key finding is that the majority of women did not want to say the real practice when asked for the first time but instead reported that their fellow women do not manage to practice EBF for 6 months. People such as significant others and TBAs were repeatedly mentioned as influential people in terms of giving supplementary feeds, indicating that they also need to be targeted when giving information to women on EBF. Involvement of chiefs and male partner support was associated with good support of women to practice EBF. However, this study found that these significant others often are not involved when giving information to the woman and highlights the need to involve them when giving infant feeding education to women. The next two chapters will now report on experiences and importance of peer counselling to support women in rural communities.

CHAPTER 8: EXPERIENCES OF WOMEN WITH HOME-BASED PEER COUNSELLING IN RURAL COMMUNITIES

8.1. Introduction

This chapter presents and discusses experiences of doing voluntary work in resource-poor settings from the viewpoint of both peer counsellors and breastfeeding mothers they supported. The chapter illuminates the complexity of using women to work as volunteers in resource-poor settings with particular reference to voluntary participation and the role of social power structure and gender roles within rural communities. It suggests how best the intervention can be planned for effective implementation. Finally, the chapter highlights the need for involvement of family members especially men in maternal and child health. To elaborate this further, I include some specific individual narratives of peer counsellors to illustrate how they were trained, how they planned their daily work and how they approached pregnant women and their reaction to the visit. Riessman, (1994) explained that the purpose of narrative analysis is to examine how participants through the telling of their stories, impose order or flow of experiences to make sense of events and actions in their lives (p. 2).

8.2. How and why women got recruited into the programme as peer counsellors?

MaiMwana used 72 volunteers who were literate members of the communities. These were selected out of a pool of other women by their local leaders especially chiefs in collaboration with the MaiMwana staff. One key informant explained that:

“One did not require having any formal professional qualifications to be selected as a peer counsellor but rather should have some form of education and be able to read and write the local language (Chichewa) and have given birth before. It does not matter whether the person is old or young provided she was willing to do the work.”
(KI004-age 40-03/07/2012)

Since the work involved women of different ages, some key informants interviewed raised a concern on the age of peer counsellors as they felt that older peer counsellors were more likely to be accepted and respected by women during the visits unlike the young ones who are normally considered as in-experienced. In addition, it was felt that most young counsellors were over-stretched as they went to conduct the visits while pregnant or with their young children unlike the older ones who were above child bearing age. One staff from MaiMwana

project reported that some of the young peer counsellors stopped doing the work. She further described the challenges of working with older peer counsellors:

“Despite the fact that older peer counsellors were more willing to do the work in practice than the young ones most of them had lower education and it was hard for them to report the actual visit outcome or monthly report. Some peer counsellors were being assisted by the supervisors to document the visit outcome and that increased workload for the supervisors.” (KI008-HCW-31/07/2013)

Interestingly, during the quarterly meetings with peer counsellors which I attended, I noted that the majority of the peer counsellors who were not performing well gave similar excuses like *“I was sick or there was a funeral in the community”* when asked to explain the reasons why they did not visit some women or for not sending their monthly reports as required.

All peer counsellors were then asked how and why they think they were selected to work as volunteer and what motivated them to accept the role without any payment. The aim of asking such questions was to gain an understanding on whether they voluntarily accepted the role, taking into considerations gender and power disparities (women volunteers being selected by male community leaders to work for international researchers), how they interpreted it and also to understand their detailed experience in relation to providing support to women in the context of Malawian culture and poverty. All of them pointed out that the project consulted chiefs who eventually selected them to perform the work as volunteers:

“I was selected by the project leaders and the chief to do this work. They asked them to suggest a name of one person who should be working with the project. So they voted for me to do this work.” (VPC006- age 64 -02/07/2012)

“They [MaiMwana project team] came in this village and hold some meetings with our chiefs where they briefed them about the study. Subsequently, I was selected and approached by our chief to do the work with the project together with other women.” (VPC001- age 37 -13/06/2012)

MaiMwana staff confirmed involving community leaders in the selection process of peer counsellors and regarded their involvement in the selection process as significant to empower the community who were the main recipients and intended beneficiaries of the intervention. This according to the project team was intentionally done to avoid selecting volunteers who they think would not be accepted by other people in their communities but rather leave the

community to select those who they trust to do the work as expected. It is also interesting to note that involvement of community leaders during selection of peer counsellors was one way to ensure that peer counsellors were answerable to them rather than to the project team who were not always available in the field. One other overarching theme that emerged about involving community leaders in the selection process was the fact that these leaders were very familiar with the personal conduct of those who were trusted and selected to do the work on behalf of the community. One member of the project team confirmed that chiefs selected peer counsellors who are usually respected members of the social network and enthusiastic to do the work assigned to them:

“We didn’t want to select volunteers who will not be accepted in the community but we wanted them to decide and chose someone who they trust to do the work. ...because these volunteers were chosen and trusted by their chiefs therefore, if any of them is not performing well the chiefs are the ones who decide whether the person should continue doing the work or not. So far as a project we have been impressed with the performance of the majority of them.” (KI008- age 49- 31/07/2012)

Peer counsellors described the ease of performing their work as volunteers after being chosen by their chiefs to do the work because beneficiaries were more responsive and easily accepted them in their homes:

“The fact that breastfeeding mothers in our communities are aware that we were chosen by the chief to do this work with MaiMwana, they easily accepted us into their homes and this helped us to conduct the visit without any problems due to the trust which they developed toward us.” (VPC004- age 26- 13/06/2012)

However, the majority of them were unsure about the reasons why they were selected but some perceived being chosen as a sign of being *“valued and trusted”* - the status that might have come from being selected within a hierarchical social environment to do the work on behalf of the entire community. Some of them assumed that the community selected them based on their positive personal conduct and previous engagements in some community-based programmes such as youth clubs, water and sanitation; giving the community leaders confidence and trust in them. One of them expressed:

“I was not told the reasons why they decided to select me to work as a peer counsellor. I personally believe that I was selected because I have previously been a member of many groups in our community and I am one of the dedicated and active

members. I believe that this made the chiefs to develop trust in me.” (VPC003- age 31- 29/05/2012)

8.3. Reasons for accepting to work as peer counsellors

Later in the conversation peer counsellors were probed to understand what motivated them to accept the role without any payment or compensation in addition to their daily work. Table 8-1 summarises some of the reasons peer counsellors gave for accepting the role.

Table 8-1: Motivating factors mentioned to work as volunteer peer counsellors

- | |
|--|
| <ul style="list-style-type: none">• Moral concerns to help others and the government in reducing maternal and infant mortality.• Involvement of community leaders in the selection process.• Community recognition and respect.• Make new friends.• Acquisition of valued knowledge and skills in infant care.• Personal growth and development.• Material/financial incentives.• Possibility for future paid employment.• Exposure to good living conditions during trainings and meetings. |
|--|

With the exception of a few, the majority of them mentioned that their involvement in the work was based on a moral concern to help the government in promoting maternal and infant health that would eventually reduce the number of women and children dying from preventable causes in their own villages. One of them explained:

“I accepted this role because I wanted to help the government to improve the health of pregnant women in our community. Once pregnant women live a healthy life, then we will be able to prevent unnecessary deaths.” (VPC006- age 64- 02/07/2012)

A number of respondents expressed a concern that these deaths directly or indirectly affect them physically and psychologically as some of them could be related to them. One peer counsellor shared with me her personal views:

“I accepted this role as a peer counsellor because I wanted to help the government to reduce these deaths pregnant mothers in our community. Since we are working within our villages some of these women are related to us and once they fall sick or die we are also affected. We spend so much time taking care of them when sick or attending to preventable deaths that occur in our villages. That is why I accepted this role without being paid anything.” (VPC006- age 64-02/07/2014)

This has been cited in the literature as being exacerbated by limitations on accessing health care among women, inadequate health facilities, deprived infrastructure and poor infant feeding counselling of which the situation is worse in the rural communities (Zere et al., 2007; Muella et al., 2011). During the time I was collecting data I observed that there was only one nurse allocated on duty in all the health centres which I visited responsible for conducting all maternal and child health activities including family planning, under-five clinics, antenatal care, assisting women to give birth¹⁸, and providing PMTCT services.

Given that most women who were working as volunteers were in a patriarchal type of marriage commonly known as “mtengwa” in the local language which means a “visitor in a strange village”, to an extent, participation in the work as volunteers was driven by their desire to gain access to a broader network of social friendships within these communities. Another key factor in their motivation to do the work was the recognition they received from their fellow women as volunteers working with a reputable international non-government organization. One peer counsellor narrated that:

“Through voluntary work I have managed to make new friends. I feel encouraged and proud to continue working as a peer counsellor because my friends admire the work we are doing in our communities. Some would ask me the reasons why I was selected to be part of the project and I explain to them that I was selected by our own chief. Because of this, we are respected and they eventually accept us in their homes. That’s why I feel that this is a very good role.” (VPC007- age 46 -03/07/2014)

As already indicated in chapter 3, in rural Malawi the majority of women have low level of education and often have little opportunities to participate in the formal labour force (MDHS, 2010). In this context, the majority are predominantly dependent on subsistence farming to feed their families. Through conversation with some key informants it appears that some peer

¹⁸ Most of these clinics are over-crowded due to high fertility rate in the country estimated at an average of 6 children per woman (DHS, 2010).

counsellors especially the young ones who were educated up to secondary school level and not employed became motivated to work as volunteers, expecting that their involvement would increase their opportunities to get paid employment with the project in the near future, despite not having higher level qualifications. Crucially however, as time passed by when this did not materialize, they became frustrated and eventually dropped out of the project because they did not see any benefit for doing the work. While researchers would like to keep levels of attrition as low as possible, through meetings and interviews with MaiMwana officials it was repeatedly mentioned that the project finds it difficult to retain some of the young peer counsellors who had achieved higher levels of education as compared to the older ones:

“Some had that feeling of getting paid employment but what they forget is that every post is advertised and they look for specific qualifications which they don’t have. So it becomes hard to consider them. So some of them complained that they have been working with the project for a long time and are not considered for a job yet they did not even apply for the post. The project was blamed for employing new people.”
(KI004- HCW- 03/07/2013)

8.4. Training satisfaction

Since many of those I interviewed have been with the project for a long time, this means that the majority of them attended the initial training where they were trained about preparation for labour, PMTCT, care of the newborn baby, infant care, exclusive breastfeeding, and how to support women with breast problems and what conditions to refer to the hospital. Peer counsellors who received on-the-job training were those who were recruited to replace those who dropped out of the project, were sick, died or were performing poorly. Peer counsellors including those who received on-the-job training felt that the training coupled with the intervention manual describing the content of each visit and simple pictorial booklet¹⁹ provided to them by the project made them to feel well prepared to execute their voluntary work in such a way that their fellow women who were visited admired them as being competent enough to assist them. One of them commented:

“What we learnt during the initial training and the information we gained through our quarterly meetings was enough for us to effectively execute our work. Some women who are not volunteers admire us because we know a lot. At the same time, the

¹⁹Adapted from WHO/UNICEF, Save the Children and Linkages

majority of them expressed satisfaction with the advice which we give them.”
(VPC007- age 46- 03/07/2012)

Peer counsellors further reported to have benefited a lot from refresher training sessions and quarterly meetings. This according to their views assisted them to share their practical experiences in the field and was often given transport money and meal allowance and expose them to good living conditions:

“Apart from the knowledge which we gained from attending refresher training, we enjoy a lot because we were away from home for some days, having a shower every day and you come home a changed person.” (VPC003- age 31- 29/05/2012)

However, just like other peer counsellors, she further raised a strong concern because these refresher trainings were not always conducted as planned due to financial problems. She was also worried that if the programme is completely handed over to the Government, these meetings may completely stop because the government does not have enough funds to sustain the programme:

“We are worried because it takes too long before we have these meetings. We are aware that as volunteers we are not supposed to be paid anything but we are happy when we go for these meetings because we are given allowances.” (VPC003- age 31- 29/05/2012)

While peer counsellors were satisfied with the training period and content, in contrast, many key informants and some of the supervisors differed in their opinion towards the duration and content of the training. The majority of them expressing their concerns that the training was inadequate for peer counsellors to comprehend the information provided to them and provide quality counselling to breastfeeding mothers:

“I don’t think the training was enough because they were trained for a short period of time like five days. I feel the days were not adequate for them to grasp all the information given to them. It is too much.” (KI005- age 26- 04/07/2012)

Some of them were concerned that the training did not cover all important topics. In particular, this was in relation to not being properly trained on how to counsel HIV positive breastfeeding mothers, yet the majority of peer counsellors reported that some HIV positive women voluntarily disclosed their HIV status to them during the visit:

“I noted that this area was not tackled much during the training and the counsellors lacked information and skills when they came across HIV positive women and most of the times when they come across HIV positive women they refer them to us for further counselling. I think it would be useful if they consider training them on how to handle HIV positive breastfeeding mothers.” (VPC005- age 40- 02/07/2012)

Interestingly and surprisingly, such judgment was contradicted by the knowledge and performance of some peer counsellors who I observed during their quarterly meetings including some of those who did not attend the first five days training. A good example is illustrated from one counsellor whom I call Anakonda (pseudonym) who joined the project in 2007. This means that she joined the project midway and did not attend the initial five days training. Since my intention was to interview both good and poor performers, she was among those who were recommended as good performers by the project team. Soon after being recruited into the programme, she was paired with one of her peers who was trusted by the project to be knowledgeable enough. Her peer was given the responsibility to mentor Anakonda on what is required at each visit and also to observe how she was providing counselling to women before she could perform the tasks on her own. Despite undergoing on-the-job training, she acknowledged to have benefited a lot from the refresher training sessions and quarterly meetings which she attended:

“In my case I joined the team in 2007 when they had already started. So I was just trained by my fellow counsellors and later we were trained by the organization at the Boma where we were privileged to meet and interact with counsellors from other villages. I learned a lot through these refresher meetings.” (Anakonda- VPC001- age 37- 13/06/2012)

I observed that her performance was outstanding during their quarterly meetings where I observed the majority of them role playing. During role-plays she was able to articulate all the required issues for the visit to her fellow counsellor who played a role as a client. She appeared very organized and was able to discuss all the topics with the client for each visit unlike some other peer counsellors who attended the initial training. In addition, I also observed that she was very active throughout the training and responded to most of the questions which they were asked. Additionally, she was able to narrate all the important aspects of what she learnt and described the physiology of milk production:

“We learnt that when a woman is not producing enough milk what it means is that she is not breastfeeding the child frequently. Actually each woman has the pituitary

glands in the brain that help milk production.” (Anakonda- VPC001- age 37- 13/06/2012)

She further narrated the advice she gave women during the visit concerning proper weaning foods:

“Normally, when we visit women in their homes we tell them to use locally available food that they have in their households. For example, if they have chickens, we ask them to mix the child’s porridge with an egg and mix well before giving the child. By doing so we are improving the nutrition status of the child.” (Anakonda- VPC001- age 37- 13/06/2012)

The quality of care and support provided by the peer counsellors is reflected in women’s positive responses and appreciation towards peer counsellors:

“I feel honoured to be visited home by the peer counsellor instead of me coming to the hospital. ...we see that those who refused to talk to the counsellors have malnourished children because they lack knowledge on the proper food to give their children since they refused to hear the message that the peer counsellor had brought to them” (LA01 – age 22- HIV negative- 22/04/2012)

8.5. The normal daily work of peer counsellors: narrative experiences

Having looked at the selection process of the peer counsellors, it was important to understand how they planned and executed their work while at the same time providing care and generating income for their families, mainly through farming and how they were trained and supported to do work. In this section I therefore, elected to use narrative case studies of selected peer counsellors. The use of narratives here is a significant way to give broader meaning to real life experiences of situations and provide an understanding of individual’s real experience with voluntary work. With this in mind, the purpose is to illustrate the day-to-day work experience of peer counsellors in the context of poverty. In addition, as a Malawian nurse myself I wanted not only to explore their experience but to further explore contextual challenges which they individually faced.

8.5.1. Negotiation to identify women to join the programme and culture

After training, peer counsellors were expected to identify all pregnant women in their allocated clusters, recruit them into the programme and visiting them for up to five visits. Peer counsellors who participated in this interview had the opportunity to narrate different strategies they used to identify and recruit pregnant women in a culturally sensitive way, how they conducted the visit and the challenges faced. The majority of them reported that their frequent active participation into numerous community public social gatherings such as funerals, village meetings, political meetings and religious sites provided an opportunity for them to effectively identify prospect pregnant women to be enrolled into the programme. The quotes below illustrate the different approach which peer counsellors used to effectively identify and approach pregnant women:

“We usually meet them during our regular village meetings, at the church and at women’s gathering places. Once we meet them we spot those whom we have seen that they are pregnant and we do have a brief chat with them and book appointment to visit them in their homes.” (VPC006 – age 64- 02/07/2012)

“Most of the times we spot them from their homes and sometimes some people within our community are able to inform us if they see someone who is pregnant.” (VPC005 –age 40- 13/06/2012)

While peer counsellors reported how they approached and identified pregnant women in a culturally acceptable way, interestingly, some of them reported having faced some challenges in the process. They explained that due to a variety of long-standing traditional and cultural beliefs related to pregnancy and child birth (Malawi Human Rights Commission (MHRC), 2005), not all pregnant women welcomed them when they approached them for the first time. Firstly, it is widely believed by the majority of rural people and advised by older women that pregnant woman should keep this secret until the pregnancy is visible to others. Secondly, during the quarterly meetings it was explained that many couples often avoid telling others about the pregnancy during the early months due to fear of having an abortion or a miscarriage mainly associated with magic, commonly known as “Kuvuwula” in the local language. Eventually, if something happens to the pregnancy, the whole community would blame them for their action. As a result, the project team advised peer counsellors to take into considerations all cultural issues and beliefs surrounding pregnancy before approaching pregnant women for the first time. One facilitator explained:

“During the initial training, peer counsellors were told to only approach women when the pregnancy was visible to others because that time the woman can no longer hide the pregnancy.” (MaiMwana facilitator, 04/07/2012)

One peer counsellor reflected her experience when some pregnant women whom she approached denied being pregnant. She explained that others questioned her how she knew that they were pregnant despite the pregnancy being visible. This can be seen in the following comment:

“Some of them when we approach them try to refuse but we try to convince them that their pregnancy is visible until they accept. You know most of them fear about witchcraft once people know that they are pregnant and fear losing the pregnancy.” (VPC 004 – age 67- 04/07/2012)

Peer counsellors explained that they were aware that it was against the cultural norm to approach pregnant women when the pregnancy was still not visible and considered this as the main barrier in terms of early identification of pregnant women to join the programme and being visited accordingly:

“Of course sometime we miss some of them or we miss some visits because it was difficult to identify pregnant women during early pregnancy.” (VPC006- age 64 - 02/07/2012)

For the project, another aim for early identification of pregnant women was to encourage them to go for early antenatal care, because reports show that most of pregnant women in the country start antenatal during second trimester.

Once the peer counsellor had spotted a pregnant woman she needed to make an appointment to perform the initial visit. Several factors were noted that helped women to be willing to be part of the programme. Firstly, as already discussed, the fact that peer counsellors were selected by their chiefs, it is not surprising to hear from the peer counsellors who reported that the majority of women who they visit were able to accept them into their homes:

“When I meet pregnant women for the first time, I firstly introduce myself as a volunteer from MaiMwana project. Then I ask them if they are willing that we should continue our discussion. The majority of pregnant women accept to be visited home because they are aware about the project and are happy with the visits which we make.” (VPC006- age 64-02/07/2012)

This may be related to the fact that chiefs are highly respected and people often respect their views. In addition, they reported to have successfully achieved this because the project briefed chiefs about their programme and the majority of the chiefs took a role in sensitizing people in their communities during village meetings, funerals or weddings about the presence of peer counsellors. Secondly, the project continued conducting community sensitization meetings and as time goes on the communities became accustomed to the presence and the good work done by peer counsellors:

“Aah many people in the community are aware that we do go and visit women in their homes to encourage them to practice exclusive breastfeeding. This is because of the continuous sensitization meeting conducted by the project as well as chiefs.”
(VPC006- age 64 -02/07/2012)

The love and comfort which women received during the frequent visits made by the peer counsellors was another reason that made the majority of them to easily accept peer counsellors in their homes. Additionally, women were aware that their fellow women in the neighbouring villages were not visited home by the peer counsellors. In some occasions, the counsellors did not even have to make any effort to identify pregnant women because a considerable number of them voluntarily approached the counsellors when pregnant or if any of their friends or relative was pregnant:

“When I am walking within our village some women approach me and disclose to me that they are pregnant and then invite me to come and visit them. This is because they are now used to the work i am doing in the community. I then tell them that I did not know that they are pregnant but i will plan to come and visit them.” (VPC 004 – age 76-04/07/2012)

Some of the peer counsellors explained that despite making initial agreements with women on the date and time of the visit, when they arrived at their homes they still needed to find out from the woman whether she had enough time to spend with them. They were doing all this to make sure that they had enough time to spend and discuss all the topics for the particular visit and allow them to ask questions so that the women grasps all that they have discussed. If the woman said she has no time then they were very flexible to reschedule the meeting on another day with which the woman feels comfortable. On the other hand, some women were not willing to be visited. A good example of resistance of women towards the visit can be

drawn from the common excuses made by the majority of them during the agreed day as seen from the following quote:

“Despite agreeing on the date and time, in some occasions we find ourselves travelling to visit some women only to discover that they are not available at home. They always gave similar reasons for not available at home such as they have gone to the field to cultivate or fetch some firewood or they have gone to the hospital for antenatal care, to seek medical care or visit a sick relation. Others will always give you excuses like look am about to go to the maize mill or to the field and I don’t have time to chat with you.” (VPC001- age 37-13/06/2012)

According to the counsellors’ views, this was one way of indirectly communicating that they were not interested to have them in their homes. One of the counsellors further commented that despite such frustrating situations where some women give excuses on several occasions, this did not put her off but rather she negotiated and discussed with the woman when she feels she will have time for her to come back for the visit. Most peer counsellors assumed that the likelihood that women would accept to be visited depended on a strong relationships and trust that eventually helped them to convince women that the visits were advantageous to them. Eventually, many of the women who gave excuses gave up and realized the importance of having the counsellors in their homes:

“We don’t give up but rather ask them to propose the day which they feel they will be free for us to come again. So we try to come back on the date which they say they will be free and mostly they agree to attend the clinic.” (VPC001- age 37- 13/06/2012)

8.5.2. Conducting home visits in rural communities

Peer counselling identified pregnant women within the allocated clusters and made five key home visits—initial visit during late pregnancy, and then first week after birth, at one month, three months, and last visit was conducted when the infant was five months old. Despite the fact that the project allowed peer counsellors to plan their visits within their own time framework, deciding on convenient times to conduct home visits in the rural communities was inherently challenging to both breastfeeding mothers as well as peer counsellors for several reasons. Firstly, although it could be argued that the majority of women in the rural community are unemployed and could have extra time to perform the job as volunteers, paradoxically as with any other woman in the village they also perform numerous roles which include: managing their households and work in the family farm in order to produce food for

their families. This type of work is socially approved and recognized as part of their daily life. In addition, this is the main source of income for the majority of women in the rural community, which creates a considerable demand on their time. In regard to this, peer counsellors as mothers as well as wives were culturally expected to divide their time to go to the field, perform their domestic roles and provide care for their children and other family members. Peer counsellors described voluntary work as doing extra job that required extra time and planning to fit into their daily activities. One peer counsellor who had a small-scale business described how she prioritized her household work and her business before going for the visit:

“Most of the times I do my household chores in the morning and go to the market. Most often I leave my business with my friends or any other relative then go for the visits in the afternoon.” (VPC003- age 31 -29/05/2012)

The majority described how they planned their work as volunteers to fit into their regular work schedule at home while making sure that they are not deviating from the cultural expectations. In the course of the interview, a good number of them confided that they normally conduct the visits twice a week and preferably in the afternoon. This plan was beneficial to effectively perform their household chores and take a role in generating income for the family before going for the visit. As can be seen in the following quote, peer counsellors assumed that conducting visits in the afternoon was good time for them as well as breastfeeding mothers when they have both returned from the field unlike visiting the women in the morning:

“I make sure that on the day which I have decided to go to conduct the visits I woke up early in the morning and do my household chores. Then around 1 in the afternoon that’s when I start off to visit women in some villages. If I go around 1 pm at least it takes almost half an hour with one woman if she was around. I don’t actually go there every day but mostly once or twice a week depending on the workload at my home.” (VPC006- age 64- 02/07/2012)

One other contributing factor to effectively conduct the visits was related to having a supportive male partner. This was pertinent in the rural community where men hold a key role as heads of the household and decision makers. Therefore, any work to be done by women is subject to approval by the male partner. One business woman narrated how the support which she received from her husband helped her to perform her work:

“As for me my husband has no problem with the work I am doing. Sometimes he is even the one who reminds me to go for the visits if I spend one week without visiting women or without sending monthly reports to the project. Otherwise if I say he is disappointed or angry when I go for the visits, then I am not being justice to him.” (VPC003- age 31-29/05/2012)

Some peer counsellors and their supervisors expressed some concerns with most women failing to be available at the agreed times because of unexpected issues despite women being given a chance to propose the date and time for the visit. Some common excuses included: the woman was either still at the field, gone to fetch water or firewood or to visit a sick relation. In some cases, the woman may relocate to her home village due to family disruption without the knowledge of the peer counsellor. One supervisor explained:

“Sometime we escort these counsellors to conduct supervision and some of the places are really very far and by the time we reach the place we find that the woman is not at home or she has gone to her home village mainly if she has separated with her husband.” (VPC005- 13/06/2012)

Since the project involved chiefs in the selection process, they made sure that women were available in their homes when the counsellors come to conducting the visit. One of them commented that:

“We ask some representative to go and call them from their fields and that is taken as an offence. We normally confront them to explain to us why they decided to leave their home despite being aware about the visits.” (KI002- age 76-03/07/2012)

Conducting home visits in the afternoon had its own disadvantages to both the peer counsellors and breastfeeding mothers. The majority of peer counsellors reported to have found the work challenging when they had to travel long distances on foot to visit women who lived far away from their homes. Despite being given some bicycles to use when going for the visits some of the places were hilly or too far and extremely difficult to go using the bicycle. One of them explained that if she starts off to conduct the visit in the afternoon, she would return back home late in the night and she was concerned about her own safety:

“Some villages are far from where I stay and I need time to walk so that I should be there by two o'clock at least. I work and by four I should be coming back. ...It happens that sometimes in a month we can only visit one woman while in other months we are able to visit all the women without any complaints.” (VPC001- age 37- 13/06/2012)

Equally, it was apparent that the majority of women in the rural community are never free the whole day. Even if the peer counsellors negotiated with the woman to choose time for the visit they would still find them busy when they reach their homes for the visit and would wait for some time for her to be free. On the other hand, the majority of women interviewed expressed a concern towards timing of the visit. The fact that these women are also supposed to do their household chores such as fetching water and firewood on top of preparing meals for their families when they returned from the field meant that many complained that the visits were taking place during the time they were extremely busy:

“Sometimes they would come for the visit and find me busy working home. If you are rude to them when they come for the first visit that put them off and never visit you again. Otherwise, if you are open and friendly to them you see them coming back for subsequent visits to chat with you.” (LA016- age 34- HIV positive-27/04/2012)

Again, if other people in the community see the volunteer visiting women raised questions on why they are being visited home while some people talk a lot of bad things about the visit with the aim of discouraging their friend:

“Some women were against it. They used to say a lot of things like you are just wasting your time with the counsellors. They are cheat you and your babies will die but we kept on working with them because we were educated and we actually believed that what they were saying was true.” (LA008- age 29- HIV positive-04/04/2012)

Some of the peers complained that the number of women to be visited per cluster were many as compared to the number of counsellors allocated per cluster. The fact that they did not have a specific number of women to visit per month, but rather visit all pregnant woman in their clusters, made it difficult for them to plan on how many women to visit in a day. Counsellors felt that there are times when they would miss some women because there were too many women in the clusters to be visited. Because of the high fertility rate in the country (average of 6.3 children per woman) most of the peer counsellors ended up conducting the visit using the guide provided to them by MaiMwana project ignoring women’s knowledge and previous experiences of infant feeding and rushed through instead of listening and reflecting on women’s stories (see table 8-2 for the topics discussed at each visit). The aim was to visit a good number of women who in the end had no time to ask questions especially those who are HIV positive (MDHS, 2010).

Table 8-2: Volunteer infant feeding and care guide

Visit 1: Pregnancy	Visit 2: After birth 1wk	Visit 3: 1 month	Visit 4: 3 months	Visit 5: 5 months
Introduction	Attachment and positioning	Attachment and positioning	Attachment and positioning	Attachment and positioning
Birth preparedness	Exclusive BF	Exclusive BF	Exclusive BF	Exclusive BF
Danger signs during preg	Vaccination	Vaccination	Vaccination	Vaccination
PMTCT	Warmth	Warmth	Warmth	Warmth
early BF	Hygiene	Hygiene	Hygiene	Hygiene
exclusive BF	Family planning	Family planning	Family planning	Family planning
Family planning		Discuss weaning at 6 months	Discuss weaning at 6 months	Discuss weaning at 6 months Discuss weaning foods

8.5.3. Involvement of significant others during the visit and power disparities: A missed opportunity

MaiMwana project aimed at promoting involvement of community members into the implementation of the two interventions that is women’s group and volunteer peer counsellors. This was because it is clear in the literature that involvement of male partners in maternal and child health is a crucial component in the optimization of services (Nyondo et al., 2014). Additionally, men often hold a key role as heads of the households and decision-makers as well as main family bread winners who spend much of their time working away from home to generate income and food for their families. Again, it is also well documented that in Malawi pregnancy and infant care does not only concern the woman alone but the entire family, especially elderly women and men (Bezner-Kerr et al., 2008). Therefore, it was pertinent to understand whether peer counsellors managed to involve significant others or needed to ask for permission from them to visit the women.

Through interaction, peer counsellors reported that initially they did not involve men and significant others during the visit the way they were involved in the women’s group intervention. Some peer counsellors explained that they did not invite men or any dominant family members who are influential to join them during the discussion. Some of them further explained that during their initial training they were told that if they found the woman and significant others at home they should only ask for permission from them rather than inviting them to join the discussion unless they are interested to join. According to my views I think this represents a “missed opportunity” to effectively promote EBF in Malawi—the most culturally acceptable way of feeding babies considering rates of under-nutrition among

children under the age of five (MDHS, 2010). The project team explained that peer counsellors were initially told to ask for permission from significant others before conducting the visit to avoid “*violating cultural beliefs and practices*” where by women have no power to make decision without consulting the male partner or significant others. In addition, when the programme started male involvement was very poor in the country:

“This programme started long time ago in 2004 and by that time Malawi as a country we had not yet started involving men in reproductive health issues because apart from exclusive breastfeeding these peer counsellors discuss issues related to reproductive health, labour and delivery.” (KI008- age 49-HCW-31/07/2012)

However, in 2008, MaiMwana in conjunction with the Mchinji district hospital started promoting male involvement popularly known as “The Mchinji Male Championship Model in PMTCT issues” aiming at increasing uptake of HIV testing and improve adherence to the PMTCT programme with the funding from UNICEF (Mwanza and Phiri, 2010). Through this programme, the project noted high response rate from men, which made Mchinji one of the successful districts in as far as involvement of men in PMTCT is concerned. For instance, Mduwa health centre reported about 80% of men being tested for HIV. Eventually, the programme advised the counsellors to start inviting the person in-charge of the compound such as men, mother in-laws, their own mothers during the visit despite the fact that the majority of them were still resistant to be part of the discussion:

“Since we didn’t involve them from the beginning, it became hard for these counsellors to involve men during these meetings. Now because in this district women are encouraged to come for antenatal clinic with their spouses, some men are now willing to join these counselling sessions in their homes.” (KI008- age 49- HCW-31/07/2012)

One other principal reason that peer counsellors may not have been willing to involve men during the visit is because of gender roles, which designates childcare as the core responsibility of women. The broader implication of this approach is that even if men were available at home, they did not see the need to be involved during the visit and some would eventually walk away instead of joining them. To make matters worse, in most situations these visits were scheduled during the weekdays, which made it difficult to find the male partner at home because mostly men are supposed to generate income for their extended families. In addition, some men who earned a living by small-scale business felt that they

wasted time by being part of the discussion during the visit instead of attending to personal business that brought money to the family. However, some men who were interviewed explained that their participation was hindered by the name of the project and timing of the visit. In support of this, one male partner who was interviewed explained that:

“I don’t join the discussion with the peer counsellor because when I heard that the programme is called MaiMwana [mother and child] then I thought it is not necessary for me to be part of the discussion. The name itself is clear that the programme is actually for these two excluding us. If they wanted men to be included then they could have named it “Mai, Bambo ndi Mwana” [meaning mother, child and the father all included].” (KI011- age 23- male partner- 13/07/2012)

Being bread winners, at times it was a common practice for men in this community to leave their wives while pregnant or when the child was still small to neighbouring countries especially Zambia to look for jobs. In their absence mother in-laws are expected to take on a greater social responsibilities to look after their wives and monitor the progress of the pregnancy and protect the unborn baby from any harmful practices as most of them are living within the same compound and have the authority to control all activities taking place within the compound. Some of the counsellors reported that they would normally find the woman with the mother in-law or sister in-laws during the visit and because of cultural rules a few women were expected to ask for permission from their mother in-law or mothers as the person in-charge of the compound.

“I asked my mother if we can have a chat. I told her that there is a lady from Mponda who would want to chat with me but I don’t know the subject and my mother gave me an okay to chat with the woman.” (LA011-age 22-22/04/2012)

In some cases, the mother-in-law was anxious about the wellbeing of the foetus and the mother and was very interested to the discussion. Some of the peer counsellors described such relatives as very inquisitive, wanting to know the purpose of the visit. This situation created a burden to the woman as she was expected to explain to the mother in-law the reason for the visit and what was discussed in case she was not around during the time of the visit. Women in the study also reported that explanation to significant others was done mainly to prevent problems if other people tell the mother in-law or spouse about the visitor from the hospital who came into their compound. Some peer counsellors saw this as an opportunity to

easily involve them during the discussion, but were deterred by the project initially from involving them. One service-user recounted that:

“Most of the times when the peer counsellor comes I am the one who is available at home. My husband is not always home but I have to explain to him or my mother-in-law what was discussed during the visit.” (LA015- age 21- HIV negative- 27/04/2012)

Another reason that some peer counsellors mentioned as hindering involvement of significant others during the visit was the fact that they might have to discuss sensitive and personal issues with women such as, the importance of HIV testing and using condoms for protection were. Thus, some of the counsellors raised a concern that the presence of significant others, especially the mother in-law, created a barrier and they felt uncomfortable to discuss such sensitive issues with the woman. Furthermore, because they were doing the work in their own communities, in some instance they ended up visiting their own relatives which made it even more difficult for them to discuss such sensitive issues in presence of their own relatives. The below quotation illustrates the perception of one peer counsellor:

“The other problem is that we are visiting these women in our own communities and it becomes difficult for us to discuss some of the sensitive issues with our in-laws. It could have been better if we were given other places outside our community to do these visits. ...By the time you reach their home you find that the woman is not home. When you try to find out why they have run away then the neighbour tell us that she did not like to discuss “zolaula” [meaning sensitive issue] in their homes that’s why they decided to run away.” (VPC 004- age 67- 04/07/2012)

On the other hand, the majority of respondents interviewed were of the opinion that it was important to ask for permission or involve the male partner during the visit because they are the decision-makers in their respective homes. For instance, through the interviews with women I also noted that when someone is visited by the hospital staff, family or community members become very inquisitive to find out why she is being visited or even join the discussion. This is mainly because it is not a common practice for HCWs in Malawi to visit people in their respective homes unless they have a specific medical problem like HIV which requires proper follow-up or they missed their scheduled appointment, which is becoming common among women due to the introduction of option B+ in the country that demands initiating lifelong ARVs to all HIV positive pregnant women regardless of their CD4 count

(MoH/GoM, 2011a). In fact, peer counsellors preferred that the couple be together during the visit for further counselling on how to feed their babies and encourage them to go for HIV couple counselling. Consequently, men who had participated in the visits inform their peers about their experiences with the visit and eventually some of them become motivated to join the discussion.

“There are many of them who are interested to be involved during the visit. In fact some are already involved when we go for the visit because sometimes before we start the discussion the woman would ask if it is possible for her sister or husband to be available during the discussion and we do allow them to do that. So this makes us to know that a lot of people in the community are interested to be present during the visit.” (VPC005- age 40- supervisor- 13/06/2012)

A further argument employed to support involvement of men was that due to low education levels among women, the majority of them find themselves in a situation where they are unable to properly explain what was discussed during the visit. Eventually, in the middle of the intervention, the MaiMwana project encouraged peer counsellors to involve men and significant others especially elderly women during the visit because some of demonstrated some interest to be involved. Their overwhelming perception was that involvement of these significant others who are well known to be influential in as far as infant feeding practices are concerned would allow women to better understand the importance of practicing EBF. A considerable number of respondents further acknowledged that men and other family members are very much willing to be involved during the visit and the majority of them who were invited accepted. Furthermore, some of the relatives, especially those who are older expressed their interest to work with the project because they feel they have been playing an important role in promoting breastfeeding even before the project started. However, the project approach did not encourage this kind of participation unless the woman wanted it:

“Sometimes if they find the woman with her grandmother, she was allowed to be present during the discussion but the counsellor was expected to ask for consent from the woman to allow her to be present during the visit. If the woman demands that that she does not want anyone to be present then the grandmother was not allowed to attend.” (KI008- age 49- HCW- 31/07/2012)

Some respondents also felt that involvement of men during the visit can often be utilized as an entry point to promote family planning issues. MaiMwana staff reported that in this

district family planning usage is extremely low because women often find it difficult to make decisions on their own due to cultural norms that give more power to men. It is however, interesting to note that some peer counsellors and women who were interviewed further pointed out that involvement of men and other family in the community present during the visit eventually helped them to gain some knowledge on the importance of EBF. Eventually, this was associated with positive outcomes such as supporting the woman while practicing EBF and reminding them to breastfeed frequently even during the night. This is evident from the quotes below:

“I was being encouraged by my husband not to give the child any supplementary food. If it was not for my husband to intervene, I would have given the child some other food like porridge because he was crying a lot. So I thought this a sign of hunger. But my husband insisted that I shouldn’t do that. Look my child is growing healthily without giving any food.” (LA011-HIV negative-13/07/2012)

8.6. Management and supervision of peer counsellors

Peer counsellors were performing their services under the supervision of the Health Surveillance Assistants (HSAs) who were selected by the District Environmental Health Officer (DEHO) to work as supervisors. A total of 24 HSAs who were employed by the government as community health care workers, mainly conducting community outreach and were believed to be living in the same villages with the peer counsellors. Due to the nature of their work, these HSAs do interact with the villagers and are knowledgeable about the socio-cultural norms of the communities in which they work. This enabled them to adequately supervise the peer counsellors in a socio-culturally acceptable manner. Supervisors were trained separately by the MaiMwana project health team for a period of 3 days. Later, the project observed that there was a gap as the supervisors did not know the training content for the volunteers and that made it difficult for them to supervise them. In view of this, combined refresher trainings were conducted to provide knowledge to the supervisors and build team work with the counsellors. They visited the peer counsellors once quarterly and documented progress, achievements and challenges they faced in executing their work. The volunteers submitted monthly reports to the project through their supervisors which helped them to monitor their performance.

Supervisors acknowledged that they were selected because they were already doing some paid work with the government in the allocated clusters. Just like the peer counsellors, these supervisors also did not receive any monetary payment for this work; instead they received allowances whenever they are invited for meetings and also received stationery in the form of pens, papers and t-shirts to be used when performing the work for the project. Despite explicitly being told by the project that this was voluntary, the majority of them had strong feelings that this was part of their job—as indicated on their job description to supervise volunteers working in their catchment area (see appendix 6). As a result of this, HSAs reported that they did not see any reason to refuse the job which was assigned to them by their employers and they further reported that they always incorporate MaiMwana supervision into their usual monthly work plan. This according to them helped them to effectively perform their role as HSAs as well as supervisors for peer counsellors:

“I was asked to be a supervisor because I work at Chikoza where home visits are done by peer counsellors.I make sure that I divide my time accordingly. The good thing is that we also have a work plan for the month so I follow what’s on my work plan. So I always include MaiMwana activities on my monthly work plan.” (VPC002-age 41- supervisor- 13/06/2012)

Some of the MaiMwana staff who were interviewed acknowledged that in facilities where supervisors are active and engaged, peer counsellors received proper guidance and input to their performance and were available to respond to any queries which they may have in relation to their job. Such supervisors observed peer counsellors as they conduct home visits and were available to assist in answering any technical questions that the client might have and at the same time provided feedback to them on their strength and weaknesses. As is widely acknowledged and emphasized in the literature that the success of CHW programmes hinges on regular and reliable support and supervision (Bhattacharyya et al., 2001), the MaiMwana staff observed that supportive supervision eventually facilitated good performance of peer counsellors and their motivation. He further explained that this is usually tracked through the number of visits these peer counsellors made in a month:

“We have observed that in the zonal areas where there is less supervision many counsellors do not do their work accordingly. We are able to track their performance through the number of visits which they make in their community through the reports which they send to the supervisor on monthly basis.” (KI004- age 40- 03/07/2014)

The majority of respondents identified a number of reasons for lack or poor quality of supervision. Through interviews with some key informants, it was reported that some supervisors were not living in the same communities with peer counsellors due to marriage as they decided to stay with their partners while others find it cheaper to stay in their own villages. The key problem revolved around limited time the supervisors had to offer the required supervision to these peer counsellors as the time needed for supervision was underestimated. Some respondents reported that the work of MaiMwana has increased the burden on the HSAs who already have limited time as they play multiple roles as community outreach workers (see appendix 13 for the roles of HSAs) in their catchment areas. During interviews with key informants it was further established that despite such numerous roles played by these HSAs, most of them accept any role assigned to them to get extra pay to boost their monthly salaries. Yet volunteers required frequent supervision in order to render quality services to clients. One of the key informants reported that:

“The problem with HSAs [Supervisors] they are able to accept any work which is given to them and they will pretend as if they will assist you but by the end of the day they will not do the work accordingly. They say this is how we work in the government.” (KI004- age 40- HCW- 03/07/2012)

On the other hand, HSAs complained of lack of provision of reliable transport and other resources by the project for them to use when going to the community to conduct supervision especially in hard to reach places. This, in their opinion, would in the long term compromise the quality of supervision offered to peer counsellors. One of them complained that:

“The project only provided bicycles to the peer counsellors but not us as supervisors and yet we need to travel long distances with the counsellors to conduct supervision. We were advised to use our transport given to us government long time ago and most of them are broken. Another thing is that we needed some career bags to use when going to the field but we were told that we needed to use our own money to buy these bags yet the counsellors were given some. So we find it difficult to go and do supervision.” (VPC002- age 41- 13/06/2012)

8.7. Referral mechanism of women for care and support services

Respondents were also asked why and how they referred clients to the hospital for care and support services since peer counsellors were not trained to handle certain cases at community level. Peer counsellors demonstrated good knowledge on the conditions which they are

supposed to manage at home mainly breastfeeding problems like breast engorgement and other problems like cracked nipples, low milk production which are associated with position and attachment of the baby to the breast and which conditions to refer. It was established that peer counsellors were able to refer women who had problems to the hospital helping women to access care and treatment in good time. However, one key issue identified was lack of referral letter when peer counsellors refer women to the health facility. It was reported that initially the project provided some referral forms which they could use to send the woman to the hospital but this was faced by negative attitudes of some health personnel towards women who were referred by the peer counsellors. This may be attributed to the gap between HCWs and the peer counsellors in terms of training period and socio-economic status, which led to negative reactions among some who perceived this as peer counsellors overstepping their role boundaries. As a way of preventing this problem, the project eventually stopped giving referral forms to the peer counsellors. However, this according to their views, made it difficult for the woman to be prioritized once she reaches the health facility and also for them to follow up whether the woman really reported to the hospital and received the required care and support. Consequently due to poor referral mechanisms some reported that it becomes difficult for most of the women to be attended in good time once they reach the hospital. Some women express discontent when they spend a considerable amount of time before being attended to despite having a referral letter. To promote referral, a few counsellors reported that they usually write a letter so that the woman can take to the hospital to present to the health worker as a referral form. However, the majority of them relied on a word of mouth from the client to explain to the health personnel the problems she had been referred for and also get feedback whether she went or not. In order to confirm whether the woman really went to the hospital one of them reported that:

“When we go back to visit them we check the booklet to confirm that she really went to the hospital. We advise them if there are no changes we ask them to go back again.” (VPC006-age 64-02/07/2012)

Contrary to this, a few women who were referred to the hospital reported that they did not face any problem at the health facility. One supervisor commented that this was intrinsically facilitated by the good working relationship with the peer counsellors as part of the health team as one of them narrated that:

“Because I am mostly based here at the clinic, the counsellors sometimes refer women direct to me and when she came and explains her problem to me I am able to go and ask the clinician to see her. So that is also the other procedure in place to assist these women. If they are referred direct to me, the nurse or clinician do not ask the woman to produce any referral form from the counsellors.” (VPC005- age 40-supervisor- 13/06/2012)

8.8. Incentives and payments

The project only compensated these peer counsellors with some non-monetary incentives in the form of tablets of soap, allowances during training and transport refund given at seminars. Additionally, each one of them was given a bicycle which was not only used for MaiMwana activities but also some personal activities. The project did not pay salaries or stipend to the counsellors for the considerable time and energy they committed that would help them to earn their daily living. During meetings and interviews with MaiMwana project staff one of them explained that the project decided not to pay any monetary incentives to these peer counsellors because their intention was to fully involve the community in the implementation of the intervention and use locally available resources, which included personnel. In addition, they also considered sustainability of the project by the government if proved to be effective.

“We did not pay any salary to these peer counsellors because there was an agreement with the chiefs to support implementation of the programme in order to reduce maternal and infant deaths in the community. We took into consideration that this project will phase out and once proved to be effective then our plan is to hand over to the government. You can agree with me the government does not have enough money to run these programmes because they rely on donor funding.” (Meeting proceedings with MaiMwana, 2011)

Although peer counsellors received non-monetary incentives, given the time involved in carrying out the work, high poverty levels in the country and that most of them were dependent on farming; these incentives were seen not to be enough to meet their daily needs. It is important to take into account the priorities of women in the rural areas which are likely to be caring for their families. This in the end affected the performance of some peer counsellors because they did not see the importance of investing considerable time in work which they will never be rewarded financially in the end. Some key informants further argued that it was unrealistic to expect these poor women from deprived remote communities to support themselves or their families through agricultural work while at the same time spend

time working for the project without pay. One key informant raised the concern that failure to provide incentives to peer counsellors might compromise their performance:

“Volunteerism is becoming hard because people in the village need some soap and something to eat and if they know that at the end of the month they will get something they work hard.” (KI004- age 40- HCW- 03/07/2012)

Through my interaction with the project team it was reported that the design of the intervention was mainly driven by the concern about issues regarding lobbying for scale up if the intervention is found to be successful and also sustainability of the project in the event that the project is handed over to the government of Malawi. In actual fact, the project staff and peer counsellors were concerned that the government would not be able to maintain the programme, which was seen to be beneficial to the poor due to lack resources. Some respondent felt that it was important to give incentives to the clients and also to promote participation of people in the community:

“There should always be some incentives to be given to people to promote participation into these programmes. People do not consider the messages but always look at what they will be given by the end of each meeting.” KI001- age 49- Traditional healer- 11/04/2012)

Similarly, being visited at home by someone especially if the individual was working for an international organization or a political party they also expect to be given some gifts. This is because in Malawian communities people have become accustomed to being given hand-outs or allowances whenever they are called for a meeting—be it political or health related meeting as a compensation for their time. It was clear from the interviews that peer counsellor volunteers working for MaiMwana project were sent to visit women in the community without any incentives for the woman but only went for the visit with their books. Unfortunately, there were also other organizations like Invest in Knowledge²⁰ who were also visiting people in this same community as part of their study and were giving incentives to their participants. Other counsellors cited that during the visit some women demanded for incentives from them just the same way other projects did. Additionally, the fact that peer counsellors were given some incentives when they go for their monthly meetings made some

²⁰ Invest In Knowledge has been involved in a large number of major research projects, including in some of the leading work on the social determinants of behaviour change, market research for the financial sector and the behavioural factors of HIV transmission in sub-Saharan countries including Malawi.

of the clients not to believe that they were doing voluntary work without payment. They felt peer counsellors did not want to disclose their payments to other people in the community. Consequently, some women were giving excuses when the volunteer booked them for a meeting or considered the messages given to them during the counselling as useless. Over time peer counsellors were able to clearly define their role as peer counsellors whose job was to give information to women and encourage them to practice EBF and that they are not paid anything for the job:

“At first when the counsellors were visiting women in their homes they were expecting that they would go with some incentives the same way it is done with other organizations which are visiting women in the same community and give them incentives. So it was difficult for us to convince them that MaiMwana counsellors do not give incentives but only give information to women on best ways of feeding their babies but now people understand.” (VPC005- age 40- supervisor- 13/06/2012)

Interestingly, having a volunteer in their homes was seen as a burden to some women because culturally it is believed that a visitor is not supposed to leave the household with an empty stomach. Eventually, some women might decide to leave their homes or give an excuse for not being available for the visit when they see that they had nothing to give to the volunteer.

Sometimes we don't have food to give visitors (laughing). Do you think a visitor should just come at your home and go with an empty stomach? We need to give them something to eat. (LA002- age 35-HIV positive-29/03/2012)

8.9. Peer counselling in resource-poor settings

Engagement into voluntary work in poor communities in Malawi had its own advantages as well as disadvantages to peer counsellors. The first advantage mentioned by the majority of them was that participation in the work enhanced their own individual knowledge and they acquired new skills on child care through the training courses provided to them by the project. This according to their feeling was not only beneficial to the service-users but was also seen to be applied beyond the remit of their work as peer counsellors. Some of them especially the young ones were still having their own children while those who were older were playing a role as grandmothers. Also some of them especially the older ones have the responsibility to advise other women and their own relations on how to breastfeed in their communities. Several of them were seen with small babies during the time of the meeting

while some were pregnant. Through interaction with some of them, they reported that they have been benefited a lot from the knowledge and skilled gained through doing the work. One young peer counsellor who was interviewed and had given birth twice since she started working for the project reported that:

“In the past I could not manage to breastfeed exclusively for 6 months. It was part of fashion to bottle-feed or give the child other drinks before 6 months elapses. I have really benefited a lot from this programme because I have given birth twice since I joined MaiMwana Project. I do appreciate the training offered by the project to us because I was able to practice EBF for 6 months with these two children.” (VPC003- age 31- 29/05/2012)

The project used to organize refresher training as well as quarterly meetings where these counsellors were brought together. The aim was to remind them about the scope of their work while in the field, what is expected from them and if there are any new developments. Moreover, this also created room for them to share their unique experiences in terms of success and the challenges as each had unique experiences and also give feedback to the project on whether the intervention is being successful or not. This on the other hand, provided an opportunity for the counsellors to intermingle and develop friendships among themselves as they were working in different clusters and some of the counsellors were new in the team:

“Apart from gaining knowledge from the training, the majority of us became friends and we were able to share our experiences which helped us to improve our skills when doing our work.” (VPC002- age 41-13/06/2012)

Furthermore, most of the peer counsellors who were interviewed acknowledged that in addition to the knowledge they gained through the training and meetings, they were exposed to good living conditions with good meals as compared to their living conditions in their deprived remote villages. Furthermore, peer counsellors felt they were perceived differently by others in their communities since they started working as peer counsellors. As a result, most of their friends, family and neighbours repeatedly ask them for health advice. They also felt proud to be perceived as the source of specialized knowledge within their social networks which made some of the women who they visit to be knowledgeable enough when they go back to the clinic. One respondent cited that:

“Some women come back to us and tell us that when they went to the under-five clinic they were able to answer all questions asked correctly which made the nurses to ask them where I learned them.”(VPC006- age 64- 02/07/2012)

8.10. Conclusion

In this chapter I have explored what motivated women in rural communities to work as peer counsellors without any pay and how this affected their daily lives. The chapter has also illuminated the advantages and the challenges of doing voluntary work in rural communities. I found that women accepted to work as volunteers in order to help promote maternal and neonatal health. A major advantage coming out from this analysis is that the knowledge gained during the training and meetings extended beyond the project to the individual as well as other members of the community who were not involved in the project.

The initial challenge was related to cultural beliefs and practices related to revealing pregnancy, which made it difficult for the peer counsellors to timely identify pregnant women and conduct the visit. However, frequent social gatherings such as weddings, funerals, church and any village meetings provided opportunities where peer counsellors could spot pregnant women within their communities. Furthermore, it was also clear that despite that not all women were happy to be visited in their homes, involvement of community leaders especially chiefs throughout the implementation process of the intervention allowed peer counsellors to effectively carry out their work as volunteers. The contradictions around provision of incentives were discussed, in that in a poor community real financial needs may constrain volunteering, yet provision of incentives may also blur the boundaries between paid and voluntary work, leading to some tensions. On the other hand, provision of incentives to women receiving visits in some other projects led to expectations of financial incentives for visiting that was intended to be voluntary and community-based.

Another major problem was related to timing of the visit. It is crucial to know that involvement of poor unemployed women in the voluntary work does not imply that these women completely have free time to do voluntary work. As seen from the analysis above, local women are busy because they are expected to be involved in income generating activities and provide care to their family member. On a more positive note, continuous support and involvement of the male partner envisaged successful voluntary work as male partner were taking a role to remind and encourage some of the counsellors to go for the visit.

CHAPTER 9: VIEWS OF RESPONDENTS ON THE IMPORTANCE OF HOME-BASED PEER COUNSELLING TO PROMOTE EBF IN THE CONTEXT OF HIV

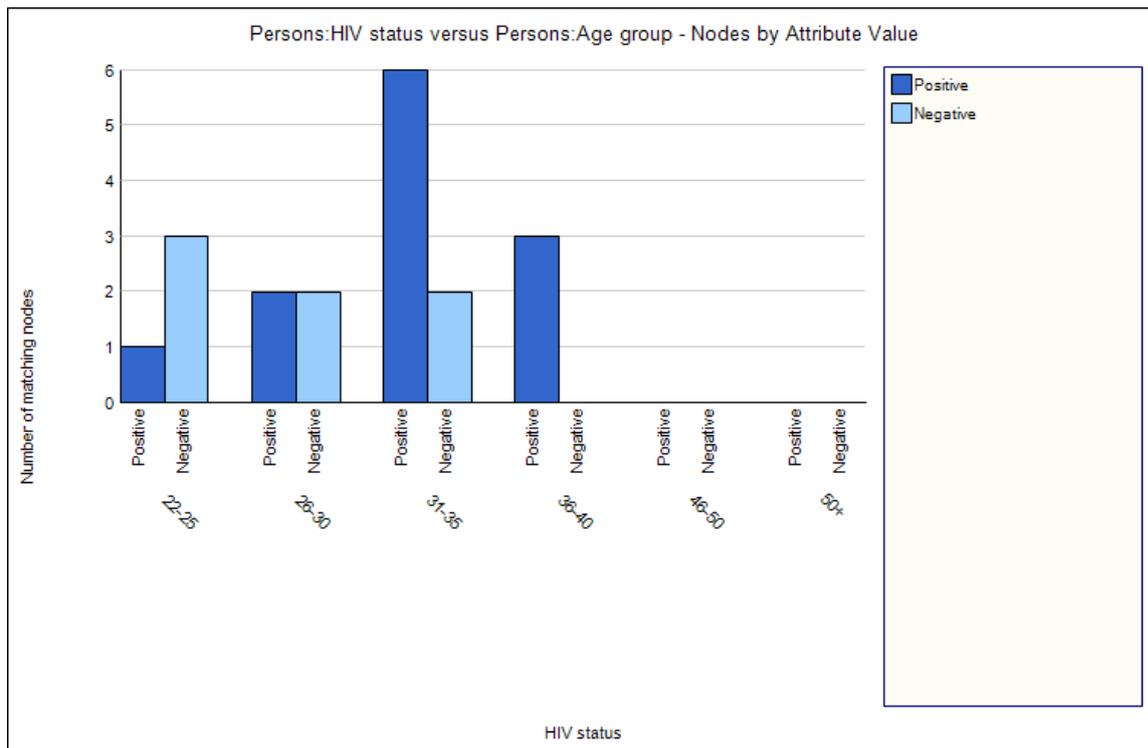
9.1. Introduction

This chapter presents major themes that emerged in relation to exclusive breastfeeding experiences and home-based peer counselling in the context of HIV. The chapter highlights the importance of working as peer counsellors in resource poor settings to both the peer counsellor and the clients. Later the chapter highlights the importance of peer counselling in promoting EBF among HIV positive women and how people perceive this. As counsellors were not advised of women's status by the MaiMwana project, the chapter also looks at the distress this may have caused to women as well as peer counsellors when they come across HIV positive women during the visit.

9.2. Summary of maternal HIV status of breastfeeding mothers and source of infection

Among the 19 breastfeeding mothers who were interviewed in this study, the majority were HIV positive (n=12) while only 7 were HIV negative. The dominance of HIV positive women in the sample was determined by my intention to explore decision-making processes among HIV positive women to breastfeed and the psychosocial effects this may have on them. This was also done to explore whether the intervention was helpful to assist them to maintain EBF and the challenges faced during the visit because of their HIV status. HIV status of breastfeeding mothers is presented in figure 9-1.

Figure 9-1: Distribution of HIV status by age group of breastfeeding mothers



The majority of mothers reported to have been tested for HIV during their first antenatal visit. Because HIV testing is routinely offered to all pregnant women at the antenatal clinic in the country since 2011 and normally the birth interval of children for the majority of women in the rural community is 2 years, some of them reported to have learnt about their HIV status with previous pregnancies (MoH/GoM, 2011a). Despite earlier criticism of routine HIV testing of pregnant women as not allowing women to voluntarily have the test (Angotti et al., 2008), many mothers in this study considered routine HIV testing at the antenatal clinic as useful and further reported that they could not refuse the test offered to them because they wanted to know their status. They further said that all they cared about was ensuring that the infant is protected from contracting the HIV through continuous counselling they were receiving and ARVs offered to them at the PMTCT clinic.

“I accepted to have the test because I wanted to know my status and be able to protect my unborn child. I was found HIV positive and I received counselling on how to protect my baby. I was also started on ARVs.” (LA002- age 22- HIV positive- 11/04/2012)

The majority of mothers who were HIV positive reported to have contracted the virus through heterosexual contact with their male partners. They further explained not to have been infected through their own risky behaviour as they try to remain faithful to one partner; but rather as a consequence of their male partners who easily engage in outside sexual relationships when they migrate to neighbouring countries or other districts to earn money and support their families. Economic migration of men to neighbouring countries was noted to be common in this district. This has been a life-cycle stage for men since the colonial period and is known to be an independent risk factor for HIV infection (Anglewicz and Clark, 2013). It was therefore, reported that women's vulnerability to contract HIV increased due to poverty and informal polygamous marriages as their spouses find substitutes once they migrate. One striking theme is that the majority appeared to be aware of their partner's risky behaviour. However, just like other women in the general population, they may lack the power and courage to demand safer sex like insisting on condom use with their married partners because of fear of abandonment and being accused of being promiscuous in their absence:

“My husband travels a lot to do some work like he can go to the north and spends some days there and he comes home once in a while.there was one time when he travelled to Kasungu district when I suspected that he is married there. One of his friends tipped me that he has found another wife there and he even impregnated herI feel he is the one who has infected me.” (LA001- age 27-HIV positive-29/03/2012)

One male partner who was interviewed admitted to have had several extra marital affairs in addition to the two wives whom he married. He believed that he contracted the virus through his numerous sexual partners:

“I feel because of my behaviour of having several wives that's why I contracted this disease.” (KI009- age 40- male partner- HIV positive- 27/04/2012)

On the other hand, when a husband dies the majority of women are forced to move back to their own villages following traditional practice commonly known as “Kusudzula” meaning that the mourning period is complete²¹. This is sometimes done to reduce the economic burden placed on the poor families of the deceased man. In this study it was further found

²¹ In most cases this takes one year and then the woman is allowed to get married again so that she can find someone to care for her as well as the children.

that some women whose partners died eventually decided to remarry due to lack of financial support to support their families²². While women and family members may have a good intention for encouraging these women to remarry, some interviewees indicated that such type of marriages can have a negative impact on the health of the woman. Such a scenario could contribute significantly to the spread of HIV as the majority entered into such marriages without knowing that the new partner is already infected with HIV.

“My first husband, father for my three children died. So I re-married with the second husband without knowing he was HIV positive who also died after two years.”
(LA008- 29 years- HIV positive- 04/04/2012)

9.3. Reasons for accepting to practice exclusive breastfeeding while HIV positive

HIV positive mothers in this study were then asked about the reason why they opted for exclusive breastfeeding despite their knowledge that they could transmit the virus to the baby. Anecdotal evidence from the interviews suggest that because of poverty health care workers advise women to practice exclusive breastfeeding for 6 months and continue breastfeeding up to 12 months or 18 months depending on availability of food without necessarily giving the knowledge about the other feeding methods and helping them to make informed choices. The majority of them reported to have agreed with the suggestion to practice EBF because of poverty and breast milk was seen to be the best and cheapest option for them:

“I was advised by the nurse at the clinic to breast feed. Since all my friends who were also HIV positive and had small babies were breastfeeding then I decided to breastfeed my child like them. They were saying if we stop breastfeeding what else shall we give the child? It is better to breastfeed the child because we have no money to buy milk until the end of six months. ...So it was cheaper for us to just practice exclusive breastfeeding.” (LA004- 38 years- HIV positive- 04/04/12)

Moreover, the surrounding maternities in the district are Baby Friendly Hospital Initiative authorised that heavily promote EBF and often do not support infant formula. Additionally, in this study it was also found that HIV positive mothers do not disclose their HIV status to all the people in the community including some of their relatives. For instance, one of them

²² Patriarchal type of marriage of marriage is common in this district where the women go and stay with the man in his home village. Once the man dies then the husband relatives took responsibility to care for the wife and children. In most cases the majority of them find it difficult to care for them because of poverty.

who I refer to as Mrs. N. decided to only disclose her HIV status to her husband and her own brother who was their immediate marriage guardian commonly known as “Ankhoswe”,²³ in the local language so that he should be aware of the problem which they were having as a family. She mentioned several reasons why she did not disclose her status to other people in the community. Firstly, she explained that she did not disclose to others due to fear of becoming isolated if she learns that her friends are HIV negative:

“I decided to disclose my status to my brother. After disclosing to him he encouraged us to follow the advice given to us at the hospital. When you disclose your status to your friends who are HIV negative you think much about your HIV status and you end up isolating yourself from them. Knowing that your friends are negative, you then gradually start losing weight, but you should feel relaxed and have no worries that other people don't know your status. Some do not keep confidentiality and talk a lot.” (LA006- age 37- HIV positive- 04/04/12)

Further, during the interview Mrs N. was asked to elaborate why she thought she may end up isolating herself after disclosing her HIV status to other people. She reported to have previously witnessed some of her friends who were highly stigmatized by some people in their community following disclosure of their HIV status to them.

“The problem in the community when you are found with HIV, let me give an example you may be able to take care of yourself but the moment you tell other people about your HIV status they talk as if you are going to die tomorrow.” (LA006- age 37- HIV positive- 04/04/12)

In support of this, one of the mothers reported that instead of helping those people who are HIV positive to have hope, some people laugh and call them by all sorts of names even those who joined support groups:

“They say we are moving corpses but we just let them talk because we know they are just like us and can as well become infected. We didn't choose to have HIV in our body. Some say they want to register them for” Dyeratu” (meaning they have to eat because they are going to die soon).” (LA003- HIV positive- 04/04/2012)

²³ Ankhoswe are usually marriage guardians or advocates who formally get together and agree to the marriage. Usually it is often a close and senior relation mostly a man (i.e. brother or uncle). In a few cases it can be a woman

Most mothers reported to have opted for exclusive breastfeeding to conform to the culturally defined way of feeding the infant in their communities which is practiced by many women in their villages. However, one of them reported to have been confronted “to stop breastfeeding” due to fear of transmitting the deadly virus to their babies and also because of the feeling that “*Since they will die soon they should not leave an infected child who is difficult to look after*” (LA013-. Age 32- HIV positive- 27/04/2014). This suggests that HIV positive people are still highly stigmatized.

Because of the feeling that “breast is best for the baby”, some of the participant women expressed some sense of satisfaction regarding their motherhood experience when they were told at the hospital that HIV positive women can breastfeed exclusively without passing on the virus to their babies. And again, the major issue here was that they did not want to be asked by people in the community as well as their relatives why they were not breastfeeding their babies as every woman is expected to breastfeed in this community. One of them for instance described this as being beneficial to the infant. As a result of this, she explained to have breastfed as much as she could because she was aware that she was expected to stop breastfeeding before her child reaches 2 years to reduce the risks of MTCT:

“I continued breastfeeding exclusively knowing that after six months I will stop. I wanted my child to enjoy the breast milk at that time.” (LA005-age 32- HIV positive- 04/04/2012)

However, one of them felt that the period which women in the country are advised to breastfeed (12-18 months)²⁴ was too long because she was aware that despite such interventions to prevent MTCT some babies may still contract the virus from the infected mother through breastfeeding:

“The doctors advised us to breastfeed our babies up to 18 months even if we are HIV positive. But I feel that’s risky. Two years is just too much for an HIV positive mother to breastfeed the baby because at that time the child has developed some teeth and can easily bite you and contract the virus which is too bad. I will only breastfeed mine up to 12 months not the recommended two years.” (LA010- age 33- HIV positive- 04/04/2012)

²⁴ The recent WHO guidelines (2010) encourage HIV positive women in poor settings to continue breastfeeding until 18 months because the majority of them do not meet AFASS criteria.

9.4. Perceptions and feelings of HIV positive mother with EBF

Because of the knowledge about the risks of transmitting HIV to the infant through breast milk, some of the mothers interviewed reported that they were worried throughout the time they were breastfeeding thinking that they have passed on the virus to their babies. This made some of them to keep on going to the hospital for early infant diagnosis as seen in the following quote from one of them:

“I always had the feeling that I have transmitted the virus to my child. ...later I went to the hospital with my baby for testing and she was found to be HIV negative. I felt good and I continued taking my ARVS as directed knowing that the chances of passing the virus to the child was minimal. I also continued to breastfeed my baby exclusively.” (LA013- age 32- 27/04/2012)

The situation became painful for the majority of them even when their babies tested HIV negative at 6 weeks, 3 months and 6 months during the time they were breastfeeding exclusively. Some of them expressed their feelings that when their baby tested HIV negative they were worried and nervous and did not want to continue breastfeeding due to fear of passing on the virus to their babies. One of the mothers reported to breastfed her baby when seen by others while she was not frequently breastfeeding when being alone because she thought that if he does not breastfeed frequently then she would reduce the amount of the virus being passed on to her baby:

“Most of the time I am affected especially when I was told that my child was HIV negative. I felt bad when I continued breastfeeding. That’s why I kept on bringing the child to the hospital HIV for testing and seek medical help. When I came again for the test, I was the happiest person to hear that he is still HIV negative. ...I used to breastfeed at interval due to fear of transmitting the virus to my baby.” (LA008- age 29-HIV positive- 04/04/2012)

Women were later asked their views on whether they feel that women should be encouraged to practice EBF regardless of their HIV status. Considering the levels of poverty, their knowledge about the benefits of EBF and that it also prevents MTCT, the majority felt despite these fears, that all women should be encouraged to breastfeed their infants exclusively regardless of their HIV status to prevent malnutrition because the majority of

them cannot afford to buy infant formula. Additionally they were afraid that the community would question them why they are not breastfeeding:

“I think both should be encouraged to practice exclusive breastfeeding regardless of their HIV status because many women could not afford to buy infant formula here in the village. Some people in the community ask a lot of question if they see a woman who is not breastfeeding.” (LA 010- age 33- HIV positive- 22/04/2012)

Peer counsellors and key informants also expressed the same feelings that HIV positive women should be encouraged to breastfeed because this is the only way the country can improve maternal and infant health:

“What I can say is that both HIV positive and negative women need to be encouraged to practice EBF so that their children grow well and health as this can help reduce the children from dying while young.” (VPC001- age 37- 13/06/2012)

In contrast, some mothers expressed a deep concern that it was rather painful for them when they considered the dangers of transmitting the virus to their infant through breastfeeding unlike their friends who are negative. One of them expressed the feeling that those who are HIV positive should not be encouraged to breastfeed beyond 6 months to reduce the risks of transmitting the HIV virus to the infant:

“For us who are HIV positive we should only be encouraged to breastfeed exclusively for 6 month not more than that because the child can easily get infected with the HIV virus that we have. It is painful to breastfeed knowing that your baby might get infected.” (LA001-age 27- HIV positive- 29/03/12)

In addition, some women further reported that HIV positive women should not be encouraged to practice exclusive breastfeeding because EBF is very demanding on the mother’s body that would potentially decrease the HIV-positive mother’s body immunity against diseases making them develop common illness like TB and eventually progress to AIDS faster than if they did not exclusively breastfeed:

“It could have been better if the government could give us some infant formula because practicing exclusive breastfeeding is not all that easy. It’s like sharing the little food which we eat with the infant and with poverty it is easy for the immunity to go down and eventually having frequent malaria attacks or develop TB.” (LA005-age 32- HIV positive- 04/04/2012)

9.5. Perceptions about peer counselling and EBF promotion in the context of HIV

In Malawi all pregnant women are encouraged to go to the hospital for antenatal care and delivery where they are encouraged to have an HIV test without consulting their spouses or family members. To understand this from the women's perspective, consider the consequences of being diagnosed with HIV during the initial antenatal visit without consulting the spouse and what is involved in option B+ which is currently being implemented in the country (MoH/GoM, 2011a). Women who are newly diagnosed with HIV during this initial visit would eventually experience several challenges and stress on how to accept their HIV status, disclose their HIV status to their spouses, negotiate condom use and how to protect the baby from contracting the virus through breastfeeding. Since HIV positive women are put on treatment right away, they would go home with bottles containing ARVs for their own health. Due to shortage of health care workers mostly women are hardly followed in their homes by HCWs to monitor how they are coping with such stressful situations and answer any questions they may have related to HIV and infant feeding.

Considering all these challenges, the majority of the women interviewed had positive feelings towards the peer counselling intervention. The first reason revolved around the one-on-one counselling which they received from the peer counsellors compared to the group counselling which they receive when they go to access ART or PMTCT services at the health. Some emphasized that the hospital situation made it difficult for the majority of them to bring out any sensitive personal issues during the counselling process in presence of other people.

It is not surprising, then, that some HIV positive women who were visited at home valued the visits conducted by the peer counsellor potentially because it provided an opportunity for them to voice their concerns in a private manner. They further stressed the importance of having someone visiting them within the community who would provide further counselling and emotional support which may help them to cope with their situation.

“Sometimes you meet challenges that would even make you cry but when you have someone coming at your house you have an opportunity to tell their story to someone.” (LA008- age 29- HIV positive- 04/04/2012)

Additionally, availability of peer counsellors within their own communities was highly favoured by the majority of the women as it reduced the burden of travelling long distances in

case they have problems related to their condition. The main perception was that having peer counsellors in their communities helped them to easily access health care services and information at their “door-step” and saved time and money instead of travelling several kilometres to reach the health facility for counselling and support.

“I feel it would be better to visit them in their homes because some have worries and it could be good to visit and counsel them so that they forget whatever they were thinking about and reduce worries. There are also times when we might be sick and could be unable to travel to the hospital. So if you are visited then they will be able to care for you too.” (LA010- age 33- HIV positive- 22/04/2012)

“It is also important to be visited at home because you are relieved from the burden of going to the hospital every time because some stay very far from the hospital, and when they visit you at your home, you are relieved as well.” (LA005- age 32- HIV positive - 04/04/2012)

This feeling was echoed by the key informants. Given the critical shortage of skilled health care workers in the country, most of them viewed peer counsellors as being instrumental in EBF promotion. The fact that most of the infant feeding takes place in the community where the peer counsellors come from, most of the health care workers believed that apart from reinforcing messages related to EBF, peer counsellors also help in PMTCT activities and also dispel some rumours and misconceptions and cultural beliefs surrounding infant birth. In addition, there was also an indication through these interviews that they also help to manage certain condition which were previously been managed at the health centre before the programme started. As a result, peer counselling was seen as one way to reduce workload while providing care to women in the countryside as the hospital personnel lack time and resources to go and visit women especially in hard to reach communities.

“For me I feel this programme is good because peer counsellors are able to follow up women in the communities and make sure that they are following the advice which is given to them at the hospital. If we give information to someone without proper follow up especially in the community then it becomes useless because many women are supported when they are in the hospital. We need to plan and prepare on how the woman can maintain the behaviour when she goes back in the community using the knowledge which she gets from the hospital.” (KI007- age 29 -HCW- 31/07/2012)

Through my observation during the time I was collecting the data, it was also striking to find that most of these clinics were overcrowded with only one nurse on duty to cater for

maternity, under-five, antenatal, family planning and ART clinics. In some circumstances, due to severe shortage of HCWs in the country, some of them work 24 hours without resting and this may eventually compromise the quality of care and counselling offered to clients. Peer counsellors also expressed the same feeling that the visit also provided an opportunity for them to reduce the worries that HIV positive women may have in relation to their HIV status and address various concerns that women may have about EBF while HIV positive and how to take Antiretroviral Therapy.

“Both needs to be visited because those who are negative need to be counselled on how they can protect themselves from contracting the virus while those who are positive they need to be supported through the counselling in order to reduce worries.” (VPC004- age 26- 04/04/2012)

Women did regard the more frequent visits made by peer counsellors as reinforcing the messages about infant feeding and creating opportunities to ask questions and gain more knowledge related to infant feeding while HIV positive unlike when they go to the hospital:

“Yes I feel they should be visited because by doing so the people will be able to follow what the counsellors advise them to do especially on how to take the medication and proper ways of feeding the infant. Worries can as well be reduced that way.” (LA003- age 32- HIV positive- 04/04/2012)

From the healthcare professional viewpoint, this model helped them to further monitor, encourage and observe the real infant feeding practice at community level and also encourage women to follow hospital advice. This according to some respondents who were interviewed eventually promoted women’s adherence to exclusive breastfeeding and antiretroviral drugs and eventually prevent early childhood illness and reduce the risks of MTCT during breastfeeding period:

We have also seen that women in those catchment areas where women are visited in their homes are able to practice exclusive breastfeeding for a recommended period of time as compared to the control areas and the health of many people have improved due to these counsellors.” (KI008- age 49- HCW- 31/07/2012)

Some health professional respondents on the other hand, felt that peer counsellors were not knowledgeable enough to counsel HIV positive women, seeing their training as not adequate

enough to handle such cases. They felt that HIV issues require more training. The following quote is a response from one of them:

“I think HIV positive women should not be visited at home because the counsellors are not knowledgeable enough to provide information to them concerning HIV and exclusive breastfeeding. When these people come to the hospital we as nurses we are able to provide more information related to infant feeding during the counselling session which the counsellors do not know.” (KI003- age 30- HCW- 13/06/2012)

Besides, women also explained that mostly the hospitals are over-crowded and the nurses do not have enough time to listen to women’s concerns and women continued with their traditional practices of introducing other foods to the infant before 6 months elapses. It was therefore, reported by the majority of service-users that the counsellors are also able to observe the real infant feeding practice.

“She observes how we are feeding our babies and gives us some advice on how to feed them if need be like we need to practice exclusive breastfeeding for 6 months and then start giving other foods such as light porridge and water when the child is 7 months old. The counsellors also inspect our homes for cleanliness.” (LA014- age 32- HIV negative- 27/04/2012)

At the same, since these peer counsellors were coming from the same community, they were able to discourage those cultural beliefs and practices related to infant feeding which are considered to be detrimental to the infant’s health especially those born from HIV positive mothers. For instance, most of the HIV positive mothers who were visited home reported that in the past they used to give supplementary feeds to their babies even during the first few days after birth despite knowing the dangers of mixed feeding. Due to the frequent visits done by the counsellors they eventually stopped the practice while their fellow women who are not visited at home still continue with the practice:

“In the past we used to care for the children anyhow without knowing the proper ways of caring for them. Specifically for us who are HIV positive they teach us how we can care for our babies and prevent transmitting the virus to them. They also advise us on the type of food which we need to give our babies and when to start. I feel that their visits have helped to reduce maternal and infant deaths in our community as compared with the past.” (LA016- age 34- HIV positive- 27/04/2012)

Also, some mothers stated that the counselling they receive from the peer counsellors helped them to realize the importance of spending more time with their babies rather than relying on

alternative people like family members such as grandmothers or infants' siblings to provide care to the infants in the event that the mother is occupied with other things like household and farming work. This according to the perception of one of them could easily expose the child to be given some food without their knowledge:

“In the past we could just ask other siblings or our grandparents to take the child away while we could continue with our work or go to the field and the child could be given foods or liquids if crying a lot without our knowledge.” (LA001- age 27- HIV positive- 29/03/2012)

Despite similarities in terms of the type of advice offered during home visits and hospital counselling, some respondents perceived that the type of information and quality of counselling offered by the peer counsellors in their homes and the counselling offered at the health facility differed. Some of women considered the advice given to them by health workers as more reliable and likely to have substantial health impact while the quality of counselling provided by peer counsellors was considered as below standard and not helpful. This is mainly because of the gaps that exist between health workers and peer counsellors in terms of education, competence and social economic status. Some women felt that peer counsellors were not knowledgeable enough because they themselves also rely on the same health workers in terms of training and supervision and receive the same advice in case they fall sick or become pregnant. Moreover, some women felt that peer counsellors did not discuss anything new with them but rather reinforced the same messages which they receive whenever they visit the hospital:

“We also get the same messages from MaiMwana counsellors who visit us in our respective homes. They tell us to start giving our children food like porridge and water after six months. We are also given the same advice when at the hospital soon after delivery.” (LA010- age 33- HIV positive- 22/04/2012)

Again, the type of counselling given by peer counsellors was viewed by other respondents as being similar to the counselling offered at the health facility in the sense that both did not concentrate on the client problem that is “not client centred counselling”. Peer counsellors reported that they were providing counselling to women following a pre-designed checklist provided to them by MaiMwana to guide them during the session. For example, one woman who was visited at home complained that:

“Their visits are very brief sometimes even less than ten minutes you see them rushing to other houses and by the time you remember to ask them something they are already gone. It’s really difficult to return them even if you have a burning issue.” (LA004-age 38- HIV positive- 04/04/2012)

Another key concern that emerged was related to the services offered by the peer counsellors during visit. Given that during the visit the counsellor was just expected to counsel the woman on infant feeding without offering other routine services which are required on monthly basis, women also considered the visits as time consuming as even if the woman is visited at home, she still needed to plan and go to the hospital to access other monthly routine health services such as family planning and weighing of the child. In their own views then, the visit was not always seen to be cost-effective they still need to travel long distances to go to the hospital on monthly basis to access basic health care that they felt peer counsellors could easily provide if they were trained to do so. Possibly related to this, some women preferred to come to the hospital because they felt that when they go to the hospital they easily combine these services in addition to immunization for their children and treatment of other ailments. In addition, they are also offered infant feeding counselling including exclusive breastfeeding counselling which is routinely done as a group education talk each morning:

“You still need to travel long distances for family planning and under-five clinic at the clinic. I would rather go to the clinic and access all the services at one visit.” (LA006 – age 37- HIV positive- 04/04/2012)

9.6. Voluntary disclosure of one’s HIV status and the consequences for home visiting

MaiMwana peer counsellors were not told about the HIV status of women before the visit (Lewycka, 2010). However, considering the high rates of HIV in the district especially among pregnant women estimated at 8%, peer counsellors are not exempted from coming across some women who were HIV positive in their communities. Furthermore, it was impossible to separate these activities from personal and social wellbeing. As a researcher as well as having counselling experience, I had opted to ask peer counsellors about how they handled HIV positive women as I anticipated that disclosure could ultimately be traumatic to some of them. Through interaction with MaiMwana staff it was reported that they did not tell the counsellors about the HIV status of the woman because the primary goal of the intervention was to promote maternal and child health including EBF to all women regardless

of their HIV status. In addition, this was done to keep confidentiality of those who were HIV positive and also the counsellors were not considered knowledgeable enough to provide specific support to HIV positive women as their training did not cover much of this. Instead, peer counsellors were encouraged by the project team to only sensitize women to go for HIV testing during the first visit and encourage those who they found to be sick to go to the hospital to access care while explaining to them the importance of having an HIV test. In some cases, the counsellors also encouraged them to disclose their status to significant others especially the spouse. Despite the fact that peer counsellors encouraged women to go for HIV testing, they were not mandated to follow-up on the outcome of the visit—whether the woman is HIV positive or not:

“We normally encourage pregnant women when we visit them to go for VCT so that they know their HIV status and to prevent the baby as well from contracting the virus if they are HIV positive.” (VPC001- age 37- 13/06/2012)

Consequently, disclosure of HIV status among HIV positive mothers was seen to be high especially to the spouse or any other family members as this is a condition to start ARVs (n=11 out of 12) at any health facility in the country. Interestingly, some disclosed to the chief so that they could be prioritized in case there were some hand-outs or when they are distributing coupons to buy reduced price farm outputs, which is done every year in the country:

“A lot of women are very open about their status. During support groups you see a lot of them singing and dancing in my presence. Whenever we have any donations in my village we give priority to those who we know that they are HIV positive. (KI002- age 76- Traditional Authority -03/07/2012)

Despite the fact that peer counsellors were blinded about the HIV status of women, some women disclosed their HIV status to the peer counsellors during the counselling session. This could be due to the trust women had towards counsellors and the private nature of the visit:

“I am one of the women who have become open and disclose my HIV status. They know that I am HIV positive because I told them and they do come and visit me at my home. They also encourage us based on our status and how we can take care of our babies.” (LA016- age 34- HIV positive- 27/04/2012)

Despite the MaiMwana policy, some of the peer counsellors expressed the views that knowledge about the HIV status of the woman prior to the visit could have helped them to prepare on what to counsel the woman in relation to her HIV status:

“It could have been important for us to know the HIV status of these women before the visit because we could have been going their already prepared on the type of advice to give to the woman.” (VPC003- age 31- 29/05/2012)

The counsellors reported that they did not view disclosure as shocking because of the wide spread of the disease in the community and availability of ARVs. They further acknowledged that this provided an opportunity for them to effectively counsel the woman on better ways to prevent transmitting HIV to the baby through breastfeeding and encouraged them to use condoms when having sex to prevent re-infection which increases the risks of MTCT. They reported those who disclosed their status were encouraged to continue taking their medication as required, to take the infant for early infant diagnosis and to use condoms when having sex to prevent re-infection, which may increase the risks of transmitting HIV to the child through breastfeeding. Moreover, this also provided an opportunity for the counsellors to encourage the woman to continue following the advice she was given at the hospital or to refer her to join support groups available in some hospitals or their communities:

“That could be a good time because then I would have advised the woman on what to do because this is the risk time when a child can easily contract the virus from the mother during pregnancy or breastfeeding time. So that could be the right time to talk to the mother and advise her to go for medication as well to protect the child. I would take that advantage to tell the mother more about HIV and breastfeeding.” (VPC002- age 41- 13/06/2012)

Generally, women who joined community-based support groups for HIV positive mothers acknowledged the importance of joining these support groups where they learn from each other on how to care for their babies including breastfeeding, care for themselves and how to deal with the stress caused by the disease. One of them narrated that through attending support groups she came to realize that she is not the only person affected by the disease in her village:

“I am no longer worried that I have the virus. I feel the support groups have also assisted me to realize that I am not the only one who is HIV positive and breastfeeding because I saw a lot of them breastfeeding too. So we always say we are not sick but those who do not know their status are the ones who are sick.” (LA016- age 34- HIV positive- 27/04/2012)

9.7. Non-disclosure of one's HIV status and reasons

However, not all HIV positive women in this study disclosed their HIV status to peer counsellors for several reasons. Some reported that they did not to disclose to the counsellors because the peer counsellor did not ask them about it. This could mainly be contributed by the fact that the counsellors did not spend much time with the woman during the visit because sometimes they may be rushing through in order to visit as many women as possible. The extract below from one HIV positive mother illustrates this:

“Yes I would have disclosed to them if they had asked about my status. I was free to tell them. If they asked me if I have any problem I would have been my status to them but since they did not ask me then I kept it secret without telling them that I am HIV positive. I cannot hide my problems. I am free to tell people especially medical personnel the way I have done with you here because what I need is to be helped. Most of the times these counsellors make short visits unlike the time I have spent with you here.” (LA004- age 38- HIV positive- 04/04/2012)

As reported earlier in this chapter, many HIV positive women do not feel comfortable to disclose their HIV status to other people in the community due to fear of stigma and discrimination. Similarly, the fact that peer counsellors were coming from the same community with the mothers who were visited home, some peer counsellors reported that some women might not to be comfortable to disclose their HIV status because they did not trust their fellow women to keep secret of their HIV status:

“It could be that some of the women don't trust us. They think if they tell us we will be telling people about their HIV status. But that's not the case. We try to keep secret of their HIV status.” (VPC2- age 41- 13/06/2012)

The other reason for non-disclosure was the fact that most of the HSAs who were recruited to supervise peer counsellors were also involved in provision of HIV services such as: HIV Testing and Counselling (HTC), PMTCT and provision of ART to HIV positive clients at the health facility and also tracing of defaulters within their catchment areas. MaiMwana decided to use them as supervisors because they already had good knowledge about the communities where the intervention was taking place. Even though the project policy was to keep the HIV status of women confidential from the counsellors and their supervisors, in practical terms, most of these HSAs were already aware about those who were HIV positive within the clusters because they work hand in hand with the hospital staff. At some point, supervisors were expected to observe some of the counselling sessions conducted by the peer counsellors

as part of supervision. Consequently, the fact that the peer counsellor would visit the woman home who at some point was in contact with the HSAs while accessing PMTCT or ART services assumed that peer counsellors were also aware of their status and so did not perceive a need to disclose to them. One of the service users narrated that:

“Most of the Health Surveillance Assistants [supervisors] who come and visit people in the community know those people who are infected and I did not bother to tell them about my status. Sometimes they hear it from other people within the community. So possibly the counsellor might be aware that I am HIV positive but I am not sure.” (LA004- age 38- HIV positive- 04/04/2012)

Some of the supervisors further reported that they keep a register of all HIV positive individuals within their catchment areas and also help sorting out clients’ master cards²⁵ at the clinic to identify defaulters. During the discussion some of them reported that they even facilitated disclosure of HIV status to the counsellors during the visit. The aim of doing this is to make sure that these women benefited from the counselling and support provided by the peer counsellors during the visit in relation to HIV and infant feeding. However, to maintain confidentiality they make sure to only disclose the HIV status of those who are open to tell others about their HIV status. One of them stated that:

“When you were coming you saw me standing with two women in the corridor. Those are HIV positive and they have been in our programme way back before MaiMwana started. So when the counsellors started visiting women in their homes we were able to disclose their status to them so that they should be able to counsel them properly. We actually did that because these women are open to disclose their status to anyone unlike others who have not yet disclosed to anyone. So that is why we were able to tell the counsellors about their HIV status.” (VPC008- age 52- supervisor- 04/07/2012)

During some visits the peer counsellor would find the woman with friends, relatives or husband and some were willing to be part of the discussion. Some women who were HIV positive expressed a concern that it was inappropriate for them to disclose their HIV status to the counsellor, even if they wanted to do so in the presence of their relatives and friends due to fear of potential risks that they may face if their friends and relatives learn that they are HIV positive. On the other hand, counsellors argued that due to lack of knowledge of the HIV status of the woman, it was rather difficult for them to provide specific counselling to the

²⁵ These are cards used to track patients enrolled into HIV care and treatment. Master cards are useful to monitor attendance of patients and track any defaulters.

woman let alone to encourage the woman to bring the child to the hospital for HIV testing and counselling. Furthermore, their responses suggested that they were prepared to handle any voluntary disclosure of HIV status and capable to provide valuable support:

“I don’t think that could disturb the whole purpose of it because as health officers we give advice to such people. If you find that a person has come out in the open to disclose her status to you then I would say that person is knowledgeable enough because most people hide their status and we could be grateful with that person and advise her accordingly.” (VPC2- age 35- 13/06/2012)

Additionally, the counsellors emphasized that if they come across HIV positive women who disclosed their HIV status to them they needed to spend more time with the woman as compared to the time spent with those who did disclose their HIV status to them. This was because the woman had so many questions to ask the counsellors in relation to their own health, how to disclose HIV status to their partners, infant feeding practices, how to take their medication and whether it is safe to their babies²⁶.

“We are not affected at all because we do have some records on who is HIV positive and negative. And also in most of the communities those people who are HIV positive form support groups where they meet and we are able to know who has the virus and who is negative. It only becomes difficult for us if the woman is not open to disclose her status to us because we are unable to counsel them properly.” (VPC004- age 38- 04/04/2012)

9.8. Community perceptions about peer counselling in the context of HIV

Some of the HIV positive and negative mothers who were visited in their homes by the peer counsellors appeared not to be comfortable to be visited home by the peer counsellors. They expressed a concern that some people in the community including relatives and spouses expressed suspicion about the frequent private visits made by the peer counsellors and wondered why the mother was visited home by someone from the hospital. For example, one of the mothers recalled being questioned by her relatives:

“You know when you receive a visitor people became interested to know what he or she has come for. I remember to have been asked by my relatives to explain what we were

²⁶ With Option B+ women are put on lifelong medication from the time they are diagnosed with HIV. This is different from the previous regimen when women were only given single dose Nevirapine to take during labour and the baby was also given Nevirapine syrup single dose within 72 hours after birth. Hence women have several questions in relation to the new regimen.

discussing with the peer counsellors. Again, the situation becomes difficult because there might be some who are aware of your HIV status and they start talking about you saying she is “HIV positive that’s why she is being visited which is bad.” (LA013- age 32- HIV positive- 27/04/2012)

This may be probably because most often health care workers in the country tend to visit people in their homes especially those who have HIV when they have missed their visits. Another important contributing factor was that the HSAs who were working as supervisors for the project were also involved in providing some HIV services at the hospital including PMTCT and tracing of defaulters in their respective catchment areas. This made the situation difficult for the peer counsellors to disassociate themselves from HIV programmes:

“The fact that the counsellors are coming from the same community with the women, some fear that they will not keep confidentiality of their HIV status. Some are afraid of marriages disruption due to the frequent visits made by the peer counsellors within the community.” (KI003- age 30- 13/06/2012)

9.9. Conclusion

In this chapter, I set out to examine whether the use of peer counsellors could help to promote exclusive breastfeeding among HIV positive women in rural Malawi. I have also described the challenges this may cause to both HIV positive mothers who are visited home and peer counsellors conducting the visits. The findings in this chapter demonstrate that HIV positive women experience emotional distress during the entire period they are breastfeeding because of fear of transmitting the virus to their infants and the majority of them are often left confused because they did not want to expose their babies to HIV infection through breastfeeding during the first 6 months. Therefore, the majority of them were supportive of the visits made by peer counsellors because they provided additional support to them and information right in the community that effectively allowed them to practice exclusive breastfeeding that enabled them to provide the required nutrition for the infant at the same time reduce the risks of transmitting the virus to the baby. This study provides evidence that these peer counsellors need more training on how to counsel HIV positive women as some of them were voluntarily disclosing their HIV status to them during the visit and the majority of them reported to have faced challenges on how to give them the right advice in relation to their status due to lack of knowledge and skills.

CHAPTER 10: DISCUSSION

10.1. Introduction

The purpose of this study was to investigate factors that affect exclusive breastfeeding (EBF) practices among women in rural Malawi. Specifically, the study aimed to understand the role of home-based peer counselling in the promotion of EBF and the challenges of doing voluntary, as well as the challenges of maintaining EBF in the context of HIV and poverty. In order to address the research question I applied qualitative case study approach described in chapter 6. This approach helped to understand people's experiences with exclusive breastfeeding and community-based intervention and also to observe how peer counsellors were prepared to perform their work and the challenges which they face. In this chapter I summarise the main findings from this study in the context of relevant literature and further highlights the specific contributions made towards what need to be done in order to promote EBF, including the use of peer counsellors in a Malawian context and within similar settings. Given the purpose of this study, the discussion of the results reflects on main findings in relation to how women translate knowledge into practice, on the issues of informed choices in the context of poverty, task shifting in resource-poor settings, the importance and acceptability of peer counsellors, selection and power dynamics and finally peer counselling in the context of HIV. The limitations are also discussed that need to be taken into accounts when considering the findings from this study.

10.2. Translating knowledge about EBF into practice and the challenges faced

The first key aim of this study was to explore factors that could influence women's intention and ability to practice exclusive breastfeeding for 6 months period in rural Malawi. As discussed in chapter 2, this aim was considered in response to the major role which exclusive breastfeeding plays in public health that is promoting infant survival especially in resource-poor settings. Evidence generally demonstrated that in spite of the well-recognized importance of EBF, the rates of EBF remains low worldwide estimated at approximately 40% (see table 2-2) (Cai, 2012; UNICEF, 2012). In light of high levels of poverty and infant death due to communicable diseases including HIV in most countries located in SSA including Malawi, one would expect to see tremendous increase in EBF rates because breastfeeding

here is culturally normative. However, data presented in table 2-2 also demonstrated low rates of EBF in Eastern and Southern Africa (47%) (UNICEF, 2012). The data presented in table 3-5 reflects relatively high rates of EBF at 6 months among women in Malawi in global terms. However, in some part of the country, the rates are reported to be as low as 5% at 6 months (Bezner-kerr et al., 2007; Kamudoni et al., 2007). The rates are worrying considering that this is the region with highest infant mortality as compared to other regions in the world mainly attributed to poor infant feeding practices, infectious diseases, poverty and the HIV pandemic (Black et al., 2010). It is further clear in the same literature that malnutrition among children under the age of five has remained high (approximately 50%) for decades in Malawi (MDHS, 2010). As such this study sought to understand breastfeeding practices among women with a view to assessing factors that hinder them to practice exclusive breastfeeding for 6 months.

The literature have further questioned the validity of global exclusive breastfeeding data most often collected through demographic surveys using 24-hour recall methodology. Research studies conducted in other settings demonstrated that use of 24-hour recall often generates over estimation of EBF rates as some infants who were given other liquids regularly might not have received them in the last 24-hours before the date of the interview while some tend not to report substances given to the baby in small quantities (Lauer et al., 2004; Arts et al., 2011).

As presented in chapter 7, one major finding in this present study is that all breastfeeding mothers (whether they were visited or not by the peer counsellors) demonstrated good knowledge about the definition of EBF and were well informed about what is involved. In addition, the results of my study showed that women in this study knew about the advantages and the dangers of giving supplementary feeds to the infant within the first 6 months period and their statements indicated that breast milk alone was considered as sufficient to meet nutritional demand of the infant within the first 6 months. The finding in terms of the level of knowledge among women in this study differs with the results of a study conducted in Ethiopia by Setegn et al., (2012) where by lack of knowledge was reported by the majority of HIV positive women as the main barrier to practice EBF and the rates of EBF among HIV positive women dropped drastically to 17% when infants were 4-5 months of age. The high levels of knowledge among breastfeeding mothers in my study could be explained in two ways. Given that all these women were coming from the MaiMwana clusters and reported to

have given birth at the hospital, they could have acquired the knowledge on exclusive breastfeeding from hospital education combined with community-based peer education. Besides, the majority of them indicated the desire to have more visits by the peer counsellors, despite the barriers that were highlighted in terms of demand on the women's time and their household resources. This was an indication that peer counsellors were accepted by the majority of women.

The findings from this study further demonstrated that breastfeeding is the cultural norm and is well accepted among women in the country. In addition, despite breastfeeding initiation soon after birth having been found to be challenging in many sub-Saharan Settings (Fadnes et al., 2010; Engebretsen et al., 2014), all mothers including those who were HIV positive (n=19) confidently reported to have initiated breastfeeding within the first hour after birth as recommended by the World Health organization and nearly all of them reported to have continued with EBF up to six months (WHO, 2010b). Key to their choices would be influenced by their own awareness of the health benefits of EBF obtained through BFHI messages in favour of exclusive breastfeeding, their low socio-economic status, cultural norms and practices and also fear of stigma if they are seen not breastfeeding. The findings in terms of breastfeeding initiation are consistent with the current DHS data in the country whereby almost all women (98%) initiate breastfeeding soon after giving birth (MDHS, 2010). The findings also cohere with the national EBF data from other countries like Ghana and Tanzania where almost all women (99%) initiated breastfeeding soon after giving birth (Aidam et al., 2005; Tanzania National Bureau of Statistics and ICF Macro, 2011). Initiation of breastfeeding within one hour after birth is recommended and is described as essential to the processes of lactation and for that matter the success of breastfeeding of any kind (WHO, 2010b).

Another important finding from this study is that the majority of breastfeeding mothers confidently reported to have managed to practice EBF for 6 months and that they no longer follow cultural practices relating to infant feeding. This is supported by available literature that mothers who are well informed and knowledgeable about breastfeeding are more likely to initiate and continue with breastfeeding (Avery et al., 2009; Brown et al., 2011). In concordance with the findings of the MaiMwana community-based intervention (Lewycka et al., 2013), the self-reported frequency of exclusive breastfeeding at 6 months among breastfeeding mothers was comparatively high in this study compared with the most recent

DHS estimates for the general public in Malawi (89.5% versus 73.3%). In line with existing evidence in the literature on the impact of community-based interventions (Morrow et al., 1999; Haider et al., 2000; Bhandari et al., 2003; Tylleskar et al., 2011; Kushwaha et al., 2014), this observed differences in EBF rates and knowledge may be due to the on-going one-on-one community-based infant feeding counselling and support which women in this study received through the MaiMwana peer counsellors. These results emphasize the importance of community-based EBF support which positively increased the level of knowledge among women and be able to practice EBF. These findings are thus, important in considering how breastfeeding support at community-level using peer counsellors can help to improve EBF rates, and be incorporated into future strategy.

One striking theme which emerged in this study was the belief breastfeeding mothers in this study had that other women coming from the same community (either being visited or not visited home by the peer counsellors) do not manage to practice EBF as advised. Thus, it could be possible that the majority of them were inhibitive of the real infant feeding practice. With exception of a few cases, the concept of “truth telling” and medical model emerged because EBF as any other behaviour would be shaped by the environment. Therefore, I was wondering how these breastfeeding mothers maintained the behaviour which they claimed to manage within the same environment where other women were described as following the culture of giving their babies other foods. One way to explain this could be that respondents may not be open because they were aware that I was a nurse/midwife. Additionally, the study was potentially perceived by some as part of MaiMwana project would have affected responses from both women as well as counsellors. In this case, women may want to tell the medical personnel what they feel they need to know in a positive way (socially desirable responses) rather than what they actually did or the actually experience (Paulhus, 2002). Secondly, another inhibiting factor for them not to tell the truth would be due to the attitude of nurses in the country towards patients whereby they always shout or blame women if they do not follow hospital advice instead of probing from the woman. Such type of attitude of nurses towards patients was also noted in other studies conducted in the country and other countries in Africa which negatively affect access to care among women (D’ambrosio et al., 2005; O’donnell et al., 2004). This illustrates the need for more client-centred counselling that attempt to elicit views, beliefs, and preferences from the individual women themselves while creating conducive environment for them to be open.

Similar to the findings from other part of Malawi (Bezner-Kerr et al., 2008; Kamudoni et al., 2007) and other settings in sub-Saharan Africa (Leshabari et al., 2006; Doherty et al., 2006; Fjeld et al., 2008; Young et al., 2010) the findings from this study also suggested that despite having good knowledge regarding the importance of practicing EBF for 6 months, some mothers (n=8) including those with HIV indicated to have given their babies some supplementary foods or drinks before 6 months elapsed. Conversely, the majority of those who gave some food or liquid remained reticent about the real practice when asked for the first time during the interview. However, it was observed that when the interview progressed and when women were asked further questions to explore how they feed their babies in the context of many challenges, they opened up and described in more detail what they gave to their babies during the first 6 months (Chapter 7). This finding is supported by results from the DHS data from different countries and other studies where women over-reported the rates of EBF in surveys using 24-hour recall (Piwoz et al., 1995; Bland et al., 2003; Lauer et al., 2004). Based on such findings, one must be very cautious to have confidence that the knowledge that women may have is indicative of their actual practice as some still did not want to report that they gave their infants other foods, tending instead to focus on the difficulties that other women in their community experienced with trying to maintain exclusive breastfeeding, rather than some level of mixed feeding.

Bland et al., (2003) further argued that just like the use of 24-hour recall, the use of 48-hour recall in their study does not accurately reflect EBF pattern since birth and that long term EBF recall tends to overestimate the duration of EBF. Given the likely impact of mixed feeding on HIV transmission, such good knowledge should not be celebrated if it is not translated into real practice as this may increase the risk of MTCT in Malawi as elsewhere in high HIV prevalence countries in sub-Saharan Africa. In support of this finding, the literature presented in chapter 2 have shown that mixed feeding among HIV positive women increases the risks of MPTCT (Coutsoudis et al., 2001; Illiff et al., 2005; Kuhn et al., 2007).

10.3. Exclusive breastfeeding and culture

This present study revealed several socio-cultural and economic factors associated with the complexity of practicing EBF for 6 months among both HIV positive and negative women. The study revealed that although women are advised to practice EBF (that is giving no other food, not even water) for 6 months and despite efforts on the part of the formal health sector

and NGO projects like MaiMwana (discussed in chapters 2 and 4) to change cultural beliefs, giving of supplementary feeds especially traditional medicines is still a deeply culturally embedded behaviour in all societies in the country that every woman would want to follow. Another important finding from this present study is that the primary reasons for giving traditional medicines and gripe water by the majority of women include to relieve colic pain, to facilitate Fontanelle closure and also to provide protection from or treatment of a perceived illness associated with early infancy, some of which are considered to originate in socio-cultural relations, such as jealousy or vengeance or through spiritual influences (see section 8.5). In addition, the majority of mothers believed that if the baby is crying a lot then it is a sign of hunger. These findings are consistent with those from other studies conducted in the country (Bezner-ker et al., 2007; Kamudoni et al., 2007; 2010; Levy et al., 2010) and elsewhere in SSA (Thairu et al., 2005; Arts et al., 2011; Desai et al., 2014) which also revealed a strong belief on the protective effects of traditional medicines against early childhood illnesses and that when the child is crying a lot then the woman was not producing enough milk to satisfy the baby. Similar issues have been identified in several countries, with fears about insufficient milk-supply and concerns about measurement being very common (Nduati et al., 2000; De Wagt and Clark, 2004; Piwoz and Ross, 2005).

One other striking theme identified in this study is that women who reported to have given supplementary feeds especially gripe water or traditional medicines to their babies reported to have breastfed exclusively for 6 months and they did not perceive such practice as mixed feeding irrespective of combining them with porridge or water. Perhaps as a result of their knowledge on the definition of EBF by the World Health Organization (WHO, 1991), which allows giving of medicines and vitamins which are medically sanctioned, the fact that mothers were not giving any infant formula or food to their infants it is likely that they considered giving of “traditional medicines” as not mixed feeding. The finding concords with those of other studies conducted in some parts of Malawi (Levy et al., 2010). Although this suggests that women did not fully understand the meaning of exclusive breastfeeding, this could be explained in terms of the World Health organization definition of exclusive breastfeeding which states that infant receiving only breast milk from birth (including expressed breast milk) from his or her mother and no other liquids or solids, “with the exception of drops or syrups consisting of vitamins, mineral supplements, or medicine prescribed by the doctor”. Therefore, due to the cultural perceptions that considered giving of traditional medicine and gripe water as “medicines” commonly given to babies for a variety

of reasons culturally perceived as illness despite the fact that medical practitioners or anthropologists do not necessarily consider such illnesses to be medical in nature.

It is also clear from this study that traditional medicines are commonly prescribed by traditional healers and traditional birth attendants who are more often present in the resource-poor communities than professional health care workers and the surrounding communities consider them as “traditional doctors”. As such, it is unlikely that women would consider these traditional medicines as food supplements because they were prescribed by the traditional doctor to protect the babies from childhood illnesses or treat an illness. The findings from this study indicate that EBF is not the dominant pattern in Malawi and call for policy argument to consider the way EBF rates are assessed as many women do not report other liquids given to their infants. From the viewpoint of authoritative knowledge and bodies such as the WHO, traditional medicines are not classified as such but as supplementary feeds, whereas communities view them in a different manner. Although some studies have been conducted relating to traditional medicines used around childbirth in Malawi, lack of formal research evidence means that it is difficult to identify whether or which medicines may be harmful, beneficial or at least neutral (see chapter 8) but a key health promotion argument remains that the ingredients, dosage and purity of medicines sold informally may be variable. The administration of such traditional medicines while traditionally seen to be protective against early childhood illness is likely to increase the risks of infections also because they were often mixed with water or other substances like light porridge (Mzuwala) in the context where women do not have access to clean water (Kramer et al., 2001; Coutisoudis et al., 2001; Jones et al., 2003; De Wagt and Clark, 2004; Black et al., 2008).

For most mothers in this current study, it appears that their decision to give other foods was largely driven by the pressure they get from family members especially grandmothers, mothers, mother in-laws, spouses and friends to follow cultural practices to give the child traditional drugs, water or/and gripe water soon after birth. It was further found that women accept to give these pre-lacteal ‘feeds’ due to the trust they have towards their senior family members and the fear of being blamed as acting against the culture in case the child fall ill. These findings are supported by findings from previous qualitative studies conducted earlier in Malawi (Kamudoni et al., 2007; Bezner-Kerr et al., 2008) and many other countries throughout sub-Saharan Africa like Mozambique (Arts et al., 2011) South Africa, (Thairu et al., 2005) and Tanzania (Falnes et al., 2011). Women who participated in these studies reported to have received pressure from significant others especially mother in-laws,

grandmother to follow cultural practices related to infant feeding that demand giving the infants other foods within the first 6 months of life. For instance, in their study conducted in the Northern part of Malawi Bezner Kerr et al., (2008) overwhelmingly concluded that the majority of women found it difficult to refuse the decision by the grandmothers to give supplementary feeds as this would seem to contradict traditional practices given their role as information providers or what Aubele, (2006) describes as ‘managers of indigenous knowledge’. This study further demonstrated that 65% of women gave their babies some food or liquids in addition to breast milk during the first week of life and only 4 percent breastfed exclusively for 6 months. The authors further found that babies were given water, tea, maize porridge, gripe water and traditional drugs even during the first week of life. Similarly, in their study conducted in Mangochi district in the southern part of the country, Kamudoni et al., (2007) found that cultural influence mainly from elderly women was the biggest barrier to practice exclusive breastfeeding behaviour for the recommended 6 months period. Thus, it appears obvious that public health interventions that are designed to promote EBF behaviour must go beyond an institutional type of approach and try to engage more with communities especially men, mothers and mother in-laws. Besides, these influential people were mentioned by women in this current study as a source of information and support especially at community level where health care workers are scarce.

In this present study the role of family support especially the spouse was mentioned by some of the mothers in this study as an important factor that had a profound impact on exclusive breastfeeding behaviour for 6 months. Just like other communities in sub-Saharan Africa, men are household heads and their power is socially and culturally constructed (Lock and Kaufert, 1998). Involvement and strong support from the spouse and other family relations within the home have proven to be a key component in promoting adoption of a health related behaviour including EBF (Maru et al., 2009). However, the results of this study revealed that most men in this community do not support women when breastfeeding because in this society infant care is considered as the role of the woman. Men lack knowledge and understanding of exclusive breastfeeding mainly because of such cultural and gender explanatory factors. Furthermore, it was found that the participants’ household structure in this district is built on a patriarchal system where gender is an important determinant of men’s role in the family and the majority of them considered infant care including feeding as the ‘role of the woman’. In this study, it was found that those men who were knowledgeable and supportive to women tended to maintain EBF behaviour as they were taking a role to

remind them not to give the infant any complementary food. Again, such support from the male partner is associated with scientific evidence that production of oxytocin hormone is useful for milk production (Heinig and Dewey, 1996). This suggests that the more support the woman receives, the greater the quantity of milk that is produced.

One other strong theme that emerged from this study was that women attempt to sustain EBF in the context of poverty, hard work and socio-economic constraints as this is highly promoted in all the hospitals through the Ten Steps to Successful Breastfeeding of the Baby Friendly Hospital Initiative which is top-down that is developed by centralized international organization and implemented globally including in poor-settings like SSA (see chapter 4) (WHO, 2003a; Perez-Escamilla, 2007). Consistent with other studies conducted in Malawi and other countries in SSA (Guay and Ruff, 2001; Doherty et al., 2006; Leshabari et al., 2006; Fletcher et al., 2008; Chimkonde et al., 2012), the interviews uncovered the practical challenges faced by women, their families and the counsellors of practising EBF when they have to work in the fields while also marketing and caring for the family. For women in this present study, it was also realized that whereas most mothers would want to spend more time breastfeeding their babies as advised, the majority of them reported that this was challenging because they found it was time consuming and also other family members including their spouses considered this as a sign of laziness. Among breastfeeding mothers who were interviewed in this study for instance, they reported to have spent their time in the field or generating income as well as caring for other members of the family while leaving the baby with other people especially their grandparents or siblings who were likely to give other food to the baby in the absence of the mother. These are likely to affect the frequency of suckling and its duration which are key determinants of how much milk is produced (Henderson and Macdonald 2004). It is not surprising that through the literature review presented on section 2.7 I found that the rates of EBF remaining lower in SSA whereby only 39 % of women manage to practice EBF for 6 months (Cai et al., 2012). As discussed in chapter 2, mixed feeding has detrimental effects to the child as it may lead to inflammatory reaction and damage to the lining of the baby's mouth, respiratory, gastrointestinal and urinary tract, which provide initial mucosal immune response increasing the risks of HIV infection (Newell, 2004).

It also appears that there is a tendency in the health promotion literature to talk about how women can successfully breastfeed even when mal- or under-nourished themselves, but this

is hardly optimal and unlikely to help them to sustain EBF. For instance, consistent with the findings from other studies (Fjeld et al., 2008; Leshabari et al., 2006; Lunney et al., 2008; Maru et al., 2009), in this study it was noted that women as well as significant others still perceived that if the child is crying a lot then it means that the woman is not producing enough milk and this was related to low food intake by the mother during breastfeeding period. Although no proper evidence exists to support a direct relationship between maternal dietary intake and health, those organizations promoting exclusive breastfeeding need to better understand that there is a danger that women in resource poor-settings who are malnourished find it difficult to sustain EBF and to fight the numerous infections and eventually fall sick. Consistent with the findings from a study conducted in Malawi by Kafulafula et al., (2013), breastfeeding mothers in this study repeatedly expressed the need for them to eat adequate and appropriate food for their own health and also produce enough milk. Moreover, these women are likely to be distressed because they have to think of what to eat and feed their families. They further reported to leave their babies with other family members as they are involved in farming and piece work away from their homes which may reduce the time they spend breastfeeding their babies. It is clearly indicated in the literature that the more the baby suckles the more milk is produced (Henderson and Macdonald, 2004). This was also reported in other qualitative studies from South Africa economic conditions were mentioned by breastfeeding mothers as one reason for mixed feeding (Thairu, et al., 2005; Doherty et al., 2006).

10.4. Reflections on informed choice of infant feeding methods for PMTCT in resource poor-settings

The WHO HIV and infant feeding guidelines recommend that HIV-infected mothers should be provided with adequate information about infant feeding options and be supported to make informed choices between exclusive breastfeeding and replacement feeding to reduce MTCT through breast milk (WHO, 2010b). Some health care workers who were interviewed in this study argued that despite their understanding about such guidelines and the knowledge that some babies may contract HIV through breastfeeding, they were constrained in their daily work to only encourage women to practice EBF because the majority of them come from extreme poverty and could not afford to buy infant formula. Although not asked directly, the fact that these clinics are located in remote areas, health care workers could not even ask women to choose infant feeding methods but rather make judgement through their

appearance which indicates that they were coming from low social class. Such judgement would be considered paramount and is further supported by the findings of a study conducted in Tanzania by Vaga et al., (2014) whereby women from those hospitals where exclusive breastfeeding was promoted expressed trust and confidence unlike those from the hospital where infant feeding choices was promoted following WHO infant feeding guidelines. This was further evidenced from the socioeconomic data of women who were interviewed in this study presented in tables 7-1 and 7-2 as the majority of the women relied on farming as their source of income. This also corresponds with the DHS data where 85% of people living in the rural community were classified as poor (DHS, 2010). The results from this study therefore, demonstrated the importance of a bottom-up (rather than just top-down) approach where authority was vested in the health workers who highly recommended exclusive breastfeeding among all women irrespective of their HIV status through the BFHI. These findings are supported by a study conducted in Botswana, which suggests some gaps on the counselling messages given to women associated with infant feeding methods (Ndumbuka et al., 2013). The only difference is that formula feeding unlike exclusive breastfeeding is common among HIV positive women in Botswana and is supported by the government. As a result, the majority of women in the study (80%) opted for formula feeding probably because health care workers commonly prescribe or encourage them to do so. This on the other hand, continues to represent the most common construction of health worker-patient relationship globally (Roter and Hall, 2006:27). Mol, (2008) on the other hand, argued that the idea of patient choice in health care and the treating of the patient as a consumer of services and information may in some circumstances compromise patient care.

These views were to an extent supported by HIV positive women themselves who reported to have accepted to practice EBF despite knowing that they could transmit HIV to their babies because they did not have enough money to buy infant formula and also the stigma attached to replacement feeding. This was also seen in chapter 4 where the majority of HIV positive women in SSA chose exclusive breastfeeding because of poverty and reflects the challenges faced by HIV positive women to make an informed choice on infant feeding method. All HIV positive mothers in this study reported to be privileged to be taking ARVs while breastfeeding and had good knowledge that if a woman is taking ARVs it reduces the chances of transmitting the virus to the baby. This was achieved through the Ministry of Health introduction of option B+ in the country in 2011 (see chapter 3) where HIV positive pregnant women are commenced on ARVs soon after diagnosis regardless of their CD4 count. As a

result, the majority of them felt more confident to practice EBF for 6 months, even though some of the women interviewed continued to express deep fears about the contamination of their milk with the virus and its potential threat to the infant. This confirms the findings from other studies where HIV positive women who had good knowledge about EBF were more likely to practice EBF (de Paoli et al., 2001) and similar results were reported in rural Malawi by Thakwalakwa et al., (2014) where 97% of women receiving ART reported to have managed to practice EBF for 6 Months. Again, in Chapter 2, some studies demonstrated that the rate of vertical transmission of HIV was reduced due to intake of ARVs (Kilewo et al., 2008; Chasela et al., 2009; 2010) and practicing exclusive breastfeeding (Coutisoudis et al., 1999; 2000; Illif et al., 2005; Kuhn et al., 2007).

The more interesting issue stems from the recognition that despite having knowledge on the dangers of transmitting the virus to the baby through breastfeeding women themselves reported that their choice was mainly influenced by their intention to practice EBF and the desire to be seen as responsible mothers by their relatives and friends who conform to the cultural practices that support breastfeeding in the country (Koricho et al., 2010; Langa, 2010). As it is the case throughout sub-Saharan Africa (Thairu et al., 2005; Leroy, et al., 2006; Maru et al., 2009), some of the women reported that if any of them opted for replacement feeding they would be looked upon with suspicion as being HIV positive, otherwise this required an explanation as to why she is not breastfeeding. Similar to the findings of a study by De Paoli et al., (2004), the findings from this study further highlight the complexity whereby HIV positive women are expected to make infant feeding decisions on their own in the face of difficult choices and without involvement of significant others. Information giving about exclusive breastfeeding is normally done at the clinic through education sessions that only target the woman while men and significant others are generally not involved. This finding in terms of lack of knowledge of significant others who have a role in family decision-making is supported by the results of a study which was conducted in Uganda where men demonstrated little knowledge about EBF due to poor involvement in the teaching which is offered to their spouses at the clinic (Engebretsen et al., 2010). It was also clear from this study that even though significant others are not present at the antenatal clinic, almost all of them are aware about the routine HIV testing taking place at the antenatal clinic in the country. Consistent with this finding were those from a previous study conducted in Tanzania (Falnes et al., 2011) that also reported that pregnant mothers were expected by their mother-in-laws to disclose any information from the clinic. Chinkonde et al., (2010) and Leshabari et

al., (2006) further argued that the WHO guidelines for infant feeding for HIV positive women do not take into account of such traditional norms when they advise HIV positive women to make an informed choice in the absence of the male partner and significant others. These findings are important because it highlights the gap between EBF promotion and culture and contexts affect the real practice among women in sub-Saharan Africa.

Although HIV positive women in this study strongly agreed with the advice to breastfeed their babies following promotion at the clinic and the desire to promote infant survival, some of them still reported not to be happy with practicing EBF due to fear of passing on the virus to through breast milk. These worries were intense especially when they could not manage to wean their babies early and also when the infant tested HIV negative for HIV at 6 weeks, 3 and 6 months. Although the testing could in theory provide relief and reassurance, the approach to testing raised the women's anxieties about breastfeeding with HIV infection, and they found the reassurance short-lived. The findings further revealed that due to this fear some women in this study reported to have reduced the frequency of breastfeeding to less than what is recommended to reduce the amount of the virus being transmitted to the baby. This would mean that the infant is getting less nutrients due to interference of breast milk intake and cries a lot and eventually been given other foods in addition to breastfeeding, thus inadvertently increasing the risks they fear. Additionally, considering the level of poverty and involvement in farming it is notable that HIV positive women expressed a concern about their own health while breastfeeding.

Additionally, a number of published articles relating to SSA show that 3 months is the common age when the majority start giving their babies other foods, especially watery porridge, because they believe that at this age milk is not enough to meet nutritional demand of the infants (Vaahtera et al., 2001; Bezner-kerr et al., 2008). Such a view of the adequacy of breast milk beyond early infancy is widespread globally (Kakute et al., 2005; Leshabari et al., 2006; Lunney et al., 2007; Fjeld et al., 2008; Wachira et al., 2009). Therefore, it is not surprising to find the majority of women in this study introducing food at this period when the baby tested negative and they were also aware that they will not be questioned by other people in their communities because this is the normal weaning practice.

This study also added to the previous knowledge that despite the evidence from previous qualitative studies that disclosure of HIV status is associated with maintaining infant feeding

behaviour, stigma still exists that hinders some women to disclose their HIV status and receive support while breastfeeding (Fjeld et al., 2008; Thorsen et al., 2008). Despite the fact that peer counsellors were visiting all women in the community regardless of HIV status, some people in the community know those who are HIV positive, since most are seen accessing PMTCT services within the same health facility where those who are HIV negative access other treatment and care like antenatal, labour and delivery as well as treatment for minor ailments. Interviews with some women in this study further revealed that despite high HIV prevalence rates in the country, women still experience some form of stigma following disclosure of their HIV status. Similar to the findings of the study conducted in urban Lilongwe by Ostergaard and Bula (2010) HIV positive women reported to have been abused with all sorts of names related to their HIV status. Some studies have therefore, argued that integrated services would be more anonymous and confidential than having people being seen going to separate HIV clinics as a means to reduce stigma (Maharaj et al., 2005; Church et al., 2013).

10.5. Reflecting on task-shifting to promote EBF in resource-poor settings

Despite the women's knowledge of breastfeeding being considered as "best for the baby" just like any other behaviour, mothers still require support from someone who is knowledgeable and respected to develop confidence and successfully breastfeed (Baumslag and Dia, 1995). Here, I now reflect on the whether the use of peer counsellors was seen to be effective in helping women to maintain EBF behaviour, understanding locally lived perception of groups of people and the challenges faced due to poverty, which was the second key aim of this study.

The literature presented in chapter 4 revealed that women are usually supported by the health care workers to initiate breastfeeding while in the maternity hospital through the Baby Friendly Hospital Initiative launched in 1991 (Perez-escamella, 2007). However, they only spend an average of 24 hours in the hospital postnatally and the hospitals are overcrowded and short-staffed. The literature has also demonstrated that the BFHI has been effective in increasing initiation of breastfeeding, while adherence to EBF for the recommended six months still remains a challenge (see chapter 4). Like previous studies conducted in Malawi and other countries in SSA (Bezner-kerr et al., 2007; Arts et al., 2011), the findings from this study have highlighted the challenges which women face while practicing EBF in the

communities where mixed feeding is common and hence, demonstrated that clinical counselling and information alone may not be sufficient for women to practice EBF for 6 months. In this present study it was striking how often mothers, including those who were HIV positive, reported that despite initiating breastfeeding in the hospital, as discussed in the previous section, they were advised by significant others to follow cultural practices of mixed feeding. Despite the fact that women need continuing support while in the community, it is rare for health care workers to follow them up in the community and provide support to them due to critical shortage of HCWs.

The World Health Organization recommends that peer counsellor services be promoted in the provision of health care services including EBF promotion as it promotes EBF practices in both developed and developing countries (WHO, 2003a). However, I found that few community-based interventions have been implemented to help to support the behaviour in this region (see chapter 5); and only one intervention has since been conducted and evaluated in Malawi (Lewycka et al., 2010), led by external NGOs and research organisations. The MaiMwana project has emerged to be an important intervention in promoting EBF in the context of poverty (Lewycka et al., 2010; 2013). The aim of peer counselling in the MaiMwana Project was to provide support to women and improve the rates of EBF beyond the hospital. The underlying assumption of the intervention was that peer counsellors have knowledge about the socio-cultural context in which infant feeding takes place and have similar characteristics to the women they support since they were coming from the same neighbourhoods (trial clusters).

The study also found that peer counsellors in this study felt that the one-week short training course coupled with refresher courses they received from the project enhanced their knowledge and skills on exclusive breastfeeding support which potentially increased EBF prevalence in the district (Lewycka et al., 2013). This clearly indicates that rural women can help to promote EBF rates in the community rather than relying on trained health care workers who are not adequate to do this. The results from the MaiMwana trial are extensively supported in the literature from other studies, as explained in chapter 3, which also demonstrated that duties delivered through various task-shifting interventions using peer counsellors yielded acceptable or improved quality of care and health outcomes including EBF behaviour (Morrow et al., 1999; Haider et al., 2000; Bhandari et al., 2003; Tylleskar et

al., 2011; Kushwaha et al., 2014). This is also supported by a systematic review conducted by Chapman et al., (2010) where they found that the majority of RCTs evaluating breastfeeding by peer counsellors indicated that peer counsellors improve the rates of breastfeeding initiation, duration and exclusivity.

The discussion held with the MaiMwana investigators revealed that the project team assumed that through home visits they were more likely to educate and involve significant others especially the spouse and elderly women who are the key decision makers, on what a breastfeeding woman needs and enlist their support in meeting these needs (Lewycka et al., 2013). Such an assumption although credible, was found to be problematic as it ignored how culture influences infant feeding practices. The findings from this study suggest that contrary to the MaiMwana assumptions of involving significant others during the visits, most peer counsellors attested that they faced a lot of challenges mainly related to the programme design, the conduct of the visit, sensitivity of the topics discussed which conflict with the cultural normal (see section 8.4.4). These hindered them to involve men as well as other key players within the household for instance, grandmothers during the visit. The household structure of participants in these communities is built on a patriarchal system where gender is an important determinant of how children are cared for within the household. Lack of involvement of these influential people consequently creates a gap on the level of understanding between breastfeeding mothers and their relatives, which may eventually affect the level of support. Despite failure to invite significant others by the peer counsellors during the visit, the results indicated that some significant others especially elderly women were interested to know what was discussed during the visit. Others expressed the desire to be part of the discussion so that they could provide support to the breastfeeding mothers.

The findings of this study further revealed that peer counselling was not only perceived to help to promote EBF among breastfeeding mothers but also enabled volunteers who were also mothers coming from the same communities to significantly increase their own personal growth and the new skills gained beyond the project. Peer counsellors reported that the training and continuous supervision they received and the counselling experience had helped them role models who were able to assist other people in their communities. Additionally, some of the peer counsellors interviewed acknowledged to have developed friendship with other community members and were able to use the knowledge gained while breastfeeding

their own babies. The fact that old women are regarded as a source of information in many communities in Malawi, old peer counsellors in this study reported to have been a source of good information related to EBF and being able to use their knowledge to dispel harmful cultural practices related to breastfeeding within their communities. The fact that old women are regarded as a source of information in many communities in Malawi, older peer counsellors in this study reported to have been a source of good information related to EBF and being able to use their knowledge to dispel harmful cultural practices related to breastfeeding within their communities and to encourage positive ones. A similar experience was reported by peer counsellors in a study conducted in Uganda (Nankunda et al., 2006; 2010). Additionally, some peer counsellors acknowledged that they developed respect and friendship with other community and were able to use the knowledge gained while breastfeeding their own babies.

10.6. Barriers to peer counselling in resource poor-settings

Although the MaiMwana interventions demonstrated the possible positive effects of task-shifting in improving EBF rates in resource-constrained settings (Lewycka et al., 2013), many of the peer counsellors in this study regarded their role as difficult as their work presented unique challenges due to the nature of the rural settings. These reactions may have been compounded by the realities of using poor women from local communities to combine such tasks with household chores as well as farming. One major reason that was cited from the interviews in this study was related to timing of the visit for both the peer counsellor and the women who were visited at home. Peer counsellors in this study reported needing to mainly conduct the visits in the afternoon and not on daily basis when they have returned from the field and completed their numerous household chores (see section 8.4.3). They reported to have assumed that the woman would also be free during this time but this was not the case. As noted from the findings of this study, women in the rural community are never free and some peer counsellors reported to have consequently failed to conduct the visit when they found the woman busy at her home. The MaiMwana investigators did not take much into consideration the burden placed on these poor women who were expected to work as volunteers in rural communities at the same time generate income for their families and perform household chores. While trying to meet the required number of visits and the distance, some peer counsellors reported to have been confronted with a dilemma and eventually conducted the visit because they could not manage to travel such long distances

again. The consequence is that, peer counsellors rushed through during the visit using the checklist provided to them by the project, which did not focus on the individual problems or provide a woman centred approach to counselling.

On the other hand, it was also learnt from this study that volunteers were spending much of their time volunteering at the same time creating time for other breadwinning activities, which often requires full-time performance. In addition to such work, their role as peer counsellors involved visiting all pregnant and breastfeeding mothers in their homes in communities where formal health services are inaccessible, documenting visit outcomes in the register commonly known as “Kaundula” and writing monthly reports. It is not unusual to learn that peer counsellors from this study reported that they usually documented the visit outcome in the night when they return from the visit. This presently constitutes a major challenge in rural communities where there is absolutely no electricity.

Furthermore, due to high fertility rate in the country, in some cases there were too many women to be visited by one counsellor. This was fuelled by the fact that during the inception of the programme, the project did not specify the number of women which each counsellor was supposed to visit in a day, week or in a month. The project failure to recruit more peer counsellors and failure to specify the number of women to be visited in a day, week or month by the limited number of peer counsellors allocated in each cluster resulted in over-stretching of peer counsellors in trying to visit as many women as they could in their allocated clusters on top of their daily family responsibilities. Therefore, they expressed their concern that voluntary work increased the workload to these peer counsellors who already spend much of their time doing unpaid work in the form of caring for their infants, household work as well as farming. Considering all these problems²⁷, it is not surprising that some key informants who were interviewed in this study expressed a concern that though the intervention seem to be cost-effective to the project and remain a good investment to provide access to health care for under-served populations living in geographically peripheral areas, it did not boost the economic status of the poor rural women who require an income. Some counsellors especially those who were younger and better educated similarly commented on the lack of impact on their career prospects.

²⁷ According to the 2010 Malawi DHS, 85% of Malawians live in the rural areas and rely on farming to earn their daily living.

10.7. Power dynamics and the paradox of voluntary participation into the programme

In this current study, the process of selection described by the peer counsellors in chapter 3—that is involvement of community leaders especially chiefs, in the appointment of peer counsellors at community level was also a strong predictor of their involvement. During the interviews, some peer counsellors expressed how honoured they were to be selected by the chief to perform the work for the entire community. However, this process raises the question of how far poor women engaged in voluntary work by choice. The interviews afford an expanded perspective on the complexity of power dynamics in relation to voluntary participation of women into the programme in this rural community. Although women reported on their motivations to participate voluntarily into the programme (which was designed and conducted by international researchers, a group of investigators from UCL), it was clear from the conversation that the values associated with power were dominant influences into their desire to work as volunteers for the project. In particular, given that the project used local individuals from below—in this case, women who were selected by community leaders mainly chiefs, such approach could be considered as implicitly coercive in some degree.

It is also clear from the literature that chieftaincy in Malawi is an important institution which is culturally much respected by all members in the community. Moreover, culture further bestows men with more power than women in different ways in the rural communities of Malawi. Firstly, the fact that chiefs in Malawi are mainly males, often subject women to gender and power disparities (Malawi Human Rights report, 2005). Secondly, patriarchal system (which literally means “the rule of the father”) (Lerner, 1989; Bhasin, 2006) where men hold power in all important institutions of the society which are socially, culturally and legally constructed, is common in this community. This means one cannot be sure of whether these peer counsellors could make a choice or could have the power to refuse any role assigned to them by the chief or someone else with higher authority in the community, even though they clearly valued being selected. This could also offer potential for manipulation of the community since those who are involved in the selection process are often influential members of the local cultural systems Hatch et al., (1993), even though the aim was to ensure the intervention was relevant to and grounded in the community. At the same time, due to power differences that exist in this community, any resistance or refusal to do the work assigned to them by someone who was more senior could have been viewed and regarded as

being disrespectful. Thus, the volunteers were clearly influenced by powerful social norms. Some researchers have argued that it is important to pay attention to the ways in which power is enacted in whatever context we find ourselves researching (Kristiansen and Bloch-Poulson, 2011).

On the other hand, if the power pushes women to agree and work as volunteers but their intrinsic motivations then develop positively with the work—feeling it is valuable, feeling valued for being chosen and able to help others in the community—then the approach may be more effective and not a simple manifestation of total powerlessness or dominant ideology. Foucault, (1980) pointed out that networks of power confer compliance and discipline to the work assigned which may in the end be beneficial not only to those that instigate them but also to the recipients. Thus, there was a working theory amongst the MaiMwana researchers that by providing these opportunities for chiefs to select women to work as volunteers might help to select the best women who would perform the job to please the community leaders. In support of this, the project team reported that very few volunteers had left the programme since the programme started. Marriage disruption, sickness/death of peer counsellors and lack of incentives were mentioned as the main factor for leaving the programme.

Involving community leaders in the selection procedure of peer counsellors – as in the case of the MaiMwana project -also poses some limitations to an external project team on how to manage the volunteers in case of poor performance. During interviews, some project members eventually expressed a concern that some peer counsellors were not performing to satisfactory level but they had no power to replace any volunteers in whom they noticed poor performance as long as the community leaders were still happy with the individual. Instead, it was their responsibility to report any misconduct of such individuals. In other words, community leaders had the mandate to approach them and find out why they were not performing the roles that have been assigned to them. The other argument was that to be sustainable once the project funding and staff have gone, a project like this needs to be embedded locally, so in the longer term, local people need to be able to select and supervise volunteers and maintain a project – or the gains might only be short-term.

10.8. The need to consider incentives and payment

While peer counsellors working in other community-based interventions conducted in sub-Saharan Africa were paid for the work (Nkoki et al., 2010), the main characteristics of the MaiMwana volunteers was that they perform the work out of their own free will and for no remuneration. This was partly because the organization wanted to promote community participation and empowerment, and partly to cut costs and increase efficiency through the use of locally available resources. The MaiMwana project was therefore, performing in what Etzioni et al. (1998) referred to as “high performance mode” in which the organization wanted to achieve much higher and sustainable performance with less efforts and stress. Thus, whereas for the organization the use of volunteers may still be an efficient and cheaper way of getting things done, for the volunteers themselves participating may have a totally different meaning, especially for women or mothers living in extreme poverty. Kreitner and Kinicki’s, (2007) content theory of motivation indicates that needs influence motivation. In this study although the desire to help other women in their communities, value of the social approval, the knowledge and confidence gained were the most frequently stated reasons for volunteering, the study revealed that volunteers were of the opinion that the project should compensate them for the work which they were doing because these were women coming from the rural areas with extreme poverty and the majority of them live on less than one dollar a day. This was evidenced from the suggestions from the majority of them to be called “peer counsellors” not as volunteer because they felt like unpaid workers for the project. This research is unique in showing understanding of what it means when peer counsellors demanded to be given incentives for the work they have done on behalf of health care workers who were employed. It exemplifies the burdens and difficulties these women continue to face while making a considerable contributions to the community in terms of their time and labour. Further, in this study some key informants raised a concern of interest to this study, namely that voluntary work did not boost the social economy of poor women but rather increased the burdens on poor women in the society already stressed to provide economic support through farming and care for their own families. Kreitner and Kinicki, (2007) argued that even though volunteers do not receive monetary incentives for work done, they need to be motivated to be involved in volunteer activities that enable them to meet some, if not all of their basic needs. Unless organizations running such projects understand what it means to involve poor women as volunteers, they risk under-estimating the burden this may cause to them and undermining the long-term sustainability they seek to ensure.

This did not only affect the peer counsellors but also the women who visited at home. One of the consequences to lack of incentives is that some of the women were said to run away when the counsellors came to visit them without any incentives. This study showed that people in the communities value their time to go and generate some income and food for the family instead of spending their time to listen to health messages without any direct incentives. Similar, findings are observed from the 2004 Malawi Diffusion and Ideational Change project longitudinal studies (Thornton, 2008). In this study, participants who received monetary vouchers were twice as likely to obtain their HIV test results from the mobile clinic as compared to those who received no cash (Thornton, 2008). The request for incentives by women who were visited at home reflects the reality that many women are poor and may need to be supported during the visit. However, it is argued in the literature that paying participants will make them reluctant to participate in future research for less than their current payment, and that this may jeopardize smaller, less well-funded studies (Singer and Couper, 2008).

Again, given the culture where the visitor cannot leave the house without giving something to those visited- let alone the visitor does not leave the house with an empty stomach, the result from this study indicated that home visits posed an economic burden to the counsellors as well as mothers who were visited. For instance, some peer counsellors in this study reported that the fact that they were working for an international NGO (MaiMwana) and that the other NGOs mainly Invest in Knowledge Project working in the same district were compensating their volunteers, a considerable number of mothers did not believe that the counsellors were working as volunteers. Some women in this study on the other hand, reported that they felt embarrassed when they did not have something to give to the visitors. It was established from this study that other NGOs run projects within the same community where providing direct incentives, thus creating certain expectations among the service users. Through the interviews it was reported that those who could not afford to provide the food to the peer counsellors decided to leave their homes or give an excuse so as to avoid being visited by the peer counsellors, which eventually affected the number of visits.

10.9. Acceptability of peer counsellors among rural women

The findings from this study reveals that peer counsellors are well accepted by women and other people in the community and that women preferred to be counselled at home than at the

clinic, although some women did point out that hospital visits were still needed for other health functions, creating a double burden on their time. Not surprisingly, in this study women preferred to be counselled in their homes by their fellow women because it was convenient for them as they did not need to travel long distances to reach the health facility which is costly and time-consuming and availability of the peer counsellors also appear to be a relief to them as they were always available within reach. This worked well for the women because they do not spend much time and money to visit the clinic and they had enough time to do other activities. These findings are generally consistent with other studies conducted in the same area on HIV testing. Angotti et al. (2009), for example, found that people favoured door-to-door testing than being tested at the hospital as it removed the burden of travelling long distances when the majority of people live more than 10 km from a health facility.

Just like findings in other studies (Nor et al., 2012), women in this current study felt well respected as the counsellors were often more perceptive and sympathetic and would spend more time to listen to the problems of women and provide necessary support, as compared with formal health workers. Peer counsellors created conducive environment needed by HIV positive women that ensures maximum feeling of safety and confidentiality. This was evident when several women who were not visited in their homes (control villages) demonstrated interested to be visited while those who were visited sought for more visits and information from the peer counsellors on how to care and feed their babies. Additionally, women in this study reported that they continuously consult the peer counsellors on issues related to infant care and concern that pertains to breastfeeding. Similar sentiments were expressed by service users in Uganda where about 95% of them expressed satisfaction with various aspects of peer counselling offered (Nankunda et al., 2010) and also in Canada where 85% of service users felt that every new mother should be offered peer counselling (Denis, 2002). This preference has to do with the respect and the way health care workers interact with clients at the clinic and shortage of health care workers in these resource poor settings. As such, up until 2007 before the TBA ban in the country, women in rural Malawi were predominantly attended to and assisted during child bearing by traditional birth attendants without formal skills, commonly referred to as “Azamba” or “village doctors” who were scattered across the country especially in the rural communities. Some researchers have pointed out that even following the ban of TBAs, their traditional practices have remained largely unchanged as women still prefer to be assisted by the TBAs rather than going to the hospital. As already explained in chapter 2, TBAs are women coming from the same community and are assisting

their fellow women in their own communities. In fact, TBAs are normally trained by their predecessors with skills being handed down from one generation to the next. One study conducted in the country found that TBAs were favoured by women during labour and delivery unlike being assisted by health care workers because of proximity and socio-cultural factors such as: exhibiting respect to the client, their fluency in local languages, a general mistrust of the national health care system, and TBAs' relative status position in the community (Seljeskog et al., 2006; Bisika, 2008; Kumbani et al., 2013).

This also was seen as a way to provide opportunities to develop social support as the peer counsellors would sit down with them and listened to their challenges and also provided advice and explanation with particular issues such as breast engorgement, sore nipples, and timing of the food, positioning and attachment which did not require skilled HCW input but did require time and personal attention. On the other hand, despite being positive about the intervention, some women argued that because they were still required to travel to the hospital to access other services due to lack of integration of services during the visit. Some expressed negative feeling towards the time spent with the counsellor and the type of counselling as it was noted that especially when pressed for time, counsellors might rush through visits and use a checklist rather than a woman-centred approach.

10.10. Perceptions about peer counselling in the face of HIV

As already explained in the introduction chapter, sub-Saharan Africa where Malawi is located remains the region most severely affected by the HIV pandemic. As such, provision of HIV and AIDS services are found to be problematic and challenging especially in health facilities located in the rural communities due to severe shortage of health care workers. The introduction of option B+ in the country, which involves provision of lifelong ARVs to all HIV positive pregnant women regardless of their CD4 count, created more challenges to these women as well as health care workers (MoH/GoM, 2011a). Firstly, the majority of women may find it difficult to accept their HIV status and how to disclose to their partners due to lack of proper counselling. Secondly, the fact that they go home with these strange medications further confuses them on how to explain to their relatives and some even fear that the ARVs may harm the baby. On the other hand, due to severe shortage of health care workers, the professionals find it difficult to provide HIV services to all women attending PMTCT clinics. Further, there is some evidence that HCWs find it difficult to follow-up all

defaulters in the community. As such, many organizations have relied heavily on non-health care workers to perform some of the tasks within the clinics and at community level (Tenthani et al., 2012).

Again, after the introduction of routine HIV testing, the majority of pregnant women get to know their HIV status during their initial antenatal visit. Since many women attended their first antenatal visit during the second trimester, this is a time when their bodies are visibly pregnant and are carefully watched by relatives, neighbours and friends. Pregnancy, as a transitional phase, is culturally elaborated with the aim to provide safety and protection of the mother so that she in turn can protect the child growing in her womb. With routine HIV testing, all pregnant women in Malawi are motivated to have a test in order to be able to safeguard the health of their expected babies. It is therefore, during this crucial period that the mother gets to know that she is HIV positive and that she is in danger of infecting her baby. For many of those HIV positive mothers who were interviewed in this study the uncertainty of the health of the baby was reported as a great burden to carry and also the thought of the baby feeding through their infected milk is very difficult to bear. In this study such women wanted to receive continuous counselling and support during this period. However, considering the shortage of health care workers in the country (see chapter 3), it is doubtful whether women are given the required counselling and information to maintain EBF in formal health facilities and whether they understand the information given regarding breastfeeding during a short visit which they make in most clinics. In this study it was found that due to lack of support of women by HCW, HIV positive women valued the presence of peer counsellors and eventually disclosed their HIV status during the course of the visit, hoping that they will get support from them.

MaiMwana peer counsellors were sent to visit women without knowing those who were HIV positive and they were not trained on how to handle HIV positive women in case they came across them. The rationale was to keep confidentiality of HIV status of women. Paradoxically, the project staff did not recognize that these peer counsellors would meet HIV positive women while executing their work and they did not provide enough information to them on how to deal with this. Most peer counsellors interviewed in this study reported that they lacked knowledge and found it extremely challenging to provide the right counselling to those women who disclose their HIV status to them, although they valued the possibility to

do so. This is consistent to the findings of a study conducted in South Africa (Nor et al., 2009; Danniels et al., (2010). The findings are also consistent with a qualitative study conducted in South Africa (Nkoki et al., 2010) where peer counsellors were also blinded on maternal HIV status. However, during the session some of the women disclosed their status to the counsellors, which made it difficult for them to handle such situations.

The findings from this study suggests that introduction of Option B+ has made peer counselling more complicated as women require more support at community level. Despite the fact that MaiMwana did not disclose the HIV status of women to the peer counsellors, it is clear from this study that the majority of them were motivated to disclose their status to the counsellor because they needed someone to listen to their stories and provide emotional support. During the analysis, there was a concern on whether peer counsellors should know the status of women in order to provide the right counselling to them. The expectations of women in this study especially those who were HIV positive was that these peer counsellors will have knowledge and skills to support HIV positive breastfeeding mothers. Paradoxically, a significant proportion of HIV positive women perceived the visits by the peer counsellors as beneficial to them because it helped them to cope with the stress of being diagnosed with HIV and feeding their babies while HIV positive. HIV positive women therefore, were able to accept their HIV status, feel safe to breastfeed their babies and resolve personal problems in relation to their HIV status. HIV positive women further valued the type of counselling and time spent with the peer counsellor as compared to the hospital counselling. In this study, the one-on-one support was valued by the majority of them as they face different physical and psychological challenges which require time and confidentiality. Normally, at the hospital HIV positive women are counselled in groups and they felt that in most cases their concerns were not taken care of. These findings concur with the findings from a study conducted by Nakhunda et al. (2006; 2010) in South Africa where HIV positive women felt that peer counsellors supported them and offered them opportunity to ask questions related to their HIV status and assisted them to cope with their HIV status.

The women's accounts show how important it is to provide emotional support to HIV positive pregnant women in the rural communities as is done with other task-shifting models (for instance, the expert client model and mother to mother programme) being implemented by different organizations in the country (Tenthani et al., 2012; Catholic Relief Services, 2014 (un published report). However, the major problem identified was that unlike these

expert clients who were trained for 1 full week on HIV/AIDS (Expert clients Trainer's manual, 2011) and who have themselves been living with the virus, the MaiMwana peer counsellors were not well trained to handle such cases at community level because their training specifically concentrated on maternal and child care including EBF, rather than HIV/AIDS counselling. Again, this study also raised another important issue in terms of when some of the peer counsellors did not ask the woman about their HIV status, some women in this study decided to remain silent about their HIV because they assumed that the fact that they were supervised by HSAs who also trace them in the community in case they miss their visits, provide HTC to them then automatically peer counsellors should be aware of their status.

10.11. Study strength and limitations

Efforts described in chapter 4, were taken to help ensure the credibility, auditability and generalization of the findings of this study. Despite of all these efforts, a number of limitations still existed throughout the process of correcting data and the data quality which need to be taken into consideration before applying the findings to other settings.

In terms of selection of study sited, the MaiMwana intervention was being conducted in 48 clusters across Mchinji district but due to shortage of fuel in the country respondents were recruited from 3 health facilities which were conveniently selected taking into consideration easy access (close to the main road). Therefore, it is likely that the most socio-economically disadvantaged women living in the hardest-to-reach places with difficult access to health care services were not included in this study which potentially may have biased the findings as their views may not have been captured. However, by recruiting respondents from two different types of health facilities (government owned and CHAM) was useful to get hold of women coming from far places. This is because the CHAM facilities are most often patronized by people from many places within the district due to availability of drugs. Also interviewing peer counsellors during their meetings and attending their quarterly meetings was thought to be a sound approach as I was able to capture experiences of those working in hard-to-reach places through observation.

In the second place, the study population was from a small purposive sample of breastfeeding mothers who were recruited from the under-five and PMTCT clinics and not all women

report to the clinic on the same day or some may have failed to report for their scheduled clinic visit. As a result of this, potentially significant respondents who were not available on the days that recruitment took place may not be included in the sample. This may eventually limit the transferability and applicability of the findings from this study. In addition, I involved clinic staff to assist with the recruitment of women to be interviewed because it was impossible for me to access the HIV status of women without consulting them. Additionally, key informants and peer counsellors were recruited through consultation with other participants and MaiMwana staff who were knowledgeable enough with the subject matter. It is possible that the findings from this study present the best situation as the health care workers and MaiMwana staff involved in the recruitment of respondents may have selected those that they perceived as best to be interviewed. It might have also been difficult for respondent to refuse to be interviewed because of the high value placed on health personnel and the respect which people had on the project. Additionally, this may have caused social disability bias as respondents would fear to say anything negative concerning the hospital or the programme. This bias may lead to underestimation of the problem which women as well as peer counsellors face in rural communities.

However, the fact that I conducted a second sensitization of all respondents referred to me for interviews gave them enough time to decide whether they really want to participate in the study or not. Surprisingly, all HIV positive women who were referred to me for interview accepted to give informed consent and participated in the study despite conducting a second sensitization while some of those who were HIV negative who I recruited on my own did not return for their appointment date. Possible explanation for this could be that HIV negative mothers could have the autonomy to choose whether to participate or not while those who were HIV positive might have felt obligated to participate in the study since they were referred by the clinic staff. Additionally, they may also be motivated to participate because they may believe that the research would benefit them to improve the care for their condition or they had fear that they would be followed up in their home if they miss the interview date as it is normally done when they miss their scheduled follow-up visit. HIV positive women could have also felt obligated to have someone to listen to their problems faced while being HIV positive. The key strength of the qualitative study was related to the flexibility of the use of open-ended questions which allowed participants to express their views and experiences freely and allowed the researcher to probe more deeply into the issues discussed, as well as other issues that emerged (Bowling, 2009). Further, much of the data for this thesis was

collected through in-depth interviews and non-participant observation of peer counsellors meetings. In this study, I was not able to live with respondents to witness how they were actually practicing exclusive breastfeeding and how the counsellors conducted the actual visit. My understanding of infant feeding practices and home-based peer support is therefore, mainly based on a single moment observation. However, this was the best way to allow respondents be open about their experience due to the sensitivity of the study (inclusion of HIV positive women). Otherwise the majority of them would not have been comfortable to talk about their HIV status and experience in presence of others. However, through review of infant feeding policies and guidelines coupled with attending peer counsellors meeting I was able to gain more insights in terms of breastfeeding practices in Malawi and the challenges faced in maintaining the behaviour as well as EBF promotion using peer counsellors. On the other hand, due to lack enough funds and fuel in the country, I spend much of my time at UNC project where they were able to provide office space for the team which was easily accessible. Otherwise it could have been more beneficial to spend more time with the research team in order to learn more of their activities. Despite doing much of the paper work at UNC project, at the time of the field work there was an opportunity to attend project meetings and dissemination meeting of the findings from the MaiMwana interventions which provided insights on effectiveness of the intervention.

Lastly, due to unforeseen circumstance that is critical shortage of fuel in the country, a research assistant was used to conduct some of the interviews which would affect the quality of data collected as she might not be able to ask some of the question the way as I would have done. However, the interviews were of good quality through the training which I provided to her and her previous experience working in the same community. In addition, I made sure to listen to all the interviews which were conducted by the research assistant and discussed with her all the areas that required more probing.

10.12. Validity, reliability and generalization of research findings

Patton, (2002) states that validity and reliability are two factors any qualitative researcher should be concerned about while designing a study, analysing results and judging its quality. Since in qualitative enquiry the researcher is the instrument, the validity hinges on the skills, competence, and rigour of the person doing field work (Lincoln and Guba, 1985; Patton 2002). Triangulation of data sources such as in-depth interviews, observation of meetings and

document review and the use of different groups of informants (see chapter 6) was one way of increasing accuracy and credibility of findings from this study because it allowed for an assessment of the issues from multiple sources (Patton, 2002; Yin, 2009).

Most importantly, despite the above noted limitations from this study, the findings are similar to the findings of other studies conducted in similar settings in the country and other countries in SSA and provide essential input on EBF promotion and the basis for generalization of findings. Additionally, the fact that I made a considerable effort to directly attend peer counsellors meetings is a major strength of this study because it is an effective approach to assess programme implementation (Patton, 2002). Through direct non-participant observation of these meetings I was able to learn about how peer counsellors conduct infant-feeding counselling rather than only relying on their self-reported infant-feeding counselling. Finally, the demographic characteristics of participants included in this study demonstrated no differences with the larger study population and the general public that would undermine from generalization of findings in similar settings in the country.

CHAPTER 11: CONCLUSION, RECOMMENDATIONS AND IMPLICATIONS

11.1. Introduction

Chapter 11, the final chapter, highlights the main findings that arose from this study and provides key policy implications of the findings for future breastfeeding promotion and promotion of child health more widely at community level. Recommendations for future research and programme implementation are also made.

11.2. Conclusion

As discussed in chapter 2, under-five mortality remains high in Malawi as well as other countries located in sub-Saharan Africa mainly contributed by poor infant feeding. Some tremendous reductions in under-five mortality have been made globally with the promotion of exclusive breastfeeding, but more efforts are required to promote EBF and reach the WHO 90% universal coverage in EBF which lays the foundation for a healthy future because of its known health benefits to the baby and the mother (Jones et al., 2003). The work presented in this thesis have illuminated some insights on the main social/cultural determinants of EBF among women in resource-poor communities, contributing to the available body of scientific literature regarding approaches to promoting exclusive breastfeeding, in particular via community-based approaches, and highlights where recommendations could be made in order to make community-based interventions successful and sustainable.

The findings from this study suggest that exclusive breastfeeding as a behaviour does not take place in a vacuum and is subjected to economic pressure, pressure from family and community members and that women need to be supported throughout the time they are breastfeeding. However, much of the promotion of exclusive breastfeeding often through the Baby Friendly Hospital Initiative has focused on the mother only through the teaching taking place at the health facility. Although this has helped to increase the level of knowledge among women, translating such knowledge into practice remains a big challenge because others especially spouses who are often not present at the clinic are not involved in the health education.

As it was noted from this study, some ambivalence was apparent in relation to women's intentions to practice exclusive breastfeeding and the relationship between abstract

knowledge about the importance of exclusive breastfeeding and the actual practice as the majority of breastfeeding mothers were expected to conform to cultural norms of giving supplementary foods and had to manage their infant feeding in the context of poverty and hard work as well as, for a proportion, living with HIV/AIDS. This thesis therefore, adds to the knowledge around the social characteristics under which EBF takes place and the effects of an HIV positive mother feeding her baby in poor communities with high rates of HIV and where mixed feeding is dominant.

The findings from my study indicate that despite the fact that mothers including those with HIV have good knowledge about exclusive breastfeeding and the dangers of mixed feeding many women fail to maintain the behaviour due to a combination of cultural practices and socio-economic conditions that support mixed feeding over exclusive breastfeeding.

This study further demonstrated that there is a gap between women knowledge about exclusive breastfeeding and the giving of supplementary feeds more especially traditional medicines and gripe water which are traditionally prescribed by the traditional healers and considered as medicines, rather than foods by many people in the rural areas.

The findings from this study may be of great significance in promoting EBF behaviour in rural communities where the majority of women as well as significant others have a strong belief towards the effectiveness of traditional medicines and would find it difficult to act against the cultural norms. These finding reflect the weakness in the infant feeding guidelines to consider practices that involve giving traditional medicines. As discussed in chapter 7, even though no proper evidence exists to support or to contradict the effects of these traditional medicines in protecting against childhood illnesses, the evidence on effects of lack of clean water and facilities indicate that introduction of even theoretically harmless traditional medicines may pose other risks to infant, and particularly where breastfeeding mothers are HIV positive.

In this study it was also found that despite their knowledge of health advice and the value placed on breastfeeding, the mothers were facing various barriers including lack information and support to maintain exclusive breastfeeding in the community especially among HIV positive mothers. Therefore, the use of peer counsellors to promote exclusive breastfeeding appears central in sub-Saharan Africa to improve infant health and is core to achieving the

MDG number 4 of reducing infant mortality and morbidity, especially in the early postpartum phase during which women are establishing infant feeding practices. The existing evidence overwhelmingly suggests that particularly in poor countries with high rate of HIV, peer counsellors' programmes remain a good investment, since the alternative in reality is no care or support at all for poor people living in geographically peripheral areas. This was evidenced from the responses from the majority of respondents in this study who expressed positive attitudes towards peer counsellors and satisfaction with the support which they received from them. Breastfeeding mothers felt that having peer counsellors in their communities was the best way to reinforce infant feeding messages given to them at the hospital and encourage them to continue with exclusive breastfeeding in the rural community. They also felt that the intervention was useful because they were able to access health advice at the 'door step' instead of travelling several kilometres to reach the health facility, while those who were HIV positive expressed the feeling that having a peer counsellor helped them to overcome emotional distress related to their HIV status. Moreover, health care workers acknowledged that the programme has helped them to sensitize significant others who are normally not present at the clinic which eventually led to change in some cultural practices related to EBF. This is encouraging considering the previous critical attitude of HCW towards previous similar task-shifting programmes in the country like use of auxiliary nurses to provide some health services (Muula, 2006).

Lastly, it was clear from the findings that despite the short training which peer counsellors received (5 days), the majority of them were confident enough to support their fellow women including those with HIV on how to effectively practice EBF. Many peer counsellors appeared to depend on their personal experience of breastfeeding. Besides, breastfeeding mothers in this study, valued one-to-one support provided by the peer counsellors during the visit despite the counselling not being client centred. This intervention was also valued by the majority of women including those who were HIV positive as they were able to access health information within their communities. And again, the fact that they were also residing within the same communities with the other women who were being visited made it easier for them to understand the common traditional practices as some of them would have also been experienced these challenges. In the end, this helped them to discourage harmful practices and promote positive ways to support exclusive breastfeeding at community level.

Although these peer counsellors did not financially benefit from the work as volunteers, the majority of them appreciated the knowledge and skill they gained and felt proud to be perceived as the source of specialized knowledge within their social networks. However, despite these positive feelings towards the intervention, some reported challenges which made their job as peer counsellors difficult. In particular, the majority mentioned timing of the visit as being a huge issue for both the client and the peer counsellors as both were expected to perform their role as mothers in their houses in addition to subsistence and market production. Others felt that they needed to be considered for incentives because their work was time consuming. In this study peer counsellors also felt that it would have been beneficial for them to know the HIV status of the woman before the visit since the majority of women disclose to them regardless of this. As a result, they found the situation difficult as they lacked preparation, knowledge and skills to handle such cases. Hence, based on available evidence (Tenthani et al., 2012), such programmes should consider using HIV positive peer counsellor to support their fellow women in the community to practice EBF. This is also one way to promote disclosure of one's HIV status as women would trust their peers who are also HIV positive. However, such community-based interventions targeting HIV positive mothers should be implemented with caution as they may cause challenges due to other factors beyond the control of the woman, such as lack of disclosure of HIV status to peer counsellors in presence of significant others which can lead to family disruptions.

11.3. Implication for policies and guidelines and future public health and health promotion

In this study it was found that despite initiating breastfeeding within the first one hour of birth mothers were facing a lot of challenges to practice EBF and that home-based support assisted them to overcome such problems. The findings from this study therefore, present important opportunities for researchers, programme managers, policy makers and implementers to develop the most feasible, cost-effective and culturally acceptable programmes to increase the rates of EBF, especially in Malawi and other resource constrained countries with high rates of HIV. This study shows that such efforts to increase exclusive breastfeeding need to take into account socio-cultural issues surrounding infant feeding and the roles played by significant others.

Since giving of supplementary feeds within 6 months appears to be mainly due to cultural norms and influence of other social networks, EBF can only be effectively promoted if interventions target the whole system in terms of the spouse, mother as well as elderly women and others who are known to be influential in deciding how the mother should care for the baby in the country (Bezner-Ker et al., 2008). Thus EBF promotion should target all people involved in the system. This can be achieved by increased access to information on exclusive breastfeeding and involvement of significant others. When possible, interventions to promote EBF should target the whole community rather than only providing information to the woman.

There are also important implications of the findings from this study for the promotion of exclusive breastfeeding in the context of HIV using peer counsellors at community level to reduce MTCT. Despite the fact that confidentiality was given high priority in the HIV-positive population, there was unexpectedly high disclosure by women themselves to counsellors due to the support needed at community level. This has implications as peer counsellors did not feel knowledgeable enough.

The use of peer counsellors in areas of high HIV prevalence calls for adequate training on infant feeding counselling in relation to HIV, with close monitoring and supervision since perceived need for emotional support is more common among HIV positive women who fear being stigmatized. This would be beneficial because many HIV positive women find it difficult to reach the nearest health facility for psychological support. One way to promote disclosure of HIV status is for programme implementers to consider employing peer counsellors who are HIV positive to use their own experience in supporting their peers in the community.

The findings from this thesis also demonstrate issues for public health interventions to consider in scaling up of peer counselling programmes and inclusion of provision of HIV related support at community level. This would be a way to reduce workload within the health facilities in the country, and also help to reduce indirect costs to the participants as most of the minor health conditions can be managed right away in the community. However, the implications are wider than simple task-shifting or cost savings since this study has shown that the work of peer-counsellors may be qualitatively different from that provided by health

professionals, owing to lower social distance, and (when managed well) a more woman-centred and enabling approach.

The findings further provide evidence to suggest that peer counsellors approach with proper involvement of community leaders and supervision is one way of promoting exclusive breastfeeding in hard-to-reach places and emphasizes the importance of giving monetary incentives to volunteers in resource-poor settings as a way to improve their socio status and motivate them. Therefore, provision of incentives to peer counsellors and participants would promote participation into community-based health promotion interventions that would help to improve health. However, this was constrained due to fear of sustainability of the intervention since the MaiMwana community-based intervention was phasing out.

11.4. Recommendations for future research

The work presented in this thesis highlights important areas for future research that can help increase exclusive breastfeeding rates as follows.

- Because mixed feeding not exclusive breastfeeding remains common in Malawi and other countries located in sub-Saharan Africa and breastfeeding behaviour still remains a socio-cultural issue over which women do not have control future studies should strive to gain a better understanding of the specific types of support that encourage exclusive breastfeeding.
- HIV positive women are usually required to consult their partners as well as significant others before deciding on infant feeding method. In addition, even with community support of EBF behaviour, it is difficult to change women's attitude and behaviour without involving significant others like elderly women and men who have greater influence on infant feeding, yet they are not involved in breastfeeding education. Therefore, future interventional research should continue to test the influence of exclusive breastfeeding education provided to women along with their spouses and family members on infant feeding practices.

- In addition, researchers should also look at the effect of breastfeeding policies and guidelines formulated by international organizations and being implemented in developing countries without taking into consideration of cultural issues.

This study also identified the need to further analyse the MaiMwana dataset which would be valuable in order to make statistical comparison of:

- Exclusive breastfeeding rates among HIV positive and negative women who were visited in their homes.
- Socio-demographic characteristics of women and EBF practices

Finally, improvement can also be made in data collection methods regarding infant feeding practices. In this study only in-depth interviews were used as a core data collection method which relied most on self-reported information in terms of exclusive breastfeeding practices and how the peer counsellors were supporting women in the community. Future ethnographic research studies should be considered where participant observations of these activities could be done in order to adequately develop understanding of the real experiences of practicing and promoting EBF in resource-poor settings.

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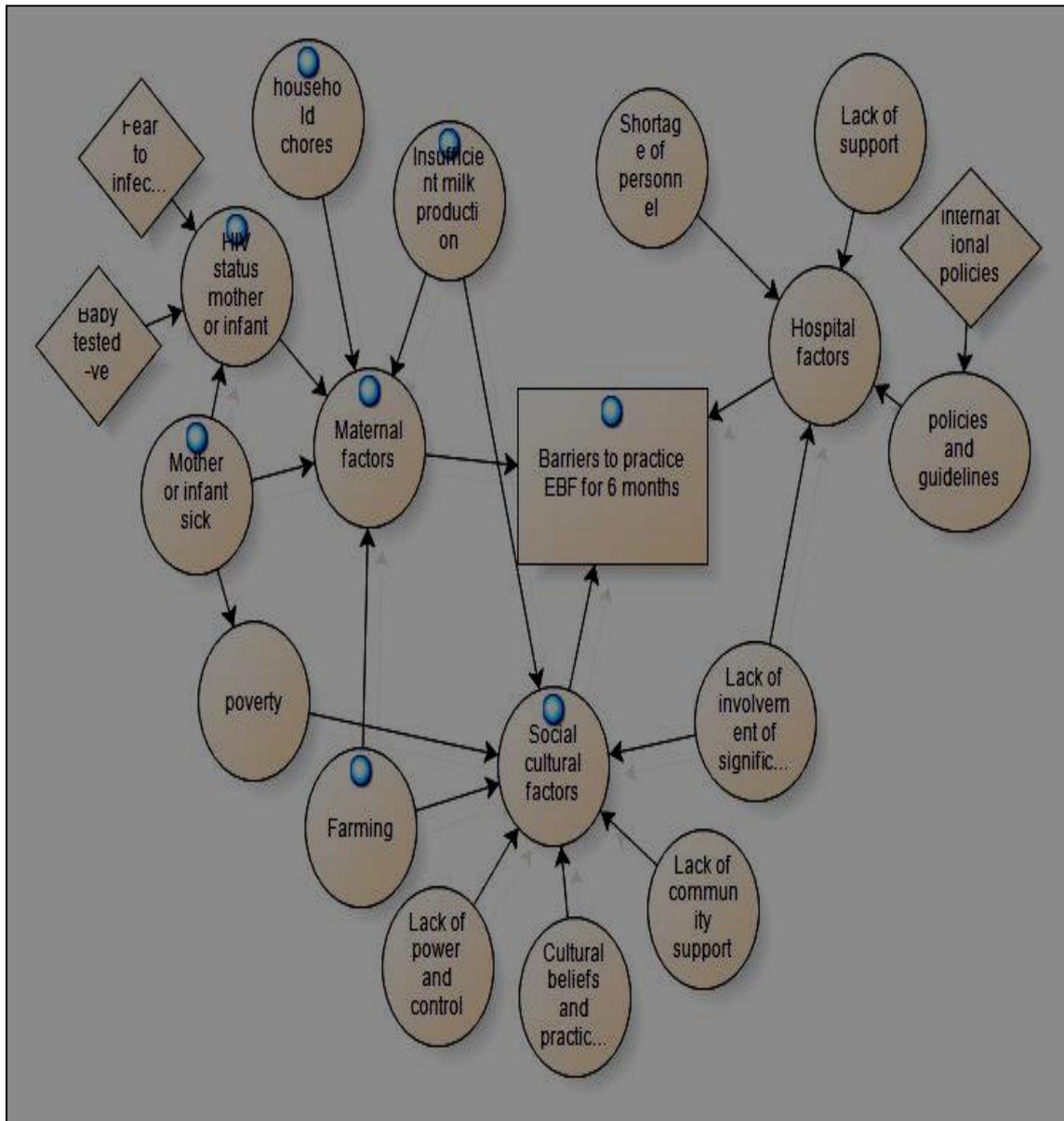
Appendices

Appendix 1: Data analysis extracts

Appendix 1.1: Study working thematic framework

Interview category	Major heading/code	Sub heading/children node
Lactating women	EBF practice	<ul style="list-style-type: none"> - Reasons for choosing EBF - Knowledge about EBF - EBF and HIV - EBF support - Male involvement
	Barriers to practice EBF	<ul style="list-style-type: none"> - Decision making and power - Insufficient milk production - Cultural beliefs and practice - Fear to transmit HIV to the baby - Mother or infant illness - Household work - Field work - Power and Control
	Promoters of EBF	<ul style="list-style-type: none"> - Partner power and support - Home support by peer counsellors - Community based support groups - Knowledge about the dangers to mixed feed - Hospital policies and support
	Perception about home based peer counselling	<ul style="list-style-type: none"> - Importance of home visits. - Issues discussed and satisfaction. - Attitude and trust towards peer counsellors - Involvement of partner and significant others - Experience with the visit - Satisfaction with the visit
Peer counsellors and supervisors	Volunteerism	<ul style="list-style-type: none"> - Training and supervision - Volunteerism and poverty - Reasons for accepting the role - Motivation/payment - Incentives and payment - Selection of volunteers and supervisors
	Experience with conducting home visit	<ul style="list-style-type: none"> - Materials used during the visit - Time management - Issues discussed during the visit - Knowledge and satisfaction - Attitude of women towards volunteers - Partner involvement
	HIV disclosure and home visit	<ul style="list-style-type: none"> - Disclosure of HIV status - Importance of disclosure and EBF - Reasons for nondisclosure - Reaction after disclosure - Experience and challenges with visiting HIV positive women
	Promoting factors	<ul style="list-style-type: none"> - Involvement of chiefs - Community awareness and knowledge - Incentives - Training and knowledge - Respect in the community
	Barriers to conducting the visit	<ul style="list-style-type: none"> - Individual women factors: Sickness, Lack of knowledge, Poverty, Marriage - Counsellors factors: Age, household work, lack of commitment, funerals, field work - Social/environmental factors: Culture (old and new), Health policies, Distances, high fertility rate, climate, poverty, funerals. - Institutional factors

Appendix 1.2: Model on factors that affect EBF practices



Appendix 1.3: Extract produced from the study

Respondent	Maternal condition- How HIV positive status affect EBF practices	Women perceptions of insufficient milk production	How farming interfere with EBF practices
KI001		“If the child is crying a lot they think it is hungry because they are not producing enough breast milk and they start giving porridge. Once they start giving porridge to the child they do forget about breast feeding because they don’t know the right amount of porridge to give to the child” (p.2)	“Most of the time women forget about breastfeeding and if the child is crying a lot they think it’s hungry because they are not producing enough milk and they start giving some porridge. Once they start giving porridge to the child they do forget about breastfeeding because they don’t know the right amount of porridge to give to the child. Most of them leave the child somewhere within the field for some time without breastfeeding while cultivating” (p.1)
LA016		“Sometimes when the child is crying a lot they conclude that the child is hungry and that breast milk is not enough. Immediately they prepare some light porridge and feed the child and you find that the child is sleeping a lot” (p.2)	“You know life in the village there are a lot of social gatherings or you need to go to the field. Most of the times you have to leave the child home and in many cases the child is left home with elderly women who eventually give the child some porridge” (p.1)
LA002			“It may happens that the woman may leave the child home her home very in the morning and go to the field to fetch some food. By the time she will be coming back it might be around 8 am without breastfeeding.” (p.1)
LA009			“I did not manage to practice exclusive breastfeeding because I am always busy with farming or household work” (p.1)
LA008	“The time I learnt about my HIV status I used to feel very hungry. My child also started troubling me a lot.” (p.4)		
La013	“I always had the feeling that I have transmitted the virus to my child. ...Later I went to the hospital with my baby for testing and she was found to be HIV negative.” (P.3)		

Appendix 2: Information Sheet and Consent Form for breastfeeding mothers

Appendix 2.1 English version

Introduction

My name is Agatha Bula; I am a doctoral student at City University London. You are invited to participate in this study. This form provides information about the purpose, benefits and possible risks of the study and what will be expected of you during the study period. I will discuss the information with you and answer any questions you may have. After the study has been fully explained to you, you can decide whether or not you want to participate. Once you understand this study, and if you agree to take part, you will be asked to sign two copies of the study informed consent form or make your mark in front of someone. You will be offered a copy of this information sheet and consent form to keep.

Please note that:

- Your participation in this study is entirely voluntary.
- You may decide not to take part or to withdraw from this study at any time without jeopardizing your relationship with MaiMwana project.
- Your identity and information will be protected and kept confidential.

What is the purpose of this study?

As you are aware, all mothers in developing countries including Malawi are counselled and encouraged to exclusively breastfeed their babies for the first six months of life. This include women who are HIV positive in order to reduce the chances of transmitting HIV through breast milk and prevent early deaths due to diarrhoea and malnutrition. This study aims at exploring what affects women ability to breastfeed their babies without giving other food or drinks, whether they are HIV positive or negative. The study will also investigate whether using peer counsellors in the community will increase the rates of exclusive breastfeeding among HIV positive and negative women. The study is further looking at the views of different groups of people on the use of peer counsellors to promote exclusive breastfeeding in the community and identify ways of promoting exclusive breastfeeding practices for a longer period of time in the country.

Why are you being asked to participate in this study?

You are being asked to take part in this study because you were either visited at home by peer counsellors or you have given birth and come from one of the villages in Mchinji district, where MaiMwana is visiting women in their homes to promote maternal and child health including exclusive breastfeeding. The findings may help to understanding the challenges faced by women that would be useful in the development of effective community- based intervention programmes to promote exclusive breastfeeding among all women and promote optimum infant feeding and reduce malnutrition, HIV transmission and infant mortality in Malawi.

What will happen if you decide to join this study?

If you decide to take part in this study, you will be one of approximately 60 participants who will be interviewed individually. Each interview will last for approximately one hour. During the interview you will be asked some questions about your views about exclusive breastfeeding, knowledge about MaiMwana Project; your perceptions about home visiting, the challenges faced and how best to promote exclusive breastfeeding in the community. A tape recorder will be used to record all the interviews in order to capture the true picture of what we have discussed that will be used in the analysis. However, if you do not want the interview to be recorded this is not a problem and notes will be taken to keep a record of what was discussed.

What are the Potential benefits of the study to you?

You may not directly benefit from this study. However, you may find it beneficial to talk with me about your health. Also, what we will learn from this study will help us in coming up with

interventions to promote exclusive breastfeeding for the first six months of life among both HIV positive and negative women in the community which may help to reduce the rate of HIV transmission through breast milk and reduce infant death in future.

What are the Risks to you if you participate?

There are no known risks for participating in this study to you. However, if you are HIV positive you may feel concerned that taking part in this study would disclose your HIV status. It is important for you to know that this study is talking to both HIV positive and negative women, and all information will be kept confidential, so this should not be a risk for any woman involved. You may also feel embarrassed to answer some personal questions related to reproductive health, sex and HIV during the interview. You can stop the session at any time. If any of the topics discussed during the session upsets you, we can refer you for further counselling to a place which you feel comfortable.

How will your Confidentiality be protected?

All interviews will take place at a private place. 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 and all the tapes used in this study will be stored securely at MaiMwana Project during data collection and then at City University until the end of the study. The data will finally be archived at MaiMwana for not less than 7 years upon completion of the study and destruction of data will be done following MaiMwana guidelines. Your personal and identification information will be kept separately from your responses and only the researcher will access such information. Personal information from your study records will not be released without your written permission and your name will never be used in any publication or presentation about this study.

What will happen to the results of the study?

The results of the study will be submitted as part of my PhD dissertation at City University London. The results will also be made available to the community and study participants through the Area Development Committees and the District Executive Committees and also to people interested in promoting infant feeding practices in the country. Findings will also be disseminated during local and international conferences and also through written manuscripts.

Will you be asked to pay or be paid anything for participating in this study?

There is no cost to you and also you will not be paid for participating in this study. You will be given, however, transport reimbursement if you are expected to come back to the health facility for the interview in the local currency equivalent of US \$5 after the visit.

Who should you ask if you have any questions?

If you have questions related to this study you should call the investigator on [REDACTED] or MaiMwana office on [REDACTED]. If you have other questions, complaints or concerns about your rights while you are in this study you may contact the Vice Chairman of the National Health Sciences Research Committee in Malawi, [REDACTED] or [REDACTED] or the Secretary to the Research Ethics Committee at City University on 004420 7040 5763, or send E-mail to [REDACTED] [REDACTED] the Secretary to the Senate Ethics Committee, City University, Northampton square, London at [REDACTED]

Appendix 2.2 Chichewa version

Information sheet

Mawu oyamba

Dzina langa ndine Agatha Bula, ndikupanga maphunziro a udokotala ku sukulu ya ukachenjede ya City University ya ku London. Mukupemphedwa kutenga nawo mbali mu kafukufukuyu. Chikalatachi chikufotokozera uthenga okhudza cholinga, phindu komanso zovuta zomwe zingakhalepo kwa inu, ndi chomwe chikuyembekezereka kwa inu pa nthawi ya kafukufukuyu. Ndikambirana nanu za uthengawu ndi kuyankha mafunso ena ali onse omwe mungakhale nawo. Pamapeto pa kukufotokozerani za kafukufukuyu mwatsatane tsatane, mutha kupanga chiganizo choti mutenge nawo mbali kapena ayi. Mukamvetsetsa za kafukufukuyu, ndipo ngati mwavomera kutenga nawo mbali, mudzafunsidwa kusaina makalata awiri a chivomerezo kapena kuyika chindindo chanu pamaso pa mboni. Mudzapatsidwa imodzi mwa chikalata cha uthengachi komanso chikalata cha chivomerezo chimene musaine kuti mukasunge.

Chonde dziwani kuti:

- Kutenga nawo mbali kwanu mu kafukufukuyu nkodzipereka nokha.
- Mukhoza kusankha kusatenga nawo mbali, kapena kusiyira panjira kafukufukuyu pa nthawi iliyonse popanda kusokoneza ubale wanu ndi a bungwe la MaiMwana.
- Mfundo zonse zokuzindikiritsani ndi uthenga wanu zidzatetezedwa ndi kusungidwa mwa chinsinsi.

Kodi cholinga cha kafukufukuyu ndi chiyani?

Monga mukudziwa, amayi onse m'maiko omwe akukwera kumene kuphatikizapo kuno ku Malawi amapatsidwa uphungu woyamwitsa ana awo mwakathithi kwa miyezi isanu ndi umodzi yakubadwa. Izi zikuphatikizapo amayi amene ali ndi kachiroambo ka HIV kuti achepetse mpata opatsira ana awo kachiroambo ka HIV kudzera mu mkaka wa m'mawere komanso kufuna kuchepetsa imfa zomwe zimachitika chifukwa cha matenda otsegula m'mimba komanso kunyentchera. Cholinga cha kafukufukuyu ndikufuna kufufuza zifukwa zomwe zimasokoneza amayi kuti asakwanitse kuyamwitsa ana awo mwakathithi popanda kuwapatsa zakudya zina kapena zakumwa, ngati ali ndi kachiroambo ka HIV kapena alibe. Kafukufukuyu adzawunikanso ngati kulimbikitsa kuyamwitsa kumadela pogwiritsa ntchito aphungu ochokera kumadela kungathandize kukweza chiwerengero cha amayi amene akuyamwitsa mwakathithi pakati pa amayi amene ali ndi kachiroambo ka HIV komanso amene alibe kachiroamboka. Kafukufukuyu adzaunikanso maganizo a anthu osiyanana siyana pa nkhani yogwiritsa ntchito a phungu pofuna kupititsa patsogolo kuyamwitsa mwakathithi m'madela ndikupeza njira zomwe zingathandize kupititsa patsogolo kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yovomerezeka m'dziko muno.

Kodi ndi chifukwa chiyani mwafunsidwa kutenga nawo mbali mu kafukufukuyu?

Mukupemphedwa kutenga nawo mbali mu kafukufukuyu chifukwa mwina aphungu anadzakuyenderani panyumba panu kapena mwabereka ndipo mukuchokera ku midzi ya ku boma la Mchinji kumene a bungwe la MaiMwana akuyendera amayi m'mamidzi pofuna kulimbikitsa thanzi la amayi ndi ana kuphatikizapo kuyamwitsa mwakathithi.

Zotsatira za kafukufukuyu zitha kudzathandiza kumvetseta zovuta zimene amayi amakumana nazo zomwe zingathandize kupanga ma pologalamu oyenerera olimbikitsa kuyamwitsa mwakathithi pakati pa amayi onse ndi kuchepetsa kunyentchera, kufala kwa kachiroambo ka HIV kwa ana komanso infa za ana m'dziko muno.

Chidzachitike ndi chiyani mukasankha kutenga nawo mbali mu kafukufukuyu?

Mukasankha kutenga nawo mbali mu kafukufukuyu, mukhala m' modzi mwa anthuwotenga nawo mbali pafupifupi 60 amene adzafunsidwe mafunso payekha payekha. Kufunsidwa mafunso kuli konse kudzatenga pafupifupi ola limodzi. Pa nthawi yofunsidwa mafunsoyi, mudzafunsidwa mafunso okhudzana kuyamwitsa mwa kathithi, maganizo anu ndi zomwe mwakumana nazo zokhudza ndi kuyendera amayi m'makomo, komanso nkhani za kachiroombo ka HIV. Tidzayenera kujambula zokambirana zimene zidzachitike mu kafukufukuyu ndi cholinga choti tithe kukhala ndi chithunzithunzi choona zomwe takambirana. Komabe, ngati simukufuna kuti zokambiranazi zijambulidwe palibe vuto kwenikweni koma ndidzayenera kulemba zina mwa zimene tidzakambirane.

Kodi phindu la kafukufukuyu ndi chiyani kwa inu?

Simungathe kupeza phinu lenileni kuchokera mu kafukufukuyu. Komabe, Mukhoza kupeza kuti ndi zothandiza kukambirana ndi wogwira ntchito ndi anthu ogwira ntchito mu kafukufukuyu zokhudzana ndi umoyo wanu. Komanso, zomwe tidzaphunzire kuchokera mu kafukufukuyu zitha kudzatithandiza kupititsa patsogolo ma pologalamu olimbikitsa kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yakubadwa pakati pa amayi omwe ali ndi kachiroombo ka HIV komanso amene alibe kachiroomboka m'madela pofuna kuchepetsa kufala kwa kachiroombo ka HIV kudzera mu mkaka wa m'mawere ndi kuchepetsa chiwerengero cha infa za ana m'tsogolo.

Pali zovuta zANJI kwa inu ngati mutenga nawo mbali mu kafukufukuyu?

Palibe zovuta zodziwikiratu kwainu potenga nawo mbali mu kafukufukuyu. Komabe, ngati muli ndi kachiroombo ka HIV mutha kukhudzidwa kuti kutenga nawo mbali kwanu mu kafukufukuyu kutha kupangitsa kuulula za m'mene mulili zokhudza kachiroombo ka HIV. Ndikofunikira kuti mudziwe zoti kafukufukuyu akulankhula ndi amayi womwe ali ndi kachiroombo ka HIV komanso amene alibe kachiroombo ka HIV, ndipo uthenga onse udzasungidwa mwa chinsinsi, choncho ichi sichikhala chiopsezo kwa mayi aliyense amene akutenga nawo mbali. Mutha kuchita manyazi kuyankha mafunso ena okhudza inu okhudzana inu mwini pa zakubereka, kugonana komanso za kachiroombo ka HIV panthawi imene mukufunsidwa mafunso ndipo mutha kuimitsa kukambirana nthawi ina ili yonse. Ngati mutu wina uli onse pa nthawi yokambirana wakukhumudwitsani, titha kukutumizani kuti mukalandire uphungu owonjezera kumalo omwe mungakhale omasuka.

Kodi chinsinsi chanu chidzatetezedwa bwani?

Kufunsidwa mafunso kudzachitikira pa malo oduka mphepo. Uthenga onse umene udzapezeke mu kafukufukuyu udzasungidwa mwa chinsinsi molingana ndi lamulo. Wotenga nawo mbali onse adzadziwika ndi nambala. Dzina lanu silindalembedwa pena paliponse ndipo matepi onse amene adzagwiritsidwe ntchito mu kafukufukuyu adzasungidwa motetezedwa ku bungwe la MaiMwana pa nthawi imene tikutolera uthenga mu kafukufukuyu kenaka ku sukulu ya City University London mpakana pamapeto pa kafukufukuyu. Uthengawu pamapeto pake udzasungidwa ku bungwe la MaiMwana kwa zaka pafupifupi zisanu ndi ziwiri (7) kuchokera pomwe kafukufukuyu wathera ndipo zidzawonongedwa potsatira ndondomeko za bungwe la MaiMwana. Uthenga onse okuzindikiritsani inu udzasungidwa mosiyana ndi mayankho anu ndipo anthu wokhawo wogwira ntchito mukafukufukuyu ndi amene adzatha kufikira uthengawu. Uthenga wonse wokuzindikiritsani kuchokera mu zolembalemba za mu kafukufukuyu siudzulutsidwa popanda chilorezo chanu cholemba ndipo dzina lanu silidzagwiritsidwa ntchito mu zolembedwa kapena muzoulutsidwa zina zili zonse zokhudza kafukufukuyu.

Kodi chidzachitike ndi chiyani ndi zotsatira za kafukufukuyu?

Zotsatira za kafukufukuyu zidzagwiritsidwa ntchito ngati mbali ya maphunziro anga a udotolo ku sukulu ya ukachenjede ya City University London. Zotsatirazi zidzakhalanso zikupezeka kwa anthu otenga nawo mbali mu kafukufukuyu komanso anthu a ku madela kudzera mu komiti ya chitukuko cha m'madela (Area Development Committees) ndi komiti ya akulu akulu ya pa boma (District Executive Committees); komanso kwa anthu amene ali ndi chidwi pa kadyetsedwe ka ana m'dziko muno komanso maiko ena. Zotsatira zidzawulutsidwanso pa misonkhano yochitika kwathu komkuno ndi misonkhano ya ku maiko akunja komanso mzolembalemba.

Kodi mudzafunsidwa kulipira kapena kuripidwa china chilli chonse chifukwa chotenga nawo mbali mu kafukufukuyu?

Simundzalipira komanso simudzalipidwa chifukwa chotenga nawo mbali mu kafukufukuyu. Komabe, mudzabwezeredwa ndalama yoyendera ya kwathu konkuno yofana mphamvu ndi ndalama ya ku America, \$5 pa mapeto pa ulendo ngati zokambiranazi zidzayenera kuchitikira kumalo ena kutali ndi kudela kwanu kapena kutali ndi ku kiliniki.

Kodi mukuyenera kufunsa ndani mukakhala ndi mafunso ena ali onse?

Ngati muli ndi mafunso wokhudzana ndi kafukufukuyu, mutha kundiyimbira telefoni pa [REDACTED] kapena kuyimbira wamkulu wa bungwe la MaiMwana pa [REDACTED]. Ngati muli ndi mafunso ena, madandaulo kapena nkhwawa zokhudzana ndi ufulu wanu pamene muli mu kafukufukuyu mutha kuwapeza amene ali wachiwiri wapampando wa bungwe la National Health Sciences Research Committee kuno ku Malawi, a [REDACTED] pa [REDACTED] kapena mlembi wa bungwe loyang'anira a kafukufuku la ku City University London pa 004420 7040 5763 kapena tumizani uthenga (E-mail) kwa a [REDACTED], mlembi wa Senate Ethics Committee ya ku City University, ku Northampton square, London pa [REDACTED]

Informed consent form for breastfeeding mothers

Participant ID Number: _____

Instructions: please tick box to indicate agreement

1. Ndikutsimikiza kuti ndawerenga/ogwira ntchito mukafukufukuyu andiwerengera chikalata cha uthenga cha pa August 2011cha kafukufuku amene watchulidwa pamwambayu ndipo ndinali ndi mwayi ofunsa mafunso komanso kuyankhidwa mafunsowa moyenerera.
2. Ndikudziwa kuti kutenga nawo mbali kwanga ndikodzipereka ndekha ndinso kuti ndili ndi ufulu wosiya kutenga nawo mbali nthawi ina iliyonse ndipo popanda kusokoneza ubale wanga ndi a bungwe la MaiMwana komanso achipatala.
3. Ndikudziwa kuti kutenga nawo mbali kwanga kutha kuchepetsedwa kapena kusiyitsidwa ngati ofunsa mafunso ataona kuti ndili ndi mantha kapena ndikusowa mtendere mu nthawi yofunsa mafunso.
4. Ndikuvomera sindikuvomereza zokambiranazi zijambulidwe pa tepi.
5. Ndikuvomera kuti zina za zimene ndalankhula/ zatuluka panthawi imene ndikutenga nawo mbali mu kafukufukuyu zidzagwiritsidwe ntchito mwachinsinsi m.malipoti kapena zosindikizidwa zili zones zkhudza kafukufukuyu.
6. Ndikuvomera sindikuvomera kutenga nawo mbali mu kafukufuku watchulidwa pamwambayu.

Dzina la wotenga mbali

Sainiya otenga mbali

Tsiku

Dzina la opanga kafukufuku

Sayini ya opanga kafukufuku

Tsiku

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

Dzina la otenga mbali-----

Dzina la mboni

Saini ya Mboni

Tsiku

Appendix 3: Information Sheet and Informed Consent Form for peer counsellors and Supervisors

3.1: English version

Information sheet

Introduction

My name is Agatha Bula; I am a doctoral student at City University London. You are invited to participate in this research study. This form provides information about the purpose, benefits and possible risks of the study and what will be expected of you during the study. I will discuss the information with you and answer any questions you may have. After the study has been fully explained to you, you can decide whether or not you want to participate. Once you understand this study, and if you agree to take part, you will be asked to sign two copies of the study consent form or make your mark in front of someone. You will be offered a copy of this information sheet and consent form to keep. Please note that:

1. Your participation in this study is entirely voluntary.
2. You may decide not to take part or to withdraw from this study at any time without jeopardizing your relationship with MaiMwana project.
3. Your identity and information will be protected and kept confidential.

What is the purpose of this study?

As you are aware, all mothers in developing countries including Malawi are counselled and encouraged to exclusively breastfeed their babies for the first six months of life. This include women who are HIV positive in order to reduce the chances of transmitting HIV through breast milk and prevent early death due to diarrhoea and malnutrition. This study aims at exploring what affects women being able to breastfeed their babies without giving other food or drinks, whether they are HIV positive or negative. It will also look at whether using peer counsellors to promote exclusive breastfeeding in the community will increase the rates of exclusive breastfeeding among HIV positive and negative women. The study is also looking at the views of different groups of people on the use of peer counsellors to promote exclusive breastfeeding in the community and identify ways of promoting exclusive breastfeeding practices for a longer period of time in the country.

Why are you being asked to participate in this study?

You are being asked to take part in this study because you are one of the counsellors or supervisors providing home counselling to women in the community with MaiMwana Project in Mchinji district to promote maternal and child health including exclusive breastfeeding.

The findings may help to understanding the challenges faced by women that would be useful in the development of effective community based intervention programmes to promote exclusive breastfeeding among all women and promote optimum infant feeding and reduce malnutrition, HIV transmission and infant mortality in this country.

What will happen if you decide to join this study?

If you decide to take part in this study, you will be one of approximately 60 participants who will be interviewed individually. Each interview will last for approximately one hour. During the interview you will be asked some questions about your knowledge about MaiMwana Project; your perceptions about home visiting, how you were involved in the implementation of the programme and how best to promote exclusive breastfeeding in the community. A tape recorder will be used to record all the interviews in order to capture the true picture of what we have discussed. However, if you do not want the interview to be recorded this is not a problem and notes will be taken to keep a record of what was discussed.

What are the Potential benefits of the study to you?

You may not directly benefit from this study. However, what we will learn from this study will help us in coming up with interventions to promote exclusive breastfeeding for the first six months of life

among both HIV positive and negative women in the community in order to reduce the rate of HIV transmission through breast milk and reduce infant death in the future.

What are the Risks to you if you participate?

There are no known risks for participating in this study to you. However, if the interview or some questions makes you feel distressed or embarrassed you are free to skip any questions or stop the interview at any time during the interview.

How will your Confidentiality be protected?

All interviews will take place at a private place. 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 and all the tapes used in this study will be stored securely at MaiMwana Project during data collection and then at City University until the end of the study. The data will finally be archived at MaiMwana for not less than 7 years upon completion of the study and destruction of data will be done following MaiMwana guidelines. Your personal and identification information will be kept separately from your responses and only the researcher will access such information. Personal information from your study records will not be released without your written permission and your name will never be used in any publication or presentation about this study.

What will happen to the results of the study?

The results of the study will be submitted as part of my PhD dissertation at City University London. The results will also be made available to the community and study participants through the Area Development Committees and the District Executive Committees and also to people interested in infant feeding practices in the country. Findings will also be disseminated during local and international conferences and also through written manuscripts.

Will you be asked to pay or be paid anything for participating in this study?

There is no cost to you and also you will not be paid for participating in this study. You will be given, however, transport reimbursement if you are expected to come back to the health facility for the interview in the local currency equivalent of US \$5 after the visit.

Who should you ask if you have any questions?

If you have questions related to this study you should call the investigator on [REDACTED] or MaiMwana office on [REDACTED]. If you have other questions, complaints or concerns about your rights while you are in this research study you may contact the Vice Chairman of the National Health Sciences Research Committee in Malawi, [REDACTED] on [REDACTED] or the Secretary to the Research Ethics Committee at City University on 004420 7040 5763 or send E-mail to [REDACTED], Secretary to Senate Ethics Committee, City University, Northampton square, London at [REDACTED]

Informed consent form for peer counselors and supervisors

Participant ID number _____

Instructions: please tick box to indicate agreement

1. Confirm that I have read/staff have read for me the information sheet dated August 2011 for the above named study and I have had the opportunity to ask questions and have these questions answered satisfactory.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without affecting my relationship with MaiMwana and hospital staff.
3. I understand that my participation can be shortened or terminated if it looks to the interviewer that I am becoming distressed or embarrassed in the interview.
4. I do agree to quotes arising from my participation in the study being used anonymously in any reports or publications.
5. I agree or I do not agree that this interview should be audio-taped.
6. I do agree do not agree to take part in the above mentioned study.

----- 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 the researcher should write the participant's name below. Witness is required for the consenting in this case.

Name of participant-----

----- Name of witness	----- Signature of witness	----- Date
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Appendix 3.2 Chichewa version: Information sheet

Mawu oyamba

Dzina langa ndine Agatha Bula, Ndikupanga maphunziro a udokotala ku sukulu ya ukachenjede ya City University. Mukupemphedwa kutenga nawo mbali mu kafukufukuyu. Chikalatachi chikufotokoza uthenga okhudza cholinga, phindu komanso zovuta zomwe zingakhalepo kwa inu, ndi chomwe tikuyembekezera kwa inu pa nthawi ya kafukufukuyu. Ndikambirana nanu za uthengawu ndi kuyankha mafunso ena alionse amene mungakhale nawo. Pamapeto pa kukufotokozerani za kafukufukuyu mwatsatane tsatane, mutha kupanga chiganizo choti mutenge nawo mbali kapena ayi. Mukamvetsetsa za kafukufukuyu, ndipo ngati mwavomera kutenga nawo mbali, mudzafunsidwa kusaina makalata awiri a chivomerezo kapena kuyika chindindo chanu pamaso pa mboni. Mudzapatsidwa imodzi mwa chikalata cha uthengachi komanso cha chivomerezo chimene musaine kuti mukasunge.

Chonde dziwani kuti:

- Kutenga nawo mbali kwanu mu kafukufukuyu nkodzipereka nokha.
- Mukhoza kusankha kusatenga nawo mbali, kapena kusiyira panjira kafukufukuyu pa nthawi iliyonse popanda kusokoneza ubwenzi wanu ndi a bungwe la MaiMwana.
- Mfundo zonse zokuzindikiritsani ndi uthenga wanu zidzatetezedwa ndi kusungidwa mwa chinsinsi.

Kodi cholinga cha kafukufukuyu ndi chiyani?

Monga mukudziwa, amayi onse m'maiko omwe akukwera kumene kuphatikizapo kuno ku Malawi amapatsidwa uphungu woyamwitsa ana awo mwakathithi kwa miyezi isanu ndi umodzi yakubadwa. Izi zikuphatikizapo amayi amene ali ndi kachirobomba ka HIV kuti achepetse mpata opatsira mwana kachirobomba ka HIV kudzera mu mkaka wa m'mawere komanso kufuna kuchepetsa imfa zobwera chifukwa cha matenda otsegula m'mimba komanso kunyentchera. Cholinga cha kafukufukuyu ndikufuna kufufuza zifukwa zomwe zimasokoneza amayi kuti asakwanitse kuyamwitsa ana awo mwakathithi popanda kuwapatsa zakudya zina kapena zakumwa, ngati ali ndi kachiro ka HIV kapena alibe. Kafukufukuyu adzawunikanso ngati kulimbikitsa kuyamwiya kumadela pogwiritsa ntchito aphungu ochokera kumadela pogwiritsa ntchito aphungu kungathanndize kukweza chiwerengero cha amayi amene akuyamwitsa mwakathithi pakati pa amayi amene ali ndi kachirobomba ka HIV komanso amene alibe kachirobomba. Kafukufukuyu adzaunikanso maganizo a anthu osiyanana siyana pa nkhani yogwiritsa ntchito a phungu pofuna kupititsa patsogolo kuyamwitsa mwakathithi m'madela ndikupeza njira zomwe zingathandize kupititsa patsogolo kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yovomerezeka m'dziko muno.

Kodi ndi chifukwa chiyani mwafunsidwa kutenga nawo mbali mu kafukufukuyu?

Mukupemphedwa kutenga nawo mbali mu kafukufukuyu chifukwa ndinu m'modzi mwa aphungu kapena oyang'anira aphungu amene mumapereka uphungu kwa amayi m'madela ndi bungwe la MaiMwana ku boma la Mchinji pofuna kupititsa patsogolo thanzi la main di mwana kuphatikizapo kuyamwitsa mwakathithi. Zotsatira za kafukufukuyu zitha kudzathandiza kumvetseta zovuta zimene amayi amakumana nazo zomwe zingathandize kupanga ma pologalamu oyenerera a ku madela olimbikitsa kuyamwitsa mwakathithi pakati pa amayi onse ndi kuchepetsa kunyentchera, kufala kwa kachirobomba ka HIV kwa ana komanso infa za ana m'dziko muno.

Kodi chidzachitike ndi chiyani mukasankha kutenga nawo mbali mu kafukufukuyu?

Mukasankha kutenga nawo mbali mu kafukufukuyu, mukhala m'modzi mwa anthuwotenga nawo mbali pafupifupi 60 amene adzafunsidwe mafunso payekha payekha. Kufunsidwa mafunso kuli konse kudzatenga pafupifupi ola limodzi. Panthawi yofunsidwa mafunso mudzafunsidwa mafunso ena okhudza maganizo anu kuyendera amayi m'makomo, kuyamwitsa mwakathithi, kutumiza anthu kukalandira chithandizo komanso njira zoyenerera kuyendetsera pologalamuyi. Tidzayenera kujambula zokambirana zimene zidzachitike mu kafukufukuyu kuti tithe kukhala ndi chithunzithunzi choona cha zomwe takambirana. Komabe, ngati simukufuna kuti kufunsidwa mafunsoku kujambulidwe palibe vuto kwenikweni koma ndidzayenera kulemba zimene tidzakambirane.

Kodi phindu la kafukufukuyu ndi chiyani kwa inu?

Simungathe kupeza phinu lenileni kuchokera mu kafukufukuyu. Komabe, zomwe tidzaphunzire kuchokera mu kafukufukuyu zidzatithandiza kupititsa patsogolo ma pologalamu olimbikitsa kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yakubadwa pakati pa amayi womwe ali ndi kachiroambo ka HIV komanso amene alibe m'madela pofuna kuchepetsa kufala kwa kachiroambo ka HIV kudzera mu mkaka wa m'mawere ndi kuchepetsa chiwerengero cha infa za ana m'tsogolo.

Kodi pali zovuta zANJI kwa inu ngati mutenga nawo mbali mu kafukufukuyu?

Palibe zovuta zodziwikiratu kwa inu potenga nawo mbali mu kafukufukuyu. Komabe ngati kufunsidwa mafunsoku kapena mafunso ena akupangitsa kusowa mtendere muli ndi ufulu kusayankha mafunsowa kapena kusiyitsa zokambiranazi nthawi ina ili yonse.

Kodi chinsinsi chanu chidzatetezedwa bwani?

Kufunsidwa mafunso kudzachitikira pa malo oduka mphepo. Uthenga onse umene udzapezeke mu kafukufukuyu udzasungidwa mwa chinsinsi malingana ndi lamulo. Wotenga nawo mbali onse adzadziwika ndi nambala. Dzina lanu silindalembedwa pena paliponse ndipo matepi onse amene adzagwiritsidwe ntchito mu kafukufukuyu adzasungidwa motetezedwa ku bungwe la MaiMwana pa nthawi imene tikotolera uthenga mu kafukufukuyu kenaka ku sukulu ya City University London mpakana pamapeto pa kafukufukuyu. Uthengawu pamapeto pake udzasungidwa ku bungwe la MaiMwana kwa zaka pafupifupi zisanu ndi ziwiri (7) kuchokera pomwe kafukufukuyu wathera ndipo zidzawonongedwa potsatira ndondomeko za bungwe la MaiMwana. Uthenga onse okuzindikiritsani inu udzasungidwa mosiyana ndi mayankho anu ndipo anthu wokhawo wogwira ntchito mukafukufukuyu ndi amene adzatha kufikira uthengawu. Uthenga wonse wokuzindikiritsani kuchokera mu zolemba lemba za mu kafukufukuyu siudzaulutsidwa popanda chilorezo chanu cholemba ndipo dzina lanu silidzagwiritsidwa ntchito mu zolembedwa kapena muzoulutsidwa zina zili zonse zokhudza kafukufukuyu.

Kodi chidzachitike ndi chiyani ndi zotsatira za kafukufukuyu?

Zotsatira za kafukufukuyu zidzagwiritsidwa ntchito ngati mbali ya maphunziro anga a udokotala ku sukulu ya ukachenjede ya City University London. Zotsatirazi zidzakhanso zikupezeka kwa anthu otenga nawo mbali mu kafukufukuyu komanso anthu a ku madela kudzera mu komiti ya chitukuko cha m'madela (Area Development Committees) ndi komiti ya akulu akulu ya pa boma (District Executive Committees); komanso kwa anthu amene ali ndi chidwi pa kadyetsedwe ka ana m'dziko muno komanso maiko ena. Zotsatira zidzawulutsidwanso pa misonkhano yochitika kwathu komkuno ndi misonkhano ya ku maiko akunjika komanso mzolembalemba.

Kodi mudzafunsidwa kulipira kapena kuripidwa china chilli chonse chifukwa chotenga nawo mbali mu kafukufukuyu?

Simundzalipira komanso simundzalipidwa chifukwa chotenga nawo mbali mu kafukufukuyu. Komabe, mudzabwezedwa ndalama yoyendera ya kwathu konkuno yofana mphamvu ndi ndalama ya ku America, \$5 pa mapeto pa ulendo ngati zokambiranazi zidzayenera kuchitikira kumalo ena kutali ndi kudela kwanu kapena kutali ndi ku kiliniki.

Kodi mukuyenera kufunsa ndani mukakhala ndi mafunso ena ali onse?

Ngati muli ndi mafunso wokhudzana ndi kafukufukuyu, mutha kundiyimbira telefoni pa [REDACTED] kapena kuyimbira wamkulu wa bungwe la MaiMwana pa [REDACTED]. Ngati muli ndi mafunso ena, madandaulo kapena nkhwana zokhudzana ndi ufulu wanu pamene muli mu kafukufukuyu mutha kuwapeza amene ali wachiwiri wapampando wa bungwe la National Health Sciences Research Committee kuno ku Malawi, a Professor. J. Mfutso-Bengo pa [REDACTED] kapena mlembi wa bungwe loyang'anira a kafukufuku la ku City University London pa [REDACTED] kapena tumizani uthenga (E-mail) kwa a Anna Ramberg, mlembi wa Senate Ethics Committee ya ku City University, ku Northampton square, London pa [REDACTED].

Informed consent form for peer counselors and supervisors

Participant ID number _____

Instructions: please tick box to indicate agreement

1. Ndikutsimikiza kuti ndawerenga/ogwira ntchito mukafukufukuyu andiwerengera chikalata cha uthenga cha pa August 2011cha kafukufuku amene watchulidwa pamwambayu ndipo ndinali ndi mwayi ofunsa mafunso komanso kuyankhidwa mafunsowa moyenerera.
2. Ndikudziwa kuti kutenga nawo mbali kwanga ndikodzipereka ndekha ndinso kuti ndili ndi ufulu wosiya kutenga nawo mbali nthawi ina ili yonse ndipo popanda kusokoneza ubale wanga ndi a bungwe la MaiMwana komanso achipatala.
3. Ndikudziwa kuti kutenga nawo mbali kwanga kutha kuchepetsedwa kapena kusiyitsidwa ngati ofunsa mafunso ataona kuti ndili ndi mantha kapena ndikusowa mtendere mu nthawi yofunsa mafunso.
4. Ndikuvomera sindikuvomereza zokambiranazi zijambulidwe pa tepi.
5. Ndikuvomera kuti zina za zimene ndalankhula/ zatuluka panthawi imene ndikutenga nawo mbali mu kafukufukuyu zidzagwiritsidwe ntchito mwachinsinsi m.malipoti kapena zosindikizidwa zili zones zkhudza kafukufukuyu.
6. Ndikuvomera sindikuvomera kutenga nawo mbali mu kafukufuku watchulidwa pamwambayu.

Dzina la wotenga mbali

Sainiya otenga mbali

Tsiku

Dzina la opanga kafukufuku

Sayini ya opanga kafukufuku

Tsiku

Appendix 4: Information Sheet and informed Consent Form for Key Informants

4.1: English version

Introduction

My name is Agatha Bula; I am a doctoral student at City University London. You are invited to participate in this research study. This form provides information about the purpose, benefits and possible risks of the study and what will be expected of you during the study. I will discuss the information with you and answer any questions you may have. After the study has been fully explained to you, you can decide whether or not you want to participate. Once you understand this study, and if you agree to take part, you will be asked to sign two copies of the study consent form or make your mark in front of someone. You will be offered a copy of this information sheet and consent form to keep. Please note that:

1. Your participation in this study is entirely voluntary.
2. You may decide not to take part or to withdraw from this study at any time without jeopardizing your relationship with MaiMwana project.

What is the purpose of this study?

As you are aware, all mothers in developing countries including Malawi are counselled and encouraged to exclusively breastfeed their babies for the first six months of life. This includes women who are HIV positive in order to reduce the chances of transmitting HIV through breast milk and prevent early infant death due to diarrhoea and malnutrition. This study aims at exploring what affects women being able to breastfeed their babies without giving other food or drinks, whether they are HIV positive or negative. It will also look at whether using peer counsellors to promote exclusive breastfeeding in the community will increase the rates of exclusive breastfeeding among HIV positive and negative women. The study is also looking at the views of different groups of people on the use of peer counsellors to promote exclusive breastfeeding in the community and identify ways of promoting exclusive breastfeeding practices for a longer period of time in the country.

Why are you being asked to participate in this study?

You are being asked to take part in this study because you either come from or you work in one of the health facilities within the communities where MaiMwana project is visiting women in their homes to promote exclusive breastfeeding.

The findings may help to understanding the challenges faced by women that would be useful in the development of effective community based intervention programmes to promote exclusive breastfeeding among all women and promote optimum infant feeding and reduce malnutrition, HIV transmission and infant mortality in the country.

What will happen if you decide to join this study?

If you decide to take part in this study, you will be one of approximately 60 participants who will be interviewed individually. Each interview will last for approximately one hour. During the interview you will be asked some questions about your knowledge about MaiMwana Project; your perceptions about home visiting, how you were involved in the implementation of the programme and how best to promote exclusive breastfeeding in the community. A tape recorder will be used to record all the interviews in order to capture the true picture of what we have discussed. However, if you do not want the interview to be recorded this is not a problem and notes will be taken to keep a record of what was discussed.

What are the Potential benefits of the study to you?

You may not directly benefit from this study. However, what we will learn from this study will help us in coming up with interventions to promote exclusive breastfeeding for the first six months of life among both HIV positive and negative women in the community in order to reduce the rate of HIV transmission through breast milk and reduce infant death in the future.

What are the Risks to you if you participate?

There are no known risks for participating in this study to you. However, if the interview or some questions makes you feel distressed or embarrassed you are free to skip any questions or stop the interview at any time during the interview.

How will your Confidentiality be protected?

All interviews will take place at a private place. 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 and all the tapes used in this study will be stored securely at MaiMwana Project during data collection and then at City University until the end of the study. The data will finally be archived at MaiMwana for not less than 7 years upon completion of the study and destruction of data will be done following MaiMwana guidelines. Your personal and identification information will be kept separately from your responses and only the research team will access such information. Personal information from your study records will not be released without your written permission and your name will never be used in any publication or presentation about this study.

What will happen to the results of the study?

The results of the study will be submitted as part of my PhD dissertation at City University London. The results will also be made available to the community and study participants through the Area Development Committees and the District Executive Committees and also to people interested in infant feeding practices in the country. Findings will also be disseminated during local and international conferences and also through written manuscripts.

Will you be asked to pay or be paid anything for participating in this study?

There is no cost to you and also you will not be paid for participating in this study. You will be given, however, transport reimbursement if you are expected to come back to the health facility for the interview in the local currency equivalent of US \$5 after the visit.

Who should you ask if you have any questions?

If you have questions related to this study you should call the investigator on [REDACTED] or MaiMwana office using on [REDACTED]. If you have other questions, complaints or concerns about your rights while you are in this research study you may contact the Vice Chairman of the National Health Sciences Research Committee in Malawi, [REDACTED] at [REDACTED] or the Secretary to the Research Ethics Committee at City University at 004420 7040 5763 or send E-mail to [REDACTED] Secretary to Senate Ethics Committee, City University, Northampton square, London at [REDACTED]

Informed consent form for key informants

Participant ID number _____

Instructions: please tick box to indicate agreement

1. Confirm that I have read/staff have read for me the information sheet dated August 2011 for the above named study and I have had the opportunity to ask questions and have these questions answered satisfactory.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without affecting my relationship with MaiMwana and hospital staff.
3. I understand that my participation can be shortened or terminated if it looks to the interviewer that I am becoming distressed or embarrassed in the interview.
4. I do agree to quotes arising from my participation in the study being used anonymously in any reports or publications.
5. I agree or I do not agree that this interview should be audio-taped.
6. I do agree do not agree to take part in the above mentioned study.

----- 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 the researcher should write the participant's name below. Witness is required for the consenting in this case.

Name of participant-----	-----	-----
----- Name of witness	----- Signature of witness	----- Date

Appendix 4.2. Chichewa version

Study information sheet

Mawu oyamba

Dzina langa ndine Agatha Bula, Ndikupanga maphunziro a udokotala ku sukulu ya ukachenjede ya City University. Mukupemphedwa kutenga nawo mbali mu kafukufukuyu. Chikalatachi chikufotokoza uthenga okhudza cholinga, phindu komanso zovuta zomwe zingakhalepo kwa inu, ndi chomwe chikuyembekezereka kwa inu pa nthawi ya kafukufukuyu. Ndikambirana nanu za uthengawu ndi kuyankha mafunso ena ali onse amene mungakhale nawo. Pamapeto pa kukufotokozerani za kafukufukuyu mwatsatane tsatane, mutha kupanga chiganizo choti mutenge nawo mbali kapena ayi. Mukamvetsetsa za kafukufukuyu, ndipo ngati mwavomera kutenga nawo mbali, mudzafunsidwa kusaina makalata awiri a chivomerezo kapena kuyika chindindo chanu pamaso pa mboni. Mudzapatsidwa imodzi mwa chikalata cha uthengachi komanso chikalata cha chivomerezo chimene musaine kuti mukasunge. Chonde dziwani kuti:

- Kutenga nawo mbali kwanu mu kafukufukuyu nkodzipereka nokha.
- Mukhoza kusankha kusatenga nawo mbali, kapena kusiyira panjira kafukufukuyu pa nthawi iliyonse popanda kusokoneza ubwenzi wanu ndi a bungwe la MaiMwana.
- Mfundo zonse zokuzindikiritsani inu ndi uthenga wanu zidzatetezedwa ndi kusungidwa mwa chinsinsi.

Kodi cholinga cha kafukufukuyu ndi chiyani?

Monga mukudziwa, amayi onse m'maiko omwe akukwera kumene kuphatikizapo kuno ku Malawi amapatsidwa uphungu woyamwitsa ana awo mwakathithi kwa miyezi isanu ndi umodzi yakubadwa. Izi zikuphatikizapo amayi amene ali ndi kachiroboko ka HIV kuti achepetse mpata opatsira mwana kachiroboko ka HIV kudzera mu mkaka wa m'mawere komanso kufuna kuchepetsa imfa zobwera chifukwa cha matenda otsegula m'mimba komanso kunyentchera. Cholinga cha kafukufukuyu ndikufuna kufufuza zifukwa zomwe zimasokoneza amayi kuti asakwanitse kuyamwitsa ana awo mwakathithi popanda kuwapatsa zakudya zina kapena zakumwa, ngati ali ndi kachiro ka HIV kapena alibe. Kafukufukuyu adzawunikanso ngati kulimbikitsa kuyamwiya kumadela pogwiritsa ntchito aphungu ochokera kumadela pogwiritsa ntchito aphungu kungathanndize kukweza chiwerengero cha amayi amene akuyamwitsa mwakathithi pakati pa amayi amene ali ndi kachiroboko ka HIV komanso amene alibe kachiroboko. Kafukufukuyu adzaunikanso maganizo a anthu osiyana siyana pa nkhani yogwiritsa ntchito a phungu pofuna kupititsa patsogolo kuyamwitsa mwakathithi m'madela ndikupeza njira zomwe zingathanndize kupititsa patsogolo kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yovomerezeka m'dziko muno.

Kodi ndi chifukwa chiyani mwafunsidwa kutenga nawo mbali mu kafukufukuyu?

Mukupemphedwa kutenga nawo mbali mu kafukufukuyu chifukwa mukuchokera kudela kapena mumagwira ntchito pa zipatala chimene chili ku mdela limene a bungwe la MaiMwana akuyendera amayi m'makomo pofuna kupititsa patsogolo thanzi la mai ndi mwana kuphatikizapo kuyamwitsa mwakathithi.

Zotsatira za kafukufukuyu zikhoza kudzathanndiza kumvetseta zovuta zimene amayi amakumana nazo zimene zingathanndize kupanga ma pologalamu oyenerera a ku madela olimbikitsa kuyamwitsa mwakathithi pofuna kulimbikitsa madyedwe oyenerera a ana ndi kuchepetsa kufala kwa kachiroboko ka HIV kwa ana komanso infa za ana m'dziko muno.

Kodi chidzachitike ndi chiyani mukasankha kutenga nawo mbali?

Mukasankha kutenga nawo mbali mu kafukufukuyu, mukhala m'modzi mwa anthuwotenga nawo mbali pafupifupi 60 amene adzafunsidwe mafunso payekha payekha. Kufunsidwa mafunso kuli konse kudzatenga pafupifupi ola limodzi. Pa nthawi yofunsidwa mafunso, mudzafunsidwa mafunso ena okhudza zomwe mukudziwa za bungwe la MaiMwana, maganizo anu okhudza kuyendera amayi m'makomo, mmene munatengera nawo mbali pamene amapanga pulogalamuyi komanso m'mene tingalimbikitsire kuyamwitsa mwa kathithi ku madela. Tidzayenera kujambula zokambirana zones zimene zidzachitike mu kafukufukuyu ndi cholinga choti tithe kukhala ndi chithunzithunzi choona cha zomwe takambirana. Komabe, ngati simukufuna kuti kufunsidwa mafunsoku kujambulidwe palibe vuto kwenikweni koma ndidzayenera kulemba zina mwa zimene tidzakambirane.

Kodi phindu la kafukufukuyu ndi chiyani kwa inu?

Simungathe kupeza phinu lenileni kuchokera mu kafukufukuyu. Komabe, zomwe tidzaphunzire kuchokera mu kafukufukuyu zidzatithandiza kupititsa patsogolo ma pologalamu olimbikitsa kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yakubadwa pakati pa amayi womwe ali ndi kachiroambo ka HIV komanso amene alibe kachiroboka m'madela pofuna kuchepetsa kufala kwa kachiroambo ka HIV kudzera mu mkaka wa m'mawere ndi kuchepetsa chiwerengero cha infa za ana m'tsogolo.

Kodi pali zovuta zANJI kwa inu ngati mutenga nawo mbali mu kafukufukuyu?

Palibe zovuta zodziwikiratu kwa inu potenga nawo mbali mu kafukufukuyu. Komabe ngati kufunsidwa mafunsoku kapena mafunso ena akupangitsa kusowa mtendere muli ndi ufulu kusayanghala mafunsowa kapena kusiyitsa zokambiranazi nthawi ina ili yonse.

Kodi chinsinsi chanu chidzatetezedwa bwani?

Kufunsidwa mafunso kudzachitikira pa malo oduka mphepo. Uthenga onse umene udzapezeke mu kafukufukuyu udzasungidwa mwa chinsinsi malingana ndi lamulo. Wotenga nawo mbali onse adzadziwika ndi nambala. Dzina lanu silidzalembedwa pena paliponse ndipo matepi onse amene adzagwiritsidwe ntchito mu kafukufukuyu adzasungidwa motetezedwa ku bungwe la MaiMwana pa nthawi imene tikutolera uthenga mu kafukufukuyu kenaka ku sukulu ya City University London mpakana pamapeto pa kafukufukuyu. Uthengawu pamapeto pake udzasungidwa ku bungwe la MaiMwana kwa zaka pafupifupi zisanu ndi ziwiri (7) kuchokera pomwe kafukufukuyu wathera ndipo zidzawonongedwa potsatira ndondomeko za bungwe la MaiMwana. Uthenga onse okuzindikiritsani inu udzasungidwa mosiyana ndi mayankho anu ndipo anthu wokhawo wogwira ntchito mukafukufukuyu ndi amene adzatha kufikira uthengawu. Uthenga wonse wokuzindikiritsani kuchokera mu zolembe lemba za mu kafukufukuyu siudzaulutsidwa popanda chilorezo chanu cholembe ndipo dzina lanu silidzagwiritsidwa ntchito mu zolembedwa kapena muzoulutsidwa zina zili zonse zokhudza kafukufukuyu.

Kodi chidzachitike ndi chiyani ndi zotsatira za kafukufukuyu?

Zotsatira za kafukufukuyu zidzagwiritsidwa ntchito ngati mbali ya maphunziro anga a udokotala ku sukulu ya ukachenjede ya City University London. Zotsatirazi zidzakhanso zikupezeka kwa anthu ku madela komanso anthu otenga nawo mbali mu kafukufukuyu komanso anthu a ku madela kudzera mu komiti ya chitukuko cha m'madela (Area Development Committees) komanso komiti ya akulu akulu ya pa boma (District Executive Committees); komanso kwa anthu amene ali ndi chidwi pa kadyetsedwe ka ana m'dziko muno komanso maiko ena. Zotsatira zidzawulutsidwanso pa misonkhano yochitika kwathu komkuno ndi misonkhano ya ku maiko akunja komanso mzolembalembe.

Kodi mudzafunsidwa kulipira kapena kuripidwa china chilli chonse chifukwa chotenga nawo mbali mu kafukufukuyu?

Simundzalipira komanso simudzalipidwa chifukwa chotenga nawo mbali mu kafukufukuyu. Komabe, mudzabwezedwa ndalama yoyendera ya kwathu konkuno yofana mphamvu ndi ndalama ya ku America, \$5 pa mapeto pa ulendo ngati zokambiranazi zidzayenera kuchitikira kumalo ena kutali ndi kudela kwanu kapena kutali ndi ku kiliniki.

Kodi mukuyenera kufunsa ndani mukakhala ndi mafunso ena ali onse?

Ngati muli ndi mafunso wokhudzana ndi kafukufukuyu, mutha kundiyimbira telefoni pa [REDACTED] kapena kuyimbira wamkulu wa bungwe la MaiMwana pa [REDACTED]. Ngati muli ndi mafunso ena, madandaulo kapena nkhwawa zokhudzana ndi ufulu wanu pamene muli mu kafukufukuyu mutha kuwapeza amene ali wachiwiri wapampando wa bungwe la National Health Sciences Research Committee kuno ku Malawi, a [REDACTED] pa [REDACTED] kapena mlembi wa bungwe loyang'anira a kafukufuku la ku City University London pa 004420 7040 5763 kapena tumizani uthenga (E-mail) kwa a [REDACTED], mlembi wa Senate Ethics Committee ya ku City University, ku Northampton square, London pa [REDACTED]

Informed consent form for key informants

Title of the study: Exploring the effects of socio-demographic characteristics of HIV positive women on exclusive breastfeeding practices and promotion in Mchinji, Malawi

Principal Investigator: Agatha Bula

Contacts:

MaiMwana Project

P.O Box 2, Mchinji, Malawi

Tel: [REDACTED] (office)

Mobile: [REDACTED] (office)

Department of Maternal and Child Health

School of Health sciences, United Kingdom

Tel (UK): [REDACTED]

email: [REDACTED]

Participant ID Number: _____

Instructions: please tick box to indicate agreement

1. Ndikutsimikiza kuti ndawerenga/ogwira ntchito mukafukufukuyu andiwerengera chikalata cha uthenga cha pa August 2011 cha kafukufuku amene watchulidwa pamwambayu ndipo ndinali ndi mwayi ofunsa mafunso komanso kuyankhidwa mafunsowa moyenerera.
2. Ndikudziwa kuti kutenga nawo mbali kwanga ndikodzipereka ndekha ndinso kuti ndili ndi ufulu wosiya kutenga nawo mbali nthawi ina ili yonse ndipo popanda kusokoneza ubale wanga ndi a bungwe la MaiMwana komanso achipatala.
3. Ndikudziwa kuti kutenga nawo mbali kwanga kutha kuchepetsedwa kapena kusiyitsidwa ngati ofunsa mafunso ataona kuti ndili ndi mantha kapena ndikusowa mtendere mu nthawi yofunsa mafunso.
4. Ndikuvomera sindikuvomereza zokambiranazi zijambulidwe pa tepi.
5. Ndikuvomera kuti zina za zimene ndalankhula/ zatuluka panthawi imene ndikutenga nawo mbali mu kafukufukuyu zidzagwiritsidwe ntchito mwachinsinsi m.malipoti kapena zosindikizidwa zili zones zkhudza kafukufukuyu.
6. Ndikuvomera sindikuvomera kutenga nawo mbali mu kafukufuku watchulidwa pamwambayu.

Dzina la wotenga mbali

Sainiya otenga mbali

Tsiku

Dzina la opanga kafukufuku

Sayini ya opanga kafukufuku

Tsiku

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

Dzina la otenga mbali-----

Dzina la mboni

Saini ya Mboni

Tsiku

Appendix 5: Study Information sheet and Informed Consent Form for Male Partners

Appendix 5.1 English version

Information sheet

Introduction

My name is Agatha Bula; I am a doctoral student at City University London. You are invited to participate in this research study. This form provides information about the purpose, benefits and possible risks of the study and what will be expected of you during the study. I will discuss the information with you and answer any questions you may have. After the study has been fully explained to you, you can decide whether or not you want to participate. Once you understand this study, and if you agree to take part, you will be asked to sign two copies of the study consent form or make your mark in front of someone. You will be offered a copy of this information sheet and consent form to keep. Please note that:

1. Your participation in this study is entirely voluntary.
2. You may decide not to take part or to withdraw from this study at any time without jeopardizing your relationship with MaiMwana project.
3. Your identity and information will be protected and kept confidential.

What is the purpose of this study?

As you are aware, all mothers in developing countries including Malawi are counselled and encouraged to exclusively breastfeed their babies for the first six months of life. This include women who are HIV positive in order to reduce the chances of transmitting HIV through breast milk and prevent early death due to diarrhoea and malnutrition. This study aims at exploring what affects women being able to breastfeed their babies without giving other food or drinks, whether they are HIV positive or negative. It will also look at whether using peer counsellors to promote exclusive breastfeeding in the community will increase the rates of exclusive breastfeeding among HIV positive and negative women. The study is also looking at the views of different groups of people on the use of peer counsellors to promote exclusive breastfeeding in the community and identify ways of promoting exclusive breastfeeding practices for a longer period of time in the country.

Why are you being asked to participate in this study?

You are being asked to take part in this study because your wife participated or gave birth in the communities where MaiMwana project is visiting women in their homes to promote maternal and child health including exclusive breastfeeding. The findings may help to understanding the challenges faced by women that would be useful in the development of effective community based intervention programmes to promote exclusive breastfeeding among all women and promote optimum infant feeding and reduce malnutrition, HIV transmission and infant mortality in the country.

What will happen if you decide to join this study?

If you decide to take part in this study, you will be one of approximately 60 participants who will be interviewed individually. Each interview will last for approximately one hour. During the interview you will be asked some questions about your knowledge about MaiMwana Project; your perceptions about home visiting, how you were involved in the implementation of the programme and how best to promote exclusive breastfeeding in the community. A tape recorder will be used to record all the interviews in order to capture the true picture of what we have discussed. However, if you do not want the interview to be recorded this is not a problem and notes will be taken to keep a record of what was discussed.

What are the Potential benefits of the study to you?

You may not directly benefit from this study. However, what we will learn from this study will help us in coming up with interventions to promote exclusive breastfeeding for the first six months of life

among both HIV positive and negative women in the community in order to reduce the rate of HIV transmission through breast milk and reduce infant death in the future.

What are the Risks to you if you participate?

You may not directly benefit from this study. However, what we will learn from this study will help us in coming up with interventions to promote exclusive breastfeeding for the first six months of life among both HIV positive and negative women in the community in order to reduce the rate of HIV transmission through breast milk and reduce infant death in the future.

How will your Confidentiality be protected?

All interviews will take place at a private place. 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 and all the tapes used in this study will be stored securely at MaiMwana Project during data collection and then at City University until the end of the study. The data will finally be archived at MaiMwana for not less than 7 years upon completion of the study and destruction of data will be done following MaiMwana guidelines. Your personal and identification information will be kept separately from your responses and only the researcher will access such information. Personal information from your study records will not be released without your written permission and your name will never be used in any publication or presentation about this study.

What will happen to the results of the study?

The results of the study will be submitted as part of my PhD dissertation at City University London. The results will also be made available to the community and study participants through the Area Development Committees and the District Executive Committees and also to people interested in infant feeding practices in the country. Findings will also be disseminated during local and international conferences and also through written manuscripts.

Will you be asked to pay or be paid anything for participating in this study?

There is no cost to you and also you will not be paid for participating in this study. You will be given, however, transport reimbursement if you are expected to come back to the health facility for the interview in the local currency equivalent of US \$5 after the visit.

Who should you ask if you have any questions?

If you have questions related to this study you should call the investigator on [REDACTED] or MaiMwana office using on [REDACTED]. If you have other questions, complaints or concerns about your rights while you are in this research study you may contact the Vice Chairman of the National Health Sciences Research Committee in Malawi, [REDACTED] at [REDACTED] or the Secretary to the Research Ethics Committee at City University at 004420 7040 5763 or send E-mail to [REDACTED], Secretary to Senate Ethics Committee, City University, Northampton square, London at [REDACTED].

Appendix 5.2: Chichewa version: Information sheet

Mawu oyamba

Dzina langa ndine Agatha Bula, Ndikupanga maphunziro a udokotala ku sukulu ya ukachenjede ya City University. Mukupemphedwa kutenga nawo mbali mu kafukufukuyu. Chikalatachi chikufotokoza uthenga okhudza cholinga, phindu komanso zovuta zomwe zingakhalepo kwa inu, ndi chomwe chikuyembekezereka kwa inu pa nthawi ya kafukufukuyu. Ndikambirana nanu za uthengawu ndi kuyankha mafunso ena ali onse amene mungakhale nawo. Pamapeto pa kukufotokozerani za kafukufukuyu mwatsatane tsatane, mutha kupanga chiganizo choti mutenge nawo mbali kapena ayi. Mukamvetsetsa za kafukufukuyu, ndipo ngati mwavomera kutenga nawo mbali, mudzafunsidwa kusaina makalata awiri a chivomerezo kapena kuyika chindindo chanu pamaso pa mboni. Mudzapatsidwa imodzi mwa chikalata cha uthengachi komanso chikalata cha chivomerezo chimene musaine kuti mukasunge. Chonde dziwani kuti:

- Kutenga nawo mbali kwanu mu kafukufukuyu nkodzipereka nokha.
- Mukhoza kusankha kusatenga nawo mbali, kapena kusiyira panjira kafukufukuyu pa nthawi iliyonse popanda kusokoneza ubwenzi wanu ndi a bungwe la MaiMwana.
- Mfundo zonse zokuzindikiritsani inu ndi uthenga wanu zidzatetezedwa ndi kusungidwa mwa chinsinsi.

Kodi cholinga cha kafukufukuyu ndi chiyani?

Monga mukudziwa, amayi onse m'maiko omwe akukwera kumene kuphatikizapo kuno ku Malawi amapatsidwa uphungu woyamwitsa ana awo mwakathithi kwa miyezi isanu ndi umodzi yakubadwa. Izi zikuphatikizapo amayi amene ali ndi kachirokoma ka HIV kuti achepetse mpata opatsira mwana kachirokoma ka HIV kudzera mu mkaka wa m'mawere komanso kufuna kuchepetsa imfa zobwera chifukwa cha matenda otsegula m'mimba komanso kunyentchera. Cholinga cha kafukufukuyu ndikufuna kufufuza zifukwa zomwe zimasokoneza amayi kuti asakwanitse kuyamwitsa ana awo mwakathithi popanda kuwapatsa zakudya zina kapena zakumwa, ngati ali ndi kachiro ka HIV kapena alibe. Kafukufukuyu adzawunikanso ngati kulimbikitsa kuyamwiysa kumadela pogwiritsa ntchito aphungu ochokera kumadela pogwiritsa ntchito aphungu kungathanndize kukweza chiwerengero cha amayi amene akuyamwitsa mwakathithi pakati pa amayi amene ali ndi kachirokoma ka HIV komanso amene alibe kachirokoma. Kafukufukuyu adzaunikanso maganizo a anthu osiyanana siyana pa nkhani yogwiritsa ntchito a phungu pofuna kupititsa patsogolo kuyamwitsa mwakathithi m'madela ndikupeza njira zomwe zingathandize kupititsa patsogolo kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yovomerezeka m'dziko muno.

Kodi ndi chifukwa chiyani mwafunsidwa kutenga nawo mbali mu kafukufukuyu?

Mukupemphedwa kutenga nawo mbali mu kafukufukuyu chifukwa akazi anu anayendera ndi aphungu a mai mwana kapena anabereka ndipo mukuchokera kudela limene a bungwe la MaiMwana akuyendera amayi m'makomo pofuna kupititsa patsogolo thanzi la mai ndi mwana kuphatikizapo kuyamwitsa mwakathithi.

Zotsatira za kafukufukuyu zikhoza kudzathandiza kumvetseta zovuta zimene amayi amakumana nazo zimene zingathandize kupanga ma pologalamu oyenerera a ku madela olimbikitsa kuyamwitsa mwakathithi pofuna kulimbikitsa madyedwe oyenerera a ana ndi kuchepetsa kufala kwa kachirokoma ka HIV kwa ana komanso infa za ana m'dziko muno.

Kodi chidzachitike ndi chiyani mukasankha kutenga nawo mbali?

Mukasankha kutenga nawo mbali mu kafukufukuyu, mukhala m'modzi mwa anthuwotenga nawo mbali pafupifupi 60 amene adzafunsidwe mafunso payekha payekha. Kufunsidwa mafunso kuli konse kudzatenga pafupifupi ola limodzi. Pa nthawi yofunsidwa mafunso, mudzafunsidwa mafunso ena okhudza zomwe mukudziwa za bungwe la MaiMwana, maganizo anu okhudza kuyendera amayi m'makomo, mmene munatengera nawo mbali pamene amapanga pulogalamuyi komanso m'mene tingalimbikitsire kuyamwitsa mwa kathithi ku madela. Tidzayenera kujambula zokambirana zones zimene zidzachitike mu kafukufukuyu ndi cholinga choti titha kukhala ndi chithunzithunzi choona cha zomwe takambirana. Komabe, ngati simukufuna kuti kufunsidwa mafunsoku kujambulidwe palibe vuto kwenikweni koma ndidzayenera kulemba zina mwa zimene tidzakambirane.

Kodi phindu la kafukufukuyu ndi chiyani kwa inu?

Simungathe kupeza phinu lenileni kuchokera mu kafukufukuyu. Komabe, zomwe tidzaphunzire kuchokera mu kafukufukuyu zidzatithandiza kupititsa patsogolo ma pologalamu olimbikitsa kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yakubadwa pakati pa amayi womwe ali ndi kachiroambo ka HIV komanso amene alibe kachiroomboka m'adela pofuna kuchepetsa kufala kwa kachiroambo ka HIV kudzera mu mkaka wa m'mawere ndi kuchepetsa chiwerengero cha infa za ana m'tsogolo.

Kodi pali zovuta zANJI kwa inu ngati mutenga nawo mbali mu kafukufukuyu?

Palibe zovuta zodziwikiratu kwa inu potenga nawo mbali mu kafukufukuyu. Komabe ngati kufunsidwa mafunsoku kapena mafunso ena akupangitsa kusowa mtendere muli ndi ufulu kusayangha mafunsowa kapena kusiyitsa zokambiranazi nthawi ina ili yonse.

Kodi chinsinsi chanu chidzatetezedwa bwanji?

Kufunsidwa mafunso kudzachitikira pa malo oduka mphepo. Uthenga onse umene udzapezeke mu kafukufukuyu udzasungidwa mwa chinsinsi malingana ndi lamulo. Wotenga nawo mbali onse adzadziwika ndi nambala. Dzina lanu silindalembedwa pena paliponse ndipo matepi onse amene adzagwiritsidwe ntchito mu kafukufukuyu adzasungidwa motetezedwa ku bungwe la MaiMwana pa nthawi imene tikutolera uthenga mu kafukufukuyu kenaka ku sukulu ya City University London mpakana pamapeto pa kafukufukuyu. Uthengawu pamapeto pake udzasungidwa ku bungwe la MaiMwana kwa zaka pafupifupi zisanu ndi ziwiri (7) kuchokera pomwe kafukufukuyu wathera ndipo zidzawonongedwa potsatira ndondomeko za bungwe la MaiMwana. Uthenga onse okuzindikiritsani inu udzasungidwa mosiyana ndi mayankho anu ndipo anthu wokhawo wogwira ntchito mukafukufukuyu ndi amene adzatha kufikira uthengawu. Uthenga wonse wokuzindikiritsani kuchokera mu zolemba lemba za mu kafukufukuyu siudzaulutsidwa popanda chilorezo chanu cholemba ndipo dzina lanu silidzagwiritsidwa ntchito mu zolembedwa kapena muzoulutsidwa zina zili zonse zokhudza kafukufukuyu.

Kodi chidzachitike ndi chiyani ndi zotsatira za kafukufukuyu?

Zotsatira za kafukufukuyu zidzagwiritsidwa ntchito ngati mbali ya maphunziro anga a udokotala ku sukulu ya ukachenjede ya City University London. Zotsatirazi zidzakhalanso zikupezeka kwa anthu otenga nawo mbali mu kafukufukuyu komanso anthu a ku madela kudzera mu komiti ya chitukuko cha m'adela (Area Development Committees) komanso komiti ya akulu akulu ya pa boma (District Executive Committees); komanso kwa anthu amene ali ndi chidwi pa kadyetsedwe ka ana m'dziko muno komanso maiko ena. Zotsatira zidzawulutsidwanso pa misonkhano yochitika kwathu komkuno ndi misonkhano ya ku maiko akunja komanso mzolembalemba.

Kodi mudzafunsidwa kulipira kapena kuripidwa china chilli chonse chifukwa chotenga nawo mbali mu kafukufukuyu?

Simundzalipira komanso simundzalipidwa chifukwa chotenga nawo mbali mu kafukufukuyu. Komabe, mudzabwezedwa ndalama yoyendera ya kwathu konkuno yofana mphamvu ndi ndalama ya ku America, \$5 pa mapeto pa ulendo ngati zokambiranazi zidzayenera kuchitikira kumalo ena kutali ndi kudela kwanu kapena kutali ndi ku kiliniki.

Kodi mukuyenera kufunsa ndani mukakhala ndi mafunso ena ali onse?

Ngati muli ndi mafunso wokhudzana ndi kafukufukuyu, mutha kundiyimbira telefoni pa [REDACTED] kapena kuyimbira wamkulu wa bungwe la MaiMwana pa [REDACTED]. Ngati muli ndi mafunso ena, madandaulo kapena nkhwana zokhudzana ndi ufulu wanu pamene muli mu kafukufukuyu mutha kuwapeza amene ali wachiwiri wapampando wa bungwe la National Health Sciences Research Committee kuno ku Malawi, a [REDACTED] pa [REDACTED] kapena mlembi wa bungwe loyang'anira a kafukufuku la ku City University London pa 004420 7040 5763 kapena tumizani uthenga (E-mail) kwa a Anna Ramberg, mlembi wa Senate Ethics Committee ya ku City University, ku Northampton square, London pa [REDACTED].

Informed consent form for male partners

Participant ID number _____

Instructions: please tick box to indicate agreement

1. Ndikutsimikiza kuti ndawerenga/ogwira ntchito mukafukufukuyu andiwerengera chikalata cha uthenga cha pa August 2011cha kafukufuku amene watchulidwa pamwambayu ndipo ndinali ndi mwayi ofunsa mafunso komanso kuyankhidwa mafunsowa moyenerera.
2. Ndikudziwa kuti kutenga nawo mbali kwanga ndikodzipereka ndekha ndinso kuti ndili ndi ufulu wosiya kutenga nawo mbali nthawi ina ili yonse ndipo popanda kusokoneza ubale wanga ndi a bungwe la MaiMwana komanso achipatala.
3. Ndikudziwa kuti kutenga nawo mbali kwanga kutha kuchepetsedwa kapena kusiyitsidwa ngati ofunsa mafunso ataona kuti ndili ndi mantha kapena ndikusowa mtendere mu nthawi yofunsa mafunso.
4. Ndikuvomera sindikuvomereza zokambiranazi zijambulidwe pa tepi.
5. Ndikuvomera kuti zina za zimene ndalankhula/ zatuluka panthawi imene ndikutenga nawo mbali mu kafukufukuyu zidzagwiritsidwe ntchito mwachinsinsi m.malipoti kapena zosindikizidwa zili zones zkhudza kafukufukuyu.
6. Ndikuvomera sindikuvomera kutenga nawo mbali mu kafukufuku watchulidwa pamwambayu.

Dzina la wotenga mbali Sainiya otenga mbali Tsiku

Dzina la opanga kafukufuku Sayini ya opanga kafukufuku Tsiku

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

Dzina la otenga mbali-----

Dzina la mboni Saini ya Mboni Tsiku

#	Question	Response categories
18	Since birth up to 6 months have you given (name of child) any of the following: <i>(Tick all that apply)</i>	<input type="checkbox"/> plain water <input type="checkbox"/> traditional herbs <input type="checkbox"/> porridge <input type="checkbox"/> Fruit juice/yogi <input type="checkbox"/> gripe water <input type="checkbox"/> Sweetened water <input type="checkbox"/> Infant formula <input type="checkbox"/> other specify_____
19	How old was (name of child) when you started giving other food?	____ ____ Months
20	Who advised you to give (name of child) other food? <i>(Tick all that apply)</i>	<input type="checkbox"/> partner <input type="checkbox"/> Peer counsellor <input type="checkbox"/> family member, specify_____ <input type="checkbox"/> Own decision <input type="checkbox"/> Other, specify_____
Section 3: HIV testing		
21	Have you ever been tested for HIV	<input type="checkbox"/> Yes <input type="checkbox"/> No →go to section 4
22	If tested: In what year were you tested?	____ ____ ____ ____
23	Why were you tested?	<input type="checkbox"/> Part of routine antenatal care <input type="checkbox"/> Just wanted to know status <input type="checkbox"/> Wanted to become pregnant <input type="checkbox"/> Sick <input type="checkbox"/> Partner sick/HIV testing <input type="checkbox"/> other, specify_____
24	What is your HIV status?	<input type="checkbox"/> HIV positive <input type="checkbox"/> negative →go to section 4 <input type="checkbox"/> don't want to disclose →go to section 4
25	If HIV positive: Did you disclose your status to anyone? <i>(Tick all that apply)</i>	<input type="checkbox"/> partner <input type="checkbox"/> Peer supervisor <input type="checkbox"/> family member, specify_____ <input type="checkbox"/> Pastor <input type="checkbox"/> other, specify_____
Section 4: Home visiting		
26	Were you visited home by the peer counsellor?	<input type="checkbox"/> Yes <input type="checkbox"/> No →Proceed with eligibility criteria assessment
27	How many times were you visited?	____ ____
28	Who else was present when the counsellor visited you? <i>(Tick all that apply)</i>	<input type="checkbox"/> partner <input type="checkbox"/> mother <input type="checkbox"/> mother-in-law <input type="checkbox"/> Grandmother <input type="checkbox"/> Friend <input type="checkbox"/> Sister <input type="checkbox"/> other, specify_____
29	Did you experience any problems with any of the following people following home visiting? <i>(Tick all that apply)</i>	<input type="checkbox"/> partner <input type="checkbox"/> mother <input type="checkbox"/> mother-in-law <input type="checkbox"/> Grandmother <input type="checkbox"/> Friend <input type="checkbox"/> Sister <input type="checkbox"/> other, specify_____

Eligibility Assessment: Interviewer answer the following question

30. Is the respondent 18 years or old? Yes No
31. Has the participant breastfed her youngest child? Yes No
32. Is the participant HIV positive? Yes No
33. Will the respondent be able to participate in the in-depth interview? Yes No
- Please describe the reasons the woman is determined not to be eligible to be interviewed. _____

Has the participant accepted to be interviewed?

- Yes →proceed with consenting process if she has time. If she has no time, agree on the date for interview and leave information sheet with her and indicate date below.
- No →Thank her for her time

Date scheduled for the IDI ____|____|____|____|

#	Question	Response categories
18	Kodi munakwanitsa kuyamwitsa mwana wanu mwa kathithi kwa miyezi isanu ndi umodzi?	<input type="checkbox"/> Inde <input type="checkbox"/> ayi
19	Chibadwireni mpakana miyezi isanu ndi umodzi kodi munamupatsapo (dzina la mwana) zina mwa izi: <i>(Tick all that apply)</i>	<input type="checkbox"/> madzi <input type="checkbox"/> Mankhwala achikuda/azitsamba <input type="checkbox"/> phala <input type="checkbox"/> Juwisi/yogi <input type="checkbox"/> gripe water/madzi <input type="checkbox"/> Madzi othira shuga <input type="checkbox"/> Mkaka ogula/wamchitini <input type="checkbox"/> Zina, Tchulani
20	Kodi (dzina la mwana) anali ndi miyezi ingati pomwe munayamba kumupatsa zakudya zina?	____ ____ Months
21	Ndi ndani amene anakulangizani kuti muyambe kumpatsa (dzina la mwana) zakudya zina? <i>(Tick all that apply)</i>	<input type="checkbox"/> Mwamuna wanu <input type="checkbox"/> wachibale, Tchulani <input type="checkbox"/> a phungu <input type="checkbox"/> oyang'anira aphungu <input type="checkbox"/> Palibe/chiganizo chanu <input type="checkbox"/> ena, tchulani
Section 3: HIV testing		
22	Kodi munayezetsako kachiroambo ka HIV?	<input type="checkbox"/> Inde <input type="checkbox"/> Ayi → go to section 4
23	If tested: Munayezetsa chaka chiti?	____ ____ ____ ____
24	Kodi munayezetsa chifukwa chiyani?	<input type="checkbox"/> Ngati gawo la chisamaliro cha amayi apakati ku sikelo <input type="checkbox"/> ndimangofuna kudziwa ngati ndili ndi HIV <input type="checkbox"/> Kufuna kutenga pakati <input type="checkbox"/> Ndimadwala <input type="checkbox"/> Amuna anga/abwenzi anga amadwala/anapezeka ndi kachiroambo ka HIV <input type="checkbox"/> Zina, Tchulani
25	Kodi zotsatira za magazi anu ndi zotani?	<input type="checkbox"/> ndili ndi ka chirombo ka HIV <input type="checkbox"/> Ndiliba kachiroambo ka HIV → go to section 4 <input type="checkbox"/> Sindikufuna kuwulula → go to section 4
26	If HIV positive: Kodi munawuzapo wina aliyense zotsatira zanu? <i>(Tick all that apply)</i>	<input type="checkbox"/> Mwamuna/bwenzi lanu <input type="checkbox"/> Wachibale, tchulani <input type="checkbox"/> A phungu <input type="checkbox"/> Abusa <input type="checkbox"/> Oyang'anira a phungu <input type="checkbox"/> ena, tchulani
Section 4: Home visiting		
27	Kodi munayenderedwa ndi aphungu?	<input type="checkbox"/> Inde <input type="checkbox"/> Ayi → Proceed with eligibility criteria assessment
28	Anakuyenderani maulendo angati?	____ ____
29	Kodi ndi ndani wina amene analipo pamene munayenderedwa ndi a phungu? <i>(Tick all that apply)</i>	<input type="checkbox"/> Mwamuna/bwenzi langa <input type="checkbox"/> Amayi anga <input type="checkbox"/> Apongozi anga <input type="checkbox"/> Agogo anga <input type="checkbox"/> Anzanga <input type="checkbox"/> Achemwali anga <input type="checkbox"/> Ena, tchulani
30	Kodi munakumanako ndi zovuta ndi anthu awa kamba koyenderedwa ndi aphungu? <i>(Tick all that apply)</i>	<input type="checkbox"/> mwamuna/bwenzi langa <input type="checkbox"/> Amayi anga <input type="checkbox"/> Apongozi anga <input type="checkbox"/> Agogo anga <input type="checkbox"/> Anzanga <input type="checkbox"/> Achemwali anga <input type="checkbox"/> Ena, tchulani

Eligibility Assessment: Interviewer answer the following questions!

31. Is the participant 18 years or old? Yes No
32. Has the participant breastfed her youngest child? Yes No
33. Is the participant HIV positive? Yes No
34. Will the respondent be able to participate in the in-depth interview? Yes No

Please describe the reasons the woman is determined not to be eligible to be interviewed.

Has the participant accepted to be interviewed?

Yes → Proceed with consenting process if she has time. If she has no time agree on the date for interview and leave information sheet with her. And indicate date below.

No → Thank her for her time

Date scheduled for the IDI ____|____|____|____|____|____|

Appendix 7: Demographic questionnaire for PCs, supervisors, male partners and key informants

Appendix 7.1: English version

Participant ID _____ Place of interview _____

Date _____ Village name _____

Interview script: This form should be used with all participants except women who were pre-screened before as demographic data has already been collected.

#	Question	Response categories
1	How old are you?	____ age in years
<i>Interviewer confirm that the participant is 18 years old and above</i>		
<input type="checkbox"/> Yes → go to question 2 <input type="checkbox"/> No → stop, do not continue (re-explain eligibility criteria)		
2	(Do not read aloud) Sex of participant:	<input type="checkbox"/> Male <input type="checkbox"/> Female
3	What is your religion?	<input type="checkbox"/> Christianity <input type="checkbox"/> Moslem <input type="checkbox"/> Pentecostal <input type="checkbox"/> Other, specify _____
4	What is the level of education that you attained?	<input type="checkbox"/> None <input type="checkbox"/> Primary school <input type="checkbox"/> Secondary school <input type="checkbox"/> Any tertiary education/post-secondary school
<i>Interviewer Skip to question 15 for community stakeholders and supervisors.</i>		
5	Are you currently working?	<input type="checkbox"/> Yes <input type="checkbox"/> No → <i>Skip to question 6</i>
6	What type of work do you do?	<input type="checkbox"/> Agricultural work/Farmer <input type="checkbox"/> Domestic worker/ gardener /Cleaner <input type="checkbox"/> Business/office work <input type="checkbox"/> Teacher <input type="checkbox"/> Other, specify _____
7	What is your marital status? (Tick only one answer)	<input type="checkbox"/> Never married → go to 8 <input type="checkbox"/> Not married but living with partner → <i>go to 7</i> <input type="checkbox"/> Married and living with partner → <i>go to 7</i> <input type="checkbox"/> Married but not living with partner → <i>go to 7</i> <input type="checkbox"/> Separated → <i>go to 8</i> <input type="checkbox"/> Divorced → <i>go to 8</i> <input type="checkbox"/> Widowed → <i>go to 8</i>
8	What is the occupation of your partner?	<input type="checkbox"/> Agricultural work/Farmer <input type="checkbox"/> Domestic worker/ gardener <input type="checkbox"/> Business man/office work <input type="checkbox"/> Teacher <input type="checkbox"/> Other, specify _____
9	How many people live in your house?	____
10	What is their relationship to you? (Tick all that apply)	<input type="checkbox"/> Brother/sister <input type="checkbox"/> mother <input type="checkbox"/> mother in-law <input type="checkbox"/> In-law <input type="checkbox"/> children <input type="checkbox"/> Other people, specify _____
11	What is the source of water at your house?	<input type="checkbox"/> Tap water <input type="checkbox"/> Bore hole <input type="checkbox"/> Well <input type="checkbox"/> River <input type="checkbox"/> Other, specify _____
<i>Ask questions 11 to 12 to male partners participants only</i>		
12	Where do you go to seek medical care? (Tick all that apply)	<input type="checkbox"/> Government clinic/Hospital <input type="checkbox"/> Private clinic/hospital <input type="checkbox"/> Traditional healer <input type="checkbox"/> Other, Specify _____
13	What mode of transport do you usually use? (Tick all that apply)	<input type="checkbox"/> Minibus <input type="checkbox"/> Car <input type="checkbox"/> bicycle <input type="checkbox"/> Walking <input type="checkbox"/> Other, specify _____
<i>Ask question 13 and 14 to community stakeholders who are not medical professionals</i>		
14	What is your position in your community/village?	<input type="checkbox"/> Village headman <input type="checkbox"/> Village elder <input type="checkbox"/> Community counsellor <input type="checkbox"/> Church elder <input type="checkbox"/> Other, specify _____
15	For how many years have you been on this position/doing this work?	____
<i>Ask questions 15 and 16 to supervisors and health professionals Only</i>		
15	How many years have you been working with the government?	____
16	<i>If doing some work with MaiMwana/ MaiMwana staff</i> How many years have you been working with MaiMwana Project?	____

#	Question	Response categories
14	Kodi mwakhala pa udindo umenewu/ mwakhala mukugwira ntchito imeneyi kwa zaka zingati?	__ years
<i>Ask questions 15 and 16 to supervisors and health professionals Only</i>		
15	Kodi mwagwira ntchito m'boma kwa zaka zingati?	__ years
16	<i>If doing some work with MaiMwana/ MaiMwana staff:</i> Kodi mwagwira ntchito ndi bungwe la MaiMwana kwa zaka zingati?	__ years

<i>Ask peer counselors/volunteers 17-29</i>		
17	Kodi muli ndi udindo wanji ku dela kwanu/kumudzi kwanu?	<input type="checkbox"/> A mfumu <input type="checkbox"/> Wamkulu wa mmudzi <input type="checkbox"/> Mlangizi wa kudela <input type="checkbox"/> Mkulu wa ku tchalitchi <input type="checkbox"/> Zina, Tchulani _____
18	Kodi mwakhala pa udindo umenewu/ mwakhala mukugwira ntchito imeneyi kwa zaka zingati?	__ years
19	Kodi mukuganiza kuti amayi amakwanitsakuyamwitsa mwakathithi kudela kwanu?	<input type="checkbox"/> Inde <input type="checkbox"/> Ayi
20	Amakonda kupereka zakudya zANJI?	_____
21	Kodi munakumanako ndi amayi amene ali ndi ka chirombo ka HIV?	<input type="checkbox"/> Inde <input type="checkbox"/> Ayi
22	Zinali bwanji mutakumana ndi amayi amene ali ndi kachirombo aka HIV fotokozani?	_____
23	Kodi pali ubale wanji pakati painu ndi amfumu?	<input type="checkbox"/> Achimwene <input type="checkbox"/> Achemwali <input type="checkbox"/> Alamu <input type="checkbox"/> Zina, Tchulani
24	Kodi anakusankhani kukhala pa udindowu ndi ndani (volunteer)?	<input type="checkbox"/> A mfumu <input type="checkbox"/> Anthu akudela <input type="checkbox"/> ena, Tchulani
25	Kodi munali ndi msonkhano wina uli wonse kuti musankhidwe kugwira ntchito (volunteer)?	<input type="checkbox"/> Inde <input type="checkbox"/> Ayi
26	Kodi mumalipidwa china chili chonse?	<input type="checkbox"/> Inde Chiyani _____ <input type="checkbox"/> Ayi
27	Mumakumana ndi mavuto anji pa ntchito yanu?	_____
28	Nanga munatumizako mayi wina aliyense ku chipatala?	<input type="checkbox"/> Inde <input type="checkbox"/> Ayi
29	Munadziwa bwanji kuti anapitadi kuchipataku?	_____
<i>Ask questions 30 and 31 to supervisors and health professionals Only</i>		
30	Kodi mwagwira ntchito m'boma kwa zaka zingati?	__ years
31	<i>If doing some work with MaiMwana/ MaiMwana staff:</i> Kodi mwagwira ntchito ndi bungwe la MaiMwana kwa zaka zingati?	__ years

ndemanga _____

Appendix 8: Interview guide for breastfeeding mothers

8.1: English version

Archival number _____ Village Name _____
Place of interview _____ Date of interview _____
Time started _____ Time finished _____

Introduction

My name is Agatha Bula; I am a doctoral student at City University London. You have been selected to participate in this interview because you were directly or indirectly involved in the MaiMwana cluster randomization trial to promote maternal and infant health including EBF or you come from the community where the trial is taking place. I am interested to understand the factors that affect women being able to breastfeed their babies without giving other food or drinks, whether they are HIV positive or negative and also look at whether counselling Lactating mothers in their homes by peer counsellors will increase the rates of EBF among HIV positive and negative women. I would also want to hear the views and perceptions of different groups of people on the use of peer counsellors to promote EBF in the community, challenges faced and identify ways of promoting EBF practices for the recommended period of six months in the country. I will now ask you some questions related to your perception and experience towards home visiting women in the homes to promote EBF practices. Please feel free to answer these questions. All your responses will be kept confidential. Please there are frankly no right or wrong answers.

Section 1: Exclusive breastfeeding practices

As you are aware all women are counselled to breastfeed their infant exclusively for 6 months, now I would like to begin the interview by asking you some questions about your experiences with EBF practices with your youngest child.

1. From your understanding, what do you know about exclusive breastfeeding?

Probes: How long do you think most mothers in this community can exclusively breastfeed their babies for 6 months? What are the common practices?

Do you think there are specific women who should practice EBF in your community? Why do you think so?

2: Did you manage to breastfeed your youngest child exclusively for 6 months?

Probes: How did you practice EBF? How long did you breastfed your baby?

When did you start giving other foods including gripe water/ water or any traditional drugs? What influenced your decision to start giving other foods/fluids?

What was the reaction of your family members and the community when you were practicing EBF?

What support did you receive from your partner, family members or friends while practicing EBF?

Did you experience any problems with EBF? Please explain.

Section 2: Knowledge about MaiMwana project and experience with home visiting

Now I would like to ask you some questions about what you know about MaiMwana project and your experiences about peer counsellors visiting women in their homes to promote EBF.

3. What do you know about MaiMwana Project?

Probes: How did you come to know about them? What activities are being carried out by the project in your community?

4. Were you visited by the peer counsellors at your home? If no go to question 6

If yes Probes: How many times? What happened when the counsellor visited you for the first times?

How often were you visited by the counsellor? Did you or the counsellor consult any of your family members before talking to you? Which other family members were present when you were visited?

What was the reaction of your spouse and other family members?

Can you tell me what the counsellor discussed with you during the visit and during subsequent visits?

What other issues do you think could have been useful to you to be discussed during the visits?

5. How did you feel about the way that you were visited at your home?

Probes: Were you happy to be visited by the peer counsellor at your home? Why?

Was there anything you didn't like about the way the counsellor visited and supported you? What did you like about it? What did you dislike about it? What could be done differently to make this a better experience?

Did you experience any problems following the visit? Explain.

How would you have felt about being visited by someone else, like a health care provider or a counsellor from the clinic other than the peer counsellor from the community?

How do you compare the counselling provided by the counsellors as opposed to the hospital?

What factors do you think affected the way the counsellor visited and counselled you at your home? (Probe about: economic status, presence or absence of relatives).

If the woman was not visited by the counsellor ask questions 6

6. What is your opinion about visiting women in their homes for counselling?

Probes: Would you be happy to be visited by peer counsellors at home? Why?

Section 3: HIV testing and opinion towards visiting HIV positive women

All pregnant women are offered to have an HIV test as part of routine antenatal care in this country. Now I will ask you some questions about HIV testing. Please remember that all that will be discussed here will be kept confidential.

7. Have you ever been tested for HIV? *Follow up questions:* When did you get the test? Why? What is your HIV status? *If negative go to section 4*

If HIV positive: Did you disclose your HIV status to anyone?

If yes: Who did you disclose to? What made you to disclose your status to these people? What was their reaction? **If no:** What made you not to disclose your status? How did you manage to keep confidentiality of your status when the counsellor visited you at your home?

8. With your HIV status, what were your feelings when you were practicing EBF?

Probes: Do you think this affected the way you practiced EBF? Please explain.

What other measures did you do to protect your baby from contracting HIV? (Probe about condom use, frequency of BF, ARVs)

If the woman is HIV positive and was visited ask question 9

9. Do you think home visiting assisted you to cope with your HIV status? Please explain.

Probes: Considering your status, how useful was it for you to be visited and counselled on EBF at home as compared to hospital counselling? Do you think this helped you to manage EBF? What problems did you face during home visiting? How do you feel about the confidentiality offered by the counsellors to you and any information that may have been shared about you or your baby?

If HIV positive and not visited ask question 10

10. Do you think you received enough counselling and support at the hospital?

Probes: What other support or information do you think could have been helpful for you?

In your opinion, how useful do you think it could have been for you to be visited by the counsellor at your home during the time you were breastfeeding your child exclusively?

Section 4: General perceptions of home visiting (ask all women)

11. In general, what do you think are the advantages of visiting women in their homes compared to going to the hospital? **Probes:** Tell me what do you think are the disadvantages of counselling women in their homes to promote EBF? Overall, how do you feel about the service provided by the peer counsellors who come from your community? How else do you think the services can be improved to promote EBF?

12. In your opinion, do you think it is important to involve partners and family members when women are visited in their homes? What makes you think in that way?

Probes: What do you think could be the best way to involve them?

What do people in the community where this intervention is taking place think about visiting women in their homes? What misperceptions about visiting women in their homes do you think the community might have?

Section 5: Referral system

Lastly, I would like to ask you a few questions about referral for care and support.

13. Were you referred for any support and care? If yes: Why? **Probes:** How helpful did you find the services? What challenges did you face when you were referred for care and support? What additional support or information would you have wanted to promote referral of women to other places?

Is there anything which you feel it is important for me to know?

Do you have any comment or questions? Thank you for your time.

Appendix 8.2: Chichewa version

Arichival number _____ Village name _____
Place of interview _____ Date of interview _____
Time started _____ Time finished _____
Mau oyamba.

Dzina langa ndine Agatha Bula, ndikupang msphunziro a za udotolo pa sukulu ya City University London. Mwasankhidwa kutenga nawo mbali mukufunsidwa mafunsoku chifukwa munatenga nawo gawo kapena munakhudwidwa mukafukufuku wa MaiMwana ofuna kupititsa patsogolo thanzi la mai ndi la mwana kuphatikizapo kuyamwitsa mwakathithi, kapena mukuchokera kudera kumene kafukufukuyu akuchitikira. Ndili ndi chidwi chofuna kumvetsetsa zifukwa zimene zimasokoneza/zimakhudza amai kuyamwitsa ana awo popanda kupereka zakudya zina kapena zakumwa, kaya ali ndi kachiroambo ka HIV kapena alibe. Kafukufukuyu adzaonanso ngati kupereka uphungu m'makomo kwa amayi amene akuyamwitsa pogwiritsa ntchito aphungu kungapititse patsogolo kuyamwitsa mwakathithi pakati pa amayi amene ali ndi kachiroambo ka HIV kapena amene alibe. Ndikufunanso kumva maganizo ndi m'mene anthu osiyanasiyana akuonera pa za kugwiritsa ntchito aphungu pofuna kupititsa patsogolo kuyamwitsa mwakathithi ku madera, zovuta zimene amakumana nazo ndi kuyang'ana njira zopititsira patsogolo kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yovomerezeka m'dziko muno. Tsopano ndikufunsani mafunso ena okhudzana ndi malingaliro anu ndi zimene munakumana nazo zokhudza kuyendera amayi m'makomo ndi cholinga chopititsa patsogolo kuyamwitsa mwakathithi. Chonde khalani omasuka kuyankha mafunsowa. Mayankho anu onse adzasungidwa mwa chinsinsi. Chonde palibe mayankho okhoza kapena olakwa.

Section 1: Exclusive breastfeeding practices

Monga mukudziwa amai onse amalandira uphungu oyamwitsa ana awo mwakathithi kwa miyezi isanu ndi umodzi. Tsopano ndikufuna kuyamba zokambiranazi pokufunsani mafunso okhudza zomwe munakumana nawo pamene mumayamwitsa mwakathithi mwana wanu wam'ng'onoyu.

1. Mmene mukumvera, kodi mukudziwako chiyani zokhudza kuyamwitsa mwa kathithi?

Probes: Kodi mukuganiza kuti amayi ambiri ku dela kwanu amakwanitsa kuyamwitsa mwakathithi ana awo? Chifukwa chiyani? Ndi machitidwe aji amene amakonda kupanga?

- Kodi mukuganiza kuti ndi gulu liti la amayi limene likuyenera kuyamwitsa mwakathithi ku dela kwanu? Chonde fotokozani.

2. Kodi munakwanitsa kuyamwitsa mwana wanu wamng'onoyu mwakathithi kwa miyezi isanu ndi umodzi? **Probes:** Munapanga bwanji? Kodi mwana wanu munamuyamwitsa mwakathithi kwa nthawi yaitali bwanji?

- Munayamba liti kumpatsa zakudya zina kuphatikizapo gripe water/madzi kapena mankhwala ena ali onse achikuda? *Ndi chani chimene chinakupangitsani kuti muyambe kumpatsa mwana wanu zakudya/zakumwa zina?*
- Kodi a pabanja panu komanso anthu a kudela kwanu anayirandi bwanji nkhani imeneyi yoyamwitsa mwakathithi? Ndi thandizo lanji limene munalandira kuchokera kwa okonedwa anu, a pabanja kapena anzanu pamene mumayamwitsa mwakathithi?
- Kodi munakumana ndi mavuto ena ali onse pamene mumayamwitsa mwakathithi? Chonde fotokozani.

Section 2: Knowledge about MaiMwana project and experience with home visiting

Tsopani ndikufunsani mafunso okhudza zimene mukudziwa za bungwe la MaiMwana ndi zomwe amayi amakumana nazo pamene a phungu akamayendera amayi mmakomopofuna kulimbikitsa kuyamwitsa mwakathithi.

3. Mukudziwapo chichani za bungwe la MaiMwana? **Probes:**

- Munadziwa bwanji zokhudza bungweli?
- M'mene mukudziwira, ndizochitika zANJI zimene bungwe limeneli likuchita ku dela kwanu?

4. Kodi munayenderedwa ndi a phungu pa khomo panu? **If no go to question 6**

If yes: Probe: Maulendo anagati? Chinachitika ndi chani pamene aphungu atakuyenderani ulendo oyamba?

- *Ndi mowirikiza bwanji pamene a phungu anakuyenderani?*
- Kodi inu kapena aphungu munapempha chilolezo kwa wina aliyense wa pa nyumba panu asanalankhule nanu? *Chonde atchuleni ngati alipo?* Ndi ndani ena a pa banja panu amene analipo pamene munayenderedwa?
- *Kodi amuna/okondeka anu ndi abale anu anayilandira bwanji nkhani imeneyi?*
- Mungandiuze zimene munakambirana ndi aphungu pa ulendo umenewu komanso ma ulendo otsatira?
- *Ndi zinthu zina ziti zimene mukuganiza kuti zikanakhala zofunikira kuti mukambirane pa ma ulendo amenewa?*

5. Munamva bwanji ndi m'mene munayenderedwera pakhomo panu? **Probes:**

- Munali osangalatsidwa kuyenderedwa ndi aphungu pakhomo panu? Chifukwa chiyani?
- Kodi panali china chili chonse chimene simunakonde chokhudza m'mene aphungu anakuyenderani ndi kukuthandizani? Munakondapo chiyani? Simunachikondepo chiyani?
- Kodi ndi chiyani chimene chinayenera kuchitika mosiyana kuti tipange izi kukhala zofunikira kwa inu?
- Kodi munakumanako ndi mabvuto ena ali onse potsatira pa ulendowo? Chonde fotokozani.
- Kodi mukanamva bwanji mukanayenderedwa ndi wina wake, monga ogwira ntchito za umoyo kapena aphungu ochokera ku kiliniki osati aphungu akumadelawa?
- Mungafanizire bwanji uphingu operekedwa ndi aphungu a kumadelawa poyerekeza ndi ku chipatala?
- Kodi ndi zinthu ziti zimene mukuganiza kuti zinasokoneza mmene aphungu anakuyendererani ndikukupatsani uphingu pa khomo panu? (*Probe about za chuma, kukhala nawo kapena kudzakhala nawo kwa abale pa zokambirana*).

If the woman was not visited by the counsellor ask questions 6

6. Maganizo anu ndi otani pa zokhudza kuyendera amai m'makomo mwawo ndikuwapatsa uphingu? **Probes:**
Mungasangalatsidwe kuyenderedwa ndi aphungu pakhomo? Chifukwa chiyani?

Section 3: HIV testing and opinion towards visiting HIV positive women.

Amayi onse apakati amapatsidwa mpata oyezidwa kachiroboka ka HIV ngati mbali ya chisamaliro cha amayi apakati m'dziko muno. Tsopano ndikufunsani mafunso ena okhudza kuyezetsa kachiroboka ka HIV. Chonde kumbukirani kuti zonse zimene tikambirane muno zidasungidwa mwa chinsinsi.

7. Kodi munayezetsapo kachiroboka ka HIV? **Probes:**
• Munayezetsa liti? Chifukwa chiyani? Zotsatira zanu za kachiroboka HIV zili bwanji?

If the woman is HIV negative skip to section 4

- **If HIV positive:** Kodi munauzapo wina aliyense za m'mene mulili pa nkhani ya HIV?
 - **If yes:** Munauzako ndani? Chinakupangitsani kuulula zotsatira zanu za HIV kwa anthu amenewa ndi chiyani? Anayilandira bwanji nkhani imeneyi?
 - **If no:** Chinakupangitsani kusawuza wina aliyense za m'mene mulili ndi chani? Chonde fotokozani? Kodi munakwanitsa bwanji kusunga chinsinsi cha m'mene mulili m'thupi pankhani ya HIV pamene aphungu anakuyenderani pakhomo panu?
8. Ndi m'mene mulili ndi kachiroboka HIV, mumamva bwanji nthawi imene mumayamwitsa mwakathithi? **Probes:**
• Kodi mukuganiza kuti izi zinakusokonezani m'mene munayamwitsira mwakathithi? Chonde fotokozani.
• Kodi ndi njira zina ziti zimene munapanga pofuna kuteteza kuti mwana wanu asatengere kachiroboka ka HIV? (*Probe about condom use, frequency of BF, ARVs*).

If the woman is HIV positive and visited home ask question 9

9. Kodi mukuganiza kuti kuyenderedwa pakhomo kunakuthandizani kukhala ndi chiyembekezo ndi m'mene mulili m'magazi mwanu? Chonde fotokozani. **Probes:**
• Ndi m'mene mulili mtupi mwanu, kodi zinali zofunikira bwanji kwa inu kuyenderedwa pakhomo ndi kulandira uphingu okhudza kuyamwitsa mwakathithi kuyerekeza ndi kulandira uphingu ku chipatala? Kodi mukuganiza kuti izi zinakuthandizani kukwanitsa kuyamwitsa mwakathithi?
• Kodi ndi zovuta zANJI zimene munakumana nazo pamene mumayamwitsa mwakathithi?
• Kodi mukuganiza bwanji za m'mene aphungu anasungira chinsinsi chanu komanso uthenga wina uli onse umene unatha kugawidwa okhudza inu kapena mwana wanu? (*probe if someone was present during the visit*).

If the woman is HIV positive and not visited ask questions 10

10. Kodi mukuganiza kuti munalandira uphingu ndi chithandizo choyenerera ku chipatala? **Probes:**
• Ndi chithandizo ndi uthenga wina uti umene mukuwona kuti ukanakhala ofunikira kwa inu?
• M'mene mukuwonera, mukuganiza kuti kukanakhala kofunikira bwanji kwa inu mukanayenderedwa ndi phungu pakhomo panu pa nthawi imene mumayamwitsa mwana wanu mwakathithi?

Section 4: General questions about perceptions of home visiting (ask all women)

11. Mu zonse, kodi mukuganiza kuti pali ubwino wANJI kuyendera amai m'makomo mwawo kuyerekeza ndi kupita kuchipatala? **Probes:**

- Tanduzani kodi mukuganiza kuti pangakhale mavuto anji okhudza kupereka uphungu kwa amai m'makomo mwawo pofuna kulimbikitsa kuyamwitsa mwakathithi?
 - Mu zonse, mukuona bwanji zokhudza thandizo limene likuperekedwa ndi a phungu ochokera m'dela lanu?
 - Kodi mukuganiza kuti tingapititse bwanji patsogolo thandizoli ndi cholinga cholimbikitsa kuyamwitsa mwakathithi?
12. M'mene mukuonera, kodi mukuganiza kuti ndi kofunikira kuti okonedwa ndi a pabanja adzitenga nawo mbali pamene amayi ayenderedwa pa nyumba? Chikupangitsani kuganiza mwa njira imeneyi ndi chani? **Probes:**
- Kodi mukuganiza kuti ndi njira ziti zimene zingakhale zoyenerera kuti anthu amenewa atenge nawo mbali?
 - Kodi mukuganiza kuti anthu a ku dera kumene kukuchitikira pologalamuyi amaganiza zotani zokhudza kuyendera amayi m'makomo?
 - Ndi nkhabakamwa zANJI zokhudza kuyendera amayi m'makomo zimene anthu a ku dela angakhale nazo?

Section 5: Referral system

Pomaliza, ndifuna ndikufunsi mafunso angapo okhudza kutumizidwa kokalandira chisamaliro ndi chithandizo.

13. Kodi munatumizidwapo kuti mukalandire chithandizo ndi chisamaliro? If yes: Chifukwa chiyani? **Probes:**
- Kodi thandizoli linali lofunikira bwanji kwa inu?
 - Munakumanapo ndi zovuta zANJI pamene munatumizidwa kokalandira chisamaliro ndi chithandizo?
 - Kodi ndi chithandizo chanji kapena uthenga wanji owonjezera umene mukanakonda kulimbikitsa kutumiza amayi ku malo ena?
 - Kodi pali china chili chonse chimene mukuona kuti ndi chofunikira kuti ndi chidziwe?

**Muli ndi ndemanga kapena mafunso ena ali onse?
Zikomo chifukwa cha nthawi yanu.**

Appendix 9: Interview guide for peer counsellors and key informants

Appendix 9.1 English version

Participant ID _____ Village name _____
Date of interview _____ Place of interview _____
Time started _____ Time finished _____

Introduction

My name is Agatha Bula; I am a doctoral student at City University London. You have been selected to participate in this interview because you were directly or indirectly involved in the MaiMwana cluster randomization trial to promote maternal and infant health including EBF or you come from the community where the trial is taking place. I am interested to understand the factors that affect women being able to breastfeed their babies without giving other food or drinks, whether they are HIV positive or negative and also look at whether counselling Lactating mothers in their homes by peer counsellors will increase the rates of exclusive breastfeeding among HIV positive and negative women. I would also want to hear the views and perceptions of different groups of people on the use of peer counsellors to promote exclusive breastfeeding in the community, challenges faced and identify ways of promoting exclusive breastfeeding practices for the recommended period of six months in the country. I will now ask you some questions related to your perception and experience towards home visiting women in the homes to promote exclusive breastfeeding practices. Please feel free to answer these questions. All your responses will be kept confidential. Please frankly there are no right or wrong answers.

Section 1 Knowledge about exclusive breastfeeding

Let's begin our interview by talking about how women practice exclusive breastfeeding in your community.

1. What are the common ways of feeding babies in your community? **Probes:**

- How are men and other family members involved when women decide on ways of feeding their babies?

3. If someone talks about exclusive breastfeeding what comes into your mind?

Probes:

- Do you think women practice EBF in your community? How long?
- When do they introduce other foods? What are the common foods given to the infant before 6 months?
- What factors do you think help women manage to practice EBF for the recommended six months?
- What do you think would be the reasons that women in the community would not be able to practice EBF for 6 months?
- What problems did women encounter while practicing EBF? (**Probe:** for common cultural practices).
- Who do you think support women while practicing exclusive breastfeeding?
- What do you think could be done to help women practice EBF for 6 months in the community?

Section 2: Knowledge about MaiMwana project (except MaiMwana staff)

Now I would like to talk with you about what you know about MaiMwana Project

3. What do you know about MaiMwana Project? **Probes:**

- How did you come to know about them?
- What activities are being carried out by the project in your community?
- How are you involved in the activities carried out by the project?
- How often are you briefed about this programme?

Section 3: home visiting

Peer counsellors/supervisors: *Now I would like to ask you some questions about your experiences with visiting women in their homes and how you were trained.*

4. How do you look at your role as a peer counsellor/supervisor for peer counsellors? **Probes:**

- How were you chosen? Why did you accept the role?
- Were you paid or given any incentive for the work?
- **Counsellor:** How do you balance your work as a peer counsellor and a mother home?
- **Supervisor:** How do you balance your work as a government staff as well as a supervisor for peer counsellors for MaiMwana Project?
- How were you trained and supported to carry out your work?
- Who conducted the training? How many days?
- Can you explain to me in your own words what you were taught during the training?

- What other information and support do you feel you should have had during the training necessary for you to carry out your work effectively?
4. How do you identify and approach pregnant women in your community? **Probes:**
- Do you think you missed some?
 - What do you think could be the best way to identify women?
 - How do women react when you visited them for the first time? What about during subsequent visits?
 - How often do you visit these women? How do you plan to visit them? How long does each visit last?
 - Did you or the woman require asking for permission from any of the family members before the counseling? Who?
 - Why did you need to ask for permission from them? What was their reaction? How did you negotiate to talk to the woman?
 - What challenges did you face while carrying out your duties?
 - Which type of women demands more visits or time than the required five visits? Why?
 - **Supervisors:** Which groups of peer counsellors require more supervision?

6. Can you please describe to me in your own words what issues you discuss with women during the visits?
Probe: Do you use counselling materials during the counselling sessions? Explain.

Experiences with HIV positive women

Now I will ask you some questions about your experiences with visiting and counselling HIV positive women in their homes.

7. Did you come across any HIV positive women? ***If no go to question 8***

Probes: How did you find out that they are HIV positive?

- How many women disclosed their status to you?
- How did you approach women whom you know were HIV positive but did not disclose their status to you?
- What was your reaction when they disclosed their status to you or when you know that the woman is HIV positive? Did this affect the way you visited and counselled them?
- Do you think you had enough knowledge and skills to support HIV positive women?
- What other information and support could have been relevant for you to counselled HIV positive women?

If she did not come across HIV positive women ask Q8

8. Did you suspect any woman to be HIV positive? **Probes:**

- What was your reaction when you suspected that a woman is HIV positive?
- What could have been your reaction if you came across HIV positive women?
- Do you think this could have affected the way you visited and counselled women?
- Why do you think women decided not to disclose their HIV status to you?

Male partners:

9. Was your partner visited by the peer counsellors at home? **Probes:**

- **If yes:** How were you involved when your partner was visited at home?
- Were you consulted or was any member of your family consulted before the visit?
- What is your perception towards the visit? Was it helpful?
- **If not consulted:** How did you react when you discovered that your wife was visited at home? How do you think other men reacted?

Section 4: Perception about home visiting (ask all respondents)

10. In your experience, do you think partners and other household members want to be involved during home visiting? Please explain. **Probes:**

- What do you think are the main barriers?
- How can we make the programme more appealing to them?

11. In general, how do you think women feel about their participation in the programme? **Probes:**

- In general, what do you think are the advantages of visiting women in their homes to promote EBF? What are the disadvantages of this approach?
- What problems, fears or issues, if any, have participants expressed with any aspect of home visiting? (**Probes:** fear of HIV-disclosure or being associated as HIV positive, fear of partner/relative reactions).

- Have any of the women who were visited reported any rumours or concerns in relation to home visiting? If yes, what are they?

12. In your opinion, what do people in your community think about home visiting of Lactating mothers?

Probes: What misconceptions about this program do you think the community might have?

- What fears might the community have towards home visiting?
- What differences has the project as well as the intervention made to you and the community?
- What could the researchers do to get local community support during home visiting of women to promote exclusive breastfeeding?
- What do you think can be the best way to improve the services?

Section 5: Perception about visiting HIV positive women in their homes (all)

13. What is your opinion towards using peer counsellors to visit both HIV positive and negative women in their homes instead of going to the hospital? **Probes:**

- Do you think they were knowledgeable enough to handle both HIV positive and negative women?
- In general, do you think it is good to visit both HIV positive and negative women home? Which groups of women need to be visited home? Why?
- Do you think home visiting assisted HIV positive women to cope with their status and practice EBF for 6 months? Please explain.
- In your opinion, do you think HIV positive women received the right support during home visiting by the peer counsellors compared to the care at the hospital?
- What fears might women in the community have toward visiting both HIV positive and negative women in their homes?
- Do you think that HIV positive women would or would not experience any stigma associated with home visiting? Why do you think in that way?
- Counsellors did not know the HIV status of women. In your opinion, do you think it is a good idea to send counsellors without knowing the HIV status of the woman? Why do you think so?
- What do you think could have happened if the counsellors know the HIV status of these women?

Section 6: Referral system

Peer counsellors and supervisors

Lastly, I would like to ask you some questions on how you referred some women for care and support.

14. Did you refer any woman for care and support? Why? **Probes:**

- Did you have clear guideline on how to refer women?
- What strategies were put in place to promote referral system of women participating in this programme?
- How did you follow up women whom you had referred?
- What was the reaction of staff at the referral centre?

Health personnel and MaiMwana staff

Lastly I would like to ask you some questions about how women are referred for care and support by the peer counsellors.

15. Did you receive any woman who was referred for care and support by the peer counsellors?

Probes: What were the reasons for referral? Were they referred in good time?

- What was your reaction when you received the woman?
 - What strategies were put in place to promote referral system of study participants?
 - What problems did you face when they referred women for care and support to you?
 - How did you give feedback to the project about women referred to you?
 - How do you think the study staff can improve the referral system of women taking part in this programme?
- **Is there anything which you feel is important for me to know?**
 - **Do you have any comment or questions? Thank you for your time.**

Appendix 9.2 Chichewa version

Category: IPC=IDI Peer counsellor, SPC: Supervisors for peer counsellors

Archival number _____ Village name _____

Date of interview _____ Place of interview _____

Time started _____ Time finished _____

Mau oyamba: Dzina langa ndine Agatha Bula, ndine ophunzira za udotolo pa sukulu ya City University London. Mwasankhidwa kutenga nawo mbali Mukafukufukuyu chifukwa munatenga nawo gawo kapena munakhudwidwa mukafukufuku wa MaiMwana ofuna kupititsa patsogolo thanzi la mai ndi mwana kuphatikizapo kuyamwitsa mwakathithi kapena mukuchokera kudera kumene kafukufukuyu akuchitikira. Ndili ndi chidwi chofuna kumvetsetsa zifukwa zimene zimasokoneza amai kuyamwitsa ana awo popanda kupereka zakudya zina kapena zakumwa, kaya ali ndi kachiroambo ka HIV kapena alibe ndiponso kuona ngati kuyendera amayi amene akuyamwitsa m'makomo mwawo pogwiritsa ntchito aphungu kungapititse patsogolo kuyamwitsa mwakathithi pakati pa amayi amene ali ndi kachiroambo ka HIV kapena amene alibe. Ndikufunanso kumva maganizo ndi m'mene anthu osiyanasiyana akuonera pa za kugwiritsa ntchito aphungu pofuna kupititsa patsogolo kuyamwitsa mwakathithi ku madera, zovuta zimene amakumana nazo ndi kuyang'ana njira zopititsira patsogolo kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi m' dziko muno. Tsopano ndikufunsani mafunso ena okhudzana ndi malingaliro anu ndi zimene munakumana nazo zokhudza kuyendera amayi m'makomo pofuna kupititsa patsogolo kuyamwitsa mwakathithi. Khalani omasuka kuyankha mafunsowa. Mayankho anu onse adzasungidwa mwa chinsinsi. Kumbukirani kuti palibe mayankho okhoza kapena olakwa.

Section 1: Knowledge about exclusive breastfeeding

Tiyeni tiyambe zokambirana zathuzi pokambirana m'mene amayi amadyetsera ana awo kudela kwanu.

1. Kodi ndi njira ziti zimene amayi amakonda kudyetsera ana awo kudela kwanu? **Probes:** Kodi abambo ndi anthu ena kumadela amatengako gawo pamene amayi akupanga chisankho cha momwe amadyetsera ana awo?
2. Kodi munthu akamakamba zokhudza kuyamwitsa mwakathithi, ndichiyani chimene mumaganiza pa zimenezi? **Probes:** Kodi mukuganiza kuti amai amayamwitsa mwakathithi m'dera lanu? Kwa nthawi yayitali bwanji?
 - Amayamba liti kupereka zakudya zina? Kodi ndi zakudya zANJI zimene amakonda kupatsa mwana asanakwane miyezi isanu ndi umodzi?
 - mukuganiza kuti ndi zifukwa zANJI zimene zimathandiza amai ku dera lanu kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi yovomerezeka?
 - Ndi mavuto ANJI amene amayi anakumana nawo pamene akuyamwitsa mwa kathithi? (Probe for common cultural practices).
 - Ndi ndani amene amathandiza amayi panthawi imene akuyamwitsa mwakathithi?
 - mukuganiza kuti tingachitike chiyani kuti tithandize amai amenewa kuti akwanitse kuyamwitsa mwakathithi kwa miyezi isanu ndi umodzi?

Section 2: Knowledge about MaiMwana project

Tsopano ndikufunsani mafunso okhudza zimene mukudziwa za bungwe la MaiMwana.

3. Mukudziwapo chiyani za bungwe la MaiMwana? **Probes:** Munadziwa bwanji zokhudza bungweli?
 - Ndizochitika zANJI zimene bungwe limeneli likuchita ku dela kwanu?
 - Munatengapo mbali bwanji mu kayendetsedwe ka zochitika zimene bungeli likupanga?
 - Ndi mowilikiza bwanji munaunikiridwa za pologalamuyi?

Section 3: Home visiting

Peer counsellors/supervisors: *Tsopano ndikufuna kukufunsani mafunso ena okhudza zomwe munaphunzira ndi kugwira kwanu ntchito poyendera amayi m'makomo mwawo.*

4. Mukuona bwanji udindo wanu ngati oyang'anira aphungu? **Probes:** Munasankhidwa bwanji? Ndichifukwa chiyani munavomera udindowu? Mumalipidwa kalikonse chifukwa cha ntchitoyi?
 - **Counsellor:** mumakwanitsa bwanji ntchito yanu ya uvolontiya/yodzipereka komanso ngati mkazi/Mayi pa khomo panu?
 - **Supervisor:** Kodi Mumayigawa bwanji ntchito yanu ngati ogwira ntchito m'boma komanso oyang'anira a phungu ku bungwe la MwaiMwana? Munaphunzitsidwa ndikuthandizidwa bwanji kuti mugwire ntchito yanu? Anakuphunzitsani ndi ndani? Munaphunzitsidwa masiku angati?
 - Kodi mungandifotokozere m'mawu anu zimene munaphunzitsidwa pa maphunzilowa?
 - Ndi uthenga wina uti komanso chithandizo chanji chimene mukuganiza kuti munayenera kupatsidwa panthawi ya maphunziro zofunika kuti inu mugwire ntchito yanu moyenerera?

5. Kodi mumapeza ndikufikira bwanji amai apakati ku dera kwanu? **Probes:** Kodi mukuganiza kuti munaphonya amayi ena? Kodi mukuganiza kuti ndi njira yiti yoyenerera yopezera amayiwa?
- Kodi amayilandira bwanji nkhanayi mukawayendera kwa nthawi yoyamba? Nanga pa maulendo ena otsatira? Ndimowirikiza bwanji pamene mumayendera amayiwa? Mumakonza bwanji kuti mukawayendere? Ulendo umodzi umatenga nthawi yayitali bwanji?
 - Kodi inu kapena a mayi munapempha chilolezo kwa wina aliyense wa pa nyumba panu asanalankhule nanu? Ndani?
 - Ndichifukwa chiyani munayenera kupempha chilolezo kuchokera kwa iwowa? Kodi anayirandira bwanji nkhanu imeneyi? Kodi munakambirana nawo bwanji kuti mulankhule ndi amayiwo?
 - ndi mavuto anji amene munakumana nawo pogwira ntchito yanu?
 - Ndi magulu ati a amayi amene amafuna maulendo ambiri kapena nthawi yambiri kuposera pa maulendo asanu amene anakhazikitsidwa?
 - **Ask supervisors only:** Ndi magulu ati a aphungu amene amafuna kuwayendera kwambiri? Munaphonyapo ulendo wina uli onse umene unakonzedwa? Chifukwa chiyani?
6. Mungandifotokozere m'mawu anu zimene mumakambirana ndi amayi pa ma ulendowa? **Probes:** Kodi mumagwiritsa zipangizo zophunzitsira zina zili zonse popereka uphungu? Fotokozani.

Experience with HIV positive: *Tsopano ndikufunsani mafunso ena okhudza magwiridwe anu a ntchito popereka uphungu kwa amai amene ali ndi kachiroambo ka HIV m'dera lanu.*

7. Munakumanako ndi amayi amene ali ndi kachiroambo ka HIV? **If no go to question 8. Probes:**
- Munadziwa bwanji kuti ali ndi kachiroambo ka HIV?
 - Ndi amayi angati amene anawulula zotsatira za magazi awo za kachiroambo ka HIV kwa inu?
 - Munawafikira bwanji amayi amene mumadziwa kuti ali ndi kachiroambo ka HIV koma sanawulule zotsatira za magazi awo kwa inu?
 - Munazilandira bwanji pamene anakuwuzani zotsatira za magazi awo kapena mutadziwa kuti ali ndi kachiroambo ka HIV? Kodi izi zinasokoneza mmene munayenera kuyendera kapena kupereka uphungu kwa amayiwa?
 - Mukuganiza kuti munalali ndi mfundo ndi upangili/luso okwanira kuti muthandize amayi amene ali ndi kachiroambo ka HIV? Ndi uthenga kapena chithandizo china chit chimene chikanakhala choyenerera kwainu popereka uphungu kwa amayi amene ali ndi kachiroambo ka HIV?

If she did not come across HIV positive women ask Q8

8. Munaganizirako amayi ena kuti angathe kukhala ndi kachiroambo ka HIV?
- Probes:** *kodi munakazilandira bwanji mukanakumana ndi amayi amene ali ndi kachiroambo ka HIV?*
- Mukanazilandira bwanji mukanakumana ndi amayi amene ali ndi kachiroambo ka HIV?
 - Mukuganiza kuti izi zikanasokoneza bwanji mmene munayenera kuyendera kapena kupereka uphungu kwa amayiwa? Mukuganiza kuti ndi chifukwa chiyani amayi sanafune kuwulura zotsatira za magazi awo kwa inu?

Male partners

9. Kodi wokondeka anu anayenderedwa pakhomu ndi aphungu? **Probes:**
- **If yes:** Munatengapo mbali bwanji pa nthawi imene okondeka anu amayendera pa nyumba?
 - Munapemphedwa kapena alipo wina aliyense wa pabanja panu amene anapemphedwa ulendo usanachitike? Munazona bwanji zokhudza ulendowo? Zinali zokuthandizani?
 - **If not consulted:** Kodi munachilandira bwanji mutazindikira kuti akazi anu anayenderedwa pakhomu? Mukuganiza kuti amuna ena anachilandira bwanji?

Section 5: Perceptions about home visiting (Ask all respondents)

10. M'mene mukuwonera, mukuganiza kuti okondeka komanso achibale ena amafuna atatenga nawo mbali pa uphungu umene umaperekedwa kwa amayi m'makomo? Chonde fotokozani? **Probes:**
- Mukuganiza kuti ndi zifukwa zeni zeni ziti zowalepheletsa kutenga nawo mbali?
 - Tingapange chiyani kuti pologalamuyi yikhale yowasangalatsa?
11. Mu zonse, kodi mukuganiza kuti amayi amamva bwanji potenga nawo mbali mu pologalamuyi? **Probes:**
- Mu zonse, kodi mukuona kuti pali ubwino wanji woyendera amayi m'makomo pofuna kulimbitsa kuyamwitsa mwakathithi? *Kodi kuipa kwa njira imeneyi ndi chani?*
 - Ndi mavuto nkhwawa kapena zinthu ziti, ngati ziripo, zomwe amayi otenga nawo mbali ananenapo zokhudza mbali ina iriyonse woyendera m'makomo?

- Pa amai amene mumawayendera alipo amene anakuuzanipo za mphekesera kapena nkhwana zokhudzana ndi kuyendera m'makomo? **If yes**, anakuuzani zotani?

12. Mukuganiza kuti anthu a ku mabela amaganiza zotani zokhudza kuyendera amayi m'makomo? **Probes:** Kodi ndi nkambakamwa zotani zokhudza kuyendera m'makomo zomwe mukuganiza kuti anthu a m'madera angakhale nazo? Ndi mantha anji amene anthu a ku mabela angakhale nawo?

- Nanga ndikusintha kotani komwe kwachitika kwa inu komanso ku dela kwanu chifukwa cha bungweli komanso pologalamuyi?
- Mukuganiza kuti ndi njira yiti yoyenerera imene ingathandize kupititsa patsogolo chithandizochi?

Section 5: Perceptions about visiting HIV positive women in their homes

13. Kodi maganizo anu ndi otani pa kugwiritsa ntchito aphungu kuyendera amai amene ali ndi HIV komanso amene alibe kachiroboko ka HIV m'makomo mwao m'malo mopita kuchipatala? **Probes:** mukuganiza kuti anali ndi mfundo zokwanira kuthandiza amai amene ali ndi kachiroboko ka HIV ndi omwe alibe?

- Mu zonse, mukuganiza kuti ndi bwino kuyendera amai omwe ali ndi kachiroboko ka HIV komanso omwe alibe kachilomboka m'makomo?
- Mukuganiza kuti kuyendera amayi amene ali ndi kachiroboko ka HIV m'makomo kunawathandiza kuvomereza zotsatira za magazi awo mwansanga komanso kuyamwitsa ana awo mwakathithi kwa miyezi isanu ndi umodzi? Chonde fotokozani.
- M'mene mukuonera, kodi mukuganiza kuti amai amene ali ndi kachiroboko ka HIV amalandira thandizo loyenerera pa nthawi imene amayenderedwa m'makomo ndi aphungu a ku mabela kuyerekeza ndi chisamaliro cha ku chipatala?
- Ndi nkhwana zANJI zimene amayi ku mabela angakhale nazo zokhudza kuyendera m'makomo amayi amene ali ndi kachiroboko ka HIV komanso amene alibe kachiroboko?
- Mukuganiza kuti amai amene ali ndi kachiroboko ka HIV angasalidwe kapena sangasalidwe chifukwa choyenderedwa pakompo? Chifukwa chiyani mukuganiza mwa njira imeneyo?
- Aphungu samauzidwa ngati amayi amene amayenera kuwayendera ali ndi kachiroboko ka HIV kapena alibe. M'mene mukuonera, kodi mukuganiza kuti ndi koyenerera kutumiza aphungu osadziwa zotsatira za kachiroboko ka HIV za a mai? Chifukwa chiyani mukuganiza motere?
- Mukuganiza kuti chikanachitika ndi chani akanakhala kuti aphungu akudziwa za m'mene amai alili pa nkhwana ya HIV?

Section 6: Referral system: Peer counsellors and supervisors

Pomaliza, ndikufuna ndikufunsi mafunso ena okhudza m'mene mumatumizira amayi ena kukalandira chithandizo ndi chisamaliro.

14. Kodi munatumizako amayi ena ali onse kukalandira chisamaliro ndi chithandizo? Chifukwa chiyani? **Probes:** Munali ndi ndondomeko yoyenerera imene mumayenera kutsata potumiza amayi ku malo ena?

- Ndi njira zANJI zomwe zinakhazikitsidwa pofuna kulimbikitsa kutumiza amayi otenga nawo mbali ku malo ena? *Mumawatsatira bwanji amayi amene munawatumiza ku malo ena?*
- *Ogwira ntchito kumalo kumene mumatumiza amayi amayilandira bwanji nkhwana imeneyi?*

Health facility staff and MaiMwana staff

Pomaliza ndikufuna kukufunsi mafunso ena okhudza m'mene amai amatumizidwira kuchipatala ndi aphungu aku madelawa.

15. Munalandilako mayi wina aliyense amene anatumizidwa kudzalandira chisamaliro ndi thandizo ndi aphungu amenewa? **Probes:** Kodi anatumizidwa pa zifukwa zANJI? Kodi anatumizidwa mu nthawi yabwino?

- Mutalandira maiyo inu munaganiza/munamva bwanji?
- Ndi njira zANJI zomwe zinakhazikitsidwa pofuna kulimbikitsa kutumiza amayi otenga nawo mbali ku malo ena?
- Munapezana ndi mavuto anji atatumiza amai kudzalandira chisamaliro ndi thandizo kwa inu?
- Kodi munapereka bwanji yankho ku polojeketi zokhudza amai amene anatumizidwa kwa inu?
- Kodi mukuganiza kuti ogwira ntchito yakafukufuku angapititse bwanji patsogolo ndondomeko ya katumizidwe ka amai amene akutenga nawo mbali mu pologalamuyi

Kodi pali china chili chonse chimene mukuona kuti ndi chofunikira kuti ndichidziwe?

Kodi muli ndi ndemanga kapena mafunso? Zikomo chifukwa cha nthawi yanu.

Appendix 10: DEBRIEFING FORM

Please use this form after each in-depth interview with all respondents
PC= Peer counsellor, LW: lactating woman KI= Key informant MP= male partner
SPC= supervisor for peer counsellor

Participant ID: _____
Date of interview: _____

Category _____

(1) What are the main themes that emerged in this IDI?

(2) Did any information contradict what was learned in previous IDI?

(3) What did participants say that was unclear or confusing?

(4) What was observed that would not be evident from reading a transcript of the interview? (Individual behaviour, etc.)

(5) What problems were encountered? (E.g. logistical, behaviour of individual, questions that were confusing, etc.)

(6) What issues need follow up in the next interviews? _____

Appendix 11: Approval letter City University



**Research Office
20 Bartholomew Close
London EC1A 7QN**

Tel: +44 (0) 20 7040 5704

www.city.ac.uk

School of Community and Health Sciences

Ref: PhD/11-12/04
6 October 2011

Dear Agatha / Christine

Re: Exploring the effects of socio-demographic characteristics of HIV positive women on exclusive breastfeeding practices and promotion in Mchinji district, Malawi

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study. However please note that final ratification of this approval is dependent on approval from the DHO.

Under the School Research Governance guidelines you are requested to contact myself once the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely

Alison Welton

Alison Welton
Research Governance Officer

████████████████████
████████████████

Appendix 12: Approval letter National Health Sciences Research committee of Malawi

Telephone: [REDACTED]
Facsimile: [REDACTED]

All Communications should be addressed to:
The Secretary for Health and Population



In reply please quote No.

MINISTRY OF HEALTH AND POPULATION

P.O. BOX 30377
LILONGWE 3
MALAWI

20th December, 2011

Agatha Bulla
City University London
UK

Dear Sir,

RE: PROTOCOL # 955: 'EXPLORING THE EFFECTS OF SOCIO-DEMOGRAPHIC CHARACTERISTICS OF HIV POSITIVE WOMEN ON EXCLUSIVE BREASTFEEDING PRACTICES AND PROMOTION IN MCHINJL MALAWI'

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

- **APPROVAL NUMBER** : 955
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE** : 20/12/2011
- **EXPIRATION DATE**
This approval expires on 19/12/2012. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS:** Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS:** Please contact the NHSRC on telephone number +265 1 726 422 or by email on mohdocentre@gmail.net.
- **OTHER:** Please be reminded to send in copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat.

[REDACTED]
For: CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE
Promoting Ethical Conduct of Research¹

Executive Committee: [REDACTED]
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB
IRB Number IRB00003905 FWA00005976

Appendix 13: Job description of a Health Surveillance Assistant

1. Inspect facilities within the community using a checklist.
The Public facilities include the following:
 - Schools
 - Markets
 - Water sources
 - Abattoirs
 - Public toilets
 - Health facilities
 - Port of entry
 - Herbalist clinics
 - TBAs places
 - Restaurant/ canteen,
 - Bars/ Bottle stores/ Beer halls
 - Prayer houses, etc
2. Plan and conduct village clinics.
 - Set up a village clinic
 - Monitor the operation of the clinic
 - Prepare a schedule for the clinic
 - Develop work plan monthly
 - Identify supplies required for the clinic
 - Estimate quantities of supplies
 - Timely ordering of supplies
 - Conduct basic diagnosis and presumptive treatment (malaria, ARI/pneumonia, nutrition/diarrhoea (worm infestation), eye infections)
 - Ability to document storage and utilization of drugs and supplies
 - Inform the people about the schedule for the clinics through the chiefs, religious leaders, schools and other local media
3. Plan and conduct outreach clinics
 - Provide childhood immunizations (vaccine-preventable diseases)
 - Conduct Growth monitoring and promotion sessions (nutrition, general)
4. Plan and conduct Home visits.
The HSA shall do the following duties where possible at a household level.)
 - Conduct environmental health management (Schistosomiasis, malaria, diarrhoea, ARI)
 - Provide and Improve water and sanitation facilities and practices (diarrhoea, schistosomiasis)
 - Promotion of exclusive breast-feeding and support (nutrition)
 - Mobilisation for immunization and other outreach sessions from the nearest health centres
 - Conduct Family planning sessions (adverse maternal and neonatal outcomes; all others through indirect benefits of child spacing and limiting)
 - Promote use of insecticide-treated nets
 - Re-impregnation of bed nets
 - Promote Condom distribution
 - Provide prophylaxis/intermittent presumptive treatment for malaria in pregnancy
 - Promotion of clean and safe delivery
 - Provide Iron/folate and Vitamin A supplementation (eye conditions, nutritional deficiencies
 - Provide mass treatment where indicated (Schistosomiasis, nutritional deficiencies + diarrhoea (worm infestation)
 - Over-seeing community-based DOTS (TB and ARV drugs)
 - Treatment of some opportunistic infections and palliative care for HIV/AIDS patients
 - Involve the people in selection of a meeting point in the event that HSA has more than one village
 - Conduct nutrition assessment for pregnant women and the under-fives
 - Participate in maternal death audit
5. Maintain a village register and filling in community monitoring tool
 - Monitor and evaluate the impact of health services in the community by using a community monitoring tool
 - Provide feedback to both the community and health facility on the status of health service in the provision of health care in an area.