

**PREGNANT WOMEN, HIV AND COMPLIANCE WITH  
FOLLOW-UP CARE IN THE PREVENTION OF MOTHER-TO-CHILD  
HIV TRANSMISSION PROGRAM: LILONGWE-MALAWI**

Thesis submitted in partial fulfillment for the award of  
Master of Philosophy (MPhil) Degree in International Community Health



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## List of Abbreviations

HIV	=	Human Immune Deficiency Virus
AIDS	=	Acquired Immune Deficiency Syndrome
MTCT	=	Mother-to-child Transmission of HIV
PMTCT	=	Prevention of mother-to-child transmission of HIV
PMTCT-PLUS	=	Prevention of mother-to-child HIV transmission with an added 'PLUS' component
UNGASS	=	United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS
NVP	=	Nevirapine
RH	=	Reproductive Health Services
KAP	=	Knowledge Attitude and Practices
ELISA	=	Enzyme Linked Immuno-Sorbent Assay
PCR	=	Polymerase Chain Reaction
MOH	=	Ministry of Health
ARV drugs	=	Anti retro- viral drugs
ART	=	Anti retro viral therapy
MCH	=	Maternal and child health
VCT	=	Voluntary Counseling and testing
Hgb	=	Hemoglobin
EGPAF	=	Elizabeth Glaser Pediatric AIDS Foundation
UNICEF	=	United Nations Children's Fund
UNC	=	University of North Carolina project

HIVNET 012 = A code given for 'Nevirapine' randomized clinical trials to reduce mother- to-child HIV transmission.

MSF = Médecin Sans Frontières

## Definitions of Terms

- MTCT = The term mother-to-child transmission of HIV (MTCT) is often used to refer to the transmission of HIV to infants. In this paper, MTCT will be used to refer to the biological process of vertical transmission.
- PMTCT = Prevention of mother-to-child HIV transmission, a term commonly used for programs and interventions designed to reduce the risk of mother-to-child transmission (MTCT) of HIV. In this paper, the term will be used to refer to prevention of HIV infection in women, infants and young children and to refer to the broad range of recommended strategies used.
- PMTCT-PLUS = Family centered and comprehensive HIV-related services for HIV-infected women and their families (partners, children). The 'Plus' component provides an essential care package with appropriate therapies for prevention and/or treatment of HIV related opportunistic infections and treatment with antiretroviral drugs.
- Non- participation/ Default = Not actively involved in the PMTCT follow up visits.
- Participation/Compliance = To act in accordance with the request by the PMTCT program to come to the PMTCT clinic for follow-up care.

### Usage of the “MTCT” concept

UNICEF *et.al* (2003) assert that “the use of the term ‘MTCT’ is not meant to attach blame or stigma to a woman who gives birth to an HIV infected child. The authors go on to say that the term does not suggest deliberate transmission by the mother who is often unaware of her infection status or un-informed about the transmission risks to infants nor should its use obscure the fact that HIV is often introduced in the family by the woman’s sexual partner ” (6).

Preble and Piwoz (2001) argue that “since ‘MTCT’ is a consequence of a chain of events that involves an infected man infecting his sexual partner through unprotected sex; and the partner passing on the virus to her next baby and potentially to other more babies born during the remainder of her reproductive cycle, the biological precise term of ‘mother-to-child’ (MTCT) transmission should be replaced with the behaviorally sensitive term of ‘parent-to- child’ transmission’(PTCT) to reflect men’s role in this chain of events” (7).

## Abstract

This short follow-up study was part of a larger prospective cohort of clients followed up for 18 months in a prevention of mother-to-child transmission program in Lilongwe-Malawi. It was set out to investigate why women in the program do not fully participate in their program's follow-up care.

During the period of data collection, this program was already in progress since April, 2002 as collaboration between the University of North Carolina project and the Malawi Ministry of health; supported by Elizabeth Glaser pediatric AIDS foundation and UNICEF-Malawi.

The program operates in four public health facilities of Lilongwe and its components were integrated into the existing Maternal and Child Health program as per Malawi Ministry of health recommendations. In total, more than 18,000 pregnant women who attend their antenatal care in these facilities are reached out every year and over 80% of these women join the program.

Despite these services in place, the program has lost to follow-up an estimated 20% of the HIV-infected women who had initially joined the program and little was known as to why women do not fully participate in their program's follow-up care.

The objectives of the study were therefore to identify the socio-demographic factors that are associated with client's continued participation in the program's follow-up care and; to identify clients' stated reasons for continued participation and the defaulters' reasons for not fully participating in the program's follow-up care.

Both qualitative and quantitative methods were used. Qualitative data was obtained through in-depth interviews and focus group discussions with both program compliers and the defaulters. Furthermore, an FGD with the participants' partners was conducted to follow-up on some of the issues affecting them that these women had raised. For the quantitative part, socio-demographic data for both program compliers and defaulters were reviewed and analyzed for any variations in between these two groups. Results of the two approaches were then converged to answer the research question.

The study reveals that education and age of pregnancy at enrollment into the PMTCT program play a role. Furthermore, it demonstrates that negative community and family reactions as well as the gender and power in-equalities can contribute to non-participation by the clients in the PMTCT program. The study points to the importance of social support for overcoming such negative reactions to women's participation, the need for male involvement in PMTCT programs and, recommends strategies to address these issues as a means of helping the women overcome their challenges to participation.

It should also be noted that whilst quantitative data has helped to identify the socio-demographic factors associated with client participation in the program's follow-up care, results obtained from the qualitative study are however most meaningful for understanding why women participate or not participate in their program's follow-up care.

**Key words: PMTCT, default, community and family reactions, power relations, culture.**

# Chapter one

## I.0 Introduction

This thesis examines why women in the Lilongwe-Malawi prevention of mother-to-child HIV transmission (PMTCT) program do not fully participate in their follow up care. In order to illustrate the complexity of the problem, various aspects of the Malawi country's profile are explored. This chapter describes Malawi, highlighting relevant aspects applicable to the study. The background and rationale follows in the next chapter before a review of relevant literature. Later on, the thesis moves on to the following chapters: methodology, results, discussion and lastly; conclusion and recommendations.

## 1.1 The Malawi Country Profile

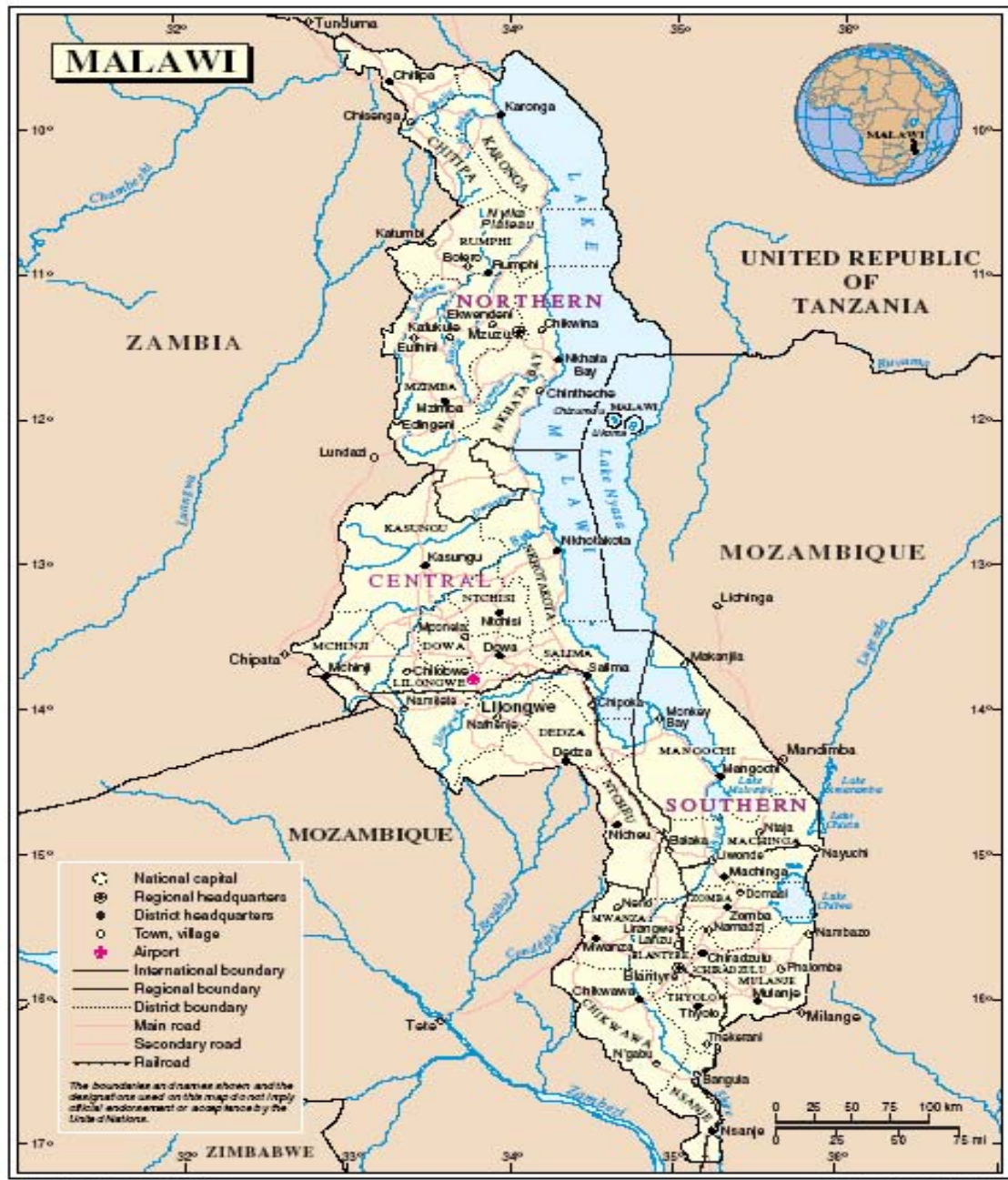
### 1.1.1 Country description

Malawi is a small, landlocked country in Southern Africa with a population of approximately 11.8 Million people (8). It lies between latitudes  $9^{\circ} 45'$  and  $17^{\circ} 5'$  S and longitudes  $33^{\circ}$  and  $38^{\circ}$  E. It is bordered by Tanzania in the north and northeast, Mozambique in the east, south and southwest; and Zambia in the west and North West (Figure1). The country is 901 km long and has a total area of 118,484 square kilometers of which one third is Lake Malawi; the largest fresh water area in Africa. The population density is estimated at 105 persons per square kilometer (9).

### 1.1.2 Administration

The country is divided into three regions, the northern, central and southern and into 27 administrative districts. The north has 6 districts, the central 9 and the south 12. Each district is further divided into traditional authorities (T/As) that are either rural or urban and presided over by chiefs. Rural T/As are divided into enumeration areas (EAs) which comprise, on average 250 households. Urban T/As are divided into wards, which are further sub-divided into EAs. The average household size is 4.5 persons (10). Lilongwe district, our study area is located in the central region of Malawi and is an urban district as well as the capital city of the country (figure 1). The two studied PMTCT sites (Kawale and Area 25) are located in the Lilongwe semi-urban (figure 2).

**Figure 1: Map of Malawi**



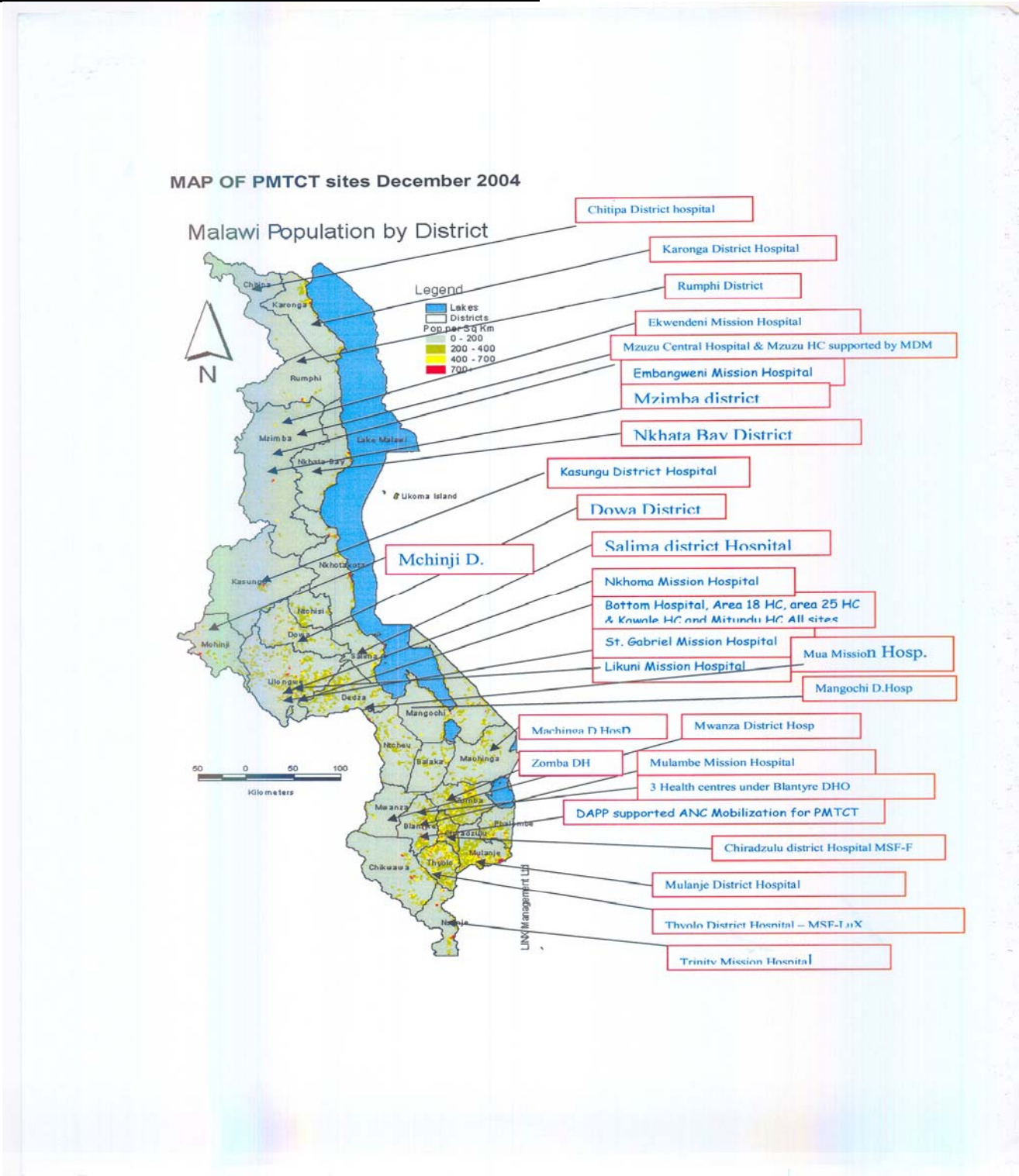
Map No. 2858 Rev. 3 UNITED NATIONS  
January 2004

Department of Peacekeeping Operations  
Cartography Section

Source: <http://www.cia.gov/cia/publications/factbook/geos/mi.html>



**Figure 2: PMTCT sites in Malawi as of December, 2004**



Source: Malawi National AIDS commission

### 1.1.3. Economy

Malawi has one of the world's lowest per capita incomes ranking 151<sup>st</sup> of the 162 countries on the UNDP development index (11-13). More than 80% of the country's total population lives in the rural area with an estimated 65.3% living in poverty and a further 27% in extreme poverty. Unemployment is estimated at 93%. In the absence of a variety of natural resources, the agricultural sector remains the most important sector of the economy. It contributes up to approximately 35% of the gross domestic product (GDP), employs about 80% of the labour force, and contributes to about 90% of Malawi's export earnings. This is followed by industry which contributes to about 20% and manufacturing, 13-14%. The rest is contributed by other services (8;14). The gross national product (GNP) per capita stands at US\$ 170. Only 44% of Malawian women are literate compared to 56% of their male counterparts, and almost half of the population is 14 years and under (Ibid).

### 1.1.4 Urbanization

According to data from population censuses 1977 through 1998, there has been a steady rise in urbanization from 9% in 1977, to 11% in 1987 and to 14% in 1998. This situation has largely been attributed to a complex array of factors related to long lasting poverty as a result of severe droughts and prolonged rainy seasons, which have led to recurring years of food shortage. Furthermore, in-equitable agricultural policies that favor commercial farmers, lack of political will and the high rates of Human Immune deficiency virus (HIV) in the country have all played a significant role (15). Consequently, there has been movement of people from the rural to the urban areas. Urban livelihood has not been smooth for majority either, with the most people engaging themselves in trading and to a lesser extent getting employed (14). Trading in the urban area, particularly street vending has therefore been characteristic of the poor who mostly reside in the semi-urban areas (Ibid).

### 1.1.5. Health indices and disease burden

Health indices are amongst the worst in the world, mostly due to preventable causes of morbidity and mortality which constitute the major contributors to the disease burden in Malawi. For example, infant and child mortality rates are estimated at 134 per 1000 live births and 189 per 1000 births respectively. The pattern of under-five and infant mortality suggests that 22% of these deaths occur during the neonatal period, 33% postnatally; and over 45% between 1-4 years (16).

Maternal Mortality has almost tripled from 620 to 1,120 to over 1800/100,000 in 1992, 2000 and 2004 respectively. Birth and death rates are currently estimated at 43.95 births/1,000 population and 23.39 deaths/1,000 populations. The total fertility rate of 6.2 gives rise to a 2% population increase annually. Life expectancy has fallen from 48 years in 1990 to 38 years in 2002 (11-13).

The national HIV prevalence is approximately 15% in the adult population. According to the 2003 sentinel report, the epidemic has risen from 1.7% in 1987 to 19.8% in 2003 amongst the antenatal clinic attendees (17). Further reports suggest that the prevalence is highest in the urban and semi-urban areas and highest prevalence is among the child bearing aged women and in young people (15-24 age range); with a 6-1 female male ratio. Infant and child mortality linked to HIV/AIDS has also been increasing and evidence shows that AIDS cases amongst the 0-4 year olds who are believed to have acquired the infection from their mothers is significantly higher than in older children 5-15 years (Ibid) and mother-to-child transmission (MTCT) of the virus remains the main cause. An overview of the demographic indicators is presented in table 1 along with other socio-economic details.

**Table 1: Demographic and socio-economic indicators**

Index	Census year		
	1977	1987	1998
Population	5,547,460	7,988,507	9,933,868
Intercensal growth rate	2.9	3.2	2.0
Total area (sq km)	118,484	118,484	118,484
Land area (sq km)	94,276	94,276	94,276
Density (Population per sq km)	59	85	105
Women of child bearing age as a percentage of female population	45.1	44.2	47.2
Sex ratio	93	94	96
Crude birth rate	48.3	41.2	37.9
Total fertility rate	7.6	7.4	6.2
Crude death rate	25.0	14.1	21.1
Infant mortality rate	165	159	121
Life expectancy:			
Male	39.2	41.4	40.0
Female	42.4	44.6	44.0

Source: Malawi Demographic and Health Survey, 2000:2

### 1.1.6. Health care delivery

Health sector operations in Malawi are guided by the national health plan and currently; service provision is based on the 4<sup>th</sup> plan which was developed in 1999 and expired in 2004. The 5<sup>th</sup> plan is underway. In the 4<sup>th</sup> plan, the goal is to “raise the level of the health status of Malawians by developing a delivery system capable of promoting health, preventing, reducing and curing disease, protecting life and fostering general well-being and productivity, and reducing the occurrence of premature death” (16). In addition to this health plan, there are other 5 supporting policies (Ibid).

In view of above, the structure of health care in Malawi follows the primary health care (PHC) concept. Within this concept, services are provided at three levels namely the primary, secondary and tertiary levels. The primary level is the first point of contact with the formal health care and services are provided through drug revolving funds (DRFs), outreach clinics, health posts, health centers and rural hospitals. Secondary level services mainly serve as back up to the primary level providing surgical procedures and; the tertiary serves as back up to the secondary level with the availability of specialist attendance (Ibid).

Service delivery is mainly provided by 3 sectors which comprise of the public sector providing 60% of the total health care, the Christian Health Association of Malawi (CHAM) 37% and the local government 1%. The remainder is provided by the private sector (16) .CHAM is the main government partner and its services are mostly subsidized by government. All services are coordinated by Ministry of health (MOH) which is responsible for policy formulation and enforcement, standard formulation and regulation and international representation (18). The district health officers are responsible for the management of all health services in their respective districts. In each region of the country, there are zone health support offices that serve each district health office and report directly to the Ministry of Health. It is important to note that the central hospitals in Malawi work independently of the zone offices and report directly to MOH. CHAM and the private institutions follow the government structures and their services are coordinated by the district health offices in each district (Ibid).

Given the high childhood and maternal mortality rates, particular attention was given to the provision of services for mothers and their children in coordination with all health sector partners. This is again reflected in the third national health plan 1986-1995 and indeed in the other previous health plans (19).

In view of this, PHC coverage was extended and upgrading of basic health facilities led among other things to the development of the maternal and child health (MCH) departments at all levels of care. These departments were mandated to specifically address issues concerned with maternal and child health. Increasing responsibility was therefore given to the regional, district and local levels (16;19). It was not until 1997 that the reproductive health unit (RHU) was established within the Ministry of health to coordinate these issues at national level. The establishment of the RHU was also in response to the International Conference on Population and Development (ICPD) recommendations held in Cairo, Egypt in 1994 (20). Despite this organization in the health care delivery however, health facilities are still

inaccessible to many people. In 2000, there were approximately 510 primary health care facilities, each serving a catchment's population of 16,000 people.

### 1.1.7 The study area (Lilongwe District)

Lilongwe district, the capital city of Malawi is situated in the central region of the country. It has a population of approximately 1,720,584 people and is 6,159 km<sup>2</sup> in size (21). There is 1 central hospital in Lilongwe, 2 community hospitals formally known as rural hospitals and 63 health centers, 37 of which are government. The community hospitals and the health centers are under the responsibility of the Lilongwe district health officer (DHO) whilst the central hospital has a different administration.

With regard to the PMTCT program, both central and district health offices have partnerships with the university of North Carolina (UNC) project through the project's collaboration with the pediatric department of the Lilongwe Central hospital. PMTCT services are offered at Bottom Hospital- a wing of the Lilongwe central hospital and in three Lilongwe district health centers of Kawale, Area 18 and Area 25. By the end of 2004, UNC's PMTCT program in Lilongwe was providing almost half of all PMTCT services that were being offered among 18 programs in Malawi (22). The world food program (WFP) donates a maternal food basket for all PMTCT clients through one and a half years post-partum period to improve the maternal and child health outcomes.

## Chapter two: Background to the study

### 2.1 Background and rationale

Since 1987, following the launch of the Safe Motherhood Initiative (SMI), the maternal and perinatal mortality levels in Africa have sadly continued to rise instead of declining (23). In the sub-Saharan African region, this has largely been attributed to the alarming rates of HIV infection which has affected an estimated 25 million people (24). The majority of the infected are women (57%) most of whom are in their reproductive ages. It is estimated that every year, about 600,000 infants become infected with HIV (25), and 90% of these infections are attributed to MTCT (26).

In Malawi, MTCT has become a major focus due to the increasing levels of this HIV epidemic. Estimated rates of between 12-17% have been sustained in the adult population over the last seven years; ranking the country as the eighth highest prevalence in the world (27;28). Women, like in other sub-Saharan African countries have the majority (58%) of the infection (29). According to the sentinel surveillance data which is the most commonly used estimate of HIV prevalence in this reproductive age group, HIV prevalence rates of between 16-30% have consistently been recorded over the past decade (2;27). The 2003 Malawi sentinel report estimates the national HIV prevalence amongst the pregnant women to be 19.8% (17); with higher rates amongst those living in the urban as compared to rural areas (21.7% versus 16.9%). In Lilongwe district, the prevalence is now 16.9% (17). As a consequence of this high HIV prevalence in the antenatal population in the country, there have been increasing rates of MTCT of the virus currently estimated at 35% (3;17;30;31).

Rates of MTCT of HIV vary from 15-30% without breastfeeding and can reach as high as 30-40% with prolonged breastfeeding (31). Malawi being one of the countries where breastfeeding is universal (10), MTCT is relatively high (17). This is the second most common mode of HIV transmission after heterosexual transmission (10).

Without any intervention, it is estimated that about a third of all babies born to HIV infected mothers will acquire the virus (32). Thus, with about 300,000-600,000 deliveries yearly, and the national HIV

prevalence of 19.8% in antenatal population in Malawi, an estimated 20,000- 40,000 infants are born with HIV infection every year.

Mortality amongst HIV-infected infants is two times higher than those without HIV infection, accounting for 15% of all infant deaths (32) . Infant mortality which had dropped from 134 to 104 per 1000 live births between 1990 and 1995 as a result of improved child survival programs is beginning to creep up in Malawi (10). Some authors have suggested that all hard won gains in child survival will largely or totally be offset by this expanding epidemic (32). For instance, the financial cost of caring for the sick and dying infected children is high, and there will be a significant loss of benefits gained from commitment of time, energy and resources that have been spent on reducing child morbidity and mortality over the recent decades (2).

PMTCT interventions are now considered a priority if gains towards reducing the high infant and child mortality rates (23;31) are to be maintained; as reflected in Millennium Development Goals (MDGs) (23).

Since 1999 when the efficacy of short term antiretroviral regimens for preventing MTCT was demonstrated in developing countries (33;34), interventions to prevent transmission of HIV from mother to child have become increasingly available in Africa (34;35) including in Malawi (3;23;30;31;33;34;36), but like in many African countries, Malawian women do not fully participate in these interventions (37). Among those women who receive HIV-positive test results at PMTCT programs and who are invited to participate in interventions, only a third may complete their necessary follow-up visits and begin antiretroviral prophylaxis (37). This problem has affected a PMTCT program at the UNC Project in Malawi, where approximately 16.9% of the pregnant women are estimated to be infected with the HIV virus (17;31).



## 2.2 The Existing PMTCT Program in Malawi/UNC Project

### 2.2.1 Background

The program, which was initiated as a component of the UNC Project is being implemented in collaboration with the Malawi MOH in Lilongwe, with funding from the Elizabeth Glaser Pediatric AIDS foundation (EGPAF) and UNICEF- Malawi. The program commenced in April, 2002 way before the official launch of the national PMTCT program on June 12<sup>th</sup>, 2003 (30) and was initiated as a pilot program in four Lilongwe sub-urban public health facilities of Bottom Hospital, Kawale, Area 18 and Area 25 Health centers, starting with one site at a time. It was the first program to partner with MOH in the central region of Malawi and the fourth site to implement PMTCT interventions after Embangweni in Mzimba, Chiradzulu and Thyolo districts (see figure 2 for the PMTCT sites). By April, 2003, all the four sites became fully operational.

The program was incorporated into the existing MCH delivery system as per the MOH recommendations (3;31) with the goal to reduce MTCT by at least 40% in 75% of all antenatal attendees (3). This target was set in line with the national goal following the Abuja declaration and United Nations General Assembly Special Session on HIV/AIDS (UNGASS) set targets (3;30;38).

### 2.2.2 Program Components

Aligned with the national strategy, the program's goal was to be achieved through the integration of HIV/AIDS education, voluntary counseling and testing of HIV (VCT); and the administration of single dose Nevirapine (NVP) therapy (HIVNET 012 regime) to mother-infant pairs into the existing MCH care delivery system (2;3). The administration of single dose NVP to the mother intra-partum and infant postpartum (within 72 hours of birth) was chosen because NVP has long half-life and effectively reduces vertical HIV transmission by almost 50% during the first 14-16 weeks of life in a breast feeding population and, during the course of 18 months after birth; it reduces the relative risk of HIV by 41% compared with Zidovudine (39;40). Furthermore, NVP regimen is less costly and cumbersome than Zidovudine regimens in Malawi (3). Treating mothers and neonates with a single dose of NVP regimen is again associated with a lower rate of vertical HIV transmission without any evidence of increase in serious adverse events over the 18 months follow-up period but one problem is resistance which is more often the

case with NVP (39). To ensure success of the PMTCT program, 100% of the HIV positive mother-infant pairs were targeted to receive the NVP prophylaxis.

### 2.2.3 The Program's Protocol

The PMTCT protocol that UNC project follows is in line with the Malawi PMTCT implementation guidelines and is as outlined below:

#### 2.2.3.1 The Integrated approach to Provision of PMTCT/VCT services

All PMTCT services are integrated within the Reproductive Health Clinic to take advantage of the high antenatal (ANC) attendance rate of 91% in Malawi as well as to maximize on the existing resources (5). When antenatal women present to the clinic early every morning (Monday-Friday), they are given health education on any public health concern (as has always been the government routine in all public health facilities) followed by a PMTCT motivational talk, which includes a discussion of the high prevalence of HIV among pregnant women in Lilongwe, the risk of perinatal transmission, the benefits of HIV testing and the importance of NVP interventions to mother-infant pairs. Before April, 2005, those who became motivated were given detailed information of the PMTCT services in small groups of 5-8 people in a private room followed by routine antenatal care before PMTCT services were provided; ("opt-in"<sup>1</sup> as opposed to "opt-out"<sup>2</sup>) while the rest of the clients followed the routine antenatal procedures done by government nurses.

Since April, 2005, the program follows the "Opt-Out" strategy which was adopted in 2003 by MOH in collaboration with the Malawi National AIDS Commission (NAC) as one of the country's national HIV/AIDS policies. This was done to ensure that all pregnant women benefit from the PMTCT services (30), without any concerns of deterring women from seeking prenatal care and subsequently resulting in fewer women returning for their test results and HIV care after testing (42). The UNC PMTCT program started implementing this new strategy initially with two of its clinics following a phase-in approach and

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<sup>1</sup> "Opt-in" refers to a strategy where pregnant women attending antenatal clinics are informed about the availability of Voluntary Counseling and Testing (41) services for HIV and these women self select for themselves to undergo the testing process. VCT is the first step towards getting PMTCT services.

<sup>2</sup> "Opt-Out" refers to a strategy where all pregnant women attending antenatal clinics are offered testing unless they specifically choose not to be tested.

by December, 2002; the remaining sites had been covered. This study was therefore conducted when this new strategy had just been introduced.

After receiving their routine care, clients are asked to join the PMTCT program followed by group counseling, then an HIV testing after obtaining consent. Other tests done are hemoglobin (Hgb) check, syphilis testing and urine tests for albumin. If any problem is identified, such as a positive syphilis test, the presence of albumin in urine or a low Hgb, appropriate treatment is given to the client or appropriate referral made to ensure that timely care is provided. For a positive syphilis test, partners are also treated. In total, there are 2 types of samples collected at this point. All these tests minus syphilis tests are done right at the clinic and the client usually waits for approximately 15 minutes before the results are determined. If a woman prefers to return on another day for her results, the PMTCT providers keep the records until that time. Though there is this provision, in practice approximately 99% of the clients still wait for their results (36).

Post-test counseling of HIV infected women is done individually and includes counseling clients on coming to the clinic for their follow up care where continued infant support and care services are provided. Also, women are encouraged to bring their partners for voluntary counseling and testing (VCT) or to encourage them to go to other VCT outlets for these services, though in practice, there have been low partner/spouse involvement. This has been a general trend and is similar to the utilization of other reproductive health services in all the PMTCT as well as other general clinics (5).

The woman's antenatal book is then coded to allow both PMTCT providers and government midwives to provide and document comprehensive PMTCT services rendered to her during the antenatal, labor/delivery, and the postpartum period up to when the baby is 18 months old. The client is then given NVP and is advised to come back to the clinic at 32 weeks gestation to check if the NVP has been kept safe and/or is available. It is also during this next visit that the client is told about her syphilis test results (usually within 2- 3 weeks). The 32-week gestation was chosen because most babies in Malawi if born prematurely would survive after this time. Referrals to the Anti-retroviral Therapy (ARV) clinic for those requiring therapy are also done.

Before July 2003, Enzyme Linked Immuno-Sorbent Assay (ELISA) tests were done on venous blood, requiring women to come a week later for their results. Since July 2003, parallel Rapid on-site testing using Determine (ABBOTT) and Uni-Gold (TRINITY) testing kits are being done to allow same day results (43). The program uses two tests to improve the specificity (100%) in its validation. This improves reliability and minimizes human error problems (43). Also, ten percent of all tests done on the client samples and all the indeterminate test results are sent to the reference laboratory for quality control and to perform other confirmatory tests respectively. Anecdotally, before rapid testing was done, only 38% of the total antenatal clients joined the program. After the implementation of rapid testing, the number of clients joining the program increased to 80% of the total women attending the antenatal care. This compares favorably with levels of participation in the follow-up care after rapid testing was introduced in PMTCT programs elsewhere in Africa (44;45).

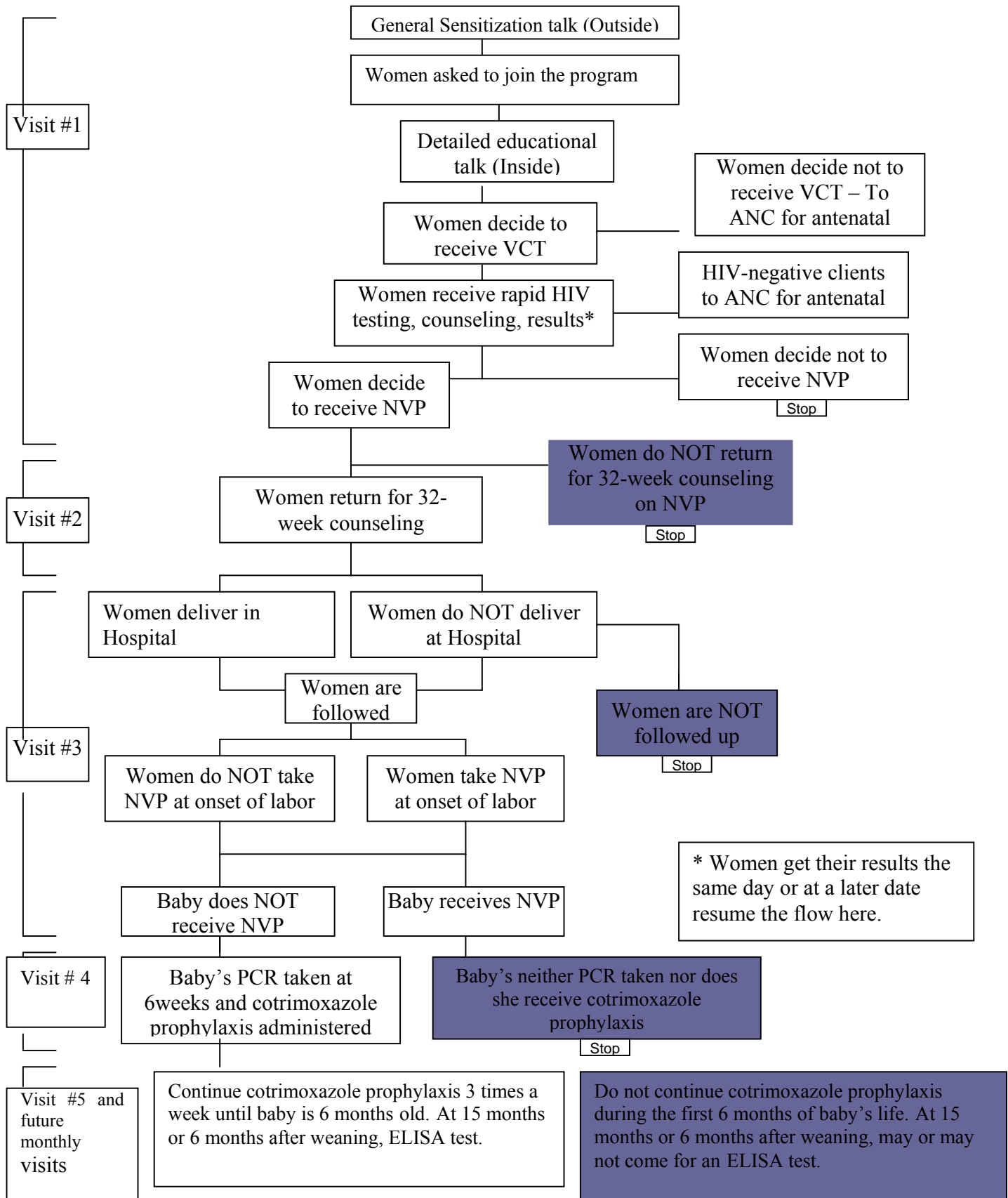
When the woman presents in labor, she is asked whether she has ingested the NVP tablet. If she reports having taken the tablet more than 48 hours prior to coming to the hospital, vomited the tablet within 30 minutes after ingesting it or if she lost her tablet, she is given an additional tablet from the secured stock kept in the labor ward. Pill counts are correlated with the registered doses administered periodically to ensure that drugs are utilized for their intended purpose. Upon birth, the infant also gets NVP syrup within 72 hours of birth or before discharge, whichever comes first. For the clients who deliver in facilities where there are no PMTCT services or at home, they are advised to bring the baby to the PMTCT clinic within 72 hours of birth or at least within 1 week for baby dosing. If the client cannot manage to bring the baby, a guardian in whom they confide should bring the baby to the clinic on her behalf. This advice is provided to the clients during antenatal care either by the PMTCT or government antenatal-care providers.

The other visits that the client makes to the clinic are as follows: At 6 weeks following delivery, for the baby's polymerase chain reaction (PCR) check and for the client to be initiated on family planning methods. Also, cotrimoxazole prophylaxis as per Malawi government recommendations is commenced for the baby from 6 weeks of birth until 6 months of age to avoid any chest infections. During these monthly visits, the client continues to receive on-going infant feeding counseling (breastfeeding or alternative feeding depending on the type of infant feeding option she is practicing) and personal care. The visits are terminated when the baby is 15-18 months old or 6 months after cessation of breastfeeding when specimen for ELISA tests are taken on the baby to rule out MTCT during the breastfeeding period. These

tests are especially important in Malawi where breastfeeding is the universal (10;32) and where approximately 96% of the program participants do breastfeed their babies (10). If the baby is infected, the mother is referred to an ARV pediatric clinic where the baby receives continued care such as initiation of ARV therapy if he/she meets the pediatric ARV criteria as stipulated by MOH.

In total, participants in the program are required to make 6 scheduled visits starting from when the client receives her HIV results to when the baby is 18 months of age. Refer to the flow chart in figure 3 for the protocol that the Lilongwe UNC PMTCT program follows for the implementation of its program activities. The highlighted areas were the researcher's interest points for the study.

**Figure 3: Lilongwe PMTCT Flowchart for Women Attending Antenatal Clinic**



Also, in February, 2003, the program initiated clinic based support groups in all PMTCT clinics where clients discuss issues of their concern. As such, it is anticipated by the program that these social support groups help the women to cope with their HIV positive status thereby ensuring positive living with the infection. Clients themselves moderate the discussions and one PMTCT provider is always there to answer any questions and clarify issues that are beyond the clients' capacity to ensure dissemination of right information to the group. These groups meet once a month. Participation is voluntary and is open to all women in the program.

### **2.2.3.2 Record Keeping**

The program keeps records of all its clients since inception. The registers kept include the following: one on clients receiving PMTCT motivational talks on a daily basis where all clients, their names, their gestational ages, ages, parity, gravidity and their addresses are recorded; the counseling register where information on the dates on when the individual clients were counseled, their identification (ID) numbers, specimens taken, results, whether post-test counseling was done or not, if not done, reasons for not doing information on transfers in and out the ID numbers of the PMTCT providers are also recorded. Furthermore, laboratory forms on where all investigations and results are written against the client ID, drug registers where all drugs given to the client/partner are recorded against the client ID and; a separate NVP register with client IDs to record those who got the NVP and on which dates are also kept. For the HIV positive clients, separate individual files are opened. In this file, clients' individual contact information is recorded in case of need to be traced in their homes like in case of illness when they cannot manage to come for a scheduled visit. In this regard, a community PMTCT provider conducts a home visit and documentation on everything done on the client and her baby is done. These records only have an identification code and are kept in a secured place by the program providers.

### **2.2.3.3 Monitoring**

To monitor the program's progress, monthly reports are compiled and the providers discuss any issues during the scheduled monthly meetings. The UNC project director usually attends these meetings to ensure that all activities are geared towards achieving the set goals. Again, a copy of the monthly reports is sent to MOH and UNICEF and a bi-annual report sent to the EGPAF.

To date, the program reaches over 18,000 pregnant women who attend antenatal care in these four facilities annually and the total number of antenatal women joining the PMTCT program has so far been more than 80% of the total antenatal clinic attendees (1). Also, the PMTCT services being offered in Lilongwe have tied its program visits to the routine MCH activities to avoid any extra visits to the clinic by the clients (2;3). So far, the program provides the bulk of PMTCT services in Malawi (4) and has served as one of the pilot projects to provide lessons for the national MOH scale up of the PMTCT services (5).

## 2.3 Problem statement

Despite the program's high initial uptake of over 80%, more than 20% of the total clients who enroll in the program default the program's scheduled follow-up visits during the first six months following their HIV positive sero-status knowledge, starting from 32 weeks gestation (36). Even when the PMTCT clients deliver in PMTCT facilities, a significant number hide their identification records which indicate their HIV status and their participation in the PMTCT program, resulting in mothers not taking the NVP tablets and their babies not receiving the syrup (1;36). Before the study was conducted, little was known on why these women do not fully participate in the program's scheduled follow-up visits.



## Chapter three: Literature Review

### 3.1 Introduction

This chapter presents a review of literature done related to the present study. Initially, global issues on HIV/AIDS and MTCT will be presented followed by that on the significance of MTCT, breastfeeding and MTCT, other factors that increase the risk of MTCT, ARV prophylaxis to prevent MTCT and an overview of interventions to prevent HIV transmission in pregnant women, mothers and their children. The presentation then moves on to the status of PMTCT implementation in Malawi; followed by a review of literature on previous studies done in Malawi and elsewhere, in relation to this study. It should however be noted that literature review has been on going and as such, part of the review was done prior to the field work whilst the remaining part was done during and after field work. The aim was to expand on the scope of understanding of the issues surrounding the present study that emerged during and after data collection. In view of this, some of the literature reviewed is further discussed in chapters 6-8.

### 3.2 Global Issues on HIV/AIDS and MTCT

HIV remains the greatest health crisis that the world faces today. By the end of 2003, UNAIDS estimated about 40 million people to be living with the virus worldwide. Furthermore, the pandemic led to 5 million new infections and claimed 3 million lives (26). The prevalence varies considerably across regions ranging from approximately 74,000 in Oceania to about 25 million people in sub-Saharan Africa. Thus Sub-Saharan Africa remains by far the most devastated region of the world and the majority (57%) of the infected are women who are mostly in their reproductive ages (Ibid).

Further evidence suggests that there are again some wide variations in national prevalence rates between countries in Africa. For example, the HIV prevalence rates are highest in Botswana and Swaziland where they are reported to be approximately 40% (26). In contrast, West Africa is relatively less affected although in some countries like Nigeria, the rates are slowly increasing from 1.9% in 1993 to 5.8% in 2001 (46).

With regard to the modes of HIV transmission, there are again some variations between the developed and the developing countries. For example, the predominant mode of transmission in most parts of the developed world remains intravenous drug use and/or commercial sex work whereas in the developing countries on the other hand, heterosexual transmission is predominant (47).

In Malawi, heterosexual transmission is prevalent and accounts for 90% of all transmission (10;48). Consequently, HIV prevalence has been sustained at 15% in adults (49); ranking Malawi the eighth highest prevalence in the world (27;28). Disaggregated data by sex shows that women and girls just as is the case in most parts of the sub-Saharan region are the most affected contributing to a prevalence of 58% of the total infected (Ibid). Because the majority of the infected are mostly in their reproductive ages (15-49 years); high rates of HIV prevalence at 19.8% have been recorded in the antenatal population. In turn, there have been high rates of MTCT currently estimated at 35% of the total transmission (17). MTCT thus ranks second as the most common mode of HIV transmission after heterosexual transmission (Ibid).

### 3.3 Significance of MTCT

An estimated 200 million women worldwide become pregnant each year of whom about 2.5 million are HIV positive (50). The majority of the infected are young and of child bearing age who may not be aware that they have HIV infection or that they may become infected while trying to get pregnant (Ibid). This has a lot of practical implications and it is in view of this that HIV infection is now considered one of the most serious health problems affecting pregnant women in Africa.

According to UNAIDS, each year more than 600,000 infants become newly infected with HIV and MTCT, which is transmitted either during pregnancy, labor and delivery, or through breast feeding accounting for more than 90% of these infections (26;33). Furthermore, more than 90% of these infections occur in sub-Saharan Africa. In contrast, new HIV infections in infants/children are becoming increasingly rare events in most parts of the world especially in industrialized countries. For example in 2003, North America and the Western Europe reported less than 1000 children to have become infected with HIV and less than 100 were reported for Australia and New Zealand (26).

This difference across regions is largely due to infant feeding practices, ARV therapy and the quality of obstetric care including caesarian sections (2;35). Evidence shows that among infants who are not

breastfed; about two-thirds of the cases of MTCT occur around the time of delivery and the rest during pregnancy (mostly during the last 2 months) (51). In breastfeeding populations like Malawi on the other hand, postnatal transmission through breast milk accounts for more than one third of all transmission (52-54).

### 3.4 Breast feeding and MTCT

Evidence suggests that the risk of MTCT may be greater in the first months of an infant's life and it continues with prolonged breast feeding (54;55). Further evidence suggests that this may be associated with breast conditions such as mastitis and/or bleeding nipples, the conditions that are common in the early months following delivery (50;56). The infants' conditions that have been found to be associated with increased risk of MTCT are immaturity of the gut making it more vulnerable for HIV to pass through (57). Furthermore, this risk is reported to be linked to the greater exposure to HIV as a result of the fact that breast milk in early life consists of the highest proportion of an infants' diet (Ibid).

Even though the risk of transmission is highest during these first months of an infant's life however, it has again been documented from studies in Africa that there is a cumulative risk of between 52-76% of HIV transmission beyond six months which is associated with breast feeding after that age (55;56). In view of this, recommendations to stop breastfeeding at an early stage of below six months have been found feasible and studies have suggested that this can significantly reduce the risk of MTCT during this period (Ibid). Furthermore, evidence suggest that the risk associated with not breast feeding is highest in the early months of life and diminishes but is not completely eliminated as the infant gets older (Ibid). The above recommendations therefore come at the right time especially for breast feeding populations in most parts of Africa including Malawi; where infant mortality is reported to be high mostly due to preventable causes of disease and conditions that do not meet the criteria for replacement feeding<sup>3</sup> (6;10;16).

In conformity with the WHO protocols, Malawi MOH adopted the above recommendations and endorsed a policy for all women to utilize PMTCT services for them to know their sero-status and to be

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<sup>3</sup> UNAIDS, WHO and UNICEF issued a joint policy statement on HIV and infant feeding which states that “When replacement feeding is acceptable, feasible, affordable, sustainable and safe; avoidance of all breast feeding by HIV-infected mothers is recommended, otherwise , exclusive breastfeeding is recommended during the first months of life” (58).

appropriately counseled on infant feeding options, starting from the time they attend antenatal care (59) (Refer to table 2 for the available options).

**Table 2: Infant feeding options for HIV positive women**

Option	Pre-condition
(a) Breast feeding options <ul style="list-style-type: none"> <li>• Exclusive breast feeding</li> <li>• Heat treated expressed breast milk</li> <li>• Wet nursing</li> </ul>	<ul style="list-style-type: none"> <li>• Up to 6 months.</li> <li>• Use within 12 hours if kept in a cool place or within 72 hours if refrigerated.</li> <li>• Wet nurse tested negative</li> </ul>
(b) Replacement feeding <ul style="list-style-type: none"> <li>• Modified cow’s milk</li> <li>• Full cream milk powder</li> <li>• Commercial infant formula</li> </ul> NOTE: Avoid mixed feeding as it causes gut inflammation that can increase risk of HIV acquisition	<ul style="list-style-type: none"> <li>• Follow protocols for preparation</li> <li>• Feed child at least 8 times in 24 hours</li> <li>• Require an average of 40x500gm packs of formula for 6 months</li> </ul>

Source: (59)

### 3.5 Other factors that increase the risk of MTCT

Some of the factors that have been proven to be associated with the high risk of MTCT include the maternal viral load, advanced maternal HIV disease, premature delivery, low CD4 count, prolonged rupture of membranes of more than four hours, no ARV prophylaxis, duration of breast feeding and breast infections such as mastitis and bleeding nipples (50). Optimal low rates of perinatal HIV transmission can be reduced to below 2% with effective interventions in place, including ARV prophylaxis (35).

### 3.6 Antiretroviral Prophylaxis to prevent MTCT

The efficacy of short term regimens for PMTCT started to be demonstrated between mid and late nineties and since then, several different regimens have been recommended for different circumstances (35).

Women may receive ARV drugs during pregnancy as part of treatment for their HIV infection which substantially also reduces MTCT or as prophylaxis to prevent infection in infants (35). According to WHO (2004), such therapeutic decisions need to be based on their need and eligibility for such treatment (Ibid). In 2000, WHO recommended short course ARV therapy, started in late pregnancy or during labor to be included in the PMTCT programs on the basis that these drugs reduce peripartum transmission by two-to-three fold (Ibid). At that time, the recommended regimens included ZDV alone or in combination with Lamivudine (3TC) and NVP. The simplest regimen consisted of NVP at onset of labor plus single dose to the infant within 72 hours of birth. This was based on the results of HIVNET 012 trial in Uganda which demonstrated reduction in MTCT by 47% during the first 14-16 weeks of life in a breast feeding population (60). PMTCT programs based on this regimen have been shown to be feasible and acceptable especially in resource constrained settings because prevention of MTCT can be achieved at a cost of US\$4 per infected mother-infant pair, which is less costly than ZDV (61).

ZDV has also been found efficacious in PMTCT programs. The results of the AIDS Clinical Trial Group-076 (ACTG-076), a multi-centre, international, placebo-controlled, double-blind study, showed that giving ZDV to relatively healthy HIV-1 infected pregnant women prenatally from as early as the 14<sup>th</sup> week, and continuously throughout labor and delivery, and to neonates for the first six weeks of life, significantly reduced the rate of HIV-1 vertical transmission (62). Again in 1998, the efficacy of ZDV regimen given to a non-breast feeding population during the last month of pregnancy and in labor was demonstrated in Thailand (63). If initiated in late pregnancy, this regimen has again shown to be feasible and less expensive (Ibid).

Results from clinical trials also show that a combination regimen of ZDV plus single-dose NVP given to a woman around the time of delivery and to the infant upon birth is highly efficacious and suggest that ,ZDV starting at 28 weeks is more efficacious than ZDV started later in pregnancy (35).

In industrialized countries, triple combination regimens are widely used in PMTCT programs. WHO however argues that there is no evidence yet from resource-constrained settings, where breast feeding is universal about the safety and effectiveness of these combinations (Ibid). Furthermore, information on safety with short term regimens in general however shows that, short term regimens are generally well tolerated and have mild and transient side-effects for the woman and her infant.

Potential drug resistance with short-course regimens for PMTCT has however become a far greater concern since early 2000. NVP resistance has been shown to develop rapidly and have been associated with longer NVP half life (39;40). On the other hand, ZDV resistance emerges after several months of partly suppressive therapy (Ibid). WHO (2004) therefore argues that concerns about resistance should be balanced with programmatic simplicity and practicality of the available regimens and the urgent need to expand PMTCT programs. For example, combinations of ZDV and NVP provided to women from 28 weeks are highly efficacious but they increase the burden on programs and on the women who participate (35). On the other hand, WHO argues that NVP regimens remain practical when ZDV-NVP combinations are not acceptable or feasible (Ibid).

In view of the above recommendations, the Lilongwe UNC PMTCT program uses NVP regime as one component of its PMTCT interventions.

### **3.7 An overview of interventions to Prevent HIV transmission in pregnant women, mothers and their children**

The joint United Nations program on HIV/AIDS strategy for prevention of transmission in pregnant women, mothers and their children takes a four-prong comprehensive approach which recommends the following strategies: Initially, it recommends that primary prevention of HIV amongst women of the reproductive age group is the best way to avoid MTCT (6;64). However, for those that are already infected, efforts should be made to counsel and support them to avoid becoming pregnant. For those that are infected and are already pregnant, interventions comprising of modified obstetric practices such as prevention of episiotomies; artificial rupture of membranes and caesarian sections; administration of short course antiretroviral therapy and; infant feeding counseling would help to reduce the risk of MTCT. The

fourth component involves the provision of care, treatment and support to HIV infected women, their infants and families (An MTCT-PLUS component of the PMTCT program) (Ibid).

UNAIDS further suggests closer integration with HIV treatment services to ensure that HIV positive mothers can easily access ARVs. Furthermore, it asserts that the integration of the PMTCT program into the MCH services can help improve coverage of PMTCT comprehensive services (Ibid). In view of this, PMTCT services in most parts of the world have been integrated into the MCH department as per the above recommendations and; integration with HIV treatment services is mainly done through referral networks at different levels in the PMTCT implementation (3;31;35;38).

It should be noted however that in most parts of the sub-Saharan region including in Malawi, efforts to reduce MTCT are mostly focused on the third component which is “the prevention of HIV transmission from HIV infected women to their infants”(35). As such, PMTCT efforts have targeted on reducing MTCT around the time of labor and delivery which accounts for one to two thirds of the overall transmission depending on whether or not breast feeding occurs, as already alluded to earlier in this chapter (Ibid).

Furthermore, ARV prophylaxis has been provided to pregnant women especially during labor in respect of the available evidence suggesting that ARV prophylaxis during labor and delivery alone, can reduce MTCT in a breast feeding population by almost two-fold following a vaginal delivery (41-47% reduction in risk) (35;60). For programs where ARVs have covered the last month of pregnancy, efficacy at six weeks has been shown to be as high as 63% (35;65). With prolonged breast feeding however, infants have continued to be exposed to the risk of MTCT for as long as the breast feeding has continued (Ibid).

At the UNGASS meeting on HIV/AIDS in June 2001, the 189 United Nations member states adopted the declaration of commitment to the comprehensive program of the international and national action against HIV/AIDS (66). These governments among others agreed that HIV testing and counseling to pregnant women should become standard practice in the antenatal care. This “opt-out” strategy was agreed upon with the aim to implement PMTCT programs on a wide-scale, especially in resource constrained settings (Ibid). Furthermore, the declaration established specific goals, including reducing the proportion of infants infected with HIV by 20% by 2005 and, by 50% by 2010 (Ibid); a goal which was set in conformity with

the MDGs (23). The four-prong comprehensive strategy for prevention of transmission in pregnant women, mothers and their children was again re-enforced at this session.

### 3.8 The status of PMTCT implementation in Malawi

In line with the above declarations, Malawi adopted its PMTCT strategies in 2001 and programs were mostly pioneered by non-governmental organizations. These first pilots (as described in section 2.2.1 of chapter 2), generated experience and information for the national scale-up program where by June, 2005; there were 36 sites. Malawi government officially launched the PMTCT program on June 12<sup>th</sup>, 2003. Of the 36 sites, 30 are supported by UNICEF (including UNC project which is partly supported by it); 2 by Médecin Sans Frontières (MSF), 1 by WHO, 2 by an AIDS network organization called “UMOYO” and one by CHAM (67).

The “core” PMTCT interventions are as those indicated in section 2.2.2 of chapter 2. UNICEF (2005) further argues that community engagement and male involvement has been found to be low in all the health facilities providing PMTCT services (67).

### 3.9 An overview of the previous studies done

#### 3.9.1 Current knowledge on client non-participation in the PMTCT follow-up visits

Previous studies have documented refusal to be tested and non-receipt of HIV test results as some of the barriers to participation in PMTCT programs. However, research on barriers of any kind related to participation in PMTCT follow up visits have been extremely limited (37). The small numbers of studies that have examined client non-participation in the PMTCT follow-up visits have used both quantitative and qualitative methodologies to quantify the magnitude of the problem as well as to examine causes of client’s non-participation in this follow-up care. Indeed these studies indicate rates of loss to follow-up ranging from 28% during the antenatal period, up to 70% by the 4th month following delivery and up to 81% by the 6<sup>th</sup> month postnatal visit (68-71). Similarly; evidence from a PMTCT program in Côte d’Ivoire, rates of losses to follow up of up to 84% before the women had started taking their Zidovudine prophylaxis have been reported (37).



It has also been found elsewhere, that factors such as quality of services delivered to the PMTCT clients, socio-cultural and socio-demographic factors influence client participation and retention in PMTCT programs (37;72;73); but the extent to which these factors may influence client participation and retention in the PMTCT programs in Malawi is not known.

### 3.9.2 Studies done in Malawi

In terms of the socio-demographic characteristics, a previous study done in Malawi identified a number of predictors and the impact of losses to follow-up. With regard to the impact, Loannidis *et al.*, 1999 found that observed rates of MTCT were significantly lower in infants who returned for follow-up care even though these infants must have had additional risk of infection from breast feeding. Again, infants of low birth weight and marginally, singletons were less likely to return for follow-up. Also, parents of lower education and low socio-economic status were less likely to return for follow-up (68). Indeed 30% of the study cohort never returned for follow-up care. The researchers then concluded that losses to follow up can impact the observed rates of MTCT of HIV.

### 3.9.3 Studies done elsewhere

In a qualitative study, Painter *et al*, 2004 found that women's stated reasons for their non-participation in follow-up care are strongly linked with the negative experiences that they encounter while interacting with the PMTCT program staff (37). Contradictory findings however have been documented in a South African Knowledge, Attitudes and Practice (KAP) study where 94% of the women participating in a PMTCT program expressed satisfaction with the PMTCT services received (72). However, it was not possible to make a sound conclusion from the above studies.

Additional reasons for non-participation in the follow-up care concern women's disbelief of their HIV status and other personal factors (37). Stringer *et al*, 2003 found out that not wanting to prevent babies from getting HIV if there is no maternal treatment available were all the reasons women gave for not testing and subsequently not coming for follow-up care to take NVP (73). These may be linked to inadequate emotional support services for the clients resulting in extreme loneliness in the time after

knowing their serostatus. Further investigation was however needed to find out what the real issues were for the Malawian pregnant women enrolled in the PMTCT program.

Fear and stigma has also been shown to play a role in influencing clients' participation in the PMTCT programs. Stringer *et al*, 2003 found out that fear of partner abuse, fear of more rapid death once knowing one's serostatus and stigma were some of the most commonly cited reasons that women raised for not taking NVP (73). Similar findings have been documented in a South African study (72). However, both studies sought responses from a different target group (pregnant women attending antenatal care) and not from those who had defaulted their visits. Since there is no documentation that the defaulters were comparable to those included in these two studies, the present study sought information from the defaulters to shed more light on their stated reasons for non-participation.

In terms of the socio-demographic characteristics, Painter *et.al* (2004) found that those who had defaulted had more marginal socio-economic status than their fellow participants (34).

### 3.10 Research gaps

Based on the above literature review; it is clear that factors related to services provided to clients in the PMTCT program, personal, socio-cultural and socio-demographic all play an important role in influencing client participation in the scheduled PMTCT follow-up visits elsewhere. Since these results do not fully represent views expressed by Malawian women, an increasingly critical area of study was the extent to which these factors influence client participation and retention in the PMTCT programs in Malawi. Also, because most of these studies were clinic based, this study hoped to fill in the gap by exploring more of the clients' perspectives on a larger community level.

### 3.11 Purpose of the study

The purpose was to explore HIV infected pregnant women's stated reasons for participation and defaulters reasons for non-participation in the PMTCT scheduled follow-up visits at UNC project PMTCT clinics in Malawi.

The results were intended to help identify areas where more efforts should be put in the PMTCT programs' service delivery to ensure that services provided meet the clients' needs; thereby promoting their participation in the program's follow-up care. Also, with an effective program in place, the government would be able to draw some lessons for its PMTCT national scale-up plan (30;31). Furthermore, once the program is effective in retaining its clients; an MTCT-PLUS component of the program which would ensure a family centered and comprehensive HIV-related services for HIV-infected women and their families could easily be established in Malawi (74). For those factors that are beyond the capacity of the program, the recommendations made would help the policy makers plan on the strategies that work in the implementation of effective PMTCT programs. The study might also provide the basis for doing large scale quantitative longitudinal studies to establish the magnitude of the problem in other PMTCT settings within Malawi and elsewhere.

Both quantitative and qualitative methods were used to complement each other in answering the research question.

# Chapter Four: Research Objectives, Questions, Hypotheses and Theoretical perspectives

## 4.1 Broad Objective

To investigate why HIV infected pregnant women in the PMTCT program do not fully participate in the program's scheduled follow up visits during the first six months after knowledge of their HIV positive sero-status, starting at the 32 weeks visit.

### 4.1.1 Specific objectives

- To identify the socio-demographic factors that are associated with client's continued participation in the PMTCT program following their initial recruitment into it.
- To identify client's stated reasons for continued participation and defaulters reasons for non- participation in the PMTCT program following their initial recruitment into it.

## 4.2 The general research question

Why do HIV infected pregnant women in the PMTCT program not fully participate in the program's scheduled follow-up visits during the first six months after knowledge of their HIV positive sero-status, starting at the 32 weeks visit?

Below are themes that were explored in the qualitative part of the study.

### 4.2.1 Specific Themes

- What do HIV positive clients enrolled in the PMTCT program say about the impact of HIV/AIDS on their lives?
- What do clients say about their own role and attitude in the prevention of transmission of HIV/AIDS from mother to child?
- What benefits do clients state for participating in the PMTCT program?

- What barriers do the clients in the PMTCT program face in trying to participate in PMTCT follow-up scheduled visits?
- Are there any negative community and family responses that clients in the PMTCT program face after receiving an HIV positive test result?

The following were working hypotheses chosen for the quantitative part of the study:

#### 4.2.2 Hypotheses

- Women who default their follow-up visits are in earlier pregnancy trimesters (up to 22 weeks gestation at enrollment into the PMTCT program) than those who do not.
- Women who attend their PMTCT visit at a busy PMTCT clinic are more likely to default their follow up visits than those who attend at a less busy one.
- Women who continue their participation in the PMTCT follow-up visits are those that have had less than four pregnancies (the MOH ideal total number of children born to a woman in her life time).
- Willingness to continue participating in the PMTCT follow up visits during the first six months of follow up care is higher for the educated, married and well to do women.

The independent variables/ exposures of interest included the type of PMTCT clinic attended by the clients; trimester during the first PMTCT clinic attendance; parity; the client's age, educational level attained marital status and socio-economic status established at the start of the PMTCT clinic attendance. The dependent variable/outcome of interest was the client's participation in the PMTCT follow-up visit.

For the purpose of this study, a complier of the PMTCT follow-up visits was generally defined as the client who comes to the clinic within three weeks of her appointment date. If she does not attend the clinic, she informs the program staff in advance. A defaulter is the one who does not come to the clinic for her appointment three weeks past her appointment date and beyond. She does not inform the program staff about anything and she generally loses contact with the clinic.

### 4.3 Theoretical perspectives of the methodology

For the purpose of this study, grounded theory was used to investigate why women in the Lilongwe PMTCT program do not fully participate in their follow up care. Since little empirical data exists related to this study, grounded theory was seen as appropriate. This is because it aims at discovery and is therefore recommended in investigations of topics with relatively little prior research (75).

Based on the American pragmatism and symbolic interactionism, grounded theory has been developed over the past thirty years primarily by sociologists Barney Glaser and Anselm Strauss (76).

As Haig (1995) asserts, grounded theory is particularly suitable for qualitative studies because “it is portrayed as a problem solving endeavor concerned with understanding of action from the perspective of a human agent” (Ibid); which when applied to this study was to understand the mechanisms associated with client participation in the PMTCT follow up care.

Haig goes on to illustrate the procedures of grounded theory as outlined below:

Grounded theory starts with gathering of data from a variety of sources including the in-depth individual interviews, FGDs and field observations. Thereafter, theories are generated from the gathered data with the help of interpretive procedures before the final write up and presentation of the findings. According to the sociologists Glaser and Strauss, the latter activity is an integral part of the research process (Ibid). This study however did not aim at generating new theory rather it was used as a problem solving endeavor as elaborated in the preceding paragraph.

Understanding of client participation in the PMTCT follow up care evolved from a combination of some data gathering techniques namely the individual in-depth interviews of both the clinic compliers and defaulters at the two study sites and the FGDs with both men and women. Men were specifically interviewed to follow up on the issues affecting them that were raised by women during both the individual interviews and FGDs. An interview guide was used during all interviews to allow for flexibility in the discussions as well as to remain focused on the themes that were to be explored (75). Some observations were also made.

The emerging themes from the analysis of the findings obtained from both the individual interviews and FGDs were then identified to explore common traits in the participants' narratives in order to gain a deeper insight of those emerging themes. This process was based on the guidelines outlined for grounded theory discussed earlier on in this section. In view of this, the emerging themes were identified and these also helped to validate findings obtained from the quantitative study.

## Chapter 5: Materials and Methods

### 5.1 Introduction

This section presents the study setting, design, study population, procedure, sample size, study instruments, data collection, management and analysis; ethical clearance, protection of human subjects, dissemination of research findings and research facilities.

### 5.2 Study Setting

The study was conducted in Lilongwe, the capital city of Malawi at 2 of the 4 public health facilities where UNC project is implementing its PMTCT program services (Kawale and Area 25 Health centers).

Originally; Bottom hospital and Area 25 health centre were chosen for the study, but Kawale, an equally busy facility was used instead of Bottom hospital because of logistical problems (see appendix 1 for approval to change sites).

Kawale, one of the health centers under the Lilongwe District Health office is located approximately 3-5 kilometers from Bottom Hospital, a referral facility for all peripheral maternity facilities in the district<sup>4</sup>. It provides antenatal, postnatal, outpatient services and has inpatient facilities for low-risk obstetric conditions. The hospital has a catchment's population of about 174,291, based on clinic vital statistics, 2004; provides antenatal care to nearly 20,000 pregnant women and conducts close to 3,000 deliveries each year. There are 4 full time nurse counselors employed by UNC project and they work hand in hand with the government nurses mostly in the labor and postnatal wards. The counselors provide a full range of PMTCT services as described in section 2.2.3 of chapter two. In total, there are four counseling rooms and one room serves as a laboratory for on-site urine collection and testing, blood for hemoglobin check using hemacule; and HIV rapid testing also done by the counselors.

The place is always busy and there is always too much to be done. Counselors hardly have time for tea/coffee breaks especially on Mondays and Fridays which are mostly regarded as the busiest days of the week. Also, support group meetings for lactating mothers are held once a month in addition to the of

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<sup>4</sup> See figure 2 showing PMTCT sites as of December, 2004.



provision nutrition supplements (Soya and vegetable cooking oil) by WFP clerks with the supervision of the program providers.

Area 25 health center is a public, government-supported primary health care facility on the outskirts of Lilongwe, approximately 7-10 kilometers from Bottom Hospital. The number 25 reflects an administrative district in Lilongwe. The clinic provides preventive services similar to those provided in Kawale. It has a catchment's population of slightly over 100,000 people. Antenatal attendance lies between 6,000 to 7,000 per year. The workload in Area 25 is lighter than in Kawale and again, there are four counselors responsible for PMTCT interventions.

All the four PMTCT program sites have a total of twenty full time PMTCT providers who work hand in hand with the government providers to provide PMTCT services during antenatal, labor and delivery as well as well as rendering postnatal care. Also, there are two community health nurses who conduct community motivational talks, conduct home visits to clients who do not come for their program appointments and; facilitate clinic based support group meetings for program lactating mothers. In case of any clients needing medical attention, both government and the UNC project clinicians are consulted to provide this additional care. The program is managed by a program co-coordinator who works hand in hand with the program outreach co-coordinator to ensure the program's smooth run and they both report to the UNC project director. The current researcher has worked in this program initially as an outreach coordinator for one-year and nine months (March, 2002- December, 2003), then as program co-coordinator for seven months (January, 2004-July, 2004).

The UNC PMTCT program was chosen for this study because it provides the bulk of PMTCT services in Malawi (77). Also, the fact that the researcher had prior experience working with the program helped her reduce the period of strangeness and non-comprehension, leading to easy adjustment to the environment which in turn, facilitated the collection of meaningful data (78). The two sites for the study were conveniently chosen because they had adequate logistics. Also at this point, first and foremost was to have a deeper understanding of the processes and relationships that were obtained through qualitative analysis. Generalization was basically related to the quantitative piece of the study. Thus the current study aimed at discovery based on in-depth understanding rather than full representativity in sampling hence the choice of the mentioned sites.

### 5.3 Design

This short follow-up study was part of a larger prospective cohort of the PMTCT program participants followed up for 18 months. The program follows all infants/children born to HIV infected women monthly from six weeks after birth until the baby is six months old, then at fifteen-eighteen (15- 18) months or six months after weaning whichever comes first, for an ELISA test (Refer to figure 1). Program participation is terminated at eighteen months when the HIV sero-negativity or positivity is finally determined on the baby. In case of a positive sero-status, further referrals are made to the pediatric HIV/AIDS clinic for continuity of care. The present study only followed women up to the first six months post delivery due to feasibility, time constraints as well as the financial limitations on the part of the researcher. However, defaulting early is more serious than later since clients would have missed their NVP and interventions during labor and delivery and more of the defaulting does happen at this time (17;33;34;70;71).

Considering the previous studies and current knowledge in this area, it was decided to use a combination of methods sometimes referred to as triangulation of methods for the study of a single phenomenon (79); which in this case was an investigation on why clients who are in the PMTCT program do not fully participate in the program's follow up care. Both qualitative and quantitative methods were used. An exploratory approach was thought to be the most appropriate because the objective was to understand the phenomenon in question. At the same time, it was striking to note that; exposed to the same socio-cultural background, some participants default their follow up care while others continue. For this reason, a review of the socio-demographic characteristics using data available in the clinic was thought to be appropriate. The aim was to establish factors that would explain the variations in the two groups and come up with some predictors of loss to follow up. In view of this, similar efforts were applied to both methodologies.

Jick as cited by Maanen (1989) asserts that; the mixed method choice aims to capture a more complete, holistic and contextual portrayal of the unit (s) under study in which case the use of multiple "measures" may uncover some unique results that might be neglected by any one method. He further argues that, it is here that qualitative methods in particular can play an especially prominent role by eliciting data and suggesting conclusions to which other methods would be blind (79;80)

Triangulation of methods also makes for more rigorous data collection, which in the end will affect the quality of the data findings and the study itself (80).

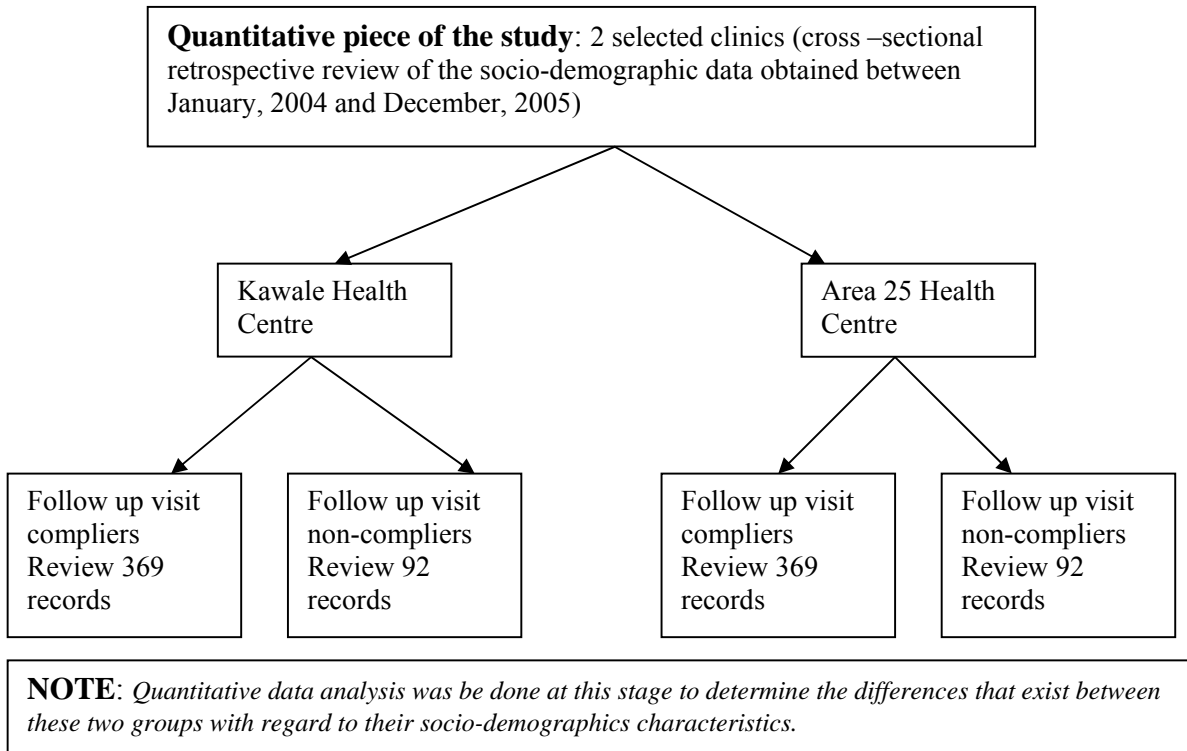
Data collection for both parts of the study proceeded simultaneously (78) and data was analyzed separately. The results of both studies were then converged to answer the research questions.

### 5.3.1 The quantitative study

The quantitative part retrospectively reviewed a cross-section of the socio-demographic data from the PMTCT program on women who complied (compliers) and those who defaulted (defaulters) at the two PMTCT sites. The review of records included clients who were recruited into the program between January, 2004 and December, 2005. The socio-demographic characteristics of compliers were then compared with those of defaulters. This helped the researcher to get a general overview of the variations that exist between these two groups of women and enabled her to develop some indicators to predict PMTCT clients' default to program follow-up visits.

Cross-sectional studies measure exposure and outcome at the same time. As such, they are relatively easy to carry out (81). The particular difficulties are that, although the study is done on a limited number of people; the results are usually extrapolated to a larger population in which case the choice of the sample may have a strong effect on the observed in relation to other factors. This being the case, the validity of extrapolation depends crucially on the representativeness of the sample (Ibid). With regard to the present study, the fact that the two-year data were grouped by month per clinic and whether clients had defaulted a visit or not; (as discussed later in section 5.5 of this chapter), this process ensured the representativeness of the sample. Also, home visits were made hence minimizing selection bias as a result of involving clinic attendees only. This community based strategy ensured capturing valuable data from non-clinic attendees hence influencing the results and conclusions (See figure 4 for organization of the quantitative part of the study).

#### **Figure 4: Flow chart showing the organization of the quantitative data collection**



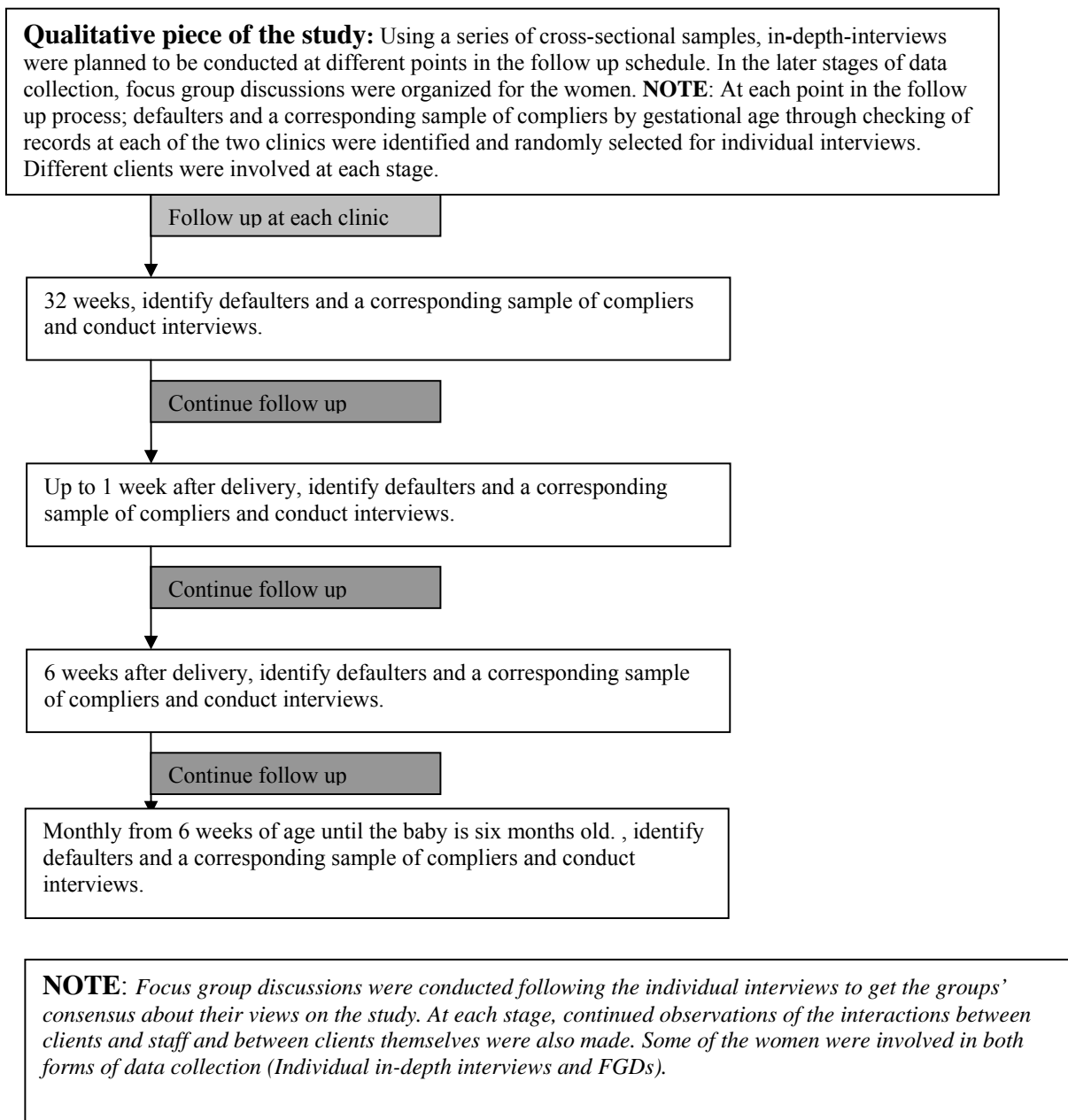
### 5.3.2 The qualitative study

The qualitative part of the study was done to obtain information on client’s reasons for compliance and defaulting in the PMTCT program follow-up care. The main aim was to engage women themselves, individually or in a small group, so they could tell their stories. As such, in-depth interviews were used to enable women articulate and unfold their experiences and uncover their lived world (82) in as far as PMTCT issues are concerned. These were complemented by focus group discussions (FGDs) of both the same women and some new ones in the later stages of data collection to give chance for repeated follow up, cross-checking and exploring further phenomenon that might emerge in the in-depth one-on-one interviews. The assumption with the FGDs was that individual’s attitudes, beliefs and actions do not form in a vacuum. People often need to listen to other’s opinions and understandings in order to form their own (82;83). In addition, the discussions would allow a collective impression of the topic under study which in turn would produce results that have high face validity (83).

Clients default their follow-up visits at different points in the post PMTCT enrollment period, hence equal numbers of defaulters at 32 weeks gestation visit, 1 week post delivery visit, 6 weeks post delivery visit,

month 3 visit, month 4 visit, month 5 visit and month 6 visit were to be interviewed. It was however difficult to get equal numbers at each stage; but interviews at each stage occurred (See figure 5 for organization of the qualitative part of the study).

**Figure 5 Flow chart showing organization of the qualitative data collection**



The focus group discussions (FGDs) were not conducted as planned because the Malawi ethical review board suggested that FGDs be done first followed by individual interviews. Because of the nature of the

study which was to conduct individual interviews first especially with the defaulters; the suggestion was only applied to the compliers. However, the interviews with the defaulters proceeded as originally planned (See appendix 2 for the ethical approval letter).

## 5.4 Recruitment Criteria

HIV infected pregnant women, age 18 to 49 years who had been enrolled in the PMTCT program at the two selected UNC project PMTCT sites were requested to participate in the study.

### 5.4.1 Inclusion criteria

- Women, 18- 49 years
- HIV positive at entry into the PMTCT program
- Willing to participate in the study

### 5.4.2 Exclusion criteria

- HIV negative at entry into the PMTCT program
- Unwilling to join the study
- Living outside the UNC PMTCT program's defined catchment's area
- Unable to comprehend the consenting process

## 5.5 Study procedure

Initially, the four clinics were grouped based on high/low attendance and ease of visiting participants at home when they miss their appointments. This definition was based on the maximum number of clients that each PMTCT provider can manage per day; in line with the national standard average of 8-10 clients/provider/day (2). Those that manage an average of more than this range were defined as high attendance clinics while those that manage less than that classified as low attendance clinics. Thus there are two high and two low attendance clinics for the program. For the purpose of this study, Bottom Hospital (one of the high attendance clinics) and Area 25 health centre (one of the low attendance clinics) were initially chosen because there was no reason to think that behavior and culture of the attendants at these two selected clinics would be different from the other two not chosen. However, whilst in field, it was discovered that Bottom hospital was congested with other on going studies. As such, it was deemed necessary to change sites in order to get unbiased data. Discussions proceeded with the local supervisor to replace Bottom with Kawale, an equally busy clinic. Communication was again made to inform the other supervisor in Norway who again consented. A request letter to change sites was again written to the national ethics chairperson who approved the request within a week<sup>5</sup>.

For the quantitative part, data on socio- demographic characteristics of the clients recruited into the program from January, 2004 to December, 2005 were collected from July to December, 2005. These records were reviewed independently. All records at the chosen clinics were grouped by month and by whether the participant defaulted a visit or not. We estimated that we needed a sample size of 922 (738 compliers and 184 defaulters) over a 24-month period and this translated to 40 participants per month (32 compliers and 8 defaulters). Each clinic randomly selected 16 compliers and 4 defaulters per month from the monthly grouped data for evaluation of the socio-demographic characteristics. The actual number of records reviewed was 960; a figure slightly higher than originally planned but this breakdown fitted well with the clinic breakdowns as stipulated above.

For the qualitative part, a short follow up design for six months was used to get clients into the study. Initially, all potential clients were interviewed at enrollment into the PMTCT program after learning their

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<sup>5</sup> See appendix 1 for a second approval to change sites.

HIV positive sero-status, to determine whether they intended to participate in the PMTCT program follow-up visits or not. This was an ongoing process at both study sites and it was aligned with the program activities.

Clients were requested to consent to be paid home visits for interviews in case they did not turn up for their scheduled program follow up visits. The visits were added on to the already existing routine program follow up activities for the defaulters. Those who consented to participate and happened to default their appointments, were paid home visits for interviews 3 weeks past their appointment dates as per the program's definition of a defaulter.

A random selection of the compliers' records was done to get compliers corresponding to their defaulters counterparts' gestational age from amongst the defaulters that were recruited for interviews. This system was used at all strategic points in the follow up process until the required number of clients for the individual in-depth interviews was reached. As discussed earlier on, it was difficult to get equal numbers of defaulters and compliers at each point although views from clients at each point were collected.

Clients who participated in the individual interviews were randomly selected from amongst all clinic attendees in the PMTCT program. Following the individual interviews, FGDs were arranged for the clients to get consensus views of issues related to the study. Permission to participate in the FGDs was sought at the end of each individual interview. The women were requested to participate in these interviews at a later date which was communicated to them later.

## 5.6 Sample size determination

For the quantitative piece of the study, the sample size was calculated based on the assumption that 30% of the third trimester mothers and 20 % of the first and second trimester women would default. A further assumption of 20% of all PMTCT attendants' default was made. Based on these assumptions, a total sample size of 922 clients (738 compliers and 184 defaulters) was estimated to be needed to determine any difference in determinants for default.

Details on how the sample size was arrived at are as follows:

P = Clinic visit compliers ( $n_1$ )



NP = Non clinic visit compliers (Defaulters) ( $n_2$ )

$P_1 = x_1/n_1$ ,  $x_1$  = proportion in 3<sup>rd</sup> trimester       $P_2 = x_2/n_2$ ,  $x_2$  = proportion in 1<sup>st</sup> and 2<sup>nd</sup> trimester

$P_1 = 0.30$        $P_2 = 0.20$

With 80% power and significance ( $\alpha$ ) = 0.05

$$\text{Standardized difference} \\ p_1 - p_2 / \sqrt{p(1-p)} = 0.30 - 0.20 / \sqrt{0.25(1-0.25)} = 0.10 / \sqrt{0.1875} = 0.10 / 0.43 = 0.2340$$

N= 590 (Sample size had been arrived at by using the nomogram. This is a simple graphical method used to determine sample sizes (81). Using a line between the standardized difference = .23, power of 80% and reading the line marked 0.05 gives N= 590).

But these were unequal sample sizes:  $n_1 = 4 \times n_2$

$n_1/n_2 = 4$  that is  $k = 4$

$$N^1 = N(1+k)^2 / 4k = 590(1+4)^2 / 4 \times 4 = 590.25 / 16 = 922$$

$$N^1 / 1+k = 922 / 5 = 184 \text{ that is } N_2$$

$$kN^1 / 1+k = 4 \times 922 / 5 = 738 \text{ that is } N_1$$

Therefore: 738 records were for the compliers of follow up visits for both clinics together whilst 184 were for the defaulters. This meant that at each clinic,  $738/2 = 369$  records for the compliers were to be reviewed and  $184/2 = 92$  records for the defaulters<sup>6</sup>. As already alluded to in the study procedure section is the fact that the total number of records reviewed went over by 38 as originally planned.

For the qualitative piece, the validity, meaningfulness and insights generated from the qualitative inquiry depends on the information richness of the cases selected and the analytical capabilities of the researcher. As such, the total number of clients interviewed were generally determined by "theme saturation", that is until no new data would emerge by conducting further interviews (84), but as a rule, 20-30 clients are usually enough. Also to note is the fact that the researcher was flexible enough to do more and not necessarily to limit herself to 20-30. Thus in total, 28 clients participated in the individual in-depth interviews; 14 per clinic, comprising of half the number being defaulters and the other half compliers. For the FGDs, two sessions were organized per clinic comprising of defaulters and compliers in each group at each clinic, to follow up on some of the issues discussed during the individual in-depth interviews. For

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<sup>6</sup> These sample sizes were thought that they might not be able to prove statistically significant differences of the two groups with regard to age and marital status because the later would need more subjects than in the calculation above.

Area 25; 7 compliers and 6 defaulters participated while in Kawale; 8 compliers and 7 defaulters did. In total, four FGDs were conducted. These interviews mostly occurred in the health facility as per participants' request although a few of the individual interviews occurred in the home setting. Transport was arranged for participants to come to the clinic.

In summary, 960 client records were reviewed for the quantitative part of the study. In relation to the qualitative part, 28 clients participated in the individual in-depth interviews and another 28 participated in the FGDs.

## 5.7 Study instruments

For the quantitative part, data was extracted from PMTCT clients' records available in the PMTCT clinics (appendix 4). The independent variables/exposures of interest were the type of PMTCT clinic attended by the clients, the trimester during clients' first PMTCT clinic attendance, parity, clients' ages, educational level attained, marital status and clients' socio-economic status which were all established at the start of the PMTCT clinic attendance. The dependent variable/ outcome of interest was the clients' participation in the PMTCT program follow up care.

For the qualitative part, an open-ended guide was used for the individual in-depth interviews (Appendix 5). The interview guide was originally prepared in English, translated into Chichewa, the local language of communication in Malawi and back to English. It was then piloted on 4 women to check for the duration and the understanding of the questions by the interviewees. Modifications were then made accordingly. Similarly, for the FGDs, a guide with important themes was prepared, translated and pilot tested (Appendix 6). Pilot testing for the FGDs was mostly done with the compliers. In both cases, pilot testing was done in the clinics that did not take part in the actual study and; clients with similar characteristics as those in the actual study participated.

## 5.8 My Position as a researcher

My position would be described as both of an insider and outsider. Insider because I had prior knowledge working with women in the PMTCT program. Also, as an outsider because I did not belong to any of the support groups and, had not been in contact with any of the women before. Citing Kvale (1996) in his

metaphor of ‘miner and traveller’ concerning the place of a researcher; I can position myself as being an ‘outsider with some basic insider’ knowledge (82).

## 5.9 Data collection, management and analysis

For the quantitative piece, raw data on socio-demographic data for both groups was entered into the computer using SPSS software package version 12.0 by the researcher. At the end of each day, all entered data was cross-checked by the researcher and her assistant (a statistician) who was employed on part time basis to ensure correct entries before commencement of the data analysis. The assistant also helped with screening of the data and offered guidance on which tests to use. Chi-square tests were then used to make comparisons in socio-demographic characteristics between these two groups. The level of significance of the findings was set at 0.05. Multiple logistic regression analysis was not done as planned due to other logistical problems.

For the qualitative part, one assistant was recruited during the first week of field work. She was a registered community health nurse with prior training in HIV counseling, PMTCT counseling and research. She mostly served as a note-taker during the entire period of data collection although she moderated some three individual in-depth interviews and one FGD during the actual data collection. She was trained for 5 days prior to data collection and had conducted one individual in-depth interview and one FGD during pilot testing.

The training included sessions on practical interviewing, note taking during the interview process, tape recording of the participant responses, making some observations which were cross-checked with the researcher’s observations at the end of each day. Other issues that were specifically dealt with during the training were learning to respect the clients’ opinions, avoiding being judgmental and respecting their confidentiality. To further improve on the quality of the interview guides for both individual in-depth interviews and FGDs, the experiences gathered from the pilot test were discussed with the assistant. She was also trained to be sensitive to the needs of the clients and to watch for signs of discomfort. Also, she was advised to step out of her role as a nurse advisor and to be neutral to the clients’ responses. As part of her orientation process also, field trips were made to the study sites a week prior to the actual data collection.

All interviews were conducted by the researcher and her assistant at the clients' convenient place following their informed consent. Each interview session was tape recorded except for one individual interview at Kawale where the participant declined to be tape recorded, in which case her views were respected. Each interview session lasted between 45 minutes to 1 hour. Notes were again taken during each interview which were later at the end of each day compared to the transcribed taped information for the earlier's reliability. These were reviewed to identify issues of clarification in the subsequent interviews.

There were only two call backs with the interviewees to get missing information; one because the interview took place close to lunch hour as such, she needed to prepare meals for her family as the interview occurred in the home and the second (which occurred at home as well) because the neighbor was deliberately frequenting the clients' home to hear what was being discussed. As such, the session was terminated to protect the client's confidentiality. For the FGDs, discussions were organized with key informants from amongst those who had participated in the concerned individual in-depth discussions in addition to involving new clients to get any missing information or clarifications. All recorded interviews had a back up in case of problems with the other tape.

Observations on the interaction patterns between staff and clients, amongst clients themselves were also done sparingly to give insight into things that the interviewees might not be willing to talk about during the interviews. This also gave opportunity to see things that may routinely escape the client's awareness. Validity was therefore ensured through persistent observations during data collection and through the contextual validation mode of triangulation (84).

Qualitative data analysis went hand in hand with data collection to promote the emergence of the themes grounded in the empirical data (84). At the end of each day, summary notes were written and attached to each field note. All data was transcribed verbatim, typed and was stored safely. At the end of the data collection, the already started data analysis process continued and data was categorized into themes and analyzed. Instead of using "NUD\*IST" computer soft ware package as originally planned; manual data analysis was done.

All data were stored in a lockable cabinet for safety and was only accessible to the study team. At the end of the study, all recorded tapes were planned to be destroyed in accordance with the research ethics.

In summary, validity and reliability was increased through use of triangulation in methods, training of the research assistant, pilot testing and continuous checking of collected data at the end of each day.

## 5.10 Ethical clearance and Protection of Human subjects

Before the commencement of the study, the research protocol was cleared with the department of International Community Health, Institute of General Practice and Community Medicine at the University of Oslo where a statement indicating that the study had been cleared was issued (See appendix 3). This statement was attached to the study protocol and together both documents were submitted to the Malawi National health sciences Committee for approval.

Thereafter, permission was sought from the concerned facilities namely UNC Project, the MOH RHU, the Lilongwe DHO, government clinic management at the two studied PMTCT clinics and team leaders of the concerned PMTCT clinics. Consent from participants was sought before each individual interview as well as FGD session (Appendix 7). Consenting for the individual in-depth interviews was in form of writing for those who could read and write. For those who could not; information was read to them after which they had to decide whether they would participate or not. If they did, a third person who was mostly the note taker was invited to witness the consenting process. For the FGDs, verbal consenting was sought. In both cases, no names were written on the interview guides. Clients were only identified by codes during the entire process. A separate register containing the client's code corresponding to their names' and addresses was however being kept in a lockable cabinet. This helped to facilitate clients' follow up during the entire study, and was planned to be destroyed at the end of the study just like the recorded tapes.

Since information for the participants in most qualitative studies tend to be more dispersed ( like in form of field notes, transcripts and tapes) and; considering the sensitivity of the topic, clients would only be identified using codes in the final write up and these have been used in the report (85).

It was envisaged that it would be a bit difficult to get to people who are defaulters of the program follow up visits because of issues of confidentiality. As a result, the requirement to be paid home visits incase they did not come for follow-up care was anticipated to likely affect their participation in these follow-up visits. This was however minimized by doing nothing beyond what the program does already. Clients

already consent to be paid home visits in case they do not come for their follow up. This is done as soon as the clients learn about their HIV positive sero-status in which case they are requested to give their locator information to be paid a home visit.

Regarding confidentiality through the follow-up home visits, the researcher and her assistant visited the homes as neutral persons, coming by public transport and; dressed in ordinary clothes and not in a hospital uniform. In this way, she was seen as any other ordinary person in the community thereby avoiding drawing of any attention from the general public. As such, client's confidentiality was ensured because they were taken as any of their fellow community members. Also, bringing the PMTCT clients together for an FGD might reflect an implicit positive status. The strategy that was followed to protect them was similar to how the program handles its clients who are in the support group. Clients chose for themselves a place where they would like to have the discussions like in a private room within the clinic premises. Also, those who were willing to participate had had their consent sought individually at the end of their individual in-depth interviews.

### 5.11 Dissemination of the research findings

Preliminary study findings were presented to UNC project just before the researcher left for Norway. Also, several dissemination techniques have been planned. A written report will be submitted to UNC Project, the National AIDS commission of Malawi, MOH and the Faculty of Medicine, International Community Health Department, University of Oslo-Norway. In addition, the findings will be disseminated via academic papers and conference presentations. Also, they will be disseminated through appropriate in-country seminars such as the annual HIV research seminars organized by the Malawi National Health Sciences Research Committee and by the Malawi National AIDS Commission.

### 5.12 Research Facilities

UNC PMTCT clinics had ample space/rooms for the clients' consenting process to participate in the study and to be paid home visits (Appendix 8). Also, both types of interviews were conducted in these rooms if the clients so wished. A lockable cabinet, space for recording the retrospective data and communication access was again available, all provided by UNC project.

# Chapter 6: Results

## 6. 1 Introduction

This section presents data obtained from both quantitative and qualitative methodologies in the study. Each approach will be presented separately; starting with the qualitative part.

## 6. 2. Results of the qualitative study:

### 6.2.1 Socio-demographic characteristics of participants

The study included 28 recently delivered women who participated in the individual in-depth interviews in Kawale and in Area 25. 14 defaulters and 14 compliers were included with half of each group participating in in-depth interviews in Kawale and the other half in Area 25. Again, another 28 comprising mostly of the same participants in the in-depth interviews also participated in 4 focus group discussions in these clinics. In the Kawale FGD, 8 compliers and 7 defaulters participated whereas in Area 25, 7 compliers and 6 defaulters did.

All women were living in the Lilongwe semi-urban and had ever attended the PMTCT program either in Area 25 or Kawale. The socio-demographic characteristics of clients who participated in the individual in-depth interviews are summarised below:

#### **6.2.1.1. Age distribution of the sample**

Women attending in-depth interviews in Kawale clinic had a mean age of 30 years ranging from 24-35 years whilst those attending Area 25 clinic had a mean age of 32 years ranging from 25-44 years. Overall, the minimum age of attendees in both clinics was 24 years and the maximum was 44 years.

#### **6.2.1.2 Marital status of the clients**

All clients from both clinics were married except for one defaulter in Area 25 who had just been recently divorced. The type of marriage was mostly monogamous. It was however noted from the participants that

most of their partners had other sexual partners. 4 of the 28 clients who participated in the in-depth interviews reported being in a formal polygamous marriage.

### **6.2.1.3 Education**

Some informants had never been to school (29% for Kawale and 50% for Area 25).

The most educated women for Kawale had 12 years of formal education and they were only 14.2% of all Kawale in-depth interview attendees and the most educated for Area 25 also received 12 years of formal education, making up 7.1% of all attendees. The illiteracy level in both clinics stands at 39.3%, lower than the national illiteracy average of 56%.

### **6.2.1.4 Parity**

The number of births that clients had in Kawale ranged from 1-7 children with an average of 3 births whilst for Area 25, the range was 2-10 births with an average of 4 births. Overall, the minimum number of births a woman had had was 1 and the maximum was 10.

### **6.2.1.5 Occupation**

Almost all clients in both clinics were house wives except for 2 clients in Kawale (1 defaulter and 1 complier) who were a cook and business lady respectively.

**Note:** Because most of the clients who participated in the in-depth interviews also participated in the FGDs, there weren't any remarkable differences in-terms of socio-demographic characteristics between clients who had participated in the in-depth interviews and those who had participated in the FGDs.

## **6. 2. 2 Results of both individual in-depth interviews and the FGDs**

In the discussions about pregnant women, HIV and client participation in the PMTCT follow up care; women talked a great deal about their lives and how these had impacted on their ability to participate in their PMTCT program's follow-up care. Several issues unfolded for their non-participation in the follow up care. The following emerging themes were identified and will be described in more detail in this section: reactions by people in the communities and in the clients' families; the embedded gender/power



relations and the women's place in society; their experiences at the program and; personal factors. Clients gave these responses when they were asked to state any challenges that they had encountered by participating in the PMTCT program.

None of these categories are discrete; rather they interact with each other to influence on their participation in the program's follow-up care. I will however discuss each issue separately to yield a thorough understanding of the complexity of the matter.

### **6.2.2.1 Women's concerns about the community reactions to their HIV positive status**

Women expressed concern over the negative community reactions towards them as HIV positive victims. Though most clients (99%, n = 28) who had participated in the individual in-depth interviews and almost all in the FGDs mentioned not having disclosed their status to the community (friends/neighbors); the latter's responses were mostly based on assumptions of an implicit HIV positive status of the clients based on some observed actions/characteristics. Such responses were mentioned by the clients as having experienced them directly or witnessing a close friend whom they are aware of their HIV positive status.

Women were concerned about reactions to their bodily changes, home visits by clinic staff, rumors/misconceptions, and issues related to Soya flour distribution, and breast feeding. Below are some direct quotes from the clients:

#### **6. 2. 2.1.1 Bodily changes**

*"My friends have been asking me why I am not gaining weight... 'Why are you not regaining your weight now that you have delivered? We thought it was the pregnancy that was eating up your weight. Are you not eating? It shouldn't be AIDS (Isakhale EDZI)"(In-depth interview: Kawale defaulter<sup>3</sup>, 32 years, para 4, House wife, no education, child 3 months, Husband barman<sup>7</sup>).*

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<sup>7</sup> This interview was conducted at home and a neighbor just walked in to ask where the visitors had come from. She thought we had gone and we heard her rushing with her steps into the clients' home. After realizing that we were still around, she just withdrew herself and went back to her home. Meanwhile, the interview was being conducted inside the client's home. After agreeing with the client, we decided to postpone the interview until the next day to be continued at the clinic. The client indeed came to the clinic as per our agreement. After inquiring about the friend as to what the client had told her; the client said that the researcher and her friend had come on a church business to find out why she no longer comes to church. She indicated that the friend got convinced.

*“When my neighbors are chatting in a group; they may be talking of another issue but once they see me, the topic changes and they start discussing and pointing at me. I have lost several friends because I am HIV positive, have lost weight and they do not want to associate with me anymore. It is one of my closest friends who came to tell me that others have stopped chatting with me because nowadays I am losing a lot of weight and that they saw me going to the PMTCT clinic. They therefore suspect that I am HIV positive and they do not want to catch the infection if they continue chatting with me (A25 defaulter3, 34 years, education 8, para 4, child 1week, House wife).*

Some of the women who mentioned community reactions related to their bodily changes expressed concern over how these reactions might affect their lives and consequently their participation in the PMTCT program:

*... “I think deeply about myself that if I continue participating in the follow-up care and if I make frequent visits to the clinic; what will people say? I do not want to raise peoples’ eye brows”(In-depth interview: “Kawale defaulter number3, 32 years old, para 4, House wife, no education, child 3 months, Husband barman).*

Although both compliers and defaulters expressed similar challenges, the compliers seemed to have developed some coping strategies that enabled them continue with their participation in the program’s follow-up care. Below are some common examples that emerged during both individual and FGDs in both groups.

*... “I always ask myself that are they doctors to know what I am suffering from. I just ignore what people say and continue with my follow up care because at the clinic, they encourage us that this is not the end of life. We can still live for another 10-15 years. With such encouragement, I do not take it to heart what people say” (Kawale complier 3, 34 years, no education, para 4, child 4 months).*

Other than getting encouragement from the clinic, more compliers than defaulters mentioned having other sources of support such as from mothers, sisters and husbands that seemed to have helped them overcome the community’s negative reactions. As such, this was found to be one of the most important factors that played a significant role in influencing clients’ participation in their follow-up care.

#### **6. 2. 2. 1.2 Home visits by clinic staff**

Clients also explained experiencing some challenges following home visits by the PMTCT program staff. Based on issues raised by the community staff during the monthly UNC general staff meetings, it became apparent that the communities where UNC project serves are aware of the program’s community staff and vehicles used because of the frequent health education campaigns and the home visits that the program

conducts in these communities. Although staff members do not wear uniforms during these activities, the communities seem to know them much better than they are aware of.

As such, even when a staff member conducts a home visit and the vehicle is left at a distance in the community's outskirts, people are still able to trace back and identify the homes where the tracer/community nurse is going.

Below is the experience of one of the Area 25 defaulters.

*"I was visited at home by the nurse who usually visits people in the program. Behind her, two boys came following her. As soon as she had gone, the boys started telling my neighbors that, that lady (the community nurse) visits people who have got AIDS (Amayendera odwala EDZI). I am now the talk of the place. Unfortunately my husband is away to a city up north. My neighbors are just telling any person who comes to my home about my positive status. I think I will not be free anymore. I will be thinking a lot that I am dying anytime. When I think of my children, I am always worried about the life that they will lead after I die. I will keep on losing weight. All this time I had forgotten about my condition but in this case, I will never forget"* (Area 25 defaulter4, 29years, no education, Para 2, House wife, baby 6weeks<sup>8</sup>).

Such are the experiences that some HIV positive clients face in their respective communities after being paid a home visit by the program staff. It should be noted that the home visits are mostly made when clients default their appointments and three weeks elapse without them coming back to the clinic. Participants therefore raised differing opinions towards such arrangements with others saying that the home visits should continue while others said they should not. The following examples illustrate this:

*"I feel this arrangement is not good enough. If the community hears something; you will be the talk. I will make sure that I come for my appointment visits. I do not want to be visited home (Area 25 complier number4, 33years old, no education, para 5, House wife, 32 weeks pregnant).*

*"The visits are made to encourage us to be coming back to the clinic. It is your (health workers') duty to take care of our lives. As for me, I will from now onwards continue to be coming for my scheduled visits"* (Area 25 defaulter number4, 29years old, no education, Para 2, House wife, baby 6weeks).

Though clients expressed differing opinions related to the home visits, most clients mentioned of continuing with their follow-up care to avoid being paid the home visits.

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<sup>8</sup> Participant called her husband to tell him about what had happened to her. He then arranged with a friend within Lilongwe to look for another rented house in a different location. She indicated that the family would relocate to a new place the following week.

### 6.2.2.2.3 Rumors/Misconceptions about the PMTCT program

Rumors and misconceptions circulate about the program. I use the term rumors because when participants had raised them during the interviews, they were asked if they had ever witnessed them in the program to confirm what they had been hearing in their communities with what they had witnessed in the clinic. They could not give any tangible evidence.

Below is a dialogue between our interviewer and one of the clients with some direct quotes

*Client: "...Let me ask you a question, 'why do you get blood specimen in two big bottles every time we come here?'"<sup>9</sup>.*

*Interviewer: Before I answer, let me ask you mine. How many times have you been coming to the clinic?*

*Client: Once when I was seven months pregnant.*

*Interviewer: Okay. How many bottles of blood specimen were collected on you?*

*Client: One*

*Interviewer: Can you describe the bottle?*

*Client: Starts describing a bottle similar to the one that was available in the counseling room (It was a five ml purple topped specimen bottle).*

*Interviewer: Pulls out one of the bottles that fitted the client's description. 'Is this the bottle that you are talking about?' Hands over the bottle to the client.*

*Client: Gets the feel of the bottle and in a low tone says that 'yes' 'I had forgotten about the size because it was a long time back since I came to the clinic. This is small.*

*(Interview with Kawale defaulter number 2, 28 years, para 2, education 5, child 3 months old)*

The misconception/rumor here relates to the sizes of the blood specimen containers and the number of times that blood is collected from the client.

This client again described rumors that surfaced in the other subsequent discussions with clients as quoted below:

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<sup>9</sup> The participant appeared very anxious. When it was brought to her attention that she looked anxious, she accepted and indicated that she was still angry with her husband to have infected her and was even bitter to have been refused by the program staff to have her husband get tested at the clinic. When follow up was made with the nurses in the clinic, they indicated that they indeed refused her to have her husband tested the previous six months because she just grabbed the husband by hand on the same day that she got her test results and directed the nurses to test him as well. They then told her that they could only test him if he had wanted to, otherwise they do not force people to get tested. She indicated that her husband was not currently at home. He had left for a city up north away from Lilongwe. He left the previous four months prior to the client interview. The client learnt about her positive status when she was seven months pregnant. She refused to be tape recorded as well.

*“...Before I answer that question, let me ask you another question: Why do they put a big metal inside our vaginas. They put a big metal why?”(Ibid).*

When the client was further asked if that had ever happened to her, she denied. She however indicated that she had heard from friends/neighbors (who are not either in the program).

It is possible that she might refer to other clients’ experiences of being examined using a speculum (a big metal), for some reason as explained in footnote 10.

Regardless of whatever reason, such type of rumors continue to circulate in the communities raising anxieties in both the current and potential PMTCT clients regardless of whether they are true or not, thereby contributing both directly and indirectly to the clients’ non-participation in their program’s follow up care.

Examples of other rumors include:

*“My friends say the clinic takes too much blood and that the health workers insert their hands with instruments in the uterus even when the baby is still inside. They say they do that to turn the position of the baby” (Kawale defaulter number 6, 35 years old, para 6, House wife, no education, child 3 months, Husband loafer).*

*“People say the program is bad. They hide the uterus after delivery” (Area 25 defaulter number 4, 29years, no education, para 2, House wife, baby 6weeks).*

*“My friend said that the tests in Kawale are not true because everyone is found with the virus. By then, I had not yet had any test. So, I told her that I would still go. I got disappointed with the results and went to another clinic to get tested again. The results were the same” (Kawale defaulter number 4, 31 years, no education 8, para 3, House wife, child 6 months).*

Because the PMTCT services are built into the already existing MCH facilities and there is a lot of on-going research in the nearby Bottom hospital, it is possible that clients have confused information related to the program and that which is for the research studies<sup>10</sup>. Also important to note is how both program and research sensitization talks are given to the clients. Such talks are given to the same audience following a health education session in the integrated MCH department before clients get their respective services.

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<sup>10</sup> UNC Project had been conducting a chorioamnionitis (HPTN 024) study at Bottom hospital for at least four years but the study had just recently ended. Bottom hospital, which is close to Kawale clinic (See figure 2) was the main site with satellite clinics in both Area 25 and Kawale. When the PMTCT program was introduced, this study was ongoing. Because part of specimen was collected from the cervix, a speculum was being inserted to aid with cervical visualization. Probably this could be the origin of clients’ fears since the program serves the same catchments’ population.

Thus after the general health talks on any public health concern is presented to the clients (for example about the importance of family planning); clients are given extra talks (one related to the PMTCT program and the other related to on-going research studies). On average these extra talks exceed 30 minutes after the clients have had a general health education session lasting for an average of 25 minutes also.

One of the challenges therefore relates to how much of that information the clients can comprehend. It may be possible that they are getting confused with the messages. This could also be linked to the 'one-way approach' of delivering health related information where clients are seen as vessels to be filled with information.

#### **6.2.2.2.4 Soya flour distribution**

All HIV positive clients have been offered Soya flour since January, 2005; the third year since the program became operational. Each client is offered about 7 kgs of Soya flour and 2 liters of vegetable cooking oil per month. This is meant to boost the mother's nutritional status during her breast feeding period. Clients continue to receive the supplement until when the child clocks 18 months at which time they are terminated from the program. During the discussions, a lot of issues again emerged in relation to Soya with participants expressing differing experiences and opinions. Clients talked of either the experiences happening to them or witnessing a friend experiencing them as cited in the following examples:

*...My friend got some Soya from the clinic. On her way home, a group of people started begging if they could taste the flour. They followed her up to her door step when she suddenly got the bag off her head and left it outside her house. When she had entered into the house, the followers started telling each other that 'I! I! I! They only give to people who are HIV infected.' My friend is now wasted (Adangotha nawonso) but she stopped attending the clinic" (FGD with Kawale defaulters: Comment by one of the participants: client number 4, 30years, education10, House wife, para3, child 3 months old<sup>11</sup>). Majority of the participants were in agreement about their communities identifying anyone who carries Soya as being HIV positive.*

*"One lady asked me already about why I receive Soya. I told her that I am sick. She asked me from what disease I am suffering from. When I said I am weak, she said no. 'This is given to people whose bodies are not well'. Nowadays she does not talk to me, she just looks at me ( Area 25 defaulter number5, 21 years, education 2, para2, House wife, baby 6 weeks).*

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<sup>11</sup> The two friends stay close to each other. Their homes are just opposite each other. They had been coming from the clinic together but the other was not getting the Soya flour because she preferred to do so. The two did not disclose their HIV positive status to each other either though they discussed about why the other did not get the Soya from the clinic.

Those clients who mentioned having abilities to overcome their friends' interrogations about why they receive the Soya said they had no problems to continue their participation in their follow up care than those who were not.

*“When I came back from the clinic, after seeing that I had Soya and vegetable oil, she started telling me that, ‘this is given to people with HIV’. She went on to ask why I had received it. I told her that the hospital did not tell me that and if she believes in what she had said; we should go to the clinic together to get more clarification from the health workers. She was shy to continue” (Area 25 complier 6, 33 years, no education, para 8, child 5 months old).*

Another feature was that it was the Soya that stimulated communities reactions in both settings compared to the vegetable oil.

Moreover, the problems related to clinic Soya distribution were rather mentioned mostly by participants in Area 25 than those from the Kawale clinic. The Area 25 distribution problems were associated with lack of privacy; for example:

*“The problem with distributing outside is that everyone sees us. They know what happens here. We are afraid because they know that we are HIV positive and by the time we reach home, the stories about us would have circulated already in the communities. That is why a lot of women are running away (amathawa chifukwa cha zimenezi)” (Area 25 complier 1, 43years, education 8, para 2, child 4 months).*

Though clients mentioned meeting such challenges in their neighborhood, most of them indicated that their friends who sometimes question them on why they receive the flour join in to eat with them when the porridge is cooked<sup>12</sup>. The Soya issues would probably be the one step to reduce HIV positive clients' negative community's reactions because it seemed to have brought people together thereby removing any barriers that existed between them. The program should however respond to the clients' concerns by probably changing the physical location where Soya flour is distributed especially in Area 25 to reduce the implicit HIV positive status of the clients by their friends.

With regard to how the Soya is transported home, the participants brainstormed a lot on this and agreed to be bringing their personal translucent bags in which case the on-lookers may not know what is inside those bags.

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<sup>12</sup> The study was conducted when there was critical food shortage in Malawi.

#### 6.2.2.2.5 Breast feeding related responses

Other concerns described by clients had to do with their experiences when they had to wean their children at six months following the infant feeding recommendations for HIV positive women (2;3). In Malawi, more than 98% of women breastfeed their infants. Children are often breast fed up to 24-36 months (86). Clients therefore experienced varied responses upon weaning their children for example:

*“My neighbors sometimes ask me why I stopped breast feeding a small child. ‘Have you been found with HIV?’ I told one of them that she can also be found with the virus” (A25 defaulter number 7, 30 years old, education 4, para3, House wife, 6 months).*

*“When my child had clocked 6 months, I decided to get a temporary job to find a reason to tell my friends if they were to ask me on why I had stopped breast feeding him. I started working as a telephone operator in a bureau. On my way back home from work on the first day of my employment, I bought some milk for the baby. The next day I did not go to work and 3 of my friends came to visit me. They happened to have small babies also. My child then started crying uncontrollably. When I was about to prepare him some milk, my friends started asking me why I was not giving him the breast. I just said that he got frustrated (wanyanyala) because I had started work. Moreover, I told them that the breast milk had gone sour. One of them immediately pulled her breasts to test my child’s frustration and my child was about to suck her breasts. All of them then said I was lying. ‘Jimmy’s mother, you are a liar, the baby wants to breast feed. Give him the breast’. I then told them that my child wanted to suck on my friend’s breast because they were not swollen. As for mine, they were, so I did not want my baby to suck rotten milk. ‘I do not want my baby to get any infection from my breast milk” (FGD with Kawale defaulters: Comment by one participant number 7, 31 years, education 8, para3, child 6 months).*

These narrations reflect the challenges that both defaulters and compliers meet with regard to community responses upon cessation of breast feeding at 6 months. Community peers seem to indicate HIV status knowledge rather than asking directly, thus there is a lot of shame and gossip in their communication.

Although the babies of most clients were less than 6 months old, they expressed their fears concerning community reactions when they stop breast feeding their babies as depicted in the quote below:

*“I am already having fear concerning what people will say when I stop breast feeding my child at six months. ‘If they ask me, what will I answer them? Ndikumakhala ndi nkhawa (I have that fear)’. I have been having that fear since I do not have the right answer” (Kawale defaulter number 3, 32 years old, education 3, para 4, child 3 months old).*

Such challenges reflect predominant cultural beliefs that continue to counteract the PMTCT program’s efforts in as far as effective implementation of infant feeding options for HIV positive women are concerned.



Although clients whose children had clocked six months old had stopped breast feeding, it was apparent that they also lacked adequate information/skills on how they should effectively wean their babies. For example:

*“I asked them (program nurses) about how I should stop breast feeding my baby. They said I should not stop him abruptly. I asked them to clarify on what they meant about that. They seemed to be in a hurry and as such; they have not told me anything” (A 25complier number 7,26years old, education 2, para 3, child 6 months).*

This was again common amongst those whose children were less than six months.

Consequently, most clients whose children had clocked six months and had stopped breastfeeding indicated having weaned their children abruptly. It was common to hear them say that they stopped breastfeeding the child and immediately introduced it to alternative feeds as cited below:

*“On the 19<sup>th</sup> (of her sixth month following delivery) in the morning, I stopped breastfeeding him and gave him some porridge. In the afternoon, I gave him Nsima (Thick porridge taken with relish). At first he was crying but he is now used. They advised me to stop breastfeeding him at six months, so I just followed the advice that I got from the clinic” (Area 25 complier number 1, 43 years old, para 2, education 8, child 6 months).*

Furthermore, because of not getting full instructions from the program on how they should stop breast feeding their babies, most clients mentioned practicing mixed feeding especially during the transition period as cited by this client:

*“I had been breast feeding my baby and in the course of stopping him from breast feeding, I introduced some milk to him on top of the breast feeding. So, the Nurse was telling me of the dangers of mixed feeding. My worry was that may be I already transmitted the virus to him and I insisted that she should be tested but they refused. They said the next test would be when he is 15-18 months since he had already been tested at 6 weeks. So, I am so worried that all my efforts will be in vain because all along I had been giving him the breast milk only and he tested negative at 6 weeks”(Kawale complier number 7, 24 years, education 12, para 1, child 5 months).*

This experience may result into some clients’ defaulting their visits because they feel they do not get adequate help from the clinics especially with regard to infant feeding counseling<sup>13</sup>.

Another issue that surfaced in relation to breast feeding concerned the clients’ lack of alternative feeds following breast feeding cessation as observed in the following scenario:

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<sup>13</sup> This issue was taken up with the PMTCT program coordinator who acknowledged the nurses/counselors lack of adequate knowledge /skills regarding infant feeding counseling. She however indicated that trainings in relation to infant feeding counseling had been organized and that some nurses had just finished their trainings the previous month (Between June and July, 2005).

*“Most of the days there is no milk coming from my breasts. We do not have anything to eat probably for 2-3 days. We therefore sleep on empty stomachs. Today is my third day going without food. I have just taken a cup of water. It will be difficult for me to find any alternative feed to breast feeding when he reaches six months<sup>14</sup>” (Kawale defaulter number 6, 35 years, para 6, House wife, no education, child 3 months, Husband loafer).*

This is one of the biggest challenges for the PMTCT program. Even when clients receive the 7 kg bag of Soya flour, it is not only the mother who eats it; it is mostly the whole family. Moreover, it does not suffice for the whole month. Since the Soya flour has stigma attached to it within the communities, just by observing clients carrying the Soya, most of them are facing other negative community responses. Although the clients may be willing to get the flour, most of the potential ones do not. In turn, this is bringing other issues concerning nutrition and the challenges continue like that in a vicious cycle.

In summary, the above community responses were reported by both compliers and defaulters. As mentioned earlier on, though the HIV status is not disclosed directly to friends and neighbors, it looks like members of the community observe what the women do and conclude that they are HIV positive. Because of such type of experiences, clients are ending up withdrawing themselves from participating in the program's follow-up care in order to protect their identities.

Another observation was that, clients who discussed the negative community reactions were coming from localized communities of these two clinics. The researcher therefore discussed with the community activities co-coordinator who confirmed the problem. She therefore indicated that she would take up the issues with her team.

It is not known if greater community efforts to more openness about HIV status will reduce the stigma and secrecy, but it may be worth an effort to try this.

### **6.2.2.2 Reactions from families**

Participants discussed several and diverse family reactions particularly after disclosure of their HIV positive status to significant others; especially their partners, sisters, mothers and in-laws. Also, issues around partners' HIV testing and condom use emerged.

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<sup>14</sup> The interview took place in client's home. We found the husband at home but he left as soon as we arrived after giving us a warm welcome. The family had literally nothing available to eat in their home and the other siblings were just miserably looking at their mother. Her breasts were also completely dry and even after squeezing them to express some milk, no milk came out. She was then advised to go to Kawale clinic the next day to get some Soya. The researcher also gave her some money to buy food and some for transport to the clinic the next day. She indeed came to the clinic and was left in the hands of one of the counselors who prescribed some Soya flour and vegetable oil after she had received the other clinic services. This time, some milk was leaking from her breasts.

### 6.2.2.2.1 Clients' experiences after disclosure of their sero-positive status

#### 6.2.2.2.1.1 Disclosure to partner

When clients were asked who they had shared their test results with; 25 of the 28 clients (89%) who participated in the in-depth interviews mentioned their partners, with most of them disclosing the same day of testing, around bedtime. For the three who did not disclose to partners, one indicated "bitterness" with their partner to have infected her and indicated no interest to disclose because the partner is a very difficult man (*Ali ndi Nkhanza*). Moreover, the client said he leaves all the work like gardening to her.

This client learnt about her status in 2003 when she had another pregnancy but she had never disclosed her status to the husband up to the time of data collection. The next participant had just been recently divorced. This was her third time to get divorced by the same husband due to causes not related to her positive status. The third client said that her husband had been a priest before. So, she feared being accused of bringing the virus into the home. Below are some of the common responses that most of the other clients cited following disclosure of their positive status to their partners:

*"He just kept quiet, so I didn't talk to him further. I wanted to see what he would do next. The next morning, he said he was going to work but never came back. He left me when my pregnancy was 6 months. I went to check for him at his work place, he was not there and I also reported to his relatives who said that I should just wait for him at home. I was living alone, doing some piece work to earn a living, no one to care for me and had problems with the pregnancy until I reached 9 months. I therefore decided to go to my mother who would help me. I came back to my home a month following delivery. He came home 3 days ago and he is still not saying anything"* (Kawale defaulter number1, 30 years, para 7, House wife, no education, child 3 months, Husband bricklayer).

*"He could not believe it. He then told me that the people who had performed the tests were wrong and that they had given me wrong results"* (Kawale defaulter number 3, 32 years, para 4, House wife, no education, child 3 months, Husband barman).

*He just said 'a! a! a!' and became mute' (adangkhalala du! u! u!). He refused food for 4 days until I had to ask him why he was refusing to eat. I reminded him that he had been marrying for seven times. "Do you mean to say that all these women you have been marrying were not infected?" It was a hot issue at that time but I just saw that slowly, he started to normalize (Area 25 complier number number3, 43 years, para10, House wife, no education, child 6 months, Husband builder married 7 times and wife married 3 times).*

*"When I reported to him, he didn't believe it. He just started laughing and told me that I would die within the year. "This is "AIDS", you will die this year"* (Kawale complier2, 29years, education 12, House wife, para1, child 6 months).

*"He became very quite and took my health booklet and started reading it. He started telling me that 'here they have written negative, here negative again'. I told him that where they had written negative, the results were for syphilis and urine. I went on to say that they (Health workers) don't write HIV test results in the booklets. So, I gave him my appointment card. He then asked me if I had received Soya from the clinic"* (Kawale defaulter number 4, 30ears, education 10, House wife, para 3, child 3months).

Despite being exposed to similar challenges, it still remains unknown why other clients are defaulting yet others still continue to comply.

One most important observation was what can be termed as supportive attitudes given to the clients by their partners. It was evident that participants who had mentioned of their partners displaying non-supportive behaviours; most of them were defaulters though a good number of the compliers shared similar experiences.

More of the compliers than the defaulters however cited their partners' responses as being supportive. For example, they cited getting the partners' reassurance that they should just continue praying to God or that the partners would not divorce them. Below are some citations:

*“If that is what the hospital personnel have said, let us just accept and live positively” (Kawale complier 3, 34 years, no education, para 4, House wife, child 6 months).*

*“This is our problem. If they have found you with the virus, that means I also have it. Let us just continue staying as usual” (A 25 complier 7, 26years, education 2, para 3, child 6 months).*

The above evidence suggests that partners' responses play an important role in influencing clients' participation in the PMTCT follow-up care.

Again, some of the clients' partners linked their spouses' positive sero-status as an obvious predictor to theirs. Though the participants cited their partners making these linkages however, there seemed to be some resistance among men to confirm their assumptions as evidenced by the majority of the participants expressing that their partners refuse to go for an HIV test.

*“When I ask him to go for testing, he just says he will go. He tries to find a reason for not having enough time to go for testing” (A 25 complier number 7, 26years, education 2, para 3, child 6 months).*

This was a common response that the participants gave when they were asked if their partners had ever had an HIV test. The partners did not tell their wives directly but found an alternative way of refusing to go for an HIV test.

For those who had ever been tested, there were different experiences based on the individually felt bodily manifestations of ailments and work requirements that had prompted them to have an HIV test as featured below:

*“He had a problem. He had swellings/enlarged neck swellings (Zotupa m’kholi), so he went to be tested for tuberculosis. When he had gone there, they also tested him for HIV where he was found positive but never disclosed to me” (Kawale complier number 6, 27 years, education 8, para 4, child 4 months old)*

*“One day he just came back from work in anger. He had something in his bag but never showed it to me. When he had gone to the bathroom, I just looked inside and realised that they were condoms. When he had come back, I never asked him anything. He just said he does not want anymore babies in the house. I knew there was something wrong. He then hid the condoms inside one of the bedroom drawers” (Kawale defaulter number 4, 30years, education 10, House wife, para 3, child 3months).*

Despite the clients’ husbands being diagnosed first, most of the clients (both compliers and defaulters) whose husbands had had an HIV test cited that men never disclosed their status to them.

*“.... He only told me about his positive status when I was disclosing mine. He said he didn’t want to disclose to me because I do not hold my temper (akuti ndine waphuma)” (Area 25 defaulter number 4, 29 years, no education, para 2, House wife, 6weeks).*

The participants linked their partners’ lack of disclosure to the husbands’ fear of abandonment. This surfaced mostly during FGDs with both compliers and defaulters in both clinics as featured in the following quotes

*“They fear that if the wife is not yet tested and they test positive, the wife will abandon them” (Area 25 FGD with defaulters).*

*“Probably they are scared that when they fall sick we will be yelling at them. Men are a problem; they think that they are not the problem causers” (FGD with defaulters in Kawale: Comment by participant number 4, 30years, education 10, House wife, para3, child 3 months). The majority of the participants were in agreement with such statements.*

These findings tie closely with the gendered relationships as discussed in more detail in section 6. 2.2.3.

#### **6.2.2.2.1.2 Disclosure to close relations**

Clients also mentioned of disclosing their status to other close relations like mother, sister or in-laws. Although for the 10 clients who had disclosed their status to close relations received some initial psychological support, some indicated having met some challenges in due course as described below:

*“I thought my sister would keep the secret for me. But when she became sick because she is also HIV positive; she started publicising to everyone at home that she is not the only one to die. ‘Lezi is also very sick, she has AIDS’. I just discovered*

*when I had gone home and my mother was asking me whether what my sister was saying is indeed true. I got so disappointed (Zinangondinyansa) because I knew that my sister had told a lot of people. I will not be free anymore” (Kawale defaulter 7, 31 years, education 8, Para 3, child 5 months and 2 weeks).*

*“My mother was very worried, ‘You will be sick so often, who will look after you since your husband is not at home?’ ” (Kawale defaulter 1, 30 years, para7, House worker, no education, child 3 months, Husband bricklayer).*

From the above narratives, it shows that although clients may be willing to be open about their positive status, the structures are not supportive enough to help them live positively with the newly diagnosed HIV infection and that unless the culture of silence is broken, HIV infection will still bring negative reactions in the communities.

Participants also mentioned their friends either not wanting to be tested or having stopped participating in the program because knowledge on an HIV positive status would just bring them anxieties. They also mentioned that their friends say they would prefer to live in ignorance because they will be at peace rather than knowing that they are HIV positive. The following quote reflects that:

*“People fear that they may die early because of having too many thoughts. Moreover they say communities would be talking about their being found with HIV/AIDS” (FGD with compliers in Area 25: Comment by one of the participants).The majority were in agreement.*

Participants went on further to say that if there was treatment for this disease; people would come into the open volunteering themselves to be tested.

*“If they hear that at such and such a place they are dispensing HIV drugs, they would come in large numbers. They would even be fighting on the queues because everyone would know that there is treatment there. But as it is now, no one can volunteer to be tested (Ibid).*

When the participants were further asked if they are aware that they could be referred to access free ARV drugs, many indicated having tried but could not access the treatment; for example:

*“The problem is that the maximum number that they say they would to see per day is low and people book in advance. You just see that they give each other signals to enter into the consultation rooms. In the end, it is us the poor who are just being returned. We (Client and her friend) went there the first time, we were returned, the second time we spent a night there, only to be returned yet we were on numbers three and four on the queue. We therefore just gave up (One client in the Area 25 during FGD with compliers narrating her experience with a colleague after being referred to the ARV clinic by the program).Majority of the participants were in agreement.*

The above experiences were again cited by a number of clients in the FGDs. This shows that although clients may be making efforts to access these important services, they are being disappointed with the reception at the ARV clinic<sup>15</sup> and this, to some extent has implications on the PMTCT program.

### 6.2.2.3 Gendered relationships/ Power issues

The images of women and men are closely linked to their relationships with each other based on the constructed social power differentials embedded in that relationship.

This impacts on the women's ability to control several aspects of their lives including protection from further HIV re-infection.

The following quotes reflect that:

*"He refuses a condom. He says he is already dead. 'You know as a woman, I may be against the idea but it does not carry any weight'" (Kawale defaulter number 3, 32 years old, para 4, House wife, no education, child 3 months, Husband barman).*

*"Even when I tell him of the risks of re-infection, he does not listen. As you know men, they do not listen to what the woman says. It is difficult to protect my life. If my friend had agreed to use a condom, maybe I would be protected but as things are, it is difficult" (A25 defaulter 3, 34 years, education 8, Para 4, child 1 week, House wife).*

These are the challenges that women are facing. They may be willing to use condoms but do not have the power to do so.

Again, the participants cited some of the consequences if they appear to challenge men's decisions.

*"If you keep on insisting about condom use, the argument can reach the marriage counselor (Ankhoswe). He may say there is something that I am doing behind his back. To avoid that, you just accept it (sex without condoms)" (Area 25 complier number 3, 43 years, para 10, House wife, no education, child 6 months, Husband builder Husband married 7 times and wife 3 times).*

*"Condom issues are so difficult. We know that we can have longer life if we do not re-infect each other. On the other hand, marriage is also important. Everything is equally important. We can not survive without men. Who will be helping us meet our needs (Zosowa zathu)" (FGD with defaulters in Area 25: comment by one of the participants and almost everyone was in agreement).*

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<sup>15</sup> The ARV clinic attends to a maximum of 180 subsequent clients and 10 new clients per day and the clinic operates from Mondays to Fridays. If the number of new clients reaches the clinic's required number, clients are told to come back the next day. The clinic operates under the instructions of the national AIDS commission based on the allocation of ARV drugs from the global fund. These instructions were laid down to avoid ARV drug shortages especially for the subsequent clients who come on monthly basis for their re-supply. The way the clinic operates is as follows: Initially, when clients come for their first time, they are educated about ARVs before getting their CD4 counts checked. They are then told to come to the clinic the following week for their results. If the CD4 count is below 200 and if clients fall within the criteria to be initiated on ARV therapy, they are given a starter pack for 2 weeks. Before those two weeks expire, clients are told to come back to check if they have tolerated well with the therapy and to see if they have not developed any side effects. If they have tolerated well, they are told to come for their re-supply every month up to six months. At six months, they are given adherence counseling and are advised to be coming to the clinic every 2 months for drug re-supply for the rest of their lives.

Because women are not able to negotiate safer sex in their respective families, they may end up defaulting their clinic visits since they say they do not see any benefits if the husband is counteracting with their efforts. The following quote covers it all:

*“It is happening that we are trying hard but the husbands are pulling us down. We come to the clinics to get condoms but they refuse to use them. So, we get disappointed and stop coming” (A25 complier number1, 43years old, no education, para 6, child’s age 5 months).*

Participants also talked of their husbands’ refusal to accept test results as the possible cause for them to refuse condom use

*“When we discuss in the support groups, most women express a lot of disappointments with their partners. For example, when clients disclose their results to their partners; the partners refuse them. Again, the very same partner refuses condom use. May be it would help if they were also taking part in the program” (Kawale complier number 6, 27 years, 8 years of education, Para 4, child 4 months old).*

The dilemmas in safer sex negotiations that HIV positive clients are facing could partly be attributed to the economic dependency that most clients have on their partners. Lack of education further increases the problem.

Some of the issues that the participants had raised such as those related to partners’ lack of disclosure and condom use refusal were taken up with men to hear their view points<sup>16</sup>.

With regard to condom use, men acknowledged that indeed they refuse to use condoms because of various reasons. Firstly, they mentioned that they take longer time to ejaculate. Since they are mostly tired from their productive responsibilities, they just want to have sex, straight away ejaculate and rest as depicted in the following quote:

*“When we use condoms, we take longer time to ejaculate (Tikalowa mkondomu timachedwa kutaya)” (Male FGD).*

The second point that the men raised was that the initial HIV messages came as a threat to them

*“You were saying that ‘AIDS’ is a killer. There is no medication for HIV/AIDS. Now you are telling us that we can still live longer, which is which?”(Ibid).*

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<sup>16</sup> Twelve men participated in the FGDs. These were men whose partners were continuing with their participation in the program. In total, fifteen men were invited to attend. Letters of invitation were sent through their partners. On the day of the FGD, twelve men turned up. The researcher asked a male note taker who is a UNC project clinician to introduce the session and later on exchanged roles.



These conflicting messages may have brought dilemmas in the men. Consequently, most of them seemed to have given up life as captured in the following quote

*“Men say if it is dying, they are already dead, so they just become careless with life forgetting that only one child in the family is infected but the rest of the children are not” ( FGD with Area 25 compliers, comment by one of the participants with majority in agreement).*

Inadequate coping mechanisms with HIV infection in most men may have led them to harbor feelings of frustration which may have been manifested in their dominance over sexual matters; rendering them even more ill health and consequently bringing a lot of negative challenges in their families<sup>17</sup>.

Furthermore, men expressed that they do not have adequate information about what is discussed in the PMTCT program clinics as quoted below:

*“Women fear us; they do not tell us everything about what happens in the program” (Male FGD).*

To some extent, the non-conducive clinic environment especially for men may be deterring their participation in the PMTCT program even when they may be willing to do so. Because they miss out on important information and that women are afraid to educate them, some men may have ended up not supporting their wives' participation in the program's follow-up care because they (men), do not appreciate the importance of such services as a result of knowledge deficit.

#### **6.2.2. 4 Experiences at the PMTCT program**

##### **6.2.2.4.1 Service related experiences**

Some clients indicated dissatisfaction with how they are handled at the clinic. For example:

*“When I went for my appointment, they told me that the clinic was busy and they gave me another date. When I went for the second time, it was the same thing. Then for the third time, I just gave up. They do not know that I walk 5-8 Km to the clinic and mostly, I start off for the clinic around 4:00 am”Kawale defaulter number 6, 35 years, para6, House wife, no education, child 3months, Husband loafer).*

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<sup>17</sup> The PMTCT program conducts motivational talks in the public places. Also, HIV/ADS messages are disseminated in the workplace. The purpose of setting up these interventions was to bring services closer to men. The clinic also promotes couple counseling right in the clinics although men have not been forthcoming.

Moreover, others complained of priority being given to pregnant women even when they are the first ones to come:

*“They start attending pregnant women. At long last, they call us yet we were told that the services are based on first come first served basis. We may come at 09:00 am, 10, 11, 12 we are still here. At 13:00 pm that is when they attend to us. We get tired, our children become weak. Next time, we just give up (Kawale complier number 7, 24 years, education 12, Para 1, child 5 months).*

Some women indicated to have forgotten the instructions:

*“I did not understand properly. There was a lot of information given to me when I first joined the program. Had it been that I had remembered my appointment, I would have come (Area 25 complier number 1, 43 years old, education 0, para 6, child’s age 5 months).*

This topic came up somewhat frequently between both the compliers and defaulters and was often related to the amount of information that is given to them upon joining the program. Compliers tended to be reminded of their next visits by their partners more than the defaulters (n = 8 of the 14 compliers).

Some women complained of staff attitudes:

*“I was just hearing from my friends that there is nurse “X” who speaks harshly. I had never believed that myself until it happened to me” (Kawale complier number 2, 29 years, education 12, House wife, para 1, child 6 months).*

Again several participants complained about staff attitudes more especially in Kawale clinic. It was therefore common amongst the defaulters to indicate that they had stopped attending the clinic because of that or else they had opted to be attending the support group meetings that meet once a month to discuss issues of their concern. For those who had opted to attend support group meetings only, they indicated that the staff members who participate in those meetings<sup>18</sup> are more supportive than those in the clinic.

*“I only attend the support group meetings because the staff members there welcome us warmly. There is this nurse “Y”. If I do not praise her, then I am a dog who cannot give credit where it is due (Ndine galu osayamika). Previously there was this nurse “Z”. She was also good but I understand she is transferred to another clinic” (Kawale defaulter number 7, 31 years, education 8, para 3, child’s age 6 months).*

The compliers indicated that they continued their participation in the program because they had keen interest to protect their babies and they wanted to benefit from the program regardless of the challenges that they meet. They therefore suggested that it could be helpful to have HIV positive staff members

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<sup>18</sup> Staff members who moderate the support group meetings do not often serve in the clinics though they work in the PMTCT program. They are mostly engaged with community activities such as conducting PMTCT campaigns and doing home visits to clients who default their follow-up care. At the end of every month, they facilitate support group meetings in all PMTCT clinics. This is done at each clinic independently.

working in the program because they would understand the women much better. One woman put it this way:

*“If you had employed staff members who are HIV positive, probably they would understand what we are going through and they would not treat us as we are being treated” (Kawale complier number 2, 29 years, education 12, House wife, para 1, child 6 months).*

At the end of the interview, the client emphasized her suggestion as quoted below:

*“Let me remind you on the point of recruiting HIV positive nurses. That should materialize. If they are there, let them come to start work. Those who are not HIV positive are only looking for salaries but I feel HIV positive nurses would work much better because they would understand our situation” (Ibid).*

The above responses suggest that staff attitudes play an important role in motivating clients to continue their participation in the follow up care. Staff members need to provide services based on first come first served basis to avoid other clients from getting frustrated if they see that priority is being given to others like pregnant women. Also, periodic exit interviews with clients should be done to determine their satisfaction with the services they receive and if issues arise, solutions should be discussed with staff members to ensure clients' continued participation in the program.

#### **6.2.2.4.2 Experiences with volunteers**

Some women (n=7) complained about the attitude of volunteers who work in the communities performing home-based care activities as being responsible for spreading the news about their positive status in the communities. This is featured in the following quote:

*“There is this group of people who stay in the locations looking after the sick and giving them medications like TB drugs. They call them home-based care volunteers. People like these ones talk a lot. When there is a funeral, they usually gossip about the deceased dying of AIDS. Two days ago, I heard it with my own ears when I went to attend a funeral. They were saying that ‘do not mind about the deceased, she has died of AIDS’. They went on to say that such and such a person also goes to the light house<sup>19</sup> (Kawale complier 6, 27 years, education 8, Para 4 child 4 months old).*

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<sup>19</sup> The light-house clinic is one of the largest clinics for people with HIV. Clients usually go there to have their CD4 counts checked and to be initiated on ARV therapy. It is located within the premises of Lilongwe central hospital a few meters off site. This place was previously meant to manage conditions that needed isolation like cholera. There is a lot of stigma attached to this clinic and people give nick names to people who visit the clinic. For example, clients who get ARV therapy are said to be getting top-ups for their lives similar to the word used when people buy top-up phone cards for extra air time on their mobile phones.

Again, these responses were more frequently raised by Kawale participants than those in Area 25. Apparently, the volunteers work within communities around Kawale.

The participants therefore indicated that issues like these are some of the factors that are contributing to many women discontinuing with their program follow up care and consequently their inability to access ARV drugs.

#### **6.2.2.4.3 Views about the program**

##### **6.2.2.4.3.1 Structure of the PMTCT clinic**

Some participants expressed dissatisfaction with how the PMTCT clinic is structured. This was mostly featured during FGDs especially in Area 25 although 5 clients expressed similar concerns during the individual interviews. Though the PMTCT clinic operates within the MCH clinic and that the PMTCT clients continue with their routine ANC follow-up care here (except for the PMTCT visits), clients complained that this system segregates them.

For example,

*“There is no security/privacy. The ANC clinic is separate and the PMTCT clinic is somewhere different close by. We do discuss everything on the benches<sup>20</sup> and whatever is discussed is heard by the other clients on the other side. This is not good at all because our friends start asking us on why we get care different from theirs” (Area 25 FGD with compliers).*

These concerns were mostly raised by Area 25 participants and they kept on resurfacing during both in-depth individual interviews and FGDs. When program staff was approached on this, they confirmed the problem and indicated that it was due to space constraints beyond their capacity. The issue was again brought to the attention of the program co-ordinator.

Changing the physical layout or full integration of the PMTCT services into the MCH department may be an option to reduce the likelihood of unwanted program visibility thereby impacting on clients' participation in their follow-up care.

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<sup>20</sup> The PMTCT clinic is located opposite the routine ANC clinic in Area 25 and often the general detailed talks are conducted on the benches in the corridor due to lack of space. Thus services are separate and not integrated- an inclination of collective secrecy breach. Whilst the PMTCT clinic in Kawale is also separate, the services are provided away from the ANC clinic in a separate building. In between, there is an OPD department which provides visual protection for the clients because the PMTCT clinic is located behind it and most ordinary patients/clients do not often know what happens there.

#### 6.2.2.4.3.2 Invitations to join the program

There were mixed opinions regarding how the participants were invited to join the program. According to the current government protocols, HIV testing is offered to all pregnant women attending antenatal clinics unless they specifically choose to decline (30).

This “opt-out” as opposed to “opt-in” strategy was a cause of concern for some women. While some indicated to have joined the program because of being motivated into it based on the various individually felt triggers, others felt they were forced into it.

*“They force us to join the program” (Kawale defaulter number 7, 31 years old, education 8, para 3, child’s age 6 months).*

The government’s policy needs to be well explained to the clients so that they do not perceive that the program as being imposed on them. Unless the clients understand the program benefits, they may continue defaulting their follow up care and may even influence others to follow suit.

#### 6.2.2.4.3.3 Views about Nevirapine (ARV drug)

There were again mixed opinions concerning Nevirapine. Whilst some indicated that the drug is effective, others felt that it is not.

For those who said it is not effective, the increasing numbers of babies who tested positive at 6 weeks caused their concern.

*“I got confused with the results because I and my baby took the drug at the right time. I tried to prevent my baby from acquiring the infection but when time was due for her to get tested, she tested positive. I got so disappointed” (Kawale complier number 3, 34 years, no education, para 4, child 5 months).*

Surprisingly, for the clients whose babies tested positive, most of them still comply with their program follow-up visits probably hoping that their babies would be assisted in one way or another; one client stated.

*“I consider the hospital personnel to be my brothers and sisters and when they counsel me, I forget my problems. Also, I benefit from the experiences of my friends in the support group” (Kawale complier 3, 34 years, no education, para 4, child 5 months).*

Program staff needs to be aware of their roles as sources of support for women in an environment where HIV/AIDS issues bring feelings of discomfort among women. Because of the culture of silence around HIV/AIDS issues, women take the program staff as their confidants. As such, even when the clients' babies end up testing positive, messages of hope should still be given to the women and referral mechanisms created for their babies to get continued care.

### **6.2.2.5 Personal reasons**

Participants gave varied personal reasons for their non-participation in the program's follow-up care.

For example,

*"I did not want to be disappointed if my child turned out to be HIV positive also. I decided to wait first without having to rush" (Area 25 defaulter number 6, 32 year, education 12, para 3, child 6 months).*

Some of the reasons concerned women's multiple roles at home

*"Who will be looking after the young ones when am gone to the hospital? Each time I go there, my first born has to be absent from school" (Kawale defaulter number 1, 30 years, para 7, House wife, no education, child 3 months, Husband bricklayer).*

Yet others complained about the long walking distances to get to the clinic

*"I got tired of walking long distances because each time I go there, my legs swell up. I usually do not have transport money to get there" (Area 25 defaulter number 3, 34 years, education 8, Para 4, child 1 week, House wife).*

Although the program cannot deal with the unexpected personal events that affect women's lives as described above, supportive health worker attitudes that are responsive to the women's concerns can play a significant role in their continued participation in the program's follow-up care.

For example, linking the women with the money lending institutions where they can access short term money loans<sup>21</sup> to improve their socio-economic status<sup>21</sup> or even organizing services in such a way that they get nearer to their appointment time may reduce the long waiting time.

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<sup>21</sup> The system to access short term loans is already in place and some women who participate in the support group meetings have managed to get those loans from money lending institutions like opportunity international bank through the program. The program serves as collateral for the clients.

In summary, the qualitative data has provided insight into causes of lack of clients' participation in the PMTCT follow-up care. Applying grounded theory to this study, the understanding of client participation in the PMTCT follow-up care evolved from a combination of some data gathering techniques, namely in-depth individual interviews and the FGDs with compliers and defaulters, an FGD with men and some observations. Factors that have contributed to their non-participation relate to community reactions about the clients' positive status, reactions from their families, embedded gender/power relations and their place in society; experiences at the program and, personal factors. These have been discussed in chapter 7 together with the results obtained from the quantitative part of the study but; the results obtained from the quantitative part of the study will be presented first before proceeding to the discussion section.

### 6. 3. Results of the quantitative study:

A total of 960 client records for Kawale and Area 25 clinics were reviewed independently to determine any differences in background parameters between the compliers and defaulters in these clinics. A total of 480 records were reviewed in Kawale and another 480 in Area 25.

Chi-square tests were then applied to prove statistical significance of the results. The level of significance was set at 0.05.

Regression analysis which was planned to be done was not applied because of logistical problems. However, as our findings were pretty straightforward, the gained insight from an added multivariate analysis would not really change our interpretation of the important factors.

The results presented here are therefore based on what was generated from the chi-square tests.

#### 6. 3. 1 Socio-demographic Characteristics

##### **6.3.1.1. Age distribution of the sample**

Records of women attending Kawale clinic had a mean age of 25.4 years, ranging from 18 -41 with a standard deviation of 4.7 years whilst those for Area 25 had a mean age of 26.1 years, ranging from 18-46 and a standard deviation of 4.8 years. Overall, the minimum age of attendees in both

clinics was 18 years and a maximum age of 46 years. The age span from youngest to oldest is 28 years with a standard deviation of 4.7 years.

### **6.3.1.2 Marital status of the clients**

For women attending the Kawale clinic, the smallest group comprised of single women (2.7%) and the largest group (86.1%) were married. The remaining 11.2% were either divorced, widowed or cohabitating. A similar scenario existed in Area 25 although the percentages differed and are 1.3% for single women and 95.4% for married women. Overall, very few women in the sample were single (2.0%), and many were married (90.7%).

### **6.3.1.3 Education**

Some informants had never been to school (5.4% for Kawale and 17.3% for Area 25). The most educated women for Kawale had 16 years of formal education and long education applied to only 0.2% of all Kawale attendees and the most educated for Area 25 received 12 years of formal education, making up 12.5% of all attendees. The illiteracy level in both clinics stands at 11.4%. This is again lower than the national illiteracy rate of 56%.

### **6.3.1.4 Parity**

Clients in Kawale had an average number of 1.7 births ranging from 0-7 children and a standard deviation of 1.4. For Area 25, the average number of births was 2.2 ranging from 0-9 children and a standard deviation of 1.6. Overall, the minimum number of births that a woman had was no previous birth and the maximum was 9 with an average of 2 births and a standard deviation of 1.5. Also, the average age at first birth for clients in both clinics was 19 years.



### 6.3.2 Pregnancy period at the start of the PMTCT clinic attendance in relation to default

The assumption was that women who are likely to default their follow up care are those who join the PMTCT program in their early pregnancy period, compared with those who are nearer to delivery when they enroll.

Thus pregnancy period up to 22 weeks gestation was defined as the early pregnancy period whilst above 22 weeks gestation was defined as the late pregnancy period. The results are presented in table 3.

**Table 3: Age of pregnancy period at the start of the PMTCT clinic attendance in relation to default**

Gestation (weeks)	Defaulters (n = 193)	Compliers (n = 767)	Total (n = 960)
Up to 22 weeks	130 (24%)	412 (76%)	542 (100%)
More than 22 weeks	63 (15.1%)	355 (84.9%)	418 (100%)
Total	193 (20.1%)	767 (79.9%)	960 (100%)

When a chi-square test was applied to this table, the results were significant, p value = 0.001.

This implies that women who begin their PMTCT clinic visits before 22 weeks of gestation are more likely to default their follow-up care than those who join in their advanced pregnancy trimesters after 22 weeks of gestation.

### 6. 3. 3 Type of PMTCT clinic attended in relation to default

The assumption was that clients who attend their follow up care at a busy PMTCT clinic (as defined by the program) are more likely to default their follow up care than those who attend at a less busy one. Thus Kawale was defined as a busy clinic whilst Area 25 was defined as a less busy clinic.

Again, chi-square tests were applied to the findings to determine their level of significance.

The overall default in both clinics was 20% with no difference.

With a p value of 0.910, it was firmly established that there was no relationship between women’s default in their follow-up care by whether they attend their care at a busy PMTCT clinic or not.

#### 6. 3. 4 Client Parity in relation to continued participation in the PMTCT program

The assumption was that women who continue their participation in the PMTCT follow up care are those that have had less than four pregnancies (the ideal number of children a woman should give birth to as defined by the MOH-RHU). The results are presented in table 4.

**Table 4: Parity in relation to continued participation in the PMTCT follow up care**

Parity	Defaulter (n = 193)	Complier (n = 767)	Total (n = 960)
Less than 4 pregnancies	178 (19.6%)	730 (80.4%)	908 (100%)
More than 4 pregnancies	15 (28.8%)	37 (71.2%)	52 (100%)
Total	193 (20.1%)	767 (79.9%)	960 (100%)

When chi-square test were applied, the above difference was not statistically significant; p value = 0.106.

This implies that there is no statistically significant relation between women’s parity and their continued participation in the program. All in all, 20% of the program participants default their follow up care.

#### 6.3.5 Level of education attained in relation to client continued participation in the PMTCT follow-up care

The assumption was that women who are educated are more likely to continue their participation in the program’s follow up care than those who are not.

It should be noted however that because of the relatively lower levels of education attained by Malawian women, the cut off point was put at 5 years of formal schooling. This being the case, those who had formal education from 0-5 years were defined as having no or less education whilst those with more than 5 years of formal schooling were defined as educated. This definition was adopted from the Malawi Ministry of Education definition. The results are presented in table 5.

**Table 5: Level of education attained in relation to continued client participation in the PMTCT follow-up care**

Level of education attained	Defaulter (n = 193)	Complier (n = 767)	Total (n = 960)
0–5 years	71 (23.9%)	226 (76.1%)	297 (100%)
More than 5 years	122 (18.4%)	541 (81.6%)	663 (100%)
Total	193 (20.1%)	767 (79.9%)	960 (100%)

When chi-square tests were employed, the difference was marginally significant with p value = 0.049. This implies that the more educated a woman is, the less likely it is for her to default care in the PMTCT program.

### 6.3.6 Client socio-economic status in relation to their participation in the PMTCT follow-up care

The assumption was that women who are well off socio-economically are more likely to comply with their follow up visits than those who are poor. Here, building material for the house was used as an indicator of the socio-economic status. This is relevant as a proxy measure of economic status in urban Malawi.

The results revealed that amongst those who live in a house built by concrete, 16% default their follow up care. For those who live in a mudded house or a brick walled house; 21% and 20% default their visits respectively. If re-categorised to two groups, still no difference is found.

When chi-square tests were applied to determine the statistical significance of the differences, the results were again not statistically significant with p value = 0.532.

This implies that clients' socio-economic status as measured by the quality of their housing is not significantly associated with the women's likelihood to continue participating in the programs follow up care.

### 6.3.7 Marital status in relation to client participation in the PMTCT follow-up care

With regard to marital status, as indicated in section 5.6 of the methodology chapter footnote 6, we assumed that the calculated sample size for this study would not be able to prove statistical differences between the compliers and the defaulters because marital status requires more subjects than that calculated for this study. As such, no tests were done to determine any statistical significance.

Almost all clients were married, in which case it would not be possible to prove any statistically significant difference to those living alone.

In summary, the quantitative data has revealed that pregnancy trimester at the start of the PMTCT program and education play a significant role in influencing client participation in the program's follow-up care. The other parameters such as client socio-economic status, type of clinic attended and parity have proved not to be significant, although such differences might have been there between those who default and those who comply taking into account these parameters if the sample size was larger or our indicators were precise.

# Chapter 7: Discussion

## 7.1 Introduction

The 20% default rate in follow up care amongst clients attending the Lilongwe PMTCT program has to be considered a shortcoming of the program. However, this default rate is better than that observed for other PMTCT programs in Malawi and from elsewhere in Africa. For example, observations from other PMTCT programs in Malawi have shown rates of cumulative loss to follow up of up to 81% amongst the PMTCT cohort by their sixth month of postnatal visit (69). Similarly; evidence from PMTCT programs in South Africa and Côte d'Ivoire have reported rates of loss to follow up of up to 70% by the fourth month following delivery and up to 84% before the women had started taking their Zidovudine (37;71).

This progressive loss to follow up demands a different way of acting if PMTCT programs are to achieve their goals towards reducing the high infant and child mortality rates as reflected in the Millennium development goals (23;31).

For these programs to effectively implement interventions that meet the clients' needs; it is a pre-requisite to take the service users' perspectives into account when planning these programs. This study was therefore designed as a first step towards this problem-solving approach with the aim to investigate why HIV infected women in the Lilongwe PMTCT program do not fully participate in their follow up care.

This chapter therefore discusses the main findings focusing on the broader issues that emerged from the study. These will be discussed within the framework of grounded theory, in which case data obtained from a range of sources, namely from FGDs with both men and women (with both compliers and defaulters), those obtained from in-depth individual interviews with both compliers and defaulters, data obtained from the quantitative part of the study and some observations made have all been incorporated to provide a full range of variations in issues around client participation in their PMTCT follow up care. This framework as applied in this study is consistent with the triangulated approach and it ensured more rigorous data to be collected which helped to improve the quality of the findings (87).

Results obtained from the quantitative study reveal that education and age of pregnancy period at enrollment into the PMTCT program influence clients' participation in their follow up care. On the other hand, findings of the qualitative study show that factors that play a significant role in influencing client participation in their follow up care are the community and family reactions, embedded gender/power relations and the women's place in society, experiences with the program and personal factors. Furthermore, the wider influences that play a significant role on the individual, community and PMTCT services are the government policies; the socio-economy, gender issues and culture.

Conversely, this study has shown that those factors that promote women's participation in their follow up care include the degree to which they have social support to deal with negative community/family reactions. These have been elaborated in more depth later in this chapter.

Whilst the quantitative data have helped to identify the socio-demographic factors that are associated with client participation in the PMTCT follow up care, results from the qualitative study are however most meaningful for understanding why women participate or not participate in the program's follow up care.

The strengths of this study and what it has added to the existing knowledge about these issues have again been highlighted. Lastly, some questions which still remain unanswered and some key methodological issues that apply to the study and the way in which they affect validity of the results have also been discussed.

## 7.2 Linking Socio-demographic data to further risks of HIV infection amongst the study participants

Women who participated in the study were mostly married, housewives and had relatively low levels of education. This suggests that these women generally have a low socio-economic status, and may also explain why there were no variations between the compliers and the defaulters in terms of their socio-economic status; because very few of our informants were truly well off.

Again, the findings obtained from the quantitative study as illustrated in section 6.3.1.4 reveal that the average age at first child birth for the women was 19 years. This implies that most women in the program

marry and become mothers early; a revelation indicating an at risk group in as far as safe motherhood is concerned (88).

Taking the above facts together, one would argue that the women in the program marry early and that probably they depend on their partners for economic support. The second argument is again based on what was gathered from the women when they indicated that they would prefer to stay in an abusive or dangerous relationship rather than lead independent lives because they would not be able to meet their economic needs if their husbands divorce them (see section 6.1.2.3). Grant and Logie (2005), DHS (2000) and African development fund (2005) report similar findings for Malawian women (8;10;89). Furthermore, the commission for Africa (2005) reports the same for African women and asserts that; three out of four youths living with HIV are women (90). Berer (1999) goes on to say that young women are particularly exposed to HIV because they marry early and mostly to older men for economic dependence (91). One would therefore argue that the gendered dimension of HIV means that more women than men are dying and that to some extent; poverty has played a significant role. This situation may also be applicable to women in the Lilongwe PMTCT program.

Again, evidence from NAC's (2003) HIV sentinel surveillance report suggests that HIV prevalence among pregnant women attending their ANC care is highest in the urban and semi-urban areas (of which the studied clinics are inclusive) compared to the rural areas (27). Furthermore, disaggregated data of HIV prevalence by sex in these areas show similar trends (29). Moreover, most of the study participants reported their partners having other sexual partners yet the partners refuse condom use. In view of this, there are higher chances that the PMTCT clients' partners may be having unprotected sex with other HIV infected women; exposing the studied women even more to higher risks of further HIV infection. As Mason *et.al* (2005) assert, the most vulnerable may no longer be in the rural areas, but may be in the semi-urban households (92).

Thus, the economic dependence of the studied participants on their partners could reinforce their increasing risk of acquiring further HIV infection.

### 7.3 The role of education on client participation in the PMTCT program

It was found that women with higher education (even at its lowest levels as seen in this study, section 6.2.5) were more likely to continue their participation in the program's follow up care than those who had never been to school. This may be related to the person's level of knowledge comprehension which is said to be higher for the educated than those with lower or no education (10).

These results have therefore helped to provide some explanations on what was gathered from the qualitative part of the study as illustrated in sections 6.1.2.2.3 and 6.1.2.4.1. Data obtained from the qualitative study revealed overall participants' concern about the amount of information given to them upon joining the program. Participants said that they had forgotten their clinic instructions to come for their follow up care. Besides that, others expressed misconceptions about the program even after being educated about what happens in it.

One would therefore argue that it is this ability to comprehend issues that is associated with understanding of the benefits of the program hence closely linked with higher chances of compliance in the program's follow up care. Similar findings have been documented by the Malawi Demographic and health survey (DHS) (2000) report. In the report, education is documented as the key determinant of the lifestyle/status an individual enjoys in a society (10). Among others, such life styles refer to reproductive behavior which with reference to this study would be the women's participation in the PMTCT follow up care.

### 7.4 Timing of enrollment into the PMTCT program

This study has shown that women who join the program in early pregnancy period are more likely to default their PMTCT follow up care than those who join in their late pregnancy period, see table 3. This may be linked to the problems of forgetting clinic instructions with the passage of time especially for those who join the program in their early pregnancy periods. It could be because the PMTCT visits are tied to those of the routine ANC and as such, follow-up visits to the ANC clinic for those who start early are usually spaced at longer intervals like four weeks for gestations below 22 weeks. For those above 22 weeks, the intervals reduce to between one to two weeks.



This finding was however intriguing because the safe motherhood initiative recommends pregnant women to start their antenatal care as early as possible to monitor the women's health and to refer those who develop pregnancy complications to secondary levels of care in time. Although this is the recommendation by the safe motherhood initiative (2;30;31;93); evidence from the DHS (2000) report shows that most women in Malawi start antenatal care in their late pregnancy periods with a median duration of 5.9 months at the first antenatal care visit (10). However, the numbers of visits increase with most women having had four or more visits by the time they deliver. This suggests that the women are aware of the importance of the regular antenatal visits. Data from the PMTCT clinic also shows that most women start their antenatal care by a gestation of 5.5 months (see table 3 in chapter 6).

In view of the above evidence, one would therefore argue that it would be worthwhile to introduce the PMTCT program to the women in their late pregnancy stages such as around 32 weeks of gestation when they are supposed to get their NVP tablets. This timing may also be convenient to the women because it will cover even for those who may deliver early (at 8 months). This cut off point is recommended by the PMTCT program based on evidence in Malawi proposing that most babies would survive at 32 weeks gestation if they were to be born prematurely (31). In the mean time, the women may just continue their participation in the routine ANC care together with other pregnant women. This would again help to safeguard their identities as HIV victims, another concern that was expressed by the women as illustrated in section 6.2.2.4.3.1.

## 7.5 Embedded gender/power relations

Based on the participants' perspectives, factors that contribute to their non-participation in the PMTCT follow up care relate to the gendered and power relations that exist between them and their partners. These were mostly related to condom use and issues to do with HIV status disclosure by their spouses. As illustrated in section 6.2.2.3, women expressed concern over their failures to negotiate for safer sex through condom use even after they had preferred to do so and had disclosed their positive status to their partners. Moreover, they expressed the consequences of challenging their partners' decisions which would result into divorce. In view of this, they indicated their preference to stay in marriage rather than to be divorced because they cannot economically survive on their own.

What is interesting in this study is the connection made between challenging their partners' decisions on safer sex negotiations, which would lead to divorce, and consequently poverty. One would therefore argue that fear of divorce with its concomitant decline into poverty inhibit women from negotiating for safer sex in marriage making them even more vulnerable to further HIV infection. As Malewezi states, "married women in Malawi are more vulnerable to contracting HIV/AIDS from within the confines and comfort of their bedrooms" (94)<sup>22</sup>. Furthermore, NAC (2003) assert that Malawian women's real freedom in sex and safer sex negotiations is still much more constrained than men's (48).

The participants also mentioned that because their partners' refusal to condom use counteracts their efforts to reduce further HIV transmission, they do not see the importance of continuing with their program's follow-up care. Thus the male partners' behaviors towards safer sexual practices have a significant influence on the women's continued participation in the PMTCT follow up care. These women's articulations are consistent with evidence from other African women's studies on sexuality and access to reproductive health (RH) services (95-97). This suggests that women in the PMTCT program share similar barriers in accessing RH services as those faced by other African women.

Some of the concerns that the women had raised were taken up with men in the FGDs to get their perspectives as well. The men indeed confirmed their refusal to condom use. They indicated preference for skin to skin contact which to them is a sign of love (see section 4.1.2.3). Bryceson *et.al* (2004) report similar findings (98). This may be associated with low risk perception of the HIV/AIDS pandemic amongst men. As NAC (2003) assert, 50% of the Malawian population do not feel affected or at risk of the HIV pandemic (48).

Men also blamed health workers for disseminating conflicting HIV messages to them. They said that the initial HIV/AIDS messages came as a threat to them<sup>23</sup> whilst the current messages are saying that they can still live for the next 10-15 years. As such, they do not know which is which. This is discussed more in

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<sup>22</sup> Dr. Justin Malewezi is the former first vice president of the Republic of Malawi and is currently chairing the parliamentary committee on HIV/AIDS.

<sup>23</sup> The initial HIV/AIDS messages were saying that 'AIDS is a killer'/'there is no cure for HIV/AIDS'. These messages were produced by the Ministry of Health-Health education unit in its efforts to deter people from indulging into risky behaviors such as having unprotected sexual relationships outside marriage which would expose them to HIV/AIDS infections. These were produced towards the beginning of the 1990s shortly after the infection was first recognized in Malawi.

section 7.7. Furthermore, they indicated that their wives do not tell them the details of what happens in the PMTCT program.

To some extent, all these issues reflect the deep rooted social cultural norms associated with the cultural construction of male and female sexuality in Malawi. Defined as the process by which sexual thoughts, behaviors and conditions are interpreted and ascribed cultural meaning; sexuality is closely linked to the cultural concepts of masculinity and femininity (99) with their associated gender roles. The latter concept refers to ‘the socially constructed roles prescribed for men and women’ (100).

In Malawi, the image of women is “one of subordination and submission to men who have the ‘upper hand’ and are the decision makers. The primary role of a woman therefore remains that of wife and mother with the husband in the ‘bread winning role’, providing financial security”(101). Thus gender roles have increased women’s vulnerabilities in several ways. For example, Malewezi (2006) argues that married women in Malawi are more vulnerable to contracting HIV/AIDS mostly because of the cultural beliefs that oblige them to be respectful of and obedient to their husbands even when there is enough ground to suspect infidelity (102).

Doyal (2002) and Grant and Logie (2005) links such vulnerabilities to cultural norms that entitle women to fewer resources (8;103). Furthermore, Coombes (2000) as cited by NAC (2003) and WHO (2002) add on to say that limited women’s education and low socio-economic status contribute to their having less access to and control over resources (48;104).

Applied to the challenges faced by women in the PMTCT program, one would therefore argue that class and gender have played a significant role in influencing client participation in the PMTCT follow up care.

Drawing on socialist feminist theories and indeed on the masculinity theories, the situation faced by women in the PMTCT program has been discussed as follows:

Socialist theorists argue that both class oppression and patriarchy equally influence gender inequality (105). With regard to patriarchy, the socialists assert that women’s subordination is mostly constructed in relation to male masculinities which is closely tied to the marriage institution. Since

patriarchy requires passive subordinates (106-108); women in the Lilongwe PMTCT program have had problems to negotiate for safer sex and accessing their PMTCT follow up care.

In view of class oppression, Grant and Logie (2005) argue that Malawian women have limited control over their sexuality due to having fewer economic opportunities and less access to cash (8). This has therefore led to their economic dependence on men as revealed in this study. Such inabilities have again been linked to fear of abandonment in terms of being divorced as found in this study. Thus women continue to stay in abusive relationships because they cannot manage to support themselves economically if their partners divorce them. Again, WHO *et.al* (2005) asserts that due to women's having less access to education, income generating activities and property ownership than men, they are not able to leave relationships even when they know that they may be at risk of HIV (109). Painter *et.al* (2004) and Jejeebouy (1994) report similar findings (37;110).

In summary, the social norms of behavior in Malawi and indeed affecting women attending the Lilongwe PMTCT program mean that these women are more vulnerable to ill health, yet they have limited opportunities to protect their health or to seek reproductive health care such as participating in their PMTCT follow-up care.

Drawing on the masculinity theories, de Keijzer (2004) assert that “ many development programs targeting women in most parts of the world find men an important obstacle-and often the main one- to women's participation and to a project's success” (111). Again Khanum *et.al* (2002) state that “ for the improvement of maternal health; interventions targeting men particularly husbands to get their support and, for their involvement in decision making for use of such services by their wives is required” (112).

One may therefore conclude that the problems affecting women's participation in their PMTCT follow-up care may be linked to their partners' attitudes based on the social norms of behavior prescribed for both men and women as already alluded to earlier in this section.

Again in Malawi, men socialize into believing that what is important to be a real man is to be heterosexually active and to be a financial provider (113). VSO (2003) report similar findings for men in general (114). Since masculinity, the most common form being hegemonic masculinity (the ascendancy

achieved in a play into the organization of private life and cultural processes) has ‘heterosexuality’ as its most important feature (115); this suggests that it is closely linked with the marriage institution. It is because of this that hegemony as it influences the women’s participation in the PMTCT program has been explored in more detail.

While evidence shows that women in the program and Malawi in general are economically more disadvantaged than men, men in Malawi may not always be the financial providers as evidenced by widespread poverty in the country where estimates show that 65.3% of the estimated 12 million Malawians are poor (8;10;89). This suggests that men may equally be experiencing financial constraints, thereby failing to fulfill their cultural expectations. In turn, they may develop feelings of insecurity. As Clever (2002) states, failure of men to achieve their culturally expected roles results into feelings of insecurity and frustration which may be manifested in form of violence (107). Because such masculinities are constructed in relation to women, women become the victims. Loannidis *et.al* (1999) report similar findings (68).

Also, men may have refused condom use for the same reason. NAC (2003) report similar findings and asserts that condom use in Malawi is still very low with only 14% of men and 5% of women using condoms (48). Also, reports of inconsistent and incorrect use have been recorded (Ibid). Because these behaviors have been reported by women in this study as counteracting their efforts to protect themselves for further HIV infection, women have in turn stopped participating in their program’s follow-up care.

Furthermore, men indicated that women do not tell them the details of what happens in the PMTCT program. Whilst the program has made it clear through its educational campaigns that couples can access PMTCT services, men have not been forthcoming. This may be linked to the non-conducive clinic environment for men owing to the fact that the PMTCT services are built-in the MCH department which are mostly seen as female environments. As such men may not be free to take part, even though they may be willing to do so. This is consistent with previous studies where “male head of households” would wish to participate in reproductive health services but are curtailed down by cultural definitions of maleness and roles of masculinity; the underlying cause being fear of being ostracized and ridiculed by other men in society who they imagine would call their manhood into question” (116).

Thus, one would conclude that lack of male role models in the PMTCT program has made re-defining masculinities even more difficult for men (whose partners are in the PMTCT program) who may have wished to challenge such restrictive beliefs.

## 7.6 Community reactions

This study has again shown that lack of clients' participation in their PMTCT follow-up care is strongly linked to the community reactions against them as HIV positive people, mostly from their residential areas.

Although the clients' HIV positive status is not disclosed directly to their friends/neighbors; the latter's reactions are mostly based on what they observe from the actions of the suspects (the clients). For example, such actions include the frequent visits that the clients make to the hospital, their being found with Soya received from the clinic, the visits paid to the program's defaulters' homes by the program staff, the clients' bodily changes and the fact that the suspects get their services from another clinic section other than from where the rest of their friends do. This is elaborated in section 6.2.2.1.

These results suggest that the clients' friends/neighbors are able to identify those who are HIV positive in their respective residential places based on the clients' actions. Similarly, the clients are aware that their friends/neighbors know that they are HIV positive. Surprisingly, there is no open communication between these two parties to discuss the HIV issues freely. Thus, there seems to be a culture of silence and secrecy related to these issues. This culture has again been reported by NAC (2003) and has been linked to stigma and denial related to HIV/AIDS (48).

This suggests that women in the PMTCT program may be trying as much as possible to keep some distance/privacy in their efforts to avoid stigma/denial; hence anything that comes into their way to obstruct these efforts is being turned down. For example, both defaulters and compliers indicated that they would rather continue their participation in the follow-up care to avoid being paid a home visit by the clinic staff. Again, they discussed amongst themselves on how they can make the Soya flour invisible by carrying it in translucent bags so that the outsiders should not know what is inside those bags. This is illustrated in section 6.2.2.2.4. The similar strategy applies to the way the women discussed on how they

evaded their friends' suspicion related to being questioned on why they had to stop breast feeding their children at six months. This is elaborated in section 6.2.2.2.5.

Due to fear of being ostracized, most clients who expressed these concerns ended up defaulting their follow-up care. This finding is consistent with the study done in Uganda by Muyinda *et.al* (1997) where fear of stigma by people living with HIV/AIDS was found to be associated with their shunning away from health and social services (117). Interestingly, though the compliers and defaulters faced similar community challenges, the compliers still continued with their participation in the follow-up care. The noticeable difference was mostly due to the support systems available to them mostly offered by their close family relations and the clinic staff to cope up with these challenges. This is elaborated in section 6.2.2.2.

Again, as illustrated in section 6.2.2.2.5; another observation was that most clients who expressed these negative community reactions were identified to have come from localized communities around the two studied clinics. This finding suggests some ongoing mechanisms which may have helped the compliers to overcome their community challenges and the defaulters' failure to overcome them. Drawing on the work done by Barnett and Whiteside (2002), one may therefore conclude that to some extent, the degree of social cohesion which reflects the cohesiveness of society and its ability to act collectively (118) may have contributed to this difference. As these authors assert, individuals' actions among other things may be rooted from their voluntary commitments based on the available support from the civil society and/or the domestic sphere (Ibid).

With regard to this study, such commitments relate to the compliers' continued participation in their program's follow up care, which may have originated from the support/encouragement given to them by their family relations. Thus with high social cohesion, chances of client commitment to continue their programs' follow up care are high and vice versa. This finding is consistent with the work done by Bryceson *et.al* (2004) where the denial and fatalism about HIV/AIDS in rural Malawi holds back the adoption of safer sexual practices and perpetuates a high-risk environment in which many people are contracting HIV/AIDS unnecessarily (98).

It may therefore be implied also for the PMTCT program, that if the negative communities' reactions from where PMTCT participants are come from persist, many women may continue defaulting their follow-up care thereby perpetuating a high-risk environment in which babies born to these HIV women will be contracting the virus.

## 7.7 Service related concerns

The major issues that surfaced concerning service relate to clients' breach of confidentiality by the service delivery structure and their experiences with volunteers; the long waiting time before getting their services; issues related to the amount of information given to them upon joining the program, issues to do with NVP and the PMTCT staff attitudes in general.

With regard to breach of confidentiality, clients especially those from Area 25 clinic complained of the PMTCT clinic structural failure to accord them enough visual/audio privacy/protection from their friends who visit the other clinic departments. This in turn they said result into their unwanted visibility of being in the program by their friends. Indeed, services are physically separated and not fully integrated into the other reproductive health services such as the routine antenatal care-an inclination of collective secrecy breach (see footnote 20 in the results section). This is again elaborated in section 6.2.2.4.3.1. What is clear in this situation therefore is an interplay embracing reproductive health rights of the women and the PMTCT services offered to them.

Although structural failure to provide enough confidentiality for the PMTCT clinic attendees in Area 25 may not be intentional by the service providers; it still holds that this picture amounts to indirect discrimination<sup>24</sup> against the women by the PMTCT program. Thus, the PMTCT clinic structure seems to be associated with shame and blame by the clients. As already alluded to in section 7.6 above, anything that seems to counteract with the women's' efforts to keep their identities is being turned down; hence

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<sup>24</sup> In this paper, 'discrimination against women'; is defined as "...any distinction, exclusion, or restriction made on the basis of sex which has an effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women irrespective of their marital status, on the basis of equality of men and women of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field" (119).



women may be defaulting their follow up care because the clinic does not offer them enough confidentiality/privacy.

Again, CEDAW reports that most poor resource settings use their countries' constrained economies as an argument to breach people's human rights<sup>25</sup>. It therefore states that lack of resources does not 'absolve the states party of its obligation to provide social protection to the most vulnerable groups' which in this case are the PMTCT clinic attendees. CEDAW instead emphasizes that 'the women's issues should always remain at the center stage even in times of economic distress' (Ibid).

In view of this, the PMTCT clinic management should therefore ensure that alternative means are found to provide services in structures that accord the PMTCT clients their right to privacy and confidentiality.

Regarding concerns over the amount of information presented to the clients during health talks, the reported misconceptions even after the presentation of accurate messages<sup>26</sup> and; the concerns raised by men that the initial HIV/AIDS messages came as a threat to them; all these issues together reflect on the approaches to health education and behavioral change strategies adopted by the PMTCT clinic.

There is now growing evidence to suggest that many health workers work within the framework of the culturally inherent bio-medical practice which takes the consumers (in this case the PMTCT clients) as passive objects to be filled with information (120). Moreover, Whitehead (2001) goes on to say that this traditional tendency may be unrealistic for behavioral change and modification in most health intervention programs (Ibid). One may therefore conclude that one of the possible explanations on why clients complain of getting too much information and having misconceptions in the process lies in the strategy adopted to convey such information. Family Health International (FHI) (2003) therefore calls for behavioral change strategies that stimulate dialogue between the service providers and the beneficiaries in order to spur action (121). With reference to this study therefore, such spurred actions would be the clients' participation in the program's follow-up care.

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<sup>25</sup> CEDAWs concluding observations on the second periodic report of Senegal, paragraph 724.

<sup>26</sup> The PMTCT clinic uses written scripts for its health education and counseling sessions. During data collection, these scripts were seen in use by the providers during service delivery. Again, some were seen posted in their respective counseling rooms.

Again, FHI (2003) and The Jakarta declaration (1997) assert that “fear campaigns” do not work. Instead, they may bring about threat to the audience and consequently may not effect positive change (121;122). One would therefore argue that from the concerns that men had raised during their FGDs (when they said that the HIV messages came as a threat to them) as illustrated in section 6.2.2.3; probably they may have given up life. Consequently, they may have ended up having low risk perceptions towards HIV/AIDS as discussed in section 7.5. This in turn could be a possible explanation for their continued indulgency in unprotected sex which they indicated was a sign of love for their wives.

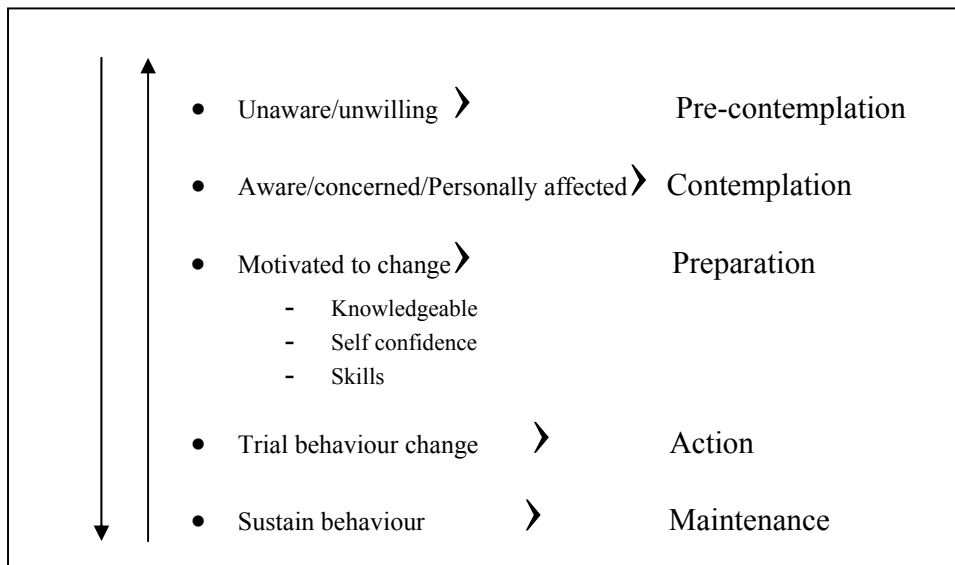
Besides the problems associated with the strategy adopted for the health education campaigns, another possible explanation for the women’s lack of participation in their program’s follow up care may be related to their readiness to learn. Drawing on the Malcolm Knowles adult learning principles as cited by Lieb (1991); learning does not take place where the environment threatens ‘the self’ (123). Again Hubley (2004) states that until adults’ concerns are resolved, they may not be ready to learn nor follow any health related advice (124). It therefore follows that the non-conducive clinic environment due to lack of privacy to some extent may have contributed to client non-participation in their program’s follow up care. Unless this concern is resolved, clients may be anxious about issues of their confidentiality and in turn may not be ready to learn.

This conclusion also takes into account the concerns raised by the women related to the negative staff attitudes. In addition, lack of support systems for some women as discussed in section 7.6 may also have played a role. All the above issues have been discussed within the framework of behavioral change as below.

## 7.8 Behavioral change: Theory and Practice

Drawing on the stages of behavioral change by Prochaska *et.al* (1991); behavior change proceeds through a series of steps moving from being unaware or unwilling to make a change (precontemplation), to considering change (contemplation) to deciding and preparing to make a change (125). The authors go on to say that genuine determined action is then taken, and overtime, attempts to maintain new behavior occur. Relapses according to the authors are almost inevitable and become part of the process of working toward life-long change (Ibid). These stages have been illustrated in figure 6.

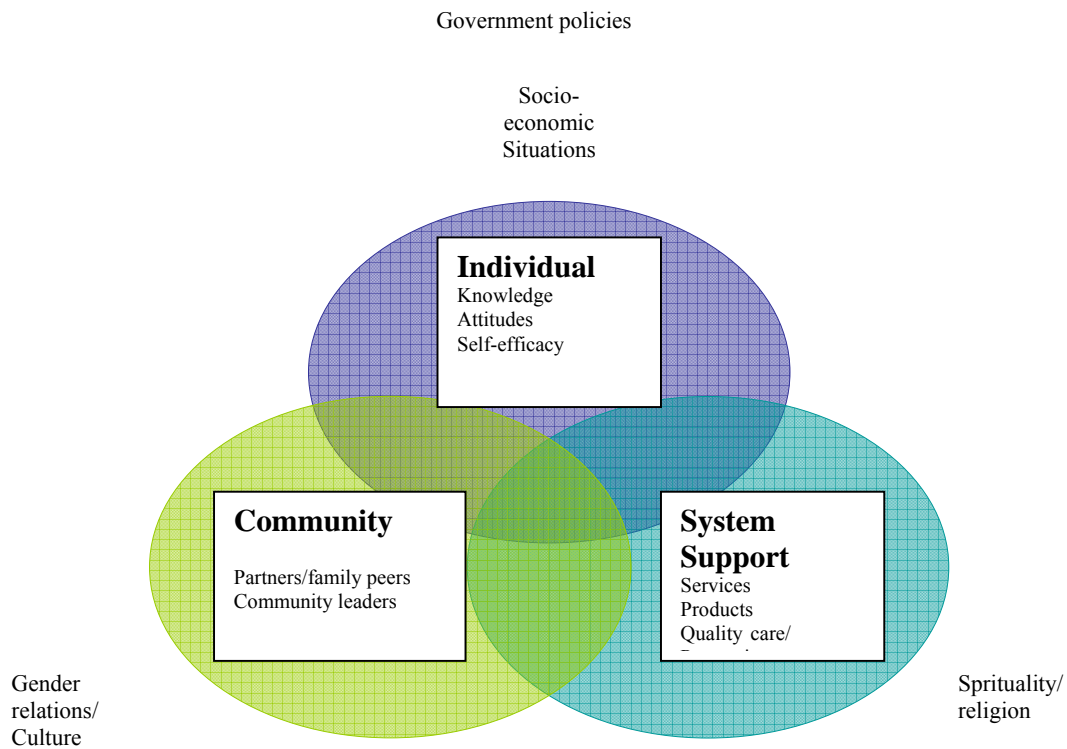
**Figure 6: Stages of Change**



Source: Adapted from Prochaska *et.al* (1992) and NAC (2003)

This approach also recognizes that behavior is influenced by many factors ranging from the individual, community and system levels as illustrated in figure 7. As such, behavioral change requires individual commitment and a supportive environment. NAC (2003) again asserts that because motivation to try and sustain behavior is dependent on individual feelings of personal power and the influence of others; there is need to analyze carefully the contextual factors that affect an individual’s behavior (48). Furthermore, the wider influences that affect the individual, community and support systems include the government policies, the socio-economic situation, culture, gender relations and spirituality/religion. These have been discussed later in the section although some of them have not been fully addressed in this study.

**Figure 7: Factors that influence individual behavior:**



**Source: NAC (2003)**

### 7.8.1 Application of the behavioral change theory to this study

#### 7.8.1.1 Introduction

Factors that influence behavior at individual, community and systems levels will be presented first followed by the wider influences.

## **7.8.1.2 Influences at individual, community and systems level**

### **7.8.1.2.1 Influences at individual level**

Applying this framework to the current study; one would argue that it is possible that the women in the program were probably hurried through the initial stages proposed by this model. This is demonstrated by some clients indicating that they were forced to join the program as seen in section 6.2.2.4.3.2. This suggests that these women probably lacked their initial intrinsic motivation to join the program. In turn, they may have felt less committed to participate in their follow up care because of this lack of motivation.

Others may have simply given up. For example, some clients indicated having defaulted their follow up care because they did not want to be disappointed if their children had tested positive also. As such, they said they needed not to rush with their follow-up visits. Again, another possibility according to this model would be that the clients did not believe that their behavior is a problem (in this case their lack of participation in the program's follow-up care); or that their non-participation would affect them negatively; yet others believed that they no longer have control. Section 6.2.2.5 illustrates this more. To some extent, all these issues again reflect on the clients' education and issues to do with power relations.

As discussed in section 7.3, education is associated with the ability to comprehend issues which is again linked with the understanding of the benefits of the program. Because of the low education levels of women in this study; they may not have appreciated the benefits of the programs follow up care and; the negative effects that their non-participation would bring. Some of the benefits being referred to here include; being referred to ARV clinics for continuity of care and, receiving support and continuous education on how they can prevent themselves and their children from acquiring further HIV infection.

Again, in view of their limited control over decision making regarding sexuality and accessing reproductive health care, some clients may not have had the chance to ask their partners for permission to participate. This would have been probably out of fear to be misinterpreted that they are challenging the husbands' decisions. These have again been discussed in the context of gender relations.

### **7. 8.1. 2. 2 Influences at community level**

At community level, the women's participation in their follow up care has been found to be influenced mostly by their friends/neighbors. As demonstrated in section 6.2.2.1; both compliers and defaulters expressed concern over the negative community reactions towards them as being HIV positive. Although their HIV positive status was not disclosed directly to their friends; these reactions were mostly based on the actions that their friends had observed in them.

Although the compliers and defaulters were both exposed to similar community challenges, what made the difference between them was the available social support especially for the compliers. As this framework asserts, the influence of others help to sustain behavior. From what transpired in this study; the compliers had support mostly from their close family members particularly their husbands which were seen to be almost non-existent for the defaulters. In turn, possibilities of having feelings of desperation despite their having perceptions of the program gains may not be ruled out. For example, as demonstrated in section 6.2.2.3; the defaulters expressed concern over their partners' condom use refusal as counteracting their efforts to prevent their further HIV infection. This again points to the need for a supportive environment to sustain behavior. The service factors will however be discussed later in this section.

### **7. 8.1. 2. 3 Influences at systems level**

At systems level; factors that have been identified to play a significant role relate to the quality of care, friendliness of the PMTCT services and accessibility.

For example, clients expressed concern over the long waiting time before getting their services at the clinic. Again, others complained of not getting adequate support from the clinics especially with regard to infant feeding counseling. For example, some clients said that they did not get full instructions on how they should stop breastfeeding their babies. This is demonstrated in section 6.2.2.2.5. Furthermore, others complained of the following: the negative/stigmatizing staff attitudes towards them as HIV positive victims, structural failure of the PMTCT clinic to offer them enough privacy, problems related to how they were invited to join the program and; issues to do with the efficacy of NVP.

All these factors as illustrated in section 6.2.2.4, have been found to play a role in influencing the clients' participation in their follow up care. Again, as mentioned earlier on in this section, some defaulters stated that they only participate in the monthly support group meetings because the health workers there are friendly. This reflects on the value of a supportive environment for the clients to continue their program's follow up care.

This said, the other issue concerns the general structure of the PMTCT services. By incorporating the PMTCT services within the MCH department; the program to some extent has mirrored the society's views and expectations of the roles of women and men. For example, the health education messages have mostly been addressed to women because they have been seen to be responsible for the health of other family members. WHO (2002) makes similar observations (104). It is therefore the failure of PMTCT services to involve men that has to some extent been identified as an important obstacle to women's participation in their PMTCT follow-up care. This has again been discussed in section 7.5.

### **7.8.1.3 The wider influences**

Some of the wider influences on the individual, community and systems proposed by the model and have been found relevant for this study include: the government policies, the socio-economic situation, culture and gender relations. Issues related to the last three areas have been linked in most places; hence their explanations have not been very discrete. Furthermore, some factors like religion have not been fully addressed in this study.

#### **7.8.1.3.1 Government Policy**

Regarding government policies; as discussed in section 6.2.2.4.3.2; the PMTCT program adopted an 'Opt-out' strategy as opposed to 'Opt-in' as per Malawi governments' recommendations. This started to be implemented in April, 2005. Because 'Opt-out' stresses that all women should be tested for HIV unless they specifically choose not to; clients perceive this as something that has been imposed on them. This in turn has had a direct influence on the program's overall success. Of course at initial enrollment into the program, 'Opt-out' has had substantial numbers of clients joining the program. For example, the 2005 PMTCT clinic monthly (from April) and annual data shows that 99% of antenatal clinic attendees joined

the program compared to 80% during when the ‘Opt-in’ strategy was being implemented (126-128). Despite the success at initial enrollment with the ‘Opt-out’ strategy however; the rates of losses to follow-up have again been substantial. A possible explanation could therefore be related to how this new strategy has been viewed by the clients.

#### **7. 8. 1. 3. 2 Socio-economy**

In view of the socio-economic situation; there have been collective influences affecting the clients’ partners and these have trickled down onto the clients. In turn, such influences have affected clients’ participation in their PMTCT follow up care.

For example, some women complained of not having transport money to come to the clinic for their follow up care. Because men assume the ‘bread winning’ role as per society’s prescriptions, their financial hardships according to the current economic situation in Malawi may have had an effect on the clients’ access to PMTCT services in terms of transport. This suggests that PMTCT services have not been perceived by men as being of priority on the agenda in which case food may have been. Another factor could be the timing of this study. Because it took place during when there was food crisis in Malawi, it could be possible that men were trying to struggle to get money for food. As such, PMTCT service access in terms of transport by the women became compromised.

#### **7. 8. 1. 3. 3 Gender Issues**

In relation to the above, gender issues have again played a role. These issues have been discussed in section 7.5. For example, due to the low risk HIV perceptions by men in this study, condom use has become compromised. In turn, even though women may have been insisting on its use, their arguments/concerns have not been heard mostly because of their general subordinated positions in society. This was again featured when women indicated that if they insist on condom use, the husband may report them to the family counselor, see section 6.2.2.3. This suggests that even if women realize the importance of the PMTCT interventions, this may not translate into their continued participation in the program’s follow up care if the husband is not supportive.



Again, as demonstrated in section 6.2.1.2; some localized beliefs have condoned male behavior to have extra-marital sexual relations. Because such beliefs have taught men to be physically strong and to be sexually active on top of having to fulfill their other ‘bread winning’ roles; some of these roles have been compromised or have been fulfilled in extreme economic pressure and effort. In turn, such inabilities have led to feelings of frustration and violence in men. As discussed in section 7.5, because masculinity is strongly linked to the marriage institution and hence constructed in relation to women; women have been their preys. Consequently, women have had compromised abilities to negotiate for safer sex and to access their reproductive health care including the PMTCT follow-up care.

#### **7. 8. 1. 3. 4 Culture**

Also linked to the above concept is the concept of culture. Culture has again indirectly affected women’s participation in their PMTCT follow-up care in several ways. For example, Malawian culture like most African cultures prescribe women’s responsibilities as that of wife and mother, taking care of the home (103;129). Not only have women in this study resumed responsibilities of caring for the children at home. Considering the current HIV/AIDS pandemic that has affected many families in Malawi (27); it is possible that most families of women participating in the PMTCT program have also been affected. In view of this, these women may have been engaged in the caring of the sick at home with hardly enough time to participate in their PMTCT follow up care. Moser (1993) argue that; this scenario can best be described by looking at ‘the triple roles of women whereby they are heavily burdened by participation in reproductive, productive and community tasks that are either undervalued or not valued at all compared to that of men (130).

#### **7. 8. 1. 4 Summary**

In summary, several factors have been seen to contribute significantly to women’s participation in their PMTCT follow-up care. These have been discussed in the context of the behavioral change theory/process with emphasis on the individual, community and serve factors. Again, the wider issues influencing these factors have been considered.

In view of the grounded theory therefore, the behavioral change process has helped to explain why the current problem of women's failure to fully participate in their follow-up care exists. If the PMTCT program is to succeed, these issues need to be addressed.

The next chapter presents some of the recommendations drawn based on this study that may help to resolve some of the identified issues. Before that, the strengths of the study, some unanswered questions and some key methodological issues applicable to this study have been discussed.

## 7.9 Strengths of the study

Research on factors, including program-related barriers, that can contribute to low levels of participation by women in PMTCT programs in Africa has been limited (37), and none has been done in Malawi. This study is unique because of its focus on these issues in Malawi, and more particularly because it demonstrates that negative family and community reactions and gender and power inequalities can contribute to non-participation by clients in PMTCT. The study points to the importance of social support for overcoming such negative reactions to women's participation, the need for male involvement in PMTCT programs, and recommends strategies to address these issues as a means of helping women overcome the challenges to participation.

## 7.10 Questions that still remain unanswered

- How can the program best improve its structure to be receptive for men?
- How can the program identify HIV positive counselors who the clients propose should be working in the PMTCT clinics in-order for them to be served better?

## 7.11 Key methodological issues relevant for this study

One of the limitations of the quantitative part of the study is that it used already existing data. As such, the ethics of secondary data related to whether the subjects, having consented to participate in the original study would be willing to allow their data to be used for other purposes (131). To avoid such challenges, the researcher reviewed the original consents where it was found that the objectives of this study were in conformity with those for which consent was already obtained.

The other limitation concerned quality of the secondary data where in most cases may be compromised due to mistakes in recording or having missing information (Ibid). Fortunately, UNC project has a quality assurance department that continuously undertakes quality checks in all its programs including the PMTCT program. Also, external assessment is conducted bi-annually. This ensures that all records are kept up to date hence keeping errors at a minimum.

With reference to the qualitative part, one of the limitations concerned the FGDs. Due to their homogeneous nature; findings that emerge from FGDs cannot be assumed to be true for the general population (132). This study however used FGDs as a follow-up of the previously conducted in-depth individual interviews, although this only applied for the defaulters. In this case, views obtained from the FGDs with the defaulters were representative of that group because most of the FGD participants had also participated in the individual interviews. Moreover, the participants in the individual in-depth interviews had been randomly selected at different stages in their follow up care thereby increasing the representativity of the FGDs. In relation to the compliers, although FGDs started first, participants were drawn based on their matched samples from amongst the defaulters. Thus, although FGDs started first, most of the participants in the FGDs also participated in the individual in-depth interviews.

The other limitation relates to the researcher's past experience working with the PMTCT program. Malterud (2001) however argues that previous knowledge is not the same as bias (133). de Paoli (2004) makes a similar argument (134). The authors however argue that unless the researcher fails to acknowledge this, then it may be equated to bias (Ibid).

One may therefore conclude that the researcher's personal/professional past experience is acceptable in qualitative research. Furthermore, Kvale (1996) and de Paoli (2004) argue that the researcher is the human research instrument in which case the interaction between the researcher and the data provides room for reflexivity thereby making the researcher part of the data rather than being separate from it (82;134).

Furthermore, this past experience helped the researcher to develop guides for in-depth interviews as well as the FGDs. Moreover, by combining both individual in-depth and FGD data collection methods, biases that may have occurred as a result of the researcher's prior knowledge were reduced.

Also, the process of transcription, interpretation of the findings and the identification of emerging themes were done with the research assistant. This again helped to reduce the possibility of bias originating from the researcher's prior knowledge. Moreover; the in-depth knowledge that the researcher had on the issue helped the level of depth and detail to develop naturally.

By taking up some of the issues that women had raised with men, validity of the results was ensured. Furthermore, triangulation of the methods also helped to strengthen the results.

With regards to representativity, out of all clients who were invited to participate in both individual interviews and the FGDs, none of them declined to participate. The interviewed sample may therefore be representative of the PMTCT clients managed by the program. In relation to men, a total of fifteen men were invited to participate in the FGDs but twelve did. In view of this, the interviewed sample may not be representative of men's views. However, this created a minimal potential of biased results given the turn up of as high as 80%.

# Chapter 8: Conclusion, recommendations and call for future research

## 8.1 Conclusion

PMTCT programs are unquestionably one of the important priorities if gains towards reducing the high infant and child mortality rates are to be maintained in Malawi; yet services in the Lilongwe PMTCT program are under-utilized by women. This has been evidenced in this study by the overall 20% default rate amongst women in the program's follow up care starting at 32 weeks gestation, up to 6 months after delivery.

Factors that have contributed to this problem among others include those related to community and family reactions, the embedded gender/power relations and women's place in society, the women's experiences at the program and, personal factors. Most of these factors have been seen to interact with each other to influence client participation in the program's follow up care.

Conversely, those factors that have been found to promote women's participation include the available support offered mostly by their partners and clinic staff during support group meetings. These have been found key for the women to fight negative community reactions.

While the quantitative data have helped to identify the socio-demographic factors that are associated with client participation in the PMTCT follow up care, results from the qualitative study are most meaningful for understanding why women participate or not participate in the program's follow up care.

## 8.2 Recommendations

Strategies to involve men in PMTCT programs therefore may need to be adopted. Eide *et.al* (2006) advocates for a similar approach (135). Although couple counseling has been advocated by the PMTCT program, men have not been forthcoming. This problem has continued to persist despite evidence from the women that they had told their husbands about their positive status as per the program's advice. Furthermore, women indicated that they would have loved to have their partners take an active role in PMTCT issues. Because of failure by men to part, women's participation has been affected and it is

proposed that unless men are targeted, it may not be possible for the women to fully participate in their program's follow-up care. Previous studies have also documented partner involvement as being desirable though this rarely occurs (37).

Participatory methodologies and improving clinic conditions may help to improve the situation. As VSO (2003) assert; "strategically, women must be at the centre of the response to HIV/AIDS; tactically, men have to be involved to address both HIV/AIDS and gender inequalities" (114). The gender analysis matrix (GAM) framework may therefore be adopted to address the identified gender issues. GAM framework, which was developed by Parker emphasizes participatory approaches and enables members (in this case men) to articulate their expectations about a particular project (136). It is expected that issues affecting them as men will be brought to surface through interaction with each other. It is this responsibility at grassroots' level that allows strengthening of responsibility for their own actions like condom use and/or issues on the number of sexual partners.

Furthermore, GAM accommodates issues related to illiteracy, time and financial constraints and; missing data. The underlying principle is that the community members (in this case men) are the experts in developing sustainable solutions. It is therefore anticipated that if this approach is adopted, the program may be sustained due to community ownership. UNDP South Africa advocates similar approaches (137). Again in Kenya, in an effort to increase male participation, Machako's district Hospital began a program called "men as partners" as part of its overall PMTCT program (138).

Some anticipated challenges with this strategy however are that the specific targeted men (whose partners are in the PMTCT program) may not easily be found due to stigma. Furthermore, it may be difficult to access men who are mostly engaged in productive work outside their homes and; how to change norms of gender discourse to include men in a constructive way. Moreover, service providers and space to accommodate men in the PMTCT facilities may be a problem. A pilot 'phase in' strategy is therefore advocated. Targeting opinion leaders who are the custodians of culture may be important to reclaim the ideas of manhood.

Evidence again shows that 'it is far easier to get men involved when the focus is on child's health and well being rather than sex and sexuality per se'(107). In view of this, it may be worthwhile to start with these

issues and later bring in issues of sex and sexuality. After all, the primary goal of PMTCT programs is to ensure child survival.

The other social networks of the women such as friends, neighbors and the community at large should be targeted to ensure that women easily follow their PMTCT program's advice. This again has the potential to reduce HIV/AIDS stigma and discrimination and in turn may encourage them to participate in the program's follow up care freely. The public campaigns addressing topics surrounding HIV/AIDS should again be intensified and should encourage open discussions. Furthermore, involvement of people living with HIV/AIDS (PLWHAs); a strategy which is already in place needs to be intensified. This helps to make AIDS a reality to the general population and may help people to identify with those infected as part of the society. Mhloyi (1992) asserts the same (139). Voluntary organizations such as NAPHAM should therefore continue to be involved in these campaigns. Positive examples which may help create a conducive climate to respect should be identified and strategies to reduce stigma be sought.

Again, social support from other women who are HIV positive and have participated in the PMTCT program may be another way of motivating the women to continue with their follow up care. These would provide a focus on issues that are important to women and wives that may be more specific/pertinent than simply having PLWHAs involved. In turn, this has a potential to help women build a sense of self-efficacy in their efforts to fight the negative community and family reactions. de Paoli (2004) advocates the same strategy (134). Women's support groups available in the clinics may be an important forum.

Because of the complex interrelationships between the clients' identified causes for their non-participation in the program's follow up care; this should again inform management that interventions that purely focus on health education may not be effective. Rather, there should be a mix in approaches to cater to the varying needs of the clients. For example, simple IEC pictorial materials depicting important PMTCT messages and/or drama may be used to complement the health education messages/campaigns.

Another concern relates to the issue of not accessing ARVs for the women even when they go to the "Light House Clinic" to get them. Although the drugs have been subsidized by the Malawi government and in most cases have been dispensed to clients/patients for free; the PMTCT clients are still not fully accessing them despite after being referred by their respective PMTCT clinics. UNC project management

should therefore liaise with the Light House management to see how best these clients can be helped. This will also help to serve as an MTCT-PLUS component of the program. As such, the services are likely going to benefit mother and the child rather than only serving the life of the child and not the mother; one way of creating so many orphans.

Informing women on how NVP works may also help them believe that the drug will help their children. Again, they need to know the conditions associated with ensuring the drug efficacy. For example, issues about the dangers of mixed feeding should be highlighted and how this works to counteract with the effectiveness of the drug. Also, the timing of drug administration to both mother and baby during labor and after delivery respectively need to be emphasized. Issues of re-infection and how this impacts on increasing vertical transmission need to be highlighted as well.

It is again apparent that the program requires providers who are competent in infant feeding counseling especially in the context of HIV/AIDS. These counselors must be able to respond to practical questions on how women should stop breastfeeding their babies when they turn six months old without having to practice mixed feeding. Furthermore, they must be able to discuss with the women on the feasible alternative infant feeding options without compromising on the health of their children and; depending on the women's individual needs. As such, in-service infant counseling trainings need to be organized for the PMTCT service providers. They also need to be trained on the current WHO infant feeding recommendations<sup>27</sup>.

With regard to ensuring client confidentiality at clinic level; there is need for greater efforts by the PMTCT/UNC management to find alternative ways to ensure that services are provided in structures that accord women their right to privacy and confidentiality. Ensuring client confidentiality in PMTCT clinics may increase the proportion of women participating in their follow up care. In turn, this positive response may go a long way in influencing behavioral change even amongst their partners; our desired goal on the preventive strategy against HIV spread.

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<sup>27</sup> To reduce post-natal MTCT of HIV, WHO generally recommends avoidance of breast feeding, but when replacement feeding is not “acceptable, feasible, sustainable and safe”, exclusive breast feeding is recommended for the first few months of life and should then be discontinued as soon as conditions for safe replacement feeding are met (58).



Also, by introducing PMTCT issues to the women during their later pregnancy periods, the duration of exposure to stigma in the clinics may again be reduced. The proposed period to introduce PMTCT issues to the clients may be around 32 weeks or slightly earlier because most babies in Malawi would survive at 8 months if born prematurely. As such, this will ensure that services are provided to everyone including those who might go into early labor. This again ties with the first follow-up visit that the PMTCT clients are supposed to make to the program. In the meantime, the women may continue attending their routine antenatal care with their colleagues who are not in the program.

Having empathetic staff members working in the PMTCT clinics is another important area for ensuring the program's success. Training sessions in interpersonal counseling and communication may help the staff members change their attitudes for the better when dealing with these clients. Besides that, frequent meetings and individual counseling sessions for the concerned staff members may be helpful. Also, occasional random exit interviews with clients to get their views about the services received and program staff supervision may help to improve their interactions with clients. Painter *et.al* (2004) and Eide *et.al* (2006) make similar recommendations (37;135).

Also, services need to be provided on first come first served basis to reduce the clients' long waiting time; one of the concerns raised by the clients at clinic level. Moreover, simple tasks like weight check for the clients may be left to the clinic attendants to give more time for the counselors to concentrate on other important tasks.

In relation to the concerns raised in relation to the volunteers as being responsible for spreading the news about the women's HIV positive status in the communities; it may be worthwhile to collaborate with the organizations that these volunteers work for to brief them about the volunteers' ethical violations in the communities that they are serving. If their training preparation does not include this element, it may be relevant for those concerned organizations to train them on this. Again, training them in good clinical practice is recommended.

Regarding personal factors; although the program cannot deal with the women's unexpected events, supportive health care attitudes can play a significant role. For example, linking the women with money

lending institutions where they can access some loans may help improve their socio-economic status. Cleaver (2002) however cautions that the empowering effects of credit on some women may result into disempowering effects on men. In turn, domestic violence may occur (107). Since the Lilongwe PMTCT program already started providing credit, it may be worthwhile to evaluate its effectiveness before implementing it on a large scale. Access to those loans by couples may be another way of evading domestic violence. As such, collaboration with the concerned money lending institutions may be necessary.

In relation to the women's' multiple roles; targeting community leaders who are the custodians of culture may help to redefine the social roles of masculinity and femininity. This strategy may help to actively involve men in the reproductive roles at home. In turn, it has the potential to relieve women of other responsibilities thereby creating more room for them to participate in their PMTCT follow-up care. Of course owing to the sensitive nature of the topic; a lot of time and efforts may need to be invested to yield positive results. Aggleton and Warwick (1998) and Kunene (2003) make similar arguments (116;140).

Finally, because the Lilongwe PMTCT program serves as a pilot site for scaling-up PMTCT services in Malawi, the identified challenges need to be considered by the government in its scale-up plans. This will help to avoid similar challenges for the other in-country PMTCT programs.

In summary, this study has filled a critical gap in knowledge on why women in the Lilongwe PMTCT program do not fully participate in their program's scheduled follow up care. To be effective in changing individual women's behaviors to ensure their full participation, PMTCT programs must address these factors many of which have to do with what happens at the interface between women and the communities in which they reside, their families and the program's health care delivery. As seen in this study, advances in the program may require a paradigm shift towards interventions addressing broader social issues that play a role in influencing client participation in PMTCT follow- up care.

Many PMTCT programs elsewhere in Africa may be facing similar challenges as those found in this study. Because research in this area has been limited, the findings of this study are believed to be relevant though they may not be generalized to other settings. Nevertheless, it is important to take a comparative view and describe what appear to be common themes on issues that have been identified in different

settings. For example, it may be worthwhile to identify what women in these different circumstances and PMTCT programs have in common and what can be the implications for improving the situation across Africa.

Ultimately, it is the national/global society and the future generations that benefit when women in the country make their efforts to protect the health of their babies/children from contracting HIV through vertical means.

### 8.3 Call for future research

Further research is required to

- Examine the causes of client non-participation in the PMTCT follow up care from six months following child's birth to the termination of the visits at 18 months.
- Examine the social-cultural infant feeding dilemmas faced by women in the PMTCT program when their children clock six months of age, and how the women negotiate with that.
- Examine the effectiveness of PMTCT programs when the child is finally terminated from the program at 18 months. This will be determined by an ELISA test and comparisons should be made between those who complied with their follow up care against those who defaulted.
- Examine health workers' perspectives about the PMTCT programs and assess their training needs.
- Determine the rates of loss to follow up during the entire period when clients are supposed to come for their PMTCT follow up care in the program. That is the whole 18 months period.
- Examine the degree to which women in different cultural and national settings, and the PMTCT programs that have been organized to serve them, share common challenges and opportunities for addressing these issues.

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**Appendix 1: Malawi National Ethics Review Board approval letter to change sites**

**Protocol # 359**

Telephone: + 265 789 400  
Facsimile: + 265 789 431

All Communications should be addressed to:  
The Secretary for Health



*In reply please quote No. ....*

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

27<sup>th</sup> September 2005

Mrs Jacqueline Nkhoma,  
C/O The Country Director,  
University of North Carolina,  
P/B A-104  
Lilongwe

Dear Madam,

**Re: PERMISSION TO CHANGE LOCATION OF STUDY ENTITLED  
'PREGNANT WOMEN, HIV AND COMPLIANCE WITH PMTCT PROGRAMS  
IN MALAWI IN THE PUBLIC FACILITIES WHERE UNC IS IMPLEMENTING  
ITS PMTCT ACTIVITIES ( PROTOCOL # 359)**

Permission is hereby being granted for you to change the study site of your research project (Protocol # 359) from LCH Bottom Hospital to Kawale Health Centre.

Please be informed that Kawale Health Centre is under Lilongwe DHO and permission also needs to be sought from them before recruitment can begin.

Yours Sincerely

  
Ms Agnes Suya

For: CHAIRMAN, NHSRC

**Appendix 2: Malawi National Ethics Review Board Approval Letter**

Telephone: + 265 789 400  
Facsimile: + 265 789 431

All Communications should be addressed to:  
The Secretary for Health and Population



*In reply please quote No. MED/4/36c*  
MINISTRY OF HEALTH AND POPULATION  
P.O. BOX 30377  
LILONGWE 3  
MALAWI

4<sup>th</sup> July, 2005

Ms. J. Chinkonde  
Dept of general Practice and Community Medicine  
University of Oslo  
P.O. Box 1130  
Blindern,  
Norway

Dear Madam,

**Re: Protocol # 359: Pregnant women, HIV and compliance with PMTCT Programs in Malawi in public facilities where UNC project is implementing its PMTCT activities**

I am pleased to inform you that the National Health Sciences Research Committee during a meeting held on 24<sup>th</sup> June, 2005 approved the above study. The committee however suggested the following: -

The Committee however suggested that it will be nice if focus group discussions be will done first.

As you proceed with implementation of your study please ensure that all requirements of the NHSRC are followed as per attachment.

Yours faithfully

  
W M Kazembe

For:

**SECRETARY FOR HEALTH**



### Appendix 3: University of Oslo Approval Letter



**UNIVERSITY OF OSLO**  
FACULTY OF MEDICINE

To whom it may concern

**Department of General Practice and  
Community Medicine**  
*Section for International Health*  
P.O. Box 1130 Blindern  
NO-0318 Oslo

**Date:** May 23<sup>rd</sup> 2005  
**Your ref.:**  
**Our ref.:**

Telephone: + 47 228 50 640  
Telefax: + 47 228 50 607  
E-mail: [g.a.bjune@samfunnsmed.uio.no](mailto:g.a.bjune@samfunnsmed.uio.no)  
URL: [www.med.uio.no/ism/inthel](http://www.med.uio.no/ism/inthel)


#### **Ethical Review of Research Proposals**

Due to a change in the routine for reviewing research ethics of proposals from students at our training for Master of Philosophy, International Community Health, their studies will not be reviewed by the Regional Research Ethics Committee in Bergen this year.

However, the students have been coursed in medical research ethics and their proposals have been reviewed by their academic supervisor at University of Oslo and found to satisfy the requirements stated in the Helsinki Declaration and CIOM's Guidelines for Ethical Review of Epidemiological Research.

In case you have any question, please do not hesitate to contact me.

Yours sincerely,

  
Gunnar Bjune,  
Professor International Health  
e-mail: [g.a.bjune@medisin.uio.no](mailto:g.a.bjune@medisin.uio.no)  
Phone: 47-22850640



M.PHIL PROGRAMME  
INTERNATIONAL COMMUNITY HEALTH  
FACULTY OF MEDICINE  
UNIVERSITY OF OSLO, NORWAY

**Appendix 4: Quantitative Checklist for information to pull out of the client records**

Clinic code..... Client study ID code.....  
 Code of interviewer..... Date of interview.....

Instructions to the data entry clerk

Ask for the clinics’ consent to have access to the clients’ records enrolled in the program from January, 2004 to December, 2005. (Take manageable number of folders at a time. Start with the oldest records and work forward in time).

Record all information on only the relevant socio-demographic information as defined in the checklist. Enter this information in the SPSS data files version 12.0.

At the end of each day, check to ensure correct entries

Follow additional instructions as stated in the questionnaire guide

*The socio-demographic information to pull out of the records includes the following:*

Client’s age..... Address.....  
 Marital Status..... Gravidity.....  
 Parity..... Gestational age at the start of PMTCT care (in wks)....  
 Highest level of education attained.... Own occupation or partner’s.....  
 Whether partner has had VCT..... Result.....  
 Type of housing ..... Source of drinking water.....  
 Whether she has electricity in the home or not.....

*If delivered*

Place of delivery..... Weight in kg..... Whether she and the baby got NVP or not.....

If the baby got NVP, how long after delivery, mode of delivery.....

*At 6 weeks visit:*

Record if baby is alive or not..... If alive, PCR done or not.....

*At six months*

Mother Breastfeeding or not..... Baby’s weight in kg.....

**Appendix 5: Questionnaire guide for in-depth interviews with individual PMTCT clients**

Clinic code..... Client study ID code.....  
Code of interviewer..... Date of interview.....  
Starting time..... Ending time.....  
Interview serial number with same client... Place of interview.....  
Indicate whether client is a complier or defaulter of the program’s follow up care.....

**Instructions to the Interviewer**

Welcome the interviewee  
Explain the purpose of the interview  
Ask for client’s consent to take notes and to record the interview  
Get the client’s background information then ask questions on all themes  
Record all answers  
Follow additional instructions as stated in the questionnaire guide  
At the end of each interview, check if all themes have been addressed. Also, ask for the client’s consent for additional interviews in case of need and her permission to participate in FGDs on which dates would be communicated later.

**Background Information**

Client’s age..... Address.....  
Marital Status..... If living with partner, duration of stay together...  
Gravidity..... Parity.....  
Occupation or partner’s..... Highest educational level attained.....

**Points to talk about**

1. General information on PMTCT issues  
(Probe for the following)  
What do you know about “PMTCT”?  
When and how did the client learn about the PMTCT program?  
What was client’s reaction when she first heard about the program?  
Whether she discussed the PMTCT program with your partner or anyone else and what the latter’s reaction was.  
What was the client’s response to this reaction?  
When did the client learn about her HIV status and what motivated her to go for the test?
2. What impact has knowledge of her HIV status had on her lifestyle?  
(Probe for the following):  
Did the client know about her HIV status before joining the PMTCT program?

What has changed in the client's life at home since she was diagnosed with HIV?  
What effect does this have on her life?

3. Are there negative family and community responses that the clients in the PMTCT program face after receiving an HIV positive result?  
*(Probe for the following)*  
Did she tell anyone about her HIV positive status? *(Probe for an explanation)*  
What made her take the decision above?  
If she disclosed her HIV status to significant others, what made her decide to share her results, how do they relate to her now that they know she is HIV positive? *(Probe on coping mechanisms and sources of support)*  
Has the partner been counseled and/or tested for HIV? *(Probe for an explanation)*. Does the client know of her friends who are HIV positive? *(Probe on how she and/or others relate to the friend; and coping strategies)*.
  4. What does the client say about her own role and attitude in the prevention of HIV/AIDS transmission from mother to child?  
*(Probe for the following)*  
Does the client see mother-to-child transmission of HIV as a problem? *(Probe for an explanation)*  
What made her decide to join the PMTCT program?  
What benefits does she get and/or her child get or likely to get from the program?  
What are her views on the way services to clients in the PMTCT program are provided? What does the client feel should be changed or improved in the way PMTCT services are currently being provided to ensure clients' good follow-up visit practices? *(Ask those who are complying: What is making them continue participating?)(Ask those who are defaulting on what is making them not to continue with their follow up care?)*.
  5. What does the client state as barriers to participation in the PMTCT follow-up program *(Probe for services, socio-cultural, socio- economic, e.t.c)*
  6. In the client's opinion, does she think that many pregnant women enroll in the PMTCT program? *(Probe for an explanation)*. How about in the follow up schedules? *(Probe for an explanation)*. What does she feel would motivate people to effectively utilize the PMTCT services including the follow up visits?  
Ask the client to identify 3 things that she would do if she were to be in charge of the PMTCT program at UNC project to ensure effective use of the PMTCT services? *(Probe for services that the client would like to see in this PMTCT program and elsewhere)*.
- Client consent to participate in future individual interviews Yes  No   
Client consent to participate in FGDs Yes  No

## **Appendix 6: Questionnaire guide for focus group discussions**

Clinic code..... Client study IC code.....  
Code of interviewer..... Date of interview.....  
Starting time..... Ending time.....  
Interview serial number with same client..... Place of interview.....  
Indicate whether the group is for compliers or defaulters of the program's follow up care.....

### **Instructions to the Interviewer**

Welcome the interviewees  
Explain the purpose of the interview  
Ask for the group's consent to take notes and to record the discussion  
Agree with the group on giving everyone the chance to talk then ask questions on all themes  
Have the moderator facilitate the discussions and the note taker take notes and record all answers  
Follow additional instructions as stated in the questionnaire guide

### **Points to talk about**

1. General information on PMTCT issues  
(*Probe for the following*)  
What do you know about "PMTCT"?  
When and how did the client learn about the PMTCT program?  
What were the group's initial reactions when they first heard about the program?  
Whether they discussed the PMTCT program with their partners or anyone else and what the latter's reaction was.  
What were the clients' responses to these reactions?  
When and what motivated them to have a test?
2. What impact has knowledge of their HIV status had on their lifestyles?  
(*Probe for the following*):  
Did the clients know about their HIV status before joining the PMTCT program?  
What has changed in the clients lives at home since they were diagnosed with HIV? What effect does this have on their daily routines?
3. Are there negative family and community responses that the clients in the PMTCT program face after receiving an HIV positive result?  
(*Probe for the following*)  
Did they tell anyone about their HIV positive status? (*Probe for explanations*)  
What made them take the decision above?

If they disclosed her HIV status to significant others, how do they relate to her now that they know the client is HIV positive?

Have their partners been counseled and/or tested for HIV? *(Probe for an explanation)*

Do the clients know of their friends who are HIV positive? *(Probe on how she and/or others relate to the friend).*

4. What do the clients say about their own roles and attitudes in the prevention of HIV/AIDS transmission from mother to child?

*(Probe for the following)*

Do the clients see mother-to-child transmission of HIV as a problem? *(Probe for an explanation)*

Do they think the treatment prevents HIV in their babies?

What made them decide to join the PMTCT program?

What benefits do they get and/or their children get or likely to get from the program? What are their views on the way PMTCT services are provided to clients? What do they feel should be changed or improved in the way PMTCT services are currently being provided to ensure clients' good follow up visit practices? *(Ask the group comprising of clients who are complying: What is making them continue participating?).(Ask the group comprising of clients who are defaulting on what is making them not to continue with their follow up care?).*

5. What does the group state as barriers to participation in the PMTCT follow up program *(Probe for services, socio-cultural, socio- economic, e.t.c)*

6. In the group's opinion, do they think many pregnant women enroll in the PMTCT program? *(Probe for an explanation).* How about in the follow up schedules? *(Probe for an explanation).*

What do they feel would motivate people to effectively utilize the PMTCT services including the follow up visits?

Ask the group to identify 3 things that they would do if they were to be in charge of the PMTCT program at UNC project to ensure effective use of the PMTCT services? *(Probe for services that the client would like to see in this PMTCT program and elsewhere)*

Group members consent to participate in further FGDs in case of need

Yes  No

## **Appendix 7: The participant's informed consent form**

My name is Jacqueline Rose Chinkonde (Mrs. Nkhoma) and I am a Malawian pursuing a Master of Philosophy course in International Community Health at the University of Oslo, Norway. This is a two year course and I am in my final year.

To fulfill the academic requirements for the award of my degree, I am expected to conduct a study in my home country. As such, I am conducting a study on pregnant women, HIV and compliance with prevention of mother-to-child HIV transmission (PMTCT) Programs in Malawi at UNC project PMTCT clinics. The purpose is to get women's views on why some participate in the program's scheduled follow up visits while others do not fully participate. To learn this, I together with my colleagues will interview some of women who comply and some of those who default these visits.

If you decide to participate in the study, you will be one of the approximately 40 women who will be interviewed. The entire study will take six months, however participation will be 3 times with a total of 10 minutes in the first interview and 45 minutes- 1 hour in the two subsequent interviews. First interview will be to ask if you intend to come for the follow up visits, if so to get your permission to participate in the study whether you come for follow up care or not. The second will be an in-depth interview on the concerned topic, and the third will be a focus group discussion with your fellow participants. Your participation is entirely voluntary and you may decide to withdraw at any point without any problem or effect on the care that you receive at this clinic as a patient or client.

Also, you do not have to participate in order to receive treatment at this clinic.

Your participation may cause some discomfort especially when your family or friends learn that you are being interviewed because you are in the PMTCT program. To reduce this, you will decide the convenient place and time to conduct such interviews. The researchers will also dress in ordinary clothes and come by public transport in which case they will be taken as ordinary community members. You will again be identified by a number and you will not be identified personally in any report or publication about this study.

You will be given a tablet of washing soap and a packet of sugar as token for your participation in the study. Also, transport will be arranged for you to attend the interviews at a place of your convenience.

There will be no costs to you for participating.

The study may not benefit you directly, but the results will benefit UNC project, Malawi and the rest of the world because this research may help to better understand the circumstances that clients in the PMTCT program are faced with and ways on how to improve their participation in these PMTCT program scheduled follow up visits.

If you have any questions about the study, you can ask me or any of my colleagues.

This study has been sponsored by the NORAD fellowship program.

.....

Subject's agreement

I have read the information above or have it read to me and have understood everything.

I agree to participate in the study

I do not agree to participate in the study

\_\_\_\_\_  
Signature or mark of the research subject

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of the research subject

\_\_\_\_\_  
Signature of person obtaining consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of person obtaining consent

\_\_\_\_\_  
Signature of person verifying consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of person verifying consent



## Appendix 8: Qualitative checklist for obtaining clients' consent to participate in the study

### *Information to the interviewer:*

Obtain client's consent in the clinic following her knowledge of an HIV positive status at the time when the program is also getting permission to pay her a home visit in case she does not manage to come for her scheduled follow up care; at least three weeks past her clinic appointment date.

Clinic code.....

### Instructions to the Interviewer

Welcome the interviewee

Explain the purpose of the interview

Ask for client's consent to be asked a few questions

Record all the information as indicated in the questionnaire

### **Points to talk about**

- Ask if the client intends to come for her PMTCT follow up visits: Yes  No   
(If no, thank the client for her time. If yes, proceed)
- Ask her if she is willing to be paid a home visit for interviews in case she does not manage to come to the clinic for her follow up visit, at least three weeks after her appointment date. Yes  No   
(If no, thank the client for her time. If yes, proceed)
- Ask her if she is willing to be interviewed even when she attends the follow up care.  
Yes  No  (if no, assure her that you have taken note of that).
- Obtain the clients background information as follows:

Client's age.....

Address.....

Marital Status.....

Gravidity.....

Parity.....

Gestational age.....

Next appointment due date.....

Client ID code.....

Date of consenting.....

Code of person obtaining consent.....

Date of obtaining consent.....

Witness signature or print incase of obtaining consent from an illiterate person.....

Date.....

Thank the client for her time and agree to meet then.