Making it happen:
Prevention of mother to child transmission of HIV in rural Malawi

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2009
Our system is one of detachment: to keep silenced people from asking questions, to keep the judged from judging, to keep solitary people from joining together, and the soul from putting together its pieces.

Eduardo Galeano, ‘Divorces’
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Abstract

The devastating consequences of HIV/AIDS have caused untold harm and human suffering globally. Over 33 million people worldwide are estimated to be living with HIV and AIDS and a majority of these are in sub-Saharan Africa. Women and children are more infected particularly in sub-Saharan countries. Globally, an estimated number of 370 000 children were newly infected in 2007, mainly through mother to child transmission (MTCT). Implementation of prevention of mother to child transmission (PMTCT) programmes has been introduced in many sub-Saharan countries during the last years.

Operational research was conducted to study the demand and adherence of key components within a PMTCT Programme among women in rural Malawi. This study was carried out at Malamulo SDA Hospital in rural Malawi and employed a mixture of both quantitative and qualitative approaches. Data sources included antenatal care (ANC), PMTCT and delivery registers, structured questionnaires, in-depth interviews with HIV positive women in the programme and focus group discussions with community members, health care workers and traditional birth attendants.

Over the three year period of the study (January 2005 to December 2007), three interventions were introduced in the antenatal care (ANC) at the hospital at different times. These were HIV testing integrated in the ANC clinic in March 2005, opt-out testing in January 2006 and free maternal services in October 2006. A steady increase of the service uptake as interventions were being introduced was observed over time. HIV testing was generally accepted by the community and women within the programme. However, positive HIV tests among pregnant women were also experienced to cause conflicts and fear within the family. Although hospital deliveries were recognised to be safe and clean, home deliveries were common. Lack of transport, spouse support and negative attitudes among staff were some of the underlying factors.

Further study on the quality of care offered in the presence of increased service uptake is required. Community sensitisation on free maternal care and male involvement should be strengthened to enable full utilisation of services. Additionally, service providers at facility and community levels, policy makers at all levels and the communities should see themselves as co-workers in development to reduce preventable maternal and infant mortality including MTCT of HIV.

Key words: HIV, PMTCT, maternal services, Malamulo SDA Hospital, Malawi
The thesis is based on the following papers:


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Abbreviations

AIDS  Acquired Immunodeficiency Syndrome
ANC  Antenatal Care
ART  Antiretroviral Treatment
ARV  Antiretroviral
CHAM  Christian Health Association of Malawi
DHO  District Health Office
FP  Family Planning
FGD  Focus Group Discussion
GDP  Gross Domestic Product
HBC  Home Based Care
HIV  Human Immunodeficiency Virus
HSA  Health Surveillance Assistant
HTC  HIV Testing and Counselling
IATT  Inter Agency Task Team
MCHS  Mother and Child Health Services
MDHS  Malawi Demographic Health Surveys
MSF  Medicins Sans Frontieres
MOHP  Ministry of Health and Population
MTCT  Mother to Child Transmission of HIV
NAC  National AIDS Commission
NGO  Non-Governmental Organisation
NVP  Nevirapine
PMTCT  Prevention of mother to child transmission of HIV
PACT  Private Agencies Collaborating Together
SDA  Seventh Day Adventist
STI  Sexually Transmitted Infection
TB  Tuberculosis
TBA  Traditional Birth Attendant
UNICEF  United Nations International Children Education Fund
USAID  United States Agency for International Development
USD  United States Dollar
VCT  Voluntary Counselling and Testing
WHO  World Health Organisation
YFHS  Youth Friendly Health Services
ZDV  Zidovudine
3TC  Lamivudine
Introduction

HIV/AIDS is the deadliest epidemic of our time. Over 33 million are currently living with HIV and AIDS worldwide and more than 22 million people have already lost their lives. In many countries, especially in Africa, the AIDS epidemic has spread rapidly, leaving illness, death, poverty and misery in its wake. In other countries, the disease is still in its early stages and its destructive effects are now beginning to be felt (UNAIDS, 2008).

By the end of 2005, women accounted for nearly half of all the people living with HIV and AIDS worldwide, and represent almost 60% of those infected in sub-Saharan Africa. Worldwide, 62% of infected young people are girls, and that number soars to 77% in sub-Saharan Africa (UNAIDS/WHO, 2005). A woman’s vulnerability to the virus is attributable not only to biological differences, but also to deeply entrenched socio-economic and gender inequalities that further compound her risk. Women are more vulnerable to contracting HIV than men, mainly because they are not the key decision-makers regarding condom use or even negotiating sex. They depend on men to protect themselves from HIV infection (NAC, 2005).

An estimated 2.7 million people became newly infected with HIV in 2007, and 2 million people died of AIDS-related causes in the same year. Young people under the age of 25 are estimated to account for almost half of all new HIV infections globally (UNAIDS, 2008).

Mother to child transmission of HIV

Mother to child transmission (MTCT) is the overwhelming source of HIV-1 infection in young children. In 2007 alone, around 370,000 children under 15 became infected with HIV, mainly through MTCT despite effective antiretroviral therapy and in total 2 million children are living with HIV/AIDS globally (Little et al., 2007; UNAIDS, 2008). About 90% of MTCT infections occurred in Africa where AIDS is beginning to reverse decades of steady progress in child survival.

MTCT occurs during pregnancy, labour and delivery, or breastfeeding. Without treatment, around 15-30% of babies born to HIV positive women will become infected with HIV during pregnancy and delivery. A further 10-20% will become infected through breastfeeding (Moodley and Moodley, 2005; Newell; 2006).

In high income countries MTCT has been virtually eliminated, thanks to effective voluntary testing and counseling (VCT), access to antiretroviral therapy, safe delivery practices, and the widespread availability and safe use of breast-milk substitutes. If these interventions were used worldwide, they could save the lives of thousands of children yearly (UNAIDS/WHO, 2005).

Prevention of mother to child transmission of HIV

Prevention of mother to child transmission (PMTCT) is an intervention aimed to reduce MTCT of HIV infection (Wilfert, 2002; Jourdain et al., 2004). Voluntary counselling and testing (VCT) in pregnancy is inseparable from the PMTCT. This is because VCT is an entry
point to care and support including the provision of antiretroviral prophylaxis. A number of interventions have been aimed at effectively providing alternatives to breastfeeding and limiting the risk of newborn infections during delivery, by using Cesarian section as the mode of delivery and administering antiretroviral (ARV) drugs prepartum and peripartum. However, all these approaches are not always possible in developing countries and the use of ARV drugs, in particular nevirapine (NVP), has been investigated in both developing and developed countries (Sullivan, 2003; Volmink et al., 2007).

A single dose (sd) of NVP administered to the woman at the onset of labour and to the baby within 72 hours of delivery reduces HIV transmission rates by 38-50% and is relatively cheap and easy to implement (Lallemant et al., 2004; Scarlatti, 2004). Short course regimens of zidovudine (ZDV) or ZDV + lamivudine (3TC), together with sdNVP are recently reported to be effective, with 6-week transmission rates below 5%. The doses are ZDV 300 mg twice daily at 36 weeks of gestation, with 600 mg of ZDV + 200 mg NVPsd at beginning of labour, or at 32 weeks consist of ZDV as previously + 3TC 150 mg twice daily; the labour dose consists of ZDV + NVPsd as previously + 300 mg 3TC. Neonates receive ZDV syrup (2 mg/kg per 6 h) for 7 days + NVPsd syrup (2 mg/kg) on day 2 (Dabis et al. 2005; Ekouevi et al., 2005; Coffie et al., 2008).

Exclusive breastfeeding reduces the risk of HIV transmission. According to the definition of exclusive breastfeeding, an infant receives breast milk only for up to 6 months (no water, formula milk, cereals etc). In most developing countries exclusive breastfeeding is not the norm and promotional activities and support need to be put into place to help mothers adhere to exclusive breastfeeding practices (Bii et al., 2008; Rollins et al., 2008). After 6 months, mothers need assistance in making optional feeding choices that are feasible in their setting. Optional feeding and follow-up of HIV positive women's infants to 18 months when the HIV status is determined are still components of PMTCT but were not part of the study.

PMTCT and its challenges

Implementation of PMTCT programmes faces challenges in developing countries due to political, financial, logistical and societal factors. In many regions of Africa, PMTCT programmes are unavailable. Even when PMTCT services are available providers in the PMTCT sites need assistance to overcome many barriers they face to implement universal HIV education, voluntary counselling and testing of women of reproductive age (Rahimian et al., 1998; Nichols et al., 2002).

Screening of pregnant women and identification of HIV positive mothers may result in violence, rejection and stigmatisation, and has to be put in the balance of programmes aiming at reducing the number of infected children (Johnson et al., 2004; Steel-Duncan et al., 2004; Semrau et al., 2005). HIV-related stigma is particularly severe as AIDS is a life-threatening illness and also firmly linked in people's minds to sexual behaviour. HIV-related stigma can be traced back to the early discourse on HIV, which served to reinforce notions about deviant behaviour by focusing firmly on groups, such as sex workers, drug users and gay men. Perceived high personal susceptibility to HIV/AIDS, barriers related to confidentiality and partner
involvement, self-efficacy regarding alternative feeding methods and religion were all shown to be associated with willingness to accept VCT (Coutsoudis et al., 2001; de Paoli et al., 2004).

HIV positive women are often reluctant to disclose their serostatus to partners, family, or friends due to stigma. Studies have shown that barriers to disclosure identified by the women included fear of accusations of infidelity, abandonment, discrimination and violence. Between 3.5% and 14.6% of antenatal women reported experiencing a violent reaction from a partner following disclosure (De Cock et al., 2002; Maman et al., 2003; Medley et al., 2004).

Adherence to antiretroviral prophylaxis in HIV positive women is challenged by many factors surrounding the women and their families (Bajunirwe and Muzoora, 2005). The challenges include; high drop outs of HIV positive women legible for NVP, shortage of human resources in PMTCT sites and centralisation of the PMTCT services (Manzi et al., 2005; Simba et al., 2008). There are traditional birth attendants (TBAs) who act as delivery points for pregnant women. This poses a challenge when HIV positive women on a PMTCT programme opt to deliver at the TBAs. In such situations, non-adherence is associated with home births (Albrecht et al., 2006). At times understanding the importance of adhering to antiretroviral prophylaxis for some women might as well pose a challenge due to low levels of education among other factors.

Promotion and support of optimal infant feeding practices should be part of all programmes for the PMTCT. It is unfortunate that women in poor settings have fewer choices to choose from when it comes to feeding as majority of them do not even have enough for themselves. Antenatal counselling for safer infant-feeding practices and postnatal support for the feeding option a woman selects may help ensure adequate nutrition and the proper growth and development of her child (WHO, 2004). All these need man power, financial and logistical resources which are inadequate in most of the areas where such programmes are being implemented. In rural setting, additional measures should be applied to enable women accustom to infant feeding options (Leshabari et al., 2007; Fadnes et al., 2009).

**Policies regulating PMTCT programmes**

PMTCT was first introduced in 2001 into the ANC as an international initiative and was adopted by different countries in Africa (WHO, 2006; Druce and Nolan, 2007). The primary aim of the PMTCT programme as put in the guidelines was to decrease the number of HIV infected babies born to HIV positive women. Primary prevention of HIV infection particularly among women of childbearing age has always been the backbone of the programme. PMTCT international re-enforcing body was then renamed the Inter-Agency Task Team (IATT) on the prevention of HIV transmission to pregnant women and their children. WHO and UNICEF were among the donor agencies included in IATT.

Universal HIV testing starting with ‘opt-in’ strategy was introduced in PMTCT programmes in 2001 following international initiatives, with efforts to reduce MTCT. ‘Opt-in’ strategy is an approach whereby all clients are encouraged to undergo voluntary counselling and testing (VCT) at their own will (Perez et al., 2006). Later, ‘opt-out’ screening was adopted by many
countries in sub-Saharan Africa (CDC, 2004). The aim was to enable all pregnant women to be screened for HIV infection. This means that screening should occur after a woman is notified that HIV screening is recommended for all pregnant women and that she will receive an HIV test as part of the routine panel of prenatal tests unless she declines (Bajunirwe and Muzooro, 2005).

PMTCT programmes adopted different policies to ensure successful intervention of the programmes. In 2002, the PMTCT-plus initiative was established which aimed to move beyond interventions to prevent infant HIV infection. It does this by supporting the provision of specialised care such as life-long ART to HIV positive women, their partners and their children who are identified in PMTCT programmes (WHO, 2004; Iliff et al., 2005).
Background

Malawi

Malawi, Administrative districts

Malawi has a population of 13 million and is one of the poorest countries in Africa with the gross domestic product (GDP) of USD 257, and over 60% of people live on less than a dollar (IMF, 2008). It is a land locked country and densely populated with a strip of land measuring 118,480 sq km of which 94,080 sq km is land and the rest is water. It is bordered by Zambia to the northwest, Tanzania to the northeast and Mozambique, which surrounds it on
the east, south and west. The country is separated from Tanzania and Mozambique by Lake Malawi (figure 1). The name Malawi comes from the Maravi, one of the original Bantu tribes to inhabit the area.

Administratively, Malawi is divided into 3 regions with 28 districts. The north has 6 districts; central and southern regions have 9 and 13 districts respectively. Malawi was a British protectorate from 1891 until 1964, when it attained its independence under a one party system of Government under the leadership of the late Dr. Hastings Kamuzu Banda (CIA, 2008). Banda through the Malawi Congress Party (MCP) ruled the country for 31 years until a multiparty system of Government led by Dr. Bakili Muluzi came about in 1994. After Bakili’s two 5 year terms of office according to the Republican Constitution, Dr. Bingu wa Mutharika took over up to the present time. Malawi’s foreign policy is pro-western and includes positive diplomatic relations with most countries and participation in several international events.

Life expectancy in Malawi has declined to 39 years from the projected level of 54 years that might have been expected without the HIV/AIDS epidemic. Malawi’s maternal mortality rate is the third highest in the world. As of 2004, the maternal mortality rate was 984 per 100,000 live births, compared to about 11 deaths for every 100,000 births in the US (MDHS, 2004). The high prevalence of HIV/AIDS is a drain on the labour force and government expenditure making a significant impact on gross domestic product. The Malawi government depends heavily on outside aid to meet development needs.

Malawi’s economy is based on agriculture with over 80% of the population living in rural areas. The Malawi government therefore faces challenges in growing the economy, improving education, health care and the environmental protection and becoming financially independent. More than one-third of gross domestic product (GDP) and 90% of export revenues come from agriculture (IMF, 2008). Tobacco, tea, coffee are the main cash crops with various products such as maize, ground nuts and beans among others as food crops.

Malawi’s population is made up of the Chewa, Nyanja, Tumbuka, Yao, Lomwe, Sena, Tonga and Ngoni native ethnic groups, as well as populations of Asians and Europeans. Major languages include Chichewa, an official language spoken by over 57% of the population, plus Chinyanja, Chiyao, Chilomwe and Chitumbuka. English is the second official language and is promoted in all schools beginning from the nursery to tertiary levels. According to 2007 estimates, approximately 80% of the population is Christian, with the Roman Catholic Church and the Presbyterian Church of Central Africa making up the largest Christian groups. There are also smaller numbers of Anglicans, Baptists, Evangelicals and Seventh Day Adventists (CIA, 2008). Around 13% of the population is Muslim, with most of the Muslim population being Sunni, of either the Qadriya or Sukkutu groups.

The average fertility rate is 6.2% and the population growth rate is 2.3%. The total literacy rate is 62.7% which is higher among men (76.1%) compared with women (49.8%). There are more girls who drop out from school than boys and primary school education has been free since 1994 (MDHS, 2004).
Malawi’s HIV/AIDS situation

Malawi has one of the highest HIV/AIDS prevalence rates in the world, with 14% of people aged between 15–49 years infected. Prevalence is considerably higher in urban areas and ranges from 19–28% (MDHS, 2004). With an estimated population of 13 million, this translates to over 1 million people infected. Of those 1 million, it is estimated that over 300,000 are in need of HIV treatment (MDHS, 2004).

In 2003, the government came up with the antiretroviral treatment (ART) plan to treat all 300,000 people who needed it and submitted the USD 1.62 billion plan to the Global Fund for HIV, tuberculosis (TB) and malaria. However, after discussions around whether Malawi would be able to implement such a plan, the final accepted plan was reduced to 25,000 people, totaling USD 196 million over 5 years. In 2003 when PMTCT was newly launched, 26,791 pregnant women in Malawi were HIV tested (MOHP, 2005). By mid 2005, 32 sites in Malawi were providing PMTCT. In 2004, out of the estimated 540,000 deliveries, 43,345 (7.9%) were tested for HIV, 6,069 (14%) women tested positive but only 2,719 (44.8%) of them received ARV prophylaxis (NAC, 2005). In 2007, a total of 23,158 pregnant mothers were put on antiretroviral prophylaxis (NVP) which is still a minority of the estimated 100,000 pregnancies at risk (UNAIDS/WHO, 2008).

Programme and setting

Malamulo mission hospital is owned by the Seventh Day Adventist (SDA) Church and is located in the southern region of Malawi, 65 km southeast of Blantyre City in Thyolo District (figure 2). It was established in 1902 and remains the headquarters of the Adventist Church in Malawi. The hospital has 15 mobile sites with 2 health centres and collaborates with other non-governmental organisations (NGOs) in the district as well as with Thyolo District Hospital. Malamulo, as a 300 bed referral hospital, covers an estimated population of over 70,000 and serves as a teaching hospital for allied health workers namely nurses, medical auxiliaries and laboratory technicians.

The Government and the NGOs deliver health care services in Malawi. There are four main agencies providing health services and these are Ministry of Health and Population (MOHP) – 60%, Christian Hospitals Association of Malawi (CHAM) – 37%, Local government – 1% and Private Organisations – 2%. Among the NGOs, there are health facilities run by faith based institutions but subsidised by the Malawi Government’s Ministry of Health through CHAM. Like any other faith based health facility in Malawi, Malamulo is a member of CHAM. CHAM coordinates all the health services that are run by faith based institutions.

Tea and coffee estates surround Malamulo hospital and most people in the area are peasant farmers who grow maize, beans and bananas among other crops mainly for home consumption. The people’s socio-economic status in this area is low as some of them work as migrant workers in the tea and coffee estates. Malnutrition and communicable diseases such as malaria, worm infestation, TB, diarrheal diseases and sexually transmitted infections (STIs) including HIV/AIDS are common. The HIV prevalence rate in this population is estimated to
be 16%, slightly higher than the national one of 14% (MDHS, 2004). Many families have experienced a loss of a member due to AIDS; therefore, the number of orphans is also high.

To complement Malawi Government’s efforts through its Ministry of Health and Population in fighting against poverty, disease and ignorance, Malamulo runs a comprehensive HIV and AIDS project. The project began in 1988 as Child Spacing Project with funding from local and international donors. Over the years, a number of activities were added to the project which thus offers community based comprehensive services. The project components are voluntary counselling and testing (VCT) and synonymously called HIV testing and counselling (HTC), management of sexually transmitted infections (STIs), home based care (HBC), youth friendly health services (YFHS), family planning (FP), prevention of mother to child transmission (PMTCT) of HIV, provision of ARVs, nutrition, static and outreach mother
and child health (MCH) services. Over the study period, the project was largely funded by USAID through local and international NGOs called Umoyo Network and later Private Agencies Collaborating Together (PACT Malawi) respectively among other donors.

Malamulo hospital’s services have been extended to its two health centres though at different levels. One of its health centres offers ANC, HIV testing, PMTCT and delivery services excluding the provision of long term ART. The other health centre offers HIV testing and general patients care since it does not meet the criteria to offer full maternal care as per recommendations by the Ministry of Health and Population. However, there is one Government health centre that offers full PMTCT services in collaboration with Medicins Sans Frontieres (MSF). In addition, other health centres in the area offer HIV testing and when the need arises HIV positive pregnant women are referred to either Government or Malamulo health facilities for full fledged PMTCT services. Malamulo’s 15 mobile sites are managed by the mobile team and work closely with health surveillance assistants (HSAs) who are based in the community but report to the District Health Office (DHO) through Malamulo hospital. HSAs have basic secondary school education, are trained in disease prevention and some of them are trained as HIV testing and counselling (HTC) counselors.

The SDA church organisations have a chain of command and Malamulo SDA hospital follows this command. At lower level, Malamulo hospital management looks at the routine services of the hospital. This includes decision making for the running of the hospital affairs, recruitment and firing of junior staff, budgetary issues and resource allocation and utilisation among others. The chief executive officer (CEO) is the chairman of the hospital management and looks at the administration of the entire hospital whereas the chief of medical staff looks at the health services and health workers. The hospital board comes at a second high level of management and monitors the functions of the hospital management and ensures that the hospital maintains high standards of care. It has the ability to recruit and fire senior staff and the Malawi SDA church president is the chairman of the board. At the third high level, there is an international body called Adventist Health International (AHI). This is the organisation that looks after all the SDA health facilities world wide. It monitors the hospital board as well as the hospital management and is based in USA. It has the capacity to fire and recruit international staff (expatriates) and reports to the general conference of the SDA church based in Washington DC, USA.

Like most of the faith based health facilities in Malawi, Malamulo hospital has got potentials and strengths. For instance, the level of bureaucracy is short so once problems are identified it does not take so long to solve them, and it is meant to address the needs of the disadvantaged communities, so is placed in a rural area. Malamulo strives to offer quality health care to all regardless of their backgrounds, has committed management, well qualified staff and offers a wide range of services to attract the beneficiaries. In addition, Malamulo has potential to mobilise and utilise its resources and achieve the intended purposes of the hospital. Therefore, the support that comes from the management is in the form of funds, materials such as equipment, medications, decisions and possibilities to train members of staff in various fields. In addition, the management involves staff members in most of the things it does.
Malamulo PMTCT and policies

PMTCT within Malamulo SDA hospital was introduced in July 2004 using an ‘opt-in’ approach. Malamulo PMTCT programme is a PMTCT plus programme because it supports the provision of specialised care to HIV infected women namely ART, STIs management, HBC, infant feeding practices and nutrition. It further adopts national and international standards according to World Health Organisation (WHO, 2004). HIV testing and counselling (HTC) are done in two static and five outreach sites whereas PMTCT services are offered at the hospital and one of the Malamulo health centres. Below is a diagrammatic representation (figure 3) of the PMTCT programme at Malamulo SDA Hospital as reflected in the guidelines:

All pregnant women are offered health education on various areas. These areas include prevention of unintended pregnancies, available contraceptives, possibilities of preventing HIV infection to the babies if they are HIV positive, available support services if HIV positive, personal
hygiene, nutrition and child care. ANC attendees are given all this information including STIs and the PMTCT programme in the waiting area.

All pregnant women are offered ANC which includes weighing, examinations from head to foot, estimation of gestational age, height, and routine laboratory investigations such as malaria, haemoglobin, syphilis, stool and urine analyses among others. Detailed information on PMTCT is given and women are encouraged to deliver at the hospital. PMTCT information comprises HIV testing, counselling on infant feeding options, psychosocial support for HIV positive women, provision of ARV prophylaxis (NVP) to the women and their babies, follow up and long term-ART. HIV test results are released 15 minutes after running the test. Parallel HIV testing is done using Determine, Unigold and Bioline as a tie breaker (MSF 2005; MOHP 2006). HIV positive women are registered in the PMTCT programme and are given a single dose of NVP 200 mg at week 32 to be taken when labour starts. All women receive routine ANC according to the government guidelines including tetanus vaccination and malaria prophylaxis with sulfadoxine pyramethamine (SP) once during the second and third trimesters.

During labour HIV positive women are further assessed to ensure that they take their NVP tablets when labour starts. If a woman had taken her NVP tablet which she got at the ANC then she informs the midwife in the labour ward so that she does not get another NVP tablet. Women who did not take their NVP tablets are encouraged to do so in the labour ward when the labour begins. If the woman’s HIV status is undisclosed then efforts are employed to counsel her to undergo HIV testing so as to benefit from this PMTCT programme. The nurses in the labour ward and those in the ANC work hand in hand to ensure that no mother is lost in the process.

After delivery, exposed infants are given single dose of NVP 2 mg/kg within 72 hours of birth1. Routine under five services are offered to the infants such as immunisations, screening for any infections and growth monitoring among others. These infants are recommended to be exclusively breast fed at least for the first six months. Further, all mothers and their infants are followed up to benefit from the long term-ART. Infants are given cotrimoxazole 40 mg/kg as prophylaxis for opportunistic infections and followed up until 18 months when their HIV status is determined.

Malamulo hospital offered ANC long before HIV testing and counselling services were started. However, Malamulo PMTCT programme development had been in the plan ever since it was initiated in 2004. The plan was to scale up the services so as to reach more women in the catchment area through the introduction of different policies over time. When VCT services were introduced, the services were offered through one central point, the outpatient department (OPD), within the VCT unit using an opt-in approach. In many cases, mothers were lost to follow-up between the ANC unit and the VCT unit. This was observed over time and as a local initiative, in March 2005, HIV testing and counselling services were integrated within ANC. In June 2005, management of sexually transmitted infections (STIs) was also integrated into the ANC.

1 Single dose of NVP was used at the time of undertaking this study. Now triple therapy is used in PMTCT comprising AZT, Douvir and NVP (MOHP, 2008).
The ‘opt-out’ strategy was introduced in January 2006 in Malamulo SDA Hospital PMTCT programme. This was a Malawi Government initiative and was adopted by public and faith-based health facilities such as Malamulo. The purpose was to minimise the number of HIV-infected women who might transmit HIV infection to their babies. When the ‘opt-in’ policy was used in PMTCT services, counsellors did one-to-one pre- and post-test counselling, since the client uptake was low. With the introduction of the ‘opt-out’ strategy, the counsellors’ work load increased. Therefore, the counsellors now conduct the pre-test phase using group counselling, to cope with the growing demand for HIV testing. However, post-test counselling continues to be provided on a one-to-one basis.

In October 2006, free maternity services were introduced at Malamulo hospital to cater for its surrounding 15 villages. The move was part of a strategy aimed to reduce maternal and infant mortality rates in Malawi. Malamulo hospital signed a service agreement with the district health office (DHO). The Ministry of Health and Population, through the DHO in the district is responsible for supporting the strategy. In this service agreement, free maternal services are offered to women from the assigned villages. Villages outside the designated ones are expected to access health care to their nearest health centres and if the health centres can not manage the cases, then they refer them to Malamulo hospital. Malamulo hospital in return gets the funds for offering the free services from the Ministry of Health through the DHOs on monthly basis. The approach has been extended to other faith-based health facilities in the country.

Image 2: PMTCT mother support group members
Study justification

Further research into affordable, feasible and locally acceptable interventions for the reduction of mother to child HIV transmission is a priority. PMTCT is an international initiative which has been adopted nationally and needs to be locally adapted. No programme will be effective if it is not being used. Effectiveness of the programme in this context means attaining the intended set goals of accessing and utilising the services to reduce MTCT of HIV. It was therefore essential to conceptualise critical activities for effectiveness of a PMTCT programme (figure 4). For the PMTCT programme to be effective, the following issues need to be considered: Availability and accessibility of ANC and HIV testing services to all pregnant women which include availability of resources; staffing, medications and HIV test kits among others. Mechanisms for sustainability of the programme are also important. For instance, the long term sources of funding need to be considered. Diversification of the funding base needs exploration to ensure continuity of the programmes. The management team should be empowered with the necessary knowledge and skills to run such dynamic programmes. This means that right from the beginning of the programmes all the members of staff should be actively involved and where training gaps exist, coverage through training needs to be done. In addition, when services are in place the communities should be well informed about this.

![Figure 4: Critical activities for effectiveness of a PMTCT programme (Adapted from Chopra, 2008)]
The programme at Malamulo SDA hospital had the intention to provide high quality services and the hospital management saw this as a priority. To see how the community responded it was decided to follow the utilisation pattern when introducing and establishing the programme in Malamulo and to study the reasons behind the women’s actions in accessing PMTCT services. It is well known that women in Malawi and in the catchment area of Malamulo commonly give birth at home. It was therefore necessary to take this specific challenge to the programme into consideration from the beginning. This study was set up to ensure a programme which would respond to the reality of the women and families in the area.
Study objectives

Overall aim
The overall aim of this thesis is to describe the utilisation of a PMTCT programme among women in rural Malawi and discuss the challenges to improve its effectiveness.

Specific objectives
• To study how the demand for antenatal care, HIV testing and hospital delivery is influenced by policy changes (Paper I).
• To follow women in a PMTCT programme up to delivery and to assess the adherence to the prophylaxis (Paper II).
• To explore women’s experiences of a PMTCT programme (Paper III).
• To explore perceptions on pregnancy and delivery care among service providers and community members (Paper IV).
Materials and methods

Overall study design

The study employed an operational research approach requiring a mixture of quantitative and qualitative methodologies in both data collection and analysis to be able to present results that can be utilised for improvement of programme operations. Quantitative methods were applied for the initial two studies aiming at determining the actual uptake of services. To be able to also capture the HIV positive women’s experiences of the services offered to them, the community perceptions about delivery care in general and the views of health care providers qualitative methods were used in the last two studies. The study is part of the Comprehensive HIV/AIDS Prevention Project at Malamulo SDA hospital; thereby increasing service acceptability and accessibility by HIV positive pregnant women within the communities and reducing HIV transmission to babies. Operational research in reproductive health is the application of systematic research techniques to improve reproductive health programmes. It involves improvement of decision making around the problems that concern the operations of the organisations and programme quality and communication with stakeholders (WHO, 2001). In this study the communication and implementation of changes as a result of the study were facilitated by the researcher also being the manager of the Community Medicine Department at Malamulo hospital responsible for the PMTCT programme.

Study timeline

The study project was conducted over a period of three years and the overall structure as well as the specific study periods are reflected in figure 5.
Paper I gives an overview of the outcomes as different innovative inputs were being adopted by the programme. Paper II shows the link between the HIV positive women’s place of giving birth and the adherence to the PMTCT programme whereas papers III and IV reflect on women’s experiences while accessing the services and community perceptions towards maternal care respectively. Table 1 gives a summary of the objectives, design, sampling, data sources and analytical approaches for the different sub-studies.

Table 1: Summary of methods for the four papers

<table>
<thead>
<tr>
<th>Papers</th>
<th>Study objectives</th>
<th>Study design</th>
<th>Study sample</th>
<th>Data sources</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To study how the demand for antenatal care, HIV testing and hospital delivery is influenced by policy changes</td>
<td>Retrospective analysis of monthly reports</td>
<td>4,528 pregnant women</td>
<td>Hospital registers</td>
<td>Descriptive/analytical</td>
</tr>
<tr>
<td>II</td>
<td>To follow women in a PMTCT programme up to delivery and to assess the adherence to the prophylaxis</td>
<td>Prospective and observational</td>
<td>719 pregnant women with a follow up of 75 HIV positive women</td>
<td>Hospital registers and structured interviews</td>
<td>Descriptive/analytical</td>
</tr>
<tr>
<td>III</td>
<td>To explore women’s experiences of a PMTCT programme</td>
<td>Qualitative</td>
<td>24 HIV positive women in the PMTCT programme</td>
<td>In-depth interviews</td>
<td>Content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>To explore perceptions on pregnancy and delivery care among service providers and community members</td>
<td>Qualitative</td>
<td>10 Focus group discussions consisting of 75 male and female participants</td>
<td>Focus group discussions</td>
<td>Content analysis</td>
</tr>
</tbody>
</table>

**Uptake of and adherence to the PMTCT programme (Papers I, II)**

**Data sources**

Hospital based registers namely; ANC, PMTCT and delivery registers were used as data sources. These registers were handwritten and no computerised system was operating at the hospital. In addition, structured questionnaire was used for paper II.

**Sampling and data collection**

The sample sizes for these studies were determined based on the women’s registration in the Malamulo Hospital ANC, PMTCT and delivery registers. All pregnant women who accessed antenatal care at Malamulo Hospital including PMTCT services from January 2005 to December 2007 were included in the study described in paper I. Policies that were introduced into the programme were also documented. A total of 4,528 pregnant women accessed the maternal care during the study period. Total numbers of women who accessed different
components of maternal care such as ANC, PMTCT and delivery before and after the introduction of different policies were noted. In addition, uptake of NVP by women and their babies delivering in the hospital was as well documented.

Paper II included all pregnant women who registered for ANC at Malamulo Hospital from January to June 2005. Women who tested HIV positive within the first 6 months of 2005 and registered in the PMTCT programme were followed up from ANC to delivery. It was assumed that women’s adherence to the antiretroviral prophylaxis (NVP) would depend on where they would deliver. Structured interviews were administered to the ANC attendees when they came for the services, to complement register data, which included education, marital status, religion, tribe and occupation. A total of 719 women were registered in the ANC during the study period and 75 of them tested HIV positive. These 75 HIV positive women were registered in the PMTCT programme and were followed up from ANC to delivery. Women who did not return for delivery in the hospital were traced and interviewed in their homes by the researcher. Data on place of delivery, NVP uptake, support, reasons for non-hospital delivery and outcome of delivery were collected from the traced mothers.

**Analysis**

Both papers I and II utilised quantitative methods. Using descriptive/analytical approach data were analysed based on the three years of the study. The uptake of the maternal care which comprised ANC, HIV testing, hospital delivery and uptake of NVP by mothers and their babies was compared between different policies that were introduced during the study period. The proportions of women who accessed ANC, PMTCT and delivery services including NVP were calculated.

For paper II the proportion of HIV positive women who gave birth at the hospital and at home were calculated as well as the adherence to NVP among the women and their babies. Means and proportions were used when comparing characteristics among the study participants: 1) HIV positive women who picked up NVP at 32 weeks and those who did not and 2) HIV positive women who delivered in the hospital and those who did not. In addition, reasons for hospital delivery as well as home delivery were compared between the two groups.

**HIV positive women’s and community perceptions of HIV testing, the PMTCT programme and delivery (Papers III, IV)**

**Data sources**

Tape recorded in-depth interviews and focus group discussions were the main tools for data collection. In-depth interviews were regarded most appropriate for paper III to explore and understand HIV positive women’s experiences as they accessed the maternal care in which PMTCT was provided. These interviews were semi-structured and guided by thematic areas focusing on the informants experiences of the antenatal care, HIV testing, hospital as well as home deliveries. For paper IV aiming to understand how the services were being perceived by
the communities and the service providers at both hospital and community levels, focus group discussions (FGDs) were regarded most suitable.

**Sampling and data collection**

In paper III, informants were purposively selected based on their registration in the Malamulo Hospital PMTCT programme. The theoretical assumption was that their experiences would vary depending on how they adhered to the programme, from HIV testing through giving birth. It was possible through antenatal, PMTCT and birth registers to retrospectively identify three groups: (1) women who delivered at the hospital and took NVP during birth and whose babies received NVP within 72 hours of birth; (2) women who delivered at home but had, during the course of ANC attendance, received NVP to be taken during birth; and (3) women who delivered at home and had not been seen at ANC after 32 weeks and therefore did not possess NVP at the time of birth. For logistical reasons, only women who lived up to 15 km from the hospital were chosen. Initially, eight women who had tested HIV positive and received NVP during their ANC visits but had not returned for delivery at the hospital were interviewed (Group 2). A preliminary analysis was conducted by a team of three researchers to guide the decisions for further data collection. After having interviewed eight women in each of the groups, it was felt that no new information was emerging and no more women were interviewed.

The in-depth interviews were conducted from June – September 2006. Village headmen and heads of households were informed that the general aim of the study was to get a deeper understanding of experiences of women who delivered at home or in the hospital. The women were then approached and asked about their willingness to participate and to agree on a suitable time and place for conducting the interview. This process was facilitated by two assistants, but the actual interviews were done by the researcher. During the interviews, the informants were asked to share their experiences, feelings and reactions in connection with deciding to take the HIV test and receiving the test result. They were also encouraged to describe their contacts with the ANC/PMTCT clinic and to reflect on the process that led to a hospital or a home delivery. All interviews were tape recorded, they lasted between 45–90 minutes and were conducted in the local language (Chichewa). After verbatim transcription, they were translated into English.

In paper IV, informants for the focus group discussions were purposively selected based on the theoretical assumption that there were variation and range of perceptions by community members and service providers towards the available maternal services. The following were approached; community members (men and women), village headmen, religious leaders, hospital based health workers and traditional birth attendants from the catchment area of Malamulo. The mobile team of nurses and the community meetings that were regularly conducted in the area facilitated the participants’ recruitment. Only participants who lived within a distance of 5–15 kilometers were approached.

The FGDs were performed from October 2006 to February 2007. To get the permission for conducting the discussions, village headmen, heads of households and the participants themselves had to consent. At the time of appointments the researcher explained the study...
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purpose and the possible benefits to the participants. All discussions were conducted in Chichewa by the researcher together with two field assistants who acted as note taker and observer respectively. To ensure privacy all discussions took place in a classroom after permission from the local school headmaster. The discussions took place in the afternoon, to accommodate the working schedules of the participants. During the discussions a thematic guide was used focusing on attitudes and norms related to pregnancy and delivery and then, more specifically, views on HIV testing as part of ANC and to the choice of place of delivery. To enhance interaction and discussion among the participants the moderator introduced two pictures drawn by a local artist. The drawings depicted two scenarios, one of a hospital delivery setting and one of a home delivery environment. The discussions lasted from 90 to 120 minutes and were tape recorded. After the tenth group it was felt that a level of saturation had been reached and based on continuous reflections and preliminary analysis, data collection was completed. To prepare for analysis all FGDs were transcribed verbatim and later translated into English to facilitate a joint analysis in the research group.

Analysis

Data from the in-depth interviews and the FGDs were analysed separately using content analysis as described by Graneheim and Lundman (2004). First selected meaning units were summarised into codes and categories from which themes were developed. The texts were coded, a process that was facilitated by using the Open Code software developed at Umeå University, Sweden (Open Code, 2007). An example of the coding procedure used for paper III is given in figure 6. Similarities and differences of the codes between the different groups were compared for developing categories that described the manifest meaning of the discussions. In the end, themes were developed to capture the interpretation of the latent meaning of what characterises the participants’ experiences and perceptions on different components of the PMTCT programme.

<table>
<thead>
<tr>
<th>Original text</th>
<th>Codes</th>
<th>Category</th>
</tr>
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</table>
| “I delivered at home …..my husband did not show any commitment that he would support me. In other ways, his behaviour …….. I remembered to swallow my pill secretly. I …decided to deliver at home so that I do not disturb my old parents. My husband used to drink and had quarrels with me so if I had gone to the hospital I knew my parents would be experiencing problems in trying to look for money to pay for my hospital bills”. | • Decided for home delivery  
• Uncommitted husband  
• Pill swallowed secretly  
• Concern about old parents not to be disturbed  
• Husband drinks and quarrels  
• No money for hospital bills | Spouse dependency |

Figure 6: From original text to category – an example of the coding procedure
Ethical considerations

Permission to conduct the study was obtained from National Health Sciences Research Committee in the Ministry of Health and Population, Malawi. Further, consent was obtained from Malamulo Hospital Administrative Council and local authorities namely chiefs and respondents. All the respondents were assured that information given would be treated with strict confidence. However, all the informants were equally informed that they could withdraw at any time if they wished to do so without implications.

To avoid being stigmatised, the HIV positive women in the villages were identified to participate in the in-depth interviews by Health Surveillance Assistants (HSAs). The HSAs work on a community level and regularly move from one household to the other while promoting women’s access to maternal care, use of bed nets by these women and their under five children among other things. The presence of these health surveillance assistants in the villages helped to remove women’s fears and feelings of being known as HIV positive when they participated in the in-depth interviews.
Main findings

PMTCT uptake and adherence to NVP (Papers I, II)

Over the three year period of the study (January 2005 to December 2007), three interventions were introduced in the antenatal care (ANC) at the hospital at different times. These were HIV testing integrated in the ANC clinic in March 2005, opt-out testing in January 2006 and free maternal services in October 2006. A steady increase of the service uptake as interventions were being introduced has been observed over time. Women's access to ANC, general hospital deliveries, deliveries by HIV positive women in the PMTCT programme, HIV testing, access to nevirapine by both mothers and their babies were all shown to have increased when the interventions were integrated (figure 7).

A total of 4,528 pregnant women accessed ANC at Malamulo hospital during the study period and of these, 4,068 (89.8%) accepted HIV testing and 635 (15.6%) of them tested positive. All these HIV positive women were registered in the PMTCT programme. Before HIV testing was integrated within ANC in March 2005, 196 pregnant mothers accessed ANC, 103 (52.6%) of them underwent HIV testing and 17 (16.5%) tested positive. After March 2005, when HIV testing was integrated within ANC, ANC attendance and the proportion of women accessing HIV testing generally increased. In this period, 1,063 pregnant mothers accessed ANC, 837 (78.7%) agreed to undergo HIV testing and 148 (17.7%) tested positive.

In January 2006, routine (opt-out) HIV testing was introduced within ANC and this increased both ANC attendance and the proportion of women accepting HIV testing. A total of 992 women accessed ANC between January 2006 and September 2006, 879 (88.6%) of them took an HIV test and 137 (15.6%) tested positive. Finally free maternal services were introduced in October 2006. This too considerably increased the women's accessibility and utilisation of the services in all the different areas of the maternal care. From October 2006 to December 2007, 2,277 pregnant mothers accessed ANC, 2,249 (98.8%) took the HIV test and 333 (14.8%) tested positive.

During the three year period, 2005-2007 a total of 2,645 pregnant women delivered in the hospital and of these deliveries, 1,134 and 1,511 occurred before and after the introduction of free maternal services respectively. The overall ratio of hospital deliveries to ANC attendees was 0.5:1 before free delivery and this increased to 0.66:1 after free delivery was introduced. To a larger extent, these hospital deliveries were normal. Deliveries by Caesarean section (C/S) were relatively few, 7 (0.3%) before free maternal care and 15 (0.6%) when the services were free. In these three years of the study, 369 HIV positive women were registered in the PMTCT programme and delivered in the hospital. The ratio of HIV positive deliveries to ANC HIV positive was 0.50:1 increasing to 0.58:1 with free delivery. Of the hospital deliveries by HIV positive women, 139 (92.7%) and 194 (88.6%) of them received their NVP tablets before and after free maternal care respectively. In the pre-intervention period, uptake of NVP syrup by babies born in the hospital was 146 (92.4%) and 216 (98.2%) of them had access to NVP syrup in the post intervention period. The life long antiretroviral treatment (ART) beyond delivery was accessed by 21/635 (3.3%) HIV positive women during the study period.
From January–June 2005, 75 HIV positive women were registered in the PMTCT programme. These women were followed up from ANC to delivery. Thirty-five (47%) women delivered at home. A total of 27 (77.2%) women were traced and 16 (59.3%) of them had received NVP after week 32 from the PMTCT clinic and all of them had taken their tablets at the onset of labour. Of these 27 traced women, 26 (96.3%) delivered at the home of a TBA and one (3.7%) woman on the way to the hospital. However, after home delivery, none of the women’s babies was taken back to the health facility for NVP syrup (figure 8). These 27 traced women had in total 27 babies. Three (11.1%) of these babies died soon after delivery and four
(14.8%) of them were reported by their mothers to be underweight. At least 21 (77.7%) women shared their test results with their husbands and 15 (55.5%) expressed to have been supported by their husbands.

When asked why they delivered at home, these women mentioned economic difficulties, lack of family support particularly from the husband, distance, sicknesses and quick labour as main causes of home delivery. There were no significant differences between women who delivered at home and those who delivered at the hospital in socio-demographic characteristics captured by the study.

Figure 8: Adherence to NVP among HIV positive women delivering at home, Malamulo PM-TCT programme, January– June 2005

HIV positive women’s experiences and community perceptions of the PMTCT programme (Papers III, IV)

How was the HIV test experienced and perceived?

The analysis of the interviews with the HIV positive women about their experiences of HIV testing, receiving the results and the disclosure of results revealed three themes which correspond well with the perceptions in the community as seen in figure 9.
The HIV positive women who had participated in the PMTCT activities during the time of the opt-in strategy mentioned that ANC and HIV testing were acceptable and they were happy with the way the nurses treated them. They stated that they were well taken care of and received adequate information. They told that the ANC information was about HIV testing, general personal hygiene, infant feeding in the context of HIV infection, antiretroviral prophylaxis and life long ART. Asked why they took the HIV test, women stated that they suspected themselves of having contracted HIV infection, therefore decided to undergo the HIV testing to know their HIV status and to protect their babies from HIV infection. To avoid living in doubts, these women decided to take the HIV test. Asked how the HIV test positive results were received, women elaborated on how they had mixed reactions ranging from hopelessness, shock, grief, crying, blaming themselves and later had hope and felt empowered to do something to avoid further infection and infecting their babies. They expressed how it was like being removed from darkness into the light or being made to see after being blind for a long time.

“At first I was worried and discouraged, but later I was very thankful and happy. Now after taking the HIV test and received the results I was relieved, because I knew about my husband and myself too” (HIV positive female, in-depth interview)

After knowing their HIV positive status, many women felt that there was no need for them to continue having babies, others felt encouraged to access long term ART, some decided to join support groups for mothers while others were simply happy that they knew their status.

“I was happy because I knew what my problem was and given information on how I should live. To me this was good because ‘sindirinso m’masamba’ I am no longer in darkness” (HIV positive female, in-depth interview).
Women also expressed fear of disclosure and found themselves in a dilemma, not being able to decide whether to share their HIV positive results with others or not. Several women took days, weeks or months before revealing their results and some never disclosed the results to anyone. A group of women described the risk involved in revealing the result particularly to their husbands risking to being ostracised, being beaten up, discriminated, blamed for being promiscuous and even divorced. However, some also expressed that they got supported by their husbands after disclosing their status.

Within the communities HIV testing was perceived as something that should be encouraged and men expressed the importance of having their wives access ANC and HIV testing so as to protect the babies. To a large extent, participants in the FGDs stated that men decided for their wives to access ANC and got prepared for the babies. Although participants viewed ANC and HIV testing as source of family protection, both male participants from religious and community leaders’ groups viewed HIV testing as a potential source of conflict if women underwent HIV testing without informing their husbands. Male participants mentioned that they needed to know before their wives took the HIV test, and others argued that the best is if the couple tested together.

“HIV testing which reveals positive results really affects the family at large. However, the thing is that when the husband agrees to go for HIV testing, then it simplifies the situation in that they now agree on what to do as a family. The problem comes when the two are disagreeing or pointing fingers that you are the one who brought the disease in this house” (Male, religious leaders’ FGD).

Where to give birth?

The analysis of the interviews and the FGDs resulted in themes which reflect the complexity of the decision about where to give birth (figure 10). The experiences expressed by HIV positive women and women in the FGDs were similar and the HIV status did not seem to be decisive for choosing place of delivery.
The community as a whole encouraged hospital delivery because it was seen to be safe and clean compared to home delivery. They further felt that the service providers at the hospital were trained and had skills, knowledge, equipment and ability to protect women from transmitting HIV infection to their babies. Also if women at the hospital were in dire need of operation to deliver or in case of any problem, they could easily be assisted. Women expressed the importance of hospital delivery but stated that they faced challenges that prevented them from actually accessing hospital delivery services. Women experienced stigma if tested HIV positive and feared hospital bills, distance and some had quick labour, husbands were not around and some lacked support so the option was to have home delivery. Women who delivered at the hospital expressed that they received support from their husbands, families, friends and found ANC supportive.

Although the hospital was regarded as ideal for delivery, women expressed fears of being neglected in the labour ward.

“I delivered all my children at the hospital but I had experienced some problems. During my first pregnancy, I did not know that I had twins but I just went to the hospital ignorantly. It was at the hospital when I was told that I was having twins and was told to wait for labour pains to begin. I waited for so long and then went into the labour ward where nurses were chatting, talking to each other without paying attention to me and I felt I was being mistreated” (Female, women’s FGDs).

However, women felt that male nurses and older women nurses assisted them well in delivery suits compared to young and inexperienced female nurses. Older female nurses had own experiences of delivery and were preferred to young female nurses. Below is an example of women viewing male nurses as more empathetic and men emphasising on respect given by older women nurses.

“Some of the nurses are not good at examining us during labour. For instance, there was a day when I went to the hospital for the ANC services, there was a nurse who examined me but she was rough. I had a lot of abdominal pains. Whereas when a male nurse does the same examinations, he is not rough but he is kind” (Female, women’s FGDs).

“Health workers, forget about their responsibilities. As chiefs we see women of different age groups and when they go into the labour ward, nurses who assist them are often very young. This is not good because such young nurse does not mind what she does because she lacks experience. This makes the woman lose confidence and feel she may not deliver successfully. Later if she becomes pregnant again, she becomes reluctant to go back to the hospital for delivery. At least nurses who are old enough are able to respect these women in labour ward” (Male, chiefs’ FGDs).

The general perception towards home delivery, revealed in both paper III and IV, was that it was offered in a more friendly manner and has been a tradition over the turn of the centuries.
It was further stated that some women had had several deliveries at home with the assistance of the traditional birth attendants (TBAs) without problems.

The women stated that TBAs treated them as human beings with love and respect during delivery. Women expressed satisfaction with the warmth they enjoyed after delivery when provided with warm bath, porridge and surrounded by their relatives. At the same time, participants regarded home delivery as dirty, unsafe and expressed concerns that it was a potential area for HIV transmission from the mother to the baby. Women’s preference for home delivery to hospital delivery for whatever reasons, were generally expressed by both health workers and TBAs. However, TBAs were quick to point out that women like to be assisted by them even though they were told to go to the hospital for delivery. Health workers in particular, felt that women delivered at home due to ignorance, traditional beliefs and lack of trust in health workers and pledged to make hospital delivery services user friendly. In some situations women felt that given the circumstances they faced and the negative attitude of some nurses made them think of home delivery simply as an option not a choice as illustrated below:

“It was because I did not have money to pay for the delivery costs. I have had four deliveries. Of these, three were home deliveries and one was delivered at the hospital. Of the three home deliveries, one of the babies died during delivery, he did not cry. The TBAs conducted the delivery at home” (HIV positive female, in-depth interview).

“The thing is that my labour pains began at night, around 10 pm they came all over sudden. Therefore, it was not possible for me to go to the hospital. I finally ended up delivering at home with the assistance of a TBA” (HIV positive female, in-depth interview).


Discussion

This research has pointed to some important factors determining service uptake which will be further discussed. During the time of the study several changes have taken place at Malmulo hospital as a result directly or indirectly of the research presented in this thesis. These changes will be highlighted.

Accessing ANC and HIV testing: the importance of integrated services and ‘opt-out’ testing

The study showed that the integration of HIV testing into the ANC resulted in an increased uptake of HIV testing which was further increased with the introduction of ‘opt-out approach’. This agrees with the findings of the studies in Barbados (West Indies), Ghana and Zimbabwe. These studies found that voluntary counselling and testing, when incorporated into antenatal care offers organisational convenience and can be expected to lead to the efficient use of resources and an increase in service uptake (Kumar et al., 2004; Baiden, et al., 2005; Chandisarewa et al., 2007). Similarly, an Ethiopian study found that women’s willingness to undergo HIV testing after integrating it into the ANC increased from 1.9-7.2 times more compared with facilities offering co-located services (Bradley et al., 2008). This has several implications; women’s feelings of stigma and discrimination may be reduced as they are not singled out when undergoing HIV testing particularly when HIV testing becomes part of the routine ANC, time saving as well as cost effective for women since less time may be spent on moving from one place to the other looking for the services and these women could go home on time. HIV testing was perceived as beneficial hence acceptable to the women and community in general. This finding is supported by a study done in KwaZulu Natal, South Africa. This study found that over 87.5% of the women were of the opinion that HIV testing in pregnancy was of benefit to the mother and her baby (Dube and Nkosi, 2008). One other structural change which took place as a result of the findings from the study is worth mentioning. Initially women in the PMTCT programme were offered NVP at 32 weeks of gestation or more. The study showed that some women delivered at home without accessing NVP in the ANC as some of them did not report to the clinic at/or after 32 weeks of their pregnancy. This procedure was revisited and a different approach was decided. The PMTCT programme therefore come to offer NVP to HIV positive women at the first contact or visit to the ANC so as not to miss the opportunity of accessing NVP.

Removing the financial barrier of user fees: important but not enough

Free maternal care proved to have partly removed the economic barrier that prevented women from accessing the services particularly for this rural setting as revealed by the study. This may suggest that in long term, maternal and infant mortality from preventable causes may be reduced. However, it is important to remember that introduction of free maternal services in these poor resource settings may have positive effect such as an overwhelming
increased coverage of service uptake particularly by the poor women as well as negative effects such as shortage of human resources, reduced medical supplies/consumables and infrastructures among others as reported before (Jacobs and Price, 2004; James et al., 2006; Jacobs et al., 2007; Witter et al., 2007). It is therefore, important for policy makers and programme implementers to consider allocating more resources in the health facilities when such policies are being adopted to cater for the growing demand. This is worse in many parts of the world particularly Malawi and other countries in sub-Saharan Africa where brain drain due to poor salaries and adverse working conditions among other factors is the order of the day (Muula, 2006; Coomber and Barriball, 2007; Bradley and McAuliffe; 2009; McAuliffe et al., 2009).

In the study setting free maternal care was important to increase utilisation of services. However, poverty remains an underlying deep rooted cause that prevents women in poor resource settings from accessing and utilising maternal care. The barriers women face range from lack of transport, lack of family support, financial constraints and fear of disclosure if tested HIV positive among others. This is reflected in this study as well as discussed by several authors before (Lindgren et. al., 2005; Homsy et al., 2006; Pai and Klein 2009).

Negative attitudes of staff: the research triggered action

It was further shown that one of the barriers was the negative attitude of the health workers, particularly midwives, towards women in the labour ward. Earlier Malawian studies established that health workers’ negative attitudes, poor communication, cultural expectations, and negative perceptions about hospital delivery prevented women from actually accessing maternal services (Manzi et al., 2005; Seljeskog et al., 2006). This implies that women would like to be respected as individuals when they go in labour and should be given the dignity which they deserve. They do not want to be seen as nuisance preventing health workers from resting but rather they have the right to health care like anybody else. Similarly, this entails that health workers in this regard have moral obligation to discharge their duties without partiality with professionalism and follow the code of ethics as determined by their professional guidelines. In this study, the women and community in general perceived the older female nurses as full of experience and mature enough to diligently conduct deliveries in the labour ward. Additionally, male nurses were regarded as kind as well as polite and treated these women in labour ward with respect and were generally preferred to young female nurses. This is important and may suggest that the long traditions disregarding male nurses in conducting deliveries in labour ward is changing.

After conducting the study, the issue of staff attitude surfaced and formed the starting point to work on. The hospital management was involved and through the Community Medicine Department which implements maternal care programmes in which PMTCT services are being carried out took an active role on this. Several strategies were put in place to improve the situation.

- Suggestion box was put in maternity ward for the women and interested parties to put in their aspirations.
- Monthly and yearly ward performance competitions began so that the best ward receives an award as a token of appreciation.
• Best health worker of the year for each department and should receive awards.
• General staff meetings organised by the management through the human resources’ office to handle personnel issues including staff attitude to patients in general. In such meetings people expressed their opinions and what ought to be done to improve the situation. Also staffing issues in such meetings were being tackled as health workers expressed concern that they were understaffed.
• The matron’s office took an active role in seeing to it that nurses and midwives performed their duties in accordance with their profession and routine meetings were held relating to this.

The effect of these interventions needs to be evaluated but it is evident that the importance of staff’s attitudes is now openly discussed and the study has triggered action.

Increasing male involvement: a way forward to get an effective programme?

The study has established that men played active role in deciding where women can access maternity care. In the study setting gender inequality and disempowerment of women are common. In another Malawian study, women regarded themselves as just vessels for their husbands (Lindgren et. al., 2005). Women’s HIV testing in the absence of their husbands posed a challenge, the study has learned. The HIV positive result of a woman might result in that the woman being bullied around, beaten up, stigmatised, ostracised and even being divorced as has already been reported by previous studies (Bwirire et al., 2008; Meiberg et al., 2008). Male involvement in the reproductive health programmes has been proposed in a range of settings (Bajunirwe and Muzoora, 2005; Bii et al., 2008; Theuring et al., 2009).

Male involvement at family level and beyond should be encouraged as reproductive services are known to be female centered and this has to be reversed to give equal opportunities of service accessibility and utilisation to all (Sarker et al., 2007; Msuya et al., 2008; Desgrées du Loû et al., 2009). In the process, couple counselling should also be advocated. The family as the basic unit of any society and the individuals surrounding this societal structure should be involved and aware of the programme.

As a reflection of the discontent with the label PMTCT which immediately associates the preventive activities as exclusively targeting the mother some prefer to label the programme prevention of parents to child transmission (PPTCT) reflecting the importance of both parents (Sinha and Roy, 2008). Further, women’s protection after accessing life long ART could also be extended to their husbands as well as their families in general, a strategy which strengthens the fight against HIV and AIDS. However, in this study, few women in the PMTCT programme accessed long term ART. This may be explained by the fact that the majority of HIV positive women were asymptomatic and healthy at the time of entering the PMTCT programme and did not qualify for the long term ART even after CD4 screening (MOHP, 2003). The challenge to follow-up these women can not be underestimated.
Before the introduction of PMTCT at Malamulo, minimal male participation in reproductive health care was observed and this went on even after PMTCT was introduced. Women in the ANC took the HIV test but after testing positive a substantial number of them did not come back to the health facility to continue with the rest of the PMTCT and maternal care in general. This was a concern as a majority of women who never returned to the health facility after testing HIV positive delivered at home with the assistance of the TBAs.

Information relating to this was shared during routine sensitisation campaigns with different stakeholders at different levels. These sensitisation meetings were held at hospital management, district and NGO partners’ levels. At health facility level both project and hospital management team members convened the meeting in which strategies on how to scale up male involvement were discussed whereas at community level, village headmen, faith based leaders, men and women including village health committee members participated in the meetings. At district level, representatives from different NGOs implementing HIV and AIDS programmes including PMTCT were the participants whereas at regional NGO partners’ meetings all NGOs implementing HIV and AIDS programmes with support from USAID through Private Agencies Collaborating Together (PACT Malawi) participated. The study findings on the importance of spouse support were fed into the meetings and facilitated Malamulo Hospital Management through the Community Medicine Department to come up with strategies to involve men in line with what the district called ‘Male championship’. This involves the following:

- Women in the ANC to be encouraged to come with their spouses to PMTCT and ANC services in general and to participate in what is called ‘couple counselling’ before and after undergoing HIV testing.
- Men to be encouraged to come with under five children to the health facility for screening, immunization, growth monitoring just as women routinely do.
- If a man comes alone to the health facility with a sick child or joins his wife to access ANC he ought not to be in the queues.
- Males may be encouraged to accompany their wives to the labour ward to see and support their wives as they undergo delivery experiences. This is optional as this issue is culturally sensitive and few men wish to participate in this way.

To enforce this, routine meetings with men and women, village headmen and faith based leaders continue to be conducted in the communities.

**Decentralisation of services: how to respond to demand while maintaining the quality?**

The programme still faces challenges when it comes to increase the points of service delivery. It would be optimal to improve the capacity of the health centres by upgrading them to offer full maternal services including PMTCT. This means training and recruitment of the staff, improving the infrastructures such as buildings, equipment, consumables, medical supplies and drugs. The mobile team from Malamulo can also potentially scale up its services. Apart
from conducting HIV testing and counselling and maternal services in the communities, the mobile team can work closely with health surveillance assistants (HSAs) and take the supervisory role. The HSAs can be involved in offering some PMTCT services particularly distribution of NVP since they are based in the villages. They carry out different activities such as hygiene, water, sanitation, nutrition, HIV and AIDS prevention including TB and encourage women to deliver at the hospital. In addition, they do under-five services such as immunisation, growth monitoring, protection of shallow wells and distribution of bed nets to mothers with children under fives. Therefore, HSAs stand a better chance of helping mothers and their babies to access antiretroviral prophylaxis if home delivery occurs.

However, the process of decentralisation of services is done in line with the recommendation from the Ministry of Health and Population (MOHP) through the DHO’s office. Malamulo hospital does not operate in isolation but follows the guiding principles for those offering health services in Malawi as laid down by the Ministry of Health and Population (MOHP). This means that Malamulo Hospital on its own can not adopt a decentralisation process. For instance, according to the rules in Malawi, for any health facility to begin offering a particular service, there is need for approval by the body mandated by the MOHP. These services that need approval include; ANC, PMTCT, delivery, provision of ART and prophylaxis and procedures for patients care in general. It is as a result of this that only one of the two Malamulo Hospital’s health centres offers full fledged PMTCT services including long term ART through the hospital. However, both health centres are eligible for offering HIV testing and counselling. The main reason why one of the health centres is not offering all the services as required is because it does not meet the criteria as it lacks capacity in terms of staffing, space and the machinery in general to handle such services as needed by the MOHP. The communities around these health centres are demanding these services. Therefore, there is potential that in future the other health centre will be able to meet the criteria for offering full maternal care and PMTCT services.

The role of TBAs has surfaced throughout the study and TBAs could potentially be involved in the PMTCT programme (Perez et al., 2008) even if issues of trust and confidentiality have emerged during the study. It is though outside the control of Malamulo Hospital to decide on that, as their involvement in health care is regulated by the MOHP. If agreed upon a group of TBAs with existing links to the MOHP could be trained using the existing curriculum to be able to do basic PMTCT services such as provision of antiretroviral prophylaxis and handling uncomplicated deliveries and referring those they can not manage on time. This is not viewed as being an optimum solution but should be explored further facing the reality of their active role in the communities.

**Strengths and limitations of the study**

The researcher’s role as a manager for the PMTCT programme was a strength in that results from the different sub-studies could be fed into the programme’s activities and communications with various stakeholders were facilitated. The managerial role could however have prevented interviewees from expressing themselves freely about the services being provided by
the programme. The prolonged engagement by the researcher in the area was crucial for the trustworthiness of this study but might also have resulted in difficulties in taking “a fresh look” when collecting and analysing data. It is recognised that some of the nuances of the interview material might have been lost due to the necessity of translating the transcripts to English. The original tapes were however frequently referred to in case of doubt. The research team used regular peer debriefing and analysis sessions to get as rich material as possible.

For register data the manually recorded data in the hospital based registers were used. It was noted that a small proportion of data were missing, incomplete and mistakenly repeated. We do not believe however that this introduced any systematic error in the estimation of uptake of services.

The study had the strength of assessing the influence of the various policies introduced over time in a rural maternal health care setting in which PMTCT was being provided and how the women and community at large experience and perceive these services respectively. Similarly, the study had the ability to demonstrate how PMTCT and reproductive health programmes in general in poor resource communities can be scaled up to reach more women and be able to reduce preventable maternal and infant mortality as well as MTCT of HIV. The study did not look into the infant feeding practices of the PMTCT which poses a great challenge in the studied population and the quality of the services given in the presence of the increased uptake and utilisation of the services.

It was not possible to estimate the true uptake of the services as well as utilisation as no baseline or follow up community survey was conducted due to limited resources. The effectiveness and impact of the programme with regards to determining HIV status of babies born from the HIV positive mothers at 18 months were not included in this thesis.
Conclusions and recommendations

The thesis revealed some encouraging findings. Increased accessibility and utilisation of maternal services can also increase the coverage of PMTCT services. Free maternal services removes partly the economic constraints that prevent women in poor resource settings from accessing the services. Similarly, the integration of services into ANC increased the women's uptake of HIV testing and hospital delivery influenced women’s adherence to antiretroviral prophylaxis (NVP). Both women as well as the community in general supported institutional delivery. Further, by encouraging hospital delivery and male involvement, more women in the PMTCT are likely to adhere to the PMTCT programme and consequently reduce MTCT of HIV. However, home delivery remains a reality and a challenge for safe delivery especially in context of poor HIV endemic regions. Interventions for inclusion of community based health workers and TBAs need to be explored. Further studies on the quality of care offered in the presence of increased service uptake, estimation of true programme coverage and effectiveness are required. Policy makers as well as potential donors need to come up with interventions that have positive effects for the disadvantaged communities. Community mobilisation regarding free maternal care should be advocated to enable full utilisation of the services by the disadvantaged communities. Operational research provides an opportunity for health care institutions to optimise the local implementation of programmes like PMTCT. The provision of such research skills should be encouraged by MOHP and donor organisations. Service providers at facility and community levels, policy makers at all levels, all stakeholders and the communities should see themselves as partners in development and should work together to reduce preventable maternal and infant mortality including MTCT of HIV.
The researcher

It is commonly said that life has no formula as one can become anything in life depending on many factors and one of them is how an individual relates to significant others. The humble upbringing at Ngolowera, a village in the outskirts of Mulanje Mountain in southern Malawi has its influences. Faced by ill forces of nature, malaria being one of them, economic inequalities and cultural heritage that groomed young citizens to become good husbands and wives at a tender age, one would never dream of denying self alienation of making the difference.

The thought was to become a primary school teacher, perhaps a business man but who are we to resist the winds of change among rare opportunities? The quest was to learn more but not knowing how to go about it. The background in clinical medicine complemented by courses in public health paved ways of exploring more about the multiple causal roots of human suffering causation and how to minimise them. It was at this stage when I worked in other health facilities in Malawi in different capacities that in one of those places I was made the project officer for an HIV/AIDS related project. This was at St. Lukes and Montfort hospitals owned by the Anglican and Roman Catholic churches respectively, which caused my interest in public health to grow.

After earning a Master’s degree in Public Health (MPH) from Tumaini University in Tanzania in 2000, the search for more knowledge increased and ideas of becoming a PhD began to surface. Later, I ended up at Malamulo SDA Hospital where I previously committed myself to work after my studies. After two years of teaching in the School for Allied Health Workers and doing clinical work, I was assigned to manage the Comprehensive HIV/AIDS Project which was being implemented by the hospital through its Community Medicine Department. Barely three months into working for this project in this capacity, was I asked to temporarily move to other new horizons.

It was during the first half of 2003, that I worked in Norway as a volunteer through the Fredskopset Programme organised by Norwegian and Malawian Governments through a Christian Health Association of Malawi (CHAM). In Norway, among other things, I worked as an HIV/AIDS resource person focusing on HIV/AIDS prevention and care strategies. While in Norway, my previous ideas of becoming a PhD became stronger and I began making some connections with the one who would be my supervisor, Prof. Peter Byass, who was once my teacher during my MPH training. The communication with Prof. Peter Byass was successful and continued until the completion of my stay in Norway. With his advice I was determined to become a PhD. After my work in Norway; I came back to Malamulo where I had to do more on the HIV/AIDS prevention project. Here I cultivated more knowledge and interest in doing something for the pregnant women and the prevention of HIV transmission from their babies. It is obvious that there are many areas one can work on, but the organisation of the programme, nature of my work and the supportive hospital management made it possible for me to undertake this career path, especially since Malawi has one of the highest rates of maternal and infant mortality.

Additionally, having the a conducive environment and pursuing a career to the level of a PhD are two totally different things altogether and the effort can not be attributed to one person, or oneself. However, both local and international individuals as well as exposures fa-
cilitated the process though it was not easy especially coming from a developing country. Therefore, one has to put others first before self as it is also commonly said ‘united we stand, divided we fall’ and ‘where there is a will, there is a way’.

Looking back in the last five years then, my PhD work in Epidemiology and Public Health has given me enormous opportunities to be close to my work and particularly the women who have been the centre of my studies. I have appreciated more the problems these women and their families face, the importance of my co-workers, both local and international communities have been my greatest admirer. Yes, with this PhD, I have now put on new glasses of seeing things differently from before and if anything, seeing that more needs to be done to contribute to the wellbeing of everybody.
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A. Appendices

1. Questionnaire used in paper II

ID No. [IDNO] _______________________________________________________

Serial no. [SERIALANC] _____________________________________________

1. Antenatal Clinic (ANC) no. [ANCN] _________________________________

2. Name [NAME] ___________________________________________________

3. Month of entry into the ANC [MONTHANC] __________________________

4. Age (n years) [AGE] _____________________________________________

5. Address, Village, TA [ADDRESS] _________________________________

6. Parity (no, of pregnancies) [GRAVIDA] _____________________________

7. Parity (no. of deliveries) [PARA] _________________________________

8. Literacy [LITERATE] _____________________________________________
   1. Literate
   2. Illiterate

9. Education (Schooling in years) [EDUCATION] _________________________

10. Tribe [TRIBE]
    1. Lomwe
    2. Yao
    3. Ngoni
    4. Others

11. Religion [RELIGION]
    1. SDA
    2. Catholic
    3. CCAP
    4. Others
12. Marital Status [MARITAL]
   1. Married
   2. Single

13. Occupation [OCCUPATION]
   1. House wife
   2. Employed

14. Gestational age when mother enters into the antenatal clinic services (in weeks) [GESAGE] ________________________________

15. Did the woman enter into the PMTCT programme [PMTCT]
   1. Yes
   2. No

16. Serial no. PMTCT [SERIALPMT] ___________________________________________

17. Surveillance no. [SURVEILLNO] _________________________________________

18. Month of entry into the PMTCT programme [MONTHPMTCT]_______________________

19. Gestation age when entry into the PMTCT programme was made (in weeks) [GESTATION]______________________________

20. HIV status [HIV]
   1. Positive
   2. Negative

21. No. of ANC visits [NOANCV] _____________________________________________

22. Was the mother given Nevirapine at 32–36 weeks [MNVP]
   1. Yes
   2. No

23. Place of delivery [DELIVERY]
   1. Malamulo Hospital
   2. Home assisted by TBA
   3. Home without the TBA’s assistance
   4. Molere clinic
   5. Thyolo district hospital
   6. Others
24. Did the mother swallow Nevirapine [MSNVP]
   1. Yes
   2. No

25. Was the baby given Nevirapine within 72 after of delivery [BGNVP]
   1. Yes
   2. No

26. Health status of the baby [BHSTATUS]
   1. Health
   2. Stillbirth
   3. Sick/abnormal
   4. Others

27. Outcome of the pregnancy [POUTCOME]
   1. Single
   2. Twins
   3. Multiple
   4. Abortions

28. Mode of delivery [MDELIVERY]
   1. Normal delivery
   2. Caesarian section
   3. Instrumental
   4. Others
2. Interview guide with hospital/home delivery women and the defaulters used in paper III

1. Please tell me about your decision to test for HIV at the health care unit and describe how your life has changed after that and up to now?

2. Why did you decide to take an HIV test when you were pregnant?

3. What happened since you decided to take an HIV test and were informed about the possible nevirapine treatment?

4. How were your feelings, reactions and actions when you got your HIV positive results?

5. Who did you talk to about your HIV test results?

6. Why did you decide to talk to the one whom you have mentioned previously?

7. What support did you get after sharing your positive results with your family, community or anybody else?

8. Given the information about taking nevirapine treatment for you and your baby if you delivered at the hospital,
   a). what other reasons made you decide to deliver at the hospital?
   b). did you pick and swallow your nevirapine tablet before delivery and why?
   c). what made you decide to deliver at home?
   d). why did you not go back to the health facility to pick your nevirapine tablet?

9. If you become pregnant again, where would you like to deliver and why?

10. What is it that can be done in future to encourage more women to deliver at the hospital?
3. Focus group discussions (FGDs) guide with service providers and community members used in paper IV

1. Men/Women/leader's role in pregnancy
   - Own
   - Family
   - Community
   - Reactions

2. Common practices related to pregnant women
   - Norms/values
   - Preparations for delivery
   - Beginning ANC, when, who decides and why?
   - Where to deliver and why?
   - Good or not and why?

3. Choice of place for delivery
   - Hospital vs. Home delivery
   - Good or bad and why?
   - Feelings/perceptions
   - Reactions
   - Related norms
   - Actions

4. ANC and PMTCT services
   - Perceptions
   - Service providers’ attitudes
   - Good or bad and why?
   - Actions