IMPROVING PMTCT IMPLEMENTATION IN MASAKA DISTRICT, UGANDA:

Drawing From Other Resource Poor Settings' Experiences

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Drawing From Other Resource Poor Settings' Experiences

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Public Health

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Declaration:

Where other people's work has been used (either from a printed source or internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

The thesis IMPROVING PMTCT IMPLEMENTATION IN MASAKA DISTRICT, UGANDA: Drawing from Other Resource Poor Settings' Experiences is my own work.

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Dedication

This thesis is dedicated to my son Raphael Mayiga, and to all HIV positive women (diagnosed or not) in Masaka district who depend on the government to help them prevent HIV transmission to their babies.

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Above all, to the almighty God who gave me the grace to complete the course successfully.

List of Acronyms and abbreviations

AIDS Acquired Immune Deficiency Syndrome

ARVs Anti retroviral Drugs
ANC Anti-natal clinic

DHS Directorate of Health Services
CBO Community Based Organisation

EGPAF Elizabeth Glazer Paediatric AIDS Foundation

ECS Elective Caesarian Section

HAART Highly Active Anti retroviral therapy

HC Health Centre

HCT HIV counseling and testing Human Immunodeficiency Virus

HSD Health Sub District

IEC Information, Education and Communication

INA Influence Network Agents
MCH Maternal and Child Health
MDG Millennium Development Goal

MoH Ministry of Health

MoFPED Ministry of Finance, Planning and Economic

Development

MTCT Mother to Child transmission NGO Non government Organisation

OFT Oral Fluid Tests

PCR Polymerase Chain Reaction

PHC Primary Health Care

PMTCT Prevention of Mother to Child transmission

PNFP Private not for profit

RCT Routine counseling and testing

RPS Resource Poor setting

SOPS Standard Operating Procedures
TASO The AIDS Support Organisation
TBA Traditional Birth Attendants
UAC Uganda AIDS Commission
UBOS Uganda Bureau of Statistics

UNAIDS Joint United Nations programme on AIDS

UNICEF United Nations Children's Fund

USAID United States Agency for International

Development

VCT Voluntary counseling and Testing

WHO World Health Organisation

Working definitions

Elective Caesarean Section: caesarean section performed before onset of labour

Exposed Infants: Babies born of HIV positive mothers

PMTCT: the prevention of transmission of HIV virus from an HIV positive mother to her baby.

PMTCT Clients: pregnant mothers who test HIV positive and are registered in the antenatal clinic for subsequent follow up care.

PMTCT Site: A health facility that offers PMTCT services

Routine Counselling and Testing: counselling and testing to all clients attending antenatal as a matter of course.

Traditional Birth Attendant: a community-based provider of care during pregnancy and childbirth

Abstract

Background: Masaka district (Uganda) has been implementing the PMTCT program for about eight years. Progressive improvement in uptake of counselling and testing services is registered. However, the fraction of HIV positive women and babies remaining in the continuum of care is persistently low.

Methodology: The thesis was an analytical and descriptive study based on review of the available literature from Resource-poor Settings including Uganda, and annual PMTCT reports, and other relevant documents from Masaka district. Drawing from other resource-poor country experiences, the major objective of the study was to identify and propose best practices for implementing PMTCT programme in Masaka District, Uganda.

Findings: The main barriers to effective utilisation of PMTCT services that were identified are individual factors: stigma and discrimination, disclosure problems, low male involvement. These are deeply entrenched in the structural factors (gender inequity, poverty and culture), and are reinforced by institutional factors particularly the low staffing levels; which limit the client-provider interaction and thus making it difficult for the clients to overcome some of their challenges.

Conclusion: Effective PMTCT programme implementation in Masaka will require further health system strengthening but more importantly active participation of the local community through outreach and home based care programmes. However, this can only be successful if there is stakeholders involvement namely Local Administrations, support groups, CBOs etc. As a long term strategy to overcome the structural barriers-which are responsible for the chronicity of the individual factors-, a multi-sectoral coordination will be important for the community empowerment process.

Key words: PMTCT, barriers, resource-poor settings, stigma, male involvement, disclosure, Traditional Birth Attendants, Best practices, and Uganda.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

Globally, approximately 420,000 children below 15 years acquired HIV infection and 330,000 died of AIDS in 2007 (UNAIDS & WHO, 2007). Eighty Five (85%) of these were resident in Sub Saharan Africa. Mother to child transmission (MTCT) accounts for more than 10% of all new HIV infections globally. In Uganda MTCT is the second leading mode of transmission of HIV (MoH, 2006) and HIV/AIDS is the fourth indirect cause of mortality among children under five in Uganda (UAC, 2009). For a country committed to achieving millennium development goals (MDGs), HIV infection among children thus directly affects the realization of MDG 4. It is against that brief overview that this thesis intends to discuss the implementation of PMTCT in Uganda and Masaka particularly.

The major objective of this thesis is to propose best practices for implementing PMTCT in Uganda's rural settings, particularly Masaka district. The paper consists of six chapters, an introductory chapter which presents background information on Uganda and Masaka and an overview of PMTCT. Chapter 2 will have the problem statement, objectives and methodology; the third chapter will describe the needs of PMTCT clients and PMTCT program implementation in Masaka. The fourth chapter will discuss the barriers affecting program implementation in Masaka; the fifth will have best practices and other countries' experiences. The sixth chapter will conclude with a discussion on the findings, conclusions and recommendations. The thesis also includes a list of references and annexes.

1.2 Background

Uganda is a landlocked country located in East Africa and lies astride the equator. It is bordered by Kenya in the east, Tanzania in the south, Rwanda in the southwest, the Democratic Republic of Congo in the west, and Sudan in the north. The country is administratively divided into 80 districts (UBOS,2007). Uganda has a decentralized system of governance and several functions have been ceded to the local governments. However, the central government retains the role of making policy, setting standards, supervision and maintaining national security. By 2007, Uganda's population was estimated at 29.6 million with a population growth rate of 3.2% and a total fertility rate of 6.7 (MoFPED, 2008). About one third of the population lives below poverty line (for further details on demographic and development indicators of Uganda, see annex 1).

HIV prevention efforts in Uganda have registered success in the past years. However, the burden of HIV/AIDS among children remains a major health sector concern. For instance, antenatal HIV prevalence is 6.2%

among pregnant women (MoH, 2006) from which it is estimated that 25,000 children could acquire HIV annually. Reduction of the burden of HIV/AIDS among children is the purpose of Prevention of Mother-to-Child Transmission (PMTCT) programs. In Uganda the PMTCT program started in 1998 as a pilot project in the national referral hospital and has since been scaled up throughout the country. Masaka district showing one of the highest HIV prevalence in the country antenatal prevalence 8.2% (DHS, 2008), has implemented the PMTCT program since 2002 and has successfully scaled up the program to many health facilities. However, the district has challenges in achieving the desired targets.

Masaka district is also one of the biggest districts in Uganda, located in south western region. Her population is estimated at 804,300 people with a female to male ratio of 52:48, and an annual growth rate of 1.7% (DHS, 2007). Majority of the people reside in rural areas, comprising 89% of the population. Literacy rates are fairly high, with 78% of adults being literate though the rates are three fold lower among women. Poverty rates are high; approximately 25.5% of population's income falls in the lowest 2 quintiles (UBOS, 2007).

1.3 Management of PMTCT services in Masaka district

Within the decentralized system in Uganda, districts are mandated to implement the national health policies, plan and manage the district health services. They are supervised by the Ministry of Health (MoH) whose central role is policy formulation, setting standards, resource mobilisation, capacity development, and technical assistance.

In terms of health service delivery, Masaka district is divided into 9 health sub districts (HSDs). Each health sub district comprises a number of health centres (HC) at various levels. These are categorised as Health centre IV, III, and II plus the village health teams. The HC 1Vs (at the Sub-county) offer basic primary care services and are equipped to handle minor surgery including the Caesarean section. The HC IIIs (at the Parish) offer basic primary care services and which offer maternity services at the Parish level. Lastly, the HC IIs offer only basic primary care, with some offering antenatal services but with no labour and delivery facilities (For details of services offered by each level of health facilities, see Annex 2). The district also has two (2) Private Not for Profit (PNFP) hospitals, and one (1) public hospital which is semi autonomous but supervised by the district.

In regard to financing; although under decentralisation the districts have the authority to raise their revenue, local revenue is usually low. Hence the financing of the district health sector budget is predominantly done by the central government through the Primary Health Care Conditional Grant, and external development partners like Elizabeth Glazer Paediatric AIDS Foundation (EGPAF), UNICEF, and Global Fund. Services at the

health facilities are financed by the government and are thus free at point of use.

In terms of geographical access to health services, the district has 81 health facilities both public and PNFP (hospitals included), and geographical access (within 5 km radius) to the health facility is estimated at 68% (DHS, 2007). Access to the PMTCT facilities is even less as only about 46% of the health facilities offer PMTCT services and worse still they are not evenly distributed (DHS, 2008). The table 1 shows the coverage of the Health Facility in terms of population and health facilities in the district by health sub-district. On average, one facility serves 11,384 people, and one PMTCT site serves 23,999 clients. This implies that accessibility of PMTCT services was still low by 2008.

Table 1-: HEALTH FACILITY COVERAGE WITHIN MASAKA DISTRICT

HSD	Population	No. of Health Facilities				Of those, No. of	
		Hospi tal	HC IV	HC III	HC II	Total	PMTCT sites
Masaka Municipality	71,772	2	0	0	6	6	3
Kalungu West	91,663	1	1	2	7	10	5
Kalungu East	96,990	0	1	3	2	6	4
Bukomansimbi	162,698	0	1	4	7	12	7
Bukoto East	92,866	0	1	6	9	16	7
Bukoto Central	87,226	0	1	1	4	6	3
Bukoto South	92,551	0	1	2	5	8	2
Bukoto Mid- West	103,206	0	1	3	2	6	4
Bukoto West	89,000	0	1	1	6	8	2
Total	887,972	3	8	22	48	81	37

Sources: (DHS, 2007; DHS, 2008)

Despite the limited geographical access, utilization of maternal and child health (MCH) services especially antenatal attendance and immunization is fairly good (see table 2). About 4 of every 5 pregnant women attend antenatal care at least once, and all children receive their first immunization (DHS, 2007; DHS, 2008). This trend of contacts of pregnant women and children with the health services provides an opportunity for reaching this group of clients with PMTCT services.

Table 2-: INDICATORS OF MCH PERFORMANCE IN MASAKA DISTRICT, 2004-2008

INDICATOR	2004/5	2005/6	2006/7	2007/8
New antenatal attendance (%)	78.7	71.3	82.1	80.2
Percentage of health facility deliveries (%)	26.7	26.3	30	27.4
Postnatal attendance (%)	9.8	8.6	8.7	8.1
BCG coverage (%)	111	106	116	109
DPT3 coverage (%)	82	78.9	84	85.5
Measles coverage (%)	82.3	81.9	96.3	91.3

Sources: (DHS, 2007; DHS, 2008)

1.4 Overview of PMTCT and MTCT

Mother to child transmission is the transmission of HIV from an HIV positive woman to her baby. It is shown to occur during pregnancy, labour and delivery, and during breastfeeding with risks of 15-25%, 50-60% and 15-25% respectively (MoH, 2006). 'Labour and delivery' presents the highest risk phase. Without intervention the overall risk of MTCT is estimated to be between 15-20% and almost doubles to 35-40% with prolonged breast feeding (WHO, 2007). Babies infected with HIV have problems with survival; without appropriate care and treatment, about 50% of them die by their 2nd birthday (WHO, 2007).

Prevention of Mother to Child Transmission interventions aim at minimizing the risk of transmission of the virus to children through modification of factors contributing to transmission viz. viral, maternal, obstetric, fetal and infant factors (see box.1). Evidence from developing countries shows that the risk of MTCT can be reduced to less than 2% with a package of interventions including ARV prophylaxis and treatment combined with elective caesarean section and avoidance of breastfeeding (Newel, 2005). Recent studies in some developing countries (Mozambique, Tanzania and Malawi) have also shown almost similar success rates (MTCT rates of 1.4 - 3.8%) where HIV positive mothers started HAART from 25 weeks of gestation to 6 months after delivery irrespective of the infant feeding option or delivery mode (Palombi et al., 2008).

Text Box 1: FACTORS CONTRIBUTING TO MTCT

- Viral Factors: High viral load is associated with a higher risk of transmission and viral drug resistance may lead to viral replication as well as high risk of transmission. Maternal acquisition of new infection increases the risk of transmission during the replication and viraemia stage. Certain viral genotypes and phenotypes may also be associated with higher risk of transmission.
- Maternal: Increased risk of transmission has been observed with depleted immune condition e.g. very low CD 4 cell counts. Other conditions that may increase the risk of transmission are poor maternal nutritional status especially vitamin A deficiency, high risk sexual behaviour and non-use of ART if necessary or poor adherence.
- Obstetrical: Increased risk of transmission has been observed with prolonged rupture of membranes (> 4 hours); vaginal delivery has a higher risk than caesarean section; intrapartum haemorrhage and invasive obstetrical procedures may also increase the risk.
- Foetal: First twin is at higher risk than the second twin; premature baby is at higher risk than term baby, and possibility of genetic factors playing a role.
- Infant: Mixed feeding exposes the baby to a higher risk of transmission than
 exclusive breastfeeding or use of replacement feeding (not breastfeeding).
 Immaturity of the infant immune system and gastrointestinal factors may also play a
 role.

Source of information: (WHO, 2007)

CHAPTER TWO

This chapter presents the problem statement, research objectives and questions, methodology, limitations as well as the significance of the study.

2.1 Statement of problem

In Masaka district Uganda, the PMTCT program aims at reducing mother to child HIV transmission by 50% of the baseline¹ by 2010. To achieve this, the MCH departments have been used as a focal point for HIV counselling and testing with targets of at least 90% of pregnant women attending ANC, providing ARV prophylaxis or treatment for all HIV positive pregnant women and their babies, providing comprehensive HIV care for 75% of pregnant women living with HIV and their families, as well as providing family planning services to 75% of women living with HIV (MoH, 2006; DHS, 2005)

Current human resource, logistics and infrastructure capacity in the district have limited PMTCT program implementation to hospitals and a few health facilities, collectively referred to as PMTCT sites (DHS, 2008). The PMTCT sites have adequate infrastructure, good logistics supply and well trained and supported staff for the job; and reach targets for counselling and testing. However, the fraction of HIV positive women and babies remaining in the continuum of care is very low. Only 45% of the HIV positive mothers identified deliver at the PMTCT facilities and consequently, only 43% of HIV exposed babies get ARV prophylaxis (DHS, 2008). The failure of the HIV positive mothers to return to the health facilities for labour and delivery care makes it impossible for the mothers to get modified obstetric care, ARV prophylaxis for babies, counselling on infant feeding or care for their health. This negates the efforts made in antenatal counselling, testing and ARV prophylaxis.

The reasons for PMTCT clients not returning to the health facilities for subsequent care remain unclear. The purpose of this research is to assess barriers to effective utilisation of PMTCT services as a basis for proposing best practices for implementing PMTCT in Masaka District, Uganda.

2.2 Research objectives

Major Objective

Drawing from other resource-poor country experiences, the general research objective is to identify and propose best practices for implementing PMTCT programme in Masaka District, Uganda.

 $^{^{1}}$ Baseline figures used in 2005 are from estimation of the MTCT risk (about 35-40%) without PMTCT intervention.

Specific Objectives

- 1. To identify the needs of PMTCT clients in Masaka's resource-poor setting.
- 2. To examine the process and impact of PMTCT programme in Masaka district
- 3. To assess the barriers that affected the implementation of PMTCT in Masaka district
- 4. To identify best practices for implementing PMTCT programme in the rest of resource-poor settings
- 5. To recommend effective measures for improving the implementation of PMTCT in Masaka district

2.3 Research questions

- 1. What are the needs of pregnant women in a high HIV prevalence setting and how do these needs vary among groups?
- 2. How was the PMTCT program designed and implemented in Masaka and how does the design compare with national standards?
- 3. How effective are the interventions and activities used in the implementation of PMTCT services in Masaka?
- 4. What barriers must have impacted on the implementation of the PMTCT programme in Masaka, and how do these barriers relate to those in other countries?
- 5. What are the various best practices, in terms of policies, packaging of PMTCT, and strategies, and what measures have been used by other RPS to minimise the barriers to effective utilisation PMTCT services?
- 6. How best can these measures be applied to Masaka in order to improve PMTCT program implementation?

2.4 Methodology

The thesis is an analytical and descriptive study based on review of the available literature on Resource-poor Settings including Uganda, and Masaka district annual PMTCT reports and other relevant government documents. The author also used her knowledge and experience in coordinating PMTCT activities in Masaka district, as well as knowledge and skills acquired from the ICHD course. The author is a medical officer with a four years experience working with Masaka district local government in Uganda and is also the PMTCT coordinator for the district.

The review of literature from low and middle income countries was done in a systematic process guided by the research objectives and questions. Exploratory studies and review articles from 1998 to date were selected. Topical issues drawn from the available literature were developed under each objective (see table 3). Pubmed search engine was used to access journal articles through VU and KIT libraries. A Google search was done to access relevant articles, reports and documents from WHO, UNAIDS, MOH Uganda, UAC, UBOS, and MoFPED Uganda websites. The key search words that were used included; PMTCT, barriers, resource-poor settings, stigma,

male involvement, disclosure, Traditional Birth Attendants, Best practices, Uganda and combinations of these words.

Review of the available literature resulted in identification of key concepts under each objective, and the table below presents the categorical concepts. From these a conceptual framework was developed (see fig 1).

TABLE 3-: OBJECTIVES AND CATEGORICAL CONCEPTS

TABLE 5 OBJECTIVES AND CATEGORICAL CONCEPTS				
Objective	Categorical concepts			
To identify the needs of PMTCT	Physiological			
clients in Masaka/ resource-poor	Safety/Security needs			
setting.	Belongingness and love			
	Esteem			
To examine the process and	Goals and objectives			
impact of PMTCT programme in	Strategies			
Masaka district	Activities			
	Impact/outcome (performance results)			
To assess the barriers that	Individual			
affected the implementation of	Institutional			
PMTCT in Masaka district	Structural			
To identify best practices of	Program support strategies			
implementing PMTCT	PMTCT components Packaging			
programme in the rest of	Human resource capacity			
resource-poor settings	Space mobilisation			
	Involving men			
	Reduction of Stigma			
	Promoting Disclosure			
To recommend effective	Overall Outcome of the Thesis			
measures for improving the				
implementation of PMTCT in				
Masaka district				

Conceptual framework

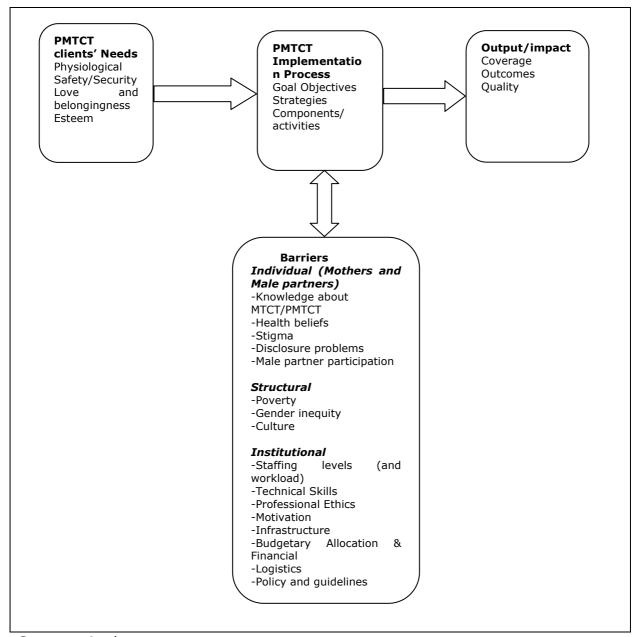
The conceptual framework shows that a comprehensive understanding of PMTCT outcome requires that three levels be analysed. The first level, also the starting point is to understand the needs of the clients. The notion of clients is used in a broad sense to refer to the women, male partners and the babies. The needs of clients determine the second level, that is, the program design/implementation process. The implementation process comprises the goal, objectives, strategies, and components. The implementation components must match the needs of the clients. However, the overall outcome as a function of the implementation process is mediated by the barriers. These barriers can be analysed at the individual, structural, and the health institution levels.

2.5 Study limitations

Limited data was available for the PMTCT program performance in the district reports, making it difficult to undertake an exhaustive analysis of program performance over the years.

The findings are not based on primary data; because of limited information on the PMTCT needs of clients in Masaka, the author has supplemented Masaka programme with findings from international literature therefore, the needs of the clients presented here may not be the actual needs of the clients in Masaka.

Fig. 1 Conceptual framework



Source: Author

2.6 Significance of Study

The thesis is primarily intended for Masaka district health team. Findings will be shared with the district council and stakeholders like Elizabeth Glazer Paediatric AIDS Foundation (EGPAF) and the Ministry of Health (MoH) Uganda. The document will also be available to anyone else who finds it important.

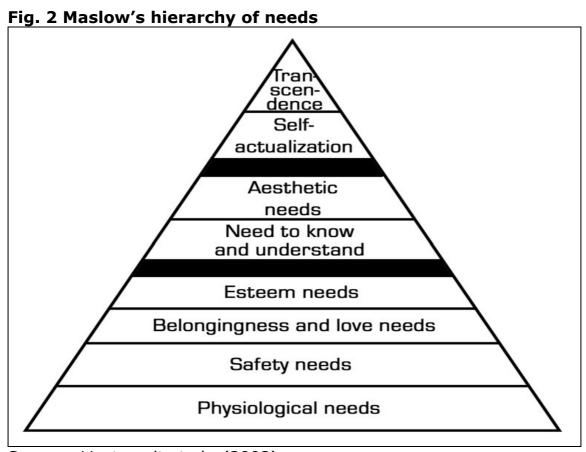
CHAPTER THREE: PMTCT IMPLEMENTATION IN MASAKA

3.1 Introduction

This chapter discusses the implementation of PMTCT in Uganda in general and Masaka in particular. The demand for certain services stems from the needs/problems/deficiencies experienced by the people themselves. This chapter opens up by discussing the needs of the clients, and goes ahead to describe the programme design.

3.2 Needs of PMTCT clients

The term need is subjective varying from individual to individual, but simply defined a need is something someone must have to live a satisfactory/healthy (Advanced learner's dictionary) life and thus whose deficiency would cause a clear negative outcome, such as dysfunction or death. Maslow posited that human needs follow a hierarchy (See fig.2). He also asserted that individuals will seek to fulfill higher needs only if lower level needs are satisfied (Ventegodt et al., 2003).



Source: Ventegodt et al., (2003)

The figure above shows that needs, according to Maslow, can be can be analyzed at eight levels namely:

- 1) Physiological: bodily comforts like food, clothes, sex, sleep etc;
- 2) Safety/security: out of danger (peace of mind), like a safe residence
- 3) Belongingness and Love: affiliate with others, be accepted;
- 4) Esteem: to achieve, be competent, gain approval and recognition;
- 5) need to know and understand: the need to know ourselves and to understand the world;
- 6) Aesthetic needs: need to use our knowledge and talents to create
- 7) Self actualization: to realize our personal meaning of life; and
- 8) Transcendence: to become an integrated and valuable part of the world

Within the hierarchy, the needs are further grouped into basic, advanced and abstract needs. The first four levels form the group of basic needs (Ventegodt et al., 2003). And using Maslow's theory it follows that basic needs have to be met before the others are sought.

I will use Maslow conceptualization of needs to elaborate how they apply to HIV/AIDS in general and PMTCT in particular. However, only those that are relevant to HIV/AIDS and PMTCT are discussed.

3.2.1 Physiological needs

The physiological needs as mentioned by Maslow are linked to the physical and psychosocial needs. Physical needs refer to those pertaining to healthy bodies and include medical and sexual reproductive health needs.

Medical

It is estimated that 20-30% of pregnant women who test HIV positive need HAART (WHO, 2007). This figure could be a little high, as HIV virus is proved to damage the reproductive physiology and subsequently reduce fertility as disease progresses (Setel, 1995). This implies that most of the pregnant HIV positive women are likely to be in early stages of infection. Nevertheless, some pregnant women present at antenatal clinics in late clinical stages with an urgent need for treatment for inter-current infections and or HAART. Women therefore need to have information on HIV/AIDS, and information on when, where and how they can receive care and treatment when they need it.

Psychosocial

HIV/AIDS is a chronic, debilitating and fatal disease (although now modified by comprehensive care including HAART). This fact creates despair and mental torture for anybody undergoing an HIV test. Given the high HIV prevalence setting of Masaka (8.2%) (DHS, 2008), all pregnant women have been exposed² to HIV/AIDS and thus know the implication of a positive HIV test. In addition, pregnancy is evidence of unprotected sexual encounter, and thus many are anxious and aware of the potential risk of being HIV positive. Over 20% of Ugandan adults believe it is very

² Exposed here refers to having had, seen, heard or even taken care of an HIV/AIDS patient and thus seen how society, family and in laws treat HIV positive people.

likely that they will get HIV (MoH & Macro, 2006). HIV testing in pregnancy has far reaching effects; evidence from a study in Zambia shows that more than half of women whose HIV was diagnosed during pregnancy developed major depressive disorders with suicidal thoughts and signs of somatic illness (Kwalombota, 2002). This creates special psychological needs for women both before and after testing.

Sexual and Reproductive Health (SRH) needs

WHO defines Sexual reproductive health as a state of complete physical, mental and social well being and not mere absence of infirmity in all matters relating to the reproductive system and to its functions and processes (WHO, 2001). SRH implies that people are able to have satisfying and safe sex life, and that they have the capability to reproduce and the freedom to decide if, when and how often to do so.

Like the HIV negative women if not more, HIV positive women have a right to a healthy sexual and reproductive life and thus need both family planning information and supplies. While prevention of pregnancy among HIV positive women is undoubtedly an effective strategy of PMTCT (WHO, 2007), in Masaka and Uganda it has to be implemented cautiously. Majority of clients infected with HIV are young and, for socio-cultural reasons, may want children. For instance, HIV prevalence among women aged 25-29 and 30-34 is 8.7% and 12.1% respectively (MoH & Macro, 2006), yet this is the prime period for child bearing in Uganda (UBOS, 2007).

3.2.2 Safety/security

Physical safety

Women who test positive for HIV are at risk of domestic abuse, abandonment (Maman and Medley, 2003). Women undergoing an HIV test need assurance that testing will not affect their position. Therefore women need enough time and space to decide whether to test or disclose their results. In this respect, confidentiality and informed consent are specific needs and rights for clients. In addition women who are likely to or suffer abandonment and domestic abuse need protection.

Financial security

A positive HIV test has several financial implications for a woman and her family; the need for routine follow up health visits, breast milk substitutes, clean water, improved nutrition, all of which require extra money. For women of good socio-economic status this is no problem but for the poor women/families these costs can be catastrophic. Unfortunately, many positive clients are poor (MoH and Macro, 2006). Likewise for the women whose spouses understand, it is no problem but for those who fail to disclose or who are abandoned, the need becomes eminent.

3.2.3 Belongingness, Love and Esteem

In the African setting people usually belong to a large extended family. For married women this family comprises two different families; the parents' family as well as the husband's family (in laws). Usually these are loving families. However in the event of a problem like a positive HIV test, family and especially the in-laws can threaten one's sense of belonging. This can be further aggravated by the bigger community especially where HIV related stigma is high. And given the high stigma levels in Uganda (MoH and Macro, 2006), the need for love, belongingness and support for self esteem are crucial.

Given those wide ranging needs it is questionable whether the PMTCT programme should strive to cater for all those needs.

3.3 PMTCT Program Design and Implementation

PMTCT implementation in Masaka district started as part of the nationwide PMTCT program scale up in 2002. Initially it was limited to the regional referral hospital and some research centres but has since scaled up in the entire district. This chapter describes and gives a brief assessment of the implementation process and performance of the program in the district.

3.3.1 Objectives and targets

The program is currently guided by the national PMTCT policy guidelines and draws its objectives and activities in line with the national program. The goal of the PMTCT programme is to achieve a new generation that is free of HIV and AIDS in Uganda.

Broad Objective

The major objective of the PMTCT program in Uganda is to reduce mother to child transmission of HIV by 50% by the year 2010.

(The MTCT risk of about 35-45% without intervention was taken as the baseline in 2005).

Specific Objectives

By 2010:

- 1. To provide counseling and testing to 90% of all pregnant women attending antenatal clinics
- 2. To counsel and support 50% of the HIV negative pregnant and lactating women from the PMTCT programme to remain free of HIV.
- 3. To provide family planning services to 75% of the women living with HIV and their partners identified under the PMTCT programme
- 4. To provide the recommended package for reduction of MTCT including anti-retroviral drugs (ARV) to all pregnant women living with HIV and their babies
- 5. To provide comprehensive HIV care to 75% of pregnant women living with HIV from the PMTCT programme and their families

6. To increase from 3% to 25%, the proportion of male partners of pregnant women from the PMTCT programme who are offered HIV counseling and testing services

3.3.2 PMTCT Core Activities

In Masaka PMTCT services are part of the routine comprehensive MCH package at PMTCT sites as recommended by national PMTCT program. A description of the PMTCT activities as executed in Masaka is here below.

The antenatal clinics are used as opportune contact points for many mothers. Antenatal schedules are designed by the PMTCT sites according to client volume and convenience. Hospitals with high volumes of clients operate antenatal clinics daily while smaller PMTCT sites often have specific antenatal days.

Counselling and testing is the entry point into PMTCT programs. To minimise missed opportunities counselling and testing is done routinely for all clients who come to antenatal with the opt-out approach. Also to minimise resources time and personnel, pre-test counselling is done in groups, then followed by Individual post-test counselling to prepare the clients who test for their results and to give any further information as the clients may dictate. For testing the sites use rapid HIV test kits; this enables clients to receive their results on the same day. Testing is done following a standard algorithm³ with 3 tests kits (Determine, Statpak and Unigold).

Mothers who are diagnosed HIV negative are further counselled on prevention and encouraged to test again after 6 months but only a few usually return. This follows the fact generally mothers don't comply with frequent visits to health centres.

The HIV positive women are further assessed for progress of HIV infection using WHO clinical staging and where possible CD4 counts done. They are then given ARV prophylaxis or treatment as per guide lines⁴. All clients are given nevirapine irrespective of gestational age (unless they object) and encouraged to return for better regimens where and when possible. In addition clients are given cotrimoxazole prophylaxis and treated for any inter-current infections.

For clients who miss counselling and testing in the antenatal period, routine Counselling and testing services are offered in labour and delivery as well as in the 'Well child clinics'. Routine counselling and testing in

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³ Testing algorithm; 1st test is with determine if positive it's followed by statpak, if both are positive diagnosis confirmed if statpak is negative, then unigold is used to confirm diagnosis.

⁴ Currently, Single dose Nevirapine given to the mothers at diagnosis at all sites. For sites with other ARV drugs (Hospitals and HC IVs), the regimen depends on gestational age at presentation and HIV stage; between 28-32 weeks- oral AZT twice daily until delivery, between 32-36 weeks- AZT/3TC. If in clinical or CD4 stage 3 or 4, HAART is given.

these periods also helps to identify more exposed infants, and mothers can then be educated on infant feeding and the babies given cotrimoxazole prophylaxis until they are tested. Exposed babies are given ARV syrup within 72 hours after delivery and start cotrimoxazole at 6 weeks. They are then tested using polymerase chain reaction (PCR) test kits at 3months or later.

PMTCT clients and their families are linked to chronic HIV care clinics for continued care and support where possible but for many of the sites, the clients have to be referred to other health facilities where comprehensive HIV care plus HAART can be accessed.

Family planning and treatment of sexually transmitted infections for clients is part of the routine MCH package for all antenatal clients, and as such even HIV positive clients receive this service.

Other activities include family support groups in which PMTCT clients with their spouses and children meet for further education, counselling, support and experience sharing. These activities are currently limited to just 4 PMTCT sites.

3.3.3 Strategies for PMTCT implementation

To ensure successful delivery of PMTCT services, the district adopted several strategies (DHS, 2005). Key strategies include:

- a) Strengthening health systems including human resource and infrastructure;
- b) Integration of PMTCT services into the reproductive and child health services, including addressing the linkages with other HIV/AIDS;
- c) Strengthening of Logistics and essential commodities for the PMTCT interventions supply;
- d) Advocacy and community mobilisation;
- e) Community involvement including groups of people living with HIV;
- f) Monitoring and evaluation of the interventions;
- g) Resource mobilization; and,
- h) Technical support supervision.

The named set of strategies is adequate for effective program implementation and if effected should yield good outcomes. However, having the strategies and effectively implementing them are two totally different things. Below is a description of the implementation of the named strategies in Masaka.

Strengthening Health systems

PMTCT services are delivered as an integrated service in the pre-existing health system and thus required that capacity be strengthened prior initiation of the PMTCT program. Of key importance were infrastructure and staff skills. For infrastructure, PMTCT sites where infrastructure was

inadequate, remodelling or new construction was done prior initiation of the program.

For staff skills, health workers were trained in relevant PMTCT and HIV/AIDS courses based on the Generic Training Package of WHO and the Centers for Disease Control and Prevention. Priority was given to those working in the MCH departments, and most sites have at least two staff midwives or nursing assistants trained in PMTCT.

In addition to the staff trainings, peer educator trainings were carried out to empower some HIV positive clients to offer counselling at the clinics, and to teach and support their peers on various issues regarding living positively, infant feeding, disclosure issues, and HIV prevention. This was intended to increase community participation and also to reduce staff workload. However, due to budgetary constraints it was limited to only four sites.

To enhance knowledge and skills from the trainings, manuals, guidelines and charts with instructions on standard operating procedures (SOPs) were provided for the PMTCT sites.

Maintenance of logistics supply

Maintenance of a steady flow of essential supplies for the program is critical for the program's success. Key logistics include HIV test kits and Anti Retroviral drugs (ARVs). To circumvent the challenge of disrupted delivery schedules of essential drugs and health supplies, PMTCT logistics were accorded a separate schedule of supply from that of essential drugs and medical supplies. Sites order for supplies every two months from the national medical stores and are supplied with six months' stocks. While the use of parallel schedules for logistics delivery in the district has its complications, a near steady supply of PMTCT logistics was maintained. The buffer stocks of supplies maintained by EGPAF also contributed greatly to this.

Advocacy, Community mobilisation and participation

To raise awareness in communities, a stakeholders meeting involving local political leaders was held prior to re-initiation of the PMTCT program in 2006. In addition monthly radio talk shows on local radios were held. Complementary to the district activities information, education and communication (IEC) on PMTCT are continuous activities within the national HIV prevention activities. Posters and leaflets in both English and local languages are disseminated through the health facilities and drama groups. Talk shows and spot messages on both the national television and central radio stations are held. Peer educators/counsellors are involved in HIV/AIDS education and home visiting but this is only for a few PMTCT sites.

Monitoring

Monitoring of programs allows for timely corrective changes. In order to keep track of progress of the program performance specific monitoring and evaluation tools were designed by MoH to capture the basic program indicators. These tools include:

- Integrated sexual reproductive health registers which were designed to capture PMTCT indicators among other MCH indicators in the respective clinics, so as to reduce the fragments of registers filled.
- A nationally recognised coding system developed by MoH is used by health workers to identify HIV positive mothers at any clinic. The sero-status codes of mothers are filled on all antenatal and child health cards and are kept by the mothers.
- Monthly and quarterly reports capturing indicators are filled by all PMTCT sites and submitted to the district from where they are analysed and copies sent to the ministry of health (national program office).

In addition, quarterly PMTCT site implementers' meetings are held at the district and are attended by all PMTCT site coordinators, district support supervision team and MOH representatives. At these meetings progress of program and challenges are discussed.

Coordination

The coordination structure mainly follows the government structure (See annex.3). The district has a coordinator and each PMTCT site has a focal person responsible for coordinating site activities. The structure doesn't show the involvement of other stakeholders and as a matter of fact, coordinating PMTCT services with other HIV services providers is minimal.

Partnership and Resource mobilisation

To avoid replication of resources and other challenges of vertical programs, PMTCT activities are integrated in MCH activities. The financial support is thus from the government PHC grant. However, the program receives some extra funds from EGPAF. These extra funds are an important driver of the district program as they support key activities such as procurement of prophylactic ARVs, HIV test kits, technical support supervision, trainings, implementers' meetings, psychosocial support group activities, and program coordination.

Likewise there is collaboration with existing partners in HIV activities. Key partners involved in HIV prevention in the district include:

- Uganda cares Masaka who provide comprehensive chronic HIV care at the main/regional referral hospital. They provide care for the clients from the PMTCT site with the hospital and attend to any referrals, and also carry out the CD4 count investigation for the various PMTCT sites.
- The AIDS Support Organisation (TASO) Masaka who also provides comprehensive chronic HIV care including food support and in addition have a community based home care program. There is no strong collaboration between TASO and the PMTCT program yet.

 Medical Research Council which mainly carries out research on HIV/AIDS.

Technical support supervision

Periodic update of knowledge and skill is important for quality delivery of services. In Masaka, routine technical support supervision is used to update health workers' knowledge and skills. All PMTCT sites are supervised every two months by a team of supervisors from the district. Supervision focuses on areas of weakness as reported by the supervisees and on issues that emerge from the monthly reports that are submitted to the district. The supervision also allows for delivery of feedback on performance and continued education. In addition to the district team supervision, the PMTCT sites which have chronic HIV care clinics receive clinical mentorship from experts from the main/regional referral hospital. The mentorship is mainly geared towards building capacity for the health workers at the sites to manage paediatric HIV cases.

3.3.4 Program Performance Results (Outcome)

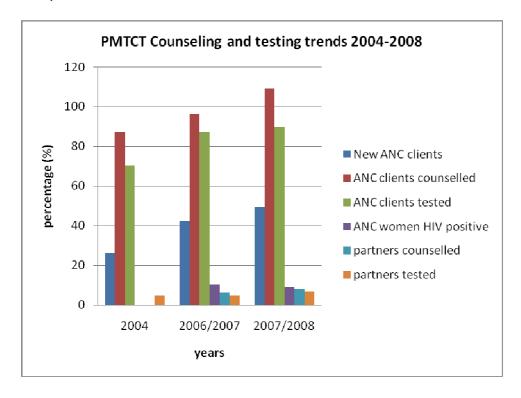
Under normal circumstances the combination of programme activities and strategies produces a good outcome. The outcome is described here below.

In 2008, of all pregnant women attending antenatal care at health facilities, 77% attended at PMTCT sites. Although this number represents only 53% of the total expected pregnant population (DHS, 2008), it points to either a strategic distribution of the few PMTCT sites currently existent, or a preference for the antenatal clients for PMTCT sites (possibly for the Counselling and testing services).

The graphs 1 and 2 show a summary of the trends of program performance in the district for years 2004, 2006/2007 and 2007/2008. The key performance indicators are linked to the PMTCT core services and the activities already mentioned above and include:

- the counselling rate which is the percentage of all new antenatal clients that are counselled;
- the testing rate which is the percentage of all clients counselled that are tested;
- the maternal ARV uptake which is the percentage of HIV positive women that receive ARVs either for prophylaxis or treatment;
- the infant ARV prophylaxis uptake; which is the percentage of babies receiving prophylaxis; and,
- The health facility delivery percentage for HIV positive women.

Graph.1



Source of data (DHS, 2005; DHS, 2008)

Graph 1 shows the outcome of PMTCT interventions for the counselling component.

The percentage of new antenatal clients attending ANC at PMTCT sites increased steadily over the years. This is because of the increase in the number of PMTCT sites which increased the geographical accessibility to the PMTCT services.

The counselling rates improved markedly and even exceeded 100% by 2008. This followed the institution of routine pre-test counselling in 2006. The counselling rate of more than 100% in 2007/2008 shows that number of clients that were counselled was higher than that of the new clients seen. There are two possible explanations for this;

- 1) extra clients who were referred from other health facilities where PMTCT services are unavailable but were not recorded as new antenatal clients; or,
- 2) errors in data recording.

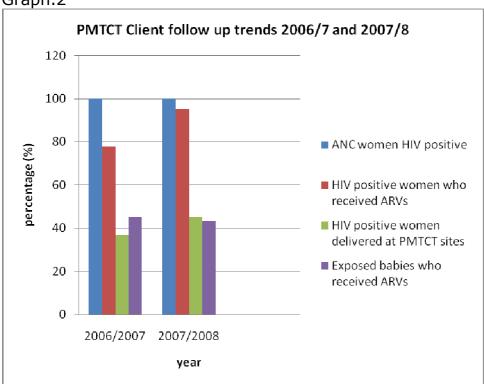
The testing rates also improved steadily. There are three possible explanations for this trend; improved supplies of test kits, improved

counselling skills of the health providers, and improved client awareness of the importance for the test.

Lastly, the counselling rates among male partners remained very low although a slight improvement is registered. No clear explanations can be made for these persistently low figures, as efforts to engage the men have been made.

Graph 2 below shows the cascade of events for the pregnant women who test HIV positive, from diagnosis, ARV prophylaxis or treatment for mother, delivery at health facility, and ARV prophylaxis for the infant. The number of HIV positive clients is equated to a hundred percent (100%) and the rest of the indicators built against this.





Source of data (DHS, 2008)

The maternal ARV uptake improved markedly to close to 100%. This figure also depicts a high results acceptance. It is the result of administration of ARVs at diagnosis as opposed to waiting until 28 weeks of gestation. The mothers delivering at health centres and infants receiving uptake remains low.

Other indicators of PMTCT performance should include: one on infant feeding, however this indicator is difficult to measure with accuracy as mothers aren't closely followed or monitored for feeding practices. Another is that on the infants who are tested for HIV and those that test

positive. These ones were confused by the monthly reporting form. The number of children tested for HIV as recorded on the report form included those children who were tested in the immunisation clinics but who had not gone through the prior PMTCT interventions, hence potentially distorting the result of the impact of the interventions.

3.4 Discussion and conclusion

This chapter was intended to assess the background information concerning Masaka PMCT programme and the context within which it was conceived. The key issues discussed here have been the needs of the clients, the implementation process/program design and the performance/outcome of the program.

The objectives of the program were in line, and many of them hinge on the four pronged strategy of PMTCT recommended internationally by UNAIDS (WHO, 2007) i.e.

- 1). Prevention of HIV infection among potential parents,
- 2). Prevention of unwanted pregnancies among HIV positive women, 3). Prevention of MTCT among pregnant HIV positive women; and,
- 4). Provision of comprehensive HIV care for HIV positive pregnant women and their families.

The PMTCT program design is good. The objectives are specific, measurable, relevant to intended clients and time-bound. With the activities and the set of facilitating strategies described above the objectives are achievable. The core activities of Masaka PMTCT program match most of the needs of the clients identified above, and directly contribute towards achievement of the objectives. Using MCH as a focal point for PMTCT activities potentially limits the extensive application of the primary prevention strategies. Only a small proportion of potential parents are pregnant and thus few present at the MCH clinics. However, the fact that the PMTCT program operates in the context of a bigger HIV prevention program should counter this.

The poor performance in some of the indicators is therefore not because of a poor program design. Rather, it is due to gaps in the implementation of the strategies, oversights like the lack of clients' needs assessment, and other institutional, structural or individual barriers.

CHAPTER 4: BARRIERS TO THE IMPLEMENTATION OF PMTCT IN MASAKA

4.1 Introduction

Despite the good program design in Masaka, implementation of the PMTCT program met several barriers. These barriers include: individual factors which are related to the clients themselves, structural which relate to the external environment in which the program operates, as well as institutional or health system related factors. In this chapter these factors will be discussed systematically.

4.2 Individual factors

4.2.1 Knowledge about PMTCT and MTCT

Knowledge about a health condition or service is a very important determinant of service utilisation by clients. For instance, if clients don't know that PMTCT services exist, they will not seek or participate in the services in the first place. Likewise if they don't know about HIV/AIDS and its consequences, they won't be moved to seek the services.

The available figures show very low levels of knowledge⁵ about MTCT and PMTCT in Uganda and Masaka. The most recent HIV sero-behavioural survey showed levels of knowledge as low as 35% by 2005 (MoH and Macro, 2006). The continued education through the use of mass media and routine counselling and education in antenatal, should have improved the levels of knowledge over the recent years. Although the magnitude of the increase cannot be ascertained, the increasing HIV testing rates suggest that knowledge is becoming a less severe barrier.

4.2.2 Demographic Characteristics

The demographic characteristics of clients, specifically education levels and socioeconomic status were shown to have little influence on knowledge and perceptions of the clients in Uganda. The 2005 sero-behavioural survey showed that the lower the socioeconomic status or education level the lower the levels of knowledge about PMTCT but only slightly (MOH and Macro, 2006). However, the socioeconomic status can lower self efficacy for the women in adhering to recommended PMTCT measures.

⁵ Level of knowledge was assessed using a composite indicator which comprised three components; 1). Knowledge that HIV can be transmitted from mother to child; 2). Knowledge that MTCT occurs during pregnancy, labour and delivery and breast feeding; and 3). Knowledge that medical personnel can offer special drugs that can be used to reduce the risk of MTCT.

4.2.3 Health Beliefs

The health beliefs were found to explain individuals' motivation towards behaviour change for HIV prevention (UNAIDS, 1999). Negative health beliefs can thus prevent PMTCT clients from testing or adhering to recommended interventions (see box.2).

Text box 2: IMPACT OF HEALTH BELIEFS ON THE PMTCT CASCADE

Health belief Perceived susceptibility to health problem	Individual's assessment Am I at risk for HIV? No	Implication No need to test or if test positive will be in denial. hence no subsequent visits
Perceived seriousness of the condition	How serious is AIDS; how hard would my life and the baby's be if we have HIV? No	No need to test or if test positive, follow up interventions are not very important.
Perceived belief in effectiveness of the new behaviour	Will the PMTCT interventions prevent transmission of HIV to my baby? <i>No</i>	No need to test or if test positive, wont adhere to interventions. Hence loss to follow up
Perceived benefits of preventive action	If I test positive, can I prevent HIV infection of my baby, can I get care for my infection? <i>No</i>	No testing
Perceived barriers to taking action	If I test positive how will i tell my husband and family? How will they and community react?" <i>No</i>	No test, or if test positive No disclosure. Difficulties in adhering to interventions

Source: author

The perceived severity of consequences of HIV infection is no barrier in Masaka, as at least every adult has by now seen someone suffering from AIDS. However, all other health beliefs appear negative. For instance, by 2005, only about one in five persons considered themselves at risk of getting HIV/AIDS (MoH and Macro, 2006). The PMTCT clients' perception of the PMTCT program as beneficial to the mothers in Masaka is not known. But, if the findings from Malawi are a guide (see excerpt below), it is probably negative. As only a quarter of the PMTCT sites have comprehensive HIV care clinics and no good referral system.

"PMTCT is much about the baby and not enough about the mother" (defaulter) (Bwirire et al., 2008)

Perceived barriers were specifically shown to prevent disclosure in some PMTCT programs in Uganda (Bajunirwe and Muzoora, 2005; Nuwagaba et al., 2007) and certainly holds for Masaka as well.

4.2.4 Disclosure challenges

Disclosure of sero-status especially of HIV infected clients particularly to sexual partners is important for two main reasons (Maman and Medley, 2004). First, disclosure may encourage a partner to have a test and subsequently engage in HIV preventive behaviour like condom use. Secondly, disclosure allows for the woman to obtain psychosocial support, which is important for her to adopt and adhere to care and treatment, infant feeding and future planning.

Unfortunately, disclosure of sero-status especially of HIV infected clients is a big challenge for PMTCT programs in Masaka. Explanations given by clients include fear of loss of economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationships. These findings are consistent with research findings in several other RPS (Maman and Medley, 2004; Bajunirwe and Muzoora, 2005; Brou et al., 2007; Kasenga et al., 2008).

4.2.5 Stigma and discrimination

HIV stigma and discrimination are defined as "a 'process of devaluation' of people either living with or associated with HIV and AIDS; Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status." (UNAIDS, 2007).

Stigma and discrimination are major obstacles for PMTCT and other HIV prevention programmes and have been reported for all countries. Unfortunately, the lack of awareness of the levels of HIV related stigma in communities is a common finding (UNAIDS, 2007), and could partly explain why it persists.

HIV/AIDS related stigma is a complex phenomenon as it stems from socio-cultural values of communities, with victims being viewed as perverts of the socially acceptable norms and behaviour and thus serving their sentence (Karamagi et al., 2006; Mawar et al., 2005; Aggleton et al., 2003). This notion breeds various levels of stigma and creates problems along the entire PMTCT cascade (Nguyen et al., 2008).

First, no one wants to be "bad" in society. So either the women will perceive themselves not at risk of HIV, or would rather not know and thus decline the test, or - if they test positive - they will be in denial or self blame and drop out of the program. Secondly, victims who test positive speculate a negative reaction from society, thereby accumulating fear. This stops them from disclosing their status and adhering to any recommended interventions and subsequent follow up. And finally, the victims who disclose or are suspected may actually be stigmatised and discriminated against by the society or suffer violence from partners.

Despite the twenty five years history of HIV/AIDS in Uganda, and the several sensitization and advocacy programs implemented (UAC, 2001); stigma and discrimination still characterize the disease. The most recent HIV/AIDS sero-behavioural survey showed that only 19% and 28% women and men respectively expressed a positive attitude⁶ towards people living with HIV/AIDS (MoH and Macro, 2006). This high level of stigma which is even higher among the women plays a big role in the drop out of clients from the PMTCT program.

4.2.6 Male involvement

Like elsewhere in Uganda and other RPS, partner involvement in PMTCT programs in Masaka is extremely low. The most recent report shows that only 8% of partners are counselled in antenatal (DHS, 2008), and very little improvement has been seen over time (see graph 1). This poses a challenge for the program as studies have shown that the willingness of women to accept HIV testing strongly depends on their partners' attitudes (Bwirire et al., 2008; Bajunirwe & Muzoora, 2005).

Efforts to involve men in PMTCT such as formal invitations through their spouses, attending to couples first in antenatal and continued information through media were done in Masaka but showed little progress. No clear explanation could be ascertained for this. Studies in other RPS reveal that the major obstacle to men's participation is the lack of knowledge and information on PMTCT/ANC services (Peacock, 2003, Mullick et al., 2005, Theuring et al., 2009), and particularly the fact that men were expected to participate. Other obstacles include:

- The lack of finances and time to attend ANC/PMTCT clinics during the usual scheduled clinic hours (Walston et al., 2005; Theuring et al., 2009);
- The negative attitudes of some service providers towards men's participation. For example, not allowing partners in examination or delivery rooms (Peacock, 2003);
- the socio-cultural beliefs and regard of ANC activities as female responsibility (Peacock, 2003, Theuring et al., 2009, Walston et al., 2005); and,
- An interesting one is that, for various reasons, actually some women do not want their partners to go to the ANC (Mullick et al., 2005). This is a very important finding since most clinics in Masaka invite partners through the women.

⁶ A composite indicator was used to determine the attitude. It included 4 questions for the respondents; 1). Whether they would be willing to buy sugar, fresh vegetables or other food staff from a market vendor who had HIV/AIDS? 2). whether a female teacher who has HIV but is not sick should be allowed to continue teaching? 3). whether they would be willing to care for a relative sick with HIV/AIDS in their household? And 4). Whether they would want to keep it secret if a family member had HIV/AIDS?

4.3 Structural Factors

4.3.1 Poverty

The ability of the client to afford a service is one of the distal determinants of utilisation of any service. PMTCT services require extra follow up visits from clients, and also require that a mother ensures a good nutrition both for herself and the baby. This creates an extra demand on the household finances. Unfortunately, not many PMTCT clients can sufficiently meet these extra costs. The poverty levels in Masaka are still high (UBOS, 2007). This leads to subsequent drop out or failure to adhere to infant feeding practices. Poverty is the biggest limitation to infant feeding choices. And with the PMTCT services still available at less than 50% of health facilities in the district (DHS, 2008), transport costs to the PMTCT sites become a very big barrier to routine follow up visits.

4.3.2 Gender inequity

Gender disparities among men and women have been implicated in the feminisation of the HIV/AIDS epidemic (UNAIDS, 2007). Many women are subjected to harmful social norms and practices that increase their vulnerability to HIV/AIDS such as:

- restricting women's access to HIV/AIDS information and services;
- severely limiting women's control over their sexual lives, leaving them vulnerable to sexual violence and abuse; and,
- depriving them of economic resources and legal rights necessary to protect themselves from HIV/AIDS.

In Uganda, and Masaka men still control women's lives including sexual matters and use of money (Okong, 2006), and thus influence women's decisions. This is important to PMTCT programs as women will only test or adhere to interventions if their partners consent.

4.3.3 Culture

Culture can prevent adherence to PMTCT recommendations even when clients have clearly understood the instructions. Breastfeeding is one of the most popular infant feeding cultures in Masaka and Uganda. This culture has been identified as a challenge for HIV positive women in making infant feeding choices in some RPS (Bwirire et al., 2008; Agadjanian and Hayford 2009); and certainly holds for Masaka. For some women a thought of not breast feeding their infants alone can prevent them from testing, while for others even after choosing the replacement feeding option, they end up breastfeeding and at worst mixed feeding. The culture of living with in-laws especially after giving birth complicates the situation further. Similarly culture has been shown to contribute to home deliveries in some parts of Uganda (Parkhurst et al, 2006) and to some extent applies to Masaka.

4.4 Institutional barriers

4.4.1 Staffing levels

The challenge of human resources is a problem for the entire health system in Uganda (MOH, 2008) and introduction of any new services only increases the burden. Currently Masaka district operates at staffing levels of 38% of the required staff numbers (DHS, 2007). The integration of PMTCT services as part of the MCH package is now the international recommendation (WHO, 2007) and the use of the regular MCH staff as opposed to separate cadres of health care providers is emphasized (Sripipatana et al., 2007). Integration increased workload for service providers as it was not matched with extra staffing. Increased workload not only increases the waiting time for the clients, but also compromises the quality of counselling, creating opportunity for loss to follow up of clients (Bwirire et al., 2008).

4.4.2 Technical Skills

Adequate training and retraining in PMTCT relevant courses has been done for MCH staff. Unfortunately, for most of the sites only the staff members working in MCH departments have been trained. This creates a gap in skills and competency among the staff in other departments, and makes it impossible for them to execute duties when the trained staff members are absent. This complicates the problem of staff shortages and becomes more troublesome when there are staff transfers, rotations, resignations or retirement.

4.4.3 Professional Ethics

Negative attitudes, discriminatory tendencies, and breach of confidentiality of health workers towards HIV positive clients are reported to hinder clients from testing or returning for subsequent care (Chinkonde et al., 2009) but the extent to which this occurs in Masaka has not been verified.

4.4.4 Motivation

Motivation of health workers in Uganda is generally poor. Occasionally, low salaries have been a cause of strikes (Mwanje and Wanyama, 2008). Staff salaries are as low as 50 US dollars per month for lower cadres (DHS, 2008). This can barely match the cost of living. Yet in the author's opinion lower cadres bear the bigger burden of the workload. Technical support supervision, trainings, and other financial incentives that are said to motivate health workers (Mathauer and Imhoff, 2006) have been seen to do so specifically when tagged to monetary incentives. Logistics shortages have also been reported as de-motivating factors by the health workers.

4.4.5 Logistics shortages

Shortages and interruption of supplies for PMTCT are common challenges for most PMTCT programs in Uganda (MOH, 2007). In Masaka logistics supply for PMTCT has been fairly stable, with minimal stock outs of the

key supplies. However, for PMTCT sites which don't have HIV chronic care clinics and HAART, supplies of the combination drugs are a problem (DHS, 2008). PCR materials are accessible at only ten of the PMTCT sites and available only quarter of the time needed.

4.4.6 Policy and operational guidelines

Currently all implementing sites in Masaka have copies of the national policy guidelines and charts of SOPs. However, in my experience of supervising implementing sites, many of the health workers don't read the guidelines or follow the SOPs. This is probably attributable to a) lack of time (since for most of the days they are busy seeing clients), and - more importantly – to, b) the rather poor reading culture among nurses.

In spite of not reading the guidelines, some of the policies are crucial and well adhered to. A popular one is RCT and group pre-test counselling. This policy saves time and minimises missed opportunities. However, routine counselling has been identified as a barrier to testing, acceptance of results, or refusal of prophylactic drugs in some programs (Bwirire et al., 2008; Nuwagaba et al., 2007). This is because some women may not be aware of the policy or ready for the test and feel coerced into accepting the test. Similarly group counselling has been found to inhibit some clients (especially private clients) from participating in PMTCT counselling (Bajunirwe and Muzoora, 2005).

4.4.7 Infrastructure

Infrastructure and space is not a big problem for Masaka, except for a few new sites where there is not enough private room for individual counselling (here, it will be a challenge to scale up activities to lower HCs, since many of the HC IIs are not spacious).

4.4.8 Comprehensive HIV Care Services

The lack of comprehensive HIV care and HAART can prevent clients from testing (the concept of "perceived benefit" discussed earlier). Currently in Masaka slightly over a quarter of the PMTCT sites have HIV chronic care clinics that provide HAART (DHS, 2008). Clients from these sites need to be referred but no clear referral system is in place to ensure this.

4.5 Conclusion

In conclusion, the major barriers affecting Masaka district are stigma and low male involvement both of which complicate sero-status disclosure and make it impossible for PMTCT clients to adhere to recommended interventions. The staff shortages and low motivation of the health workers reinforce the individual barriers, as not enough time can be accorded to the clients to help them overcome their challenges.

CHAPTER 5: BEST PRACTICES; EXPERIENCE FROM RESOURCE POOR SETTINGS

5.1 Introduction

Different countries have had different strategies of coping with the challenges of the PMTCT programme. This chapter presents experiences of best practices in implementing PMTCT programs and addressing specific challenges in different countries. Special focus will be on those strategies that address challenges and barriers similar to those experienced in Masaka district as presented in the preceding chapter which include: strengthening human resource capacity, stigma reduction, promoting disclosure, and involving men.

5.2 PMTCT components packaging

5.2.1 Counselling and testing

Routine counselling and testing for HIV in antenatal is the current policy and practice in many RPS and has showed increase in uptake of PMTCT services (Manzi et al., 2005; Creek et al., 2007; Kebaabetswe et al., 2007; Mugore et al., 2008). RCT was found to offer several benefits such as:

- normalising HIV testing and thus reducing stigma around HIV/AIDS (Creek et al., 2007);
- minimising missed opportunities, if health workers are well trained and have the necessary standard guidelines (Bajunirwe and Muzoora, 2005);
- quickly diffusing awareness in communities; pregnant women who go through the process inform the rest of the services provided (Mugore et al., 2008); and,
- Reducing workload for the health providers (when RCT is accompanied by group pre test counselling) (Bolu et al., 2007).

Re-screening of HIV negative women in the later gestational age or during labour and delivery is highly recommended. Increasing numbers of women who seroconvert after the first HIV test have been reported (Bolu et al., 2007).

5.2.2 ARV Drug Administration

ARVs dramatically reduce the maternal viral load thus reducing the risk of MTCT (Volmink et al., 2007) and are thus a core component of PMTCT. A shift from single dose nevirapine to more efficacious prophylactic regimens is now an effort for many PMTCT programs. However, even the success from use of single dose nevirapine can't be ascertained, since measuring adherence at many sites has been hard.

Currently, in Masaka mothers are given nevirapine at diagnosis and this increases uptake. However, whether mothers eventually swallow the drug is hard to ascertain; as many don't return for subsequent visits. In Rwanda, US government supported PMTCT sites have a tracking system to follow up women in the communities reminding them of their appointments and some deliver the nevirapine to the mothers at their homes (USAID, 2005). This approach guarantees a higher degree of certainty.

5.2.3 Labour and delivery

Elective Caesarean Section (ECS) as a component of PMTCT has been the subject of several studies. In their review of 26 studies, Read and Newel (2005) found out that Elective Caesarean section (ECS) highly effective in reducing MTCT. However, in the only randomised controlled study by Eur Model Del, (1999) the findings were highly significant with 80% reduction in MTCT, but only among mothers who had not taken ARVs (cited in Read and Newell, 2005). This implies that in RPS where ECS is not feasible for the lack of doctors, cost, and lack of equipment and the associated maternal morbidity and mortality (Lamptey and Gayle, 2001), attempt to invest in ECS strategy rather than strengthening adherence to prophylactic ARVs is unwarranted.

5.2.4 Infant Feeding

To maintain gains achieved by antenatal and peri-natal interventions, postnatal MTCT has to be mitigated. Safe infant feeding is crucial to this end, and supporting mothers to adhere to exclusive replacement feeding or breastfeeding is important. In Zambia, Infant feeding counselling is done at every opportunity from the group sessions during ANC, pre- and post- test counselling, after delivery, growth monitoring visits. This is similar to how it is done in Masaka except that in addition, women in Zambia have the option of visiting community based counsellors for one to one infant feeding counselling (Horizons, 2003). The community counsellors are nearer the clients and easier to reach than health workers at the distant health units.

5.2.5 Early Infant Diagnosis

To prevent AIDS among HIV infected infants and to alleviate the unnecessary costs for uninfected HIV exposed babies to attend PMTCT follow up clinics, early diagnosis is important. Commonly used serological tests provide false positive results among babies (until after 12-18 months) as babies still have maternal antibodies and are thus not useful. PCR tests confirm HIV status as early as 6 weeks. However, in breast feeding populations the continued risk of MTCT through breast feeding warrants further HIV testing at later stages (Sherman and Jones, 2005) and the test is not readily accessible in most RPS.

Sherman and Jones (2005) in their study in South Africa demonstrated Oral Fluid HIV Tests (OFT) as a feasible diagnostic strategy in RPS. OFTs

performed at 11 months or more offered a markedly lower false positive rate (negative predictive value >99%, Sensitivity 87-95% and specificity 93-97%) than serum HIV ELISA tests. Using OFTs reduces the need for re-testing, requires minimal expertise for sample collection, and samples are stable for fairly long (21 days). This allows for their use even in the remotest areas with transportation problems. The non invasive sample collection procedure increases the acceptability by mothers and their infants, and the minimal skills required increase accessibility. Oral fluid tests provide a good alternative for PCR. Unfortunately, no further studies to support Sherman and Jones' findings in South Africa could be found.

5.3 Program support strategies

5.3.1 Quality Assurance

Ensuring a good quality of the PMTCT services is important for sustained uptake of the services. Quality assurance is one of the ways this can be achieved. Unlike Masaka, where quality assurance is predominantly done by the district team, in Rwanda, PMTCT sites have their own quality assurance teams that closely analyse the process of PMTCT service delivery, identify and implement key changes necessary to improve quality. The quality assurance teams also closely monitor the performance indicators, identify good practices and share them with other sites (USAID, 2005).

5.3.2 Community Participation

Maintaining links between health facilities and the communities is essential for the promotion of services and follow up support for PMTCT clients. In Zambia, a strong Community component was established (Horizons, 2003). Various community groups including: home-based care groups, mother support volunteers, positive living groups, TBAs, child health promoters, and community-based distributors were trained and involved in several MCH/PMTCT activities such as;

- Educating the community about HIV, MTCT, and VCT;
- Providing support to mothers after they returned home following delivery;
- Educating men about their role in MTCT prevention and other reproductive health issues;
- Facilitating activities with male community health workers acting as role models for other men; and,
- Providing health education and individual counselling at growth monitoring posts.

The system is further supported by a strong referral network among the community based organisations (CBOs) was established including: the development of a referral directory, referral slips, and a system of regular meetings between partners.

5.3.3 Strengthening Human Resource capacity

Strengthening human resource capacity in RPS has been done in several ways. Innovative strategies that have been used in some RPS are presented here below.

In Zambia, some sites pay the existing trained health workers an overtime allowance to work in their free time. Health workers during their off duty time often work in other private clinics. This fact was exploited by the program. Instead of letting the staff to work elsewhere they are paid to continue with the services at the sites. This strategy is more cost effective than recruiting and training extra staff that would require full time salaries and training costs (Chi et al., 2005).

In Zimbabwe, Botswana and South Africa, training of new cadres such as lay counsellors to offer services has been done. In Botswana high school graduates are trained for two weeks in counselling and then recruited for counselling (Sripipatana et al., 2007). The use of peer counsellors (HIV infected women) in Zimbabwe was shown to have extra benefits. Peer counsellors act as mentors for the newly diagnosed on several complex issues like, negotiating safe sex, coping with bereavement, domestic abuse, spousal abandonment, discordant test results and family planning (Shetty et al., 2008).

Involving community workers such as traditional birth attendants (TBAs) in the delivery of PMTCT services; TBAs have been engaged at varying levels in different programs in Tanzania and Cameroon (Sripipatana et al., 2007). In Cameroon TBAs went as far as testing for HIV. The success rates in infant nevirapine uptake was a lot better with use of TBAs than at the health facilities 85.7% and 41.3% respectively (Wanyu et al., 2007).

As to effective task allocation and reallocation, skilled health providers should be allowed to perform the tasks they alone can do. Those that can be done by junior staff should be left for the juniors for instance: tasks like registry of clients need not be done by nurses (Sripipatana et al., 2007).

5.3.4 Mobilising space

The need for privacy raises a need for enough space. Where resources cannot allow for construction of new buildings, innovative strategies have to be used. In Uganda antenatal services were shifted from single clinic days to daily thus reducing crowding on any day. In Kenya truck containers were modified with windows and air conditioning facilities and in Zambia tents are used (Sripipatana et al., 2007). The latter options offer opportunity for scaling up of services where space could be the limitation.

5.4 Involving men

Involving men in participation in PMTCT and MCH activities is a challenge for many RPS, but some countries have implemented strategies that yielded impressive results in some sites. For instance, some countries have adopted more proactive strategies that involve reaching out to the men as opposed to waiting for the men to come to the clinics –like is done in Masaka-. In Zambia, health providers talk directly to the male leaders rather than the women. Similarly in Kenya community education sessions on PMTCT are given in places where men gather and other male support groups, and have seen increase in participation of up to 40% testing rates (UNICEF, 2003).

In Rwanda a PMTCT partner involvement initiative was set up. The initiative comprised three activities: 1) inviting partners to accompany their wives to the ANC through letters, 2) involving men in the reproductive health services given to their spouses like prenatal counselling, and 3) a community provider approach which promotes male involvement by challenging attitudes and behaviours of men that compromise their own health and that of their families. The initiative raised partner testing rates from as low as 10% to 88% in a 2 years period (USAID, 2005). The activities of this initiative are similar to those of Masaka except for the third component, and thus the difference in performance in Masaka and the sites in Rwanda re-emphasizes the importance of a community provider approach.

Other interventions that have been used but with varying levels of success include: operating weekend or evening clinics for men as that is the time they may be available, and coordinating with local companies to grant their employees paid leave when they escort their wives to clinics (Sripipatana et al., 2007).

5.5 Reducing Stigma and Discrimination

Several interventions have been used to reduce HIV related stigma and discrimination.

In their review of eleven studies in developing countries - Uganda, Tanzania, Jamaica, Israel (Ethiopian community), India and Zimbabwe - , Brown et al (2001) revealed four types of interventions whose effect on stigma reduction (at least short term) had been proved:

- 1). Information based approach in which information or facts, written or verbal are disseminated to individuals or communities through leaflets, media advertisement, peer education, guided group discussions, classroom style factual presentation.
- 2). Counselling approach which provides support for people living with HIV/AIDS (PLHA) through one to one counselling and support groups.
- 3). Coping skills acquisition which involves role plays, reframing and relaxing techniques, master imagery, scripting and group desensitization.

4). Interaction of affected groups with general public through live testimonies, visualization of being a PLHA; in which the people living with HIV/AIDS themselves take the initiative to overcome self stigma.

The use of multiple approaches and the targeting of communities like commercial farmers and their employees in Zimbabwe, primary school children in Tanzania, the youth in Jamaica offer a cumulative effect.

While stigma reduction with comprehensive approaches such as named above can be achieved, can low levels of stigma be sustained? (Brown et al, 2001). Experience from Brazil and Haiti delivers hope on this issue. Improving the quality and access to clinical services for HIV care greatly reduces stigma in communities. In Brazil and Haiti, people previously overtly stigmatised in some communities were able to regain their status in communities after successful treatment with HAART (Castrol and Farmer, 2005; Abadı´a-Barrero and Castro, 2006). This finding offers hope for PMTCT programs that are now tailored to a comprehensive package of care for mothers and their families.

5.6 Promoting Disclosure

Most PMTCT programs report disclosure challenges and thus no concrete or tested best practices could be deduced. However, many studies on the barriers to disclosure have been done and offer insight into possible good practices for disclosure. Important findings from these studies include the following:

Although fear of a negative reaction from partners is a big hindrance of mothers from disclosing their sero-status to their partners, very few women who disclose their status actually suffer the risks of disclosure. In their review of twenty studies Maman and Medley (2004) found that in eighteen of the studies majority of women reported benefits of disclosure. These findings are reaffirmed in several more recent studies (Varga et al., 2006, Brou et al., 2007, Ezegui et al., 2009). It is also revealed that the risk of violence following disclosure is higher among women with history of violence in the relationships (Maman and Medley, 2004; Kiarie et al., 2006).

In their study in Cote d'Ivoire, Brou et al., (2007) reveal special categories of mothers who find problems disclosing their status. These categories include: women who don't live with their partners and thus lack opportune time; women living with their co-spouses, mothers in law or other family members and thus lack confidentiality or privacy; and women who are very young mothers and thus don't have enough conjugal experience. In the same study three opportune moments for disclosure were identified. The first is at a few weeks just before delivery. The second is at resumption of sexual activity; and the third, at weaning. This implies that psychosocial Support for HIV positive mothers can be better targeted to

these special categories and or at these opportune moments to yield better results.

Proposed interventions to improve disclosure (Maman and Medley 2004) include:

- 1) identification and referral of domestic violence in HIV counselling and testing programs;
- 2) cross training of HIV and domestic violence staff;
- 3) modification of HIV counselling approaches;
- 4) community based initiatives to empower women and minimise HIV related stigma; and,
- 5) Partner notification policies.

Counselling approaches which by far should be the easier intervention can take any of the following forms. First, use of role plays and behaviour rehearsal techniques to help women develop their communication skills. Secondly, ongoing counselling and HIV support groups in which repeated counselling on disclosure is done and specific disclosure plans developed. Thirdly, mediated disclosure in which a counsellor or client's trusted friend mediates the disclosure process, and finally, couple counselling and testing.

Couple counselling is highly recommended (WHO, 2007) as it completely alleviates the need for the woman to disclose to the partner however, getting couples to attend clinics together is a challenge. In attempt to solve this challenge, in some sites in Zambia and Rwanda influential people like community leaders, religious leaders, NGO/CBO representatives, collectively referred to as Influence Network Agents (INAs) within the vicinity of VCT centres were trained and charged with encouraging and inviting couples for VCT on one-one level (Allen et al., 2007). The INAs were paid an allowance according to the number of couples they mobilized.

5.7 Conclusion

In conclusion, the key message is that effective PMTCT implementation in RPS requires empowering communities to actively participate in the various PMTCT activities. Active community involvement not only reduces the burden on the health workers, but also increases awareness in communities, reduces stigma surrounding HIV and ownership of the PMTCT program all of which improve effectiveness of the PMTCT core activities.

CHAPTER SIX

This last chapter presents a discussion on the emerging key findings, a conclusion and recommendations.

6.1 Discussion

The overall objective of this thesis was to identify best practices for improving PMTCT implementation in Masaka district Uganda. The first section presented a description of the PMTCT clients' needs, program design/implementation process and outcomes of the PMTCT program in Masaka. The second section presented the barriers to implementation and the third section presented the best practices in RPS. The key findings are discussed here below;

Pregnant women have various needs that range from basic to abstract needs. These needs vary with time throughout the antenatal and postnatal periods, and thereafter. The basic needs vary over time and among clients depending on the socio-economic environment of the clients.

For good program outcomes, the program design should be able to meet the needs of the clients, and to counteract potential barriers. The program design of Masaka was adequate as the objectives were specified and implementation strategies instituted. The objectives and activities matched most of the clients' basic needs identified. However, many of the needs identified here emerge from international literature and thus may not be the actual priority needs of the clients.

The combination of the strategies is adequate. However, in the author's experience and experience from other RPS, gaps in implementation of some of the strategies exist. For instance, the separate supply schedule of PMTCT logistics; it may have contributed to the steady flow of supplies, as specific attention and time is accorded to management of the supplies. However, this parallel system duplicates work for the health workers and often leads to late submission of orders. Streamlining the flow of the essential drugs and health supplies and merging the schedules should be the way forward. Not only will it reduce the burden for the health workers but also ensure availability of other drugs and health supplies which are equally important for the PMTCT program.

Quality assurance doesn't feature strongly. The routine technical support supervision visits are used to assess quality of services issues. However, this is inadequate as a thorough assessment can't be done. The Rwandese model of quality assurance teams at the PMTCT sites is a better strategy (USAID, 2005). This requires capacity building for the PMTCT sites and for

the case of lower units where staffing is low, health unit management committee members can be included on the teams.

Community mobilisation and participation in PMTCT is very limited. The involvement of peer educators/counsellors at only a few sites is insufficient, and so is just a single stakeholders' meeting. Media shows and the IEC and posters/leaflets are passive and cannot adequately elaborate the necessary details. Active community involvement using various community based groups and volunteers like in Zambia (Horizon, 2003) should offer better results. This requires additional financial resources than currently available in the district and will thus call for stronger partnerships with existing stakeholders, and more sourcing of funds.

How far community involvement in PMTCT activities should go, is debatable. For instance, Should the TBAs be involved in administration of PMTCT prophylaxis? Over five years ago, Kironde et al., (2003) proposed that TBAs be used to supplement the efforts of health providers in PMTCT services in Uganda. They argued -plausibly- that; lay people had been used successfully to deliver and supervise more complicated therapy like TB treatment; TBAs are closer to the women and in some areas more popular and influential than the health facility workers, and many of the TBAs had received some official training in MCH (Kironde et al., 2003). The tremendous success achieved by some of the PMTCT programs in Cameroon who actively involve the TBAs in administering ARVs for the PMTCT clients (Wanyu et al., 2007) further supports their arguments.

The hesitancy of involving TBAs in PMTCT in Masaka and Uganda stems from the evidence of lack of impact on reducing maternal mortality despite training them (Bergström S and Goodburn E, 2001). This hesitancy is unwarranted. Recent evidence from a Meta analysis of sixty studies reveals that trained TBAs can contribute to reduction of maternal mortality (Canavan, 2009). They just need a supportive environment. A bigger concern would be confidentiality as raised by clients in Zimbabwe (Perez et al, 2008). However, evidence in Cameroon shows that sensitizing and training the TBAs effectively overcomes this problem (Wanyu et al., 2007).

Pregnant women meet a host of socio-cultural and economic barriers. It may take time before these barriers are surmounted. Therefore, expecting mothers to deliver at health facilities is a mirage for the health system in Masaka and Uganda. For example, despite efforts to attract pregnant women to health facilities, the past four years' records show persistently low health facility delivery percentages of less than 33% in Masaka and Uganda (DHS, 2008, MOH, 2008). If the success achieved at counselling and testing in ANC in Masaka is to be maintained, the potential role of the TBAs and other volunteers in PMTCT prophylaxis should be explored.

Effective involvement of TBAs and other community volunteers requires extra financial resources to build capacity through trainings, support supervision and other logistics including transport and stipend. For Masaka where PMTCT services are still confined to only public and PNFPs and only about half the health facilities, this poses another question. What should the district's priority be; scaling up of services to all health facilities or building capacity among community volunteers where PMTCT sites are present?

The scaling up of services to the lower health facilities is not contestable as it is part of the national plan to attain universal coverage of PMTCT services (MOH, 2006). The health facilities are within the formal health sector, have the advantage of pre existing salaried personnel and are supervised by the different levels of administration. Responsibility, accountability and sustainability within the structure are easy to ensure. However, both national and district reports (MOH, 2007; DHS, 2008) show that scaling up drastically improves only counselling and testing, which in itself is not an end for the program. Concretising current successes with extra hands from community volunteers will help the program mature faster, allowing for scaling up of a mature program.

Judging from program performance results it is clear that the PMTCT program is not meeting special resistance as a program per se. This is because the pattern of events following initial contact of the PMTCT clients with the antenatal clinic almost follows the same trend as the usual maternal care (see table 2). For instance, counselling and testing is almost done for all clients just like other MCH activities moreover almost all HIV positive clients receive their ARV prophylaxis. The subsequent loss to follow up is at labour and delivery and yet with better rates than the general population.

However, the fact that special information on protection of the babies is presumably given to the PMTCT clients, makes their loss to follow up a special case. Findings from this study reveal that the cause of the loss to follow up is a complex interaction between individual, structural and health institution factors. Key individual factors include stigma, disclosure problems, and low male involvement. These are deeply rooted in structural factors of gender inequity, poverty and culture; and are complicated by the prevailing institutional factors of low staffing levels and motivation, lack of comprehensive HIV chronic care services at PMTCT sites.

The structural factors (gender inequity, culture and poverty) are responsible for the chronicity of many of the individual barriers. Communities need empowerment to overcome these issues. However, this cannot be done by the health sector alone. Collaboration with other sectors especially education, gender, agriculture is important.

Stigma is often attributed to lack of knowledge or misconceptions about HIV/AIDS (UNAIDS, 2007). However, the levels of stigma revealed in Uganda by 2005 (MoH and Macro, 2006) disqualify the notion. After 23 years of implementing all proven stigma reduction interventions of information based approach, counselling approach, coping skills acquisition and interaction of affected groups with general public, one would expect very low levels of stigma. Perhaps this reaffirms the doubts of Brown et al., (2001) that once reduction of stigma has been achieved low levels can be sustained, and supports the concept of stigma being a product of societal values (Aggleton et al., 2003; Mawar et al., 2005; Karamagi et al., 2006).

For their proven role, the stigma reduction interventions should continue. But they should be better targeted to the youth who in Masaka Uganda seem to harbour a lot of stigma (MoH and Macro, 2006) mainly because they don't consider themselves at risk, school children who can spread to the adults as well. However, improving the availability of quality chronic HIV care in Masaka should supersede; as it has been proven to reduce stigma and reverse its consequences for the victims (Castrol and Farmer, 2005; Abadı a-Barrero and Castro, 2006).

The fact that disclosure of HIV status is not associated with many or frequent negative reactions as feared by many clients (Maman and Medley 2004; Varga et al., 2006; Brou et al., 2007; Ezegui et al., 2009) should offer hope for the program. Clients should be informed of the same. However, recognition of the clients who are at risk of negative effects is crucial. Health workers should proactively elicit history of domestic abuse in relationships during the counselling and offer the appropriate support. This requires that health providers' capacity to manage domestic violence is built and that referral centres to handle cases of domestic violence are available.

Modification of counselling approaches; to use role plays and behaviour rehearsal techniques to help women develop their communication skills, ongoing counselling and HIV support groups, mediated disclosure and couple counselling and testing is very much needed. However, it requires more human resources than currently present in the district. The use of peer counsellors has been applied in a few of the PMTCT sites and its impact at the sites is yet to be measured. Scaling up the use of peer counsellors to other PMTCT sites will require careful assessment of motivation issues. For couple counselling improved male partner participation is a prerequisite.

The persistently low male partner participation in Masaka despite attractive practices suggests that men are not eager to attend ANC. This is similar to findings in Tanzania, where couple counselling in ANC, and male clinics showed little progress in the involvement of spouses in PMTCT (Msuya et al., 2008). The findings in Zambia, where men were 4 times

more willing to take an HIV test outside the ANC than at ANC -where crowding was a factor- (Burke et al, 2006 cited by Msuya et al., 2008) support a change in strategy. Like in Rwanda, Zambia, and Kenya, the strategy should be, actively reaching the men with RCT in other clinics where they present, and in the community where they gather using a community provider approach.

In Masaka, RCT has taken firm root and like other RPS has increased PMTCT uptake rates. Although advantageous, RCT in antenatal has raised concerns for human rights activists (Gruskin et al., 2008) and has been identified as a cause of loss to follow up (Bwirire et al., 2008). The extent to which the policy affects the PMTCT cascade in Masaka is hard to interpret. The high HIV test acceptance and the higher percentage of HIV positive clients than the general population delivering at health facilities, suggests a welcome policy. On the contrary, the high loss to follow up of PMTCT clients despite the various contact points in the immunisation clinics could indicate that some clients feel coerced into testing; and that pre-test counselling could have been reduced to simple information giving.

6.2 Conclusion

The reduction of MTCT rates in Masaka Uganda to rates reported for developed countries is feasible and highly achievable. To achieve this, mere identification of sero-positive women is not enough. Clients should be maintained in the continuum of PMTCT and HIV chronic care. The PMTCT program design in Masaka is responsive to most of the needs of clients; and most of the objectives and activities match international recommendations and best practices identified in other RPS. The gaps in performance are a result of the combination of inadequate implementation of the planned strategies, and the complex interaction between the individual, structural, and institutional barriers. But also echo the preexisting challenge of the health system capacity to adequately follow up pregnant women. Effective PMTCT implementation will require task shifting to involve community workers and deeper engagement of community than currently done in Masaka; A shift from a facility-based approach to a community-based approach.

6.3 Recommendations

From the findings and conclusions of this study, below is summary of the recommendations.

Policy level

- ✓ Active community involvement: identification of potential CBOs and volunteers should be done, and motivation & logistics issues carefully assessed.
- ✓ Quality assurance teams should be established at the PMTCT sites. These will require support and training of site teams as well the health unit management committee members where necessary.

- ✓ Strengthen partnership and coordination with various stakeholders
- ✓ Establish a strong referral link between the PMTCT sites without comprehensive HIV care services to those that have. Strategies to improve the availability of these services to all sites in the long term should be devised.
- ✓ The impact of peer counsellors and family support groups at the PMTCT sites where present should be assessed with prospects for scaling up.
- ✓ The flow of the essential drugs and health supplies should be streamlined and the PMTCT logistics schedule merged with the essential drugs schedule.
- ✓ A multi-sectoral collaboration with education, gender, and agriculture should be established.

Site implementers

- ✓ Health providers should proactively elicit history of domestic abuse in relationships during the counselling and offer the appropriate support.
- ✓ Psychosocial support and counselling for disclosure should be better targeted to PMTCT clients who need it more.
- ✓ RCT services should be extended to all other clinics, and PMTCT messages included in the counselling.
- ✓ Counselling approaches should be modified to include use of role plays and behaviour rehearsal techniques, mediated disclosure, ongoing counselling.

For research

- ✓ The impact of the RCT policy on follow up of PMTCT clients in Masaka should be explored.
- ✓ The potential role of the TBAs and other volunteers in PMTCT prophylaxis should be explored.

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Annex 1. UGANDA: KEY DEMOGRAPHIC, SOCIAL AND DEVELOPMENT INDICATORS 2007

SUMMARY OF INDICATORS 1. Total Population (million) 29.6 2. Total Male Population (million) 14.2 3. Total Female Population (million) 15.2 4. Total Urban Population (million) 3.9 5. Population Growth Rate (%) 3.2 6. Urban Population Growth Rate (%) 5.7 Maternal Mortality Ratio per 100,000 live births 435 8. Infant Mortality Rate per 1,000 live births 76 9. Under five Mortality Rate per 1,000 live births 137 10. Total Fertility Rate 6.7 11. Contraceptive Prevalence Rate (%) 24 12. Supervised Deliveries (%) 42 13. Full Immunization (%) 46 14. Unmet Need for Family Planning (%) 41 15. Stunted Children (%) 38 16. HIV Prevalence Rate (%) 6.4 17. Literacy Rate (%) 69 18. Life Expectancy (years) 50.4 19. Population in Poverty (%)) 31 20. Human Development Index 0.581 21. GDP per capita in 2007 (US \$) 370 22. Real GDP Growth Rate 2007/08 (%) 8.9 23. Private investment Growth in 2007/08 (%) 15 24. Public investment Growth in 2007/08 (%) 23

Source: MoFPED (2008)

Annex 2. MASAKA DISTRICT ACTIVITIES BY LEVEL

District level

- Policy implementation and planning.
- Human resources management and development.
- Quality assurance and support supervision.
- Disease and epidemic control/disaster preparedness.
- Advocacy for health services.
- Health systems research.
- Health management implementation system activities.
- PHC development activities.

Health Sub District/HC IV

- Extremely simple surgery.
- Planning and management.
- Support supervision of lower level units.
- Health management information activities.
- Simple surgery including caesarean sections.
- Blood transfusion.
- Plus activities of HC III for sub-county.

Health centre III

- Maternity services including inpatients
- Hygiene and sanitation
- Treatment of common illnesses
- Static immunization activities
- Minor dental services
- Family Planning
- Basic laboratory services
- Data collection
- Health Education
- Plus activities of HC IIs for the parish.

Health centre II

- Immunization activities
- Treatment of common illness
- Health Education
- Family Planning
- Data collection
- Outreach clinic services.

District PMTCT Coordinator District PMTCT Implementation Team **HSD Site Coordinator** Hospital Site Coordinator Health Health Maternity Antenatal Centre IV Centre III Ward Clinic **PMTCT PMTCT PMTCT PMTCT** Coordina Community Members/Pregnant Women

Annex 3. PMTCT COORDINATION STRUCTURE

Source (DHS, 2005)