

**IMPACT OF PMTCT ON MOTHER BABY PAIR RETENTION AT THE  
TREATMENT POINTS IN LIRA SUB COUNTY, LIRA  
DISTRICT- NORTHERN UGANDA**

**BY:**

**OKULLO EMMANUEL OGOLE**

**BSW/39175/123/DU**

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## DECLARATION

I, **OKULLO EMMANUEL OGOLE** declare that this is my original work except where acknowledged by reference and that has never been submitted in any other institution of higher learning in any form for any Award or qualification before and I take full responsibility for submitting it for examination.

Sign .. *Okullo* .....

Date..... *12/09/2015* .....

## APPROVAL

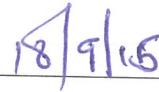
I do confirm that this research dissertation has been carried out under my supervision

Signed



Mr. ACHODA Dennis

SUPERVISOR



Date

## **DEDICATION**

I dedicate this piece of work to my family members especially my mother Mrs. Florence Ogole and my father Mr Wilson Ogole Okullu for your love, encouragement and support throughout my education time.

May The Almighty God bless you.

## ACKNOWLEDGEMENT

My first thanks go to the almighty God for giving me the strength and wisdom to finish this monumental work.

Secondly I express my gratitude to my supervisor for his immeasurable guidance, support and supervision during the exercise.

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## ACRONYMS/ABBREVIATIONS

3TC	Lamivudine
AIDS	Acquired Immunodeficiency Disease
ANC	Ante Natal Care
APIN	AIDS Prevention Initiative Nigeria
ART	Anti Retro viral Therapy
ARV	Antiretroviral
AZT	Zidovudine
DNA PCR	Denucleic Acid Polymerase Chain Reaction
EFV	Efeverenz
EID	Early Infant Diagnosis
EMTCT	Elimination of Mother To Child Transmission
FSGs	Family Support Groups
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
LTFU	Loss to follow up
MOH	Ministry of Health
MTCT	Mother To Child Transmission
NGO	Nongovernment Organization
NMS	National Medical Stores
NUSAF	Northern Uganda Social Action Fund
PEPFA	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother To Child Transmission
STAR - EC	Strengthening TB and HIV Response in East-Central Uganda
TDF	Tenofovir
UDHS	Uganda Demographic Health Survey
VHTs	Village Health Teams
VSLA	Village Savings and Loans Associations
WHO	World Health Organization

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## ABSTRACT

A study was carried out among pregnant women in Lira sub county, Lira district with the purpose of assessing impact of PMTCT on mother baby pair retention at the treatment points in Lira sub county. A descriptive and cross sectional design was employed and 100 (thirty) respondents were selected using simple random sampling procedure. Data was collected using an interview guide and observational tool.

A total number of 100 pregnant women were included in this study. The age of pregnant women included in this study ranged between 15 and 45 years.. About 67.3% of the respondents reported that they had undergone voluntary counseling for HIV testing. 97.6% of the pregnant women who underwent counseling were tested for HIV and 94.8% of those who were tested received the test result. Rural women were more likely to decline individual voluntary counseling after group information in the antenatal setting [AOR (95%CI)= 0.22 (0.14, 0.35)]. With respect to occupation of women, farmers were more likely to decline counseling compared to those who are not farmers [AOR (95%CI)= 0.44 (0.22, 0.99)]. Pregnant women who had formal schooling were more likely to undergo voluntary HIV counseling compared to those without formal schooling (AOR (95% CI) = 3.67 (1.56, 8.61)). Most respondents were aware of VCT, though some were skeptical about PMTCT, even when information was readily available.

## CHAPTER ONE

### BACKGROUND TO THE STUDY

#### 1.0 Introduction

This study report is made up of five chapters, chapter one showing the background of the study, problem statement, general objectives, specific objectives, research questions and conceptual framework, chapter 2 has the review of literature, chapter 3 has the methodology, chapter 4 results, chapter 5 has the discussion, conclusion and recommendations.

#### 1.1 Background of the study

HIV is a leading cause of death worldwide and the number one cause of death in Africa. In 2011, 1.7 million people died of AIDS representing a 24% decrease since 2005. Sub-Saharan Africa is the hardest hit region and is home to more than two-thirds 69% of people living with HTV. Globally, by 2011, 34 million people were living with HIV, 23.5 millions of these representing 69% were in Sub-Saharan Africa and 3.3 million were children. Approximately 17.3 million children have lost one or both parents due to HIV and 88% of them live in Sub-Saharan Africa (US Global Health Policy Fact Sheet, December 2012) By the end of 2010, there were 2.7 million (2,400,000-2,900,000) new HIV infection and among these 390,000 (340,000-450,000) were children less than 15 years. (WHO, 2011)

In Latin America and the Caribbean combined together, about 1.6 million people are estimated to be living with HIV and in 2011, 96,000 people were newly infected with HIV. In Eastern Europe and Central Asia, an estimated 1.4 million people are living with HIV and in 2011; there were 140,000 newly infected people which indicated an increase in new infections in the region. The epidemic in this region is mainly attributed to drug users although sex also plays an important role. (UNAIDS, 2012)

Over 90% of new infections in infants and young children occur through Mother to Child Transmission (MTCT). In 1980, early cohort studies were performed which showed that mother to child transmission (MTCT) (WHO, Prevention of Mother to Child

Transmission: Briefing Note., 1<sup>st</sup> October 2007) of HIV could occur during pregnancy, labor and delivery as well as during breast feeding. (Sophie Le Coeur et al :) In Africa, which is a breast feeding population, transmission rates varied from 25% to 43% (Dabis F, Msellati P, et al, February 17-20, 1992) well as in developed countries where formula milk was provided to the exposed babies, the rates were much lower ranging from 13% to 25% (Sophie Le Coeur et al:). The exact timing of transmission was estimated respectively by studying the kinetics of viral makers after the birth of the infants and was confirmed by observing the preventive effects of different timed interventions and the results confirmed that transmission of HIV from mother to child can occur during pregnancy (in utero), during labor and delivery (intra-partum), or through breastfeeding (postpartum). In the absence of any preventive intervention, the risk of transmission was estimated to be approximately 10% in utero, 15% intra-partum and up to 15% postpartum depending on the duration of breastfeeding.

Still in the same studies of 1980, it was established that the risk of MTCT was associated with high maternal viral load, together with advanced stage of the disease, and the duration of the exposure of the infant during delivery and breast feeding (Borkowsky W, Krasinski K, Cao Y, et al., 1994; 125(3):345-351). These observations on the timing and factors associated with transmission, led to the eventual development of preventive interventions now called Prevention of Mother To Child Transmission (PMTCT).

In 1994, the efficacy and safety of Zidovudine (AZT) which was the first ARV drug discovered were established in the land mark Pediatric AIDS Clinic Trials Group (PACTG) 076 clinical trial (Connor EM, Sperling RS, Gelber R, et al, 1994). The final result demonstrated a 67.5% reduction of the transmission rate from 22.6% in the placebo to 7.6% in the AZT group (Sophie Le Coeur et al :). This was the genesis of PMTCT.

Globally, according to Global HIV/AIDS response updates 2011, 57% of the estimated 1.5m pregnant women living with HI V/AIDS received the most effective ARVs for PMTCT. Geographically, Europe and Central Asia had an estimated coverage of 79% with the lowest at 65% and highest at 94%. Latin America had an estimated coverage of 64% with the lowest at 47% and highest at 95% (WHO, United Nations Program on HIV/AIDS, United Nations Children's fund, 2011).

In Africa alone, over 1600 infants become infected with human immunodeficiency virus (HIV) each day despite the advances in prevention of mother to child transmission (PMTCT) (Musoke, December 2004). In South Africa, around 30% of all pregnant women were HIV positive in 2010 and half of all deaths in children younger than 5 years were associated to HIV. By 2011, population surveys reported that transmission rate had reduced to 2.7% from 3.5% in 2010 (Peter Barron, Yogan Pillay et al). In western and Central Africa, the estimated percentage of women who had the most effective ARVs for PMTCT according to the Global HIV/AIDS response updates 2011 was 18% with the lowest being 15% and highest being 20% (WHO, Global HIV/AIDS responses, epidemic update and health sector progress towards universal access: Progress report, 2011).

In sub Saharan Africa a region most affected by HIV, an estimated 60% of people living with HIV are mostly women in reproductive age and each year approximately 1.4 million HIV positive women become pregnant making the vertical transmission the main cause of infection among children (Zgambo, Fatch W.Kalembo and Maggie, 2012). According to the Global HIV/AIDS response update 2011, the estimated percentage of women who received most effective ARVs for PMTCT in sub Saharan Africa is 50% with the lowest at 45% and highest at 56% (WHO, United Nations Program on HIV/AIDS, United Nations Children's fund 2011)

In East Africa, according to UNICEF in 2009 an estimated 860,000 pregnant women were found to be living with HIV in Eastern and southern Africa more than in other region of the world.

East Africa according to this UNICEF report was a home to 47% of the global total of children living with HIV of which 90% were infected through Mother to Child Transmission during pregnancy, delivery, and breast feeding: (UNICEF, 2009). In a programmatic analysis using data from a number of clinics in East Africa by Braitstein et al (2011), it was found that the incidence of loss to follow up was 16.5 per 100 person years to follow up. Loss to follow up is more in Pre ART patients and those with CD4 counts of less than 250 that have just been initiated into ART (Geng et al, 2011). In a

study in a clinic in south western Uganda, 21% of the clients enrolled into care were lost to follow up at 12 months (Geng et al 2011).

Uganda is generally considered one of Africa's most successful countries combating HIV/AIDS and was one of the first countries to recognize the growing epidemic and make it a nationwide matter, in 1986. Although there was a significant reduction originally, HIV continues to weigh heavily on maternal and child mortality in some countries (UNAIDS, 2010). The Ministry of Health 2010 Uganda national PMTCT review showed that only 12% of the mothers and 14% of babies were linked into chronic care, and only 8% of the mother baby pair completed the PMTCT-EID cascade. Uganda started offering PMTCT services in 2000 with mothers getting single dose Niverapine during labor and the baby also a single dose NVP immediately after delivery.

The HIV prevalence of the Middle Eastern region of Uganda where Lira District lies is 5.8% (6.7% for women and 4.3% for men). According to the estimated population of Lira 5% of the population is expected to be pregnant mothers thus it is estimated that there are 7,368 pregnant women per year of whom 420 are estimated to be HIV positive (UBOS, 2011). In 2010 STAR EC carried out a study about "increasing uptake of PMTCT-EID services in a rural setting: a case of Lira District in Uganda" and the results suggested that 90% of the health workers at the various levels of health care in the district had been trained in PMTCT-EID guidelines and that a total of 15 health facilities including hospitals, health centre IVs, IIIs and one H/C II offer PMTCT services. The study also showed that the enrolment of HIV positive pregnant women onto prophylactic ARVs significantly increased to 90%. (Uganda Demographic Health Survey Report, 2011)

## **1.2 Statement of the Problem**

Mother-to-child transmission (MTCT) is by far the largest source of HIV infection in children below the age of 15 years. From the MOH PMTCT-EID strengthening program of 2010, many tracking tools were introduced both at the PMTCT and EID care points to try and capture the missed appointments so that follow up can be done to prevent loss to follow up. Some of the tools include the appointment books, the triplicate referral forms, and the integrated longitudinal ANC registers. Mechanisms to trace and bring back the

patients who have missed appointments were introduced which included phone calling which involves providing of airtime to the health workers to call mothers/exposed infants who have missed the appointment, Home visiting which is done by expert clients and VHTs to reach out to patients who have missed appointment at their homes and FSGs where HIV positive pregnant and breastfeeding mothers form groups and adequate psychosocial support is provided to the mothers with the aim of supporting mother baby pair retention into care.

Despite all this, there is still a staggering loss of pregnant mothers and exposed infants throughout the PMTCT - EID cascade. For example, a review done in 2010 revealed that only 8% of mother baby pair completed the PMTCT-EID cascade and according to the review done in 2012 MOH, it revealed that Only 21% of HIV-positive pregnant women were linked and enrolled at an ART clinic for long-term chronic HIV care and management.

### **1.3 Purpose of the study**

To determine factors associated with mother baby pair retention and treatment at the at the PMTCT EID care and treatment points in Lira sub county, Lira District.

### **1.4 Specific objectives of the study**

To examine the rate of loss to follow up of mother-baby pair at the PMTCT-EID care and treatment points in Lira sub county, Lira District

To investigate the patient factors affecting mother baby retention at the PMTCT - EID care and treatment points in Lira sub county, Lira District

To examine Institutional factors affecting mother baby retention at the PMTCT- EID care and treatment points in Lira sub county, Lira District

To explore strategies to improve retention of mother baby pair retention at the PMTCT - EID care and treatment points

### **1.5 Research Questions**

This study was guided by the following research questions;

What is the rate of loss to follow up of mother-baby pair at the PMTCT-EID care and treatment points in Lira Sub County, Lira district.



What are the patient factors affecting mother-baby pair retention at the PMTCT - EID care and treatment points in Lira sub county, in Lira District?

What are the Institutional factors affecting mother-baby pair retention at the PMTCT - EID care and treatment points in Lira sub county, Lira District?

What strategies can be used to improve mother-baby pair retention at the PMTCT - EID care and treatment points in Lira sub county, Lira District?

## **1.6 Scope of the study**

### **1.6.1 Content scope**

The study concentrated on factors associated with mother baby pair retention and treatment. The researcher mainly concentrated on rate of loss to follow up of mother-baby pair, patient factors affecting mother and baby retention and strategies to improve retention of mother baby pair retention at the PMTCT - EID care and treatment points

### **1.6.2 Geographical scope**

The study was conducted in the sampled parishes of Amua, Barapwo and Omito, all located in Lira sub-county, Lira district.

### **1.6.3 Time scope**

The research took a period of 3 months, to ensure that the study was conducted efficiently and effectively as required by the University. Therefore, the research was conducted from the month of June to August 2014.

## **1.7 Significance of the study**

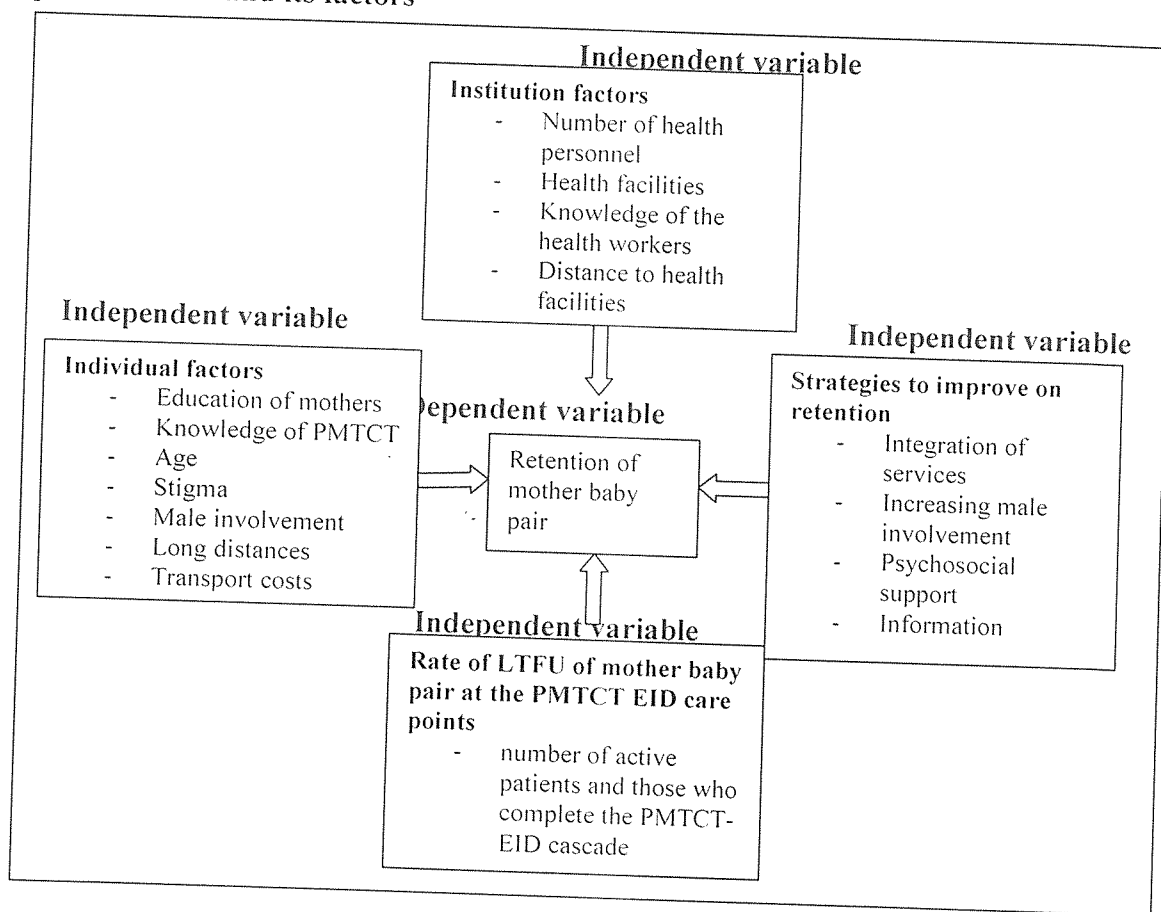
The study may act as a source of literature for related studies on HIV, PMTCT

The study would provide decision making guides concerning PMTCT

The study would also provide strategies plus measures that will be used to improve mother-baby pair retention at the PMTCT - EID care and treatment points, not only in Lira district but also Uganda as a whole.

The study would be of great benefit to pregnant mothers and newly born babies who are being protected against HIV /AIDS

**1.8 Conceptual frame work Figure 1: Showing relationship between mother baby pair retention and its factors**



Source: Developed by the researcher based on the ideas of Peltzer et al, (2005:29)

In this conceptual frame work, the independent variables which are the rate of LTFU of mother baby pair, patient factors, institutional factors and the strategies for improving retention are variables that if manipulated have a direct effect on the dependent variable which is being measured which in this case is the retention of mother baby pair. The

retention of mother-baby pair is the dependent variable which is affected by the independent variables and in this study it is the outcome variable.

### **1.9 Operational definitions**

For the purpose of this study,

Retention in this study is defined by mother-baby pair attending all scheduled appointments in the last 12 months.

Adherence strengthening entails strengthening counseling both at the PMTCT and EID care points to ensure that the mother does not miss an appointment

Patient follow up includes phone calling, home visiting and use of FSGs to make sure those who miss appointments are tracked and brought back to the clinic.

PMTCT-EID cascade means mother baby pair going through the following services: maternal HIV counseling and testing, CD4 cell count determination, initiation of ARVs, ARV monitoring, delivery care, infant ARVs, cotrimoxazole prophylaxis, early infant diagnosis of HIV, linking of mother into chronic HIV care, ART for the HIV infected infant and discharging of the HIV negative infants at 24 months.

PMTCT mothers means HIV positive pregnant and breast feeding mothers

Exposed Infants means babies who are born to HIV positive mothers

**Expert clients** mean the HIV positive clients who are working together with the health workers to deliver services to HIV positive patients.

**Mother-** Baby pair retention means mother goes through the PMTCT cascade and delivers the baby in the health facility and also brings the baby to the EID care point and the baby completes the EID cascade until when either discharged at 24 months when declared HIV negative or referred to ART clinic for enrollment if the baby tests HIV positive.

**Triple Therapy:** this means three different kinds of ARVs are combined as a dose and given to the patient.

**Missing appointments** is defined as not responding to scheduled physician, laboratory, pharmacy and counseling session appointments for a period of 1 month or longer.

**Loss to follow-up** is defined as no contact with a patient within 90 days after the last scheduled clinic appointment. Patients are lost to-follow-up if they have not returned to the clinic 3 months after they were expected and are not known to have transferred out, stopped, or died.

**Stigma** is defined as a significantly discrediting attribute possessed by a person with an undesirable difference.

## CHAPTER TWO

### LITERATURE REVIEW

#### **2.0 Introduction**

This chapter focuses on what other scholars have written about various factors affecting mother baby retention at the at the PMTCT and EID centers. Specifically, the chapter highlights the personal, institutional factors affecting mother baby pair retention and the strategies for improving mother baby retention at the at the PMTCT and EID centers from other studies conducted by other scholars.

#### **2.1 Rate of mother baby pairs LTFU at the PMTCT-EID care points in Lira Sub County, Lira District.**

In resource limited settings where HIV is highly prevalent, retention of mother baby pair is very important to prevent transmission at all stages that is in utero, intra partum and postpartum. (UNAIDS, 2010)

In cohort studies carried out in the 1980s, it was estimated that in the absence of any prevention, the risk of transmission was 10% in utero, 15% intra partum and up to 15% postpartum depending on the duration of breastfeeding. (Sophie Le Coeur et al:) This shows that retention and follow up of mother baby pair is not only necessary for the mother's ART monitoring and identifying infants already infected with HIV to ensure timely treatment and care but also to avoid postpartum HIV transmission and improve overall infant outcome. (Zgambo, Fateh W.Kalembo and Maggie, 2012) Hence, establishing the prevalence of mother baby pair retention helps to measure the quality and effectiveness of PMTCT services given which in turn will be used to identify the challenges and the strategies of overcoming these challenges. There are so many challenges that have been identified through different studies that are responsible for the fact that implementation of the successful research results of PMTCT has failed to live up to their potentials in the countries most affected by HIV even after over ten years since the treatment to reduce MTCT of HIV was discovered.

In the study carried out by Fatch and Maggie, it was found out that 18 studies had been carried out about identifying the rate of LTFU in 8 countries in sub Saharan Africa (4 in Malawi, 3 in South Africa, 3 in Zimbabwe, 1 in Zambia, 1 in Ivory Coast, 1 in Mali, 3 in Ethiopia and 2 in Kenya) between 1990 and 2011. The results showed that the rate LTFU was between 19% to 89.4%

Knowing this helped in identifying the challenges/causes of LTFU like Health facility factors, stigma and discrimination and social economic factors among others (Zgambo, Fatch W.Kalembo and Maggie, 2012). A similar study was carried out in Malawi by Manzi M, where the rate of LTFU was found to be higher in hospitals with 9.9% compared to the rural health centers with 1.5% which led to the findings that transport costs, travel time, and long clinic waiting time were responsible for low retention of mother baby pair and it was concluded that decentralization of services is associated with improved retention of mother baby pair (Massaquoi M, Zachariah R, Manzi M.et al, 2009).

## **2.2 Patient factors affecting mother baby retention at the PMTCT and EID care points**

The literature reviewed indicates that there are a number of patient factors affecting mother baby retention at the at the PMTCT and EID care points. For example, in a study conducted by Julliet Charity Yauka Nyasulu (2007:27), on the factors Contributing to the low uptake of PMTCT Services in Blantyre and Balaka Rural in Malawi, the majority of respondents from the 6 Focus Group Discussions (FGD5) were not knowledgeable of the PMTCT services available at the health facilities as a result none of them was sure of the quality (Nyasulu, December 2007). In the context of this study, this lack of knowledge will be investigated if it affects mother baby retention at the PMTCT and EID centers in Lira sub county, Lira District.

### **Stigma and discrimination**

Stigma and discrimination was one of the personal factors identified in sonic of the literature reviewed. For example, the study carried out in Mali in 2011 by T Mute, A Akonde, A Doumbia et al indicated that fear of testing, non disclosure and stigma were the main reasons for LTFU (T. Mute, 2011). The same reasons were earlier on identified

in a similar study carried in Malawi in 2008 by L. D. Bwirire et al (L.D.Bwirire, M. Fitzgerald, R. Zachariah et al, 2008). In another study by V. Bond, E. Chase and P. Aggleton entitled “stigma, HIV/AIDS and prevention of mother to child transmission in Zambia” was carried in 2002 and it revealed the same reasons of stigma and fear of being blamed and losing husbands by women if they disclose to their husbands (Stigma HIV/AIDS and prevention of mother to child transmission in Zambia, Evaluation and Program planning, 2002). In a similar study conducted by Juliet Charity Yauka Nyasulu (2007:21), the results indicated that those mothers who were HIV positive but did not join the PMTCT program were asked about the reasons for refusing to join the PMTCT program and all the 10 PMTCT non up takers mentioned stigma and discrimination against those who are HIV positive as the greatest barrier to PMTCT uptake (Nyasulu, December 2007) hence the need to find out if the same is affecting mother baby retention at the PMTCT and EID centers in Lira sub county, Lira.

#### **General awareness of PMTCT services**

In another study conducted by Youth Research Working Paper No. 4, (2006:27), entitled, “An Assessment of Services for Adolescents in Prevention of Mother-to-Child Transmission Programs in Kenya”, General awareness of PMTCT services was limited but substantially greater among the 20-24 year old PMTCT clients. Multivariable results suggest that adolescents were significantly less likely than older youth to report ever having heard of, or know of PMTCT even after controlling for potential confounding factors. However, this study intends to make an investigation whether the situation in Kenya is similar or different from that in Uganda.

#### **Lack of male involvement**

In addition, the lack of support from men has also affected mother baby pair retention at the PMTCT and EID care points. According to (Peltzer et al., 2005: 30), the involvement and support from men is crucial if problem free PMTCT interventions are to be observed as their participation in PMTCT programs is likely to increase women’s uptake of PMTCT services. Unfortunately men’s involvement in this intervention is very minimal (Karl Peltzer, Donald Skinner, Sakhumzi Mfecane, Olive Shisana, et al, 2005).

### **Presence Traditional Birth Attendants (TBA)**

Besides, although most pregnant women visit an antenatal clinic, another additional possible constraints to ensuring effective PMTCT coverage and possibly mother baby retention at the PMTCT and EID centers is that most births occur at home or from Traditional Birth Attendants and not in a health facility (Karl Peltzer, Donald Skinner, Sakhumzi Mfecane, Olive Shisana, et al, 2005).

### **Long distances against lack of transport**

Other personal factors that may affect the retention of mother baby pair in PMTCT and EID program from the literature reviewed are; long distances as seen in the study carried out in Malawi by Manzi M et al, which is also similar to the studies carried out in Ivory Coast, Rwanda and Zimbabwe (Y. Lim, J. Y. Kim, M. Rich et al, 2010).

### **Education level of mothers**

Another factor which is thought to affect the retention of mother-baby pair is the education level of the mother. In a study carried out in Kenya by I. A. Moth, et al entitled "Assessment of utilization of PMTCT services at Nyanza Provincial Hospital, Kenya," the results showed that lack of maternal secondary education was associated with mother baby pair non adherence to nevirapine (NVP)

### **Joining Family Support Groups**

Family support groups (FSGs) are made up of HIV positive pregnant and breastfeeding mothers and they are mainly at health centers and supported by health facilities or in the community supported by the expert clients and VHTs. Their main aim is to give psychosocial support using HIV positive mothers as peer educators (expert clients) to the fellow HIV positive mothers. In the review made in sub Saharan Africa by Eatch W Kalembo, it was found that mother to mother clubs were significant in making women receive CD4 testing, receiving nevirapine and adhering to safe infant feeding practices (Zgambo, Fatch W.Kalembo and Maggie, 2012).



### **2.3 Institutional factors affecting mother baby retention at the at the PMTCT and EID care points.**

Some of the institutional factors that affect retention of mother baby pair at the PMTCT EID care points in the literature reviewed are: staff shortages, shortage and interrupted supply of materials, shortage of space for counseling, long waiting time for posttest counseling, inadequate information given to the clients during counseling, and lack of documented data leading to poor follow up.

#### **Lack of proper documentation**

In a study conducted in southern Ethiopia by B. Merdekios et al., about the “Effectiveness of interventions to prevent mother to child transmission of HIV in South Ethiopia,” the results revealed lack of documented information on HIV positive mothers who enroll in PMTCT but fail to come back which results into poor follow up of clients (Adedimenji, 2011).

#### **Inadequate counseling**

A study carried out by A. Coutsoydis et al., “influence of infant feeding patterns on early mother to child transmission of HIV- 1 in Durban, South Africa,” revealed that there is inadequate counseling given to the mothers as findings indicated that 68% of the participants received less than 5 minutes, 21% had 5-10 minutes and only 10.7% had more than 10 minutes of posttest counseling. This study also revealed that there was no adequate confidentiality during counseling (A. Coutsoydis, 1999). In another study conducted in Malawi by L. D. Bwirire et al., similar findings were revealed as antenatal mothers thought that they were not prepared well for HIV testing which indicate inadequate counseling and had delays in getting services at the ANC (L.D.Bwirire, M. Fitzgerald,R. Zachariah et al, 2008). In Kenya, a study carried out by T. Mute et al., in 2011 revealed there was shortage of space for counseling which is similar to the above findings. On top of that, this study also revealed that there were shortages and interruptions in the supply of materials and shortage of health care workers (Zgambo, Fatch W.Kalembo and Maggie, 2012). Poor counseling was also revealed in a study conducted by Stringer EM, et al., Coverage of niverapine based services to prevent

mother to child HIV transmission in 4 African Countries (Stringer E M, Ekouevi DK, Coetzee D, et al, 2010).

### **Long clinic waiting time**

Long waiting time at the HIV clinics is also thought to be another factor affecting retention of mother-baby pair. This came out of a study carried out in Malawi by Manzi where long clinic waiting time was found to be responsible for low retention of mother baby pair and it was concluded that decentralization of services is associated with improved retention of mother baby pair (Massaquoi M, Zachariah R, Manzi M, et al, 2009)

### **Lack of integrated health services**

Other institution & factors include lack of integrated services as seen in a study conducted in Malawi by Braun M, et al which revealed that only 54% of the exposed infants whose mothers received prophylaxis underwent early infant diagnosis a problem which was attributed to the separate programs for maternal and infant HIV prevention care services (Braun M, Kabue MM, McCollum ED, et al, 2011).

### **Inadequate number of facilities with PMTCT services**

Another institutional factor is found in a study conducted Juliet Charity Yauka Nyasulu (2007), entitled; "Factors Contributing to the Low Uptake of PMTCT Services in Blantyre and Balaka Rural in Malawi, "the results indicated that inadequate PMTCT service providing facilities has also proved to be a major challenge to PMTCT uptake and hence mother baby retention (Nyasulu, December 2007).

## **2.4 To establish strategies to improve retention of mother baby pair at the PMTCT and EID care points**

Different studies carried out in different countries have shown many strategies that can be used to improve mother baby pair retention. For example, in a study carried out by C. Back and N. Rutenberg, in 1999-2007 "looking backward, moving forward: implementing PMTCT programs in resource constrained settings, Horizons studies, it was found out that psychosocial support from peers improves on the mother baby pair

retention for example using HIV positive mothers as peer educators. Similar results were obtained in the study carried out in South Africa by Futterman D. et al., “a pilot study combining a cognitive behavioral intervention and mentor mothers with PMTCT services in South Africa.” The findings revealed that peer mentoring programs provide coping skills to the HIV positive mothers through giving HIV knowledge and social support (Futterman D, Shea J, Besser M, et al. Mamekhaya; 2010;22:1093-LIOO).

### **Integration of health services**

Integrating health services is another strategy that was seen to improve on retention of mothers and babies as indicated in the findings of a study in rural Zimbabwe in 2008 by De Baets AJ, et al., where primary healthcare workers were trained on PMTCT guidelines in a district without physicians which led to the increased rate of referrals and testing for early infant diagnosis. The study also showed that a greater number of mothers and infants were reached with preventive messages. Similar results were got in Rwanda in 2010 by Tsague L et al., in a study about examining service delivery models of PMTCT care among 32 clinical sites. The PMTCT and ART services were integrated which led to significantly increased proportion of women retained in the PMTCT care.

### **Information system strategy**

Information system is another strategy for improving retention of PMTCT mothers and exposed infants. For example, in Rwanda and South Africa, cell phones are used to assist in patient follow up and to provide medical access to the data like laboratory tests. Similarly Malawi and Rwanda developed an information system that uses an innovative touch screen interface and HIV electronic medical records which helps in identifying clients requiring follow up care (Zgambo, Fatch W.Kalembo and Maggie, 2012).

### **Increasing male involvement**

Increasing male involvement in PMTCT EID services is another strategy that can improve on the mother baby pair retention. A study carried out in 2008 in northern Tanzania by Msuya showed that male involvement is associated with increased retention of mother baby pair in care. Similar results were achieved by Richards B A in both

studies carried out in 2004 and 2011, about male antenatal attendance increasing HIV free survival in children (T. Mute, 2011).

This research seeks to find out if these are the same factors affecting the mother baby pair retention in Lira sub county, Lira and if the same strategies for improving retention are the same which will be identified because not all factors that work in other areas may be the same in Uganda for example, In a study that was carried out in Malawi by Massaquoi M, in 2009, it was concluded that decentralization of services can improve retention of mother baby pair as it reduces on clinic waiting time, and transport costs. However in a study carried out in Uganda by C. Mugasha et al., about the intra facility linkage of HIV positive mothers and exposed infants into HIV chronic care: rural and urban experience in a resource limited setting. Retention was more in urban than in the rural facilities which is contradict the findings in the study carried out in Malawi.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.0 Introduction**

This chapter describes the procedures that are followed in conducting the study. It gives details regarding research design, study area, sample size and sampling techniques, study population, data collection techniques, data analysis and interpretation, limitations of the study, quality control issues and ethical consideration.

#### **3.1 Study design**

The study was a cross sectional study that employed both qualitative and quantitative data collection methods. It involved the review of client records at the EID care points for clients enrolled at 3 health centers and surveys at the PMTCT - EID care points in the health facilities offering PMTCT and EID services.

#### **3.2 Study Area**

The study took place in Amuca, Barapwo and Omito parishes, in Lira sub county, Lira District in 3 health facilities and the activities of the study included the preparation of tools, selecting and briefing of research assistants, plus data collection and analysis.

#### **3.3 Study Population**

The study population included the Professional Health Workers, mothers and babies seeking PMTCT- EID services, Village Health team members, expert clients, and PMTCT mothers who are lost to follow up within the study area. However, the total population of the whole sub-county is estimated to be 5000

#### **3.4 Sample size**

A sample refers to a representation of the larger picture. In this case it's a sample size of a population where 100 people which included 15 professional health workers, 60 mothers seeking PMTCT-EID, 10 village health team members, 5 expert clients, and 10 PMTCT mothers who are lost to follow up within the study area.

### **3.5 Sampling techniques**

In order to eliminate bias, different methods of sampling were used; first, purposive sampling will be used to select the health facilities where the study was conducted in Lira S/c H/C III, and 3 other health centers

The second sampling method used was systematic random sampling and was used at the health facility to select PMTCT mothers for interviewing. Every first PMTCT mother to be registered at the triage on a clinic day will be selected. Hence after the first mother one mother is skipped and every 2 PMTCT mother at the triage registration table was selected, taken through the consenting process and then interviewed using questionnaires. Purposive sampling was used to get the Loss To Follow Up (LTFU) mother-baby pairs for follow up and only those with proper documentation for direction on the care cards will be selected for follow up. Secondary data from the exposed infant registers will also be used to measure the rate of LTFU of mother-baby pair retention.

### **3.6 Sources of data**

This study had two sources of data, primary and secondary data.

#### **3.6.1 Primary data**

This will be collected from participants using detailed structured questionnaires, observation and Focus Group Discussions. Questionnaires will be used to obtain quantitative and qualitative primary data while FGDs will be used to obtain only qualitative data.

#### **3.6.2 Secondary data**

This was obtained through reviewing exposed Infant registers in the health facilities and the data.

### **3.7 Data collection techniques**

Both qualitative and quantitative data collection methods will be used. The quantitative tools to be used will mainly involve a structured questionnaire and the qualitative tools will mainly be a focus group discussion guide and a check list for the observational technique.

### **3.7.1 Questionnaires**

Pre-tested, standard questionnaires with both open and closed ended questions will be administered to the PMTCT mothers. The questionnaires were designed in accordance with the objectives of the study. According to Amin (2005), questionnaires are popular with researchers because information can be obtained fairly, easily and the questionnaire responses are easily coded. However, the major weaknesses of questionnaires are that they do not provide detailed information to the problem.

### **3.7.2 Focus Group Discussions (FGDs)**

For the collection of qualitative information, Focus Group Discussions (FGDs) will be conducted to find out the factors affecting mother-baby pair retention. 3FGDs will be conducted with expert clients and VHTs, 1 with the health workers providing PMTCT-EID services and 1 with PMTCT clients themselves. A FGD guide will be used to keep the discussion on track.

### **3.7.3 Observation**

The study will also include observational technique which will be done using already known HIV positive mothers (expert clients) who are not known by the health workers who also come to seek antenatal services at the health facilities. This will help in checking the customer care given to the PMTCT mothers by the health workers, the waiting time for the mothers who have tested HIV positive and the quality of counseling and health talks given if any. These mothers will have the check list with indicators to be measured.

## **3.8 Data analysis and interpretation**

All the variables in quantitative data will be coded before the data is entered into a computer. Data will be entered into excel software package, cleaned and stored on a daily basis by the researcher. Qualitative data will be cleaned and entered into the computer at the end of each data collection day to prevent the researcher from forgetting some of the scripts and verbatim used by the respondents. Qualitative data analysis will be done manually in excel using content analysis.

### **3.9 Quality control issues**

**Training of Research Assistants:** two Research Assistants will be trained by the principle investigator on how to interview PMTCT mothers using appropriate language and on the terminologies used in the questionnaire and the other guiding tools.

**Field editing of data:** Data collected will be reviewed and edited at the end of each day by the Research Assistants and the Principle Investigator at the field site. This will help in correcting mistakes and making adjustments to the questionnaire during data collection.

**Missing Data:** Data will be checked at the end of each day of data collection for any missing and incorrect data. This will be corrected in the subsequent interviews after harmonizing the questionnaire to ensure that no more data is missed.

**Controlling bias:** In order to reduce on bias, triangulation of data collection techniques will be done and more than one sampling method will be used during sampling.

### **3.10 Limitations of the study**

Inadequate funds whereby the researcher may have limited funds while carrying out the study that is to sat purchasing data collection tools, facilitation of the study and collection of fieldwork.

Limited time of carrying out the study whereby it will only take a period of 3 months. This will need much effort of the researcher in order to accomplish the research in the shortest time possible.

### **3.11 Ethical consideration**

#### **Informed consent**

Permission to conduct the study was sought from Kampala International University. Informed consent forms that elaborate on the purpose of the study, study procedures, voluntary involvement, potential benefits, and potential risks of the study will be developed in English and Lango to be used to conduct the informed consent process.



**Protecting participant confidentiality:**

Each patient record will be given a unique ID number. Data identifying individual subjects will be restricted to those involved in the study. All records and forms will be stored in locked drawers when not in use. Access to computer records will be protected by a password. Names and other identifying information from subjects will be obtained for quality assurances purposes only and no individual will be identified by any study report.

## CHAPTER FOUR

### DATA PRESENTATION, ANALYSIS AND INTERPRETATION

#### 4.0 Introduction

This chapter involved presentation, analysis and interpretations of the data collected. In this chapter the researcher puts down the findings in respect to the study. The data gathered was presented in tables and frequencies expressed in percentages and quantitative presentation in an attempt to improve the quality of the data collected. The research questions set earlier on were empirically proved or disapproved depending on various variables and the data collected. However the interpretations found here in, mainly depend upon the answers which were given by the respondents, they either supported or disagreed with the research questions and hence taken as true and helps in generalizing the findings.

#### 4.1 Demographic Profiles of the Respondents

**Table 1: Socio demographic characteristics of the Ante Natal Care Attendees in 3 health centre's of Mbalamuti Sub County**

Characteristic	Frequency	Percentage
<b>Age (years)</b>		
15-19	15	15
20-24	45	45
25-29	10	10
30-34	18	18
35-39	07	07
40-45	05	05
<b>Residence</b>		
Urban	35	35
Rural	65	65
<b>Religion</b>		
Protestant and catholic	55	55
Islam	30	30
Others	15	15
<b>Marital status</b>		
Married	45	45
Single	35	35
Divorced	20	20

<b>Educational status</b>		
No formal schooling	50	50
Attended primary	25	25
Attended secondary	15	15
Tertiary/university	10	10
<b>Occupation</b>		
House wife	35	35
Farmer	30	30
Civil servant	10	10
Daily laborer	20	20
Others	05	05
<b>Husbands occupation</b>		
Civil servant	35	35
Farmer	25	25
Daily laborer	10	10
Merchant	15	15
Self employed	08	08
Others	07	07

**Source: Primary Data, September, 2014**

A total number of 100 pregnant women (98% response rate) were included in this study. The age of pregnant women included in this study ranged between 15 and 45 years with mean age (+SD) of 25.40 (+5.43) and median 25years. The majority, 55 (55%) and 90(90%), were Christians and married, respectively. A large proportion (82.5%) of the respondents had two or less number of live children. Thirty five (35%) were urban dwellers, and 65 (65%) were rural dwellers. Some 18 (19.7%) rural residents traveled more than two hours to reach a health facility with VCT service. More than half of the respondents (52.4%) had never had formal schooling at any time prior to interview. (For details see table 2.) About 67.3% of the respondents reported that they had under gone voluntary counseling for HIV testing. 97.6% of the pregnant women who underwent counseling were tested for HIV and 94.8% of those who were tested received the test result. Rural women were more likely to decline individual voluntary counseling after group information in the antenatal setting [AOR (95%C.I.)= 0.22 (0.14, 0.35)]. With respect to occupation of women, farmers were more likely to decline counseling compared to those who are not farmers [AOR (95%C.I.)= 0.44 (0.22, 0.99)]. Pregnant

women who had formal schooling were more likely to undergo voluntary HIV counseling compared to those without formal schooling (AOR (95% CI) = 3.67 (1.56, 8.61)).

#### **4.2 Comparative Analysis of PMCT Services**

A woman infected with HIV can pass the virus to her baby during pregnancy, labor and delivery, or breastfeeding. Without preventive intervention, roughly 15 to 30% of newborns of untreated HIV-positive women will become infected with HIV during pregnancy and delivery and an additional 10 to 20% during breastfeeding. The risk has varied by region-with rates of 15-to 25% transmissions in industrialized countries of Western Europe and the U.S., but higher rates (25 to 35%) reported from developing countries. Some studies have found rates as high as 43% in Sub-Saharan Africa. Variations could be due to differences in epidemiology of STIs, availability of safe obstetric practices, utilization of ARV drugs.

Recently, interventions to prevent transmission of HIV from mother to child have become increasingly available in Africa. There are three main strategies that are essential for achieving maximum effective reduction of MTCT of HIV: primary prevention of HIV among “would be parents”, prevention of unwanted pregnancy among HIV positives, prevention of HIV transmission from HIV infected females to their infants [through antiretroviral therapy to pregnant females (reduce maternal viral load with ARV drugs) and infants, prevention of avoidable exposure to maternal virus at birth through improved obstetric practices (strict application of infection prevention (IP) precautions, and where applicable, caesarian section) and reduction of exposure to HIV through breast feeding or replacement feeding for the infant] .

Testing during antenatal period offers several advantages including early counseling on the prevention of MTCT and on maintaining health; to take steps to prevent exposing partners; plan for treatment and follow-up for the baby; receive support to maintain her health, including proper nutrition, treatment of sexually transmitted infections (STIs), and care for other infections, such as tuberculosis (TB) or malaria. If a woman is negative, she and her partner can be counseled on risk reduction. This may be particularly important in areas where taboos on sexual activity during pregnancy or postpartum might

cause a man to seek other partners, thereby placing a woman at risk when she resumes sexual activity with her partner.

The most effective way to prevent MTCT is to prevent the woman from becoming infected in the first place, and to provide access to family planning to HIV-positive women who want to prevent pregnancy. It includes HIV education, safe-sex practices, avoidance of sharing contaminated needles, early treatment of sexually transmitted diseases (STDs) and change in moral behavior and attitude of the community. In the developing countries, most of the mothers are getting infection from their husbands through sexual route; i.e. fathers are equally responsible for the transmission of HIV to their children. Hence, in order to ensure that mothers alone should not be blamed for MTCT, PMTCT has been renamed as PPTCT (prevention of parent to child transmission) in India.

Researchers in some parts of sub Saharan Africa conducted various studies on PMTCT of HIV to determine coverage, to see problems and challenges and find out solutions for programmatic effectiveness. In Coast Provincial General Hospital (CPGH), Mombasa, Kenya, Marleen Temmerman et.al made a hospital based observational study over one year period among 3564 pregnant women with first-ANC visit to review coverage of the nevirapine in the existing PMTCT model. They found a counseling rate of 71% and a testing rate of as high as 97%. In 2003- 2004, Kampala, Uganda Marina Giuliano et.al made evaluation of a five-year performance of a Hospital PMTCT programme to identify potential reasons affecting its uptake. They found a 76.0 % testing rate and a 79.9% acceptance of test result. In Zimbabwe, Freddy Perez et.al estimated PMTCT programme uptake using routine monitoring data collected over 2½ years period. It was found that 92.9% were counseled and 74.3% received posttest counseling, while only 24% received complete mother-child antiretroviral prophylaxis. Similarly, in a one year cohort of 3136 ANC attendee in Malawi 96% were pre-test counseled and 95% underwent HIV testing as well as post-test counseling.

Thomas M Painter et.al in Abidjan, Ivory coast, made a clinic based qualitative interview of 27 HIV positive pregnant women over 8 months time. In that study, negative experiences that pregnant women had had while interacting with programme staff or to their views about the programme was an important barrier for returning back. Some women are dissatisfied with how HIV testing had been explained-horrible consequences of the disease emphasized. On the other hand, Nuwagaba-Biribonwoha H. et.al pointed out that among the challenges with the PMTCT programme are staff shortages, overworked and under-motivated staff. In Kigali, Rwanda a 13 months prospective cohort study of factors associated with failure to return for HIV post-test counseling in pregnant women revealed that the only variable significantly associated with failure to return for post-test counseling was a positive HIV test result. In a cross sectional study conducted among pregnant women following ANC in Tanzania on attitudes to voluntary counseling and testing, the major concern of women was for the reaction of their male partners to the possibility of a positive HIV test and low confidence in the confidentiality of HIV testing.

Other team of investigators has also identified that enrolment in to PMTCT programme were lower in married or cohabitating women than single women.

Many women do not participate in PMTCT programs. Missed opportunities to offer, or low uptake of voluntary counseling and testing (VCT) during routine ANC; refusal to be tested for HIV both by pregnant women and partners; inadequate acceptance of ART offered to HIV+ women at ANC; poor adherence to "take-home" antiretroviral drugs (ARV) for mother and newborn when given to HIV+ women at ANC; insufficient use of facility-based delivery where improved obstetric practices can be used and antiretroviral therapy (ART) for mother and newborn can be supervised; low coverage of newborns with ART even when delivered in facility; and non-receipt of HIV test results have been studied as barriers to participation. The reason why less than one third of pregnant women who receive HIV positive test results eventually start taking antiretroviral prophylaxis is not examined well. A study in Burkina Faso revealed that up to as much as 53% of pregnant women declared not to know the existence of MTCT risk, reminding the

existence of wide knowledge gap. In a community-based survey on knowledge and attitude towards VCT in northwest Ethiopia on 992 residents, it was indicated that most of the interviewed individuals were lacking the correct knowledge on mode of transmission and prevention measures.

While VCT campaigns continue to focus on the benefits of testing before conception, 'Planning to have children' was among the least expressed reasons for accessing VCT services. Despite prior knowledge of HIV seropositivity 36% of women in a Jamaican study had circumstances of repeat pregnancies and poor partner notification. Denial of HIV positive test results is not uncommon among women and even some do not believe that ARV prophylaxis is effective in preventing MTCT of HIV. Reasons for refusing include concerns over privacy and confidentiality, stigma attached to the HIV test and "fear" of a positive result. Fear of stigma and discrimination against people living with HIV/AIDS discourages some women from taking precautionary measures that can greatly reduce the risk of MTCT, such as to find out their HIV/AIDS status, seeking counseling if they are HIV-positive and pregnant, taking ARVs while pregnant; or choosing not to breast feed.

Acceptance of HIV test and enrolment in the PMTCT program were lower in married or cohabitating women than single women, in women belonging to the minorities/marginalized segments, and in lower educational status. At times the only variable significantly associated with failure to return for post-test counseling can turn out to be a positive HIV test result. These indicate that the fear of being identified as HIV positive in the family, fear of being recognized by service providers and lack of awareness are still strong limiting factors. The major concern of women in VCT is for the reaction of their male partners to the possibility of a positive HIV test and low trust in the confidentiality of HIV testing. Particularly the role of husbands in the success of PMTCT programs is pointed out to be critical, since partner participation in VCT and couple counseling increases uptake of nevirapine and formula feeding by many folds.

Low health service utilization and lose to follow up common among African pregnant women further complicates the problem. In Ethiopia, heavy workload, lack of access to

health services, poverty, traditional practices, poor social status and decision-making power, and lack of access to education are among the highly prevalent socio-cultural factors that potentially affect the health of women.

In a Kenyan study, only 29% of HIV-infected women who received posttest counseling at 23<sup>rd</sup>-24<sup>th</sup> weeks of gestation collected nevirapine at 34<sup>th</sup> week, and only 20% of infected women eventually took the drug in labor, partly due to the time lag between testing and providing the drug. In other part of Africa similar low uptake was reported in 2004. Only 30% of the pregnant women who attended antenatal care in the facility with PMTCT services delivered in that facility.

The vast majority delivered at home or in another health facility. In Ethiopia, progressive assessment of the pilot implementation sites of Hareg project revealed that 50% HIV+ pregnant women received complete course of ARV prophylaxis to reduce risk of MTCT, but nobody knows how many of them actually took/swallowed the drugs

In the past 5 years, in Western, Eastern and Central Europe, MTCT rates were reduced to as low as 1.6% through combined efforts. By using nevirapine alone MTCT of HIV can be reduced by 50 %. Lesson from programs of tuberculosis, river blindness and many of the most successful programs of HIV/AIDS itself show that systematically engaging the communities (most concerned parts of community, peers and family members) is critical for large scale coverage of nevirapine uptake. The inclusion of these people will help to overcome the key obstacles to an effective response, including denial, stigma and discrimination; hence they critically determine how women- as part of the community understand PMTCT.

Traditional birth attendants constitute an extensive network, reaching millions of individuals infected and affected by HIV/AIDS, potentially capable of expanding and simplifying access to comprehensive HIV care through various entry points. Over time, these practitioners have, and have remained actively engaged years after their initial involvement, a definite sustainability advantage over conventional community health workers. Most of them are eager to collaborate; they can be trained to support voluntary



counseling and testing, the prevention of mother-to-child transmission of HIV and ART, to strengthen existing referral facilities, and to build a functional traditional health practitioner–biomedical health practitioner cross-referral system.

In the method known as directly observed highly active antiretroviral therapy (DOT-HAART) in Haiti, community health care workers known as accompanateurs visit people receiving ARV therapy at home on daily basis.

#### **4.3 Knowledge and Impact of PMCT Services in Iira Sub County**

Almost all the respondents the researcher approached about 99.8% and 96.9% of the pregnant women respectively said that they had heard about HIV/ AIDS and PMCT before, many of them had multiple sources of awareness; namely, health facilities 91.1%, radio 75.8%, friends 43.9%, social ceremonies 36.6%, relatives 34.6%, school teachers during their school ages 34.4%, news paper 24.8%, and television 55.0%. Pregnant women who were first informed by school teachers were more likely to have voluntary counseling for HIV testing when compared to others sources. Meanwhile women who were informed first in social ceremonies were less likely to have voluntary counseling for HIV testing when compared to other sources

Forty-one 41% of pregnant women believed that HIV is a curse sent from GOD as a punishment of the sin of people. These women were more likely to refrain from getting voluntary HIV counseling. With regard to transmission of HIV from a mother living with HIV/ AIDS to the fetus (MTCT) 68.8%, 61.7% and 76.1% had the correct knowledge that MTCT of HIV occurs during pregnancy, labor and breast-feeding respectively. Pregnant women who have the correct knowledge that MTCT occurs during labor were more likely to undergo voluntary counseling for HIV testing

Fifty women 50% knew at least one method of prevention of HIV transmission. Specifically, 98.4%, 72.9%, 40.7% mentioned to be faithful, to abstain and to avoid breast-feeding respectively.

Coming to PMTCT, 96.9% of the pregnant women had heard of it and of these, 91.6% mentioned chemotherapy while 6.2% believed that there is a vaccine for PMTCT. Pregnant women who had the correct knowledge that MTCT of HIV can be prevented using chemotherapy were more likely to have voluntary counseling for HIV testing. Of the 87 pregnant women who had the correct knowledge that MTCT of HIV occurs during breast-feeding, only 36 mentioned that PMTCT is possible through avoidance of breast-feeding.

Pregnant women were asked what they think about the reason for which many other pregnant women are not attending ANC. Fear of consequences of positive HIV status mentioned by 29.3%, lack of awareness as to the benefits of ANC by 32.0% and work load of women by 20 (20%) were among the perceived reasons.

Only 55.5%, 64.8% and 54.7% of the interviewee talked about HIV/ AIDS with their husbands, with health personnel and other people respectively in the 12 months preceding the survey. Among reasons stated for differing discussions about HIV/AIDS with husband: thinking that they are safe 66.5% felt it is not important issue, 27 addressed that such discussions cause marital disharmony; yet 46 (46%) others refrained from commenting.

Sixty seven (67%) of the respondents had undergone voluntary counseling for HIV testing. The timing of counseling was premarital VCT in 30 (30%), preconception VCT in 35 (35%), and the current pregnancy in 57 (57%). 55.9% mentioned counseling was user-initiated i.e. to plan for marriage in 15.9%, to plan for having baby in 38.8% and to know self status in 2.4%. 44.1% said it was provider- initiated at health facility visit. Seventy eight (78%) of the respondents know that HIV testing is mandatory in each of the subsequent pregnancies.

Reasons given for not counseled ever or up until the time of survey were fear of being identified as HIV positive in the community in 52.6%, low perceived risk of having HIV in 77 (77%), the need to consult the husband in 41(41%), fear of discussing the horrible

picture of HIV with the counselor in 42 (42%), and other reasons like lack of awareness as to the benefit or the presence of VCT and by chance in 58 (58%). Pregnant women who were afraid of being identified as HIV positive in the community were more likely to abandon VCT in the ANC setting

One hundred (100%) of the entire respondents suspect that their husbands might have HIV and specifically, 54.5% of the pregnant women who had not known their status expected their HIV test result to be positive for HIV. Of the 67 pregnant women who had expectations of having positive HIV test result, 23 (23%) were not willing to take the drug for PMTCT. The reason given by 14 of them was to avoid discrimination by the family, and that by 9 was lack of trust on the effectiveness of the drug.

Fifty six (56%) of pregnant women had never discussed about MTCT of HIV and the possible outcomes of the current pregnancy with partner, and 50.0% about the issues of HIV testing in the current pregnancy. About 72.4% of pregnant women believed that their husbands support couple testing, while the other 62(62%) believed that their husbands want the wife to be tested alone or not to raise the issue at all.

The Likely reaction of husbands/sex partners to positive test result was such that the husband will not accept the result trusting the wife in 71 (71%), while 48 (48%) expected to be thrown out of home/out-casted and physically violated/abused respectively. Likewise 81 (81%) and 61 (61%) of the respondents expected that the family and the community respectively will out cast and physically violate/abuse the HIV positive women. Pregnant women who perceived that the community out cast PLWHA was more likely to differ from undergoing voluntary counseling for HIV testing compared to those who thought that they are cared for.

Regarding the preferred place of delivery, 29.4% planned home, 24.6% did not decided until the time of the survey. Among 72 pregnant women interviewed in health centers, 76%) planned to deliver in another facility (the nearby hospital). With respect to the desired number of additional children 79.0% need to have no more child if by chance mother is positive for HIV, 52 (52%) one or two more children, 10 (10%) more than two

children. These could probably be due to lack of envisage to appreciate the service provided by maternity staffs in the health centers.

#### **4.4 Successes Stories, Emerging Concerns and Way forward To Specific Groups**

##### **1. Lack of Awareness:**

As stated by TBAs and counselors lack of awareness of the benefits of having ANC is said to be common among urban and rural women. “Some think as having minimal risk of HIV as they are living with the ever partner in life.” (PMTCT Nurse, Amuca SDA health center)

##### **2. Fear of stigma, discrimination and self-coping**

“Women fail to have VCT because many lack the skill how to cope and what to do if positive. Afraid of stigma and discrimination, many women do not like to be seen in the VCT rooms”. (39 years old female TBA) “Due to the fear of discussions about HIV with health care provider women want to avoid counseling.” (PMTCT Nurse, Barapwo health center). Likewise all the interviewees mentioned the fear of being identified as positive and the consequent stigma and discrimination by family and villagers. “Particularly women are afraid of having HIV positive test result while status of the husband is unknown or negative. In that case the family will discriminate the woman and even abandon from home.” “Women are afraid of rearing children knowing that they have the deadly disease”.

##### **3. Work load of and low status of women**

“To be a mother is to shoulder the over loaded home tasks and out of home activities. Mothers have little time to think and care for themselves. Even those who make visits do not tolerate the slightest time lost while waiting for turn.” (PMTCT Nurse, Lira Hospital) “Among rural communities, the norm does not allow women to walk out of door unattended. The husbands do not trust wives, especially young ones. Furthermore unless it is holyday the husband gives priority to his farming activities rather than accompanying his wife.” (PMTCT Nurse, Lira health center IV).

##### **4. The way providers treat pregnant women**

All of the TBAs pointed out that the government facility health care providers are not polite in handling patients. They do not explain when doing procedures; miss place records and reject referrals sent by TBAs. However the counselors stated that there is

unreal circulating gossip in the community about health care facilities that the service is cumbersome.

The TBAs believed that they have acceptance over health care providers in the community. “We are friendly to women in the community, are transparent to them, explain everything done for them, and keep secrets.” (42 years old female TBA)

#### **4.5 Suggested measures to scale up the PMTCT service**

1. Continuous health education: community based and facility-based education, peer group discussions in the community and group education among HIV positives. “By appointing HIV + pregnant women at the same time, raise the issue (related to being HIV + pregnant woman) and discuss. They themselves do not know whom they are with until the discussion is raised. This creates a sense of belongingness, builds their ability to cope.” (PMTCT Nurse, Ayira health center)

2. Social Mobilization: Four of the interviewees suggested strengthening health education outreach community based education (through churches and schools by the help of priests and teachers) and programmatic facility based education. The other respondent emphasized the importance of having contact persons for HIV + pregnant women from the start which will be crucial for tracing. (PMTCT Nurse, Lira health center IV) “No matter whether the TBA or health worker made the counseling we (the TBAs) can manage the follow up, provided that confidentiality is shared. We are the trusted providers.” (39 years old female TBA) “Since we (the TBAs) are the front line providers, monitoring of our activities, coordinating joint outreach visits regularly with a health worker capable of performing screening for medical problems, and providing supplies like IP materials and drugs for family planning.”

##### **4.5.1 Summary result of FGDs among Husbands to Pregnant women and pregnant woman who do not attend ANC**

- Knowledge and Attitudes regarding HIV testing
- Both pregnant women not following ANC and husbands to pregnant women know what HIV and AIDS are and how HIV is transmitted. However, self-risk perceptions for HIV are variable. One woman said that “I know only my husband as a partner; there is no possibility that I can acquire HIV.” (40, FAL, illiterate)

- In both groups of husbands the discussants believed that sick people should undergo HIV testing for possible initiation of ART, otherwise people should be tested when planning for marriage.

- 

**Possible reasons of not using PMTCT services by pregnant women:**

The most frequently stated reasons by the discussants were fear to cope for self if positive for HIV and fear of discrimination by the community in taking ARV drugs; they better not know their status. Even some husbands in the community do not allow the wife to be tested. If the wife is positive for HIV while the husband is not, they may even divorce.

Pregnant women perceive that the drugs used for PMTCT does not prevent MTCT of HIV. One pregnant mother (age 39, FAL student, no formal schooling) said, “While AIDS has no cure, advocating that it can be prevented by medication is to cheat mothers”.

The other reason agreed by the respondents is that health professionals do not treat clients with courtesy.

## CHAPTER FIVE

### CONCLUSION, RECOMMENDATIONS AND AREAS FOR INTERVENTION

#### 5.0 Introduction

This chapter entails the researcher's conclusion, recommendations and areas for intervention suggested to different stakeholders.

#### 5.1 Conclusions

- ✓ Individual counseling is highly effective in the studied facilities. Interventions triggered towards encouraging women to come for individual counseling can ensure program's effectiveness.
- ✓ Being a rural resident and being a farmer seem strong limiting factors for pregnant women to undergo HIV counseling.
- ✓ Educational status and correct knowledge of women about MTCT of HIV and PMTCT were positively associated with voluntary counseling and testing for HIV in the ANC setting.
- ✓ Fear of stigma of HIV positive pregnant women by the husband, family, and the community was regarded as a barrier for utilizing counseling, testing and intension to take drugs.
- ✓ Scale up of the program may be possible through a decentralized approach by community mobilization and use of TBAs in the system to provide HIV/AIDS education and refer mothers to health facilities for testing.

#### 5.2 Recommendations

- Increasing access to VCT before and during pregnancy by integration of PMTCT services into routine reproductive health services and strengthening referrals within the facilities should be practiced. Enroll pregnant women with missed opportunities of VCT during their facility visit for any reason.

- Promoting PMTCT services in all health care facilities to provide essential care to women and her fetus in the catchments areas may improve the utilization of the services.
- Community based education and sensitization on HIV/AIDS; MTCT, and PMTCT, and specific education against stigma and discrimination targeted to women and the community is required in the catchments areas.
- Out reaches and community mobilization among rural people served by PMTCT programs.
- More community based and qualitative research is needed on determinants of PMTCT coverage and compliance.

### **5.3 Suggested interventions for wide coverage:**

Improve the conducts /the ways by which providers handle clients)

Husbands should be informed how to handle pregnant women; supportive home environments should be created for women to enable them in decision.

Establishment of women friendly associations in the community working at household levels to provide social support and empower women was recommended.



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## APPENDICES

### Appendix I: Questionnaire

I am Okullo Emmanuel Ogole a student of Kampala International University pursuing a bachelor's degree in social work and social administration. Currently am carrying out a research study in this Sub County on the impact of Mother Baby Pair at the PMTCT-EID Care and Treatment Points in this sub county

This questionnaire has a set of questions which I would ask you to answer with a lot of honesty such that they meet the objectives of this study. Any idea, view or opinion that you will give is going to be treated with utmost high confidentiality and will be used only for the purpose of this study to enhance me to fulfill my academic requirements.

#### Section A

#### Demographic information:

Tick the appropriate answer

1. Age of the respondent 18-25  26-30  31-35  Above35

2. What is your level of education?

None  0 level  A level  Degree

3. What is your marital status?

Married  widowed  Divorced

4. Religion

Anglican  Catholic,  Moslem,  Pentecostal

#### Section B:

1. At what age was your current/last baby tested for 1 DNA-PCR?

In the first 2 months

After the first 2 months

Not tested

2. How many wives does your husband have?

One

More than one

Not married

3 Are you a member of the FSGs?

Yes

No

4. Have you ever missed a scheduled appointment in the last 12 months?

Yes

No

5. Reason for missing appointment.

Lack of transport

Stigma

Forgot

Other (specify) .....

N/A

6. Husband tested for HIV?

Yes

No

8. Husband in care?

Yes

No

9. Has your baby received a 2nd DNA-PCR test?

Yes

No

10. Mother disclosed HIV status to partner

Yes

No

11. How do you comment about the waiting time at the ART clinic?

Less than 1 hour

1-4 hours

Above 4 hours

12. Mothers occupation

House wife

Employed

Self employed

Others (specify) .....

13 Comment on the availability of drugs (Septrin and ARVs) at the health facilities

Always available

Sometimes available

Rarely available

14 Comment on the quality of counseling at the HIV clinic

Good

Fair

Poor

15. Comment on the health workers customer care

Good

Fair

Poor

16. Were you escorted by your husband when you were pregnant (male involvement)?

Yes

No

17. How long have you been in care?

Less than 1 year

1-4years

Above 4 years

18. Status of mother

Active in care

Loss to follow up (LTFU)

**Section C:**

19. What do you think are the major reasons for poor retention of mother baby pair at the PMTCT-EID care points?

.....

20. What strategies do you think you can employ as a community to improve on the retention or reduce the LTFU of mother baby pair at the PMTCT and EID care point?

.....

.....

21. What changes need to take place at the health facility in order to improve the retention of mother to child retention or reducing on the LTFU?

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.....

22. What do we need to do in order to improve on male involvement so that we can achieve the benefits of PMTCT interventions?

.....

23. How are the family Support groups helping in the retention of mother baby pair at the PMTCT and EID care centers?

.....

## Appendix II: Research Budget

Item	Unit Cost	Quantity	Total
Transport	16000	4	64000
Stationary	750	100	75000
Binding	20000	3	60000
Research assistants	30000	2	60000
Research instruments	40000	2	80000
Miscellaneous	50000	1	50000
<b>Total</b>			<b>389.000</b>

**Appendix III: Ghant Chart (Time Frame)**

Item	Time (Months) 2014				
	May	June	July	August	September
Proposal development					
Proposal approval					
Data collection					
Data analysis					
Report writing					
Final report submission					