
AN ASSESSMENT OF RETENTION MOTHERS INTO THE PMTCT	PREGNANT AND LACTATING HOSPITAL, NTUNGAMO
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A POST GRADUATE DISSERTATION SUBMITTED TO THE INSTITUTE OF HEALTH
POLICY AND MANAGEMENT IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE AWARD OF DEGREE OF MSc PUBLIC HEALTH (MPH)

INTERNATIONAL HEALTH SCIENCES UNIVERSITY

ABEL ASIIMWE

2010-MPH-RL-FEB-033

SEPTEMBER 2014

Declaration

I, ABEL ASIIMWE, declare that I have read the rules of International Health Sciences University on plagiarism and hereby state that this work is my own.

It has not been submitted to any other institution for another degree or qualification, either in full or in part.

Throughout the work, I have acknowledged all sources in its compilation.

Signature of the Researcher

Date.....

Abel Asiimwe

This dissertation has been submitted for examination with my approval

Signature..... Date.....

Mrs. Mary Gorrethy Mboowa

DEDICATION

This work is dedicated to my sons (Ahabwe Alvin, Atukunda Arian, Abibaasa Abey and Asingura Alethia) as an encouragement to read widely and acquire more ideas for a bright future.

ACKNOWLEDGEMENTS

In a special way, I wish to acknowledge and appreciate my research supervisor Mary Gorrethy N. Mboowa for the guidance during the proposal development stage and finding time to review the draft reports and final approval of this write up.

I am equally grateful to my work colleagues who reviewed the proposal and shared great ideas on how to improve the proposal and key issues to spice up the research findings. These include: Dr. Edward Bitarakwate, Country Director Elizabeth Glaser Pediatric Aids Foundation, Mr Kajungu Eliab, Senior Monitoring & Evaluation Manager and Dr. Ibrahim Kirunda, Director Quality Improvement both working with Elizabeth Glaser Pediatric Aids Foundation.

I am highly indebted to my wife Allen Asiimwe and children Ahabwe Alvin, Atukunda Arian, Abibaasa Abey and Asingura Alethia for encouragement and tolerating me while I concentrated on this course and research project.

My sincere thanks go to my friends Mr. Turyamureeba Medard, Mr. Mwesigwa Robert and Mr. Katugume Fred who gave more insights to my initial proposal ideas and encouragement throughout the data collection, analysis and writing final report. I thank Mr. Nuwagaba Denis for inspiring me to take up this MPH course after my first Master's Degree in Development Studies.

ABSTRACT

Introduction:

Globally, over 90% of pediatric HIV infections are a result of mother to child HIV transmission (Ayalu A. et al, 2012). Available data has shown that the PMTCT care can reduce the risk of HIV transmission to less than 2% among the children (Besigin T. et al, 2009). In Uganda, the percentage of children exposed to HIV from their mothers remains high at 46%. The study therefore aimed at finding out possible strategies to reduce child HIV transmission.

General objective:

The study aimed as assessing the existing retention strategies for pregnant and lactating mothers on PMTCT program at Itojo Hospital, Ntungamo District

Methods:

The study used in-depth interviews, focus group discussion and documentary review methods to collect data. Primary data collection methods included the use of questionnaires and interview guides while secondary data collection methods included review of hospital registers.

Results:

A total of 160 respondents were involved in the study. The majority of these were pregnant and lactating mothers (82.5%), 54.1% were in the aged below 30 years, 39.1% were in range of 30-39 followed by 6.8% were between 40-49, 73.9% of the respondents were married and 65.2% had primary level education while 47.4% came from hospital radius of more than 5 kilometers.

The study findings revealed that factors responsible for lost to follow up of pregnant and lactating mothers at Itojo hospital were identified as; distance to the hospital, and occupation. Other factors were; failure to disclose to partner and other family members and lack of partner support, stigma, poor staffing of health workers and inadequate preparation of mothers to start PMTCT.

Limitations of retention strategies being used to retain pregnant and lactating mothers revealed pregnant and lactating mothers were 24 times more likely not to return to the facility for PMTCT care due to drug stocks outs (χ^2 24.08 95% CI 0.004-0.007) P-Value 0.006 which was statistically significant, were 25 times more likely not to return due high costs of follow up (χ^2 25.03 95% CI 0.003-0.006) P-Value 0.005 which was statistically significant. Wrong telephone numbers was 11 times more likely to affect follow up (χ^2 11.1 95% CI 0.008-0.008) P-Value 0.001 which was statistically significant while wrong physical address was 8 times more likely to affect return to facility (χ^2 7.996 95% CI 0.009-0.009) P-Value 0.005.

Retention strategies used in other facilities included; introduction of community department to mobilise and refer people from community to hospital, use of community quality improvement projects, local leaders, expert patients and VHTs.

Conclusion:

The results from the study revealed that drug stocks, distance to the hospital, wrong telephone numbers by patients failure to disclose to partner and lack of partner support and stigma had influence on retention into PMTCT. Different strategies used to retain them in care for a long period must always be monitored and evaluated to ensure compliance.

Recommendations:

Proper preparation of pregnant and lactating mothers as they start PMTCT, encouragement of males to support their partners, allocation of enough funds and PMTCT scale up to lower units were recommended to improve retention.

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LIST OF ABBREVIATIONS/ACRONYMS

AIDS	:	Acquired Immunodeficiency Syndrome
PMTCT	:	Prevention of Mother to Child HIV Transmission
ANC	:	Antenatal Care
ART	:	Antiretroviral Therapy
CD 4	:	Cluster of Differentiation
FGD	:	Focus Group Discussion
HIV	:	Human Immunodeficiency Syndrome
HMIS	:	Health Management Information System
MoH	:	Ministry of Health
MTCT	;	Mother To Child HIV Transmission
PNC	:	Post Natal Care
UNAIDS	:	United Nations Joint Program on HIV/AIDS

USAID : United States Agency for International Development
WHO : World Health Organisation

OPERATIONAL DEFINITIONS

1. Retention:

In this study, retention was defined as remaining connected to medical care, once enrolled on PMTCT program that is to say continuous engagement from diagnosis stage in a package of prevention, treatment, support and care services. “Retention in care is defined as initial engagement into the care for the person diagnosed with HIV including assessment for eligibility and starting of lifelong ART treatment” (Ayalu A. e tal, 2012).

2. Lost to follow up:

In this study “loss to follow up” was defined late for scheduled consultation or medication pickup for 90 days or more.

3. Retention strategies:

In this study, a retention strategy was defined as deliberate effort put in place to improve maternal/infant retention into the PMTCT programs. Retention strategies are supposed to be comprehensive and covering a

range of services including; prevention, support and care services from any health facility. (Ayalu A. e tal, 2012).

4. **Attrition:**

This was defined as the discontinuation of PMTCT including death, loss to follow up, and stopping ARV medication while remaining in care.

5. **Expert patient:**

This was defined as a patient who was initiated on PMTCT and adhered well to the PMTCT treatment cascade and works as an example to other patients who are newly enrolled on PMTCT.

CHAPTER ONE

INTRODUCTION

1.0: Introduction

This chapter introduces the study including the variables, looks at the background to the problem under investigation, the statement of the problem, study objectives, research questions, scope of the study, justification of the study, and the conceptual framework.

Patient retention was critical to reducing HIV transmission through effective adherence to ART and linkages for HIV prevention. Future strategies to promote retention into care require understanding of several methods to ascertain patient outcomes (Ayalu A. e tal, 2012).

Globally, over 90% of pediatric HIV infections are a result of mother-to-child HIV transmission (Ayalu A. e tal, 2012). Available data has shown that the use of antiretroviral regimens offered in prevention of mother-to-child (PMTCT) transmission and the use of highly active antiretroviral treatment (HAART) during pregnancy can reduce the risk of HIV transmission to less than 2% among the children (Besigin T. etal, 2009)

Efforts aimed at retaining patients into care are part of national HIV prevention strategy (2011-2015) that is based on the global commitment to zero new HIV infections, zero AIDS related death and zero discrimination (MoH, 2011).

Thus, this study aimed at assessing the various strategies for increasing retention of pregnant and lactating mothers into the PMTCT program at Itojo

hospital of Ntungamo District in Uganda in order to contribute to this national and global commitment.

The dependent variable was retention of pregnant and lactating mothers into PMTCT. Independent variables are; Providers-related factors, health system related, community related factors, patient characteristics related factors, and social economic related factors while Itojo hospital retention strategies are intervening variables which are a focus of this study.

1.1: Background

Globally, approximately 33.3 million people are living with HIV of which 15.9 million people are women of child bearing age representing 48% (UNAIDS, 2011). In Sub-Saharan Africa, 22.5m are living with HIV and 12.1 million (53.7%) are women and 2.3 million (10.2%) are children (UNAIDS, 2011). The Uganda AIDS Indicator Survey (MOH, 2012) reported that the prevalence of HIV among adults in the country increased from 6.4% in 2004/5 to 7.3% and about 2.6 million people are infected with HIV. More women (7.7%) in age group 15-49 infected than men (MOH, 2012). General HIV positivity rate for Ntungamo district was 4.9% and 17,162 have been enrolled on ART with females representing 66.8% and males at 33.2% (Ntungamo District HMIS Data, 2013).

Over 90% of pediatric HIV infections are a result of mother-to-child HIV transmission (Ayalu A. e tal, 2012). PMTCT reduce the risk of HIV transmission to less than 2% among the children (Besigin T. etal, 2009). Retention into care for people living with HIV across the continuum of care is essential for optimal health outcomes. Globally, data on the proportion of people who are retained in care overtime in low and middle income countries showed that

most people drop out within first year of initiation to treatment. Generally, it is reported that losses to follow up occur between testing and enrolment up to 80% (WHO, 2012). In 2011, the average retention at 12 months later starting treatment was 81% (92 reporting countries), 75% at 24 months (73 reporting countries) and 67% at 60 months (46 reporting countries) (WHO, 2011).

Retention in selected countries of the world in 2011 showed 59% for Viet Nam while Brazil retained 88% at 12 months, 78% at 24 months, 60% at 60 months and China retained 86%, 80% and 70% at 12, 24 and 60 months respectively, and Cambodia retained 87%, 84% and 78% at 12, 24 and 60 months respectively (WHO, 2012).

In African countries, few countries reported retention into care in 2011. Burundi reported highest retention at 90%, 81% and 59% at 12, 24, 60 months respectively, Botswana with 88%, 80% and 74% at 12, 24 and 60 months respectively, Swaziland 85%, 78% and 66% at 12, 24, and 60 months respectively, Kenya 80%, 72% and 72% at 12, 24 and 60 months respectively, Malawi 79%, 76% and 78% at 12, 24, and 60 months respectively and Namibia at 79%, 76% and 78% at 12, 24 and 60 months respectively (WHO, 2012).

In Uganda, retention at 12 months was 87%, 82% at 24 months and 68% at 60 months (WHO, 2012). Approximately, 1.6 million women get pregnant in Uganda annually, 6.5% are living with HIV which translates into 104,000 babies at risk of acquiring HIV each year with average transmission rate of 30%. It is estimated that 31,200 babies would be infected with HIV (MOH, 2012). Prevention of Mother to Child transmission of HIV through PMTCT care

coupled with good retention is therefore still far way considering transmission rate of 30%.

PMTCT is one of the critical pillars for achievement of a new generation that is free of HIV and attainment of Millennium Development Goals 4, 5 and 6 (UNDP, 2010). It was introduced to reduce the number of children contracting HIV from their mothers. Retention of mothers in service to ensure mother and infants complete treatment cycle is important in ensuring prevention of HIV from mother to infant.

In Ntungamo District it is estimated that out of the population of 491200, 51.7% are females and 48.3% males, 4.3% (21,121) are children under 1year, 20.2% (99,222) are children under 5years and 24,560 estimated pregnant women. A total of 17,162 are on ART including 11,478 female adults, 5674 male adults and children. The district ART retention in 12 months was 84.3% which is below the National target of 95%. At Itojo, the retention in ART for mothers on ART was 84.3% (***Ntungamo district HMIS report 2013***).

Itojo hospital is a Government District Referral established in 1973; and serves a catchment population of about 450,000 people. It offers a wide range of services that include preventive, promotive, curative and rehabilitative under a number of department's namely general medicine, surgery, ophthalmology, pediatric, community health, Dental, obstetrics and gynecology among others. At Itojo hospital located in Ntungamo district, PMTCT service started in 2005.

The table 1.1 below presents, **the status of PMTCT service delivery** at Itojo hospital. Much as the retention rate in 12 months for mothers on ART

improved from 71.7% to 84.3% in two years, the rate continued to be below the national target of 95%.

Table : PMTCT Retention Status at Itojo Hospital over period October 2010 to Sept 2012

Retention indicators	Oct 2010 - Sept 2011		Oct 2011 - Sept 2012	
	Number	%	Number	%
Pregnant and lactating mothers who started on ART 12 months ago	99	100.0%	242	100.0%
Pregnant and lactating mothers still on ART after 12 months on ART	65	65.7%	187	77.3%
Pregnant and lactating mothers on ART who died within 12 months	3	3.0%	6	2.5%
Pregnant and lactating mothers on ART who transferred out to other health facilities within 12 months	3	3.0%	11	4.5%
Pregnant and lactating mothers on ART lost to follow up within 12 months	28	28.3%	38	15.7%
Retention rate against National target of 95%	71	71.7%	204	84.3%

Source: ART Registers - Itojo Hospital, 2012

1.2: Problem statement

Despite worldwide scale up of services to prevent mother to child transmission of HIV (PMTCT), coverage in low and middle income countries continue to remain unacceptably low. Poor identification, preparation and enrolment of mothers in PMTCT together with poor retention largely explain this (WHO, 2012). (WHO, 2011) (UNDP, 2010)

Globally, over 90% of pediatric HIV infections are a result of mother to child HIV transmission (Ayalu A. e tal, 2012). Available data has shown that the use

of antiretroviral regimens offered in during PMTCT care can reduce the risk of HIV transmission to less than 2% among the children (Besigin T. etal, 2009).

While the government of Uganda has made great strides to increase coverage of PMTCT to 85% for hospitals, 93% for Health Centre IVs and 24% for Health Centre IIs services, the percentage of children exposed to HIV from their mothers remain high at 46% in the country (MOH, 2012). The PMTCT program mainly focuses on enrolment and retention of mothers through ANC and PNC visits but these efforts have not translated into reduced number of children getting HIV from their mothers as PMTCT continue to contribute 18% of new HIV infections in Uganda (MoH , 2011) as retention continues to be unacceptly low with 87%, 82% and 68% at 12, 24 and 60 months respectively (WHO, 2012).

Innovative intervention strategies such as family support groups (FSGs), attachment of patients to peer educators, phone call follow up with patients, facility and community based linkage facilitators and drug companions have been introduced to improve retention of pregnant and lactating mothers enrolled into care at Itojo hospital. Despite these interventions, retention of pregnant and lactating mothers on PMTCT program has continued to be a major hindrance to achievement of positive results in PMTCT.

Review of previous studies done on related strategies for retention have not done in-depth examination on the limitations of retention strategies put in place by health care system. The rate of adherence and retention of patients into PMTCT continues to be low (71.7% in 2011 and 84.3% in 2012 as indicated in the table 1 above) compared to national recommended rate of 95%.

Consequently, this has continued to contribute to more babies being born with HIV in the District. According to Ntungamo HMIS report 2013, 216 HIV positive children were enrolled on ART during the period October 2012 and September 2013 in Ntungamo district and 19 children were from Itojo hospital while in Uganda, about 31,200 babies or more are born with HIV every year (MOH, 2012). This negatively affects the PMTCT program efforts geared towards reducing the number of children contracting HIV from their mothers which is one of the critical pillars for achievement of a new generation that is free of HIV and attainment of Millennium Development Goals 4, 5 and 6 (UNDP, 2010). Thus, it is from these facts that the study aimed at assessing the retention strategies for the pregnant and lactating mothers into PMTCT at Itojo hospital, Ntungamo District as part of global commitment to zero new HIV infections, zero AIDS related deaths and zero discrimination.

1.3: General Research Objectives

The study aimed at assessing the retention strategies for pregnant and lactating mothers on the PMTCT program at Itojo Hospital, Ntungamo District.

1.4: Specific Research Objectives were;

- i. To examine factors responsible for lost to follow up of pregnant and lactating mothers at Itojo hospital.
- ii. To examine limitations of retention strategies being used to retain pregnant and lactating mothers on the PMCT program at Itojo hospital.

- iii. To explore retention strategies which have been used in other facilities in increasing retention of pregnant and lactating mothers into the PMTCT program.

1.5: Research Questions

- i. What factors are responsible for lost to follow up of pregnant and lactating mothers at Itojo hospital?
- ii. What are the limitations of retention strategies used to retain pregnant and lactating mothers on the PMCT program at Itojo hospital?
- iii. What retention strategies have been used in other facilities to increase retention of pregnant and lactating mothers into the PMTCT program?

1.6: Significance of the study

- i. It is hoped that the study will inform future modification of current strategies to avert the possible barriers to realizing retention for all clients enrolled into care.
- ii. The study findings could facilitate evidence-based PMTCT programming in increasing uptake, retention and adherence to PMTCT service and reduction of MTCT at Itojo, Uganda as a country in general.
- iii. A few of studies have been conducted in area of retention strategies. Findings from this study will contribute to increased uptake of PMTCT service and retention into care and contribute to reduction HIV infection rate through MTCT at Itojo hospital
- iv. The study findings will create more awareness among the hospital staff about the importance of retention and adherence and

thus contribute towards the proper management of Itojo clients and provision of quality of care.

1.7: Scope of the study

1.7.1: Geographical scope

The study was undertaken at Itojo hospital and in Itojo sub-county. This is because the hospital is a district hospital with a big catchment area and one the health facilities that started provision of PMTCT services more than 10 years. The hospital has enrolled over 2000 people on ARVs and most of the pregnant and lactating mothers enrolled into PMTCT. The hospital was purposively selected since this was in easy reach of the researcher. Itojo hospital is about 48 kilometers from Mbarara town.

1.7.2: Content scope

The study included pregnant and lactating mothers enrolled on PMTCT program at Itojo hospital. The study also targeted male partners of the pregnant and lactating mothers because of their influence on uptake of services. The issues explored include factors responsible for lost to follow up

of pregnant and lactating mothers and limitations of these strategies at Itojo hospital.

Itojo hospital retention strategies

- Family Support Groups
- Expert patient attachment
- Phone follow up
- Adherence counseling
- Drug companion

National Health system strategies

- Stock of drugs & supplies
- Access to health care
- Monitoring and evaluation
- Motivation

1.8 Conceptual framework

Independent variable
Intervening variable
Dependent variable

- v.
- vi.
- vii.

Retention of pregnant and lactating mothers in PMTCT Program

viii.

ix.

x.

xi.

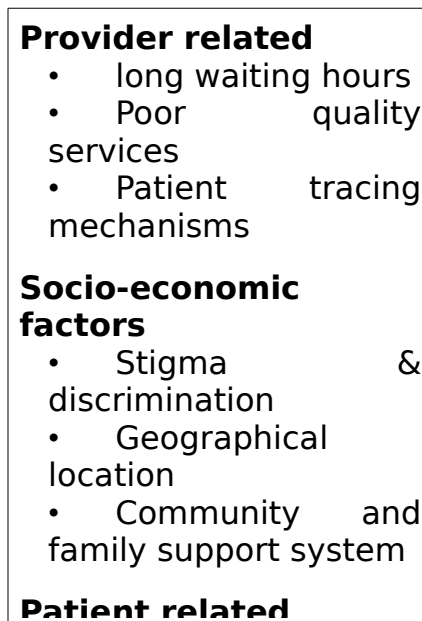


Figure : Analytical and Conceptual Framework

Retention of pregnant and lactating mothers on PMTCT is dependent on the strategies being implemented at national level and Itojo hospital level.

National Health care system related factors include stock out of PMTCT drugs and supplies, access to health care, monitoring and evaluation measures, pill burden, management of opportunistic infections, policy environment, patient tracing procedures, management of toxicities and nutritional support.

Itojo hospital strategies which act as moderating factors included; Family Support Groups (FSGs) where PMTCT services including psychosocial support and Antiretroviral drugs are provided during FSG monthly meetings, peer educator patient enrolled attachment, phone for follow of patients who miss appointments or the lost to follow up, adherence counseling is also provided on every contact with the patient by peer educators and health workers. Drug

companions who are family members, neighbours or friends of the patient are identified by patients and introduced to health workers for preparation to support the patient on treatment prior to enrolment on PMTCT program.

The strategies mentioned above are influenced by the following factors;

At Itojo hospital, provider related factors are central to retention of pregnant and lactating mothers in PMTCT. Factors that affect retention include; long waiting hours, late coming of providers, poor quality services, patient tracing mechanisms, capacity to follow up, poor motivation of providers, knowledge gaps and poor attitude of providers,

Socio-economic factors that affect retention of pregnant and lactating mothers include; stigma and discrimination, occupation of mothers, genders related issues, cultural beliefs, attitudes, lack of transport, poverty, disclosure of HIV sero-status, geographical location and lack of treatment supporter.

Patient related factors include; age, level of education and knowledge about PMTCT, income, HIV testing, partners support, stigma, symptoms of AIDS, cultural beliefs, attitudes, adherence counseling, drug abuse including alcohol. Patient's health seeking behavior may also be influenced by behavior change and communication messages.

Community factors include; community support systems, stigma and discrimination, traditional healers and herbalists, family support to patients on disclosure drug adherence, cultural beliefs and attitudes.

CHAPTER TWO

LITERATURE REVIEW

2.0: Introduction

This chapter highlights contributions of various researches in relation to objectives of this study. Literature review is guided by the retention strategies and contributions presented here have been discussed to establish gaps and other issues in focus of this study.

2.1: Factors responsible for clients lost to follow up

The literature shows that high dropout rate within PMTCT programs was mainly attributed to LTFU and not mortality. Dropout rates in Sub-Saharan Africa range from 20–28% during antenatal up to 70% at four after delivery and reached close to 81% at six months after delivery (Fatch, W. et al, 2012; Elvin, H. et al , 2010).

Most of the countries are targeting national coverage of PMTCT services. .However, children born to HIV positive mothers are systematically being monitored after delivery and missing important services. Children are expected to be monitored during postpartum period to identify eligible children for initiation to treatment and care in order to improve infant health outcomes.

Therefore, exposed infants and children suspected of having HIV need to receive comprehensive care. (Fatch, W. et al, 2012) Showed that infants and children who were are exposed to HIV and started antiretroviral therapy after their immunity was compromised never improved on treatment even after five years. Such children are more likely to die compared to those who started treatment at an earlier stage of identification (Hassan, et al, 2012).

A number of factors were identified by studies as reasons for follow up (LTFU) under PMTCT in sub-Saharan Africa (Hassan, et al, 2012; Fatch, W. et al, 2012; Holly, 2012). These included health facility factors, fear of HIV test, stigma and discrimination, home deliveries, and socioeconomic factors.

Health Facility Factors

Studies conducted in Uganda and Kenya revealed that shortage of PMTCT staff, interrupted medical supplies, lack of space for counselling service were some of the reasons leading to loss of clients in PMTCT program (Fatch, W. et al, 2012). These constraints resulted into long waiting hours for the patients who needed counselling service resulting into some women leaving without receiving their HIV test results. The constraints also compromised privacy and confidentiality of mothers. Similar findings in Kenya where 92% of the respondents lacked privacy in counselling rooms due to having more than two people in the room. (Hassan, et al, 2012).

A study in South Africa by Braun, et al (2011) found out that patients had not received adequate information on PMTCT services, given that they could not remember any information shared by health workers during counselling sessions. The patients only made use of counselling services on the first visit and never went for counselling services during next visits irrespective of their HIV status and health condition. This could have been due to poor rapport by health workers during initial visits by the patients. Experiences of patients with confirmed HIV results who had did not get privacy and assurance for confidentiality indicated that 68% of the participants received less than 5

minutes of post test counselling, 21% had 5-10 minutes while only 10.7% had had more than 10 minutes.

Similar findings were found in a study conducted in Malawi where antenatal mothers thought that they were inadequately prepared to undergo HIV-1 testing. Positive mothers also thought that PMTCT had no benefit for them since ART was seen as not a part of PMTCT program. Mothers also complained of delays in getting service at ANC.

A study conducted in Ivory Coast revealed that mothers were afraid of being scolded at by health staff and that health workers were not attending to them when they had come for follow-up visits. In Ethiopia, a study revealed that poor monitoring of PMTCT services by health workers was one of the reasons to poor follow ups in PMTCT program because health facilities did not have registered information on HIV positive mothers who enrolled in PMTCT but failed to return for follow-up care.

Fear of HIV Test, Stigma and Discrimination

Studies in Malawi and Mali indicated that fear of HIV test; stigma and disclosure of HIV-1 status were main reasons for LTFU in PMTCT (Braun, et al, 2011). In another study, women feared reaction of their spouses. Most women feared separation from their spouses and thought that a woman's HIV infection and pregnancy would result into death of the baby, herself and the spouse. Some woman also feared that family members would blame and isolate (Beatrice M, 2007).

Home Deliveries

Accessibility of health services during pregnancy, labour and delivery are key ingredients to successful PMTCT program. Studies done in Malawi and Zimbabwe showed that PMTCT program had high loss to follow up due to many mothers delivering at home rather than health facility especially in rural areas (Ayalu A. e tal, 2012). In a study done in Ethiopia, 16% of the deliveries were attended by a trained health worker while in Uganda, 71 (95.9%) of HIV positive women did not keep appointment for delivery at health facility (Ayalu A. e tal, 2012). Cultural beliefs, poor socioeconomic status and stigma associated with HIV status were key factors that influenced delivery choice by location.

Understanding the socioeconomic factors that influence the communities to appreciate the role PMTCT program will facilitate resource constrained countries to develop strategies to achieve retention into PMTCT (Kenneth, M, et al, 2009; Ayalu A. e tal, 2012). The studies done in Malawi and Uganda indicated that poverty, geographical relocation and lack of partners support affected the capacity of families to comply with PMTCT follow. Similarly, loss to follow up was also associated with health facility user fees for every service or free maternal and child health services (Ayalu A. e tal, 2012).

In a study conducted in sub-Saharan Africa, the barriers to HIV disclosure amongst women varied from 16.7% to 86% and that between 3.5% and 14.6% of women indicated violent reaction from a partner following HIV status disclosure (Elvin, H. et al , 2010). The studies done in Rwanda, Ivory Coast and Zimbabwe showed that the major hindrance to PMTCT program was women travelling long distance to the health facility while in Kenya, lack

of maternal secondary education was linked to mother baby pair non adherence to Nevrapine (NVP) (Elvin, H. et al , 2010).

2.2: Strategies for retention of pregnant and lactating mothers and their limitations

Studies have proposed several strategies to address LTFU. Some of the strategies include psychosocial support, family-focused approach, home visits, monitoring and evaluation, and health information systems.

Psychosocial Support

Psychosocial support from peers in a group helps members to adhere to PMTCT. A good example is Family Support Groups supported by Strengthening TB and IV Response in South Western Uganda, a USAID project supporting clinic based a group that provides health education to HIV positive mothers in the group. This intervention by observed a difference in retention between mothers in family support group (93%) compared to 77% retention for other clients not in the group (USAID STAR-SW, 2014).

Psychosocial support from peers helps women adhere to PMTCT program recommendations. A good example is Mothers2mothers (m2m), a clinic-based, peer-support program that provides education and psychosocial support to HIV positive pregnant women and new mothers in sub-Saharan Africa.

Mother2mothers (m2m) clinic also employs peer educators as expert patients and care providers in health facilities to improve quality of PMTCT services. The organisation helps women access existing PMCT services and follows up women and infants to ensure good adherence to treatment. It helps women

access existing PMTCT services and follow-ups with mothers and infants after delivery (Barnabas R.A et al, 2012).

An evaluation of mother2mother project revealed that mothers who participated in the m2m program were significantly more likely to reveal their HIV status to at least one person; CD4 testing, receive nevirapine syrup for their infants and practice an exclusive method of infant feeding (Barnabas R.A et al, 2012). Male partner and community involvement were found by m2m project to provide psychosocial support and eventually improved retention and adherence of mother in PMTCT.

Family-Focused Approach

The family focused approach was a distinct model of HIV care which was pioneered by MTCT-Plus initiative at the international Centre for AIDS Care and Treatment Programs (ICAP) (Elvin, H. et al , 2010). MTCT-Plus model of care was established to address the long-term care and treatment needs of women identified as HIV infected in prevention of mother-to-child transmission (PMTCT) programs (Fatch, W. et al, 2012; Holly, 2012; Merdekios B, 2011). In this model, the pregnant woman was a key person who served as an example to her family and household to access HIV treatment services. The model approach was distinguished by the attention to the needs of both children and adults and to the provision of comprehensive HIV prevention for all the household members (Fatch, W. et al, 2012; Thomas A. et al, 2008)

Peer family support groups (FSGs)

In the study conducted by Uganda Program for Human and Holistic Development (UPHOLD) progress report (2009), Peer Family Support Group (FSG) have a positive and symbiotic effect on male involvement in PMTCT

program and eventually improve adherence and retention into PMTCT program. This was because both couples were involved in taking HIV treatment and nevirapine for the infant and the couples were able to remind each other on taking the daily doses (Beatrice, M. et al, 2009).

Home Visits

Upon enrolment into PMTCT care, home visits are arranged to ensure constant touch with the mother and family in order to ensure adherence and retention into care. Home visits include psychosocial support counselling, health education and basic care at home by health workers and this helps to reduce loss to follow up in PMTCT programs (Fatch, W. et al, 2012). Home visits include counseling and education to the families on importance of following PMTCT protocols.

Monitoring and Evaluation

Monitoring and evaluation of PMTCT services involve developing a system to record medical records for individuals including physical address, telephone contact and name of care taker at home in order to ease follow up in case one drops out of care (Hassan, et al, 2012; Elvin, H. et al , 2010). The medical records system help in following up of individuals enrolled in care, percentage of individuals getting treatment, deaths, loss to follow and those who do self referral (Elvin, H. et al , 2010).

Information Systems

Malawi and Rwanda developed an information system using an innovative touch screen interface and HIV-1-electronic medical record (Fatch, W. et al, 2012). A monitoring and evaluation team uses data collected by the system to identify clients requiring follow-up care. In Rwanda and South Africa

several projects have used cell phones to assist in patients follow up, encourage patients' compliance with treatment, and to provide medical access to medical data such as laboratory tests. This technology is at an early stage in development and evaluation.

Improving Maternal Retention

Engagement in care after a new HIV diagnosis is essential to achieve the lifesaving and prevention benefits of ART. Multiple studies from resource-limited settings have described this challenge among adult patients enrolled in HIV care programs, reporting LTFU rates of 45% within the first year after starting ART (Holly, 2012).

In particular, pretreatment losses between HIV diagnosis and CD4 cell count staging account for a significant proportion of clients that dropped out of care (Carolyn B. etal, 2010). A study done in South Africa, only 63% of people who tested HIV positive were able to return back for CD4 count measurement after 6 months from the initial test yet there was free treatment services in the neighborhood to the clinic (Holly, 2012; Carolyn B. etal, 2010). Although these data pertain specifically to adult ART services, the urgency of initiating ART is even more pressing among pregnant women.

Strategies that target inefficiencies within patient care systems may serve as particularly effective ways to reduce attrition. To address pretreatment loss, point-of-care HIV testing and point-of-care CD4 count determination with immediate treatment stratification have been examined as strategies to improve retention.

In a study from Mozambique, point-of-care CD4 testing in an adult ART treatment setting reduced the proportion of patients lost to follow-up before completion of CD4 staging from 57% to 21% (Holly, 2012; Elvin, H. et al , 2010). A study in South Africa, the CD4 count testing significantly increased the number of clients reporting for further care, from 34% with standard CD4 testing to 48% (Elvin, H. et al , 2010). This approach is particularly intriguing for PMTCT programs, and additional data on the impact of point-of-care CD4 testing among pregnant women in antenatal settings are needed.

Decentralization of services has also been associated with improved retention by reducing transportation costs, travel time, and clinic wait times, among other benefits. In a study from Malawi, the LTFU rate was significantly higher at hospitals (9.9%) than at rural health centers (1.5%), such that the use of rural centers resulted in a 77% reduction in risk for attrition (Holly, 2012).

Treatment partners also improve PMTCT utilization. In particular, involvement of male partners has been associated with increased retention, adherence to PMTCT antiretroviral regimens, and better infant outcomes. In addition, peer-mentoring programs may provide critical social support, increase HIV knowledge, improve coping skills, and increase attendance at follow-up visits. Whether peer mentoring improves outcomes for pregnant mothers living with HIV is a topic of ongoing investigation.

Provision of incentives

Provision of incentives as nutritional supplements and reimbursement of transportation costs, as was provided to women in rural Nepal if they gave birth with the help of a skilled healthcare attendant, showed potential to improve adherence and reduce loss (Holly, 2012).

Integrating Services

Inadequate coordination of services contributes significantly to patient attrition. In an assessment of infant diagnosis outcomes in Malawi, only 54% of infants whose mothers received prophylaxis underwent early infant diagnosis (Braun, et al, 2011). The investigators attributed the high attrition rate to different PMTCT services for mothers and the infant HIV prevention care services.

However, in a cluster randomized trial studying effect of Labour ward based PMTCT services, infant nevirapine coverage increased by 10% compared to control sites through enhanced integration of services (Holly, 2012). Similarly, in a study examining service delivery models of PMTCT care among 32 clinical sites in Rwanda, a system that integrated PMTCT and ART services significantly increased the proportion of women receiving combination antiretroviral prophylaxis, as well as subsequent ART, compared with stand-alone PMTCT services.

In addition, primary healthcare centers can serve as an important entry point for HIV-exposed infants. For example, by building capacity building of health workers on PMTCT policy in a district without physicians in rural Zimbabwe, rates of referral and testing for early infant diagnosis increased and a greater number of mothers and infants were reached with prevention messaging to reduce late infant transmissions. Particularly among countries with inadequate numbers of trained healthcare workers, the integration of services may improve patient care without requiring an increase in the total number of care providers.

Streamlining Treatment Protocols

More recently, simplification of treatment protocols has been viewed as a potentially effective strategy to reduce opportunities for loss. In 2010, WHO issued updated PMTCT guidelines that represented a major step toward promoting more efficacious prophylaxis regimens (Holly, 2012). According to these guidelines, countries can adopt: zidovudine monotherapy (Option A) or triple ART prophylaxis (Option B) as the preferred PMTCT regimen for women who were not eligible for HIV treatment and had CD4 less than 350 cell count. It was recommended that antiretroviral prophylaxis be stopped after delivery or cessation of breastfeeding.

In April 2012, WHO issued a new PMTCT guidelines related to use of ARVs to prevent mother to child HIV transmission (Ngarina M. etal, 2014), a new, third option (Option B+) was described (Holly, 2012) a single triple antiretroviral regimen (tenofovir/lamivudine/efavirenz) for all pregnant and lactating mothers regardless of CD4 cell count and to be a life time treatment. WHO concludes that this strategy has several advantages, including prevention of HIV negative partner, prevention of HIV transmission in future pregnancies and helps a mother against implications of stopping and starting treatment again.

Notably, this strategy avoids the need for baseline CD4 measurement before treatment stratification, thus decreasing delays as well as opportunities for patient loss between HIV diagnosis and ART initiation. This may solve the difficulties related with provision of ART treatment at primary care level especially where laboratory testing services for CD4 cell count may not be available, thus reaching women in increasingly rural settings (obermeyer C. e tal, 2013). Nevertheless, although the theoretical benefits of such a strategy

are clear, whether utilization of Option B+ will result in improved retention, maternal health, and infant outcomes remains to be seen.

Improving After-Delivery Linkage and Infant Follow-up

Investing in solutions aimed at improving maternal retention will only partially achieve the goals of PMTCT care. Data from the Harvard/APIN program and several other outcomes analyses have shown that a significant proportion of loss within the PMTCT care cascade occurs after delivery (Hassan, et al, 2012). This loss is not unexpected when one considers that maternal and pediatric care often provided by distinct healthcare providers and typically occurs in physically separate locations. Linkages in HIV care are important and help in improving adherence and reducing drop outs.

For example, in a study from Mozambique, improved linkage and referral service to patients who were manually walked to point of service delivery before maternal discharge subsequently improved early infant diagnosis from 26% to 54% (Holly, 2012; Gay, J. e tal, 2010). Similarly, in Kenya, implementation of an active patient tracking system reduced LTFU from 21% to 15% among HIV, PMTCT, and tuberculosis patient cohorts during the study period (Holly, 2012). Innovative staffing strategies and reorganization of the delivery of care such that infant prophylaxis and testing are integrated into routine childhood care and immunization visits may also improve uptake of services.

Mobile technology

Finally, mobile technology is an exciting strategy that has been found to be cost-effective in a variety of resource-limited settings. In a study in South Africa, text messages were sent to mothers for 10 weeks after delivery.

Among mothers who received the texts, 74% brought their babies to HCI clinic for testing after 6 weeks of birth compared to 58% of mother in control group, suggesting that text messages may significantly improve adherence to follow-up (Holly, 2012).

2.3: Retention strategies used in other facilities

Transportation to clinic

Distance to the health facility and lack of transport are major challenges to retention and adherence in most of the ART care centers in Africa and Asia. A study done in Uganda among 111 clients who were lost to follow up, the most common reason for not attending the clinic was due to lack of transport fare in 50% and excessive distance up to 42% (Elvin, H. et al , 2010). Similarly, in Malawi, 35% of clients who dropped out of care and were followed up gave reason for being lost as of high transport costs. Also, in multisite study by the International Centre for AIDS Care and Treatment (ICAP) in Western, Eastern, and Southern Africa, were using a 6-month absence as the outcome. The findings revealed poor adherence where the travel to health facility was more than 2 hours (Elvin, H. et al , 2010).

A study done in Cambodia among 6688 clients where 4150 were on ART revealed that coming from out the province was the only reason for failure to come back to the clinic (Elvin, H. et al , 2010). In Rajasthan, India, 106 clients failed to honour appointment for 90 days and 20% gave reason of distance and lack of transport fare while among clients on study in Jinja in Uganda revealed that 44% failed to get transport to return to clinic (Elvin, H. et al , 2010). In Kenya, one study also linked lack of transport and distance as the

major barrier to returning to the clinic (Hassan, et al, 2012). The consistent relationship between transportation and distance on retention has prompted the only randomized trial on retention.

Poverty

Financial challenges feature most in clients failing to adhere to treatment and follow up studies. In South Africa, 34% of lost clients indicated lack of money for transport while in rural Uganda it was 35% (Elvin, H. et al , 2010). Among poor families, work and childcare responsibilities can compete with retention in care.

Social support, stigma, and disclosure

Social determinants of adherence and retention have been found to be important in several health service deliveries and example was among clients in Uganda, Nigeria and Tanzania where 252 qualitative interviews were conducted and revealed social relations as barriers to remaining in care. (Kenneth, M, et al, 2009; Elvin, H. et al , 2010).

In addition, a study done in Kenya targeting providing social support for adolescents found 70% had remained in care compared to 55% at a facility that was not offering social support and HIV disclosure which is linked to social support was associated with 70% rise in the odd of retention in 3362 clients on PMTCT Plus network supported by ICAP patients (Hassan, et al, 2012; Elvin, H. et al , 2010).

Although qualitative interview on stigma done in South Africa did not show a big problem related to adherence, in Malawi, a study on stigma led to non-

adherence in 45.8% of clients on pre-ART and 25% of clients on ART (Hassan, et al, 2012; Elvin, H. et al , 2010).

Models of care

Some health care program strategies have been linked to having high retention rates. Since most of the barriers to retention include transport and distance, more focused decentralised strategies may improve retention. The AIDS Relief organisations revealed four different model of health care and retention of 13,391 clients from 27 health centers in eight countries from August 2004 to June in 2005 (Elvin, H. et al , 2010). The organisations found that, compared to clients that received adherence counselling only, programs that had home visits had attrition of up to 5% and 1% compared to 14% (Elvin, H. et al , 2010).

CD4 level

Higher and lower CD4 cell counts have been associated with poor retention. In 11 study cohorts in West Africa, retention was lower in clients with less than 50 CD4 cell counts compared to clients with CD4 cell count more than 200 (Elvin, H. et al , 2010). Interestingly, among 50,275 pre-ART clients in Kenya, CD4 less than 200 increased the risk of attrition by 3/49 fold (Elvin, H. et al , 2010).

Sex and or Gender

Gender issues were also discussed as a challenge in retention of clients in care especially for women. The decisions of women to seeking health care services are usually influenced by their male partners, mothers-in-laws and fathers. Power and wealth too influence retention at household level

depending on who has the money which may hold greatest power over health care decision making. It is therefore important to involve family members in health care in order to promote service delivery to women. (WHO, 2012).

Male partners continue to influence retention. A study conducted in South Africa, 42% of missed appointments were by men during the 60 days window even when the 30% of clients at the clinic were men while in West Africa, males had a 14% higher rate of attrition compared to females (Elvin, H. et al , 2010).

Toxicities of ART

Toxicities is seen as one the least reason for attrition. In the Themba Lethu clinic in Johannesburg, among 70 clients who dropped out, only 14% gave reason for side effects for failure to adhere and later at the same clinic, only 4.1% indicated side effect as a reason for drop out. (Elvin, H. et al , 2010). Again in another clinic in Johannesburg, only 2.9% of the 90 dropped out clients had reported toxicity as a reason for the drop. However, another study in South Africa among 30 dropped out clients (Elvin, H. et al , 2010). Lack of clinical, counselling skills and lack of confidence among health workers to provide comprehensive PMTCT services especially in area of adherence and retention were also major hindrance to PMTCT program, as well as lack of standardised guidelines and job aids (Elvin, H. et al , 2010).

2.4.: Summary of the literature review

Most of the studies reviewed above that have discussed retention of pregnant and lactating mothers have identified a number of strategies used and they include; psychosocial support, family-focused approach, home visits, monitoring and evaluation, and health information systems. In addition,

innovative interventions strategies like phone call follow up with patients, attachment of patients to peer educations.

The previous studies have not done in-depth investigation of the limitations of these retention strategies used to retain pregnant and lactating mothers put in place by the health systems especially in the rural areas.

Therefore, this study uses the case study research design taking Itojo hospital in Ntungamo District to assess the retention strategies for the pregnant and lactating mothers to PMTCT in the rural areas. The next chapter focuses on the methodology that was employed to conduct this study.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0: Introduction

This chapter presents methods that were used to collect and analyze data. It gives description of the research design, the sample size estimation and sampling strategy, sources of data, study population, data collection methods and tools that were used including data analysis, quality control and ethical considerations.

3.1: Study design

The study adopted cross-sectional research design. The study was carried at one point in time and for short period of time to help answer research questions related to retention issues targeting pregnant and lactating mothers enrolled in PMTCT at Itojo hospital. Pregnant and lactating mothers who spent 3 months without picking their monthly refills were considered lost to follow up. The study was designed to cover the Itojo hospital and looked at the time between 2012 up to 2013 considering the mothers who were either pregnant or lactating. Within this period, the study was able to examine the mothers who were pregnant or lactating and on PMTCT program at Itojo hospital. The study considered not only the voices and perspectives of the primary respondents, but also the relevant individual key informants and the interaction between them. It involved both quantitative and qualitative approaches to increase the validity and scientific rigor of the findings. Descriptive approaches were also used to capture the existing situation about retention at Itojo hospital.

3.2: Source of data

Data was obtained from primary and secondary sources. Primary data was collected using in-depth questionnaire and administered to the pregnant and lactating mothers, and conducting in-depth interviews with health workers, expert patients, hospital administrators, local and opinion leaders at local and district levels, male partners to the mothers who accompany them to hospital and Village Health Teams (VHT) based at hospital.

To support the primary data, secondary data was obtained from patient files, hospital registers including; pre-ART and ART registers, Family Support Group register, appointment books, ANC registers, PNC register, drug dispensing log and HCT registers. Quarterly and annual reports of the hospital were utilized to pick unique information regarding retention and adherence.

3.3: Study population

The pregnant and lactating mothers were the primary respondents. Other respondents included; health workers, expert patients/peer educators, hospital administrators, local and opinion leaders at local and district levels, male partners to the mothers who accompany them to hospital and Village Health Teams based at hospital at Itojo Hospital.

Table : Category composition of the sample

Category of respondents	Number
Pregnant and lactating mothers	132
Estimated key infants	
Male partners	5
Health workers	6
Hospital administrators	3
DHT members	3

Government officials	4
opinion leaders	2
Expert patients/ Peer educators and VHTs	5
Total	160

Inclusion and Exclusion criteria

The study included pregnant and lactating mothers enrolled in the PMTCT at Itojo hospital and attended the clinics at least in last 3 months. Those who had not spent 3 months on PMTCT were not included since lost to follow was considered those who missed drug pick up in 3 months. Females who were not pregnant or lactating were not included in the sample since they were not on PMTCT program. Males that were not partners to pregnant and lactating mothers were not included in the sample since they had no direct influence on mothers attending PMTCT. It was important to include male partners of the pregnant and lactating mothers due to role they play in reproductive health and decision making regarding seeking of health by the mothers. Expert patients and VHTs were involved since they provide psychosocial support and referral services to the mothers and provide health talks during PMTCT services and all mothers are supposed to learn coping mechanisms from them.

Health workers were involved because they routinely interface with the pregnant and lactating mothers while providing them with health services

including assessment and enrollment on PMTCT, monitoring patients on treatment and ensure adherence and retention into care. Hospital administrators included medical superintendent and principal nursing officer supervise and monitor health activities for patients enrolled in care to ensure availability of quality services including drugs and other logistics at the hospital.

The local and opinion leaders included elders in the area, government officials like District Health Team (DHT) to include; district health officer, district health educator, district and hospital based PMTCT Focal persons), chairperson at local council I, II, III, secretary for health, chairperson health management committee, and Sub-county chief. These were involved due the support they give to the PMTCT program at Itojo Hospital and influence on social, health, economic and political matters community and district levels.

3.4: Sample size determination and sampling procedure

The sample size of the study was determined using Krejcie and Morgan (Krejcie R. e tal, 1970) sampling frame work based on the following formulae;

$$S = \frac{X^2 NP (1-P)}{d^2(N-1) + X^2 P (1-P)}$$

Where; S = required sample size

X^2 = the table of value of chi-square for 1 degree of freedom at the desired level (3.841),

N = the population size,

P = the population proportion (assumed to be .50 since this would provide the maximum sample size),

D = the degree of accuracy expressed as a proportion (.05).

Thus, a sample size of 132 persons was selected for this study. This included pregnant and lactating mothers randomly selected from 200 mothers receiving PMTCT services at the hospital. The sample was obtained using simple random sampling techniques. This is probability sampling technique in which each sampling unit has the same chance of being included or excluded from the sample. This was done to reduce the bias from the study findings by incorporating in all the categories of mothers and all villages around Itojo hospital.

Categories of key informants who were purposively selected include; health workers based in PMTCT section, hospital administrators, DHT members, Government officials (Local council I, II, III, Sub-county chief and Secretary for health, Chairperson health management committee), opinion leaders at district level and from hospital neighborhood and peer educators and or expert clients and VHTs. Purposive sampling technique was used to select key informant due to information they have on PMTCT and important views that can influence behavior of beneficiaries to the study.

3.5: Data collection methods

Primary data

Primary was collected by administering questionnaire which contain structured and semi structured questions to collect Quantitative data. In depth interviews and focus group discussions were carried out to explore the questions that were not addressed by the questionnaires. The primary respondents were found and interviewed at Itojo hospital ART clinic during

the refill clinic days. Some pregnant and lactating mothers who were selected and never returned during the clinic days were followed up to their home to establish reasons for failure to return for drug refill. Focus group discussions were also held at Itojo hospital during PMTCT clinics.

Qualitative data was collected by holding two Focus Group Discussions (FGDs) with pregnant and lactating mothers, their partners and key informants (KIs) interviews with health workers, Male partners, Hospital administrators, District Health Teams (DHT) members, Government officials, opinion leaders, Expert patients/ Peer educators and VHTs. The key informant respondents especially local leaders were found at Itojo sub-county headquarters on appointment while others preferred meetings at their homes. Health workers and hospital administrators were met at the hospital while the DHT were met at Ntungamo district headquarters on appointment.

Focus Group discussion (FGD) for pregnant and lactating mothers and their partners who attend clinics with mothers were held separately each targeting 8 to 10 persons. This was aimed at generating views that helped to compare and enrich data got from interview guides. Michael Bloor argues that the discussion within the group provide a rich data on understanding of the group since the discussion was conducted in local language (Bloor, 2001).

Secondary Data

Secondary data was gathered through documentary review from other related studies, existing registers and reports available at the hospital. This was generated from text books, internet and articles. Secondary data was

helpful in achieving objective three of the study and enhancing primary data generated from the field.

3.6: Study Variables

The dependent variable was retention of pregnant and lactating mothers into PMTCT. Independent variables are; Providers-related factors, health system related, community related factors, patient characteristics related factors, and social economic related factors while Itojo hospital retention strategies are intervening variables which are a focus of this study.

3.7: Data collection tools

The primary data from pregnant and lactating mothers was collected by administering structured and semi-structured questionnaires and focus group discussion guides. The questionnaires contained structured questions relating to retention and adherence strategies. Data from key informants was collected using interview guides. The interview guide had a designed set of open ended questions to explore views from respondent and gave respondents more freedom to recall events, and latitude in developing their responses which resembled an informal conversation rather than a question/answer session.

3.8: Data entry and analysis

The raw data was checked for completeness, cleanliness and consistency. Data was then entered into excel and later exported to SPSS version 12 for analysis. Descriptive data was presented by frequency table to display distribution of variables for univariate analysis.

Data was analysed at two levels;

1. Univariate level analysis was performed in order to generate frequencies and proportions of the respondent's characteristics.

2. Bivariate level analysis was done to test associations between dependent and independent variables.

The odds ratio, confidence intervals and P-values were used to establish the association between the independent variable and dependent variables. The researcher analysed the text content for the data from key respondents to better understand the qualitative data.

Qualitative data collected from the field was analysed using thematic analysis where objectives were developed into themes and sub themes in presenting the findings. The essence was to ensure that the objectivity of the study was maintained and it allowed the researcher to use people's narrations which formed verbatim quotations.

3.9: Quality control

The following methods were used to ensure that data collected in of high quality and integrity. Methods included:

- (i) *Training and close supervision of Research Assistants:* All research assistants hired to participate in on the study were trained to apply data collection tools appropriately and closely supervise them during data collection.
- (ii) *Pre-test of data collection tools:* All data collection tools were pre-tested outside the study catchment area to perfect them,
- (iii) *Field and post editing of questionnaires:* The researcher ensured that all questionnaires filled were edited on the daily basis and after field work.
- (iv) *Appropriate data analysis and interpretation:* The research ensured that data was entered into computer using Excel sheet data entry

page, cleaned and exported to SPSS for analysis and interpretation line with objectives and conceptual framework of this study.

3.10: Ethical consideration

The researcher did the following;

- i. An introduction letter was obtained by the researcher from IHSU University and presented to hospital and district leadership for authorisation to carry out research.
- ii. Ensured high level of confidentiality and anonymity of data.
- iii. Obtained consent from study respondents before data collection and appointments were made before interview date and as a way of being socially accepted in the field.
- iv. Explained the purpose of the research and how data is to be used to respondents in order to build confidence among respondents. Respondents were allowed to ask questions in order to reach mutual understanding.
- v. **Information bias:** The research identified and trained research assistants to collect data in order to avoid bias by the researcher on collecting specific information.
- vi. **Recall bias:** In order to avoid bias by research assistants, specific dates of enrolment were given by the health workers after visiting mothers' files.
- vii. **Sampling bias:** PMTCT clinic at Itojo had specific dates for collection of drugs and the research assistants visited the hospital on scheduled clinic days for the interviews.

3.11 Limitations and delimitations of the study

There was withholding of some data by pregnant and lactating mothers which necessitated deep probing especially those that had stigma related to HIV that hindered free sharing of information by patients including those who were followed up in their homes. The researcher assistants had to mitigate this challenge by explaining the purpose of the study and ensured the respondents of confidentiality of their information.

More so, failure to get some key respondents on the set time during field study necessitated the research assistants to go back to the field several times.

Most of the respondents were met at the hospital as they came for services. Respondents were interviewed as they waited for services though some were called to receive services before being interviewed and the research assistants had to request them to spare few minutes for interview after getting a service and before they left the hospital.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.0: Introduction

This chapter presents findings from data collected and their interpretation in relation to the study objectives. The findings were based on responses from research questionnaires, in-depth interviews and Focus Group Discussions. The study objectives included; examining factors responsible for lost to follow up of pregnant and lactating mothers, limitations of retention strategies

being used, and to explore retention strategies used in other facilities to increase retention of pregnant and lactating mothers into the PMTCT program at Itojo hospital.

4.1: Response rate

The survey response rate was 129/132 (98%) for pregnant and lactating mothers. This was attributed to the researcher’s approach of targeting the respondents on their monthly PMTCT refill clinic days. In addition, some respondents who had missed their appointments were followed to their homes. A total of Male partners were also interviewed to find out their opinion on retention into PMTCT.

Descriptive Analysis

Table 3 showing the descriptive analysis of social demographic characteristics of pregnant and lactating mothers enrolled on PMTCT services at Itojo hospital.

Table : Descriptive statistics

Variable Name	Frequencies(N)	Percentages (%)
Sex		
Male	6	4.4
Female	129	95.6
Total	135	100
Age		
Less than 30	72	54.1
30-39	52	39.1
40-49	9	6.8
Total	133	100
Variable Name	Frequencies(N)	Percentages (%)
Distance		
Less than 3km	26	19.3
3km-5km	45	33.3
More than 5km	64	47.4
Total	135	100
Marital status		

Single	9	6.7
Married	99	73.9
Separate / Divorced	16	11.9
Widow / Widower	10	7.5
Total	134	100
Religion		
Catholic	34	25.2
Protestant	80	59.3
Other Christian	11	8.1
Muslim	7	5.2
Orthodox	2	1.5
Others Specify	1	0.7
Total	135	100
Education level		
Primary	88	65.2
Secondary	36	26.7
Technical / Vocational Cert	5	3.7
College Diploma	5	3.7
University Degree	1	0.7
Total	135	100

Source: Field data, 2014_

Most of the respondents in the study were females 129 (95.6%) and males were 6 (4.4%). This was because the study targeted pregnant and lactating mothers. Thus, females were the centre of focus and featured prominently in the study.

The researcher was also interested in the age groups of the respondents in order to ensure that the emerging patterns are captured in the study. According to information in table 3 above, most respondents were in the age range less than 30 years representing 72 (54.1%), followed by the between 30 - 39 range 52 (39.1%) and few were between 40-49 years range representing 9 (6.8%).

The findings show that the majority of the respondents came from a distance of more than 5 kilometers representing 64 (47.4%) and the least were from a radius of 3 kilometers rated at 26 (19.3%). Thus, distance travelled is far from Itojo hospital and this could be a challenge to retention strategies for pregnant and lactating mothers into the PMTCT program at Itojo Hospital, Ntungamo District.

Marital status of the respondents

According to the figure2 below, the married were the majority representing 99 (73.9%) and the least were the single mothers with 9 (6.7%). This implies that the respondents had more knowledge on pregnancy and lactating and were well conversant with PMTCT in Ntungamo District.

Level of education of the respondents

According to table 3 above, most respondents 88 (65.2%) in the survey had the primary level, followed by those in the secondary level rated at 36 (26.7%). Few pregnant and lactating mothers attained higher education rated at 5 (3.7%), and only 1 (0.7%) had attained university degree and above. PMTCT is presumed to be basic knowledge that comes within the scope of primary level.

Table : Bivariate analysis of social demographic factors

Variable Name	Response yes to Retention PMTCT care N (%)	Response yes to PMTCT care N (%)	Chi-Value X2	P-value	95% confidence Interval
Age	(N=128)				
Less than 30	71 (98.6%)	1(1.4%)			
30-39	50(98.0%)	1(2.0%)	0.214	0.899	1.374 - 1.485

40-49	9(100.0%)	0(0%)			
Distance					
Less than 3km	51(98.1%)	1(1.9%)			
3km-5km	51(98.1%)	1(1.9%)	10.223	0.008* **	0.006 - 0.010
More than 5km	25(83.3%)	5(16.7%)			
Variable Name	Response yes to Retention PMTCT care N (%)	Response yes to PMTCT care	Chi-Value X2	P-value	95% confidence
Marital Status					
Single	9(100.0%)				
Married	94(95.9%)				
Separate / Divorced	13(81.2%)				
Widow / Widower					
Religion					
Catholic	32(23.9%)	1(0.7%)	10.25	0.137	0.130 - 0.143
Protestant	76(56.7%)	4(3.0%)			
Other Christian	11(8.2%)	0(0.0%)			
Muslim	6(4.5%)	1(0.7%)			
Orthodox	1(0.7%)	1(0.7%)			
Others Specify	1(0.7%)	0(0.0%)			
Education level					
Primary	81(60.4%)	7(5.2%)	3.861	0.304	0.295 - 0.313
Secondary	36(26.9%)	0(.0%)			
Technical / Vocational	4(3.0%)	0(.0%)			
College Diploma	5(3.7%)	0(0.0%)			
University Degree	1(0.7%)	0(0%)			

*** Statistically significant

From the table above, pregnant and lactating mothers distance to hospital was 10 times more likely to affect return to hospital for PMTCT care (χ^2 10.223, 95% CI 0.006-0.010, P-Value 0.008) which was statistically significant. Other factors like age, marital status, religion and education were

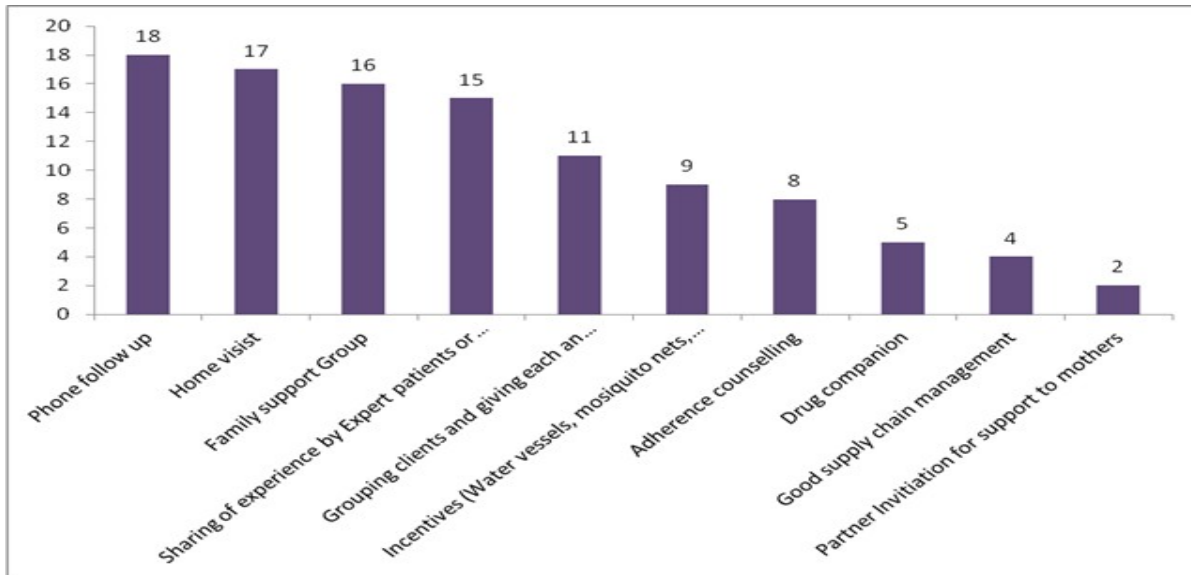
found not statistically significant to affect return of pregnant and lactating mothers to PMTCT care.

4.3: Retention strategies used to retain pregnant and lactating mothers into the PMTCT

During the focus group discussions and in-depth interviews, various retention strategies used to retain pregnant and lactating mothers into the PMTCT program at Itojo hospital in Ntungamo District were discussed. Respondents shared strategies such as grouping of clients and provision of incentives like water vessels. In the figure 2 and table 5 below; 18 (47.4%) of the respondents identified phone follow up, 17 (44.7%) home visits, 16 (42.1%) family support group, and 15 (39.5%) sharing of experience by expert patients or peer attachment.

The other strategies identified included; Grouping clients and giving each an appointment, Incentives like water vessels, and mosquito nets, adherence counselling, drug companion, good supply chain management, and partner visitation for support to mothers.

Figure : Retention strategies retain pregnant and lactating mothers



Source: Field Data, 2014

Table : Retention strategies used to retain pregnant and lactating mothers

Strategies	Frequen cy	Percentag e
Phone follow up	18	47.4
Home visits	17	44.7
Family support Group	16	42.1
Sharing of experience by Expert patients or peer attachment	15	39.5
Grouping clients and giving each an appointment	11	28.9
Incentives (Water vessels, mosquito nets, refreshments)	9	23.7
Adherence counselling	8	21.1
Drug companion	5	13.2
Good supply chain management	4	10.5
Partner visitation for support to mothers	2	5.3

Source: Field Data, 2014

Adherence assessment

Respondents were also questions on how adherence is assessed. The findings revealed that adherence assessment was done by Patient self-report. This was revealed by 75 (57.6%) of the respondents because a client knows himself better and self-revelation easily confirms this. Pharmacist judgment

was mentioned as yet another aspect of assessment of adherence. A pharmacist was able to tell depending on the prescribed drugs which were used. Pill count was rated 0% and adherence over this amount typically reflected lost or shared medication. This method of adherence assessment was inherently unable to account for lost to follow up.

Table : How is adherence assessed during the visit?

Response	Frequency	Percent
Patient self-report	75	57.69
Pharmacist judgment	41	31.5
Pill count	13	10.0
Others	5	3.76
Verifying refill dates	1	0.77
Total	130	100.0

Source: Field Data, 2014

Table : Adherence support to ART patients

Response	Frequency	Percent
PLHA support group	67	52.3
Treatment support	27	21.0
Adherence support group	21	16.4
Home based care workers	13	10.1
Total	128	100.0

Source: Field Data, 2014

When asked on the nature of Adherence support to ART and how they felt about someone monitoring taking of pill per day, majority of the respondents 67 (52.3%) mentioned PLHA support group as a reliable adherence support approach. This according to many had improved adherence rates in the area of study.

Adherence support groups were identified as another effective weapon for compliance as rated at 16.4%. This was linked to the attachment of mothers to expert patients for experience sharing and consultant information giving. Home based care workers were rated by 13 (10%). The importance of health care workers as the main sources of information regarding retention and

adherence in particular had been underscored. However, there was a need to adequately equip home based care workers with knowledge and skills in adherence to enable them support women at the grass roots with adherence issues.

On whether clients were expected to refill their ARV drugs, most pregnant women interviewed reported that it was important to refill their ARVs. When probed further to know how often; interestingly, majority of the respondents' revealed monthly refill of ARV. The uptake rate was at 95.9% of the respondents which is very high for PM PTC in the area of study. It was clear that a big number of the respondents were willing to refill their ARV drugs. The reason pregnant and lactating mothers gave for this was their willingness to keep themselves healthy and not to infect their children.

From the FGD, it was reported that women had taken actions to prevent HIV transmission to their infants. This included undergoing HIV counseling and testing during pregnancy, delivering from health facility and remaining faithful to their partners.

Still there was majority consent that clients never miss monthly refill of ARV, this has been a successful retention strategy for pregnant and lactating mothers on the PMTCT program in the area of study. When asked as to whether they had ever done anything to prevent transmission of HIV from a mother to her baby, majority of the respondents confirmed that they had personally taken action to prevent MTCT.

4.4: Factors responsible for lost to follow up of pregnant and lactating mothers

The study investigated into the factors responsible for loss to follow up of pregnant and lactating mothers at Itojo hospital. The factors responsible for lost to follow up identified during focus group discussions and in-depth interviews included the following;

Lack of transport fare; distance to the hospital; failure to disclose to partner and others; stigma, denial, and discrimination; drug side effects; staff attitude; partner not supportive; loss of hope; improved health and seeing no need to go back; stopped by religious leaders; fear of drug stock out and misguidance from traditional herbalists.

Others factors included; lack of enough food to support treatment, incomplete ART preparation by health workers and nature of mothers' household chores as shown in table 7 below;

Table : Factors responsible for loss to follow up

Factors	Frequency	Percentage (%)
Lack of transport fare	18	47.4
Failure to disclose to partner/ others	18	47.4
Stigma, denial, and discrimination	15	39.5
Lack of partner not supportive	15	39.5
Distance to the hospital	11	28.9
Self-referral	8	21.1
Drug side effects	7	18.4
Staff attitude/clinic has staff that knows me	5	13.2

Improved health and no need to go back	5	13.2
Stopped by religious leaders;	5	13.2

Source: Field Data, 2014

The findings also indicated that majority of the respondents enrolled for PMTCT at Itojo hospital in 2010. When asked why they chose to receive services from the facility, out of the 131 participants, majority said they chose Itojo for two major reasons; has a wide range of services and its accessible to many.

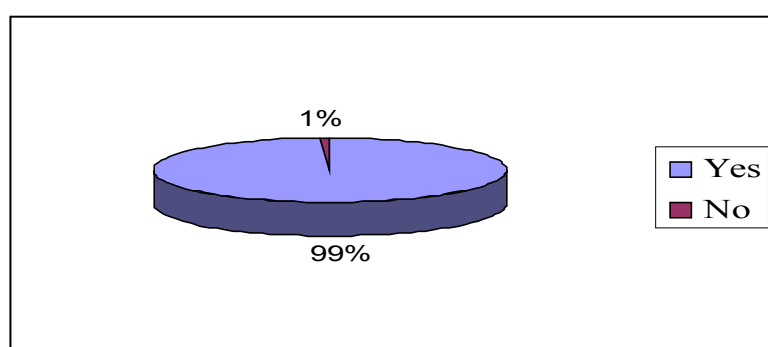
Table : Reasons for choice

Reason of choice	Frequenc y	Percentag e
Wide range of services	120	91.6
Accessibility	110	84.0

Source: Field Data, 2014

As to whether respondents were still under care at Itojo hospital under PMTCT the following was revealed;

Figure : Whether respondents are still care under Itojo hospital



Source: Field Data, 2014

From figure 3 above, 99% of the respondents were still care under Itojo hospital as opposed to the minority 1%. This implies the vast majority of respondents were in a better position to assess retention strategies for pregnant and lactating mothers into the PMTCT program at Itojo Hospital, Ntungamo District.

In addition, all the 134 respondents revealed that they received adherence rated services from the hospital. As to whether respondents received counseling from Itojo hospital, 125 (93.3%) of the respondents revealed that they received counseling. Thus, respondents being regular users of counseling had knowledge on retention strategies for pregnant and lactating mothers into the PMTCT program at the hospital as shown in the cross tabulation on variable of counselling.

Table : Pregnant and lactating mothers who received counselling

Variable name	Frequencies (N)	Percentages (%)
Do you receive counseling services at Itojo hospital?		
Yes	125	93.3
No	4	6.7
Total	134	100
Who normally counsels you about adherence to ART?		
Medical doctors / officers	20	15
Clinical Officers	11	8.3
Nurse / Midwife	48	36.1
Treatment Nurse/ Adherence counselors	23	17.3
Social Workers	5	3.8
Expert Patients/ Peer educators	25	18.8
Others	1	0.8
Total	133	100

Pre ARV medication counselling		
Yes	122	90.4
No	13	9.6
Total	134	100
Follow up counseling to receive ARV medication		
Yes	97	78.2
No	27	21.8
Total	124	100
How is counseling offered?		
Individual	69	53.5
With treatment support	6	4.7
As a group	54	41.9
Total	129	100

Source: Field Data, 2014

From the table above, a total of 125 (93.3%) pregnant and lactating mothers received counselling services. Majority, 48 (36.1%) were counselled by the Nurse/Midwife, 25 (18.8%) by expert patients/peer educators and 20 (15%) by the medical doctors. A total of 122 (90.4%) received pre ARV counselling, 97 (78.2%) received follow up counselling and 69 (53.5%) received counselling as individuals compared to 54 (41.9%) who received group counselling.

Table : Bivariate analysis of counselling services and effect on retention for pregnant and lactating mothers

Variable Name	Response yes to Retention on PMTCT care	Response yes to PMTCT care	Chi-Value X2	P-value	95% confidence
	N (%)	N (%)			Interval
Do you receive counseling services at Itojo hospital?					
Yes	118(88.1%)	7(5.2%)	0.532	1	1.000 -1.000

No	9(6.7%)	0(0.0%)			
Who normally counsels you about adherence to ART?					
Medical doctors / officers	19(14.3%)	1(0.8%)	20.201	0.003* **	0.044 - 0.053
Clinical Officers	10(7.5%)	1(0.8%)			
Nurse / Midwife	47(35.3%)	1(0.8%)			
Treatment Nurse/ Adherence counselors	21(15.8%)	2(1.5%)			
Social Workers	5(3.8%)	0(0.0%)			
Expert Patients/ Peer educators	24(18.0%)	1(0.8%)			
Others	0(0.0%)	1(0.8%)			
Follow up counseling to receive ARV medication					
Yes	93(75.0%)	4(3.2%)	0.164	0.347	0.338- 0.356
No	24(19.4%)	3(2.4%)			

*** Statistically significant

Pregnant and lactating mothers were 20 times more likely to return to hospital for PMCT due to counselling they received especially from medical doctors (χ^2 20.201, 95% CI 0.044-0.053, P-value 0.003)

It was also important to find out who normally counselled the pregnant and lactating mothers to enable them take an HIV test after counseling and whether this had any influence on adherence. The findings revealed that more than half of the respondents 48 (36.1 %) were counselled by nurses. This was more so because they are most accessible and the two aspects of the study pregnancy and lactating are within the realm of the midwives work.

During focus group discussion, most respondents clearly justified that the health workers were friendly and that the general counseling services were carried out well. This response could have been influenced by the fact that the interviews took place in the Antenatal clinic and the respondents feared talking anything that was negative about the health service providers.

However, respondents who were not satisfied with counseling services due to the reason that counseling was done in group sessions and this could have been uncomfortable to ask personal questions. One respondent Kabandize Speriano said;

“Abakazi abamwe nibatiina kureebwa nemibazi yakakooko kaasirimu kandi abashaija abamwe tibarikushagika bakazi baabo” translated as

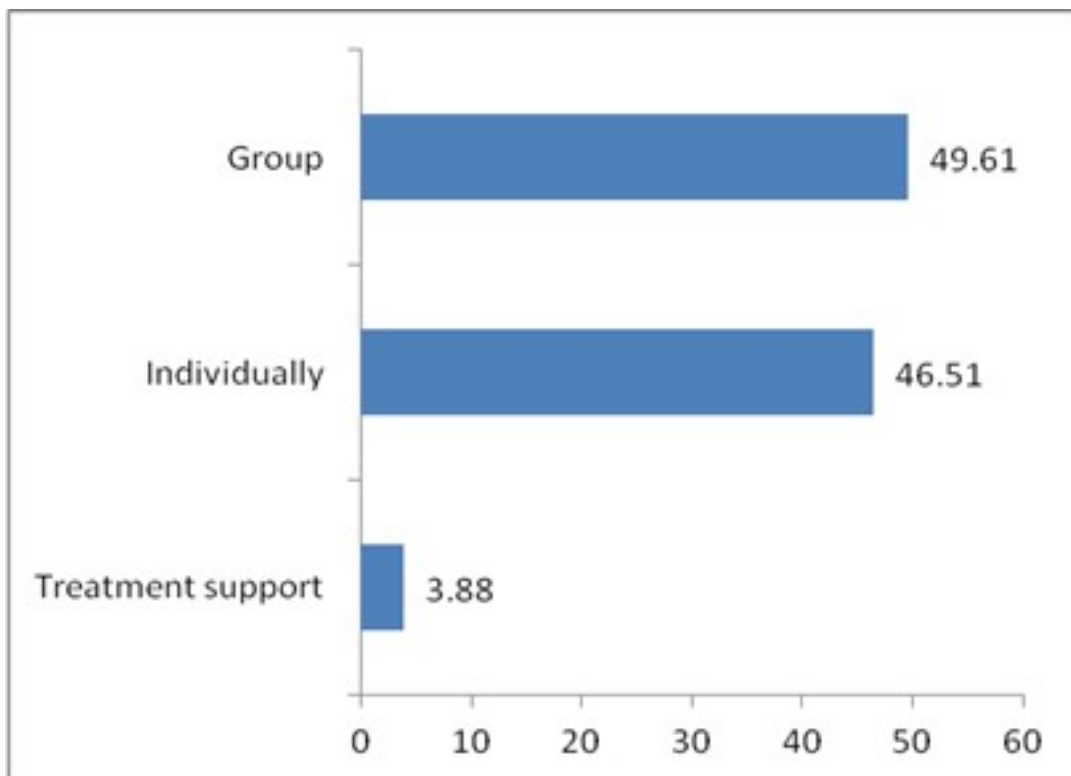
“Some women fear to be seen on drugs and some spouses are not supportive of their pregnant and lactating wives”

According to the information in table 10, majority of the respondents reported that they did receive pre-ARV medication and counseling on various aspects as discussed further below; majority 122 (90.4%) agreed to having received pre-ARV medication and counseling while the least 13 (19.6%) disputed this. These figures correlate well with the baseline retention rates at 84.3% and 15.7% respectively.

Respondents were also asked about the nature of counseling that was offered. 49.6% of the respondents revealed that group counseling was commonly used at Itojo hospital, followed by individual counseling rated at 46.5%, and lastly treatment support at 3.8% as shown in figure 7 below. Thus, it is evident that majority of the respondents have been counseled as a

group as well as the education retention strategies for pregnant and lactating mothers into the PMTCT program at Itojo Hospital, Ntungamo District.

Figure : Nature of counseling service offered



Source: Field Data, 2014

4.5: Limitations of retention strategies used to retain pregnant and lactating mothers

The study investigated the limitations of retention strategies used to retain pregnant and lactating mothers on the PMCT program at Itojo hospital and the following limitations were gathered;

Table : Univariate analysis of limitations of strategies to retain pregnant and lactating mothers

Limitations of retention strategies * Are you still under PMTCT care at Itojo hospital Cross tabulation

		Are you still under PMTCT care at Itojo hospital		Total
		Yes	No	
Limitations of retention strategies	Stigma at community level	20	2	22
		14.90%	1.50%	16.40%
	Wrong physical addresses	11	1	12
		8.20%	0.70%	9.00%
	High costs of follow up	47	1	48
		35.10%	0.70%	35.80%
	Wrong telephone numbers	20	2	22
14.90%		1.50%	16.40%	
Limited staff for follow up	5	0	5	
	3.70%	0.00%	3.70%	
Lack of support from spouses	24	1	25	
	17.90%	0.70%	18.70%	
Total		127	7	134
		94.80%	5.20%	100.00%

Source: Field Data, 2014

From the above cross tabulation on table 12, limitations of retention strategies, high costs of follow up stood out as the most limiting factors with 48 (35.8%) from the total population of whom 47 (35.1%) agreed that this was a limitation and only 1 (0.7%) respondent disagreed. The use of facility phone which was one of the first alternatives to follow had 22 (16.4%) as the second most limiting factor from total population of whom 20 agreed that wrong telephone numbers of mothers was a limiting factor and only 2 (1.5%) disagreed.

Lack of support from the spouse also limited strategies to retention with 24 (17.9%) agreeing to this and only 1 (0.7%) disagreeing.

Table : Bivariate analysis of limitations of strategies to retain pregnant and lactating mothers

Variable Name	Response yes to Retention PMTCT care	Response yes to PMTCT care	Chi- Valu e X2	95% confiden ce	P-value
	N (%)	N (%)		Interval	
Stigma at community level					
Agree	89(67.9%)	5(3.8%)	0	0.638- 1.000	0.984
Disagree	35(26.7%)	2(1.5%)	1		
Drug stock out					
Agree	109(82.6%)	3(2.3%)	24.0 78	0.004 - 0.007	0.006** *
Disagree	15(11.4%)	3(2.3%)	1		
Wrong physical addresses					
Agree	42(31.3%)	6(4.5%)	7.99 8	0.009 - 0.009	0.005** *
Disagree	85(63.4%)	1(0.7%)	1		
High costs of follow up					
Agree	111(84.1%)	3(2.3%)	25.2 94	0.003- 0.006	0.005** *
Disagree	13(9.8%)	3(2.3%)	1		
Wrong telephone numbers					
Agree	111(83.5%)	3(2.3%)	11.0 83	0.008 - 0.008	0.001** *
Disagree	15(11.3%)	4(3.0%)	1		
Limited staff for follow up					
Agree	105(79.5%)	3(2.3%)	22.3 27	0.008- 0.012	0.01
Disagree	19(14.4%)	3(2.3%)	1		
Luck of support from spouses					
Agree	105(79.5%)	4(3.0%)	3.677	0.134- 0.148	0.141
Disagree	19(14.4%)	3(2.3%)	1		

*** Statistically significant

From the table 13 above, pregnant and lactating mothers were 24 times more likely not to return to the facility for PMTCT care due drug stocks outs as some of them had experiences it (χ^2 24.08 95% CI 0.004-0.007) P-Value 0.006 which was statistically significant.

Pregnant and lactating mothers were also found to be 25 times more likely not to return to the facility for PMTCT care due to high costs of follow up by the facility (χ^2 25.03 95% CI 0.003-0.006) P-Value 0.005 which was statistically significant. This was same for the case of wrong telephone numbers given by pregnant and lactating mothers which limited health workers to follow up and found at 11 times more likely to affect follow up (χ^2 11.1 95% CI 0.008-0.008) P-Value 0.001 which was statistically significant. Lastly, physical address was also 8 times more likely to affect pregnant and lactating mothers to return to facility as distance to facility was considered long and affected return to facility (χ^2 7.996 95% CI 0.009-0.009) P-Value 0.005).

From the FGD, the nature in which counseling is done explains the rate at which retention for pregnant and lactating mothers into the PMTCT program at Itojo Hospital. It was revealed that majority of the respondents were given counseling in a group. This negatively affected retention for pregnant and lactating mothers into the PMTCT program.

From the discussion it was revealed that;

“Nitwiija aha reero abashaho batwegyesa ahabyamagara obariiremu okutangira akakooko kasirimu omubaana kuruga ahari baanyina, kwonka nikiitugumira kusharamu kwekyebeza akakooko aha

*bwobwoba ahabwokubura omugisha gwokubuuza ebibuuzo aha
bowkugira ngu emishomo nitugitungira omugurupu”*

Translated into English as

“Whenever we come here, the health workers give health talk which includes prevention of HIV transmission from mother to child. However, I am not usually convinced to take HIV test because health education and counselling services are given in groups which make us fear to ask personal questions about HIV and testing”

In an in-depth interview with the district PMTCT focal person Mr. Twesigye Francis, the greatest hindrance to retention for pregnant and lactating mothers into the PMTCT Program at Itojo Hospital included; The big catchment area and hospital not able to follow up each and every client, self-transfers of mothers to lower health units as well as the attitude of health workers being poor. Lack of outreaches services in the area with no functional community program, long distance to the hospital, and Limited infrastructure setting that may not give adequate attention to needs of the many clients served by the hospital.

It was also learnt from the district PMTCT focal person that although HIV testing was an entry point into PMTCT program, a big number of the pregnant

mothers were not willing to take an HIV test. This was due to the stigma associated with HIV/AIDS as well as the long distance to the hospital. Some pregnant women were worried about taking drugs that might cause unknown side effects.

4.6: Possible solutions to the challenges

Respondents shared the following solutions to the challenges related to PMTCT uptake;

Majority of the respondents suggested that pregnant women needed to be encouraged to come for antenatal with their partners. This could be done by developing programs, which target men at community level. It was also suggested that health workers could enforce a rule that require mothers to attend antenatal clinic with their spouses.

There was also a suggestion to train more counselors. This would give mothers an opportunity to get counselling service since the hospital had few counsellors and counselling service was being given a group. Other counselors would be provided with transport and day allowance to go to outreach to reach more mothers and which could also motivate health workers and counselors.

The assistant district health officer suggested scaling up of PMTCT services to health centre IVs and centre IIIs that were nearer the people and would minimise lost to follow up. He also revealed that in order to avert the long distances to Itojo, "There is need for partnership with other organizations working the district that support referrals, demand creation activities and phone usage, family support group and facilitation of expert patients at the health facility".

The government should ensure that there is adequate supply of testing kits, syringes, and necessary equipment for the program.

There was a need for involving other stakeholders in the community sensitization. This was linked with Linkages through VHTS at village level as suggested by the district PMTCT coordinator. However, there was need to first train all the people that would be involved in community activities especially the community leaders, religious leaders and opinion leaders in order ensure active community participation.

From the peer counseling sessions, some women had advised their peers to deliver from hospital and to regularly take drugs as advised by health worker. This was an important aspect of health education and information sharing, and also moral and social support. Women who had received information regarding PMTCT were good example to others. However, only 3.8% of respondents had mentioned that they had received information regarding PMTCT from an expert patient.

4.7: Retention methods/ strategies used in other facilities

During the in-depth interviews, the retention methods/ strategies used in other facilities that can be employed to increase retention of pregnant and lactating mothers into the PMTCT program were established and are presented below;

Introduction of community department to improve retention of pregnant and lactating mothers especially working with VHT structure at community level to improve referrals and attachment of mothers on PMTCT and to VHTs for

follow up and remind on appointments. Conducting of regular community health education and to mobilize and educate community on health priorities.

Active referral of all identified mother before initiation on to PMTCT to lower health facilities of HCIV and HCIII to reduce on challenge of transport and long distance instead of enrolment at hospital yet it is not the best option for the mothers on PMTCT.

Introduction of community quality improvement projects to address the challenge of poor retention of mothers on PMTCT. This would help health workers to review baseline data and quality improvement projects to improve retention including working with the community structures to follow up mother and remind the about the appointment and documentation of strategies put in place.

Male involvement strategy especially use of male champions at community and hospital level to improve partner involvement in health of mothers and children.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0: Introduction

This chapter presents discussion of the study findings and how literature review informed the study.

5.1: Factors responsible for lost to follow up of pregnant and lactating mothers

The study findings showed high attrition rate within PMTCT programs at Itojo hospital. However, good adherence was associated with beliefs regarding the benefits of medication and quality of life. This was supported by Elvin .et al (2010) who contended that characteristics of the commercially available drug formulations such as taste, palatability, size of pills, availability of liquid formulations, and adverse effects could significantly affect adherence rates in a given setting.

The study revealed that shortage of PMTCT staff, interrupted supplies of materials, shortage of space for counseling were some of the reasons leading to loss of clients in PMTCT program. These are in agreement with Fatch et al(2012). Thus, the constraints led to long waiting hours during post-test counseling, and some women left without getting their HIV test results especially where counselling was done in a group.

It was found out that people were still stigmatized about AIDS. Some pregnant mothers feared to test because they were worried of the public or community's reaction in case they were found to be HIV positive. Some respondents reported that once a pregnant woman was infected with HIV, it

was no longer confidential since some community members would get to know through others. This was in support with the revelations of Edidah Ariyo a VHT who stated that “stigma at community level still existed and this limited some mothers”.

This was further confirmed by one opinion leader in the community who stated that;

“Emibzi yakakooko neeretera abakazi bamwe baayoma, kandi eki kiretera bataagumizamu nayo, abamwe babura amaani hamwe nokwanga kurya ebyokurya”

Translate into English as:

“ARVs make some women dry during sex and this may affect continual use of ARV, others get weak and fail to do their routine work besides there is loss of appetite” male Bibiana Kakinoni-opinion leader”

Some individual pregnant women reported that it was difficult to take an HIV test due to lack of support from their spouses. Some women would be blamed for having brought the disease in the family in case they tested HIV positive. This showed that enrolment into care itself was closely linked to attitude which would later lead to dropping out from PMPTC Program.

This was further confirmed by the responses from females during focus group discussion where women insisted that they were always tasked to consult and seek permission from their spouses before taking an HIV test (Monday Justine) who stated that “some mothers test for HIV without their spouses

consent, some women fear to be asked all the time where she was going every particular day of the month”.

To some mothers, testing to know ones status was regarded as disaster in case one was found HIV positive. They did not see PMTCT as an opportunity for someone who was HIV positive to start benefiting from it, but rather may increase problem at family level. In relation to this, a study in South Africa by Braun in 2001 found out that clients had inadequate information on PMTCT services, given the fact that they could not recall the information shared with them during counselling sessions (Braun, et al, 2011). It was further found out those clients only made use of counselling services one during their first visit and not subsequent visits irrespective of HIV status, suggesting limited rapport by health workers with clients.

Lack of male and community involvement was also cited as a problem that could hinder pregnant mothers from accessing PMTCT services leading to mothers to withdraw from PMTCT program. Fathers did not take initiative to find out what took place within the health centers where their wives went for antenatal services.

It was also found that some religious beliefs posed challenges to PMTCT service accessibility. Some religious beliefs in some areas were still attached to some health issues. For example it was not asy for a mother not to breast feed, because of the faith she had in her religion and the pastor in particular. One Moses Komunda a parish chief revealed that “Religious leaders of born again churches like Dove Ministries convinced their followers to stop treatment and resort prayers to in order to get healed” Even other churches

like Baptist church and Stella church had castigated enrollment into ART and PMPTC.

Still, there lack of sufficient information by the less educated and non-educated mothers in the PMTCT program. It was found out that the educated mothers had more access to media and therefore had more knowledge on most health issues than the rest. Besides, they were exposed and therefore interacted more with the 'outside world' than the rest. There was therefore need for local translated literature to be given out to mothers and more education programs in the local language (Runyakore) for those who cannot read English.

Another problem that affected PMTCT program was found to be lack of knowledge about benefits of PMTCT program by the communities in general and mothers in particular. This could be the reason as to why some people had scanty information on PMTCT.

“Namazima tukiine orugyendo ruhango, rwokushomesa abantu ahabyokutangira akakooko kasirimu omubaana kuruga ahari baanyina. Obuhereza nobwabusha kandi ehururu negyenda omumaisho, kwonka nikiza kutwara obwiire abaantu kukyetegyereza, ebiro byokwaakira emibazi yakakooko nibyerarikiriza abakazi abamwe baburirayo”

Translated as;

“Yes, we still have a long way to go as far as sensitization and promotion of PMTCT services was concerned. It was true the services are free, and sensitisation was being carried out, but for sure the

program was so sophisticated that it may take time to explain to people to understand it especially the community, specific days for ARVs collection stigmatize women and they never returned” (Komunda, parish chief)

The ignorance about PMTCT services by some women and community members was setback to the progress of the PMTCT program. Information gap needed to be closed so that women could access and continue PMTCT services.

5.2: Limitations of retention strategies used to retain pregnant and lactating mothers

The study established that the vast nature of the catchment area served by Itojo hospital has posed transportation problems to care users. Distance to Itojo hospital ART clinic and transportation in Ntugamo district were major barriers to retention in care in addition to wrong telephone number provided by the pregnant and lactating which limited instant follow up buy health workers. These finding were in line with Elvin et al (2010) who conteded that in rural Uganda, among patients lost to follow-up, the most common reasons for absence were lack of transportation (50%) and long distance (42%). Thus, this was still a replica of the current situation at Itojo hospital.

Focus group discussions revealed that stigma is a key determinant to retention of pregnant and lactating mothers on the PMCT program at Itojo hospital. This is both at community level and individual family level; some women revealed that their spouses don't want them to take part in such a programme because they are perceived as the ones who brought the disease. This revelation concurred with Hassan, et al (2012) who conteded

that although qualitative interviews from South Africa found stigma had not represented a big challenge to retention, in a study from Malawi, stigma led to non-retention was 45.8% for pre-ART and 25% for ART patients which could explain the same scenario at Itojo hospital.

The study also revealed that fear for disclosure of HIV status was yet another hindrance to both adherence and retention. It was also revealed that women feared the reactions of a partner or husband as disclosed in the FGDs. Women feared losing husbands and believed that a woman's infection and pregnancy would spark off a chain of deaths after delivery of a baby, herself and then her husband's dying. It was this scare that some women had feared the negative response of their families, believing that they will be ignored, isolated, and openly disgraced and blamed hence the worst case scenario come with loss of such a client. The male support affected the capacity of families to comply with the PMTCT follow-up program.

5.3: Strategies for retention of pregnant and lactating mothers and their limitations

No one single strategy was effective in averting challenges to retention, however, a combination of psychosocial support, family-focused approach, home visits, phone follow up, use of expert patients, use of incentives, monitoring and evaluation, and health information systems in varying degrees have been at the centre of retention strategies of lactating mothers on the PMCT care.

It was revealed that patients needed to be encouraged by health care workers to disclose their HIV status. However, studies on interventions to facilitate disclosure were lacking. Social institutions like the church,

nongovernmental organizations (NGOs) and food aid services played crucial role in issues ranging from creating awareness about the illness, mobilizing support, facilitating treatment to promoting adherence.

Continuous monitoring of both adherence and correlating it with clinical outcomes created an interactive feedback mechanism that could lead to optimal clinical states and improved quality of life for patients. There was need for further research and development in the area of ART adherence, adherence support, and patient behavior overall. It was established that psychosocial support from peers helped women adhere to PMTCT program recommendations. Adherence support groups by women were pivotal to successful adherence of women on ART and subsequent Adherence. This helped women access existing PMTCT services and follow- ups with mothers and infants after delivery.

Treatment support was identified as another solution to the problem of non-adherence. It was found true that family support groups had a positive and symbiotic effect on male involvement in PMTCT services which in turn improved their retention into the PMTCT program. The study pointed out that where both couples were involved, taking of Niverapine and eventually ARV became easy in that the couple reminded one another, and once in the group, it became like a larger part of the family where home visits to those who may be too ill to participate in meetings were carried out to find out reasons for abstention (Beatrice,M. et al, 2009).

The study revealed that home based care workers have been pivotal to adherence and retention. This is in agreement with Fatch, et al (2012) who argued, home visits provided by health and peer workers upon enrolment to

PMTCT program as well as follow-up visits if needed in case of non-adherence to scheduled visits or in case of social difficulties was helping to reduce loss to follow up in PMTCT programs. Home visits include counseling and education to the families on importance of following PMTCT protocols.

Furthermore, monitoring and evaluation of PMTCT services involve developing comprehensive medical record system to collect individual patient information and to support patient care and follow-up care (Hassan, et al, 2012). Program implementation and outcomes were routinely followed including number of individuals enrolled, percentage of eligible individuals receiving ART or prophylaxis, program discontinuation (death, loss to follow up, and patient withdrawal), determination of infant HIV status, and CD4 cell count.

It was paramount that mothers know all the risks of MTCT and the full package of PMTCT because inadequate knowledge was as bad as no knowledge at all.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.0: Introduction

This chapter presents the conclusions, recommendations, and the areas for further research.

6.1: Conclusions

Socio-economic and demographic factors responsible for lost to follow up of pregnant and lactating mothers at Itojo hospital were identified as; age, education, distance and lack of transport fare to the hospital, and

occupation. The age of the respondents, education and knowledge of PMTCT services influenced the uptake of PMTCT services as well as retention.

In addition, failure to disclose to partner and other family members including drug companion and lack of partner support, stigma, denial and discrimination, poor staffing and attitudes levels of health workers which at times increased waiting hours and inadequate preparation of mothers to start PMTCT were some of the factors responsible for loss into care.

It was arrived at that, limitations of retention strategies being used to retain pregnant and lactating mothers on the PMCT program at Itojo hospital were;

Limitations of retention strategies being used to retain pregnant and lactating mothers revealed pregnant and lactating mothers were 24 times more likely not to come return to the facility for PMTCT care due to drug stocks outs (χ^2 24.08 95% CI 0.004-0.007) P-Value 0.006 which was statistically significant, were 25 times more likely not to come return due high costs of follow up (χ^2 25.03 95% CI 0.003-0.006) P-Value 0.005 which was statistically significant. Wrong telephone numbers was 11 times more likely to affect follow up (χ^2 11.1 95% CI 0.008-0.008) P-Value 0.001 which was statistically significant while distance while distance was 8 times more likely to affect return to facility (χ^2 7.996 95% CI 0.009-0.009) P-Value 0.005.

Other limitations included; lack of transport and distance to the hospital, self-transfers of mothers to lower units, lack of outreach services in the area yet there is no functional community program, limited setting that may not give adequate attention to needs of the many clients served by the hospital.

PMTCT services were affected by the insufficient knowledge on PMTCT program and its benefits. In addition, lack of partner support also affected both retention and adherence to ART under PMTCT services.

Retention strategies which have been used in other facilities in increasing retention of pregnant and lactating mothers into the PMTCT program include; introduction of community department to mobilise communities and health educate them on PMTCT and use of VHTs to support cross referrals, use of community quality improvement projects supported by local leaders and involve expert patients and VHTs to remind mothers on their appointments before they get lost, male champion as strategy to involve men in health programs and active linkage to nearest health facilities to overcome challenge of self-referral.

Thus, getting people tested for HIV is one thing; getting them onto antiretroviral (ARVs) is another; and retaining them in care for a long period is something else entirely and the most important of all.

6.2: Recommendations

- i. Some mothers and people in the community knew about PMTCT program. However, majority did not have full information on PMTCT and efforts should be done by district health office to educate mothers and the community on PMTCT program.
- ii. Male partners were not supporting their spouses on PMTCT program. The male champions should be identified to show good example fellow men and educate them to support pregnant women to take up PMTCT services. In particular, male partners should be encouraged to escort their wives for ANC services and promote adherence.

- iii. The number of health workers should be increased to handle the PMTCT program at Itojo Hospital. This could be done by ensuring minimum staff numbers and training more PMTCT health workers to handle the big number of the pregnant women who seek antenatal services.
- iv. In addition, available health workers should be given continuous medical education regarding PMTCT in order to improve their knowledge and skills and offer better services to the pregnant and lactating mothers.
- v. The ministry of health should scale up PMTCT services to all health centre IIIs in order to improve access to PMTCT services since distance creates delay to access services.
- vi. Health facilities with big catchment area like Itojo hospital should be encouraged to refer all PMTCT mothers to their nearest health facilities to limit self-referrals and costs related to follow up.
- vii. The Government should allocate enough funds to health facilities, formulate policies and guidelines that promote PMTCT and strengthen supervision of health facilities to ensure delivery of minimum health package. This will support implementation of option B+ strategy that has been introduced as a new PMTCT strategy (Holly, 2012).

6.3: Areas for further Research

The study recommends future researchers to;

- i. Explore how to reduce transport costs for PMTCT services to enhance retention.
- ii. Explore referrals to lower health units to limit self-referral in relation due to distance.

- iii. Explore how best to involve males in uptake of PMTCT services
- iv. Explore contributions of pre-medication and routine adherence counseling to retention.

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Appendix 1: Questionnaire for pregnant and lactating mothers

INTERNATIONAL HEALTH SCIENCES UNIVERSITY

AN ASSESSMENT OF RETENTION STRATEGIES FOR PREGNANT AND LACTATING MOTHERS INTO THE PMTCT PROGRAM AT ITOJO HOSPITAL, NTUNGAMO DISTRICT

Introduction

Dear respondent,

My name is _____. I am here as part of a research team conducting a study ART delivery, adherence and retention of patients in PMTCT programs in a post-conflict setting. This research is being conducted by ABEL ASIIMWE, a student of Masters of Science in Public Health at International Health Sciences University. The information will help assess the different retention Strategies for pregnant and lactating Mothers in to PMTCT Program at Itojo hospital.

You have been selected randomly to be one of our respondents in this study.

All the information provided in this study is subject to data privacy and will be treated with maximum confidentiality. The findings of this study will strictly be used for academic purposes only and will not be published in any way for public use.

The questionnaire is divided in to two sections. Section A seeks responses providing general information about the respondents' back ground. Section B is designed to retention and adherence of Pregnant and lactating mothers.

Do you have any questions or concerns about the study? May I start the interview?

YES _____ (please check) Thank you for agreeing to participate. (Continue below)

NO _____ (please put a cross here and stop). Thank you for your time. Is there another person or organization you think we should talk to instead?
_____.

Section 1: Interview Information

1. Questionnaire ID Number
 2. Interviewer Name.....
 3. Record Patients health facility number
-

4. Date of Interview

Section 2: Patient Characteristics

Please **fill out the space** or **tick** or **circle** the number with the appropriate response

No	Question and filters	
1.	Record Sex of respondent	Male ⁵ Use tick (√) Female ⁵
2	How old were you at your last birth day?	Less than 30 ⁵ Use tick (√) 30 - 39 ⁵ 40-49 ⁵ Above 49 ⁵
3	Record village name of current place of residence	
1. 2	Distance in km to the hospital	<3km ⁵ Use tick(√) 3-5km ⁵ >5km ⁵
2. 2	What is your marital status?	Single ⁵ Use tick (√) Married ⁵ Separated/ Divorced ⁵ Widow/widower ⁵
3. 2	What is your religion?	Catholic ⁵ Use tick (√) Protestant ⁵ Other Christian ⁵ Muslim ⁵ Orthodox ⁵ None / No religion ⁵ Others (specify).....
4. 2	What is the highest grade or level of education you have completed?	Primary ⁵ Use tick (√) Secondary ⁵ Technical/vocational cert. ⁵ College Diploma ⁵ University Degree ⁵

Section 3: Adherence

Are you s Please **fill out the space** or **tick** or **circle** the number with the appropriate response

No	Question and filters	Coding category
1.	Why did you choose to receive services from this facility?	
2.	When did you register for PMTCT at this facility?	
3.	Are you still under care at Itojo Hospital?	Yes ⁵ No ⁵ Use tick (√)
4.	What adherence related services do you receive from the HIV clinic?	ART adherence counseling ⁵ Use tick (√) Out-reach home based care ⁵ Referrals for community services ⁵ Others.....
5.	Do you receive counseling services from this facility?	Yes ⁵ No ⁵ Use tick (√)
6.	Who normally counsels you about adherence to ART at the hospital?	Medical doctors/officers ⁵ Use tick (√) Clinical officers ⁵ Nurse/Mid wife ⁵ Treatment Nurse /Adherence counselors ⁵ Lab and pharmacy staffs ⁵ Social workers ⁵ Expert patients/peer educators ⁵ Others.....
7.	Did/Do you receive the following services; (a) Pre-ARV medication counselling (b) Follow up counselling to discuss adherence to ARV	Use tick (√) Yes ⁵ No ⁵ Yes ⁵ No ⁵

	medication	
8.	How is counseling offered	Individually ⁵ Use tick (√) With a buddy or treatment support ⁵ As part of a group ⁵ Others.....
9.	Is adherence assessed at every refill visit by pharmacists/dispenser?	Yes ⁵ No ⁵ Use tick (√)
10.	How is adherence assessed during the visit?	Use tick (√) Patient self-report ⁵ Pill count ⁵ Pharmacists judgment ⁵ Verifying Refill dates ⁵ Others.....
11.	What has enabled you to adhere to treatment?	
12.	Is the HIV clinic offering the following adherence support to all ART patients?	PLHA support group ⁵ Use tick (√) Adherence support group ⁵ Home based care workers ⁵ Treatment supports ⁵ Others.....
13.	How do you know/remember the next refill date?	
14.	How often are you expected to refill your ARV drugs?	Every week ⁵ Every two weeks ⁵ Use tick (√) Once a month ⁵ Others.....
15.	Client missed appointment/lost to follow up	
16.	Have you ever missed any monthly refill? If yes, how many days/months and what was the reason?	Yes ⁵ No ⁵ Use tick (√)

		<p>If Yes days</p> <p>1. ≤ 7 days ⁵</p> <p>2. ≥7 but ≤30 days ⁵</p> <p>3. 1 month (30 days) ⁵</p> <p>4. 2 months (60 days) ⁵</p>
17	For how long have you not been on care	<p>1. ≤ 7 days ⁵</p> <p>2. ≥7 but less than 30 days ⁵</p> <p>3. 1 month (30 days) ⁵</p> <p>4. 2 months (60 days) ⁵</p>
18	Have you received any ART service at any other facility after registering here? If yes, what could have motivated you?	<p>Yes ⁵ No ⁵ Use tick (√)</p>
19	What are the reasons for stopping to go to Itojo Hospital?	<p>(a)</p> <p>(b)</p> <p>(c)</p>
20	What was done by hospital staff when you missed/failed to come back?	
21	Have you received any of the following as a process to trace clients for missed appointment/follow up?	<p>Telephone cell ⁵ Tick as appropriate (√)</p> <p>House visits ⁵</p> <p>Others.....</p>
22	What are the top three reasons why have not responded?	<p>(i)</p> <p>(ii)</p> <p>(iii)</p>

END

THANK YOU VERY MUCH FOR YOUR TIME AND PARTICIPATION

Appendix 2: Key informant interview form: PMTCT focal person

INTERNATIONAL HEALTH SCIENCES UNIVERSITY

AN ASSESSMENT OF RETENTION STRATEGIES FOR PREGNANT AND LACTATING MOTHERS INTO THE PMTCT PROGRAM AT ITOJO HOSPITAL, NTUNGAMO DISTRICT

KEY INFORMANT INTERVIEW FORM: PMTCT FOCAL PERSON

Dear respondent,

My name is _____. I am here as part of a research team conducting a study on adherence and retention of patients in PMTCT programs. This research is being conducted by ABEL ASIIMWE, a student of Masters of Science in Public Health at International Health Sciences University. The information will help assess the different retention Strategies for pregnant and lactating Mothers in to PMTCT Program at Itojo Hospital.

You have been selected randomly to be one of our respondents in this study and as the person in charge of the PMTCT services in this facility we would like to ask you questions such as the activities in the clinic, adherence, and retention and follow up at Itojo Hospital. All the questions will be about your program. Your contribution is important and will help the country to better understand PMTCT services experiences in retaining patients and supporting adherence in hospitals.

Do you have any questions or concerns about the study? May I start the interview?

YES _____ (please check) Thank you for agreeing to participate. (Continue below)

NO _____ (please put a cross here and stop). Thank you for your time. Is there another person or organization you think we should talk to instead?

Section 1: Interview Information

1. Interviewer Name.....
2. Date of Interview (DD MM YY)
3. Start time of interview __ __: __ __ [Hour: minute]
4. End time of interview __ __: __ __ [Hour: minute]
5. Position of persons interviewed [*Write exact name of job title for each person who provided information*].

.....

.....

Section 2: Adherence and Retention of Pregnant and Lactating Mothers		
No	Question and filters	Coding category
	Adherence	Please fill out the space or tick the number with the appropriate response
1.	How do you understand adherence and retention?	
2.	Are the following adherence related services provided by the HIV clinic?	ART adherence counselling ⁵ Out-reach home based care ⁵ Referrals for community services ⁵ Others..... ..
3.	How many pregnant and lactating mothers does	

	the ART clinic see on family support group day?	
4.	How many pregnant and lactating mothers does the ART clinic see per month?	
5.	How many current HIV positive children are registered in ART program?	
6.	Does the clinic limit the patients seen for HIV care during a typical day?	Yes ⁵ No ⁵ Use tick (✓)
7.	How many patients may the HIV clinic see on a typical day?	Write number
8.	How many HIV Pregnant and lactating mothers are enrolled on ARV drugs on a family support day?	Write number
9.	Are there any adherence guidelines or formal documents that you follow in this health facility?	Yes ⁵ Use tick (✓) No ⁵
10.	Is there a system for making individual HIV client appointment?	Yes ⁵ No ⁵ Use tick (✓)
11.	What guidelines or formal documents do you use to guide you on adherence?	
12.	Who counsels patients about adherence to ART here?	Medical doctors/officers ⁵ Use tick (✓) Clinical officers ⁵ Nurse/Mid wife ⁵ Treatment Nurse /Adherence councillors ⁵ Lab and pharmacy staffs ⁵ Social workers ⁵ Expert patients/peer educators ⁵

		Others.....
13.	Do you offer the following; (c) Pre-ARV medication counselling (d) Follow up counselling to discuss adherence to ARV medication	Use tick (✓) Yes ⁵ No ⁵ Yes ⁵ No ⁵
14.	How is counselling offered	Individually ⁵ Use tick (✓) With a buddy or treatment support ⁵ As part of a group ⁵ Others.....
15.	Is adherence assessed for each patient at every refill visit by pharmacists/dispenser/clinician?	Yes ⁵ Use tick (✓) No ⁵
16.	How is adherence assessed during the visit	Patient self-report ⁵ Use tick (✓) Pill count ⁵ Pharmacists/clinician judgement ⁵ Verifying ⁵ Refill dates ⁵ Others..... ..
17.	Does the facility have links with community based health care workers or volunteers?	Yes ⁵ Use tick (✓) No ⁵
18.	Is there a formal system for making the referrals to other departments and the other organisations such as referral slip?	Yes ⁵ Use tick (✓) No ⁵
19.	Do you have a system for	Yes ⁵ No ⁵

	tracking patients transferred to another facility for ART care?	Use tick (✓)
20.	If yes, what method is used for referrals?	
21.	Retention and client lost to follow up	
22.	Does the HIV clinic know the retention rate for ART patients?	Yes ⁵ No ⁵ Use tick (✓)
23.	If yes, what is the retention rate among how many patients	Adherence rate Total number of patients
24.	Does the HIV clinic offer the following adherence support to all ART patients?	PLHA support group ⁵ Adherence support group ⁵ Home based care workers ⁵ Treatment supports ⁵ Others.....
25.	What are the retention strategies used by the hospital in order of effectiveness?	(i) (ii) (iii) (iv) (v)
26.	What are the reasons for retention strategies used by the hospital?	(d) (e) (f)
27.	What are the limitations to retention strategies used by the hospital?	(i) (ii)

	 (iii)
28.	Do you have a system for making individual HIV client appointment?	Yes ⁵ No ⁵
29.	Is there a process in the hospital for tracking clients on ART who are lost to follow up?	Yes ⁵ No ⁵ Use tick (√)
30.	What process is used to trace clients for follow up?	Telephone cell ⁵ Use tick (√) House visits ⁵ Others.....
31.	After how long do patients start to drop out from the program	Number in days/weeks/months
32.	What are the commonest barriers to retaining clients in care?	(iv) (v) (vi)
33.	What are the top three reasons why patients become lost to follow up?	(vii) (viii) (ix)
34.	Do you have a system for tracking patients transferred to another facility for ART care?	Yes ⁵ No ⁵ Use tick (√)
35.	Where is the transfer information recorded?	General OPD register ⁵ Specific register ⁵ Client chart/medical record ⁵ No record kept ⁵ Others.....

END

THANK YOU VERY MUCH FOR YOUR TIME AND PARTICIPATION

**Appendix 3: Key informant interview guide for health workers,
local/opinion leaders and district officials**

**RETENTION OF PREGNANT AND LACTATING MOTHERS AT ITOJO
HOSPITAL IN PMTCT PROGRAM**

**KEY INFORMAT INTEREW GUIDE FOR HEALTH WORKERS, LOCAL
/OPINION LEADERS AND DISTRICT OFFICIALS**

Date of Interview

Venue of Interview.....

Starting time.....

Closing time.....

Introduction

Good morning/afternoon Sir/ madam?

My name is Our team is a conducting a study on adherence and retention of patients in PMTCT program. This research is being conducted by ABEL ASIIMWE, a student of Masters of Science in Public Health at International Health Sciences University. The information will help assess the different retention Strategies for pregnant and lactating Mothers in to PMTCT Program at Itojo hospital.

The purpose of this interview is to gather your opinions on and experiences with the PMTCT program at this health unit in order to recommend appropriate interventions that could further improve the quality of care for

pregnant and lactating living with HIV/ AIDS. This interview is voluntary, private and confidential.

Please fill free to discuss any issues and give your frank and honest opinions.

I will be writing down your opinions for record purposes. The record will be kept confidential. May I continue?

Demographic Characteristics of the Respondent

Category of respondent: 1. Community leaders 2. Service providers

Respondent's Position held.....

Age..... Sex Female ⁵ Male ⁵ **(Tick one)**

Level of Education: Primary Level ⁵ O- Level ⁵ A- Level ⁵ other (specify) ⁵

Religion:

Question Guides

1. How do you understand adherence and retention of clients enrolled in care?
2. How would you describe the process of enrolment of pregnant and lactating mothers into PMTCT care at facilities like Itojo hospital?
3. How do you ensure adherence and retention of pregnant and lactating mothers enrolled at your care centres/like Itojo hospital?
4. What challenges do pregnant and lactating mothers encounter during this period of antiretroviral therapy?

5. What direct costs do pregnant and lactating mothers incur in order to access antiretroviral therapy at Itojo hospital?
6. What are the most probable reasons why some pregnant and lactating mothers who start on antiretroviral therapy decide to discontinue the treatment later on?
7. What are the main barriers to adherence to PMTCT program in your community?
8. What strategies have been/are being applied to retain pregnant and lactating mothers on ARV at Itojo Hospital?

Probe for: - logistics management, staff recruitment and retention, monitoring and support visit, policy making/guidelines, data use, research, infrastructure renovation/development, technical guidance in developing strategies for retention

9. What are the limitations for the retention strategies you have mentioned above?

Probe for Stigma or Discrimination: Budgeting process, resource allocation, have you experienced any form of stigma and or discrimination in the community or at this health unit as a result of HIV status? **Probe for Cultural and religious beliefs:** In your opinion, are there any cultural or religious beliefs that hinder patients from continuing with use of antiretroviral therapy? If yes, describe those cultural / religious beliefs.

10. To what extent has the community you live in supported the pregnant and lactating mothers to continue accessing antiretroviral therapy from this health unit?

Probe: For male involvement, GBV management

11. What do you think should be done at the health unit level in order to ensure that pregnant and lactating mothers who start on antiretroviral therapy at this health unit do not discontinue treatment?

12. What do you think should be done at community level in order to ensure that pregnant and lactating mothers who start on antiretroviral therapy at this health unit do not discontinue treatment?

Additional for peer educators/expert patients

13. As expert patients, what services do you provide to pregnant and lactating mothers to ensure adherence and retention of in care?

14. How do you identify/know a mother who is not adhering to treatment and what would you do to keep them motivated?

15. What lessons can you share on adherence and retention

We have come to the end of this interview.

I would like to thank you for the free and frank discussion. The information you have provided to us will be very valuable for this survey. Have a good day

Appendix 4: FGD question guide

**RETENTION OF PREGNANT AND LACTATING MOTHERS AT ITOJO
HOSPITAL IN PMTCT PROGRAM**

FGD QUESTION GUIDE

Date of Interview

Venue of Interview.....

Starting time..... Closing
time.....

Introduction

Good morning/afternoon Participants?

My name is Our team is a conducting a study on adherence and retention of patients in PMTCT program. This research is being conducted by ABEL ASIIMWE, a student of Masters of Science in Public Health at International Health Sciences University. The information will help assess the different retention Strategies for pregnant and lactating Mothers in to PMTCT Program at Itojo hospital.

The purpose of this interview is to gather your opinions on and experiences with the PMTCT program at this health unit in order to recommend appropriate interventions that could further improve the quality of care for pregnant and lactating living with HIV/ AIDS. This interview is voluntary, private and confidential.

Please fill free to discuss any issues and give your frank and honest opinions.

I will be writing down your opinions for record purposes. The record will be kept confidential. May I continue?

Question Guides

1. What adherence related services do you receive from the HIV clinic?
2. Do you receive counseling services from this facility? If yes, what is the counseling about?

Probe: How is counseling offered?
3. Is adherence assessed at every refill visit by pharmacists/dispenser?
How is adherence assessed during refill period?
4. What are the factors that have enabled you do remain on this program up to this time?
5. What challenges you encounter during this period of antiretroviral therapy?
6. What are the most probable reasons why some pregnant and lactating mothers who start on antiretroviral therapy decide to discontinue the treatment later on?
7. What are the main barriers to adherence to PMTCT program in your community?
8. What strategies have been/are being applied to retain pregnant and lactating mothers on ARV at Itojo Hospital?

Probe for: - Family support groups, - Adherence counseling, - expert clients/ peer Support, and Telephone calls.

9. What are the challenges do you find with the retention strategies you have mentioned above?

Probe for Stigma or Discrimination: Have you experienced any form of stigma and or discrimination in the community or at this health unit as a result of HIV status? **Probe for Cultural and religious beliefs:** In your opinion, are there any cultural or religious beliefs that hinder patients from continuing with use of antiretroviral therapy? If yes, describe those cultural / religious beliefs.

10. To what extent has the community you live in supported the pregnant and lactating mothers to continue accessing antiretroviral therapy from this health unit?

Probe: For male involvement

11. What do you think should be done at the health unit in order to ensure that pregnant and lactating mothers who start on antiretroviral therapy at this health unit do not discontinue treatment?

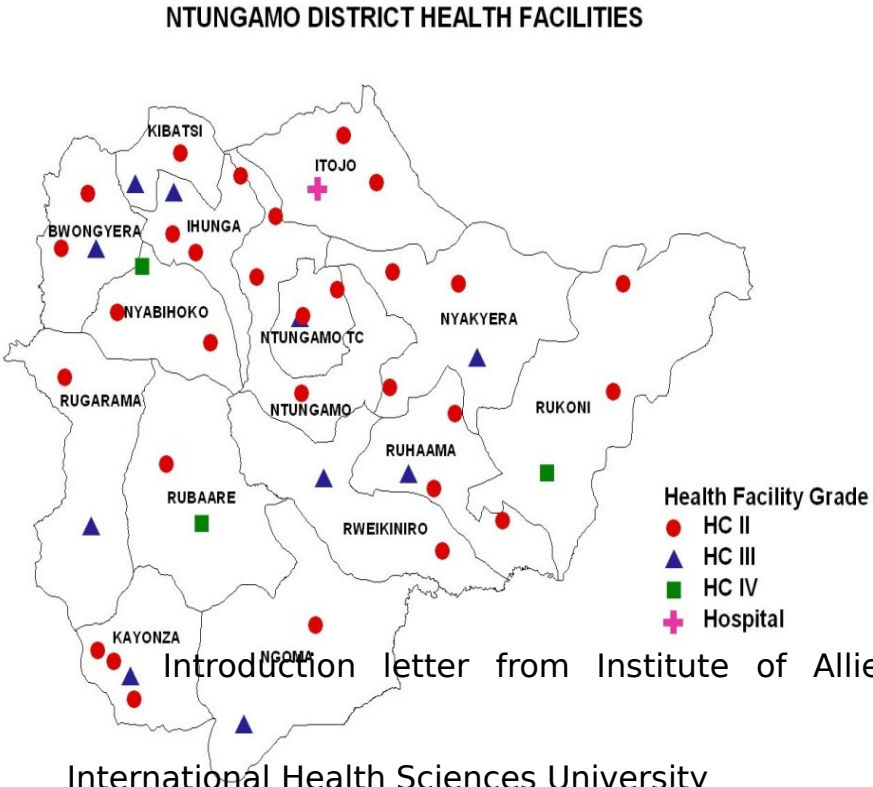
12. What do you think should be done at community level in order to ensure that pregnant and lactating mothers who start on antiretroviral therapy at this health unit do not discontinue treatment?

We have come to the end of this interview.

I would like to thank you for the free and frank discussion. The information you have provided to us will be very valuable for this survey. Have a good day

.....

Appendix 5: Map showing Itojo hospital and distance to other health facilities in Ntungamo district



Appendix 06
Sciences

The
The chief Administrative officer,
Ntungamo district.

Kampala, On the 27th of January 2014
CHIEF ADMINISTRATIVE OFFICER
08 MAY 2014
P.O. BOX 10 NTUNGAMO
The researcher is hereby permitted to conduct research in Itojo Hospital; please offer him the necessary support.
Daff 08/5/2014

Re: Assistance for Research

Greetings from International Health Sciences University.

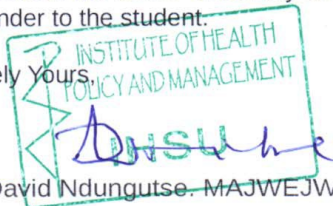
This is to introduce to you **Mr. Asiimwe Abel** Reg Number 2010-MPH-RL-FEB-033 a student of this University. As part of the requirements for the award of a Masters Degree of Public Health of this University, the student is required to carry out field research for the submission of a Research Dissertation. **Asiimwe** would like to carry out research on issues related to:

Assessment of retention strategies for pregnant and lactating mothers into the PMTCT program at Itojo hospital , Ntungamo district.

I kindly request you to render this student any assistance necessary for his research.

I, and indeed the entire University are thanking you in anticipation for the assistance you will render to the student.

Sincerely Yours,


INSTITUTE OF HEALTH POLICY AND MANAGEMENT
IHSU

Prof. David Ndungutse-MAJWEJWE

Dean, IHPM

International Health Sciences University
P.O. Box 7782 Kampala – Uganda – East Africa
Tel (+256) 0312 307400 email:directorihpm@ihsu.ac.ug
web: www.ihsu.ac.ug
the teaching college of International Hospital Kampala