# SOCIO-CULTURAL FACTORS INFLUENCING CONTINUED BREASTFEEDING AMONG PMTCT PROGRAM MOTHERS:

# A CASE OF MOTHERS IN BUYAGA COUNTY, KIBAALE DISTRICT

 $\mathbf{BY}$ 

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# **DECLARATION**

I, Okello Odeke Peter hereby declare that, the work being presented in this report is out of my own					
research and carried out in Buyaga County, Kibaale District. The topic for the study was "Factors for					
continued breastfeeding among PMTCT program mothers" A case of mothers in Buyaga County,					
Kibaale district. To the best of my knowledge this research and therefore report is original and has					
never been submitted by any other person or student to this University or any other institution for any					
academic award.					
Signature					
Date					
This dissertation has been submitted with the approval of my supervisor:					
Signature					
Date					

# **DEDICATION**

To my wife Florence Ajulo Okello and my Children: Agatha, Joshua and Jorem for the patience, comfort, care, social and spiritual support they offered which enabled me to organise this work successfully for submission to Makerere University and for the memory of my late father, Leonard Odeke who showed me the value of education.

#### **ACKNOWLEDGEMENTS**

This work is a concerted effort of many benevolent persons whose moral, spiritual, financial and academic support cannot be measured. However, I owe special appreciation to particular people whose moral claim to this research cannot be ignored. I applaud the invaluable contribution of my course coordinator and supervisor Kyaddondo David (DR) who placed his intellectual expertise selflessly at my disposal. I thank him for the guidance and tireless efforts in improving, directing and encouraging me through this research.

I owe appreciation to Kibaale District local Government for the financial support extended to me and special thanks to Mr. Kimono S. (CAO) for his emphasis on capacity building and personal development that provided an inspiration to me. I am equally indebted to the Medical Superintendent of Kagadi Hospital, Bateganya George (Dr) for his encouragement and support. To the staff of Kagadi Hospital, the clients who participated in the study and the entire community of Kibaale district who made a contribution in one way or the other, I say thank you and may God bless you.

Special appreciation goes to my research assistants: St. Specioza Nabukeera and Ms. Amongin Florence (RIP) whose inputs contributed a lot especially in data collection and analysis. I thank all those who have been there for me always especially my brothers in-law (the Williams), my Uncles Gerald and Vincent, course mates and friends that I have not mentioned in individual capacities. I will always remain greatly indebted to all of you. Lastly, I sincerely thank Nsita Margaret for typesetting this report.

#### **ABSTRACT**

This study focused on establishing the socio-cultural factors influencing continued breastfeeding among mothers enrolled in the PMTCT program. The justification of the study is to high light the need for thorough understanding of the socio-cultural and economic values associated with breastfeeding that influence the decisions of HIV positive mothers in order to promote child survival in the context of HIV/AIDS. The study was exploratory, analytical and descriptive in nature covering HIV positive mothers and expectant mothers who were attending antenatal services at Kagadi Hospital. Structured interviews were administered to mothers enrolled in the program and those attending antenatal services, In-depth interviews were conducted with health workers in the PMTCT clinic and Focus group discussions were held with community members. Documents in the hospital PMTCT clinic were reviewed and two research assistants helped in data collection.

Breastfeeding is strongly valued for cultural, psychosocial and economic reasons. There is a strong attachment between breastfeeding and the baby's health and while there is general awareness about channels of HIV transmission and available safe infant feeding options, it is not matched with enrolment and positive outcomes on the PMTCT program. There are conflicting messages both to the health workers and to mothers with regards to breastfeeding: ie on one part, HIV positive mothers are advised not to breastfeed at all yet on the other hand, breastfeeding is emphasised and recommended as the best option. This confuses the health workers and the mothers. Male involvement in the PMTCT program is low and there is low awareness about PMTCT in the community. Incentives to attract mothers to enrol in the PMTCT program are limited. The PMTCT program in the community is perceived to focus only to the mother and her baby. Mothers have limited social networks and are less supported and empowered economically to cope up with the breastfeeding dilemma.

The study recommends emphasis on community ownership of the PMTCT program to enhance community involvement, awareness creation on mother to child transmission of HIV and mobilization to fight socio-cultural stigma for better child survival as a primary solution. Guidelines relating to breast feeding and safe infant feeding options in the context of HIV need to be popularised and clearly understood by the health workers so that they ably counsel mothers.

The PMTCT program needs to be redefined and refocused to embrace the mother, farther/husbands (Family), the entire community through vigorous awareness campaigns. Mothers need social and economic support for meaningful and gainful involvement in the PMTCT program.S

The researcher invites the attention, commitment and involvement of all stake holders: Policy makers, health providers, CBO's/NGO's and the entire community to address the socio-cultural issues that influence breastfeeding so as to prevent Mother to Child transmission of HIV through breastfeeding for increased child survival in the context of HIV/AIDS.

#### **Definition of Key Concepts and list of abbreviations**

AIDS Acquired Immuno-Deficiency Syndrome:

ACPA: American Committee on paediatric AIDS

ANC: Antenatal Care

CBO's Community Based Organizations

CDC: Centre for disease Control.

CAO: Chief Administrative Officer

CHDC Child Health Development Centre

DHT: District Health Team

DDHS: District Director of Health services

M/S Medical Superintendent

NGO's: Non-Governmental Organizations

PMTCT Prevention of Mother to Child Transmission

PLWA: People Living With Aids

STD: Sexually Transmitted Disease.

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization

UNICEF: United Nations International Children Educational Fund

MOH: Ministry of Health

LC: Local Council

UDHS: Uganda Demographic and Health Survey

VCT: Voluntary Counselling and Testing

FGD: Focus Group Discussions

HIV: Human Immuno-Deficiency Virus

QR: Qualitative Report

#### **CHAPTER ONE**

#### 1.0 Introduction

The study sought to identify the socio-cultural factors that influence the decision and choice by HIV/AIDS positive mothers not to breast feed as an option for safe infant feeding in the context of HIV. It dealt with examination of awareness about HIV transmission through breastfeeding, factors promoting breastfeeding among mothers and the support given to HIV positive mothers enrolled in the PMTCT program. The study was carried out in Buyaga County, Kibaale district and this chapter presents the background to the study, statement of the study problem, objectives of the study, justification and scope of the study.

#### 1.1 Background to the study

Mother to child Transmission (MTCT) of HIV is the primary way that children get infected and without prevention, over 40% of the children born to HIV positive mothers get infected. Of those infected through MTCT, over 66% get infected during pregnancy and deliveries while 33% get infected through breast-feeding (MOH/PMTCT: 2004/5). For children under 2 years of age, this is almost the only way they get infected (MOH: 2004). Taking the Ugandan birth rate of 52.2 per 1,000 populations, about 5.2% of the female population is expected to be pregnant annually and with the 2002-population census of about 24.6 million; approximately 1,248,000 females get pregnant each year in Uganda.(UNHPC: 2002).

The current estimates indicate that approximately 25,000-30,000 MTCT infections occur annually in Uganda and this implies that over 85,000 babies born each year in Uganda are likely to be infected with HIV as the positive mothers continue breastfeeding their children. Most of these children will be dead by their second birthday (MOH/ACP: 2005/6, HIV/AIDS Strategic Plan Implementation Report, October 2008).

In Uganda, the HIV epidemic continues to exert a high toll on children and Uganda's goal 2012 is to reduce MTCT of HIV by 50%. The high burden of paediatric HIV disease, estimated at 120,000-150,000 children living with HIV/AIDs in 2007, stems from a 7.5% HIV prevalence among adult women aged 15-49 years. This is also associated with the relatively low exposing 18% of the new borns to HIV through MTCT. Ugandan women also have a very high fertility rate coupled with low contraceptive prevalence rate (approx 24%) among women aged 15-49 years. Part of the fertility rate is due to un intended pregnancies, which, if occurring in HIV positive women, contributes to thousands of paediatric HIV infections. The high infection rate among women of reproductive age has serious implications on Mother to child transmission of HIV (National HIV/AIDs strategic Plan- 2007/8 to 2011/12, Uganda AIDs Commission).

UNAIDS reported HIV transmission through Breast-feeding as a major public health problem in low-income countries like Uganda where breast-feeding is a norm. Low up take of PMTCT services by exposed mothers who often suffer stigma and societal barriers hindering utilization of PMTCT packages such as replacement feeding for mothers who opt not to breastfeed is of concern. This is because it reflects low health facility based deliveries. Despite the various interventions, concern still exists because positive mothers continue breastfeeding resulting into infant infection with HIV (HIV/AIDS Strategic Plan Implementation Report, October 2008).

To respond to this HIV/AIDS epidemic, most global strategies recommended by World Health Organization (WHO) have been implemented in Uganda and this includes "Prevention of Mother to Child Transmission of HIV" (PMTCT) strategy. However, the 2008 October HIV/AIDS National Implementation Report indicates that PMTCT currently reaches less that 50% of the eligible women and less than 45% of the facilities providing ANC have active PMTCT services (MOH, STD/ACP Annual Report on PMTCT, 2007).

Whereas active prevention strategies involving voluntary counselling and testing services (VCT) as well as increase in the number of centres offering PMTCT services have sustained the downward trend in HIV prevalence from over 10% to 6.4%, this figures are still very high in low income countries like Uganda(HSSP: Mid Term Review Report: 2000/1-2004/5).

Constraints remain because 6.4% of adult Ugandans aged between 15-49 years are infected and out of these, 8% are women compared to 5% men. During July-June 2007, 533,436 new mothers attended ANC facilities with PMTCT services in Uganda and about 80 %( 419,171) were tested and 7% tested positive. Despite the numerous prevention methods, the number of HIV infected mothers and children continue rising dramatically because women and children still account for over half of those living with HIV/AIDS throughout the world (Insights to health: March 2006). Currently, about 20-25% of HIV transmission in Kibaale District is attributable to perinatal transmission from infected mothers to their babies HIV strategic Plan, Kibaale)

In the 1990s, UNICEF, WHO and UNESCO formulated guidelines for infant feeding in the context of HIV/AIDS and consequently, the UN issued recommendations intended to discourage HIV infected mothers from breast-feeding. In 1995, the United States Food and Drug Administrations (FDA) Magazine published an article saying, "Women who are HIV positive should not breast-feed their infants" (George Kent, 1999).

In 1997, UNAIDS/WHO and UNICEF issued a joint HIV/AIDS and infant feeding policy statement saying: "HIV positive mothers were free to choose the best method for feeding their children but, they should be informed of the dangers of breastfeeding. The American Academy of paediatrics' committee on AIDS further stated that where suitable alternative nutrition sources exist, HIV positive mothers should be counselled not to breast-feed or wet nurse their children (AAPC: 1997).

It is against this background that the government of Uganda in collaboration with UNICEF, WHO, UNAIDS and other partners, introduced the PMTCT program in the year 2000, with the aim of reducing the rate of MTCT of HIV/AIDS. The national PMTCT program was therefore introduced to foster the scale up and implementation of the program. Under the program, community sensitization programs have been developed, health workers have been trained and all pregnant mothers are encouraged to attend ANC services provided by qualified health workers and deliver in a health facility. Mothers are encouraged to test for HIV and those who test positive are counselled on safe infant options. The available safe options include: Replacement feeding using formula, cow's milk and breastfeeding exclusively for 6 month and not breastfeeding at all. Under the PMTCT program, all pregnant mothers are counselled for HIV and encouraged to take an HIV test and all those found positive are counselled on safe infant feeding and exposed to available safe infant feeding options.

A number of preventive strategies and packages including guidelines on safe infant feeding have been adopted under the PMTCT program by Ministry of Health (MOH) in Uganda and the PMTCT program is being implemented in many districts in the country including Kibaale.

#### 1.2. Statement of the Problem

Breastfeeding is the natural and healthy way mothers should feed their infants. In the context of HIV/AIDS epidemic however, great concern has arisen because the HIV virus can get transmitted from the positive mother to her baby through breast feeding. Following the introduction of the PMTCT program in Kibaale district in the year 2002, HIV positive mothers are counselled on safe infant feeding options. Positive mothers who choose to breast feed are encouraged to practice exclusive breastfeeding for not more than six month. During this time, no other food, drink or water is given to the baby and there after, stop breast feeding and give other foods. For mothers who choose replacement feeding, they are advised not to breast feed at all, observe proper hygiene while preparing alternative baby feeds and follow the appropriate instructions including adhering to not breastfeeding at all.

Whereas HIV positive mothers who enrol in the PMTCT program and choose replacement feeding (the option of not breast feeding at all), are assumed to be ware and make informed decisions relating to safe infant feeding, this seems not to be the case. This is because the Ministry of Health/ACP PMTCT report 2006, states that over 44% of the mothers enrolled in the PMTCT program who choose not to breastfeed at all, continue to breastfeed their babies exposing them to the risk of HIV infection. The reasons as to why these mothers continue breastfeeding their babies are not very well known.

There may be a number of factors that make these mothers to continue breastfeeding their babies and this study therefore aimed at establishing the socio-cultural factors contributing to this practice among mothers enrolled in the PMTCT program in Buyaga County, Kibaale District.

#### 1.3. Objectives of the study

#### **1.3.1** General Objective

To establish Socio-cultural factors contributing to continued breast feeding among mothers enrolled in the PMTCT program and opt not to breastfeed in Buyaga County, Kibaale district.

#### 1.3.2. Specific objectives

The specific objectives of the study are therefore;

- To assess awareness about HIV/AIDS transmission through breast-feeding among mothers enrolled in the PMTCT program.
- 2. To identify factors promoting breast feeding among mothers enrolled in the PMTCT program.
- 3. To examine available support services for promoting safe infant feeding among PMTCT program mothers

#### **1.4.** Justification of the study

Successful implementation of PMTCT as program and the choice of not breastfeeding requires thorough understanding of the Socio-Cultural values, behaviours, perceptions and attitudes of the people towards breastfeeding in a given community. PMTCT as a program therefore, might be faced with implementation problems because the community's Socio-cultural factors relating to breast feeding have not been well considered.

This study will provide important information regarding Socio-cultural factors associated with breast feeding in the context of HIV/AIDs. This information will be useful to policy makers, Ministry of Health and other stakeholders involved in programming PMTCT interventions that are relevant to the local settings.

The information will be useful in Kibaale district especially to the health department, civil society organizations and the community in promoting implementation of PMTCT program by providing additional information to existing literature in the area of breast-feeding and HIV/AIDS. The study is of academic significance to the researcher since it is submitted as a partial requirement for the award of a Master of Arts degree in Social Sector planning and Management of Makerere University.

#### 1.5. The scope of the study

The study was based on establishing the socio-cultural factors for continued breast feeding among mothers enrolled in the PMTCT program that choose not to breastfeed as an option for safe infant feeding in Kibaale district.

The study was carried out in Buyaga County consisting of 8 sub counties and 20 health units. Kagadi hospital was the focal area for the study because it is the headquarters of Buyaga Health sub district as well as the coordinating centre for PMTCT services for Kibaale district. The study took a period of one month that involved field visit for data collection, analysis and report writing and consequently submission to the university authorities for marking.

#### **CHAPTER TWO**

#### LITERATURE REVIEW

#### 2.0 Introduction:

This section presents the literature review relating to the objectives of the study. It is presented in sections: Awareness about HIV transmission through breastfeeding; Factors for continued breastfeeding among mothers enrolled in the PMTCT; Examination of available support services for promoting safe infant feeding among PMTCT program mothers. The section closes with a summary of the literature reviewed in relation to the alternatives available for mothers, costs involved and challenges faced by PMTCT program mothers as well as the gaps identified in the study.

#### 2.1 Awareness about HIV transmission through breast breast-feeding

Whereas breast-feeding is a cultural norm and a public act concerning the whole community, great concern has arisen because the HIV virus can get transmitted from the positive mother to her child through breast milk. HIV transmission through Breast-feeding is therefore a major public health problem in low-income countries like Uganda where breast-feeding is a norm (UNAIDS/WHO: 2002). Also the issue of MTCT of HIV remained unclear as HIV was mainly known to be transmitted through heterosexual contacts with less emphasis on Mother to Child transmission because there was still a debate on whether HIV/AIDS was transmittable through breast milk/breastfeeding in Uganda. With progress in research however, Mother to Child Transmission (MTCT) of HIV was confirmed to occur in three ways namely: during pregnancy (15-20%), at birth (60-70%), and through breast-feeding (15-20%) (UNAIDS, MOH: 2000).

Mother to child transmission of HIV therefore, is now known as the primary way through which children get infected with this virus. Currently it is known that over 40% of the children born to HIV positive mothers in Uganda get infected, 33% of which get infected through breast-feeding (MOH/PMTCT: 2000) and for children under 2 years of age, this is almost the only way they get infected (MOH: 2000).

Due to new knowledge and awareness about this phenomenon, UNICEF, WHO and UNESCO formulated guidelines for infant feeding in the context of HIV/AIDS. In 1997, UNAIDS/WHO and UNICEF issued a joint HIV/AIDS and infant feeding policy statement saying: "HIV positive mothers were free to choose the best method for feeding their children but, they should be informed of the dangers of breastfeeding. It was also emphasised that "Women who are HIV positive should not breastfeed their infants" (George Kent, 1999). The United Nations meanwhile issued recommendations intended to discourage HIV infected mothers from breast-feeding. In the year 2000 therefore, government of Uganda in collaboration with UNICEF, WHO, UNAIDS and other partners, introduced the PMTCT program with the aim of reducing the rate of MTCT of HIV and the AIDS disease. A package of preventive strategies have been recommended by UNAIDS and adopted by MOH and the program was piloted and was scaled down to all the districts in the country.

Through this program information about diseases transmitted through breast-feeding was made generally available. The ministry of health and other partners in development conducted various trainings and mothers were counselled and supported to adopt safe infant feeding practices. The result should be that there is increased awareness of mother to child transmission of HIV and there is some information to this effect.

For example an HIV/AIDS situation analysis done in Kibaale District by AMREF and Ireland Aid (2000) revealed that 98.6% of the people interviewed were knowledgeable or had heard about HIV and were aware of the modes of its transmission but there was no particular mention about HIV transmission through breast-feeding, implying that the HIV scare had not caused any significant changes in breast-feeding values and patterns in the community.

Other studies suggest that the impact of counselling about breast-feeding risks and alternative feeding methods has not been studied systematically (Elisabeth A. Preble, MPH a et al: 1998). Therefore it is still unknown what toll fear of infecting an infant through breast-feeding- a practice with deep evolutionary, cultural and emotional roots-takes on the mothers and the society.

According to the Child Health development Centre qualitative report (MOH: 1994), it was reported that a well fed mother would breast-feed properly and because she was healthy, she could not transmit diseases through her breasts. In this same report, ill health in a baby was associated with mistreatment of a mother by her spouse and many respondents reported not to have seen mothers with AIDS, but had heard that babies could get HIV/AIDS from the mothers' milk through breast-feeding (MOH/CHDC: 1994).

It also seems that awareness about HIV transmission through breast-feeding was not matched with knowledge on prevention because rural uptake rates suggested that only 23% of the mothers opted for substitute feeding since there was no apparent danger in breast-feeding (UDHS; 2000-2001). For example the World Health Organization (WHO) collaborative study in 1981 showed that 65% of rural mothers in India, Guatemala, Ethiopia and Zaire were still breast-feeding at 18 month (WHO, Geneva: 1981).

#### 2.2. Factors promoting breastfeeding among PMTCT program mothers.

Human milk is a living fluid. It has an ancient title of "White blood" and a Chinese text by Sun Simiao referred to milk as "Xuegi" which literally means "blood and vital energy". Breast-feeding (Lactation) is the secretion of milk and its injection into the mammary glands following a normal pregnancy (Cowie: 1972). It is a cooperate effort where a baby with a well developed rooting for suckling and swallowing reflexes drains the milk from the mothers breast and "the let down reflex" is responsible for milk ejection/breast emptying (Ebrahim; 1980, Newton; 1967). Since ancient times, breast-feeding was the way man fed his young and was believed to transmit character and personality to the baby. The earliest medical encyclopedia "The papyrus Ebers: 1550 BC" written during the Egyptian civilization recognized this fact (Okwi, 1988). During the Greek and Roman civilizations, breast-feeding was done by the mother and wet nurses employed by the aristocracy (Wickess; 1953). The last Chinese emperor had a wet nurse for over 12 years (Circa, 1906) and in Europe, direct feeding from animal teats especially Asses was done (Jelliffe: 1968).

It is therefore possibly true that every cultural group holds some values attitudes, perceptions and beliefs about the primary function of a woman's breast and milk, and these values determine breast-feeding practices and behaviours among their communities. Other studies however depict contradictory information for the mothers. For example, some studies promote breast feeding because it is considered to be a major source of energy and fat and is a sign of love and bondage between the mother and her baby (UDHS: 2000/2001). Another WHO collaborative study report, concluded that full breast-feeding reduces current childhood deaths from diarrhoea by 66% (WHO: 2000). Other researchers further argue that breast-feeding contributes to reduction of fertility and child spacing and thus it was universally accepted, valued as necessary, on demand, permissive and initiated soon after birth (Mathews; 1955, D.B Jelliffe, Bennet; 1962, Omololu; 1972).

WHO /UNICEF (1994) shared this view by defining optimal and healthy infant feeding as the initiation to breast-feeding within one hour after birth, exclusive, frequent and on demand breast-feeding. Studies carried out in the Philippines and Rwanda by UNAIDS (2000) confirmed the view that breast-feeding was beneficial to both the mother and the infant, and WHO/UNICEF (2000) recommended exclusive breast-feeding for the first six month and introduction of complementary food at the seventh month.

Similarly Calventon (1995) observed that healthy infant feeding consisted of breast-feeding and supplementary feeding when appropriate and a good mother was the one who performed her traditional roles as a caregiver and a homemaker and above all, the one who breast-fed her children. Frequent breast-feeding including night feeds were important in ensuring sufficient milk let down, maintenance of the supply and helped the baby to gain weight (UDHS: 1995, 2000/2001).

Dangers of not breast-feeding were experienced in Europe during the renaissance period where poor sanitation, lack of adequate and safe water, ignorance and poor socio-economic conditions led to high infant mortality with diarrhoea as the leading cause (Okwi, 1988). Religion recognized the value of breast-feeding as Moses the receiver of God's commandments was breast-feed by a wet nurse (Exodus 2: 7-10). This was further illustrated in "Ishar" the mother goddess of ancient Babylon and "Oduadua" the Yoruba (Nigeria) goddess of fertility (Jelliffe: 1968) and the Koran advises Moslem mothers to breast-feed for at least 2 years.

The Uganda Demographic and Health Survey (UDHS: 2000-2001) showed that appropriate feeding practices were fundamental for the survival, growth, development, health, and nutrition of children. Health benefits of breast-feeding both for the mother and the child influenced the intensity, duration and the age at which complimentary feeds were introduced.

# 2.3. Available support services for promoting safe infant feeding to PMTCT program mothers

Availability of support services to mothers in the PMTCT program is an integral and important aspect for promoting safe infant feeding because they have a bearing in its Acceptability and sustainability.

The interim findings on the national PMTCT pilot sites (Feb, 2000) identified the difficulties and constraints to full and effective implementation of PMTCT as being systemic in nature, and relating to poor functioning of the health care system in general.

The Uganda Demographic and Health Survey (UDHS: 200-2001) revealed that health care services were accessible to a small percentage of the population due to lack of money for treatment, long distances to the health facilities, poor communication and road networks. It was further reported that men dominated decision making on health seeking behaviours and women especially those infected with HIV faced discrimination even among health workers.

According to the Annual Health Sector Performance report (2000/2001), human resources for health were a problem because health personnel with the right skills remained grossly inadequate. The available health workers had low morale, were over worked and had poor attitudes. HIV clients faced discrimination and stigma and due to poor infrastructure, confidentiality was compromised while testing for HIV was limited. With the decentralized staff recruitment, many posts remained unfilled especially in the rural remote and not easy to reach areas where rudimentary staff like nursing aides manned the health units. Massive backlog of dilapidated infrastructure due to previous neglect adversely affected access and quality of services that were characterised by rampant drug stock outs, lack of diagnostic equipment and general lack of essential medical supplies.

The Uganda health facility Survey (MOH: 2002) reported that within the health care delivery system, PMTCT is constrained by inadequate supervision and low adherence to medical ethics by health workers. The healthcare system has limited capacity to offer adequate counselling, testing and follow-up especially of mothers counselled on safe infant feeding and less than 6% of the facilities surveyed were providing PMTCT services while only 15% of health centre IV's were offering PMTCT services. Provision of care for the HIV positive mothers and their children remains a challenge to the health care delivery system of Uganda. In order to improve on the quality of care, sustainability of PMTCT services, safe infant feeding in general and child survival in particular, the broader health issues need to be addressed concurrently.

Breast-feeding was positively valued and regarded by humanity, culture and religion as healthy, normal and the natural way of parenthood and this is a big dilemma to mothers in the context of HIV where mothers are discouraged from breastfeeding so as to avoid infecting their babies with the HIV virus. Changing these values poses a big challenge because of the very nature of HIV/AIDS.

Despite the fact that PMTCT policies and guide lines now exist in Uganda, they are not widely known in the community and this highlights a critical gap in the PMTCT program. In addition, there are conflicting messages to the community from Ministry of Health like, "PMTCT mothers should exclusively breast feed in the first six month" and that, "HIV positive mothers should not breast feed". The languages used for communicating to mothers, content of the messages, methods of delivery, advocacy and social mobilization seem to be inadequate in the program as reported in the Communication strategy for PMTCT (2003-2005).

In addition, male involvement in the PMTCT program where they are important stake holders is very minimal. The costs involved in artificial infant feeding especially in formular feeds are prohibitive especially to rural mothers. Even where formular feeds are available and affordable to some mothers, the core issue of non disclosure and stigma still prevails.

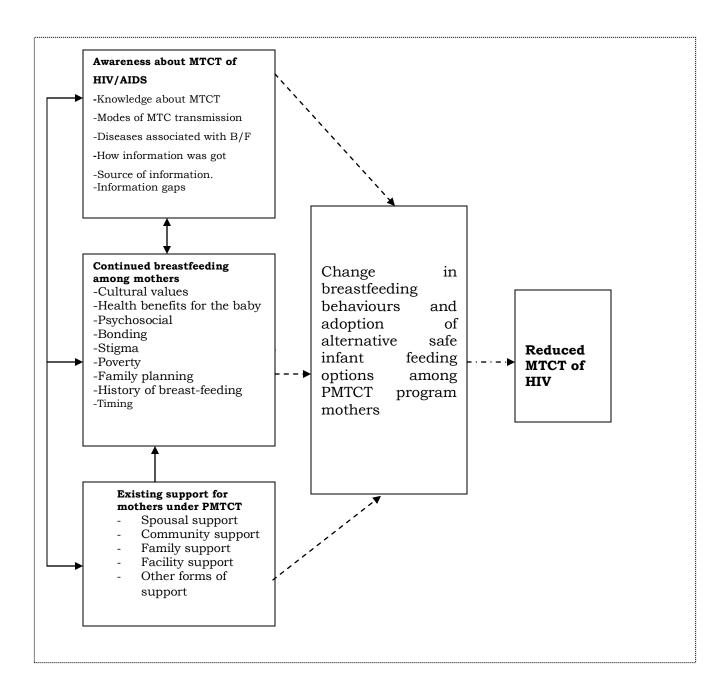
#### 2.4. Conceptual Framework on factors for continued breastfeeding among mothers.

Awareness about MTCT of HIV through breastfeeding is taken to include knowledge about HIV transmission, sources of information, modes of communication, awareness about diseases transmitted through the breasts/milk and the associated information gaps.

These were conceptualised to have a direct influence on the Socio-Cultural factors influencing breastfeeding behaviours of mothers that include: Cultural values of milk and breastfeeding, health benefits of breastfeeding to the baby, poverty, stigma, bondage and social recognition, people's attitudes and perceptions. Available support to mothers is conceptualised to have a direct influence on the source, nature and type of support that mothers get from their spouses, family, community, facilities and other networks in order to prevent HIV transmission through breastfeeding.

These factors were conceptualised to influence adoption of alternative and safe infant feeding practices among PMTCT program mothers leading to change in behaviours and practices associated with breastfeeding among HIV infected mothers. The interaction of these factors is assumed to cause change in breastfeeding behaviours among PMTCT mothers leading to adoption of safe infant feeding options that will ultimately result into reduced MTCT of HIV through Breastfeeding. This relationship is illustrated in figure one below.

Figure: 1 Conceptual Framework on factors for continued breastfeeding among HIV positive mothers.



#### **CHAPTER THREE**

#### **METHODOLOGY**

#### 3.0 Introduction

This chapter covers details of the methods used in carrying out this study. It includes the research design, area of study, study population, sample size, sampling procedure, data collection methods, ethical considerations, data analysis and limitations of the study.

#### 3.1 Research design

This was an exploratory, analytical and descriptive study that aimed at discovering and analysing the socio-cultural factors contributing to continued breastfeeding among HIV positive mothers in the PMTCT program using both qualitative and quantitative methods for data collection.

#### 3.2. Area of study

The study was carried out in Buyaga County; Kibaale district located in mid-western Uganda. The District is bordered by Lake Albert to the west, Hoima district to the north, Kiboga district to the east, Mubende district to the south and Kyenjojo district on the south-western boarder. It is about 215 km from Kampala City and covers a total area of approximately 4,400 sq kms, of which 319 sq kms is covered by water bodies.

The study focussed on Buyaga County because it is where (Kagadi Hospital) the district referral hospital, the headquarters of Buyaga Health Sub District and the district PMTCT coordinating centre is found. Buyaga County has a population of over 267,546 and covers a total area of 1,575-Sq kms. It consists of 8 sub-counties, one town council, 36 parishes and 442 villages. The County witnessed a tremendous population growth due to resettlers from other districts and countries like Congo, Zaire and Rwanda and the predominant tribes are Banyoro and Bakiga while smaller tribes include Bakonjo, Congolese, Bamba, Alur and Batoro.

Buyaga County has an HIV prevalence rate estimated at 6.7% among mothers attending antenatal services (Uganda 7.0 %) and PMTCT rate was estimated at 5.8 % in 2005. Out of the total district population of 491,273, over 50% is resident in Buyaga County with a density of over 93.7 persons per sq km. Much of the population is rural (98.9%] with a growth rate of 5.4% (Uganda 3.4%) and the fertility rate is 7.8 children per mother (Uganda 6.9). The infant mortality rate is 122/1,000 live birth (Uganda 83/1,000) and under five mortality rate per 1,000 live birth is 205/1,000. The average age at first marriage is 17.8 years, while the average age at first birth is estimated at 18.7 years. (Kagadi Hospital sentinelle surveillance site data, 2004)

With HIV/AIDS prevalence rate of 6.4% among the population in Kibaale, it is notable that 5.8% PMTCT prevalence rate is high. Coupled with the peasantry nature of the population, breastfeeding is the common practice. Given the dilemma of breastfeeding in the context of HIV/AIDS, PMTCT was therefore introduced in 2002 to promote child survival. (DPU- Population / Statistics Kibaale, 2005, Population Census 1991 and 2002, UDHS 1995, UNHS 2002/3, and UNICEF 2001)

#### 3.3. Study population

The study considered 127 mothers who had undergone counselling, tested positive and agreed to enrol in the Hospital PMTCT clinic. In addition, 75 expectant mothers (irrespective of their sero status) who were attending antenatal services at the hospital during the study period were considered in the study because they formed a body of potential mothers and as they were already attending ANC at the clinic, it was noted that they received HIV counselling and all were encouraged to under take an HIV test. Involving these mothers was seen by the researcher to add value to the study since those found positive would have to be encouraged to enrol in the PMTCT program for support.

Health workers who were on duty during the study period were interviewed to generate supplementary information and local community representatives consisting of local council leaders, religious leaders, client representatives and spouses who accompanied their wives for antennal review (irrespective of their sero status) contributed to the study.

#### 3.4. Sample size

A total of 65 mothers were sampled for the study. In-depth interviews were held with 9 health workers in the PMTCT clinic and 4 focus group discussions each consisting of 8 respondents were conducted.

**Table 1: Distribution of the sample size** 

Tubic 1.	Distribution of the sumple size			
Number	Category	Type of interviews		
35	Positive mothers enrolled with PMTCT clinic	Structured questionnaires.		
30	Mothers attending ANC at hospital	Structured questionnaires		
9	Health workers in the PMTCT clinic	In depth interviews		
4	Community representatives	Focus group discussions.		

### 3.5 Sampling procedure

#### 3.5.1 Selection of breastfeeding mothers

Using records from Kagadi hospital PMTCT clinic covering January 2003 to December 2005, the researcher established that 127 mothers had enrolled in the PMTCT program and this constituted the population where the sample size was drawn. Records further revealed that most mothers enrolled in the PMTCT program are members of the association of People Living with AIDS (PLWAs) in existence based at the hospital. After consulting with the in-charge of the PMTCT clinic, 54 mothers were purposively selected on the basis that they are active on the program, are being followed up by health workers, are members of the Association of people living with HIV already in existence and could easily be mobilised for the study.

The researcher with guidance from the HIV/AIDS project coordinator, sought for assistance from the chairperson of the Association of PLWAs who willingly agreed to mobilise the mothers for the study. With assistance from the chairperson of the association, 35 out of the 54 mothers agreed to participate in the structured interviews.

#### 3.5.2 Selection of expectant mothers attending antenatal services.

The researcher felt that the sample size of 35 mothers who had chosen the option of not breastfeeding at all was not representative enough for the study and decided to include additional mothers among those who were attending antenatal services in the hospital clinic at the study time. After consulting with the midwife in charge maternal and child health (MCH) and with the aid of the antenatal register, the researcher established that 75 mothers had come for antenatal on the day of the study and this provided the sampling frame.

Out of the 75 names extracted from the antenatal register, 30 mothers were purposively selected with the help of the midwife on duty for administration of the structured interviews basing on the criterion that those selected are not co wives or close relatives, are coming from within Buyaga County and willingly agreed to participate in the study as they were still within the hospital. This was done to ensure confidentiality, validity and to generate non-biased responses from the mothers.

#### 3.5.3 Selection of health workers for in-depth interviews

Health workers were purposively selected on the basis that they directly interact with mothers as they work in the PMTCT clinic and were on duty during the study period. Following this criterion, 9 staff: A medical officer, a clinical officer, two mid wives, two HIV counsellors, one nursing assistant, a clinical writer and the Hospital HIV/AIDS project coordinator were selected for administration of In-depth interviews.

# 3.5.4 Selection of participants for Focus group discussions

Purposive sampling was used to select participants for focus group discussions following the criteria for each category with specific reasons as illustrated in table 2 below:

**Table 2:** Categories of participants in Focus Group discussions

Category	No:	Criteria used	Why selected
ANC Mothers	8	-Identified from the antenatal register with	These are potential mothers
		Assistance of the midwife I/C MCH.	since they are pregnant
		-Sero status not considered	
		-Not relatives or co-wives	
		-Coming from within Buyaga	
		-Consented and willingly agreed to participate.	
		-new attendants	
Spouses	8	-Identified by their wives.	These are potential
		-Purposively selected because they accompanied	supporters to mothers/their
		their wives/mothers for antenatal review in the	wives
		Clinic.	
		-Received counselling	
		-No consideration of sero status	
		-Consented and agreed to participate	
PLWA's	8	-Selected by the C/person of the PLWAS	These are clients who have
3 Female &		-No Consideration of position held	opened out publicly and have
4 Male		-Individual testimony	testimonies from real life
		-Time of joining the association	experience
		-Proximity to the hospital	
		-Consented to participate	
		- Agreed to come to hospital for the interview.	
Community	8	-Religious leaders in the locality (3)	These are stake holders and
Representatives		(Catholic, protestant, and Moslem)	have influence in the
		-LC1 Vice (Secretary children affairs (2)	community
		-Member of the Kibaale AIDS network. (1)	
		-Representative of CBO in the area (2)	
		-Consented to participate	
		-Chairperson LC3 Kagadi	
		-Agreed to come to hospital for interviews.	

#### 3.6. Methods of data collection and instruments used.

#### 3.6.1 Focus group discussions

Focus group discussions were held with each of the four categories of respondents as detailed in the purposive sampling procedure in (**Table 2**). A date was fixed when each group was invited to the hospital for the interview. Space was secured within the ANC unit as avenue for the discussions. Before starting each group discussion the researcher introduced the research team, explained the purpose of the study and went through the FGD guide. The researcher would always request the discussants to introduce themselves and sought for their consent before commencing each discussion with the aid of the focus group discussion guide. The researcher guided the discussions while taking keynotes and one of the research assistants recorded the discussions using a tape recorder set.

The Focus group discussions helped in generating information about socio economic characteristics of mothers, values associated with breastfeeding in the community, awareness about MTCT of HIV through breastfeeding and support available to HIV positive mothers to reduce breastfeeding in the community. Focus group discussions were carried out using a Focus Group Discussion guide (Appendix: Three) that was constructed following the objectives of the study and the themes in the conceptual framework and administered to each respective FGD group.

#### 3.6.2 Structured interviews.

Structured interviews were administered to the selected mothers in the PMTCT clinic and new mothers who were attending antenatal services for the first time during the study period.

The questionnaires were constructed following the objectives of the study and were divided into four sections ie Socio demographic characteristics of the mothers, Values associated with breastfeeding, Awareness about HIV transmission through breastfeeding and support to positive mothers to reduce breastfeeding in order to prevent MTCT of HIV through breastfeeding. The method gave respondents a chance to express their views with guidance of the research assistants.

#### 3.6.3. In-depth interviews

In-depth interviews were held with health workers in the PMTCT clinic using an in-depth interview schedule that was constructed following the objectives of the study. The in-depth interviews covered inquiry into the background information of mothers, perceived values health workers have about breastfeeding among the mothers they serve, opinion of health workers relating to awareness of mothers about MTCT of HIV through breastfeeding and how positive mothers are supported to prevent infection through breastfeeding in order to promote child survival in their day to day interaction with mothers.

#### 3.6.4 Review of records

Records at Kagadi hospital were reviewed to generate secondary data about the history of the hospital and progress in the PMTCT clinic. Information about antenatal mothers was extracted from the antenatal register and the client register provided the sampling frame where HIV positive mothers enrolled in the PMTCT clinic were selected for the study. The membership register, minutes of meetings and copies of reports indicated that an Association of PLWAs is in existence and most PMTCT mothers are members. The attendance sheets, counselling forms and progress reports provided the back up for purposive sampling.

#### 3.7. Data collection process.

# 3.7.1 Structured questionnaires to mothers in the association of PLWAs enrolled in the PMTCT program

In order to administer the structured interviews to the mothers, the chairperson of the Association of People Living with AIDS (PLA) volunteered to mobilise mothers to meet the research team at the hospital where a venue had been organised. Information was passed and through the local FM Radio-Kibaale Kagadi Community Radio (KKCR), a meeting was convened for mothers to meet the research team on the set date and time.

During the meeting day, the researcher introduced himself and the research assistants. He explained the purpose/objectives of the study and went through the questionnaire. Consent of mothers to participate was sought before the questionnaires were distributed and the research assistants helped to administer the interviews by explaining some of the questions and filling the questionnaires where necessary.

After each interview session, the researcher with the assistants checked through the questionnaires to ensure accuracy and completeness. Where gaps were identified, relevant corrections were made with the respective respondents. The meeting was closed with a re assurance on confidentiality and mothers were always thanked for participating in the study. Through this process a total of 35 mothers consented and freely agreed to participate in the administration of the structured questionnaire (appendix one). At the end of the meeting, the questionnaires were all collected back, checked for accuracy and securely kept for further analysis.

#### 3.7.2 Structured questionnaires to new mothers attending antenatal services.

The interviews were administered during the antenatal clinic day at the hospital and at the point of exit. During the date of the interview, the midwives gave the researcher an opportunity to address mothers during the health education talk session. In the brief, the researcher introduced himself and the research assistants. He gave a brief about the purpose/objectives of the study and went through the questionnaire.

The procedure for selecting mothers to participate was explained and consent of mothers to participate was sought. After antenatal reviews, the selected mothers were directed to a room that had been prepared for them to meet the research team for administration of the questionnaires. The research assistants helped in the distribution and administration of the questionnaires by explaining some of the questions and helping mothers fill in the questionnaires whenever necessary. Through this process, 30 mothers were purposively sampled for the administration of structured questionnaires following the procedure discussed in (3.5.2) and at the end of each session, the filled questionnaires were collected, checked for accuracy and securely kept for further analysis.

#### 3.7.3 In-depth interviews to health workers

In-depth interviews were held with 9 hospital staff working in the PMTCT clinic using an In-depth Interview schedule (*Appendix Two*). The researcher scheduled a meeting with the clinic team with assistance of the medical superintendent to introduce him and the research assistants, to explain the purpose and objectives of the study and to go through the interview schedule. After the meeting, the researcher undertook to seek for individual appointments with each of the selected staff during the clinic day while distributing the interview schedules.

On the agreed time and before starting each interview, the researcher introduced his team as per the appointment and sought for consent. The researcher held face-to-face interviews with each of the selected staff to probe on some issues while taking notes. At the end of each session, all the interview schedules were collected back, checked for accuracy and securely kept for further analysis.

#### 3.8. Ethical considerations

The researcher was introduced to the district authorities to ensure that the study is in conformity with the district values and the chief Administrative Officer (CAO) at the district introduced the researcher to the Assistant (CAO) Buyaga and the medical superintendant Kagadi hospital, where the study was carried out from.

Before starting each interview session, the researcher explained the purpose of the study to the respective respondents and both individual and group consent would be sought before proceeding with the interviews. Individuals who failed or refused to participate were replaced in accordance to the sampling procedure and all the collected data was kept confidential and only used for the study purposes. After each session, the researcher undertook to thank the respective participants.

Aware that HIV/AIDS is a sensitive issue, individual names are not mentioned and confidentiality was highly observed. This was one of the key reason as to why the researcher preferred purposive sampling as the main method of data collection with due consideration of the feelings of the participants without compromising the quality of the data. Assistance and advice from the chairperson of the Association of PLWAs and the midwives was also very vital for ethical reasons.

# 3.9. Data Management and Analysis

### 3.9.1. Data management

The researcher secured assistance of two research assistants who underwent an orientation training and pretested the research tools before carrying out the research. The data was cleaned on a daily basis by editing the completed questionnaires before releasing the respondents to ensure uniformity, accuracy, consistency, status legibility and comprehensibility. This exercise ensured that raw data was made ready for entry into the computer and the cleaned data was filed and stored securely for final analysis.

# 3.9.2. Data analysis

# Qualitative data

Qualitative data analysis was a continuous process where themes were identified from the conceptual framework and data was grouped into responses according to the specified categories, sections and subsections in the questionnaires in order to ensure a uniform flow of information. The data was ordered using Nnivo soft ware that helped to generate data according to objectives of the study. The data was then ordered, reduced and coded according to the different themes and where other themes and subthemes were identified, data was summarised making it meaningfull and reported using thematic analysis...

The themes identified were: Awareness about HIV/AIDS transmission through breast-feeding; Factors promoting breastfeeding among PMTCT program mothers; and supportive interventions given to mothers. The coded data was then entered into the computer using MS access and analyzed using the Statistical Package for Social Sciences (SPSS) and presented using data displays.

#### **Quantitative data**

Quantitative data analysis was carried out to generate information about demographic and socioeconomic variables relating to breast-feeding and this information was presented in form of descriptive statistics using simple tables.

# 3.10 Limitations of the study

The topic under investigation relates to HIV/AIDS which is a sensitive issue characterised with secrecy and stigma. Some mothers had suspected that the study was aimed at exposing those who are HIV positive and this made them reluctant to give information while others thought the researcher had gone to distribute incentives and drugs.

However, the researcher engaged research assistants who are counsellors. Since some of the respondents are members of the Association of People Living with AIDS, they ably, willingly and freely participated in the study with close interraction with the research team and this enabled the researcher to capture valuable information that is contained in this report.

Due to financial and time constraints the study was only limited to the PMTCT clinic and mothers attending antenatal services in the hospital. A small sample was therefore covered and the findings do not cover all mothers infected with HIV/AIDS especially those who have not yet enrolled with the PMTCT clinic at the hospital.

The study was done in Buyaga County and generalising its findings to cover the whole district and other areas has to be done with caution because the views and challenges faced by these mothers could be peculiar to Buyaga County.

Not withstanding the aforesaid limitations however, the researcher stimulated responses by building good rapports with individual respondents. The research team worked closely with health workers at the hospital and members of the association of PLWAs who willingly participated and provided the required information thus giving value to the study. The researcher is convinced that the methodology and tools used in the study yielded reasonable and satisfactory out come for the purpose of the research.

## **CHAPTER FOUR**

# **FINDINGS**

#### 4.0. Introduction

This chapter presents the findings of the study. The findings are presented and interpreted basing on the objectives of the study and are discussed in view of the literature reviewed. The findings are presented in sections that cover; Socio-demographic characteristics of mothers: Awareness about MTCT of HIV transmission through breastfeeding; Factors promoting continued breastfeeding among mothers enrolled in the PMTCT clinic and supportive interventions to positive mothers to reduce infant infection through breastfeeding.

# 4.1. Socio Demographic Characteristics of mothers

Socio-demographic characteristics of mothers were considered to enable the analysis and for the purpose of the study, age, marital status, number of children, educational levels and economic activities of mothers were selected as variables for analysis.

Table3: Age, Marital status, Number of children and education levels of mothers

Characteristic	Frequency	Percentage
Age		
18-25	40	61.5
26-33	20	30.8
34-41	5	7.7
Total	65	100.0
Marital status		
Married	52	80.0
Single	8	12.3
Divorced/separated	4	6.2
Widow	1	1.5
Total	65	100.0
Number of children		
1-2	47	72.3
3-4	8	12.3
First pregnancy	5	7.7
None	5	7.7
Total	65	100.0
Education levels of mothers		
None	11	16.9
Primary education	45	78.4
UCE	7	10.8
UACE	2	3.0
Tertiary/Diploma certificate	0	-
Graduate	0	-
Total	65	100.0

# Age of the mothers:

The findings show that most mothers (61.5%) are young and within the age group of 18-25 years and half of this proportion (30.8%) are aged between 26-33 years. There are few older mothers represented by (7.7%) and these fall in the age bracket of 34-41 years. Given the HIV prevalence of 6.2% among the population in Buyaga and MTCT HIV prevalence of 5.8% in the hospital sentinel site, most pregnant mothers are within the sexually active age bracket making them potentially prone to HIV infection.

#### Marital status of the mothers:

(80%) of the mothers in the cohort are married with (12.3 %) still single. (6.2 %) of the mothers had divorced and (1.5 %) are widowed. The average age of marriage for the cohort was 17.5 years indicating early marriage. The age at first married may be associated with the high spread of HIV because it implies early sexual involvement, marriage and early exposure to the risk of HIV infection.

# Number of children per mother:

Most mothers are of the age 18-25 years age (72.3%), have an average of 1-2 children aged below five years and this explains the district fertility rate of 7.9. Given that mothers get married early, (at the ages of 17.5-25) and coupled with the high MTCT prevalence rate of (5.8%), most mothers therefore have young children that they are likely to breastfeed hence infecting them with HIV. A small proportion of mothers (7.7%) reported to be on their first pregnancy.

#### **Education levels of the mothers.**

A majority of mothers (78.4%) are educated up to primary although (16.9%) has never gone to school at all. Generally, few mothers (10.8%) have reached secondary school level and only (3.8%) have some kind of a certificate. Mothers associated low education levels to early school dropping out due to early pregnancies and this explains the early marriages as reported by (12.3 %.) of the mothers. This result shows that most mothers cannot read or write properly. Mothers reported that some times they do not understand what they are told during the counseling sessions due to their low education and this puts them at a disadvantage when making decisions about child feeding.

# **Economic activities of mothers**

Table 4: Economic activities, income ranges and income planning

Characteristic	Frequency	Percentage		
<b>Economic activities</b>	Economic activities			
Cultivation	46	70.8		
Rearing animals	2	3.1		
Brewing local beer	5	7.7		
Trading	8	12.3		
None	3	4.6		
Tailoring	1	1.5		
Total	65	100.0		
Income ranges				
20,000-30,000/=	51	78.4		
50,000-80,000/=	10	15.4		
100000/=and above	2	3.1		
Don't Know	2	3.1		
Total	65	100.0		
Responsibility for planning for the income				
Husband	32	49.2		
Wife	15	23.1		
Both husband and wife	18	27.7		
Total	65	100.0		

Most mothers in the study (70.8%) are cultivators and (12.3%) are involved in simple retail trade. (7.7%) of the mothers are involved in brewing local alcohol, (3.1%) are involved in rearing local livestock and (4.6%) are not involved in any activity of significant economic gain. Most mothers come from a peasantry background of rural nature and they engage in activities that are basically of low scale and for daily family survival.

#### Levels of income

(78.4%) of the mothers in the study reported to get between shs. 10, 000= and shs 20,000= annually while (15.4 %) earn between shs 30,000= and shs 50,000= with only a negligible proportion of (3.1 %) reporting to earn an income of shs 50,000= and above.

The average house hold incomes are low and are used to meet the entire family demands. Even among the fairly high average income level house holds, the range of 30,000= to 50,000=per month is still very low for an average family with over seven dependants as reported by the mothers. The high house hold income families that earn shs 50,000= and above represents mothers coming from stable families who have opened out publicly and have been supported.

## Planning for income

Almost half of the mothers (49.2%) reported that husbands are responsible for planning of the family finances. A considerable number of mothers (27.7 %) reported that they jointly plan for the family income with their spouses. Most mothers held a common view that men are more knowledgeable than women in financial matters.

## 4.2 Awareness about HIV transmission through breast-feeding

One of the objectives of this study was to assess awareness about HIV transmission through breastfeeding among mothers and how it influences continued breastfeeding among mothers enrolled in the PMTCT clinic. The researcher considered involvement in PMTCT program activities, knowledge about MTCT of HIV through breastfeeding, content of antenatal and postnatal information given to mothers and the perceived usefulness the information is to mothers.

To enable the analysis, the frequency at which mothers get information relating to PMTCT, the researcher considered analyzing information gaps and general knowledge among mothers about MTCT of HIV through breastfeeding.

### 4.2.1 Awareness and Involvement of mothers in PMTCT

The table below shows data collected on awareness about MTCT of HIV and involvement in the PMTCT program activities by mothers.

Table 5: Awareness and Involvement of mothers in PMTCT program

Characteristic	Frequency	Percentage		
Awareness about MTCT of HIV through breastfeeding				
Yes	58	89.2		
No	6	9.2		
Don't know	1	1.5		
Total	65	100.0		
Involvement in the progra	m			
Yes	30	46.2		
No	35	53.8		
Total	65	100.0		

Most mothers (89.2%) reported to be aware of MTCT of HIV through breastfeeding and (9.2%) reported not to be aware at all. Comparatively, (46.2 %) of the mothers are involved in PMTCT program activities and yet a bigger proportion (53.8 %) of mothers are not involved. This implies that awareness about MTCT of HIV among mothers does not necessarily translate to uptake and involvement in PMTCT program and this was reported to be among the possible reasons for continued breastfeeding among HIV positive mothers.

# 4.2.2. Awareness of mothers about HIV transmission through breastfeeding

Focus group discussions were used to examine levels of awareness, perceived spousal support, precautions mothers should take to prevent MTCT and perceived reasons for continued breastfeeding among HIV positive mothers in the community. From the focus group discussions with community representatives, the study established that there is low awareness about MTCT of HIV through breastfeeding. There is an apparent physical and information gap between the health providers and the community. For example one FGD participant among community representatives commented thus, "Health workers tell people not to reveal their sero status, they have death registers but they have never recorded a death called HIV" (PLWA in the FGD). The community representatives further reported that mothers do not disclose their sero status making it impossible to have them helped and this is one among the major causes of low awareness because mothers do not want to discuss their status.

The researcher made a comparison between involvement of mothers in PMTCT and awareness about MTCT of HIV. The findings revealed that most mothers seem to be aware of MTCT of HIV, but virtually half of the mothers interviewed (53.8%) are not involved in the program. This further re enforces the earlier finding that awareness does not necessarily translate to involvement for a number of other factors. ANC mothers in the focus group discussion for example reported that information given to them during the counselling sessions is not clear. "Health workers may think that mothers have fully understood what they are told, but this is just an assumption"

Mothers among the community representatives in the focus group discussion reported that a mother can infect her baby during pregnancy, childbirth and by breast-feeding. However, when the researcher further probed, some mothers reported that they doubt on the possibility of infecting their babies through breast milk as the discussants held a view that breastfeeding is the safest way a mother can feed her baby. One of the female religious representatives in the focus group discussion had this to say" *Until I see my baby sick, that is when I will stop breastfeeding*". (A member in FGD)

Through probing in the focus group discussions, the researcher established that most of the discussants have some knowledge about MTCT but the knowledge is not matched with concrete information about MTCT of HIV through breastfeeding. There is general awareness about the channels through which HIV gets transmitted to the baby, but because of the knowledge and information gaps, some mothers continue to breast feed exposing their babies to infection.

# 4.2.3. Information about MTCT of HIV through breastfeeding

As discussed in the previous section, mothers and the community is aware and informed about MTCT of HIV through breastfeeding but some mothers still continue to breastfeed their babies. The study saw it necessary to analyze the information mothers have regarding MTCT of HIV through breastfeeding. This was done by examining the sources of information, the content, importance of the information and the perceived gaps so as to determine what knowledge mothers have about MTCT of HIV and the breastfeeding. The findings are as shown in the table below:

**Table 6:** Sources of Information about MTCT to mothers

Sources of information	Frequency	Percent
Health workers	36	55.4
Mass media	16	24.6
Community leaders	3	4.6
All the above	9	13.8
Don't know	1	1.5
Total	65	100.0

## **Sources of information**

Over half of the mothers interviewed (55.4%) get information from health workers when they go for antenatal services. (13.8%) get information from the mass media especially the local radio stations while (3.1%) reported to get information from the community leaders. It was however noted that mothers who do not go to health facilities have limited access to information about PMTCT. Mothers reported that PMTCT information conveyed through the radio/media is not very clear, it is sometimes distorted and they can not get details about what is being said yet a substantial proportion of them (13.8%) get information through this medium.

The lower proportion (3.1%) of mothers who get information from the community leaders reveals that there are limited sources of information about PMTCT and MTCT of HIV through breastfeeding in the community. Among the 25 mothers who confessed to have continued breastfeeding, one of the key reasons reported was that there is limited information about MTCT of HIV through breastfeeding and some of them get misinformed. They further reported that some of the information is incomplete and they end up misinterpreting facts. The content of information was analyzed as presented in the table below:

**Table7: Perceived content of the information.** 

Perceived content of the information	Frequency	Percentage
Exclusive breastfeeding reduces transmission	21	32.3
Supplementary feeding Increases Risk of HIV Transmission	1	1.5
HIV positive mothers should choose breastfeeding for 6 months or not	42	64.6
To breastfeed at all		
Don't know	1	1.5
Total	65	100.0

## **Content of the information**

(64.6%) of the mothers perceive that HIV positive mothers should breastfeed for six month or not breastfeed at all. (32.3%) of the mothers understand that exclusive breastfeeding reduces MTCT of HIV and (1.5%) perceive that supplementary feeding increases the risk of MTCT of HIV for a positive mother. The reported content of the information to mothers does not emphasis the danger of breastfeeding by the HIV mothers positive. When health workers tell mothers to breastfeed exclusively for only six moths or not to breast feed at all, reportedly get confused when they are told that breastfeeding may lead to HIV infection.

**Table 8:** Perceived Importance of the information

Responses	Frequency	%
Yes	72	95.4
No	2	3.1
Non Response	1	1.5
Total	65	100.0
Content of the Information		
Informed of safe infant feeding	30	46.2
Breastfeeding is risky to the baby	36	55.4
Don't Know	1	1.5
Total	65	100.0

A majority of the mothers (95.4%) perceive that this information is important to them because they understand that breastfeeding is risky to the baby. This supports the general high level of awareness about MTCT of HIV through breastfeeding. A considerable number of mothers (55.4%) reported that the information they get from the various sources regarding PMTCT is important because they understand that safe infant feeding alternatives are available however, (43.1%) reported that they have never been informed of other safe infant feeding options for HIV positive mothers.

However, mothers reported that this perception is lacking among some of their spouses who take the program to be for the mother and her baby and this limits disclosure and sharing of sero status among couples yet this is very crucial in promoting safe infant feeding. One mother actually lamented thus, "Men usually aspire to satisfy their sexual desires minding less of the resultant effects". Mothers argued that this makes some of them to continue breastfeeding irrespective of the counseling they may have got (ANC mother)

 Table 9
 Information gaps to mothers

Problems	Frequency	Percent
Health Workers not friendly	2	3.1
Information is too difficult to understand	38	73.8
Information given in not practical	2	3.1
Awareness programs are not frequent	12	18.5
Don't know	1	1.5
Total	65	100.0

# Information gaps among mothers.

The majority of mothers (73.8%) reported that information is too difficult for them to understand and this reinforces the problem already discussed in the content of the information. A number of mothers reported that awareness programs are not frequent represented by (18.5%) while (3.1%) reported that health workers are not friendly. An equal proportion (3.1%) held the view that the information given to mothers is not practical. Some mothers argued that some of them get captured as they come to the hospital seeking for antenatal services. One mother actually admitted with the comment thus... "Some of us actually pretend that we have understood and agree to enrol in the program for convenience when in reality we are ignorant about the PMTCT program and continue to breast feed the babies." (Breast feeding mother in FGD)

A matrix was used to further analyse awareness about MTCT of HIV among mothers. This was done by making an inquiry to the perceived constraints by mothers; establishing the coping mechanisms; the perceived outcomes and their implications to the program against which possible solutions were generated as presented in the table below:

Matrix 1; Showing perceptions of mothers on low awareness about MTCT of HIV through breastfeeding and suggested solutions.

Perceived contributory	Perceived Outcomes	Coping	Implication	<b>Suggested Solutions</b>
factors to low	awareness by	Mechanism by	to the PMTCT	to low awareness by
awareness by mothers	mothers	mothers	program	mothers
-Long distances	-Fail to come for	Mothers stay	Low program up	Establish and
to health	Services. Low	Home.Use relative	take	strengthen
facilities	adherence	to help or go to	Continued	Outreach services
	-Drop outs	traditional healers	Breastfeeding	
-Stigma	-Low service uptake	-Stay at home-	-Scanty information	Increased sensitisation
	-Less adherence	-No disclosure	-Negative attitude	and mobilization of the
	-More infection	-Continue	-Misinformation	Community about
		Breastfeeding	-No support	PMTCT
				Increased male
				involvement
-Lack of	-Low adherence	-Continue Breast	-Objectives not	-Improve outreaches
Incentives	-High risk of MTCT	Feeding, Use of	achieved	-Follow up on program
	-Low child survival	Mixed feeds,	-Low program	Mothers -Home visits
		abandon	support	-Establish peer groups
-Poverty and	High risk of MTCT	-Continued	Program objectives	Economic empowerment
Limited econ	Low levels of	Breastfeeding	not achieved	of the program mothers
Activity	Adherence	-Low	Low participation	though income
		participation	In the program	generating activities

Among the perceptions mothers have about low awareness about the PMTCT program are that: The distance to the hospital is too long, mothers get tired and are not set listen to health workers. Hence they do not have ample time to understand the program. Due to stigma, some of the mothers reported that they fear disclosing their status but are forced to breastfeed to avoid community stigma. The mothers also argued there are tangible incentives to attract them to this program. They are just told not to breast feed but are not given money or anything else with which to start up. Some mothers argued that they are poor village women, just getting cow milk can sometimes be a problem. Real poverty exists and they basically engage in subsistence farming with limited sources of money. In the nut shell, the out comes of these limitations were reported by mothers to be among the factors that make some them continue to breast feed against the decision initially taken not to breastfeed at all.

Accordingly, some mothers fail to come for review in the hospital and others drop out completely leading to low service up take and low adherence to counselling instructions hence continued breastfeeding. Some mothers just stay at home or send relatives/friends to find out what is happening in the clinic while others resort to traditional healers for services as copying mechanisms. Due to these limitations, the mothers therefore continue to breastfeed and use mixed feeding normally against the choice of replacement feeding with limited disclosure to their spouses or any other relatives in the community.

The resultant effects of these limitations include: Low program up take, misinformation, negative attitude to the program and ultimately, continued breastfeeding leading to un controlled infection of babies with HIV. Mothers suggested that there is need to strengthen community out reaches to reach the villages, increase sensitization and community mobilization, follow up of mothers, and support mothers to join peer groups and empowerment economically to access income generating activities for self support.

Mothers advanced the need to create incentives to enhance more male involvement at all levels as a key entry point to awareness improvement. This to mothers could be through enacting supportive by laws, conditional registration as a requirement during antenatal reviews, couple counselling and testing, involvement of community leaders and direct male participation in the program among other interventions.

The matrix analysis above reveals some key bottlenecks that have forced mothers to continue breastfeeding and unless these factors are addressed, HIV positive mothers will continue exposing their babies to the risk of HIV infection.

# 4.3. Factors promoting breastfeeding among HIV positive mothers

The second objective of the study was to examine factors that promote breastfeeding among the mothers and how they influence continued breastfeeding among PMTCT program mothers.

# 4.3.1. Values mothers have about breast-feeding

The values mothers attach to breastfeeding were classified into the following four categories: Cultural, Economic, Psychological and child health values as presented in the table below.

Table: 10 A table showing values mothers have about breastfeeding

Values of Breastfeeding	Explanation			
Cultural	It is a natural practice			
	Normal behaviour.			
	<ul> <li>It is permissive</li> </ul>			
	Historical practice			
	Cultural requirement			
	• It is a taboo			
Economic	<ul> <li>It is free food for the child,</li> </ul>			
	• It is cheap,			
	<ul> <li>Affordable and available</li> </ul>			
	<ul> <li>It can't go bad.</li> </ul>			
	• It is sustainable			
Psychosocial	<ul> <li>Bonding between a mother and the baby</li> </ul>			
	<ul> <li>A sign of love</li> </ul>			
	<ul> <li>Gives a mother happiness</li> </ul>			
	<ul> <li>Good bringing up of a baby</li> </ul>			
	<ul> <li>A sign of a healthy mother</li> </ul>			
	<ul> <li>Family cohesion</li> </ul>			
	<ul> <li>Good parenthood</li> </ul>			
	Gives a mother respect			
Child health	<ul> <li>Breast milk is solid and complete food</li> </ul>			
	<ul> <li>Nutritive and good for babies' growth.</li> </ul>			
	Balanced diet			
	<ul> <li>Good for brain development</li> </ul>			
	<ul> <li>Protects a baby from diseases</li> </ul>			
	<ul> <li>Safe and fresh</li> </ul>			

Source: Focus group discussions

#### **Cultural values**

Breastfeeding is valued as cultural norm, it is a natural behaviour and permissive, it is a cultural requirement and a taboo. Breast-feeding is universally accepted as necessary, on demand and initiated soon after birth. The general feelings from all focus group discussions was that a mother should breastfeed her baby and these results tally with the findings of the study by Okwi (1988). (*Pg 12 Literature review.*)

#### **Economic values**

Breastfeeding has economic values. It is free; cheap, affordable and available for the baby. It does not go bad and is sustainable and this influences their child feeding behaviours. One of the ANC mothers had this to say during the focus group discussion, "Breast milk is free, cheap, and affordable and can't go bad ". Another mother also commented thus, "Amatta geibere tegagulibwa ate ndi na maingi. Omwanawange ayonke. Oba oku fa, affe". Literally meaning that breast milk is not sold and I have much. My baby should breastfeed and if it is death, let it be. These responses emphasise the economic value mothers attach to breastfeeding and shows why some mothers continue breastfeeding irrespective of the counselling they get.

#### **Psychosocial values**

Psychosocially, a breast feeding mothers is respected in the community. Breastfeeding is a sign of love and depicts a loving and caring mother. Breastfeeding leads to good bringing up of a baby and is a sign of a healthy mother, promotes family cohesion and shows good parenthood in the community. Not breastfeeding can make a mother to lose her recognition and respect in the community. One of the mothers among the PLWAs in the focus group discussion gave her testimony thus: "As I was moving out of a taxi in Kagadi town, the baby was crying and some people asked me, why are you not breastfeeding the baby, have you stolen it?"

This comment shows how the community values breastfeeding and a mother who does not breastfeed suffers such insults. PLWA'S in the focus group discussion raised concern that although HIV positive mothers feel bad to breastfeed their babies, these psychosocial values, community and family ties force them to breastfeed. One program mother shared this view citing that some of them fear not to breastfeed because they will be questioned whether the child is hers, or she doesn't have milk and sometimes she can be insulted or looked at as undisciplined or mad woman.

# **Bonding**

Breastfeeding promotes bonding and love between the mother and her baby said one of the breastfeeding mothers during the focus group discussion. This bonding determines how the mother treats her child and is important for the baby's brain development.

A mother in the ANC focus group discussion had this to say, "Okuyonkya omwana liberasanyu lya mamawo mwaana" meaning breastfeeding a baby is happiness to the mother of the baby and it is sometimes a greeting and helps to bond the wife and her mother in law as quoted from one of the mothers in the ANC focus group discussion who reported thus: one morning, her mother in law greeted her saying, "Akaana okukonkya kirungi, Webale mwana wange" meaning that the baby suckles properly, thank you my daughter. This reflects strong bondage from a mother in law.

The breastfeeding mothers in the focus group discussion argued that whereas some of them would have the desire not to breastfeed, the feeling of love and the value of losing bondage with the baby compromises the desire and they consequently continue breastfeeding their babies. This is normally seen and expressed in the desolation a mother suffers when a baby dies argued one mother during the focus group discussions with PLWAs.

Community representatives in the FGD observed that denial of breastfeeding to babies is among the causes of quarrels and fights among some families. Some mothers are denied support, become more depressed, frustrated and in extreme cases, family and marriage breakages occur, commented one of the religious leaders during the focus group discussion. One member in the FGD with community representatives confirmed that there is concern whenever a father or other close relatives find a baby crying and the poor woman may even be slapped for leaving the baby to cry. This argument is further supplemented by one of the respondents among the PLWA's focus group discussions who gave her testimony thus, "..... Takwenda kwonkya omwana waitu. Nayenda affe agende handi", meaning, she does not want to breastfeed our baby so that it dies and she goes elsewhere.

## The sex of the baby

Associated with bonding, the study revealed that the sex of the baby sometimes influences breastfeeding behaviours among mothers. An antenatal mother in the focus group discussions commented " *Eliyo omuhimbo gwo kwejunna okuzaara omwana omussajja gwo akwenda*" meaning that there is happiness in producing the right sex of a baby your husband wants and mothers argued that there will be a positive tendency to breastfeed such a baby irrespective of the sero status of the mother. On the contrary however, when the researcher probed in the discussions, a mother who delivered a kid of the non-preferred sex had this to say, "*Era Nnzaire omwojjo, baggenda okungoba*" Meaning, again I have produced a boy. They are going to chase me away. In this circumstance, mothers argued that there would be a negative tendency to breast-feed this baby. According to the researcher, this perception promotes the desire not to breastfeed and hence reduces the risk of the positive mothers infecting their babies.

#### Child health values

Mothers were asked how important they perceive breastfeeding, why they feel obliged to breastfeed and how frequently they wish to breastfeed. The findings are presented in the table below:

Table 11. Importance of breastfeeding

Importance	Frequency	%
Protects a baby from infectious diseases.	36	55.4
Major source of child nutrition	24	36.9
Reduces fertility among mothers	3	4.6
Don't know	2	100.0
Total	65	100

Source: Field study May 2004

Many mothers perceive that breastfeeding protects a baby from infectious diseases (55.4%), (36.9%) perceive that breastfeeding is the major source of child nutrition and (4.6%) reported that it reduces fertility among mothers.

Mothers reported that there is a strong association between breastfeeding and the health of a baby. They argued that breast milk is solid and complete food. It is nutritive, good for a baby's growth and brain development. It is a balanced diet, protects a baby from diseases, safe and is fresh. The mothers contended that some mothers continue to breastfeed because of the perceived need to promote the health of the baby even when they know that they expose the baby to HIV infection.

Mothers were asked whether they feel obliged to breastfeed, why they feel obliged and how frequently they wish to breastfeed their babies. The results are shown in tables 12 and 13 below.

Table 12. Perception of mothers about breastfeeding

Responses	Frequency	%	<b>Cumulative %</b>
Feeling obliged to breastfeed	57	87.7	87.7
Not obliged to breastfeed	7	10.8	10.8
None response	1	1.5	1.5
Total	65	100	100

Source: Field study May 2004

A majority of mothers felt obliged to breastfeed (87.7%) against (10.8%) who did not feel obliged. Mothers reported that because most of them feel obliged to breastfeed; there is a tendency to continue breastfeeding despite the counseling they get. The reasons they gave are summarized in table 13 below:

Table 13. Why mothers feel obliged to breast-feed

Responses	Frequency	%
Major source of child nutrition	49	75.4
Reduces fertility	2	3.1
Demanded by society	4	7.6
Makes a mother responsible	8	12.3
Don't Know	1	1.5
Total	65	100.0

(75.4%) of the mothers reported that they feel obliged to breastfeed because milk is a major source of nutrition for the baby, (12.3%) reported that it makes mothers responsible and (7.6%) responded that it is demanded by the society. Mothers are obliged to breastfeed for the good of both the mother and to meet the expressed needs of their babies. (3.1%) of the mothers reported that breastfeeding contributes to reduction in fertility and child spacing. Although this is a small proportion, it reflects a very important value of breastfeeding as the desire to reduce fertility among HIV positive women is of particular importance in PMTCT.

**Table14.** Frequency of breastfeeding among mothers

Number of times	Frequency	Percentage
5 times a day	5	7.7
6 times a day	10	15.4
As required by the baby	39	60
Twice a day	11	16.9
Total	65	100.0

There is a close relationship between the frequency of breastfeeding and the needs of the baby. Many mothers reported that they prefer to breast feed whenever required by the baby (60%), 16.9% preferred to feed the child twice a day and 15.4% reported to prefer feeding the child for over 6 times a day. Most mothers do not have a particular timetable, routine or frequency for breastfeeding but it is determined by the need of the baby. To them, when a baby does not breastfeed, it signifies a problem either with the baby or the mother. Mothers argued that not breastfeeding would mean that a mother is not responding to the needs of the baby and hence some of them continue breastfeeding because the baby wants.

# 4.4.0 Other perceived factors that promote breastfeeding among mothers

Mothers were interviewed to find out other factors they perceive to promote breastfeeding and the findings are presented in the table below:

Table 15. Factors that promote breastfeeding among mothers

Factor	Frequency	Percent
Stigma	61	78.4
Privacy	2	3.1
Discrimination	5	7.7
Poverty	4	6.2
Don't know	3	4.6
Total	65	100.0

A majority of mothers (78.4%) reported that fear of stigma and discrimination (7.7%) respectively are the biggest factors that make most of them fail to adhere to the counseling and they continue breastfeeding. Although some of them come from poor economic backgrounds, poverty is not the major problem represented by as smaller proportion of (6.2%). The finding indicates that stigma is still very high and this makes some mothers to continue breastfeeding.

Breastfeeding is strongly valued for it's cultural, psychosocial, economic and child health values. In the context of HIV, these values have a considerable influence on the breastfeeding behaviours of the mothers and they determine the mother's desire and willingness not to breastfeed.

# 4.5 Available support for promoting safe infant feeding in the PMTCT program

The third objective of the study was to examine existing support and interventions for promoting safe infant feeding among PMTCT program mothers. Through this objective, existing incentives for mothers to join the program within the family, in the hospital and from the community were evaluated so as to ascertain what influence these incentives have on continued breastfeeding among program mothers.

The researcher was interested in finding out how spouses support their wives, frequency of the support, social networks mothers have, services mothers receive from the hospital and how often they access these services. The findings are as shown below.

# **4.5.1** Financial support to mothers from their spouses

Table 16. Financial support by spouses to mothers

Availability of financial assistance	Frequency	%
Yes	56	86.2
NO	7	10.8
Don't know	2	3.1
Total	65	100.0
Frequency of financial assistance		
Daily	4	6.2
Weekly	3	4.6
Monthly	10	15.5
Whenever needed	46	70.8
Don't know	2	3.1
Total	65	100.0
Sufficiency of financial support		
Sufficient	12	18.5
Not applicable	11	16.9
Not sufficient	40	61.5
Don't know	2	3.1
Total	65	100.0

Most mothers (86.2%) reported that they get financial and other assistance from their spouses however; this is limited to money for transport and for medical bills not specifically on issues of child feeding. (10.8%) reported that they do not get any support. (70.8%) of the mothers reported that the support is given whenever they need, the support is not sufficient represented by (61.5%) of the responses against (18.5%) who reported that the support is sufficient.

Through probing, the researcher established that some mothers fend for themselves because they are not married or they have been abandoned and this is represented by (16.9%). The study established that mothers who are members of PLWA Association constitute the big proportion of those who get support from their spouses and mothers reported that this is because they opened out and have disclosed their status.

Although mothers receive some support, it is not particularly ascribed to PMTCT. Mothers reported that there is a low incentive for adherence due fear of stigma and discrimination from the community. Further probing revealed that most mothers would not wish disclose their status and faced with this dilemma, most of them continue breast-feeding though aware of the danger of infecting their babies. This argument is supported by the fact that some mothers are less informed about PMTCT and do not necessarily seek for PMTCT services but get captured during antenatal visits as already discussed.

# 4.5.2 Social networks and community support

Many mothers (61.5%) do not have any social networks. (35.4%) of the mothers reported that they belong to some networks and support from the networks is sufficient represented by (15.4%). However, (16.9%) of the mothers reported that although they belong to some kind of networks, the support from the networks is not sufficient. A big percentage of mothers do not have any social networks and this was given as a reason as to why some HIV positive mothers continue breastfeeding disregarding its dangers to the baby.

The findings reveal that the only existing network is the association of PLWAs that basically plays the role of unifying members and for advocacy but does not have any particular undertakings for supporting positive mothers under the PMTCT. Most mothers do not have social networks to enable them substitute breastfeeding and due to lack of such supportive networks, some mothers admitted that they find themselves continuing to breastfeed as away to cope up despite the risk involved for the baby.

#### 4.5.3 Services in the PMTCT clinic

The study took interest to find out the services provided in the PMTCT clinic and what mothers perceive about these services.

# **Counseling and testing services**

Mothers reported that they receive counseling but they do not fully understand what they are told because it is done for every short time. The clinics are usually very crowded and manned by only two midwives. Mothers complained that they are confronted with many issues within a short time.

The midwives do not give them ample time to ask questions or consult. Mothers said that midwives are rude, they command and direct mothers to do what they say and mothers end up doing things they do not understand. For example, one antenatal mother reported that her blood sample was taken by the health worker and little did she know that she was being tested for HIV. Mothers reported that sometimes they agree to be tested but they bounce from the laboratory due to shortage of testing kits and reagents or, when samples are taken, results take long, get lost or are duplicated. One mother for example reported that she received both negative and positive results and she was confused until she took another test.

#### Home visits and follow-ups services

Mothers reported that some of them are being visited and followed up in their homes but this is not frequent. Health workers tend to visit mothers whose homes are near the hospital and those they personally know. Follow up services are too scarce as one mother said, "It is only when we come to the hospital that we meet the staff" (PMTCT mother). Mothers are not monitored by health workers so as to avail them the necessary support and the program is not felt in the community.

#### **HIV Health education talks on PMTCT**

Mothers reported that some health education talks are conducted at the hospital during antenatal but they are too short and mostly conducted in English a language most mothers do not properly understand. During the in-depth interviews with health workers, it clearly came out that the clinics are too busy and overcrowded. The staff are too few and do not have ample time for health education. Health education talks are not adequately delivered to mothers. From the focus group discussions with community representatives, the study reveled that information about breastfeeding alternative, replacement feeding and child nutrition are generally lacking among mothers in the community.

#### **Demonstrations on child feeding**

Mothers reported that they have never had any demonstrations on how to prepare alternative baby feeds yet some feeds are locally available. They are normally encouraged to buy alternative artificial feeds like formular which are expensive and most of them can not afford. Some mothers reported to have heard about "*Mwana mugimu*" in Mulago and felt they need this kind of project in Kibaale and some mothers expressed interest and willingness to learn how to prepare and adopt the local alternatives if supported.

# Personnel and service delivery for PMTCT

Results from in-depth interviews held with health workers revealed that trained staffs are few and the workload is heavy. One staff for example had this to say, "We have inadequate information and we sometimes guess certain things since there are no seminars or refresher courses specifically to address PMTCT issues." (Nursing aide)

There are no incentives for the staff to be devoted to the program and staff morale is low as on other staff commented thus, "Our work is to give them the information and that is all. We even don't have a source pan or a plate to conduct a demonstration for mothers". (Midwife). The ANC mothers and the health workers shared the view that the working areas are over crowded and confidentiality is compromised. The study revealed that although the hospital is supposed to provide a full PMTCT package, in reality, this is not fully done.

# Physical/Tangible benefits to mothers

From the focus group discussions, mothers reported that they are not given any tangible benefits and that PMTCT services are generally in adequate. Mothers said that they are not given tea or any kind of food. They stay for long hours and get very hungry. There are no incentives to attract them to the program. One mother actually said "the health workers use us for their researches, get their benefits but don't give us anything" (Antenatal mother).

Health workers equally reported that apart from the counseling and the treatment they give to mothers, the program does not provide any physical incentives that would attract mothers to the program. Some mothers get demotivated discouraged and this makes some of them to continue breastfeeding their babies exposing them to HIV infection risk.

# 4.5.4 Perception of mothers about PMTCT services

A majority of the mothers perceive that PMTCT services are not accessible to them. The reasons mothers advanced in support of this perceptions are that they face transport problems and services are expensive. However, some mothers perceive that the PMTCT services are available and these mainly consisted of mothers who are members of association of PLWAs.

Community representatives on the other hand reported that PMTCT services are not pronounced in the community. Mothers are less aware about the services and this makes them perceive that the services are not available. It is until they visit the hospital that they get to know about the services. Access to PMTCT services is also limited to mothers because of the perceived long distance to the hospital and some mothers choose to stay home because of the perceived high costs of the services.

#### 4.6 Interventions for promoting safe infant feeding among mothers

Using matrix analysis, the study undertook to find out the understanding of mothers about channels of HIV infection, perceived spousal assistance, suggested precautions and reasons for continued breastfeeding from the community.

# 4.6.1 Perceptions of mothers about channels of MTCT of HIV through breastfeeding

From focus group discussions, community representatives reported that a mother can infect a baby when she is still pregnant, during childbirth and during breast-feeding. The PLWA's, ANC mothers and spouses shared the same view but added that infection can occur during cord cutting, when the mother has cracked nipples; when the mother is infected with STD/STIs like syphilis and when the baby's skin is bruised during delivery.

The ANC mothers further reported that infection can occur when the mother has sores in the nipples, when there are sores in baby's mouth, when there is poor cord management and if an injury occurs to the placenta and the baby is contaminated with blood.

The study established that there is general knowledge about the channels of MTCT of HIV/AIDS by all the categories of respondents in the focus group discussions but the discussions revealed that this knowledge is not translated into practices that promote substitution of breastfeeding for HIV positive mothers to enhance safe infant feeding.

# 4.6.2. Contribution from the spouses to support mothers.

Mothers require that husbands should support them to access and utilise services at the hospital. Men should avail and use condoms to prevent re-infection. The husbands/spouses should support mothers to access prompt and proper diagnosis as well as treatment of opportunistic infections.

Among the spouses themselves, the findings were that there is need to be faithful to mothers, assist mothers to go to hospital early, give care and encourage mothers to deliver in health facilities where they can be attended by trained medical personnel. Where as the findings in the perceived required spousal assistance seem to indicate that there are interventions to support mothers and the community is aware of what mothers need, mothers argued that this is not in practice and it is why some program mothers continue breastfeeding.

# 4.6.3. Suggested precautions for mothers to prevent MTCT of HIV through breastfeeding.

Mothers suggested a number of precautionary measures to prevent MTCT of HIV and they include: Faithfulness of Couples to each other, open discussion about HIV and information sharing about safe infant feeding with HIV positive mothers. Mothers strongly suggested that mothers and pregnant women should be encouraged to seek for voluntary counselling and testing together with their male partners. The results should be known and shared right from the start to improve on disclosure and reduce stigmatisation of mothers. They argued that this will encourage the male partners to take responsibility and contribute willingly towards the welfare of the mothers as opposed to them being tested alone where some of them do not disclose their status to their partners.

Mothers further suggested that it is easier to breastfeed exclusively for a short time (three months) than not to breastfeed at all given the psychosocial, economic and child health values associated with breastfeeding. Avoiding mixed feeding with other options seems simple but is not very practical among mothers given the interaction of these socio cultural factors. Given the local settings and due to factors of non availability and costs involved in replacement feeding mothers find themselves continuing to breast feed against their will. Mothers suggested that seeking early and prompt treatment is very necessary and possible with support from the spouses, friends and the community in as long as the health status of the mother is known.

Mothers argued that there is need for a deliberate effort to encourage men to support HIV positive mothers in the PMTCT program. This will help in demystify the perception that the program is only for mothers and their babies. Discussants in all the focus groups shared the view that mothers should seek for constant medical reviews, proper diagnosis and prompt treatment of opportunistic infections to improve on their health and that of the baby.

All the FGDs findings were in agreement that mothers should attend antenatal care and deliver from a health facility, positive mothers should not share sharp objects with their babies and it clearly came out from the FGD discussions that infected mothers should use all possible prevention measures including use of condoms to prevent further infection.

Community representatives in the FGD stressed that mothers should be enabled to access information about MTCT of HIV with emphasis on the dangers of breastfeeding through community sensitization. Services should be taken nearer to the people through outreaches and mothers who have not yet tested be encouraged to do so.

## 4.6.4. Perceived reasons for continued breastfeeding among mothers

Antenatal mothers from the focus group discussion reported that the fear of stigma and discrimination is a prime factor that makes most mothers to continue breastfeeding because they fear to share information or disclose their sero status as stigma is still very rampant in the community.

The PLWA mothers reported that some of them fear to be blamed and denied support including breakages in relationships because they get suspected of being sick when they are seen not to breastfeed and sometimes they get frustrated as quoted from one of the discussants, "Some mothers get frustrated and keep the baby on the breast so that they die together" (Discussant among PLWA). Community representatives shared this view when one of the discussants observed that some mothers are just frustrated and have I don't care attitude so they don't mind whatever happens to the baby (Vice chair person LCI/Secretary children affairs)

Mothers reported that low education is among the factors for their continued breastfeeding. One of the discussants among the ANC mothers had this to comment, "..Itwe tetusomere munno.." (ANC mother) and because of this low education, some of them do not understand what they are taught and often fear to ask questions. This was evidenced during the FGD discussion with ANC mothers when one of them expressed doubt as to whether really a mother can infect her baby with HIV when she breastfeeds thus, "..Until I see my child sick that is when I will stop breastfeeding..,"

The PLWA mothers also observed that some of them are still attached to the taboos and seek for services from herbalists who discourage them from seeking for services from the hospital. To this effect, one of the mothers expressed a feeling that this gap between knowledge and information makes some mothers to continue breastfeeding.

PLWA mothers who are members of the association reported that not breastfeeding or use of alternative artificial feeds is safer for the baby but they argued that these interventions are expensive. Some mothers perceive that the costs involved in substituting breastfeeding with other alternatives are very high and they can not afford and that is why some of them continue breastfeeding.

Mothers reported that there is low spousal involvement in PMTCT activities and this makes some of them to continue breastfeeding because they are not supported by their husbands. Mothers argued that most of them go to the hospital alone and they keep whatever information they get to them selves for fear of stigma and denial. Some spouses in the focus group discussion held the perception that they do not accompany their wives to hospital because of poverty and this is why some mothers continue breastfeeding however, there was an argument among the spouses themselves that some of them do not support to their wives blaming it on poverty yet they use the money they get for drinking alcohol.

Some of the discussants among the spouses admitted that most men are ignorant about PMTCT and their wives seek for services from the local medicine men just like the PLWAs had reported. This argument was further shared with some of the discussants from the community representatives who held that some taboos are still strong in the community. While quoting an option like expressing milk from the mother's breast, one of the discussants argued that this is against their taboo and strongly condemned it as quoted... "How does a woman begin expressing milk from her breast?. She must be a witch!" (Religious leader in FGD).

PLWA mothers reported that men focus less on real reproductive issues but just want to satisfy their sexual desires and do not care of their sexual behaviour outcomes. The ANC and PLWA mothers hold a perception that men feel the program is for mothers and not necessarily for the father "Mother to child", yet this is an issue of concern for both parents and the community in general.

Community representatives reported that information about PMTCT is inadequate though there is general knowledge about HIV. It also became evident from the discussion with PLWA's that they have general information about HIV/AIDS transmission but they lack adequate knowledge about MTCT of HIV through breastfeeding and they identified this to be among the contributory factors to continued breastfeeding among program mothers.

Health workers from in-depth interviews reported that there is low community involvement in PMTCT activities. There are few sites that are actively implementing PMTCT services. Almost all the staff who were interviewed reported that the services are concentrated in the hospital and not much emphasis has been put to mobilise the communities about PMTCT as a program.

The Health workers further reported that they do not have money for conducting demonstrations where they would teach mothers how to prepare local alternative feeds yet this would be the basis for home visit follow ups. Health workers further reported that most interventions have tended to focus on the clinical aspects of infection and how to prevent it but less on the social and psychological effects of the infection to the affected person. In support of this argument, the medical officer for example commented that a positive HIV diagnosis has a powerful and often devastating impact on the life and coping mechanisms of a mother and her family. Unless these social issues are addressed then mothers may continue breastfeeding risking their babies with infection.

#### **CHAPTER FIVE**

## SUMMARY, CONCLUSION AND RECOMMENDATIONS

# 5.0 Summary

Breastfeeding is the natural and healthy way mothers should feed their infants but great concern has arisen about breastfeeding because the HIV virus can get transmitted from the positive mother to her baby when she breastfeeds the baby. Despite the fact that positive mothers are counselled on safe infant feeding methods and discouraged from breastfeeding under the PMTCT program, most mothers have continued to breastfeed their babies exposing them to the risk of HIV infection. The overall objective of this study was to establish factors that make HIV positive mothers who have been counselled and enrolled in the PMTCT program, continue breast-feeding their babies exposing them to the risk of HIV infection in order to promote child survival in Kibaale district.

The study focused on awareness about MTCT of HIV through breastfeeding, factors promoting breastfeeding among mothers and support to HIV positive mothers in order to promote child survival in the community. It enabled the researcher to directly interact with the infected and affected families and, to appreciate the plight and the challenges mothers meet in bringing up children in the context of HIV/AIDS.

# 5.1 AWARENESS ABOUT MTCT OF HIV/AIDS THROUGH BREAST FEEDING AMONG MOTHERS.

The study established that there is general awareness about MTCT of HIV in the community but this awareness is neither backed with concrete information and knowledge about the dangers of breastfeeding to babies born by HIV positive mothers nor is it translated into interventions or practices that support reduction of infant infection among positive mothers.

There is a gap between the community and PMTCT as a program. Most mothers do not necessarily seek for PMTCT services in the health units but they get captured when they go for antenatal services. Many HIV positive mothers agree to enrol in the program for convenience not necessarily that they have fully understood the purpose and the usefulness of the PMTCT program.

The study established that there is an eminent language barrier because health workers use English that is not very well understood by most mothers. PMTCT information is concentrated among health providers and is limited to mothers who do not visit health facilities. There are no incentives to attract mothers into the program and they have to walk long distances to the hospital where some fail to come or drop out completely.

There is low male involvement in PMTCT activities and information sharing on HIV/AIDS is limited among couples leading to low disclosure of sero status among mothers hence making them less supportive to mothers on PMTCT program.

# 5.2 FACTORS PROMOTING BREASTFEEDING AMONG PROGRAM MOTHERS

#### **Cultural values**

The study established that breastfeeding is valued as a cultural norm, a natural behaviour, universally accepted, on demand and initiated soon after birth. It is believed that mothers who do not breast feed their babies are social outfits in the society, this conditionally makes mothers to continue breastfeeding despite the knowledge on its dangers to the baby.

#### **Economic values**

Economically mothers value breastfeeding because it is free, cheap, affordable and available. These makes breast feeding more friendly to mothers as compared to other infant feeding options given their poor economic status.

## Psychosocial values

Psychosocially, breastfeeding gives a mother respect; is a sign of love and depicts a loving and caring mother. It is a sign of a healthy mother, promotes family cohesion and shows good parenthood in the community. Some mothers feel that by not breastfeeding, they may be denied these values. These perceptions negatively influence mothers desire to breastfeed hence they continue breastfeeding exposing the babies to HIV infection.

#### Child health values

There exists a strong association between breastfeeding and the health of a baby. Mothers reported that breast milk is a solid and complete food. It is nutritious, good for a baby's growth and brain development. It is a balanced diet, protects a baby from diseases, safe and is fresh. Some mothers therefore continue to breastfeed because of the perceived need to promote the health of the baby even when they know that they expose the baby to HIV infection.

#### Birth control measure:

Breastfeeding also reduces fertility among mothers where desirability for reducing fertility among HIV positive mothers is of particular importance in MTCT. It is considered by mothers as one of the easier natural methods of family planning and for child spacing. With the challenges of modern methods of family planning, mothers especially those in rural areas and the non –working prefer to maintain their babies on breast milk for at least two years or so despite the fact that they are putting them at a high risk of the HIV infection.

# Attachment to the sex of the baby.

The study also established that when the wanted sex of a baby is produced, there is a positive tendency to breastfeed such a baby irrespective of the sero status of the mother. On the contrary, when a baby of the non-preferred sex is produced, there is a negative tendency to breast feed this baby and this perception promotes the desire not to breastfeed and reduces the risk of infection.

# **Mother- Baby Bondage**

Mothers value breastfeeding because it promotes bonding between the mother and her baby. Whereas HIV positive mothers would have the desire not to breastfeed, the danger of losing bondage with their babies' makes them continue breastfeeding their babies.

# **Domestic Violence and gender issues**

Breast feeding is reported as one of the indirect causes of domestic violence among families. Research findings reveal that spouses in some cases reprimand their partners/Wives when they find a baby crying and not breast fed. In extreme cases some divorce may occur. In order to avoid the related repercussions, mothers continue breast feeding babies in order to maintain harmony despite the risk of HIV infection

# Fear of stigma and discrimination

The study established that 80% of the mothers fear being stigmatized and discriminated. In order to avoid consequences related to stigma and discrimination, mothers tend to shy away from the PMTCT programs and hence they deliberately continue breasting their babies.

# 5.3. AVAILABLE SUPPORT FOR PROMOTING SAFE INFANT FEEDING AMONG MOTHERS.

#### **Individual level:**

The study establishes the need for individual HIV positive mothers to identify with the HIV infection problem and embrace the PMTCT programs. This means that the individual mothers ought to change their attitudes and perceptions relating breast feeding and seek for adequate knowledge, care and support on how to ensure HIV free babies.

# Family/Spouse level

The study established that there is low male involvement and low family support to HIV positive mothers on PMTCT program. Findings indicate that mothers who have been supported by their spouses and family members adhere to the program and lead quality life .this support is reflected in terms of accompaniment to the health facility, provision of transport, love, care and baby related items.

#### Community support and networks for mothers

The limited community support and networks for mothers as found out from the study deters many HIV Positive mothers from opening up with a fear that they will be discriminated and stigmatized. HIV Positive mothers do not see the need to identify with the PMTCT program and the resultant effect is that mothers do not access the expected care, support and referrals hence making mothers to continue breast feeding their babies as a coping mechanism.

# Health service delivery factors

PMTCT services are generally inadequate. There is a gap between mothers and the PMTCT program in terms of time, space and quality of services. Although the hospital is expected to provide a full package of comprehensive quality care and support for PMTCT, this is not possible due to shortage of trained staff, heavy workloads and low motivation. These challenges pose a dilemma to the HIV positive mothers who try to seek for the services. The observed contradictory messages from Ministry of Health like "mothers should exclusively breastfeed in the first six month" and that "HIV positive mothers should not breastfeed" represents a communication problem from the ministry to the providers, and between the providers and the beneficiaries and this was sited among the reasons for continued breast feeding among the program mothers.

#### 5.4 CONCLUSION

Awareness about MTCT of HIV through breastfeeding is very vital for the successful implementation of PMTCT program in the community. When awareness is neither backed with concrete information nor knowledge about the dangers of breastfeeding to babies born by HIV positive mothers, it becomes a challenge for the interventions or practices that support reduction of infant infection among positive mothers to yield positive results.

Therefore, where as breastfeeding is strongly valued in the community as a cultural norm with pronounced health association for the baby, our communities are faced with the challenge of transforming their values, beliefs, attitudes, practices and behaviours towards breastfeeding by appreciating the fact that HIV is an epidemic that affects all of us and the fight against its spread especially to the infants through breastfeeding is of grave concern.

Community interventions and networks to support mothers need to be enhanced with deliberate efforts to increase male support to mothers and involvement in PMTCT interventions geared towards supporting the health of the mothers and reduction in infant infection through breastfeeding is a paramount factor if child survival is to be achieved through PMTCT and the ch0ice of not replacements breastfeeding in particular.

#### **5.5 RECOMMENDATIONS**

- 1. The communities need support to out rightly fight stigma and discrimination by ensuring full ownership and involvement in PMTCT through intensive sensitization and mobilization.
- 2. Mothers need social and economic support for empowerment and to improve their capabilities for self reliance and coping skills through the provision of supportive counselling, exploration of disclosure options and drawing a forward looking family plan that enhances the involvement of all the parents and the entire community on issues of infant feeding in the context of HIV/AIDS.
- 3. There is need for meaningful and gainful involvement of HIV positive mothers and their family members in planning and implementation of child survival programs by having PMTCT services integrated into reproductive health services at policy, program, resource mobilization, management and service delivery levels targeting all women and men of reproductive age.
- 4. There is need to build on the existing structures to enable comprehensive support to mothers by facilitating access and linkages with existing services by developing a strong continuum of care that promotes networks and information sharing, capacity building and setting up a proper referral systems for HIV positive mothers in the health care system.

- 5. The PMTCT program needs to be redefined from being perceived as "Mother to her child centred" but to embrace both parents while focusing on the family and the Community as the primary sources of care and support for HIV positive mothers.
- 6. Districts and other stake holders should be encouraged and supported to conduct operational research on socio cultural issues relating to breastfeeding to generate social change that will promote child survival in the context of HIV/AIDS.

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# Appendix 1: STRUCTURED QUESTIONNAIRE FOR THE MOTHERS

TOPIC: Preventing mother to child transmission of HIV (PMTCT) through breast-feeding, the case of mothers in Buyaga County, Kibaale District

# Dear respondents/Madam,

This study is intended to analyse the factors contributing to continued breast-feeding among mothers participating in PMTCT program so as to suggest possible and appropriate intervention for preventing mother to child transmission of HIV through breast-feeding. Your information is quite crucial in order to assess those issues reiterated above. Your information will be kept with utmost confidentiality.

SECT	ION A
1.	Village
2.	Parish.
3.	Sub County.
Demo	graphic information of respondents
	Age:
	a. 18 to 25
	b. 26 to 33
	c. 34 to 41
	d. 42 to 49
	e. Above 50
5.	Marital status:
	a. Married
	b. Single
	c. Divorced/Separated
	d. Widow
6.	Occupation/Economic activities undertaken
	a. Farmer/Farming
	b. Cattle keeper
	c. House wife
	d. Civil servant
	e. Others (Specify)
7.	Level of Education
	a. None
	b. Primary level
	c. Ordinary level
	d. Certificate level
	e. Diploma level
	f. Degree level
	g. Others (Specify)
8.	Number of Children produced
	a. 1 to 5
	b. 6 to 10
	c. Above 10
	d. Others (Specify)

# **SECTION B**

# Values Associated with Breast-feeding among Mothers in PMTCT

9. Is PMTCT part of the package offered to you during your antenatal visits?
a. Yes
b. No
10. Are you aware of the objectives of this programme?
a. Yes
b. No
11. If yes, what are the objectives of this programme?
a. Prevention of mother to child transmission of HIV/AIDS through breast feeding
b. Supporting mothers with HIV/AIDS
c. Supporting orphans
d. Others (Specify)
12. Are you involved in the PMTCT program?
a. Yes
b. No
13. If yes, for how long have you been involved with PMTCT?
a. Not at all
b. One month
c. Six month
d. For one year
e. For two years
f. Others (Specify)
14. Do you breast feed or intend to breastfeed your child?
a. Yes
b. No
15. If No, why
If yes, how often would or do you breast-feed your child?
a. Once a day
b. Twice a day
c. Once a week
d. Twice a week
e. Many times a day (Specify)
f. Many times a week (specify)
16. For how long would you breast-feed your child before putting off breast-feeding?
a. For 3 months
b. For 4 months
c. For 6 months
d. For a year
e. Others (Specify)
17. How do you perceive breast-feeding?
a. Promotes the health of the child
b. Healthy for the mother
c. Not good for the mother
d. Dangerous to the child
e. Others (Specify)
18. Who determines whether you should breastfeed or not breast-feed your child?

a.	Self
b.	My husband
	Relatives
	Community
	· · · · · · · · · · · · · · · · · · ·
	Others (Specify) etermines how long should breast-feed your child?
	Self
	My husband
	Relatives
	Community
	Others (Specify)
	factors do you think influence breast-feeding among mothers with HIV/AIDS?
	Privacy
	Stigma
	Discrimination
d.	Others (Specify)
	s the major health factor associated with breast-feeding?
	Reduces diseases among children
b.	Major source of nutrition for the child
c.	Reduces fertility among mothers
d.	Others (Specify)
22. Do you	a feel obliged to breast feed?
a.	Yes
b.	No
23. If yes,	why do you feel obliged to breast-feed?
•	It is the major source of nutrition for the baby.
	Reduces fertility
	Demanded by society
	You become responsible mother
	Others Specify
	problems do you think are associated with breast-feeding?
	Transmitting HIV/AIDS to the child
	Irregular breastfeeding reduces breast milk
0.	Makes mothers vulnerable to infections.
c.	Others (specify)
u.	Others (specify)
SECTION C	
Awareness al	out HIV/AIDS transmission through Breast-feeding among program mothers
	u aware that HIV is transmissible through breast-feeding?
a. Ye	<u> </u>
b. No	
	how did you get informed?
-	By health workers
	From mass media
	Community leaders
d.	Others (Specify)
	often have you been informed about HIV/AIDS transmission through breast-
feeding	
	Very often
b.	Quiet often

d.	Rarely told
e.	Others (Specify)
	messages/information have you been told about HIV transmission through breast-
feedin	g?
a.	That exclusive breast-feeding by a positive mother reduces chances of HIV
	transmission to the child.
	Supplementary feeding increases the risk of HIV transmission to children.
	HIV positive mothers should choose either to breast-feed exclusively for six or not to breast-feed at all.
	Others (specify)
	ne information about HIV transmission through breast-feeding been helpful to you?
	Yes
	No
	how helpful is this information to you?
	I have been informed of safe infant feeding methods.
	That breast-feeding can be risky to the child's health
c.	That I should avoid catching HIV because it can also be transmitted to the child.
	Others (specify)
31. If no,	why do you think this information is not helpful to you?
a.	The information is vague, not clear
b.	There is no other choice other than breast-feeding
c.	The information given to us is technical to understand and apply
d.	Others (specify)
32. What	problems do you find with obtaining the information about HIV transmission
	gh breast-feeding?
_	The health workers are not friendly
	The information given is too technical to understand
	The information given is not practically helpful
	The awareness programs are not frequent
	Others (specify)
SECTION D	:
Socio-econon	nic characteristics of mothers enrolled in the PMTCT program
	economic activities do you undertake in your home?
	Cultivating
	Rearing cattle, goats, chicken
	Brewing local beer
	. Trading
	l. Others (specify)
34. How 1	much income does your economic activities produce a month?
a.	Between 20,000= and 50,000=
	Between 60,000= and 100,000=
c.	Between 150,000= and 250,000=
	Above 300,000=
35. Who i	s responsible for planning for this income?
a.	Husband
h	Wife

c. Often

c. Together as husband and wife

	d.	Others (specify)
36.		the husband who controls the income, why is it so?
		He is the head of family and therefore the planner
		Gender inequality
		It is the social order of society
		He has knowledge of financial management
		Others (specify)
37	If it is	the wife who controls the income, why is it so?
57.	a.	
		It is agreed on by both husband and wife
		The husband is a careless financial controller
		Others (specify)
38.		u think the money you are getting monthly is enough to meet your family needs?
	•	Yes
	b.	No
39.	If no,	how does the insufficiency of your income affect your well being as a
	Mothe	er who is breast-feeding/or expectant?
	a.	Poor feeding
	b.	Insufficient breast milk
	c.	Diseases
	d.	Quarrels between husband and wife
		Sick child.
		Others (specify)
40.	How o	lo you relate with your husband economically?
	a.	Very well
	b.	Well
	c.	Quite well
		Not well at all
41.	-	in your answer in Question 39 above
		Gender inequality
		We share our income
		There are imbalanced power in controlling finances in favour of the husband
		Access to finances in barred by my husband
4.0	e.	Others (specify)
42.		u get financial support from your husband?
		Yes
12		No
43.	•	how often do you get the support?
		Daily
		Weekly
		Monthly
		Whenever in need
11		Others (specify)
44.		support you get sufficient for you as a mother?
		Yes No
15		NO u have any social networks to help you financially
_ 1		

b.	No
46. If yes,	how often do you secure financial support from these social networks?
•	Very often
b.	•
c.	Others (Specify)
	support you get from the social networks sufficient for your needs?
	Yes
b.	No
48. What f	inancial constraints do you get when you declare your HIV/AIDS status?
	Family discord
	Denial of economic support
c.	Poor relations between husband and wife
d.	Others (specify)
SECTION E:	
	port for mothers to promote safe infant feeding
8 11	
49. What p	postnatal services do you receive about safe infant feeding?
a.	Proper feeding for generating breast milk
b.	Checkups to avoid breast-feeding related diseases
c.	General cleanliness
d.	No services given to us
	Others (specify)
	ften do you access the above services regarding safe infant feeding?
	Very often
	Quite often
	Not often at all
	Others (specify)
	o you think you access the services the way you do?
	They are quite not easily available to us
	They are easily available
	They are not easily accessible due to transport problems
	We are poor people yet they are expensive
	We do not think these services are necessary to us
f.	Others (specify)
	etermines when you should get post-natal services regarding infant feeding?
	Myself My byshard
	My husband The Doctor
	The Doctor Others (greeify)
u. 52 Do voi	Others (specify)
•	Yes
	No
	what post-natal services do you receive concerning safe infant feeding?
•	
55. What p	problems do you experience in accessing safe infant feeding in you area?
a.	Discrimination
	Poverty
	Inaccessibility due to long distances
d.	We don't know whether or not such services exist

a. Yes

e.	e. Others (specify)										
56. What	suggestions	would	you	give	to	improve	the	PMTCT	program	in	this
area											

Thank you for your cooperation.

# Appendix 2: INTERVIEW SCHEDULE FOR HEALTH WORKERS

Dear respondent,

I am carrying a study on the prevention of mother to child transmission of HIV/AIDS (PMTCT) through breast-feeding in Buyaga County, Kibaale District. The main objective of this study is to examine factors contributing to continued breast-feeding among PMTCT program mothers so as to suggest possible and appropriate interventions for promoting the program in the district. The specific objectives are:

- 1. To assess the level of awareness about HIV/AIDS transmission through breast-feeding among PMTCT program mothers in Buyaga County.
- 2. To find out the factors promoting breastfeeding among mothers in the PMTCT program in Kibaale
- 3. To find out available support for promoting safe infant feeding among PMTCT program

The study seeks your expert views, opinion, attitudes and experiences on the factors that contribute to the continued breast-feeding among mothers participating in PMTCT program. This study is a requirement for the award of a Master of Arts in Social Sector Planning and Management of Maker ere University. I am aware of your busy schedule, but because of your vast knowledge and experience, I thought it necessary to select you for the study. I kindly ask you to grant an interview with you. Note that the information you give will be treated with confidentiality. I am grateful to you for sparing your time to listen to me in this interview.

#### **SECTION A:**

#### Background information about the respondent

1.	Name (Optional)
2.	Age
3.	Sex.

4.	Department
5.	Your current position.
6.	Period you have occupied this position.
SE	CCTION B:
Va	lues associated with breastfeeding among mothers in PMTCT
7.	How long have you been involved with PMTCT?
W	That are the objectives of PMTCT?
8.	Do you think these objectives have been achieved? Explain your answer:
9.	What are the common values associated with breast-feeding among mothers in the PMTCT
pro	ogram in Kibaale?
10	. How have these values proved a hindrance to achievement of PMTCT objectives?
11.	. How can the hindrances in 8 above be best managed?
SE	CCTION C
Av	vareness about HIV/AIDS transmission through breast-feeding
12	How is information on PMTCT disseminated in this community?
13.	Briefly explain how the information dissemination is organised in Buyaga
coı	mmunity
14	Briefly give your view about the PMTCT information dissemination in Buyaga community.
15	How have you been organising these campaigns
SE	CCTION D:
So	cio-economic characteristics of mothers in the PMTCT program
16	What are the common economic activities the mothers enrolled in the PMTCT program in
Bu	yaga?
	What is your assessment on the economic status of the PMTCT program mothers in Buyaga?
17	Comment about gender equality on financial matters among families in Buyaga county
	.What are the socio-economic constraints that are common among mothers in the PMTCTC
pro	ogram in Buyaga?

- 19. What effects could these constraints have on PMTCT services delivery to the program mothers?
- 20.Suggest possible solutions to these constraints that are applicable to the local setting of Buyaga.

# **SECTION E:**

# Existing support for mothers to promote safe infant feeding

20.	hat are	the	availab	le materna	l and	child	services	in	Buyaga	county?
21.	How	is t	the or	ganisation	of t	he pr	ovision	of	these	services?
				essibility of t			the benefic	ciaries	in Buyag	a county?
23. Is	s there an	y suppo	ort given	to mothers to	promote	e safe in	fant feedin	g?		
Give r	easons fo	or your a	answer							
24. I	24. How would you assess the effectiveness of these services in promoting safe infant									
feeding	g?									
25.	What pr	oblems	are ass	ociated with	the ex	sisting s	services fo	r mo	thers in	PMTC T
progra	ım?	•••••								
				ould you sug		improve	PMTCT	throug	gh breast-	feeding in
27. V	What gen	eral co	mments	would you n	nake reg	arding I	PMTCT in	nplem	entation i	n Buyaga
County	y?									
Thank	you for	your co	operation	1						

# **Okello Peter Odeke**

# **Appendix 3:** Focus Group Discussion guide for ANC mothers

#### 1. Self-introduction:

- a) Researcher;
- b) Members of FGD;

# 2. Introducing the topic and its objectives

This is a study on Prevention of Mother to Child Transmission of HIV/AIDS, and its main objective is to examine the factors contributing to continued breast-feeding among PMTCT program mothers so as to suggest possible and appropriate interventions for promoting the Program in Kibaale district. The specific objectives are:

- 1. To assess the level of awareness about HIV/AIDS transmission through breast-feeding among the PMTCT program mothers in Buyaga County.
- 2. To determine factors promoting breast feeding among PMTCT program mothers.
- To find out available support for promoting safe infant feeding among PMTCT program mothers in Buyaga.

As potential mothers who may have to enrol on the PMTCT program, you have been considered for this study to give your views, aspirations, experiences, knowledge and opinions about the program in order to meet the study objectives.

## 3. Procedure:

In this discussion we shall look at the following: Values associated with breast-feeding mothers in PMTCT, awareness about HIV/AIDS transmission through breast-feeding, socio-economic characteristics of mothers and existing Support for mother for promoting safe Infant feeding. The information will be for the purpose of the study and will be treated with at most confidentiality and, your personal identity will not feature anywhere.

In this discussion, each individual is expected to freely express her opinion and knowledge on the topics and one topic will be discussed at a time to enable orderly and effective recording. The discussions are expected to last not more than two hours.

I therefore welcome you to participate in the study and wish to thank you in advance for your cooperation.

#### **Section One**

# 1. Values associated with breast-feeding mothers in PMTCT:

It is known that whenever a child is produced the mother has to breastfeed that child.

- a) Why do mothers' breastfeed their children?
- b) When after delivery, do mothers begin breast-feeding their children?
- c) What factors influence initiation of breast-feeding among mothers in this community?
- d) How frequent do mothers breast-feed their children in your community?
- e) What factors influence the frequency of breast-feeding among mothers?
- f) For how long do others breast-feed their children?
- g) What factors influence the duration of breast-feeding among mothers?
- h) At what age do mothers introduce supplementary feeds to their children?
- i) Why?
- i) What are some of the problems associated with breast-feeding?
- k) What are the factors that promote breast-feeding among mothers?

#### **Section Two**

# 2. Awareness about HIV/AIDS transmission through breast-feeding

It is known that an HIV positive mother can transmit the HIV/AIDS virus to her baby.

- a) What are the possible ways that this can happen?
- b) How can mothers prevent transmitting the virus to their children?
- c) Under the program, mothers are advised on safe infant feeding practices and some precautions are suggested. What are these precautions?
- d) What are the reasons as to why some mothers have continued to breast-feed despite the advice and precautions given?
- e) Given the reasons advanced in 3.4 above, what advice do you give these mothers?

#### **Section Three**

#### 3. Socio-economic characteristics of mothers

Women are expected to contribute to the socio-economic well being their families.

- a) What economic activities do women in this community undertake?
- b) What constraints do you face when carrying out this economic activity?
- c) Does this economic activity enable you to meet the family requirements?
- d) Suggest ways in which mothers can improve on their socio-economic situations.

# **Section Four**

# 4. Available Support for mother for promoting safe Infant feeding

PMTCT services are available to help mothers promote safe infant feeding.

- a) Where do mothers get these services?
- b) How often do mothers get these services?
- c) Comment on the way these services are provided in view of staff, infrastructure and other resources.
- d) Suggest ways through which these services can be best provided.
- e) Are there any comments you have?

Thank you for your cooperation

# **Appendix 4:** Focus Group Discussion guide for Spouses

#### 1. Self-introduction:

- a) Researcher;
- b) Members of FGD;

# 2. Introducing the topic and its objectives

This is a study on Prevention of Mother to Child Transmission of HIV/AIDS through breast-feeding, and its main objective is to examine the factors contributing to continued breast-feeding among PMTCT program mothers so as to suggest possible and appropriate ways for promoting the program in Kibaale district.

# 3. The specific objectives are:

- 1. To assess the level of awareness about HIV/AIDS transmission through breast-feeding among the PMTCT program mothers in Buyaga County.
- 2. To determine the factors promoting breastfeeding among mothers in the PMTCT program in Buyaga County.
- 3. To examine available support for promoting safe infant feeding among PMTCT program mothers in Buyaga.

As spouses to mothers who are enrolled in the PMTCT program, you have been considered for this study to give your views, experiences, knowledge and opinions about the program in order to meet the study objectives.

#### 4. Procedure:

In this discussion we shall look at the following: Values associated with breast-feeding among mothers in the PMTCT program, awareness about HIV/AIDS transmission through breast-feeding, socio-economic characteristics of mothers and existing Support for mother for promoting safe infant feeding. The information you give will generally be for the purpose of this study and will be treated with at most confidentiality and, your personal identity will not feature anywhere.

In this discussion, each individual is expected to freely express his opinion and knowledge on the topics and one topic will be discussed at a time to enable orderly and effective recording. The discussions are expected to last not more than two hours. I welcome you to participate in the study and wish to thank you in advance for your cooperation.

# 1. Values associated with breast-feeding mothers in PMTCT:

It is always known that whenever a child is produced the mother has to breastfeed that child.

- a) Why do mothers' breastfeed their children?
- b) When after delivery, do mothers begin breast-feeding their children?
- c) What factors influence initiation of breast-feeding among mothers in this community?
- d) How frequent do mothers breast-feed their children in your community?
- e) What factors influence the frequency of breast-feeding among mothers?
- d) For how long do others breast-feed their children?
- e) What factors influence the duration of breast-feeding among mothers?
- f) At what age do mothers introduce supplementary feeds to their children?
- g) Why?
- h) What are some of the problems associated with breast-feeding?
- i) What are the factors that promote breast-feeding among mothers?

#### 2. Awareness about HIV/AIDS transmission through breast-feeding

It is known that an HIV positive mother can transmit the HIV/AIDS virus to her infant/child.

- a) What are the possible ways that this can happen?
- b) How can men help the mothers to prevent transmitting the virus to their children?
- c) Under the PMTCT program, HIV positive mothers are advised on safe infant feeding practices and some precautions are suggested. What are these precautions?
- d) What are the reasons as to why some mothers have continued to breast-feed despite the advice and precautions given?
- e) Given the reasons advanced in 3.4 above, what advice do you give these mothers?

#### 3. Socio-economic characteristics of mothers

Women are expected to contribute to the socio-economic well being their families.

- a) What economic activities do women in your community undertake?
- b) How significant is women's contribution to family well being in your community?

- c) What constraints do women face when carrying out economic activities in your community?
- d) Suggest ways through which mothers can be helped to improve their socio-economic status in your community.

# 4. Available support for promoting safe Infant feeding in the PMTCT program

PMTCT services are available to help mothers promote safe infant feeding.

- a). Where do mothers get these services in your community?
- b) How often do mothers get these services?
- c). How do men in your community help mothers to access PMTCT services?
- d). Comment on the way these services are provided in view of staff, infrastructure and other resources.
- e) Suggest ways through which these services can be best provided.
- f). Are there any comments you have?

Thank you for your cooperation

**Okello Peter Odeke** 

# **Appendix 5:** Focus Group Discussion guide PLWAs

#### 1. Self-introduction:

- a) Researcher;
- b) Members of FGD;

# 2. Introducing the topic and its objectives

This is a study on Prevention of Mother to Child Transmission of HIV/AIDS through breast-feeding, and its main objective is to examine the factors contributing to continued breast-feeding among PMTCT program mothers so as to suggest possible and appropriate ways for promoting the program in Kibaale district.

# 3. The specific objectives are:

- 1. To assess the level of awareness about HIV/AIDS transmission through breast-feeding among the PMTCT program mothers in Buyaga County.
- 2. To find out factors promoting breastfeeding among PMTCT program mothers in Buyaga.
- 3. To examine available support for promoting safe infant feeding among PMTCT program mothers in Buyaga.

As mothers who are enrolled in the PMTCT program, you have been considered for this study to give your views, experiences, knowledge and opinions about the program in order to meet the study objectives.

#### 4. Procedure:

In this discussion we shall look at the following: Values associated with breast-feeding among mothers in the PMTCT program, awareness about HIV/AIDS transmission through breast-feeding, socio-economic characteristics of mothers and existing Support for mother for promoting safe infant feeding. The information you give will generally be for the purpose of this study and will be treated with at most confidentiality and, your personal identity will not feature anywhere.

In this discussion, each individual is expected to freely express his opinion and knowledge on the topics and one topic will be discussed at a time to enable orderly and effective recording. The discussions are expected to last not more than two hours. I welcome you to participate in the study and wish to thank you in advance for your cooperation.

#### 1. Values associated with breast-feeding mothers in PMTCT:

It is always known that whenever a child is produced the mother has to breastfeed that child.

- a) Why do mothers' breastfeed their children?.
- b) When after delivery, do mothers begin breast-feeding their children?
- c) What factors influence initiation of breast-feeding among mothers in this community?
- d) How frequent do mothers breast-feed their children in your community?
- e) What factors influence the frequency of breast-feeding among mothers?
- f) For how long do others breast-feed their children?
- g) What factors influence the duration of breast-feeding among mothers?
- h) At what age do mothers introduce supplementary feeds to their children?
- i) Why?
- j) What are some of the problems associated with breast-feeding?
- k) What are the factors that promote breast-feeding among mothers?

# 2. Awareness about HIV/AIDS transmission through breast-feeding

It is known that an HIV positive mother can transmit the HIV/AIDS virus to her infant/child.

- a) What are the possible ways that this can happen?
- b) How can men help the mothers to prevent transmitting the virus to their children?
- c) Under the PMTCT program, HIV positive mothers are advised on safe infant feeding practices and some precautions are suggested. What are these precautions?
- d) What are the reasons as to why some mothers have continued to breast-feed despite the advice and precautions given?
- e) Given the reasons advanced in 3.4 above, what advice do you give these mothers?

#### 3. Socio-economic characteristics of mothers

Women are expected to contribute to the socio-economic well being their families.

- a) What economic activities do women in your community undertake?
- b) How significant is women's contribution to family well being in your community?
- c) What constraints do women face when carrying out economic activities in your community?
- d) Suggest ways through which mothers can be helped to improve their socio-economic status in your community.

## 4. Available Support for promoting safe Infant feeding in the PMTCT program.

PMTCT services are available to help mothers promote safe infant feeding.

- a) Where do mothers get these services in your community?
- b) How often do mothers get these services?
- c) How do men in your community help mothers to access PMTCT services?
- d) Comment on the way these services are provided in view of staff, infrastructure and other resources.
- e) Suggest ways through which these services can be best provided.
- f) Are there any comments you have?

Thank you for your cooperation

Okello Peter Odeke

# **Appendix 5:** Focus Group Discussion guide Community representatives.

#### 1. Self-introduction:

- a) Researcher;
- b) Members of FGD;

# 2. Introducing the topic and its objectives

This is a study on Prevention of Mother to Child Transmission of HIV/AIDS through breast-feeding, and its main objective is to examine the factors contributing to continued breast-feeding among PMTCT program mothers so as to suggest possible and appropriate ways for promoting the program in Kibaale district.

# 3. The specific objectives are:

- 1. To assess the level of awareness about HIV/AIDS transmission through breast-feeding among PMTCT program mothers in Buyaga County.
- To find out factors promoting breast-feeding among mothers in the PMTCT program in Buyaga County.
- 3. To examine available support for promoting safe infant feeding among PMTCT program mothers in Buyaga.

As Community representatives, you have been considered for this study to give your views, experiences, knowledge and opinions about the program in order to meet the study objectives.

#### 4. Procedure:

In this discussion we shall look at the following: Values associated with breast-feeding among mothers in the PMTCT program, awareness about HIV/AIDS transmission through breast-feeding, socio-economic characteristics of mothers and existing Support for mother for promoting safe infant feeding. The information you give will generally be for the purpose of this study and will be treated with at most confidentiality and, your personal identity will not feature anywhere.

In this discussion, each individual is expected to freely express his opinion and knowledge on the topics and one topic will be discussed at a time to enable orderly and effective recording. The discussions are expected to last not more than two hours. I welcome you to participate in the study and wish to thank you in advance for your cooperation.

# 5. Values associated with breast-feeding mothers in PMTCT:

It is always known that whenever a child is produced the mother has to breastfeed that child.

- a) Why do mothers' breastfeed their children?
- b) When after delivery, do mothers begin breast-feeding their children?
- c) What factors influence initiation of breast-feeding among mothers in this community?
- d) How frequent do mothers breast-feed their children in your community?
- e) What factors influence the frequency of breast-feeding among mothers?
- f) For how long do others breast-feed their children?
- g) What factors influence the duration of breast-feeding among mothers?
- h) At what age do mothers introduce supplementary feeds to their children?
- i) Why?
- j) What are some of the problems associated with breast-feeding?
- k) What are the factors that promote breast-feeding among mothers?

#### 6. Awareness about HIV/AIDS transmission through breast-feeding

It is known that an HIV positive mother can transmit the HIV/AIDS virus to her infant/child.

- a) What are the possible ways that this can happen?
- b) How can men help the mothers to prevent transmitting the virus to their children?
- c) Under the PMTCT program, HIV positive mothers are advised on safe infant feeding practices and some precautions are suggested. What are these precautions?
- d) What are the reasons as to why some mothers have continued to breast-feed despite the advice and precautions given?
- e) Given the reasons advanced in 3.4 above, what advice do you give these mothers?

#### 7. Socio-economic characteristics of mothers

Women are expected to contribute to the socio-economic well being their families.

- a) What economic activities do women in your community undertake?
- b) How significant is women's contribution to family well being in your community?
- c) What constraints do women face when carrying out economic activities in your community?
- d) Suggest ways through which mothers can be helped to improve their socio-economic status in your community.

## 8. Available support for promoting safe infant feeding in the PMTCT program

PMTCT services are available to help mothers promote safe infant feeding.

- a) Where do mothers get these services in your community?
- b) How often do mothers get these services?
- c) How do men in your community help mothers to access PMTCT services?
- d) Comment on the way these services are provided in view of staff, infrastructure and other resources.
- e) Suggest ways through which these services can be best provided.
- f) Are there any comments you have?

Thank you for your cooperation

#### Okello Peter Odeke