ASSESSMENT OF THE PSYCHOSOCIAL SUPPORT INTERVENTIONS OF THE FAMILY MODEL OF CARE OF MAKERERE UNIVERSITY–JOHNS HOPKINS UNIVERSITY RESEARCH COLLABORATION (MUJHU)

BY

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MakSPH-CDC HIV/AIDS FELLOW

2012
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JULY 2012
DECLARATION

I, Okalo Paul do hereby declare that this research report entitled assessment of psychosocial support interventions of the Family Model of Care of Makerere University-Johns Hopkins University Research Collaboration (MUJHU) was prepared by me. It was submitted in fulfillment of the requirements of Makerere University School of Public Health/Centers for Disease Control and Prevention (MakSPH/CDC) HIV/AIDS Fellowship Program and has not been submitted for any academic qualifications.

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Signed ……………………………… Date……………………………

Ms Juliane Etima
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Signed ……………………………… Date……………………………

Professor Joseph Konde Lule
Academic Mentor
Dedication

I dedicate this report to mothers living with HIV, their children and partners whose lives have been devastated by HIV/AIDS pandemic. I offer this report in solidarity with you and with the determination to contribute towards improving your wellbeing, and uphold your rights. I sincerely request all people whether infected and affected to rise and face the challenge, because this is the only way we shall work towards HIV free generations.
Acknowledgement

Special thanks go to my mentors Professor Joseph Konde Lule and Ms Juliane Etima for professional guidance throughout my fellowship. Indeed, you devoted your time and wisdom to ensure that I produce tangible outcomes. Your efforts and dedication is what enabled me to successfully complete my fellowship. I am greatly indebted to Rhoda Wanyeze and Joseph Matovu who cheerfully and patiently made my work easier and more of a pleasure than it would have been without them. My sincere thanks also go to the Centres for Disease Control and Prevention, whose financial support made this study possible.

I also want to thank the management of MUJHU for not only facilitating implementation of my activities but also for providing a conducive environment which enabled me to carry out activities that I was assigned.

I appreciate my family who missed my company especially during this study. I further appreciate Rose who typed this report. Her patience and hard work made writing this report easier, quicker and more of a pleasure than I deserved.

There are many people, not named, who have assisted with good insights, guidance and ideas. To list them all will be impossible. I ask them all, to accept my thanks offered to them generally.
Abstract

Background:
MUJHU Care has implemented a family focused model of care code named Mother To Child Transmission of HIV (MTCT) Plus since 2003. In this model, a pregnant HIV positive woman identified at antenatal clinic serves as a guide, steering her family and household members to access HIV care and treatment services in a single health facility. The overall goal of MTCT Plus is to provide life long care and treatment for HIV positive mothers, their children and partners living with HIV. To achieve this goal, peer education, psychosocial support meetings, income generating activities, infant and child nutritional education form its core tenets. These psychosocial support (PSS) interventions aim at increasing disclosure, promoting adherence and adoption of appropriate infant feeding practices.

Objectives
The aim of this study was to explore views of program participants regarding the family focused model of HIV care and PSS interventions and to understand how they influence disclosure, adherence, and adoption of appropriate infant and child feeding practices.

Methods
This was a cross sectional study involving a comparative assessment of self reported adherence to ART, disclosure of HIV status, and infant and child feeding practices among MTCT Plus program participants and non program participants. The views of respondents were solicited using interviewer administered questionnaire. The respondents included 162 randomly selected program participants, selected from the MUJHU clinic database and 162 non program participants randomly selected from ART clinic registers in Kawolo hospital, Church of Uganda Health center, Mukono health center IV and Nagalama

Results
Overall, MTCT plus program was appreciated and liked by the program participants. Among the beneficiaries, 113 (99%) of the program participants
appreciated the family model of HIV care as a good intervention, 102 (90%) said that peer education greatly benefits them, and 93 (82%) said that the psychosocial support meetings are helping them cope with the infection. Income generating activities were least appreciated with only 33 (29%) of program participants saying they derive benefits from the current income generating activities. A larger proportion of program beneficiaries 104 (96%) reported that they had disclosed their HIV status to their sexual partners compared to those that had not participated in the program 38 (23%).

A higher proportion of program participants 108 (95%) reported adhering to their medication as compared to 127 (78%) non program participants. Where as the biggest challenge reported by program participants regarding infant feeding was the cost of rapid early weaning, 51 (74%), the biggest challenge among non program participants was disclosure of HIV status 123 (42%).

**Conclusion**
This model is highly appreciated by most beneficiaries as appropriate model for HIV care. The MTCT plus (Family Model of Care) improves disclosure of HIV status and adherence, and reduces non-cost related challenges to infant feeding. The MTCT plus model was also appreciated by the beneficiaries.

**Recommendation**
The Family Model of Care should be scaled-up to improve HIV treatment and prevention outcomes for women and their families. The component of income generating activities should be reinforced, with emphasis on support for costs related to child weaning.
### Key Conceptual Definitions

**Family**

A family is defined as a group of two or more persons related by birth, marriage, or adoption and residing together (adapted from US Census Bureau, 2003). This definition is contextual and culturally relative in that communities may recognize a different meaning of “family” that may include not only members of the immediate family who reside together but members of the extended family who may live in adjacent or distant homes.

**Household**

A household includes all the persons who occupy a housing unit. Households are subdivided into family households and non-family households. The occupants may be a single family of related persons, one person living alone, two or more families living together, or any other group of related or unrelated persons who share living arrangements (US Census Bureau, 2003). This definition is relative, in that communities may recognize a different meaning of “household” based on the local context.

**Family-centered care**

Family-centered care is based on a bio-psychosocial systems approach where the primary focus of healthcare is the client in the context of their family; and, the client, family, and clinician are partners in healthcare (McDaniel et al, 2005).

**Family-centered approach**

In the context of this study, family-centered approach is defined as a comprehensive, and a coordinated care that addresses the needs of both
Comprehensive care refers to the concurrent prevention and management of multiple physical and emotional health problems of a patient over a period of time in relationship to their family, life events and environment (American Academy of Family Physicians, 2007). In the context of this paper, comprehensive care for families made vulnerable by HIV/AIDS refers to a range of quality healthcare and social support services for children and adults affected by HIV and AIDS that may range from primary health care (preventive and curative); HIV/AIDS prevention, care and treatment; food security and nutrition; formal education and vocational training support; legal support; child protection services; shelter support; household socioeconomic strengthening (includes cash transfers and livelihood support); psychosocial support; and, spiritual support.

In the context of this study, coordinated care is a system of service programs and/or service providers that are linked through a referral network(s) that is (are) (preferably) formalized or non-formalized and in which referrals made and referrals completed can be tracked and evaluated in a cost effective manner.
through efficient communication channels (Family Health International internal discussions, 2007)

Medical adherence

For the purpose of this study, the definition adopted is taking medication as prescribed (Cramer et al 2003). It is chosen as a basis for calculating the sample size because it is an important issue in clinical practice and in chronic diseases.
### Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune deficiency Syndrome</td>
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<tr>
<td>ANC</td>
<td>Antenatal services</td>
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<td>ART</td>
<td>Ant Retroviral Therapy</td>
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<td>ARV</td>
<td>Ant Retroviral drugs</td>
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<td>CTA</td>
<td>Call-To-Action</td>
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<td>COU</td>
<td>Church of Uganda</td>
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<td>FDG</td>
<td>Focused Group Discussion</td>
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<td>FMC</td>
<td>Family Model of Care</td>
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<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
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<td>MTCT</td>
<td>Mother-to-child transmission of HIV</td>
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<tr>
<td>MUJHU</td>
<td>Makerere University – Johns Hopkins University</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission of HIV</td>
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<td>PSS</td>
<td>Psychosocial Support</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>UN</td>
<td>United Nations</td>
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<td>UNAIDS</td>
<td>United Nations Program on HIV/AIDS</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children's Fund</td>
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<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session on AIDS</td>
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1.0 Introduction and background

1.1 Introduction
Mother to child transmission (MTCT) of Human Immunodeficiency Virus (HIV), also known as vertical HIV transmission is the primary cause of HIV infection in children below 10 years of age (UNAIDS 2009). While 1,700 children or more become infected worldwide, 1,600 children become infected with HIV in Sub-Saharan Africa every day (UNAIDS 2008). In most of the developing countries, the prevalence of HIV transmission from mother to child is about 30%, the highest risk of infection being at the time of birth (UNAIDS 2008).

1.2 Background
In 2001, the United Nations’ Declaration of Commitment by the General Assembly Special Session on AIDS (UNGASS, 2001) made the fight against pediatric HIV infection as a priority. It called for 50% reduction in the number of infected infants by 2010. The declaration committed member states to ensure that 80 percent of pregnant women in the antenatal care have information, counseling and HIV services. The Kampala Call-to-Action (CTA) emphasized extreme vulnerability of women and children to HIV infection and called for donors to respond rapidly with funding and development of innovative programmes to immediately address mother to child HIV transmission and treatment of HIV infected mothers and children. This was affirmed by the United Nations Special Session on Children which confirmed the urgency of global commitment to fight HIV/AIDS among mothers and infants.

Realizing that everyday there are nearly 1,800 new HIV infections in children under 5 years of age and more than 90% occurring in the developing world, the high level global partnership forum held in Abuja Nigeria in December 2005 committed UN member states to achieve the goal of an HIV free generation. WHO then designed a four pronged approach of reducing MTCT which includes the following strategies primary prevention of HIV infection among women of
childbearing age; preventing unintended pregnancies among women living with HIV; preventing HIV transmission from women living with HIV to their infants, and providing appropriate treatment, care and support to mothers infected with HIV their infants and their families.

Family Model of Care (FMC) was an initiative conceived and designed by World Health Organization (WHO) in 2001 as a response to the five-point Call to Action on HIV/AIDS issued by the then Secretary General of the United Nations (UN), Kofi Annan. It was designed to increase access to care and treatment in resource limited settings. The intervention also illustrates the effective use of antenatal care as an entry point to treatment, care and support of families. The design of the program provided for a comprehensive treatment, care and support to HIV infected women identified through programs for the prevention of mother to child transmission (PMTCT), and their HIV positive family members. This enables the family model of care to link treatment initiative to a prevention programs in order to further reduce vertical transmission of HIV and to strengthen families, communities as well as individuals.

In Uganda, the national programme goal for the prevention of mother-to-child transmission is to provide a comprehensive package of antenatal care to pregnant mothers in order to reduce the risk of HIV transmission to infants. Over the years, efforts to prevent MTCT transmission of HIV have rapidly expanded, using a well established package of low cost and effective practices, including the use of antiretroviral medications (ARVs).

In 2004, with funding from the Columbia University and Bill Gates Foundation, Makerere University–Johns Hopkins University (MUJHU Care Ltd), a joint collaboration between the two universities started implementing FMC, also referred to as the Family Model of Care (FMC). Through the FMC, MUJHU Care Ltd provides treatment, care and support aimed at improving the quality of life by providing health care for HIV infected mothers, their children and partners.
through a continuum of services, which range from patient education to HIV specific treatment. In this way, the program provides lifelong treatment and care to women living with HIV/AIDS identified through the PMTCT program, their children and partners. HIV infected women who are pregnant are the entry point to the program, and once enrolled, women are asked to bring their family members to the program. Providing maternal health is aimed at reducing the number of children orphaned by HIV. FMC is also aimed at preventing illness, to enable adults to live longer, stay healthy and continue working to support their households.

All eligible women, their infants and partners are provided with a range of healthcare benefits including diagnostic HIV testing for their family members, ART, and prophylaxis of opportunistic infections, such as TB, cryptococcal meningitis and treatment of acute infections. In addition to clinical care and treatment, the program provides peer education, psychosocial support meetings and income generating activities aimed at promoting disclosure, adherence, and follow up of the participants. FMC also provides nutritional support in form of nutritional education, in order to contribute towards reducing HIV transmission to infants by encouraging HIV positive mothers to adopt appropriate infant feeding methods.
2.0 Literature review

2.1 Family Model of Care

The effects of HIV pandemic have led to a search for appropriate programs for care, treatment, and support for people infected and affected by HIV. According to Tearfund (2008), in the past mother-child centered approach was adopted where ARV therapy was provided to only pregnant and lactating mothers in order to prevent the transmission of the virus from the mother to the baby. It was realized that this approach risked labeling women as the main bearers and transmitters of HIV virus to their babies (Attawell, 2008), and yet there was a need for comprehensive family care for the good of the mother, baby, father and the community.

The 21st Century has witnessed a realization that HIV/AIDS is a unique disease which requires exceptional interventions that are not isolated from the communities and are within the family context, because it involves complex family dynamics, sexual behavior, behavioral change and stigma. According to Attawell (2008), if progress is to be made, interventions must not focus on preventing transmission of HIV to their infants alone. They must consider preserving the health of mothers and that of their family members. Such programs will benefit from informed community involvement and support. This family model of care that was code named FMC.

What is fundamental about FMC is the family centered care which provides integrated services including clinical care, nutrition, other supportive care as well as antiretroviral therapy to HIV positive mothers and their family members. Provision of ART to eligible pregnant women living with HIV especially those with advanced HIV infection and high viral load, contributes to improved maternal health and child survival (Attawell, 2008). In addition, testing both parents increases the knowledge and understanding of the man and allows him to
take increased responsibility for his health and that of his wife, other sexual partners and his family (Attawell, 2008).

While anecdotal information indicates that the family model of care is beneficial to HIV positive mothers and their family members, little was known about the barriers that hinder the participation of all HIV positive family members in the family model of care. This study was therefore helpful in revealing whether the psychosocial interventions of the family model of care promote adherence, partner disclosure, and adoption of appropriate infant feeding practices and how it enhances social support for HIV infected women, their children and partners. In addition, this study was helpful in understanding views of the program participants about peer education, PSS meetings, income generating activities and how infant nutrition education has changed the child feeding practices of HIV positive mothers.

2.2 Social support mechanism
One of the prerequisites for effective implementation of family model of care is ability to influence behavior of participants. It is their behavior that influences participants’ adherence to ART, disclosure, and adoption of good infant feeding practices. A strategic approach to providing comprehensive family care must recognize the role of behavior change if benefits of FMC are to be maximized. This was the basis for peer education and psychosocial support groups put in place by MUJHU. This section highlights importance of social support mechanism for promoting behavioral change in order to influence adherence to ARV, disclosure of serostatus and adoption of good infant feeding practices and to make the program more effective and comprehensive.

2.2.1 Peer education
While MUJHU has put in place mechanisms for peer education aimed at influencing behavior of her participants, behavior change does not only result from increasing knowledge, because there are many contextual factors, including
the behaviors of the family and community networks which influence individual behavioral change. Creating enabling environment for appropriate behavior by addressing barriers to family care is indeed very critical. The support of the elder female members of the family who promote traditional practices associated with pregnancy and breastfeeding for example is particularly important. Understanding the goals of FMC and the commitment required for successful therapy and knowing what to do when and how are very critical if good immunological outcomes are to be achieved.

It is the knowledge of participants which influences their ability to change their behavior. This is an essential component in improving participation and adherence to interventions that form part of FMC package. However, receiving information about FMC does not automatically mean that the information is understood or believed. Moral, sexual or other belief systems can override factual information and inhibit processing of such information into knowledge and to make it actionable (UNICEF, 2001). One of the factors that negatively affect the transformation of information into action is the risk perception. The relationship between HIV information, risk perception and behavior is complex, because in a study done in Zambia, a half of the women who recently delivered and believed that they were at low or no risk of HIV infection tested HIV positive! A self assessment study of personal risk among 1,000 Antenatal Care (ANC) attendants in Kwa Zulu Natal revealed that 20% of ANC attendants said that they had other sexual partners, yet only 15% believed that they were personally at risk of contracting HIV (Ottolenghi, 2002).

UNAIDS gives an example of a survey done between 2007 and 2008 which showed that, in many countries with recent population based surveys, less than half of women and men 15-49 years old have comprehensive and correct knowledge of HIV. Inadequate knowledge about drug or ART preventive efficacy may affect the level at which women take precautions aimed at improving their lives. Since Knowledge is power, women’s attitudes and practices depend on the
way levels of risk, efficiency of ART to reduce risk, and perceived ART effects on breast milk, have been explained to them. It was therefore important that this study was done to understand whether participants understand what is expected of them and their perceptions regarding peer education offered by MUHJU.

2.2.2 Adherence to ART and disclosure
Adherence is accurate participation of an informed patient in a plan of care. It includes attending appointments and tests as scheduled, taking medication as prescribed, modifying lifestyles as required, and avoiding risk behaviors. According to WHO (2003), adherence to medication is a cornerstone of successful HIV/AIDS care and must be the focus of FMC education. However, understanding factors that influence drug or ART adherence is critical if program effectiveness has to be increased. Factors affecting drug or ART adherence include difficulty in tolerating drug side effects, difficulty integrating treatment schedule into activities of life and fear of revealing HIV status if seen taking medications (Forsythe 2002, Golin 2002, Volberding 2002). Some studies have shown that women often abandon medicine because they fear revealing their HIV status to their husbands (Attawell, 2008). In a study done in Zambia providing universal single dose NVP to all pregnant women attending ANC, 32% of the participants did not ingest the single dose NVP tablet issued to them at ANC, despite reminders and availability of replacement tablets (Stringer, 2003).

According to UNAIDS (2009), active involvement of male partners is critical to address issues related to stigma, discrimination, domestic violence and, more importantly, to support the uptake of available services. Great emphasis should be placed in couple HIV testing and counseling. In many cases, women fear to be rejected and abandoned by their husbands, which hinders them to disclose their HIV status. In Botswana and Zambia where disclosure of HIV status among pregnant women is relatively high, families and male partners are involved in decision making regarding intake of ARV (UNAIDS 2009).
Taking ARVs regularly, arriving to the health facility for delivery on time, and ensuring that the newborns of mothers living with HIV get ARV and feeding regimen they require are very critical for success of any family based model of care program. Social support has been identified as a principle coping and adjustment mechanism for HIV infected individuals (Hough et al 2003). In addition, HIV positive women who have stronger social support networks report better quality of life and self care practices (Gielen 2001). Although the family model of care was designed with the awareness that adherence to treatment and disclosure of HIV status is critical for success of individuals and the program as a whole, providers must consider barriers to disclosure and adherence (WHO, 2003).

2.2.3 Follow-up

Despite the child centered approach of many MTCT interventions, follow-up of known HIV exposed infants is a major challenge in most countries. Studies from Swaziland and Zambia which have attained a high HIV exposed infant follow-up coverage show that their strategy was to include HIV specific information on child cards to enable care workers to identify infants needing HIV testing, care and support. Mobile phones to contact mothers living with HIV and their infants were used (UNAIDS 2009). While FMC program is reported to be using the same innovative approaches like mobile phones, it is not known how their use has benefited HIV exposed infants and improved their follow-up.

2.3 Infant feeding education

Understanding attitudes and practices related to breastfeeding and perceptions associated with not breastfeeding are critical for FMC. Many African cultures have historically stigmatized women who do not breastfeed as “bad mothers”. HIV infection among lactating mothers has enhanced this stigma as described in different studies in Botswana (Rantona et al, 2000); Cote d’Ivore (Desclaux et al, 2000); Zambia (luo et al, 2000); and in Zimbabwe (Gottlieb et, 2000). There are many reasons associated with such stigma. First, women’s perceptions especially
on breastfeeding contributes to their difficulty in avoiding breastfeeding or weaning early. Women, seen as nourishing mothers, are the main actors in this practice which is traditionally a feminine domain (Bonnet, 1988). Secondly in many traditional societies, breastfeeding is a symbol of “good mothering” (Desclaux, 2002). In countries like Uganda where exclusive breastfeeding is not a usual pattern, mothers consider it necessary to feed their infants with other liquids such as sugared water, tea or juice (Becquet et al, 2005). The contrast between exclusive breastfeeding, and non exclusive prolonged maternal breastfeeding, presents an important social risk for women because they expose them to revealing their HIV positive status,

Cultural necessity of breastfeeding coupled with fear of disclosure of HIV status can cause serious deviation from expected behavior. For example, in South African ARV study, HIV positive women who were given infant formula on discharge from the hospital frequently left the formula at the hospital gate (Coutsoudis, 2002). It was also noted that some HIV positive mothers in South Africa used to give formula at home, but breast fed in public just to maintain culturally accepted breastfeeding practices (OttoIenghi, 2002). This type of mixed infant feeding is associated with the highest risk of HIV transmission. According to Desclaux et al (Eds), mothers’ perceptions about breastfeeding and ART are at the center of increased MTCT in Africa. Low observance of exclusive breastfeeding amongst mothers under ART will occur if mothers think that milk is fully protected from HIV by ART. Local understanding of physiology in Cameroon, as in many other African countries, means that the mother and the baby being related through breastfeeding, medicine taken by the mother will also treat the baby Desclaux et al (Eds). Such perceptions provide a model for understanding ARV intake and breastfeeding practices of mothers. In addition, available information and country specific studies highlight confusion about appropriate infant feeding advice to mothers living with HIV. In Ethiopia, Guatemala and India it was found that health workers often gave mothers who are HIV positive incorrect advice or no advice at all! Most health workers felt that
they should advice women living with HIV not to breastfeed and should only provide formula feeding. In Guatemala, mothers who were HIV positive could not afford to buy formula, a few who could afford, were unsure how to use it. In India mothers living with HIV believed that their infants would die if they are breastfed (Attawell, 2008).

According to Desclaux et al (Eds), some women in Nigeria think that ART is present in breast milk. Such women deductively think that since the virus is found in the body, to them since treatment goes to breasts and therefore passes into the milk it implies that breast milk is safe if a women is on ART. Desclaux et al (Eds) added that in Nigeria, there are popular perceptions of physiolology of lactation, which consider that milk is produced from all elements ingested by the mother. Drawing analogy between food and medicines such women argue that food eaten by the mother can be useful or harmful to a baby, likewise treatment taken by a mother may also be either efficient or dangerous to the baby. Such perceptions fit with the rich corpus of food prescriptions during breastfeeding that have been described by ethnologists in various social and cultural settings Desclaux et al (Eds).

In Zambia, despite the fact that her national policy follows WHO guidelines that promote exclusive breastfeeding for six months, country specific studies show that mothers living with HIV were using mixed feeding, as a result of unclear messages and advice regarding infant feeding given to women living with HIV (Attawell, 2008). In countries like Uganda where mixed feeding is a norm, because of concerns about breast feeding and inadequate knowledge, the risk for mixed feeding of infants whose mothers are HIV positive may be high taking into consideration the culture of prolonged breastfeeding, which has been the norm.
3.0 Statement of the problem and justification

3.1 Statement of the problem
MUJHU Care Ltd has implemented the family model of care also referred to as MTCT Plus since 2003. Throughout this time, the program has employed people living with HIV as Peers to provide peer education to program participants. In addition, the program has also financed psychosocial support meetings, and income generating activities to promote adherence to ART, disclosure of HIV status, and to reduce loss to follow up. However, the participants’ perceptions regarding the psychosocial support interventions especially the family model of care, peer education, psychosocial support meetings and income generating activities were unknown. In addition, the impact of the psychosocial interventions in terms of influencing adherence to ART and disclosure of HIV status was not known. It was therefore important that a study was carried out understand the perceptions of the beneficiaries regarding the family model of care, peer education, psychosocial support meetings and income generating activities.

Secondly, since 2003, the program has supported nutritional education of mothers living with HIV to enable them not only understand the risks of HIV transmission from mothers to their babies during breastfeeding, but also to enable them to be able to prepare nutritious food for their children after the six months of exclusive breast feeding or after rapid early weaning of their babies. While infant nutrition education continues to be done, it was not known how that education was put into practice and used to reduce the risk of HIV transmission to their babies. While anecdotal information suggested that the family model of care was filling an important gap, the program had not been formally evaluated to determine the barriers that HIV positive mothers and their partners are experiencing in trying to apply the knowledge they have acquired from the program. It was therefore imperative that this study was carried out to understand how mothers living with HIV and their partners were applying infant education knowledge and the barriers they face during when applying recommended infant feeding practices.
3.2 Justification of the study

For interventions to be effective, their design must be evidence based, otherwise critical gaps will continue to exist, (UNAIDS, 2009). Even programs that are being implemented, efforts to scale them up can only be done if implementation is accompanied by continued data collection, analysis and use of data to help in the formulation of evidence driven interventions. This is the purpose of this evaluation. This evaluation was aimed at providing vital information which will be used for improving design and implementation of future MTCT related programs. It will inform policy and on future program design and implementation.

Available data from similar UNICEF supported ART demonstration programs show that many implementation problems occur, including high dropout rate during voluntary counseling and testing resulting in a large proportion of women in need not being identified and not benefitting from antiretroviral prophylaxis. Fundamental operational studies are therefore required to understand such important operational challenges, to fill the knowledge gap and provide answers to improve future design of ART programs

HIV/AIDS care and treatment cannot be delivered effectively in a vacuum, because more is needed than drugs. A program that is not responsive to the real world environment in which people with HIV/AIDS live is unlikely to be successful. While MUJHU has established a supportive environment using the psychosocial support groups, a mechanism for people living HIV to come together and support each other, it was imperative that this study was undertaken to assess participants’ perceptions regarding the family model of care, peer education, psychosocial support meetings, and income generating activities and how they contribute towards disclosure, adherence, and reducing loss to follow up. It was also important to understand through this study how infant nutritional education is being translated into practice and the barriers that hinder the translation of such knowledge into practice.
3.3 Conceptual framework

The conceptual framework below shows the relationship between the variables that determine the successful implementation of the family model of care. It shows that the family model of care is being implemented within the dictates of the reality of fear and stigma surrounding HIV/AIDS pandemic. It shows that while the ultimate aim of family model of care is to reduce MTCT, and morbidity and mortality among mothers living with HIV, their HIV positive children and partners, it must first increase, adherence to ART, disclosure of HIV status, increase follow up and increase adoption of good infant and child feeding practices.

The conceptual framework also shows that social support mechanisms put in place and infant feeding education are independent variables which should have a direct influence on the dependant variables which are adherence to ART, disclosure of HIV status, follow up and adoption of appropriate infant and child feeding practices by program participants.

The independent variables are therefore interventions that are aimed at reducing negative effects of fear and stigma by trying to change behavior of the participants in order to maximize the benefits of the program outcomes to the affected families. However, the questions to ask “are those interventions helping to reduce fear and stigma in order to maximize benefits of the family model of care to affected families? What are the perceptions of the participants regarding such interventions? How do such outcomes as adherence to ART, disclosure of HIV status, loss to follow up, and adoption of appropriate infant feeding practices of program participants compare with those of non program participants? In the participants’ views, how can MUJHU improve such interventions to make them more beneficial to all family members?”
Figure 1: Conceptual framework

*Conceptual framework of psychosocial support interventions*

**FAMILY MODEL OF CARE**
- Comprehensive HIV care for all family members
- Supplementary services eg TB screening, reproductive health services, child play therapy etc

**SOCIAL SUPPORT**
- Peer education
- Psychosocial support meetings
- Income generating activities

**INFANT FEEDING EDUCATION**
- Demonstration of local food preparation for Infants
- Exclusive breastfeeding
- Early rapid weaning

**IMPROVED QUALITY OF LIFE**
- Measured by:
  - Reduced paediatric HIV infections
  - Reduced morbidity of PHAs
  - Reduced mortality of PHAs

- Increased disclosure
- Increased adherence
- Increased follow-up
- Appropriate infant feeding
3.4 Limitation of the study

This study should not be viewed as a comprehensive evaluation which assesses was limited to assessing psychosocial support interventions and how they impact on the adherence, disclosure and adoption of appropriate infant feeding practices. Its major limitation was its reliance on self reported adherence to ART, disclosure of serostatus and infant feeding practices. Patients were asked to report their own practices regarding adherence to ART, disclosure of sero status, and infant feeding practices. It is on the basis of self reported practices that a comparative analysis between the two groups was made, and this was report written.
4.0 Objectives of the study

4.1 General objectives
The overall objective of this study was to explore views and perceptions of program participants regarding FMC, peer education, psychosocial support meetings, income generating activities and infant feeding education. This study was also a comparative one aimed at understanding how peer education, psychosocial support meetings, income generating activities and infant feeding education are contributing towards influencing disclosure of HIV status, adherence to ART, follow up, adoption of appropriate infant and child feeding practices of program participants vis-à-vis non program participants.

4.2 Specific objectives
This study was designed to achieve the following specific objectives;

1. To explore and describe perceptions of program participants regarding the psychosocial support interventions including the FMC, peer education, psychosocial support meetings, income generating activities and infant/child feeding education.

2. To undertake a comparative assessment of adherence to ART and disclosure of HIV status by program participants, vis-à-vis none program participants.

3. To undertake a comparative assessment of infant and child feeding practices of program participants, vis-à-vis non program participants.

4. To explore barriers that hinder adoption of appropriate infant and child feeding practices among both program and none program participants.
5.0 Methodology

5.1 Study area
Since this was a comparative study, it was conducted in two fronts according to the type of respondents. Firstly, this study was carried out in Kampala at MUJHU Care Ltd among the program participants. This front was mainly covering participants who are currently benefiting from the program living in and around Kampala. Secondly, the study was conducted in Kawolo hospital ART clinic, Mukono COU ART clinic, Nagalama hospital ART clinic and Mukono health center IV ART clinic which were chosen for this category of respondents because they are not affected by program contamination like in many ART clinics in Kampala.

5.2 Study population
The study participants comprised of two categories. The first category was program participants who are currently benefiting from the program. The second category of respondents was a comparative group which was composed of respondents from Kawolo hospital ART clinic, Mukono COU ART clinic, Mukono health center IV ART clinic and Nagalama hospital ART clinic. These ART clinics were chosen because they are not contaminated by the by program. Respondents who were not in the reproductive age group (18-49 years), were excluded from this study.

Other study participants included the key informants who were selected from the leaders of the psychosocial support interventions. 10 key informants participated in this study. Ordinary members of the psychosocial support groups participated in the focused group discussions.

5.3 Study design
This was a cross sectional design involving a comparative assessment of self reported adherence to ART, disclosure of HIV status, and adoption of appropriate
infant and child feeding practices by program participants and non program participants. Their views were solicited by interviewer administered structured questionnaire from a total sample of 324 respondents compost of 162 program participants and 162 non program participants. The potential differences between those who participated in the program and those who have never participated in the program were analyzed and assessment report was written.

5.4 Sample size determination

Since the outcomes of this study followed a binomial distribution, the required sample size per group was estimated using the following formula:

\[ n = \frac{(1.96 + 0.841)^2 [\pi_1(1-\pi_1) + \pi_2(1-\pi_2)]}{(\pi_1 - \pi_2)^2} \]

Where

\[ n \] = Sample size

\[ \pi_1 \text{ & } \pi_2 \] = Are probabilities of outcomes. The study outcomes include adherence to ART, disclosure of serostatus, adoption of appropriate infant and child feeding methods. Program participants and non program participants being two independent groups whose outcomes were compared the above formula was adopted for computing the sample size. The probabilities of outcomes used for calculating the sample size were based on an assessment of a similar program in South Africa. Adherence to ART for program participants and non program participants in South Africa was 93% and 83% respectively. Substituting these outcomes in the above formula gives sample size for adherence as 162.

\[ n = \frac{(1.96 + 0.841)^2 [0.93(1-0.93) +0.83(1-0.83)]}{(0.93-0.83)^2} = 162 \]

Another outcome studied was disclosure of serostatus among program and non program participants. Disclosure was a study outcome because it facilitates adherence to ART. It was also examined because it is an explicit goal of the psychosocial support interventions to encourage and support program participants to disclose their serostatus. According to Baek C et al (2006) disclosure among
program participants benefiting from a similar psychosocial support program in South Africa was 97% as compared to 85% disclosure among none program participants. Substituting the above disclosure outcomes in the above formula gives sample size of 85.

From the same study, outcomes for adoption of exclusive methods of infant or child feeding were 89% and 76% participants of psychosocial support program and non program participants respectively. Substituting the above outcomes in the formula gives a sample size of 130.

From the above calculated sample sizes, the sample size for each group was the greatest calculated sample size, (162). This means that 162 program participants and 162 non program participants were selected for this study giving a total sample size of 324 respondents. However, 47 program participants were disqualified by MUJHU Regulatory department.

5.5 Study variables
5.5.1 Dependent variables
Dependent variables included adherence to ART, disclosure of serostatus, follow up, family participation, acceptance of FMC, and adoption of appropriate infant or child feeding methods.

5.5.2 Independent variables
Independent variable were age, gender, educational level, occupation of participants, peer education, psychosocial support meetings, income generating activities and infant and child feeding education.

5.6 Sampling procedure
The selection of MUJHU Care clinic was purposively done because it is where the psychosocial support interventions are being implemented. 162 Program participants were randomly sampled from the participants' database. Sampling
was done using simple random sampling from a computer generated list of participants in the database. For purposes of comparison, four health facilities offering ART services were purposively selected. These included Kawolo hospital ART clinic, Mukono COU ART clinic, Mukono Health Center IV ART clinic and Nagalama hospital ART clinic which were selected because they have implemented ART services for quite a long time. Probability proportionate to size sampling was used to determine the number of respondents interviewed at each ART clinic for non program participants. 162 respondents were randomly selected from the ART clinics’ registers of the selected health facilities for non program participants. The proportion of respondents for each facility was determined according to the number of HIV positive mothers who were enrolled in the ART program. During data collection time, program participants who were attending MUJHU clinic and non program participants from the selected ART clinics who meet the inclusion criteria were interviewed after obtaining prior signed consent. Interviews were started with the first eligible respondents and subsequent respondents were interviewed as they report to the clinics.

5.7 Data collection

This study assessed whether there are better outcomes for the program participants as compared to non program participants. The central research question for this evaluation is “Do the FMC, peer education, psychosocial support meetings, income generating activities and infant feeding education influence adherence to ART, disclosure of serostatus, adoption of appropriate infant and child feeding practices of participants?” The study hypothesis was that program participants have a higher rate of adherence to ART, disclosure of serostatus, and adoption of appropriate infant and child feeding practices than non program participants. To determine the effect of FMC, peer education, psychosocial support meetings, income generating activities and infant and child feeding education the study team compared responses from program participants and non program participants for adherence to ART; disclosure of HIV status; and infant and child feeding practices.
Quantitative data was collected using interviewer administered questionnaire, which was a modification of the questionnaire prepared by Laura Nyblade and Kerry MacQuarrie of the International Centre for research on Women (ICRW). This questionnaire was reviewed by the United States Agency for International Development. This means that its reliability has been tested. The interviewer administered questionnaire was administered in MUJHU clinic or in other selected ART clinics when the respondents reported for their clinic days. Clients who stopped to benefit from program voluntarily did not participate in interviewer administered interviews. For all respondents consent was sought before they are interviewed.

Key informant interviews were organized to enable the study team to grasp in-depth perspectives from knowledgeable and experienced respondents. 10 leaders of the psychosocial support groups were purposively selected to participate in the key informant interviews. They were selected based on their knowledge and their level of involvement in the psychosocial support interventions. Focus for key informant interviews included prerequisites for effective implementation of family model of care which is its ability to influence behavior of participants, which in turn influences adherence to ART, disclosure of serostatus, infant and child feeding practices. In addition, importance of participation of an informed patient in a plan of care was discussed. These included attending clinical appointments and tests as scheduled, taking medication as prescribed, modifying lifestyles as required, and avoiding risk behaviors. According to WHO (2003), adherence to medication is a cornerstone of successful HIV/AIDS care and must be the focus of FMC education. Understanding such a focus and factors that influence drug or ART adherence is critical if program effectiveness has to be maximized. Such factors that influence ART adherence including difficulty in tolerating drug side effects, difficulty integrating treatment schedule into activities of life and fear of revealing HIV status if seen taking medications were the main issues during the key informant interviews. In addition, understanding attitudes
and practices related to exclusive breastfeeding and perceptions associated with not breastfeeding which are critical for FMC were discussed.

Four FGDs were held with members of the PSS groups which included the Gardening group, Handcraft group, Young Generation Alive and Book Binding Project. 8 participants with similar characteristics but segregated by gender to ensure that gender concerns were captured constituted a FGD. During the FGD, the facilitators guided the discussions into various topics assisted by a FGD guide. To enhance the quality of reporting and presentation of findings, tape recording and note taking of the FGD proceedings were done. Recording of the FGD proceedings was done after seeking consent of participants. Issues discussed during the FGDs include how program participants perceive the FMC, peer education, income generating activities, psychosocial support meetings, and infant and child feeding education and their contribution towards influencing program participants to adhere to ART, disclose of HIV status, adopting appropriate infant and child feeding practices. The FGDs sought to answer such questions as; how were the psychosocial support interventions reaching program participants beyond MUJHU Care Ltd? How were the psychosocial interventions establishing a supportive social environment in the homes and in the communities? How was nutritional education translated into tangible benefits to children and other family members living with HIV? What challenges were program participants facing that hindered adoption of appropriate? The study also sought suggestions from program participants on ways of improving psychosocial interventions in order to maximize benefits to beneficiaries.

5.8 Quality control

5.8.1 Training of Research Assistants
Criteria for selection of field staff (Research Supervisors and Research Assistants) included fluency in spoken and written luganda because the local language spoken in the area of study is mainly Luganda. Other criteria for selection of
Research Assistants included prior experience in conducting social research studies and possession of at least a degree in Social Sciences or related discipline. To enable the field staff to conduct the assignment as competently and efficiently as possible, a training covering basic research methodology, study objectives, study procedure, ethical considerations and data collection tools was organized. The training was structured to focus on the participatory assessment of individuals and communities as well as analyzing results. The training also covered the following aspects; research protocol, importance of evaluation, tasks, outputs and outcomes of the psychosocial support interventions. Terms and concepts such as monitoring and evaluation were introduced to ensure consensus on interpretation, review of interviewing techniques and sampling techniques including probing and in-depth interviews, techniques of questionnaire administration and hands-on application of each tool, detailed review of questionnaires and interview guides, teamwork development and discussion on code of conduct for evaluation studies, developing action plan for data collection during the study. Research Assistants were guided on a daily basis on how to fill the questionnaires correctly. They were instructed to make sure that the respondents were consented prior to the interview and that the respondents understand the objectives of the study.

5.8.2 Pretesting of study tools
The study tools were pretested before they are used in the field to fine tune them by removing inconsistencies, repetitions, redundancies as well as ascertaining their relevance and applicability during data collection. Pretest was carried out within the program area but not in communities where the respondents who are sampled for the study reside. Specifically, the pretest sought answers to the following concerns; whether the respondents were willing to answer the questions in the way they have been asked; whether any of the questions were difficult to answer or addressed sensitive issues; whether the questions could be understood well by respondents; whether the Research Assistants understood the interview instructions; whether the research questionnaire was designed with adequate writing space and whether the coding of the answers was clear; How much time
the interview would take? Apart from testing the study tools, the pretest exercise also served as additional training exercise for the Research Assistants.

5.8.3 Field editing of data
In order to maintain data quality throughout the entire evaluation study, the Team Leader assisted by the Study Supervisors guided the Research Assistants. Each of the Research Assistants was required to manually crosscheck the filled questionnaires for accuracy and completeness on a daily basis. Besides, the study team met daily to plan and review the field performance as an avenue for enhancing reliability and consistency of the collected data.

5.9 Data management and analysis
5.9.1 Data management
Experienced Data Entry Clerks were recruited to enter the collected data. They were supervised daily by a Data Analyst. The Data Entry Clerks carried out visual checking of questionnaires for consistency, accuracy and completeness. EpiData was used for designing data entry screens which allow for automatic range checks and internal consistency. In addition, data cleaning to detect the missing and duplicated data was carried out before the compilation of data dictionary. Double data entry was used to minimize errors during data entry. To ensure that data is not lost, data was backed up to removable disks on a daily basis and stored on separate files. Data analysis trial testing was done before a full blown data analysis exercise. All filed questionnaires were entered in Epidata. The data was then exported to STATA for cleaning and analysis.

5.9.2 Data analysis
STATA software version 10 was used for data analysis. Univariate analysis was carried out to generate frequency tables and other descriptive parameters. In addition, bivariate analysis was done to compare the dependent variable with the independent variables using chi-square P values. Qualitative studies often result in a massive amount of data from interviews, observational notes and researcher’s
own records of ongoing observations. This data was analyzed early in form of a field diary. All the interviews were audio recorded and the data transcribed. To ensure quality of the transcripts, and verbatim documentation of the content, the study team carefully checked the transcripts against original recordings.

Once the data was transcribed, the study team went through all the data transcripts and field notes to identify an initial set of themes. Data was systematically searched for recurring themes. Emerging patterns and the themes were coded and categorized. Manual coding was carried out using margins of sheets of paper containing the transcribed data. Once the coding was completed, the data was repeatedly read and reread to remove non relevant material which is not related to the study topics. Lists and categories of codes were then made which were grouped together as major themes. Ultimately, emerging themes were used in writing up research findings. Some respondents were quoted verbatim.

5.10 Ethical considerations

The study protocol was submitted to Uganda National Council for Science and Technology and Institutional Review Board (IRB) of Makerere University School of Public Health for approval. Interviewers were trained on the importance of following ethical guidelines, including maintaining confidentiality. Written informed consent was obtained from all participants who were interviewed. Participants were not asked to give their names except to sign a written informed consent form. The signed forms were stored in a locked office, and kept separately from the data, which was in electronic format. Interviews were conducted in convenient places in MUJHU clinic, or selected health facilities in Mukono district.

Table 1: Sample sizes and types of interviews

<table>
<thead>
<tr>
<th>Structured and key informant interviews</th>
<th>FDGs for members of PSS groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV+ mothers</td>
<td>Handcraft group</td>
</tr>
<tr>
<td>Handicraft</td>
<td>324</td>
</tr>
<tr>
<td>HIV+ mothers</td>
<td>Book Binding</td>
</tr>
<tr>
<td>Gardening project</td>
<td>10</td>
</tr>
<tr>
<td>Gardening project</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>Total</td>
</tr>
<tr>
<td>HIV+ mothers</td>
<td>Total</td>
</tr>
<tr>
<td>Handicraft</td>
<td>334</td>
</tr>
<tr>
<td>Gardening project</td>
<td>32</td>
</tr>
</tbody>
</table>

25
This chapter presents results of the study findings. It presents tabular representation of socio demographic data of the respondents and graphical analysis of the responses of program and non program participants and the levels of statistical significance among the two groups

**Table 2: Characteristics of respondents enrolled in the study**

<table>
<thead>
<tr>
<th>Socio-demographic characteristics</th>
<th>Program participants (N = 114)</th>
<th>Non-program participants (N =162)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td><strong>Age:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 20 years</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20 – 29 years</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>30 – 39 years</td>
<td>65</td>
<td>57</td>
</tr>
<tr>
<td>40 – 49 years</td>
<td>35</td>
<td>31</td>
</tr>
<tr>
<td><strong>Marital status:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Married</td>
<td>69</td>
<td>61</td>
</tr>
<tr>
<td>Widowed</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td>Divorced/ separated</td>
<td>26</td>
<td>23</td>
</tr>
<tr>
<td><strong>Religion:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catholics</td>
<td>31</td>
<td>27</td>
</tr>
<tr>
<td>Protestants</td>
<td>41</td>
<td>36</td>
</tr>
<tr>
<td>Moslems</td>
<td>21</td>
<td>18</td>
</tr>
<tr>
<td>Pentecostals</td>
<td>21</td>
<td>18</td>
</tr>
<tr>
<td><strong>Level of education:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never schooled</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Primary</td>
<td>46</td>
<td>40</td>
</tr>
<tr>
<td>Secondary</td>
<td>40</td>
<td>35</td>
</tr>
<tr>
<td>University</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td><strong>Employment status:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>25</td>
<td>22</td>
</tr>
<tr>
<td>Civil servant</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>-------------</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Self employed</td>
<td>59</td>
<td>52</td>
</tr>
<tr>
<td>Peasants</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Volunteers</td>
<td>18</td>
<td>16</td>
</tr>
</tbody>
</table>

Table 2 above shows the socio-demographic characteristics of the respondents. It is clear from the table that most of the program participants who took part in the study were 30-39 years old (57%), while the majority of non program participants were 20-29 years old (64%). This is because the program participants were enrolled in the program in 2003, when they were already in their reproductive age. Considering the marital status, religion and level of education, there were no significant differences between the two groups. Employment status showed significant differences between the two groups. 25 (22%) of the program participants were unemployed as compared with 77 (48%) none program participants. 59 (52%) program participants were self employed as compared to 48 (30%) of non program participants. This may be due to that fact that some program participants were trained in income generating activities and were now putting what they learnt into practice. 18 (16%) program participants were working as volunteers as compared to 13 (8%) non program participants. Overall, a majority of program participants reported to be engaged in active employment as compared to none program participants. This is a clear indication that when people living with HIV take ART and are well guided, they can become as productive as those without infection.
When asked whether they benefit from family model of care, peer education, psychosocial support meetings and income generating activities, 113 (99%) respondents said they benefit from family model of care, 102 (90%) respondents said the benefit from peer education, 93 (82%) said they benefit from psychosocial support meetings , and only 33 (29%) said they benefit from income generating activities. It is clear from the graph that most program participants appreciate the model of care where HIV infected mothers, their children and partners are treated in one health facility. The least appreciated intervention are income generating activities with 81 (71%) of respondents saying they do not benefit from them.
Graph 2 above shows disclosure of sero status to partner(s). 104 (96%) program participants reported to have disclosed to their sero status to their partner(s) compared to 38 (23%) non program participants. 4 (4%) program participants said they have not disclosed their HIV status to their partner(s) as compared to 124 (77%) of non program participants. There was a statistically significant difference between the number of program participants and non program participants who said they disclosed their sero status to their partners (P value 0.000). There was also a significant statistical difference between program participants and non program participants who never disclosed their sero status to their partner(s).
The significant differences between the two groups can be attributed to existence of psychosocial support interventions where program participants get together and share experiences. Unfortunately such organized psychosocial support interventions seem to be nonexistent among non program participants.

**Graph 3: Reasons for non disclosure of HIV status to partner(s)**

Graph 3 above shows the responses from the two groups regarding reasons for non disclosure of HIV status to partner(s). 5 (4%) program participants did not disclose their HIV status to their partner(s) because they feared of being accused of infidelity as compared to 119 (73%) non program participants. Only 4 (3.5%) program participants reported not to have disclosed their sero status due to fear of domestic violence as compared to 117 (72%) non program participants. While 6 (5%) and 1 (1%) program participants feared rejection and loss of income, 114 (70% and 20 (12%) did not disclose the HIV status to their partners due to fear of rejection and fear of loss of income respectively. For all the four variables fear of being accused of infidelity, fear of domestic violence, fear of rejection and fear of
loss of income, the differences between program participants and non program participants were statistically significant (P values 0.000).

**Chart 1: Disclosed HIV status to other people other than partner(s)**

The pie chart above shows that a greater percentage of program participants disclosed their HIV status to other people other than their partner(s) as compared to non program participants. The difference between the program participants who disclosed their HIV status 98 (86%) and non program participant who disclosed their status 16 (14%) was statistically significant. Like non disclosure to partner(s), fear was reported as the main reason for not disclosing HIV status to other people other than partner(s). The difference between the two groups was statistically significant (P value 0.000).
Graph 4 above shows that there were more program participants 53 (47%) than non program participants 42 (26%) who reported to be having treatment buddies. The difference between the two groups was however not statistically significant. This means that although treatment buddies may be necessary, they are not sufficient to ensure adherence to ART. What is required is the participation of informed patient in a well defined plan of care which includes attending appointments and carrying out tests as schedule, taking medication as prescribed, modifying lifestyles as required, and avoiding risk behavior.
When asked whether they take medication as prescribed, a majority of program participants 108 (95%) confirmed that they do. Only 6 (5%) program participants said they do not take medication as prescribed. The reasons for not taking medication as prescribed by the program participants given the holistic nature of the program included busy work schedules. 127 (78%) non program participants reported not to be taking medicine as prescribed. With the p value of 0.000, there was a statistically significant difference between program and non program participants.

**Table 3: Infant feeding practices**

<table>
<thead>
<tr>
<th></th>
<th>Program participants</th>
<th>Non program participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclusive breastfeeding</td>
<td>64 (70%)</td>
<td>131 (92%)</td>
</tr>
<tr>
<td>Rapid early weaning</td>
<td>28 (30%)</td>
<td>12 (8%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>92</strong></td>
<td><strong>143</strong></td>
</tr>
</tbody>
</table>

Table 3 above shows responses regarding infant feeding practices. While 28 (30%) program participants reported to have practiced rapid early weaning only 12 (8%) non program participants reported to have practiced rapid early weaning.
This difference can be attributed to the fact that many of the program participants are in productive employment and some of them earn some income from income generating activities being implemented by the program. Infant feeding practices among the two groups were statistically significant (P value 0.000).

**Graph 6: Challenges of exclusive breast feeding**

Graph 6 above shows the responses from both program and non program participants on the challenges they face while practicing exclusive breast feeding. Cost of rapid early weaning was cited as the greatest challenge reported by 51 (45%) program participants as compared to 130 (80%) non program participants. Fear of disclosing HIV status, fear of drug side effects, and fear of being labeled a bad mother among the program participants was insignificant while among the non program participants, these were pronounced. The differences were statistically significant among the two groups (P values 0.000 for the four variables). The difference can be attributed to income generating activities which program participants are facilitated to engage in, nutritional education which promotes use of local foods and psychosocial support interventions that reduce fear and stigma. There were significant differences among the challenges faced by the two groups.
The above graph shows that a greater percentage of program participants 82 (87%) reported weaning their children within the first three months than non program participants 94 (66%). While all the program participants reported to be weaning their children in the first six months some proportion of non program participants 5 (4%) reported weaning their children between the seventh and twelfth month. Child weaning practices between the two groups were statically significant P value 0.001).
7.0 Discussion of results

This chapter discusses study findings. It discusses views of program participants regarding the family model of care, peer education, psychosocial support meetings and income generating activities. It also gives a comparative analysis of disclosure of HIV status to partner(s) and other people, adherence to medication, and infant feeding practices of HIV positive mothers.

7.1 Views on family model of care

This study revealed that the family model of care was the most appreciated intervention by the program participants. 99% of the program participants said the family model of care is a good intervention. They said that what is fundamental about this model of care is its provision of integrated services.

Providing clinic care, nutrition, psychosocial support, as well as antiretroviral therapy to HIV positive mothers and their family members in a holistic manner makes MTCT plus program very unique. This finding is in total agreement with Attawell (2008), who asserted that if progress has to be made interventions must consider preserving the health of mothers and that of their family members. He added that when both parents are involved in the program, the knowledge and understanding of the men and allows them to take increased responsibility for their health and that of their wives, other sexual partners and his family. It is not therefore, surprising that the program participants reported that their treatment buddies were their partner(s).

7.2 Views on peer education and psychosocial support interventions

One of the prerequisites for effective implementation of a family model of care is its ability to influence behavior of participants. It is their behavior that influences participants’ adherence to ART, disclosure of sero status and adoption of appropriate infant feeding practices. In addition to learning, peer education and psychosocial support meetings are aimed at changing the behavior of program
participants and reduce challenges of living positively with HIV infections. When asked to give their views on peer education, a majority of the program participants 102 (90%) reported that the peer education is a good intervention. Among the benefits of peer education reported by program participants are the reduced self imposed fear and stigma which has positively impacts on adherence to ART and disclosure of sero status. The program participants also reported that since MUJHU Peer Educators are trained and educated on many issues of HIV/AIDS and they have experiences to share with them, peer education gives them opportunity to learn from experiences of their peers. 93 (82%) program participants appreciated the psychosocial support meetings saying that they are particularly good in improving their psychosocial wellbeing. One participant said; “Yes, they are useful and helpful because am one of the beneficiaries. We have peer educators who have worked like role models. They go to communities and tell people what they have benefited through drama and exhibitions”

It is therefore not surprising that when asked to describe their psychosocial wellbeing, a majority of program participants reported living positively and being in control of their lives.

7.3 Views on income generating activities
Income generating activities were the least appreciated by the program participants 81 (71%). Some program participants reported not to have participated in these activities due to their busy schedules and more profitable ventures outside MUJHU. Others acknowledged that apart from the funding they got from US Embassy, there is no substantial investment committed by MUJHU that is commensurate with the number of beneficiaries. Others desired to participate in the farming project however, their major concern is the distance they have to travel and transport costs since the project is located in Luwero district.
The above study findings were affirmed by many of the participants in both KII and FGD interviews. One FGD participant summarized the benefits of psychosocial support interventions by saying;

“They have helped us a lot. I have gained confidence in myself after knowing my status. Now I know I have a lot to do in future and I will live for a long time. I have also learnt some skills from the income generating activities. In like Mama Papa group I make my small bags and bring them here for sell and earn something”

“Yes they are very good programs because they have helped so many people. Mama Papa, (handcraft group) for example started with a few people when the coordinator contributed 25,000. But now I am not sure what they have on their bank account. Mothers have earned a living through getting transport to clinic and also some got skills. I think there is still a need to involve a committee when deciding on some issues like selecting someone coming on board”

However, management of revenue from income generating activities was reported to be a major challenge which affects the group coherence. When asked how income generating activities can be improved, one program participant said; “I will base my solutions on handcraft. We should have transparent means and ways of managing our finances. Members need to know how the products are priced and why”

7.4 Disclosure of sero status

This section discusses disclosure of sero status to partner(s) and reasons for non disclosure of sero status among program participants and non program participants. In addition, it discusses disclosure of sero status to other people other than partner(s). This study revealed that a majority of program participants 104 (96%) disclosed their sero status to their partner(s) as compared to non program participants 38 (23%). In addition, more program participants 98 (86%) disclosed their HIV status to other people other than their partner(s) as compared with only
16 (14%) non program participants. The main reasons given for non disclosure of HIV status includes fear of accusations of infidelity, fear of domestic violence, fear of rejection and fear of loss of income. Disclosure of HIV status was found to be higher among program participants than non program participants. This difference was attributed to active participation of partner(s) in MTCT plus program. These study findings agree with UNAIDS (2009) who asserted that active involvement of male partner(s) in HIV/AIDS program is important especially in addressing issues related to stigma, discrimination, domestic violence and in supporting uptake of services. These findings also agreed with the study done in Botswana and Zambia where disclosure of HIV status among pregnant women is relatively high due to involvement of family members and male partners in making decisions regarding intake of ARV (UNAIDS, 2009). It is therefore not surprising that disclosure of HIV status among in the two groups was statistically significant.

7.5 Adherence to ARV
Adherence to ART among program participants was found to be very higher as compared to non program participants. 108 (95%) program participants and 127 (78%) non program participants reported to be taking their medication as prescribed. The difference between the two groups was statistically significant mainly due to lack of follow-up among non program participants. This is not surprising given the fact that MTCT plus program has a mechanism of reminding the clients when their clinical appointments are due and monitoring their adherence to ART. These findings are in accordance with the studies carried out in Swaziland and Zambia whose programs use mobile phones to contact mothers living with HIV (UNAIDS 2009). Intensive follow-up of program participants to ensure adherence to ART notwithstanding, 6 (5%) program participants reported not to adhere to their medication. The reasons given by program participants for not taking medication as prescribed include not being reminded, lack of money and sickness.
However, there was a general appreciation of the program by the program participants. The program provided many avenues of promoting shared learning. It was generally accepted that sharing experiences among HIV positive individuals have been very helpful to program participants. One key informant said;

“It has helped. We have testimonies which give encouragement to people and get to know that being HIV positive is not the end of the world. We also talk about adherence because in our meetings we get trainings and gain knowledge which we pass on to others. We tell them the problems they can face if they do not adhere. They know that they will find their fellow peers who they can talk with. We tell them what we have benefited as we talk from the waiting area”

The following quotations adequately summarize the perspectives and the views among the program participants. They reflect the general consensus among the participants of KII and FGDs regarding psychosocial support interventions.

“When I got to know that I was HIV positive, I got devastated and did not know how to tell my husband. When I came here, I was told how to handle the situation. After knowing that I was positive and he was negative, he abandoned me. Mama papa trained me to make different products. I have spent two and a half years without a job but the different things I make have helped me a lot. Since I loved my husband so much, sometimes I would get so bored but psychosocial group has removed the boredom. Infant feeding helped raise my baby healthy”

“Psychosocial support interventions helped us a lot. When I got to know that there are other people like me and are living a healthy life, it gave me more courage”

7.6 Infant feeding practices

This study revealed that there were more program participants, 28 (30%) who reported to have practiced rapid early weaning as compared to 12 (8%) non program participants. In addition, while fear of disclosing HIV status was a major
challenge among non program participants, the only major challenge facing program participants was the cost of rapid early weaning. Fear was almost anon issue among program participants. The study also revealed that more program participants stopped breast feeding their children within the first three months as compared to non program participants.

The differences can be attributed to the fact that many of the program participants are in productive employment and some of them earn some income from income generating activities being implemented by the program. That probably explains why infant feeding practices among the two groups were statistically significant.

When asked whether they benefit from nutritional education, the quotations below provide some of the answers from KII and FGDs.

“*It has helped us. They teach us how to use that little money to have a balanced diet. Some of us thought good feeding meant eating meat or blue band. We know how to have a small garden around our verandas and save money and have a balanced diet. What they teach us is not expensive to prepare*”

“*It has helped them so much. They teach us that even the mother should have a balanced diet in order to get enough breast milk. Many have managed to breastfeed their babies. They demonstrate for us how to breastfeed our babies and how to prepare balanced die*”.

“*Some families where disclosure has not been done, when practicing exclusive breastfeeding, they face challenges because other family members can feed their babies on other solid food. That is why we encourage them to disclose*”
8.0 Summary, conclusions and recommendations

8.1. Summary
Implementation of the family model of care requires a paradigm shift. Health facilities which are not one stop centers for services cannot implement such a model. Availability of comprehensive set of services that meets the needs of individuals in a family holistically has been the key tenet of MTCT plus.

8.2. Conclusion
This study revealed that the family model of care, peer education and psychosocial support meetings were appreciated by the program participants as key interventions that are beneficial to them. The main reason was that the psychosocial support interventions helped them to reduce fear among them. This study also revealed that the psychosocial support interventions have a significantly strong influence on adherence to ART, disclosure of sero status to partner(s) and others other than partner(s) and adoption of appropriate infant feeding mechanisms. In addition, availability of social support services such as counseling, peer support and psychosocial support meetings was reported by program participants to be very helpful in adherence to ART through improved understanding of one’s condition.

8.3. Recommendations
This study revealed that high costs of service delivery notwithstanding, psychosocial support interventions have resulted into better health outcomes of program participants as compared to non program participants. In order to reduce costs, there is need to train peer educators in psychosocial counseling, supporting behavioral change and treatment adherence. Training of lay providers for peer counseling and adherence support was recommended by program participants as a means of not only proving job opportunities but also as a way of increasing adherence and disclosure. This will also help in reducing the burden on the already overworked clinic staff.
Management of revenue from income generating activities and sharing of dividends was highlighted as a major challenge. There is need therefore, for farther training of group members in financial resource management.

Evaluating MTCT plus program was not an easy task given the fact that there were no baseline figures. Measuring progress of such program without baseline values is a nightmare. In many organisations, evaluation is too often taken as an afterthought in the process of program implementation. It is therefore recommended that program evaluation must be taken as a critical part of initial phases of program planning and must be planned for if effective HIV/AIDS treatment, prevention, care and support interventions are to be delivered.

Although in MUJHU, counseling is tailored to individual needs and model children who live by example are available, child counselors and child peer educators have not been trained. There is need to train peer child counselors and child peer educators to counsel children, youths and adolescents. This will make interventions age sensitive.

Since treatment buddies were reported to be an inconvenience by many respondents, it is therefore recommended that to promote adherence, use of electronic reminders such as beepers, cell phone, watches, should be adopted to prompt patients to self administer their medications at given times.
References


28. Tearfund (2008), Scaling up prevention of mother-to-child transmission of HIV, Tear fund, United Kingdom


44. WHO and UNICEF (2008), Rapid assessment of HIV and infant feeding in Kenya and Zambia. WHO. UNICEF Regional Office for Eastern and South Africa
Client’s questionnaire

Instruction for interviewers

After consenting participants, please read the question and tick appropriate answer(s) from the list of possible answers given. In case the response given by the respondent is not in the list, please write it under “Others”…………………. Please, DO NOT read the answers as this may bias the responses from the respondents. Please note that section 1.0 of the questionnaire is to be answered by the program participants only. Also note that the underlined words after each question are instructions requiring you to explain the question so that respondent understands what is being solicited from him or her.

0.1 GENERAL INFORMATION (To be answered by all respondents)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q0.01. What is your occupation?</td>
<td>Unemployed</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Civil Servant</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Self employed</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Peasant</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Other (specify)</td>
<td>5</td>
</tr>
<tr>
<td>Q0.02. What is your age?</td>
<td>Less than 20</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>21 - 29</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>30 – 39</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>40 – 49</td>
<td>4</td>
</tr>
<tr>
<td>Q0.03. What is your religion?</td>
<td>Catholic</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Protestant</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Moslem</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Other (specify)</td>
<td>4</td>
</tr>
<tr>
<td>Q0.04. What is your marital status?</td>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Separated/divorced</td>
<td>4</td>
</tr>
<tr>
<td>Q0.05 What is your highest educational attainment?</td>
<td>Never been to school</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Primary</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Secondary</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>University</td>
<td>4</td>
</tr>
</tbody>
</table>

1.0 Views and perceptions of program participants (To be answered by program participants only)

<table>
<thead>
<tr>
<th>Question and Filter</th>
<th>Response and Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>In your view, is the Family Model of Care (FMC) a good intervention? (explain FMC)</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td>Question</td>
<td>Option 1</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>Is peer education being offered in MUJHU beneficial to your family?</td>
<td>1. Yes</td>
</tr>
<tr>
<td>If yes, how has it benefited your family?</td>
<td>1. ART adhere support</td>
</tr>
<tr>
<td></td>
<td>3. Involvement of my family in care</td>
</tr>
<tr>
<td></td>
<td>5. Others (specify)</td>
</tr>
<tr>
<td>Are psychosocial support meetings helping you in any way?</td>
<td>1. Yes</td>
</tr>
<tr>
<td>If yes, in which way are the meetings helpful to you?</td>
<td>1. ART adhere support</td>
</tr>
<tr>
<td></td>
<td>3. Involvement of my family in care</td>
</tr>
<tr>
<td></td>
<td>5. Others (specify)</td>
</tr>
<tr>
<td>Are you really benefiting from the group income generating activities?</td>
<td>1. Yes</td>
</tr>
<tr>
<td>If yes, how are you benefiting from group income generating activities?</td>
<td>1. Increased family income</td>
</tr>
<tr>
<td></td>
<td>3. Freely disclosure of my serostatus</td>
</tr>
<tr>
<td></td>
<td>5. Others (specify)</td>
</tr>
<tr>
<td>How is nutrition education benefiting your family members?</td>
<td>1. -------------------------</td>
</tr>
<tr>
<td></td>
<td>3. -------------------------</td>
</tr>
<tr>
<td>Which of the psychosocial support interventions is most beneficial to you?</td>
<td>1. Peer education</td>
</tr>
<tr>
<td></td>
<td>3. Income generating activities</td>
</tr>
</tbody>
</table>
### 2.0 Disclosure of sero status *(To be answered by all respondents)*

<table>
<thead>
<tr>
<th>QUESTION AND FILTER</th>
<th>RESPONSE AND CODES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you ever disclosed your HIV status to your partner(s)?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>If no, why haven’t you disclosed your serostatus to your partner(s)?</td>
<td>1. Fear of being accused of infidelity 2. Fear of violence 3. Fear of abandonment/rejection 4. Loss of economic benefits 5. Other</td>
</tr>
<tr>
<td>Other than your partner(s), have you ever disclosed your HIV status to anyone else?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>If yes, whom have you ever disclosed to?</td>
<td>1. Mother/Father 2. My children</td>
</tr>
<tr>
<td>QUESTION AND FILTER</td>
<td>RESPONSE AND CODES</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| If no, why haven’t you disclosed your serostatus to anyone else other than your partner(s)? | 1. Fear of being accused of infidelity  
2. Fear of abandonment/rejection  
3. Loss of friends  
4. It does not help  
5. Other (specify)------------------ |
| Have you been visited by any member of the social support team in the last one month? | 1. Yes  
2. No |
| Please, kindly suggest ways of increasing disclosure of serostatus. | 1.-----------------------------  
2.-----------------------------  
3.-----------------------------  
4.----------------------------- |

**3.0 Adherence (To be answered by all respondents)**

<table>
<thead>
<tr>
<th>HAVE YOU EVER MISSED ATTENDING A SCHEDULED CLINICAL APPOINTMENT?</th>
<th>RESPONSE AND CODES</th>
</tr>
</thead>
</table>
| 1. Yes  
2. No If no go to |                      |
| If yes, why did you miss a scheduled clinical appointment?     | 1. No one reminded me  
2. I had no money  
3. I was too sick to walk  
4. I felt fatigued  
5. Others (specify)------------------ |
| Have you ever missed prescribed medical tests?                 | 1 Yes  
2 No If no go to |                      |
| If yes, why did you miss prescribed medical tests?             | 1. I have no treatment support  
2. I was very sick  
3. Forgot  
4. I felt fatigued  
5. Other (specify)------------------ |
| Do you take medications as prescribed?                         | 1. Yes  
2. No If yes go to |                      |
<table>
<thead>
<tr>
<th>QUESTION AND FILTER</th>
<th>RESPONSE AND CODES</th>
</tr>
</thead>
</table>
| If no, what makes it difficult for you to take medicines as prescribed? | 1. Fear disclosing status  
2. Drug stock outs  
3. Forgetting  
4. Side effects  
5. Others (specify)----------------- |
| Do you have adherence support or treatment buddy? | 1. Yes  
2. No If no go to |
| If yes, who is your treatment buddy? | 1. Partner(s)  
2. Mother/father  
3. Brother/sister  
4. Friend(s)  
5. Other (specify)----------------- |
| Kindly suggest ways in which psychosocial support interventions can be improved in order to promote adherence | 1.-------------------------------  
2.-------------------------------  
3.-------------------------------  
4.------------------------------- |

4.0 Infant feeding practices and *(To be answered by all respondents)*

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>RESPONSE</th>
</tr>
</thead>
</table>
| Have you had children since you learnt of your serostatus? | 1. Yes  
2. No |
| If yes, how many children have you had since you learnt of your serostatus? | ------------------- |
| Has your family ever practiced exclusive breastfeeding? | 1. Yes  
2. No |
| What challenges has your family faced while applying the recommended infant feeding practices? | 1. Fear of disclosing serostatus  
2. Fear of drug side effects  
3. Cost of rapid early weaning  
4. Fear of being called bad |
<table>
<thead>
<tr>
<th>QUESTION AND FILTER</th>
<th>RESPONSE AND CODES</th>
</tr>
</thead>
<tbody>
<tr>
<td>parent</td>
<td>5. Other (specify)---</td>
</tr>
</tbody>
</table>
| When did you introduce solid or liquid food other than breast milk to your baby (s)? | 1. 1 - 3 months  
2. 4 - 6 months  
3. 7 - 12 months  
4. Other (Specify)--- |
| If infant feeding education is to be improved, please, kindly suggest ways of improving nutrition education. | 1.--------------------------  
2.--------------------------  
3.--------------------------  
4.-------------------------- |

THANK YOU FOR PARTICIPATING IN THIS STUDY
KEY INFORMANT INTERVIEW GUIDE

Good morning/afternoon participants,
You are all welcome to this discussion. We are a team assessing the psychosocial interventions of the Family Model of care being implemented by MUJHU. We would like to get your views regarding peer education, psychosocial support meetings, and income generating activities. We would also like to collect your views regarding infant or child feeding education and your practices on infant feeding. Please fill free to discuss, participate and ask questions. Kindly note that the information you will provide will be confidential. You do not need to reveal any personal information if you do not want to, but if you are willing to share your experiences, it will be helpful to us in understanding issues relating to the care and support provided to you by FMC program. Please kindly be audible and speak one at a time so that all your important views are understood and written down. Please, we kindly request that we tape record our discussions to help us capture important issues and to ensure that we do not miss anything. May we use it? (Moderator seeks consent). In case some participants do not want to be audio taped, the moderator should thank them for their interest and request them to leave. Thank you very much.

Self introduction

A. Promotion of disclosure beyond the household
1. Are there any interventions that encourage your members to disclose their sero-status other than to their treatment buddies? Probe for interventions beyond family members.
2. What social and cultural concerns do your members have on disclosure? Probe
3. What barriers hinder your members from disclosing their serostatus? Probe

B. Assessment of adherence
4. What concerns do your clients have that affect adherence to ART? Probe for side effects, pill fatigue, social or family support
5. What barriers do they face that affect their adherence to ART?
6. How is the program supporting adherence at community level?
7. In your view, are social support interventions helping to promote adherence?
8. How would we improve psychosocial support interventions in order to promote adherence of your members?

C. Male partners’ involvement and nutrition
9. How is the program promoting male partner involvement in infant and child feeding?
10. Beyond nutritional education, how is the program supporting lactating mothers?
11. Is the program able to monitor practices of lactating mothers?
12. What factors hinder HIV+ mothers from adopting appropriate infant feeding practices?

13. Can you suggest other ways of improving nutrition education to make it more beneficial to HIV+ mothers and their families?

Thank you for participating in this study
Good morning/afternoon participants,
You are all welcome to this discussion. We are a team assessing the psychosocial interventions of the Family Model of care being implemented by MUJHU. We would like to get your views regarding peer education, psychosocial support meetings, and income generating activities. We would also like to collect your views regarding infant or child feeding education and your practices on infant feeding. Please fill free to discuss, participate and ask questions. Kindly note that the information you will provide will be confidential. You do not need to reveal any personal information if you do not want to, but if you are willing to share your experiences, it will be helpful to us in understanding issues relating to the care and support provided to you by FMC program. Please kindly be audible and speak one at a time so that all your important views are understood and written down.

Please, we kindly request that we tape record our discussions to help us capture important issues and to ensure that we do not miss anything. May we use it? (Moderator seeks consent). In case some participants do not want to be audio taped, the moderator should thank them for their interest and request them to leave.
Thank you very much.
Self introduction

A. Psychosocial social support

1. Are psychosocial support interventions (peer education, psychosocial meetings and income generating activities) helpful to participants? 
   *Probe for emotional, socio and economic well being*
2. How is the program promoting psychosocial support within the households? Probe for social support beyond the household
3. Are the current interventions promoting disclosure of serostatus, adherence to ART, and adoption of appropriate infant feeding practices? Probe

B. Family support system

4. How are the PSS groups reaching HIV+ mothers in their homes? 
   *Please probe.*
5. Are the PSS groups helping in establishing a supportive environment for HIV+ mothers in their homes and communities? *Please probe*

C. Infant nutrition education

6. Is nutritional education helping the mothers improve nutrition of their family members? *Probe*
7. Do you think nutritional education is helpful to lactating mothers? *Please probe*
8. What hindrances are lactating mothers facing while applying infant nutrition knowledge?

9. What challenges do the PSS groups face?

10. Suggest ways of improving the PSS interventions

Thank you for participating in this study
Good morning/afternoon Sir/Madam. My name is------------------------------------
-----I am a research assistant working with Mr. Okalo Paul, a MUSPH/CDC Fellow attached to MUJHU, P.O. Box 23491, Kampala, telephone +256 -777-202-107, e-mail address; pokalo@mujhu.org. We are conducting a study of the psychosocial support interventions of the Family Model. Participants in this study will include adults participating in the program.

Study procedure
We shall ask you a set of questions to solicit your views on social support, disclosure of serostatus to your partner(s) or any other family member(s), adherence to ART, and your infant feeding practices. If you are a program participant, we would like to hear your views regarding the Family Model of Care, peer education, psychosocial support meetings and income generating activities. Secondly we would like to know from your experience how the family model of care, peer education, psychosocial support meetings and income generating activities are influencing disclosure of participants’ serostatus to none household members, adherence to treatment, loss to follow up and enhanced their participation in HIV care. We would also like to know your infant or child feeding practices and barriers you experience when applying the recommended infant or child feeding practices.

Rights of respondents
Entry into the study is entirely voluntary and you will not incur any penalty if you decide not to participate. Should you wish to stop answering questions for any reason, you are free to do so and this will not affect the benefits you are receiving from the program. In case you are not happy with the way in which I interview you, you may contact: Professor Fred Wabwire Mangen the Chairman Makerere University Research & Ethical Committee P.O. Box 7072, Kampala. Tel +256-41-532207/543872.
Benefits
The information you and others will provide will help program planners and implementers to make informed decisions that will improve service delivery and to inform the design of future programs. This study does not in any way expose you to a risk of any kind.

Confidentiality
Since this study is confidential, you will not be personally identified with your names or any contact information. Researchers shall therefore not ask for your name or your contact information.

Compensation
You will not receive any payment for participating in this study.

Consent statement
I understand that I am consenting to answer questions regarding my views on the family model of care, psychosocial support interventions put in place by MUJHU, adherence to ART, disclosure of serostatus, infant feeding practices and obstacles to adoption of appropriate infant feeding methods.

_________________________    ______________________
Signature/Thumbprint           Date

Consented by----------------------Date---------------------