

**THE DECISION-SUPPORT NEEDS OF HIV-POSITIVE MOTHERS
REGARDING INFANT FEEDING AT A PMTCT CLINIC IN KENYA**

BY

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MAY, 2011

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I declare that this report is my original work and has not been presented for a degree in any other university or institution.

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DEDICATION:

To the thousands of women living with HIV and are voiceless

To those who, selflessly, dedicate their energies towards advocating for

The rights of women

Hoping that this is a milestone towards enabling women to make rightful decisions for

Themselves and for their families

I dedicate this work.

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ABSTRACT

Introduction: It is estimated that 630,000 children worldwide became infected with HIV/AIDS in 2003. More than 90% of these infections are through mother-to child-transmission (MTCT) (UNAIDS 1998). The risk of HIV transmission through mother's milk has rendered infant feeding choice a most critical issue and so far it has created considerable uncertainty and fear among the HIV-infected childbearing women.

Objective: The study aimed at exploring the decision-support needs of HIV-positive mothers who attend the Prevention of Mother to Child Transmission of HIV (PMTCT) clinic at the Academic Model Providing Access to Health care (AMPATH), Moi Teaching and Referral Hospital (MTRH) facility in Western Kenya regarding infant feeding.

Setting: Moi Teaching and Referral Hospital, AMPATH centre, Western Kenya.

Study design: This was a cross sectional descriptive study.

Study population: The target population encompassed HIV infected antenatal mothers who were above 18 years of age, and who were followed-up in the PMTCT program at the AMPATH centre.

Methods: Participants were selected using consecutive sampling. A pre-tested structured questionnaire was used based on the Ottawa Decision Support guide.

Data Analysis: The SPSS V.12.01 programme was used to analyse the data. Data was summarized using proportions for categorical data and the mean for continuous data.

Results: A total of 164 (95.9%) participants completed the questionnaire. Their mean age was 30 (sd 5.6) years. The mean gestational period was 31.9 (sd 7.9) weeks. The majority, 104 (63.4%) chose to breastfeed while 60(36.6%) chose not to breastfeed. Thirty four, (21%) had difficulties in making a choice because they were unsure of what was best to do and that infant formula was too expensive. One hundred and twenty one, (74.7%) sought help from health care providers in choosing the best feeding option for the baby while, 98 (59.8%) reported that the purpose for choosing the best feeding option was in order to reduce HIV transmission. The major problems faced by HIV infected mothers in choosing the best feeding option included: Forty eight, (29.3%) cannot afford to buy infant formula and forty six (28%) mentioned HIV status as a hindering factor towards choosing the best feeding option.

Conclusion: Decision making capacity among HIV infected women is generally low especially regarding infant feeding. There is also evidence of knowledge gaps regarding HIV positive women's decision making about infant feeding options.

Recommendations: There is need to incorporate a multi-disciplinary decision-support framework using the Ottawa decisional support guide into the AMPATH PMTCT program in order to empower women with knowledge regarding infant feeding in the context of HIV and to enable them to become effective decision-makers in areas pertaining their own health and that of their family members.

LIST OF ABBREVIATIONS

AFASS-Available, feasible, affordable, safe and sustainable

AIDS-Acquired Immune Deficiency Syndrome

AMPATH-Academic Model Providing Access to Primary Health Care

HAART- Highly Active Antiretroviral Therapy

HIV- Human Immunodeficiency Virus

MTCT-Mother-To-Child Transmission of HIV

MTRH-Moi Teaching and Referral Hospital

NASCOP-National AIDS and STDs Control Programme

ODSF-Ottawa Decision- Support Framework

PMTCT-Prevention of Mother-To Child Transmission of HIV

UNAIDS- United Nations Programme on HIV/AIDS

UNFPA-United Nations Population Fund

WHO-World Health Organization

CLARIFICATION OF TERMINOLOGY

Breast milk substitutes: Any foods given represented as a partial or total replacement to

breast milk, such as commercial formula or modified animal milk.

Breast milk substitutes/ replacements: Any food being marketed or otherwise represented as a partial or total replacement for breast milk whether or not suitable for that purpose.

Cessation of breast feeding: Complete stopping of breastfeeding, including suckling.

Commercial infant formula: Breast milk substitute formulated industrially to satisfy the nutritional requirements of infants during the first months of life up to the introduction of

Complementary foods.

Decision making support: Providing information and support for a patient who is making a decision regarding health care.

Exclusive breastfeeding: When an infant receives only breast milk and no other liquids or solid, not even water, with the exception of drops or syrups consisting of vitamins,

mineral supplements or medicines.

Exclusive replacement feeding: The process of feeding a child who is not receiving any breast milk with a diet that provides all the nutrients the child needs

Health coach approach: A shared decision making style of counselling based on the Ottawa Decision-Support Framework that is designed to support individuals in making decisions that is consistent with personal values.

Heat treated expressed breast milk: Expressed milk treated with heat to inactivate micro-organisms including HIV.

Home-modified animal milk: A breast milk substitute prepared at home from fresh or processed animal milk (cow's, goat's, or sheep's milk), suitably diluted with water and with the addition of sugar and micronutrients.

Milk banks: Storage of breast milk collected from HIV negative mothers.

Mixed feeding: Feeding with both breast milk and other foods or liquids.

Other breast milk: Breast milk donated by HIV negative mothers and wet nurses.

Ottawa Decision-Support Framework: It is an evidence-based, practical, mid-range theory for guiding patients in making health or social decisions.

Weaning: It is the process of introducing semi-solid foods to infants, usually at the age 6 months.

Wet nursing: Breast feeding by a woman who is not the infant's biological mother.

CHAPTER ONE: AN OVERVIEW OF THE STUDY

1.1 Introduction

HIV/AIDS has become the world's most devastating epidemic, particularly in developing countries. Women and girls make up a growing proportion of those infected by HIV/AIDS. At the end of 2004, UNAIDS reported that women made up almost half of the 37.2 million adults (aged 15-49) living with HIV/AIDS worldwide (USAID Health; 2007). The transmission of the HIV from the mother to child can occur during pregnancy, birth and during the period of breast feeding (UNAIDS 2004).

Antenatal care is often the entry point for women into the health care system. In many countries, it is also the first time a woman will undergo, or be offered HIV testing if she has not been tested previously. Pregnancy; therefore, can create a chain of complex health issues for women, particularly when HIV/AIDS is a concern (Douall et al., 2006:280).

Douall also argues that when a woman tests positive for HIV she is faced with a cascade of complex and sensitive issues which depend on context and resources available. Traditionally, women follow the advice of health care workers or family members (Basset, 2000: 128), but often lack the information, support and resources to make an informed decision.

To better inform the health team about strategies to provide patient/client-centred decision-support for HIV-positive mothers regarding infant feeding, we first of all

need to understand the HIV-positive women's decision-support needs and factors influencing their involvement in decision making. A better understanding of the decision-support needs of HIV-positive mothers, as it relates to infant feeding choices, will inform interventions to assist practitioners to tailor counselling and health education models to address their clients' decision-support needs (Douall et al., 2006:288). In addressing the decision-support needs of HIV-positive mothers there is the potential to increase adherence to safe feeding options and improve health outcomes for both mother and infant. Thus in turn might decrease the burden of disease on the health care system of Kenya.

1.2 Background and rationale for the study

The rate of HIV infection in women, of reproductive age in Kenya, coupled with the high total fertility rates of HIV, is 5/1000 on average, translates into an estimate of 30,000 to 40,000 children under the age of 5 years who become infected with HIV/AIDS annually (assuming 40% of the transmission is from mother to child) (KDHS, 2003).

Findings from the Africa Centre for Health and Population Studies clearly indicate the risk of mother to child transmission through breastfeeding during the first months of life (Keith Alcon, 2007:1). Furthermore, the differences in transmission risk between women with advanced HIV disease and those with an intact immune system are demonstrated.

The risk of Mother to Child Transmission (MTCT) is less with exclusive breastfeeding because breast milk strengthens and protects the intestinal mucosal

integrity. More complex proteins such as cows' milk may lead to a greater damage to the lining of the stomach, allowing the virus to pass through the gut wall. Exclusive breastfeeding is also associated with fewer breast health problems such as mastitis and breast abscesses, which can increase the amount of virus in the mother's breast milk (Keith Alcon, 2007:1).

The WHO's recommendations on infant feeding which were formulated in 2006 in the absence of ARV interventions recommended that, breastfeeding should stop after the infant has reached six months of age. The recommendations have however changed.

The 2009, WHO report recommends that, mothers known to be HIV infected should be provided with lifelong anti retroviral therapy or antiretroviral prophylaxis to reduce HIV transmission and to exclusively breastfeed their infants for the first six months of life, while introducing appropriate complimentary foods thereafter, and to continue breastfeeding for the first 12 months of life(WHO, 2009;2).

In most of the African communities, including Kenya, neither exclusive breastfeeding nor exclusive non-breastfeeding is the cultural norm as mixed feeding is the predominant method of infant feeding (Iliff et al., 2005). According to a study done on infant feeding practices in Lusaka, Zambia, only babies aged four months or younger were exclusively breastfed. HIV-infected mothers introduced both alternative fluids and complementary foods earlier than HIV-uninfected mothers and often before two months. Breast milk substitutes were being used by less than one-quarter of all the mothers, with commercial infant formula most popular with HIV-uninfected

mothers, and a greater proportion of HIV-infected mothers using modified cow's milk (Omari et al., 2003).

The PMTCT program aims at prevention of mother to child transmission during pregnancy, labour, delivery, and breastfeeding. One of the major responsibilities of the program therefore is to counsel HIV positive mothers on the recommended infant feeding options. The decision of which option to adopt is then left to the HIV infected mother whose decision is greatly influenced by others such as her husband, mother, mother-in-law and the community at large (Wachira, 2004:2). This requires of the woman to act as an autonomous decision-maker in a setting where women traditionally follow the advice of health care workers or family members (Bassett et al., 2000).

Counselling HIV infected mothers should be done with great consideration of personal, cultural, social and environmental factors that influence the selected infant feeding option (Bassett et al., 2000). The PMTCT program at Moi Teaching and Referral Hospital (MTRH) was started in March 2002 with the objective of reducing MTCT of HIV-1.

The program initially provided free formula coupled with safe water initiatives to mothers in the PMTCT programme, with combined antiretroviral therapy (cART). The HIV infected pregnant women were followed up from 2002 to 2007. The results indicated that 133 (2.2%) infants tested had a positive 6-week HIV DNA PCR (Nyandiko et al., 2010:2). Currently, exclusive breastfeeding up to 12 months with combined antiretroviral therapy (cART) is promoted.

In this particular case, multiparous women who previously participated in the PMTCT programme were advised to exclusively formula-feed their babies with formula sponsored by the programme. The problem this particular group of women will be confronted with when pregnant again, is the contradiction in the advice and this might confuse them.

Experience also indicate that other HIV-positive women attending the antenatal clinic received the message that free formulas are provided for women attending the clinic and on that grounds decided to take the risk to fall pregnant. The ethical dilemma arising from this situation necessitates that health professionals urgently look at how women can be supported in decision making in order to make safe choices.

Given this background, it became imperative that a context-specific evidence-based decision-support framework, used by health care workers or trained lay workers to coach women through this decision, is investigated (Douall et al., 2006:280). However, little is known about the decision-support needs of HIV-positive women attending the local PMTCT clinic. In understanding these needs, the PMTCT team would be better informed as to how to develop a shared decision-support intervention.

1.3 Problem statement

Infant feeding in the context of HIV is complex because of the major influence that feeding practices and nutrition have on child survival. Depending on the availability of interventions to reduce HIV transmission pregnancy and delivery, HIV transmission through breastfeeding is responsible for between 30-60% of all HIV infections in children. However in many resource-limited settings, infants who are not

breastfed are up to six times more likely to die from malnutrition, pneumonia and diarrhoeal illnesses. (WHO, 2009; 2)

Against this background it became imperative that HIV infected women attending the PMTCT clinic at the MTRH should be supported in their decision making on safe infant feeding as many of them might be confused by the previous regime and need additional decision-support. However, little is known about their decision-support needs in terms of safe feeding choices.

1.4 Research Question

What are the decision-support needs of HIV-positive mothers regarding infant feeding in a rural context in Kenya?

1.5 Research Objective

To explore the decision-support needs of HIV-positive mothers who attend the PMTCT clinic at AMPATH, MTRH in Western Kenya.

1.5.1 Specific objectives

1. To describe the decision-support needs of HIV-positive mothers attending the antenatal clinic at AMPATH, MTRH in Western Kenya.
2. To describe interventions that may enhance and develop women's decision-making capacity regarding infant feeding in HIV/AIDS at AMPATH, MTRH in Western Kenya.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Mother-to-child transmission of HIV (MTCT) represents a major threat to the gains in child health achieved during the last decades in Kenya. Furthermore, it represents a huge public health problem in HIV-affected populations, especially as it threatens breastfeeding (Preble et al., 2001). It is estimated that in the absence of any intervention, 30-45% of infants born to HIV-positive mothers who breastfeed for 18-24 months will be infected with HIV either during pregnancy and birth or during breastfeeding. It is further estimated that 40% of HIV infection may occur during breastfeeding when it is extended for two or more years (De Kock et al., 2000).

The above background gives us a picture of the magnitude of the problem. It shows the dilemma that HIV infected women face in choosing the best feeding options for their babies.

2.2 Benefits and harms of exclusive formula feeding

In comparing formula feeding with breast feeding alone, formula feeding in a setting where clean water and health education are available is more effective than breast feeding alone at reducing the risk of MTCT of HIV infection at 24 months of age (Nduati, 2000).

All the evidence suggests that mixed breast and formula feeding is the most dangerous feeding option for the young infant. It increases the risks of HIV and other infections. Regimens that support formula feeding as a way of reducing mother to

child transmission of HIV need to consider the risks of non-compliance. Even in a sophisticated clinical trial in which urban Kenyan women were assigned to either breast or formula milk feeding groups, poor compliance was reported in the formula group. Furthermore, the women often experienced community, family or spousal pressure to breastfeed, and were sometimes concerned about maintaining confidentiality of their HIV-1 status. Thus, it was difficult to ensure exclusive formula feeding, even in mothers who had been carefully counselled and had agreed to participate in the clinical trial in which formula milk was provided free (Nduati et al., 2000).

When formula feeding is compared with breast feeding in combination with antiretrovirals for infants, at the age of seven months, formula feeding is more effective at reducing HIV infection (Mbori-ngacha et al., 2000). Formula feeding; however, can alert a woman's family or community to the fact that she is HIV-positive and may result in stigma or other negative attitudes towards the non-breastfeeding mother and /or her family (De Paoli et al., 2002; Rollins et al., 2002; Nduati et al., 2000). According to a study done in Botswana, where formula feeding in HIV-positive women was strongly encouraged and offered free through PMTCT programmes, it was concluded that adherence to exclusive formula (no breast milk) was sub-optimal and potentially under reported (Shapiro et al., 2003). However, another study done in Botswana (the Mashi Study) reported very high levels (91%) of adherence to formula feeding compared to only 18% adherence to exclusive breastfeeding (Clayden et al., 2005).

From the above studies it is clear that replacement feeding with formula is not a realistic or affordable option in low income settings where safe water and adequate formula may not be available, even for literate urban women.

2.3 Breastfeeding practices

Breastfeeding protects the child against childhood diseases, malnutrition and waterborne diseases and has beneficial health effects for mothers, including reduction in breast cancer, ovarian cancer, and lactation amenorrhea that promotes greater birth spacing (Weinberg et al., 2000; Coutsooudis et al., 2001).

However, a randomized controlled trial of breastfeeding versus formula feeding in Nairobi found that 44% of HIV transmissions occurred through breastfeeding and a 16.2% higher post-natal transmission of HIV in breastfeeding than in formula feeding (Nduati et al., 2001). Mixed feeding however seem to be the common practice.

Piwoz and Humphrey (2005), de Paoli et al. (2002), Bland et al. (2002) and Chopra et al. (2000), found that women of unknown HIV status who started with exclusive breastfeeding, introduced formula and/or solid foods to their babies from one to three months old.

Another study also indicated that mothers of unknown HIV status reported to have introduced fluids as early as 48 hours after birth (Bland et al., 2000). Studies from Cote d'Ivoire and Uganda also indicate that mothers who are HIV-positive, who initially began with exclusive breastfeeding, later on switched to mixed feeding by the time their babies were three months old (Bakaki, 2002; Bequet et al., 2005). However,

breast-feeding is superior to mixed feeding. Exclusive breastfeeding reduced post-natal transmission of HIV by 61% compared to mixed feeding and this protective effect was still significant 18 months post-delivery (Ilf et al., 2005). Mixed feeding is more harmful than exclusive formula feeding and is associated with a four-fold increase in the risk of HIV-positive mother-to-child transmission during the first six months of life, and a three-fold increase in HIV transmission plus death (Coutsoudis et al., 2001; Leroy et al., 2003; Iliff et al., 2005).

The increased risk of transmission with mixed feeding may be due to reduced immune benefits from the minimal breast milk that infants ingest as well as introduction of other foods to an immature system which may cause damage to the mucosal linings of the gut allowing the virus easier passage (Coutsoudis et al., 2000; Willumsen et al., 2003).

The main obstacle to exclusive breastfeeding is that it is not the norm in Kenya. In most sub-Saharan countries mixed feeding is the norm.

2.4 Current recommendations

In October 2006, the HIV and infant feeding policy was revised. The new evidence was that early exclusive breast-feeding is protective against postnatal transmission of HIV compared with mixed feeding. The 2006 report also specified that, breastfeeding should continue beyond six months if a replacement feeding is not available, feasible, affordable, safe and sustainable (AFASS) (Ilf et al., 2005; Rollins et al., 2007). Therefore even though replacement feeding remains the best option for HIV infected women in situations with plentiful nutritious foods and breast milk substitutes ,good

sanitation, clean water, and cooking fuel, it is still not feasible in most settings (Humphrey, 2010;4).

The criteria of AFASS pertaining to alternatives for breastfeeding are currently being studied in Zambia, Zimbabwe and Cote Divoire (Leshabari et al., 2007). However, breastfeeding has been proven to be ideal in reducing infant and child morbidity and mortality, as it greatly reduces the risks of contracting enteric infections and it also provides good nutrition to infants, particularly in resource poor settings (UNICEF, 2001; WHO, 2009; Bhandari et al., 2003).

The AMPATH program which is working under the National Aids and Control Council (NACC), adopted the WHO's recommendations on infant feeding in HIV where mothers who are HIV-infected, and whose infants are HIV uninfected or of unknown HIV status, are counselled about exclusive breastfeeding for the first six months of life, where after they can introduce appropriate complimentary foods, and continue breastfeeding up to 12 months of life (WHO, 2009: 2).

An often overlooked alternative feeding option is the use of the mother's own expressed breast milk, which has been heat-treated to kill the HIV. Heat treating expressed breast milk could prove to be safer than formula feeding in many settings where there is no reliable access to clean drinking water or a consistent supply of formula (Israel-Ballard et al., 2006). Furthermore, it is stated that heat treated breast milk may be most feasible during times of high risk, such as mastitis during and after abrupt weaning. According to the current WHO's recommendations regarding heat-treated breast milk, it could be considered as a potential approach to safely provide

breast milk to the exposed infants although more research is needed in this area of HIV prevention and child survival (WHO, 2009:20).

2.5. Factors influencing HIV positive mothers' decisions on infant feeding

Despite these recommendations, common practice in Kenya is that of mixed feeding. Factors that could influence many women in Africa to breastfeed, despite counselling recommending otherwise, include: the high cost of alternative feeding options, fear of disclosing HIV status, and lack of awareness about the risks of not breastfeeding their children (Basset et al., 2000; Coutsooudis et al., 2001).

2.6. Mothers' perceptions concerning breastfeeding

Mothers often have a misconception that breast milk alone is not sufficient for healthy child development. There are also cultural taboos associated with colostrums and early milk production. In some settings HIV-infected mothers perceive their milk as harmful to their infants, and therefore they introduce breast milk supplements and complementary foods earlier, which might be the problem women in this study face (Basset et al., 2000).

2.6. Perceptions of others about breastfeeding in HIV

Clients/patients normally expect their healthcare providers to be proficient in decision support, or at least to direct them to trustworthy resources. However, this is not the case in many African countries, as studies indicated that health professionals are not necessarily comfortable to actively engage patients in decision making. Hence, they may not recognize decisional conflict, and focus their attention mainly on information

giving without addressing a patient's values and preferences (Makoul et al., 1995; Stacey et al., 2003).

In many settings, breastfeeding is linked to social and cultural norms and expectations. HIV-infected mothers who are not breastfeeding often feel that society do not accept them. Women reported that they may be abused, ridiculed or interpreted as selfish (Basset et al., 2000; Seidel et al., 2000). They also face social stigma and are often suspected of being promiscuous, ill with HIV or pregnant (Omari et al., 2003:161).

In other studies regarding perception, some health care workers are unsupportive of formula –feeding. A study in South Africa found that nurses insisted on women to breast-feed after delivery, regardless of personal choice, and they did not counsel women about potential risks of breast-feeding if HIV positive (Seidel et al., 2000). Research from Tanzania found that counsellors often received contradictory information about breastfeeding and transferred this uncertainty to their clients (de Paoli et al., 2002).

Research in Zambia and Kenya found that counsellors provide appropriate information but fail to account for women's social and economic circumstances when making feeding recommendations (Coutsoudis et al., 2001).

2.7 Decision-support needs

Decisional conflict, which is defined as a state of uncertainty about a course of action, occurs when two or more clinically reasonable options have benefits and are valued

differently by the patient (Dawn et al., 2007). Best evidence may point to formula-feeding as the safest option but this may not be applicable in places where there is no safe water. Decision conflict can be affected by modifiable factors, such as insufficient knowledge, unrealistic expectations, unclear personal values, and inadequate support and resources for decision-making (O'Connor, 1995). Unresolved decisional conflict leads to decisional reversal, dissatisfaction, regret, and blaming providers for poor outcomes (Sun, 2004; Gattellari & Ward, 2005).

A decision-support strategy may assist in realigning expectations regarding infant feeding options and clarifying evidence and misinformation (Doull et al., 2006). The role of decision-support further assists people in making the choice that is most consistent with individual values, which will vary from one region to the other.

2.8 Conceptual framework

The Ottawa Decision-Support Framework provides a framework (See Fig. 2.1, p. 13) to promote high quality decisions, which are informed and consistent with individual values (O'Conner et al., 1998). The Ottawa Decision Support Framework bases its argument on the fact that decision quality improves when both patients and practitioners participate in decision making. Decision coaching also facilitates patient engagement and empowerment in shared decision making (Dawn et al., 2007). According to the framework, the role of the primary practitioner is to identify clinically reasonable options based on the patient's needs, screen for decisional conflict, determine the patient's decision making needs, provide initial decisional support and, if necessary refer the patient for decisional support (Dawn et al., 2007).

Dawn (2007) further illustrates patients/clients' role in shared decision-making. Patients/clients need to be informed by the evidence and share their personal values and priorities shaped by their social circumstances (Coulter, 2002). Evidence indicates that patients/clients who are actively involved in making decisions have better long-term health outcomes (Hark et al., 2006). However, when faced with value-sensitive decisions, patients frequently experience decisional conflict and need support in decision making (Bunn et al., 2006; Doull et al., 2006; O' Connor et al., 2003).

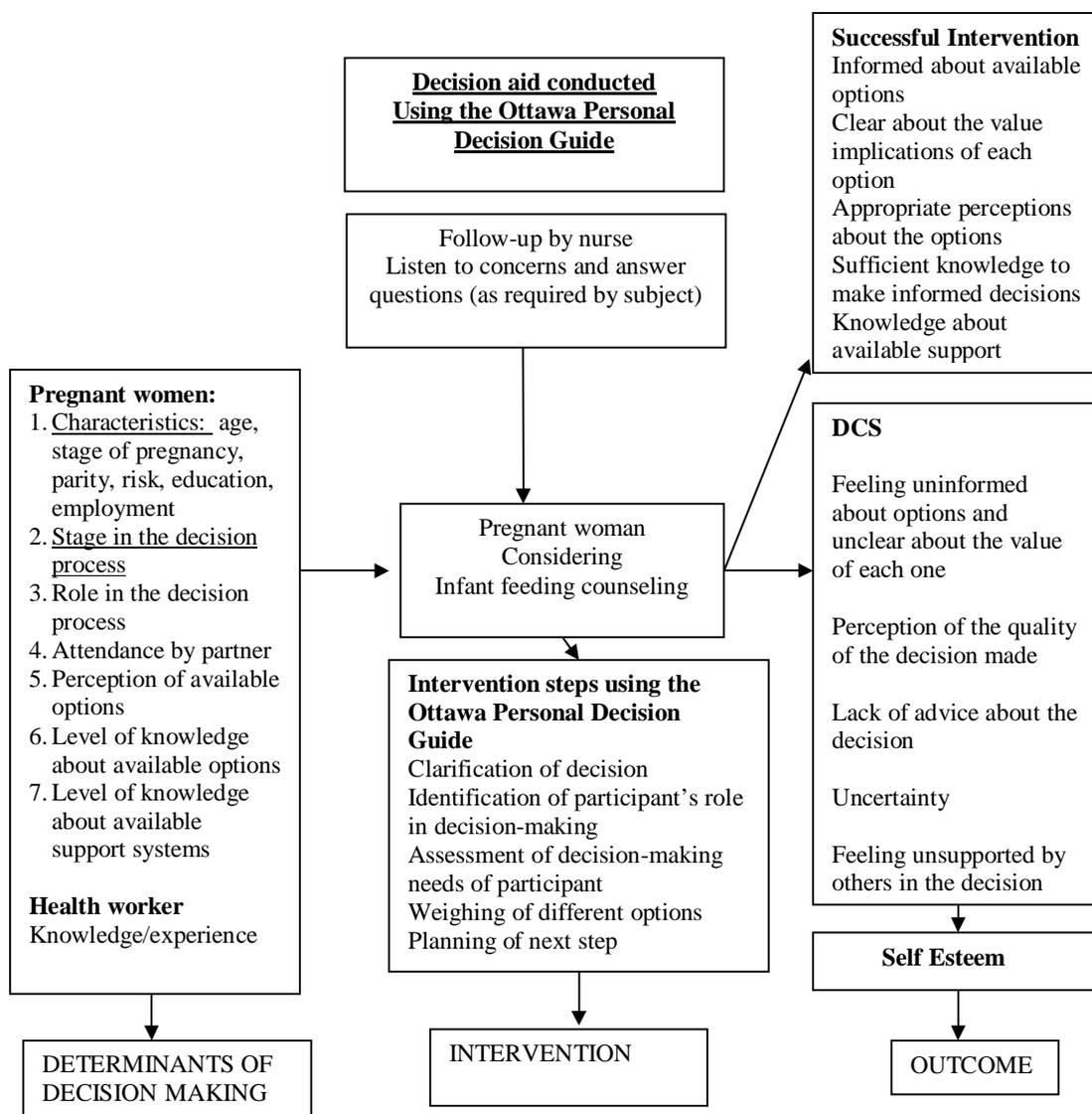


Figure 2.1 Conceptual framework based on the Ottawa Personal Decision Guide (Arimori, 2006:121)

Decision coaches recognize patients in decisional conflict and intervene by guiding them through the decision-making process as outlined in the Ottawa Decision Support

Framework (O'Connor et al., 1998). The overall goal is to support patients to be involved in decision-making and achieve quality decisions (Dawn et al., 2007). The questionnaire that was used to collect the data was drawn from the above framework, (Figure 1). It is hoped that by using the above framework, HIV infected women will be able to make quality decisions regarding safe feeding options for their infants.

CHAPTER THREE: METHODOLOGY

3.1 Study area

The research was conducted at Moi Teaching and Referral (MTRH) which is located in Rift Valley Province, Uasin Gishu District along Nandi Road Eldoret town. HIV/AIDS is one of the top ten morbidity diseases in the Uasin Gishu District. The most affected group is the age group 15–49 years who are in their reproductive years.

MTRH is one of the two national referral hospitals in Kenya, the other being Kenyatta National Hospital (KNH), which is based in Nairobi, Kenya's capital. MTRH began in 1917 as a cottage hospital with a bed capacity of 60 to cater for the health needs of Kenyans. Since then it has grown into a referral hospital with a capacity of nearly 500 beds. Its catchment's area includes the rural Rift Valley, mainly the North Rift, and the Western province, a region in which slightly more than one-third of the Kenyan population lives. It serves about 1000 out patients per day.

The hospital runs a comprehensive HIV care program at the AMPATH centre, within which an elaborate PMTCT program is incorporated. The AMPATH HIV care programme has its headquarters located within the hospital (MTRH) and has 18 main rural satellite sites. Patients in the care programme are seen as outpatients and those who require admission are taken to the hospital wards. The centre has four outpatient HIV care clinics, comprising of three adult clinics (module 1, 2 and 3) and one paediatric clinic (module 4). The study was conducted at one module 1 clinic of the AMPATH centre to which antenatal mothers are referred for care after testing positive for HIV.

3.2. Study design

A descriptive study was employed. This design was appropriate because the main focus of the study was to assess the decision-making support needs of HIV-positive pregnant mothers attending an AMPATH PMTCT clinic. This descriptive study design provided a picture of situations as they naturally happen (Burns & Grove, 2005:232). Quantitative methods were used. Closed-ended and open-ended questions were used in collecting data.

3.3. Study population

The target population encompassed HIV infected antenatal mothers who were above 18 years of age, and who were followed-up in the PMTCT program at the AMPATH centre.

INCLUSION CRITERIA

To be included in the study the women needed to:

- Have a positive HIV test and be pregnant and being followed up at AMPATH module one clinic
- Have visited the antenatal clinic at least once before during current pregnancy
- Be available and willing to participate

EXCLUSION CRITERIA

- Clients of unsound mind and are unable to make decisions
- Pregnant clients who are ill and requiring immediate obstetric or other medical care

3.4. Sample size determination

The sample size required for the study was determined by using a 95% confidence interval and a sample error of 5%. The following formula was used:

$$n = \frac{z^2 pq}{d^2}$$

Where:

Z: is the statistical constant representing a 95% confidence interval = 1.96

P: proportion of the study attribute in the target population (0.5 since it is unknown)

q: is the equivalent to 1 – p

d: is the sampling error = 5% or 0.05

$$n = \frac{(1.96)^2(0.5)(0.5)}{(0.05)^2}$$

$$n = 384$$

Since the target population of pregnant women who tested positive at the ANC and were referred for care at AMPATH clinic during the period of January to December of 2008 was 307, which is less than 10,000, we adjusted the sample size using the adjustment factor $n / (1+n/N)$. Hence,

$$N = 384 / (1+384/307)$$

$$= 171 \text{ study participants.}$$

3.4. Sampling technique

This is the process of selecting the desired sample for the study (Polit & Beck 2004; Burns & Grove, 2005). Participants were selected using consecutive sampling where any eligible participant was included in the study as they presented one after the other until the total sample size (171) was obtained. If the participant was not eligible or did not give consent, the next eligible participant was sampled.

Besides the benefit of overcoming the practical difficulties of meeting sample size requirements in clinical research, consecutive samples are useful in minimizing volunteerism (Stephen et al., 2001). The principal researcher flagged the files of all eligible antenatal mothers who were already enrolled into a module one AMPATH clinic.

After they were reviewed by the clinicians during their clinic visit, the antenatal mothers who were eligible were sent for the interview.

3.5. Pilot study

A pilot study with 14 women (10% of total sample) was carried out at Uasin-Gishu District Hospital PMTCT site (a satellite clinic of AMPATH). According to Burns and Grove (2005), reliability is the consistency of measure obtained in using a particular instrument and is an indication of the extent of random error in the measurement method. Validity, as noted by Burns and Grove (2005), is the determination of the extent to which the instrument reflects the construct being examined.

3.6. Data Collection tools and Method

A structured questionnaire (Appendix 2), with both open- and closed-ended questions, was used to determine the decision-support needs of HIV infected mothers on infant feeding. The questionnaire was adopted from the Ottawa decision Support Framework and the questions were written in a simplified manner to allow for easy understanding by the study participants. This Framework is an evidence-based, practical, mid-range

theory for guiding patients /clients making health or social decisions (O'Connor et al., 1998). The tool was administered in English. The pre-tested structured questionnaire was then administered to the HIV-infected antenatal mothers attending the PMTCT clinic at a module one clinic at the AMPATH centre. Responses were filled by the researcher as the interview took place. Each interview lasted for approximately thirty minutes.

3.7. Data management, entry and analysis

Data entry was done by the researcher with the assistance of the statistical package SPSS. Data cleaning (missing data and data entry errors) was done by entering it into Epidata where spelling mistakes were corrected and wrong code insertion detected to ensure uniformity of the data collected. The data was then exported to SPSS V.12.0 for analysis. Data analysis was done with the assistance of a statistician. Data storage was done in a computer and back ups. The information was also stored in a memory flash drive. The questionnaires were kept safely by the interviewer in carton boxes. Data was summarized using proportions for categorical data (e.g. demographics) and mean for continuous data. The chi-square test was used to check for association between social-demographics and having information to make the right decisions regarding infant feeding. T-test was used in case of a continuous variable e.g. age and gestation period. P-value of less than 0.05 was considered significant. Representation of the results was done using frequency tables, pie-charts and graphs.

3.8 . Limitations of the study

Since the study was a cross sectional survey, no causal inference can be made from the associations, as the temporal order of events could not be established. However, the findings can form a basis on which several hypotheses can be generated and

possibly tested with analytical epidemiological studies. The study population was small and centered on population of HIV infected women attending the PMTCT clinic at AMPATH Centre; hence the data obtained may not be representative of all the HIV infected antenatal mothers population in Kenya. Also, participants in this study may have received counseling and education on infant feeding options and were likely to be knowledgeable than the general population in Kenya since they were already enrolled in a PMTCT program.

3.9. Ethical considerations

After the research proposal had been accepted by the supervisors and the Department of Nursing Sciences, Moi University, the following were ensured:

3.9.1. Clearance by the Ethics Committee

Before commencing the study, the research proposal was submitted for approval to the Institutional Research and Ethics Committee (IREC), Moi University and MTRH.

3.9.2. Permission to carry out the study

Following the approval by the IREC, permission was sought from the AMPATH Research Committee (Appendix 3) to allow me to proceed with the study in the institution.

3.9.3. Respect for autonomy

The identified participants who met the eligibility criteria had full explanation about the purpose of the study. After agreeing to participate, they signed a consent form that gives the details of the nature of the study. They were free to withdraw from the

study without penalty. In this case, the researcher was very cautious when dealing with the group of HIV positive women; because they were considered vulnerable to some extent because of their status, to ensure that the research does not subject them to any harm. (Burns & Grove, 2005:189).

3.9.4. Confidentiality

Confidentiality of the participants was assured by ensuring that their names were not appearing in the final drafts of the study and that all the questionnaires for the interviews were locked up and keys kept safe (Burns & Grove, 2005:189).

3.9.5. Principle of beneficence

Beneficence imposes a duty on the researcher to minimise harm and to maximise benefits. Every effort was made in the study to protect subjects from discomfort and ensure non-exploitation of the participants. The participants were assured that their participation or any information they provide was not be used against them in any way. Information provided by the participants was not being exposed to any harm by the researcher (Polit & Beck, 2008:170-171).

CHAPTER FOUR:

RESULTS

4.1. Demographic information

A total of 164 (95.9%) participants completed the questionnaire. Their mean age was 30 (sd 5.6) years. The majority, 106 (64.6%), were from an urban residence area and 124 (75.6%) were married. More than three quarters, 130 (79.3%), had secondary and below level of education. More than half, 104 (63.4%), had no occupation and almost all, 162 (98.8%), were Christians. The mean number of children was 3 (sd 2.3), while the mean gestational period was 31.9 (sd 7.9) weeks. Only occupation was significantly associated with having enough information to make decision ($p=0.046$), as indicated in table 4.1 below.

Table 4.1: Association between demographic characteristics and having enough information to make a decision (n=164)

characteristic	Having enough information to make decision		chi-sq/t-value	p-value
	No	Yes		
Residence			1.56	0.212
Urban	37(34.9)	69(65.1)		
Rural	26(44.8)	32(55.2)		
Marital status			1.151	0.765
Single	12(42.9)	16(57.1)		
married	45(36.3)	79(63.7)		
Divorced/sep	4(50)	4(50)		
Widowed	2(50)	2(50)		
Education			3.178	0.529
None	14(53.8)	12(46.2)		
Primary	24(34.8)	45(65.2)		
Secondary	13(37.1)	22(62.9)		
College	10(35.7)	18(64.3)		
University	2(33.3)	4(66.7)		
Occupation			8.006	0.046
None	45(43.3)	59(56.7)		
Formal employment	4(20)	16(80)		
Business	12(46.2)	14(53.8)		
Farmer	2(14.3)	12(85.7)		
Age	29.8±5.6	30.2±5.6	0.463	0.644
Preg. gestation	31.4±8.0	32.3±7.9	0.692	0.490
No. of children	2.6±2.3	2.9±2.3	0.794	0.428

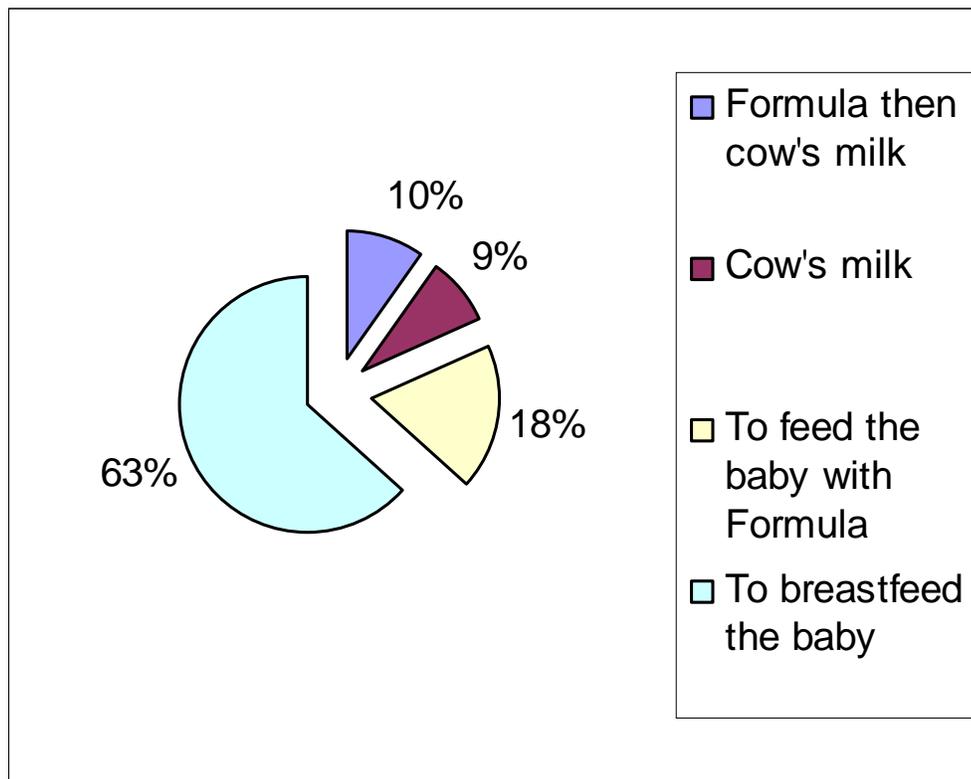


Figure 4.2. Types of decisions (n=164)

As indicated in figure 4.1 above, more than half of the respondents, one hundred and four (63.4%) chose to breastfeed, sixty mothers chose not to breastfeed, of which thirty (18.3%) chose to use formula, fourteen (9%) chose to feed their baby with cow's milk, and sixteen (10%) chose to initially start with formula after which they then switched to cow's milk later on.

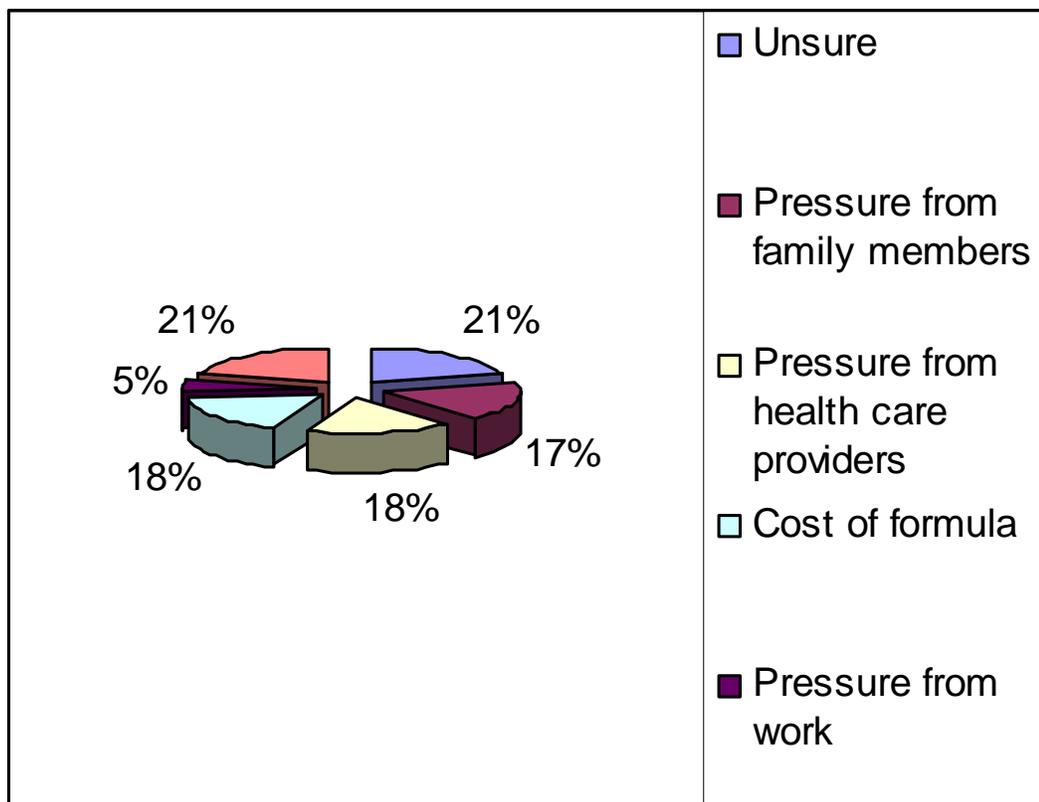


Fig 4.3 Difficulty with decision making (n=164)

Regarding difficulties in making a choice on how to feed the baby, thirty four (21%) mentioned that they were unsure of what method is the best for their babies. Twenty eight (17%), reported that they experienced pressure from family members, and thirty (18%), reported that they experienced pressure from health care workers. One respondent, (5%), experienced pressure from work. Thirty (18%) reported that infant formula was too expensive for them. Others, thirty four (21%), attributed the difficulty in making a decision to: lack of enough food in the family, financial problems, and past experiences of having had their baby infected with HIV after breastfeeding.

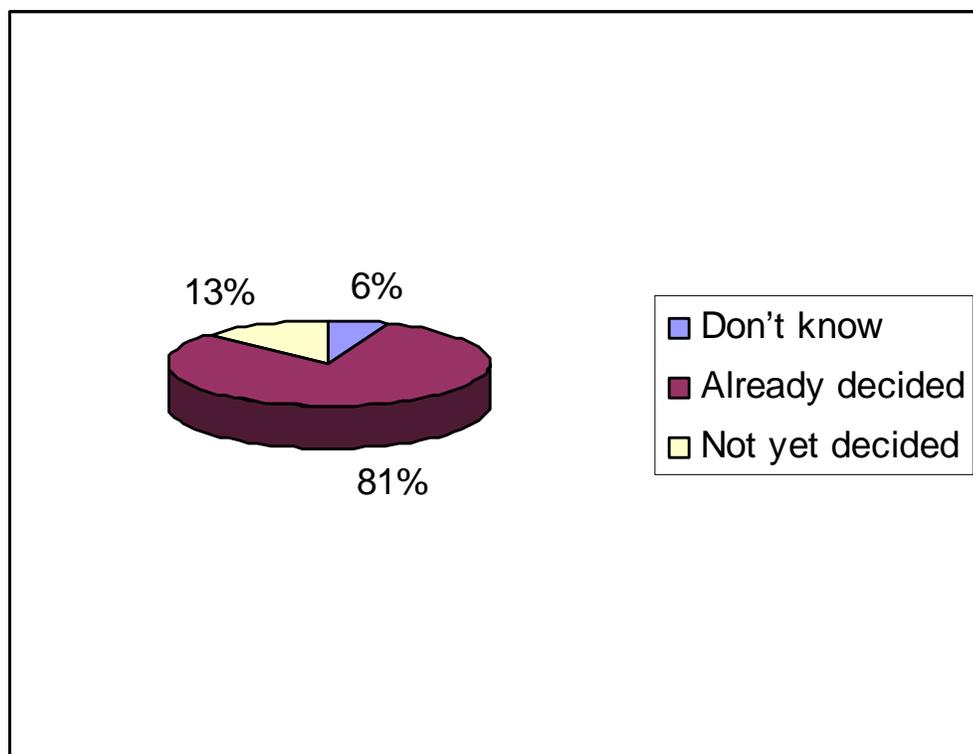


Fig 4.4 Stage in decision-making process (n=164)

The majority of the respondents, one hundred and twenty one (80.9%), had already decided on which method to feed their baby with. Only twenty one (13%) of the group indicated that they have not decided on what to feed the baby after delivery, as shown in figure 4.3 above.

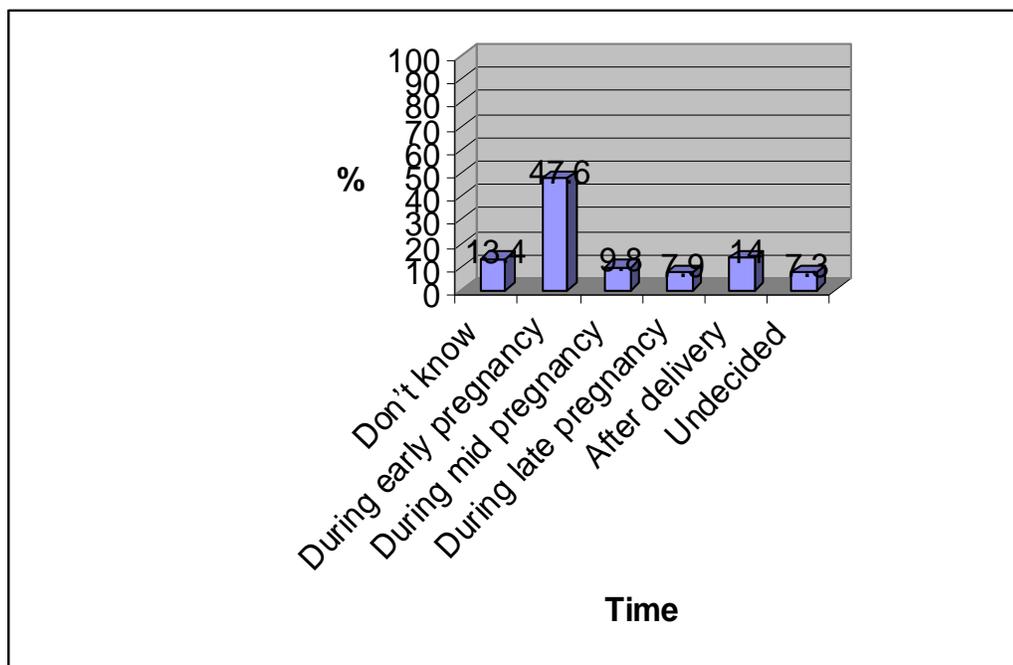


Fig 4.5 Best time to choose baby feeding method

(n=164)

In figure 4.4 above, almost half of the respondents, seventy eight (47.6%), indicated that the best time to choose a baby feeding method is early in the pregnancy, twenty three (14%) indicated after delivery is the best time, and twenty two (13.4%) did not know when is the best time to decide on a method of feeding the baby and another eleven (7%) were undecided on what to do.

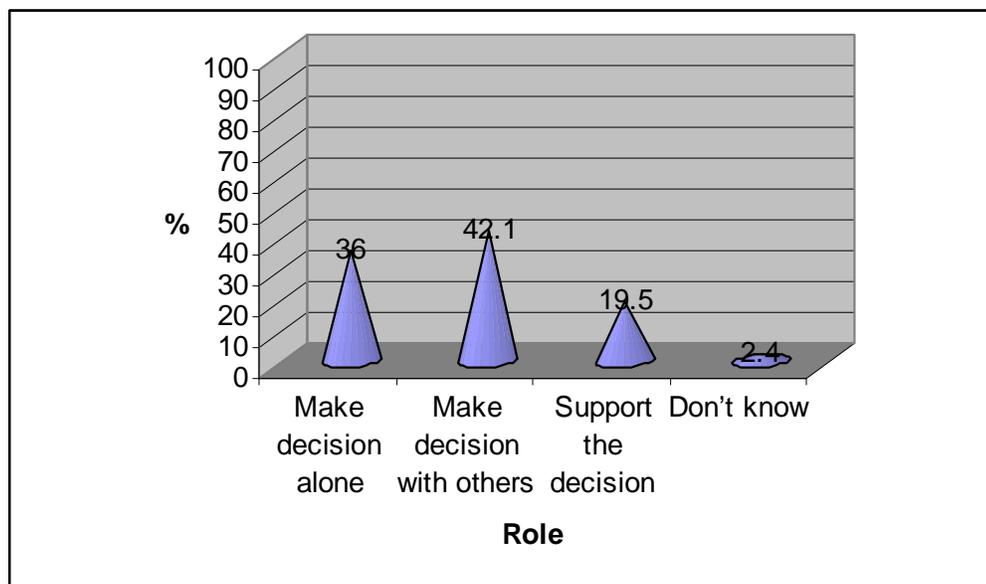


Fig 4.6 Role of HIV mothers in the decision-making process (n=164)

With regard to the role played by respondents in choosing the best method of feeding the baby, sixty nine (42.1%) reported that the decision was made with help from others i.e. husbands, mothers, mothers-in-law, health workers, sisters and friends. Another fifty nine (36%) of the respondents reported that they made the decision alone, while thirty two (19.5%) just supported the decision already made by the health care worker or the husband. Other respondents, four (2.4%), were not aware of their role in the decision- making process regarding infant feeding.

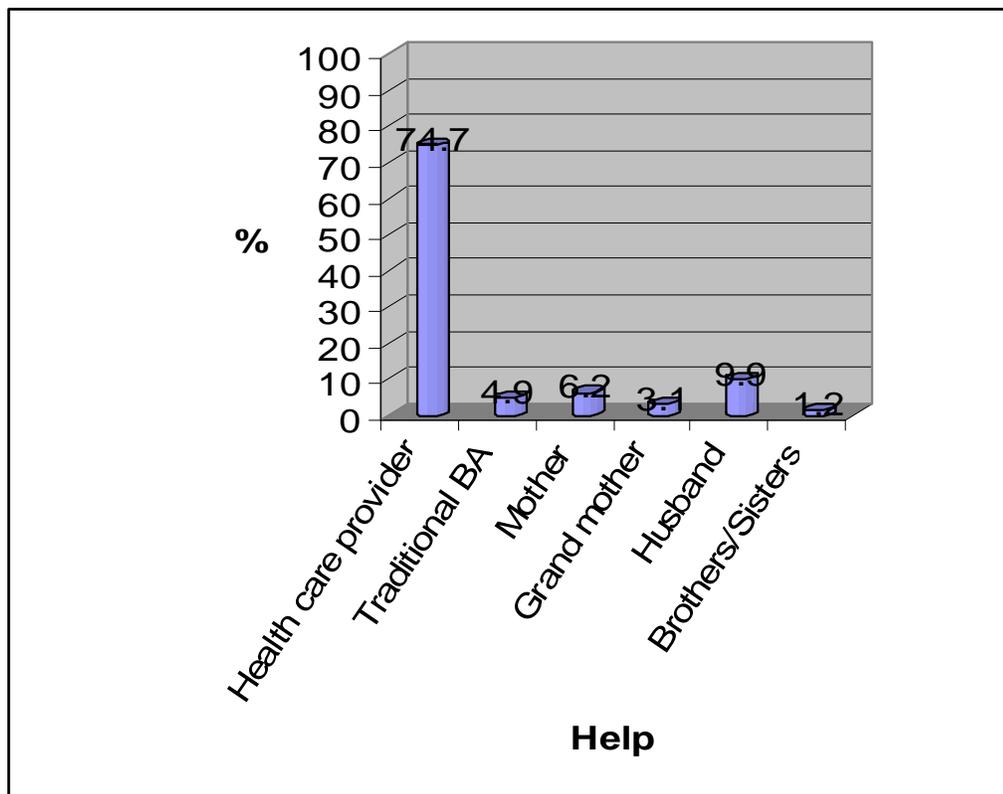
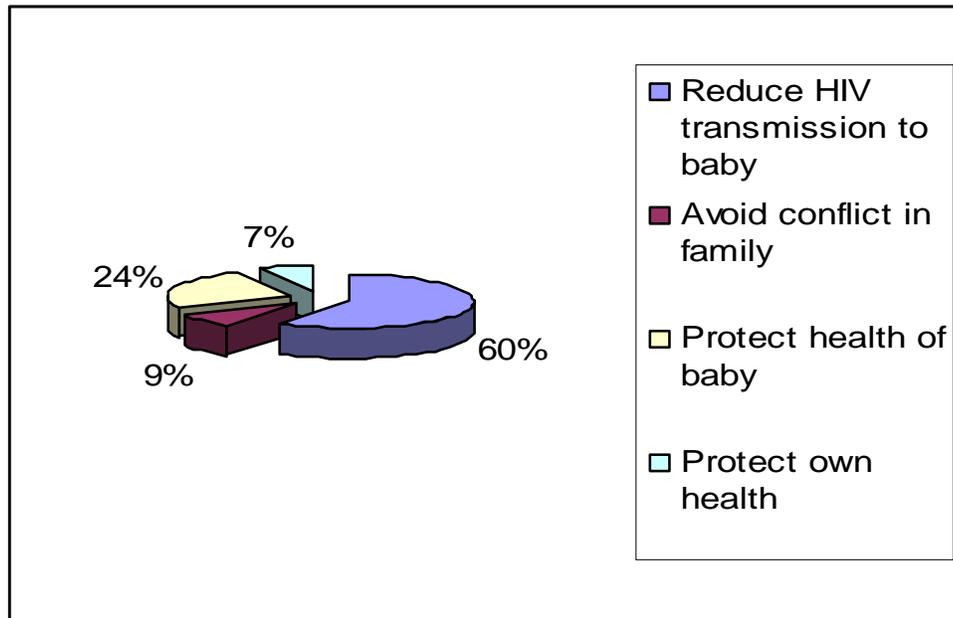


Fig 4.7 Preferred resources to support decision making (n=164)

The preferred resources to support their decision making, as indicated by the respondents, included: three quarters of the respondents, one hundred and twenty one (74.7%), sought help from health care providers in choosing the best feeding method for their baby. Sixteen, (9.9%) sought help from their husbands, ten (6.2%) from their mothers, eight (4.9%) from traditional birth attendants, five (3.1%) from their grand mothers, and two (1.2%) from brothers and sisters, as shown in figure 4.6 above.



**Fig 4.8 Reasons for choosing a particular feeding option for the baby
(n=164)**

More than half of the respondents, ninety eight (59.8%), chose a specific infant feeding method in order to reduce the risk of HIV transmission to their baby. Over forty (24.4%) indicated that the reason was to protect the health of the baby, and forty (24%) mentioned that it was to protect their own health. A further fourteen (8.5%) indicated that it was to avoid conflict in the family as indicated in figure 4.7 above.

Table 4.2. Factors contributing to the degree of difficulty in making decisions**(n=164)**

Decisional Conflict Scale (DCS)			
		No	Yes
Certainty	a) Are you clear about the best infant feeding choice for your baby after delivery?	33(20.1)	131(79.9)
	b) Are you sure of which option to feed your baby after delivery?	31(18.9)	133(81.1)
Informed	c) Are you aware of the baby feeding option that one can use when infected with HIV?	55(33.5)	109(66.5)
	d) Do you know the advantages of the baby feeding options?	62(37.8)	102(62.2)
	e) Do you know the disadvantages of the baby feeding options	74(45.1)	90(54.9)
Values	f) Are you clear about which advantages of infant feeding options are most important to you?	68(41.5)	96(58.5)
	g) Are you clear about which disadvantages of infant feeding options are most important to you?	89(54.3)	75(45.7)
Supported	h) Is there someone who is helping you in choosing the best method to feed your baby?	56(34.1)	108(65.9)
	i) When choosing the best infant feeding method for your baby, are you having any pressure from others?	102(62.2)	62(37.8)
	j) Do you have enough information to make the right choice on which infant feeding option to use after delivery?	63(38.4)	101(61.6)

As indicated in table 4.2, on the previous page, more than half of the respondents, one hundred and thirty one (79.9%), were certain about the best infant feeding option for their baby while thirty three (20.1%) respondents were not.

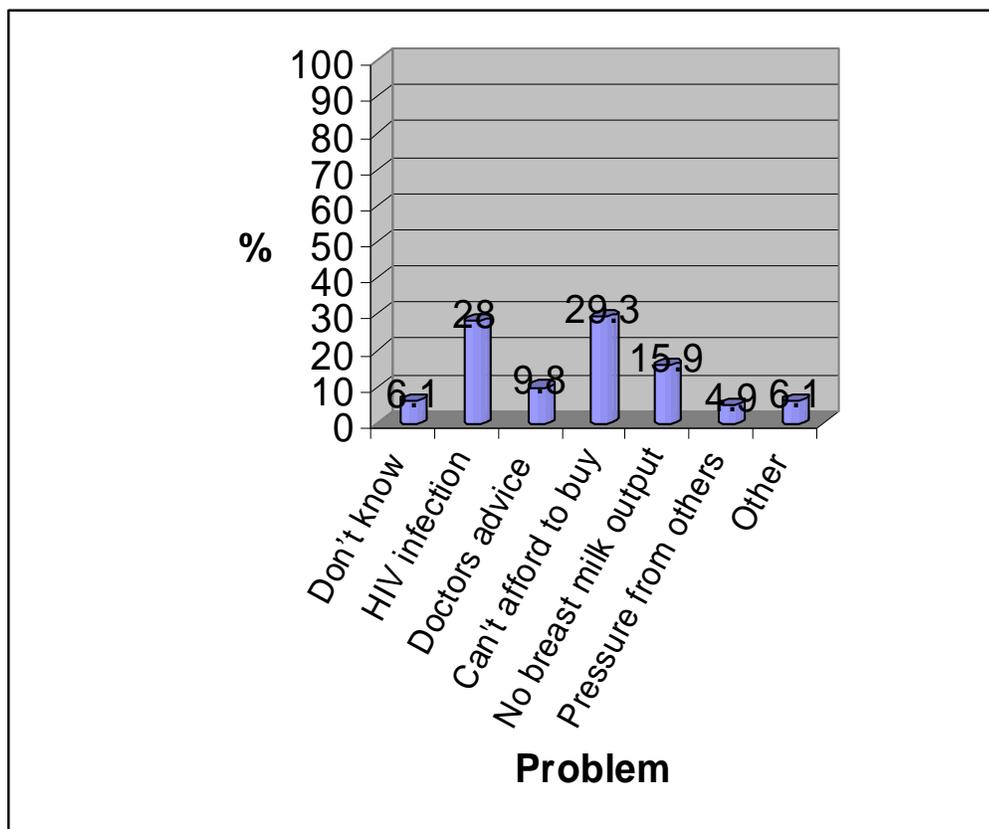
Regarding information on infant feeding options in HIV, one hundred and nine (66.6%) respondents reported that they were informed while fifty five (33.5 %) reported that they were not aware of the baby feeding options that one can use when infected with HIV.

Concerning the advantages and disadvantages of infant feeding options, one hundred and two (62.2%) respondents were aware of the advantages of baby feeding options while sixty two (37.8%) indicated that they were not aware. Regarding the disadvantages, seventy four (45.1%) were not aware of the disadvantages of infant feeding options in HIV while ninety (54.9%) were aware of it.

When asked if there was someone helping them in choosing the best feeding option for their baby, 108(65.9%) reported that there was someone, while fifty six (34.1%) respondents reported that they did not have support from any one. When asked if they were having any pressure in choosing the best feeding options for their baby, sixty two (37.8%) reported that they experienced pressure while one hundred and two (62.2%) were not under pressure.

When asked as to whether they had enough information to enable them to make the right choice about which infant feeding option to use after delivery, one hundred and one (61.6%) reported that they had enough information while some of the

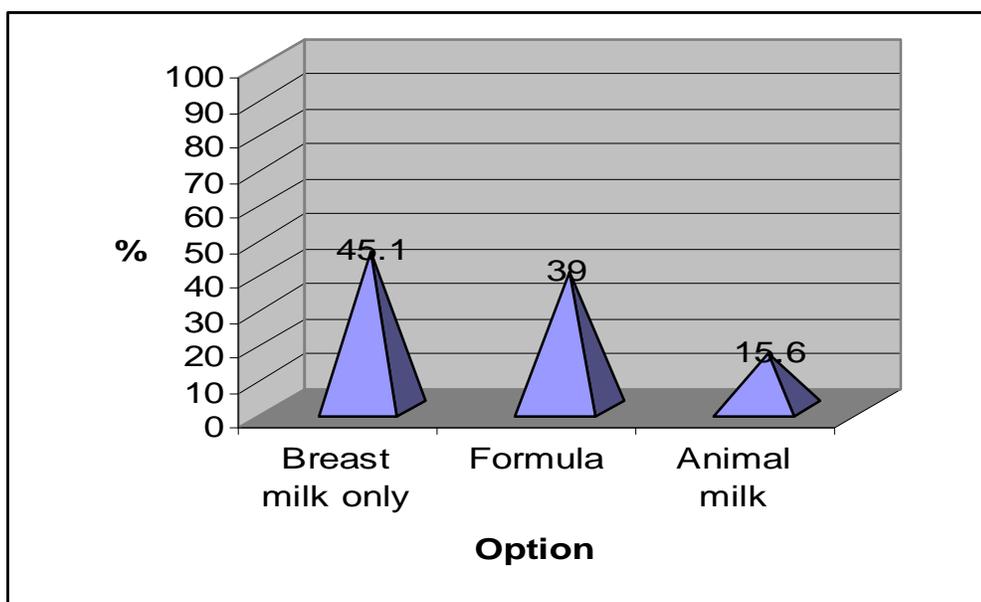
respondents, sixty three (38.4%), reported that they did not have sufficient information .



**Fig 4.9 Problems hindering choice of best feeding option
(n=164)**

Figure 4.8 above indicates that with regard to problems that may prevent one from choosing the best feeding option for their baby, forty eight (29.3%) stated that they could not afford to buy formula for their babies, forty six (28%) mentioned HIV status as a hindering factor towards choosing the best feeding option. Twenty six (15.9%) reported that they often experienced low breast milk output and this prevented them from exclusively breastfeeding their baby and they ended up with mix feeding. Sixteen (10%) of the respondents reported that health care workers would some times

advise them to choose certain feeding options which may not be congruent with their personal preferences, and ten (6.1%) pointed out that they experienced pressure from others including family members, friends and neighbours.



**Fig 4.10 Perception of available feeding options
(n=164)**

Regarding perceptions on available feeding options when infected with HIV, seventy two (45.1%) of the respondents reported that breast milk only was the best option, sixty four (39%) mentioned infant formula, while twenty four (14.6%) indicated that animal milk(cow's), was the best feeding option as indicated in figure 4.9 above.

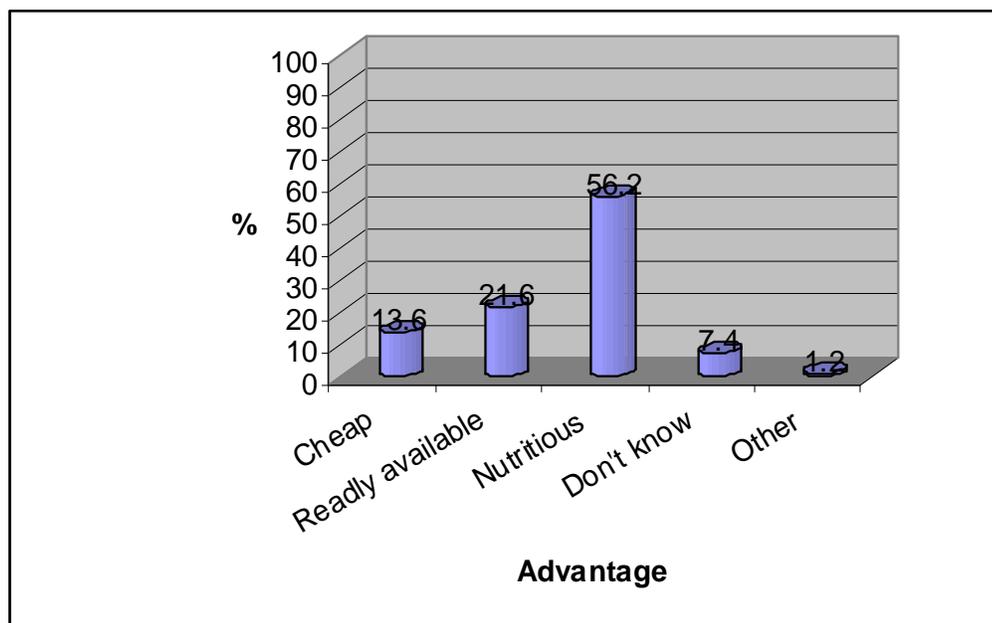


Fig.4.10.1 Advantages of breast milk
(n=164)

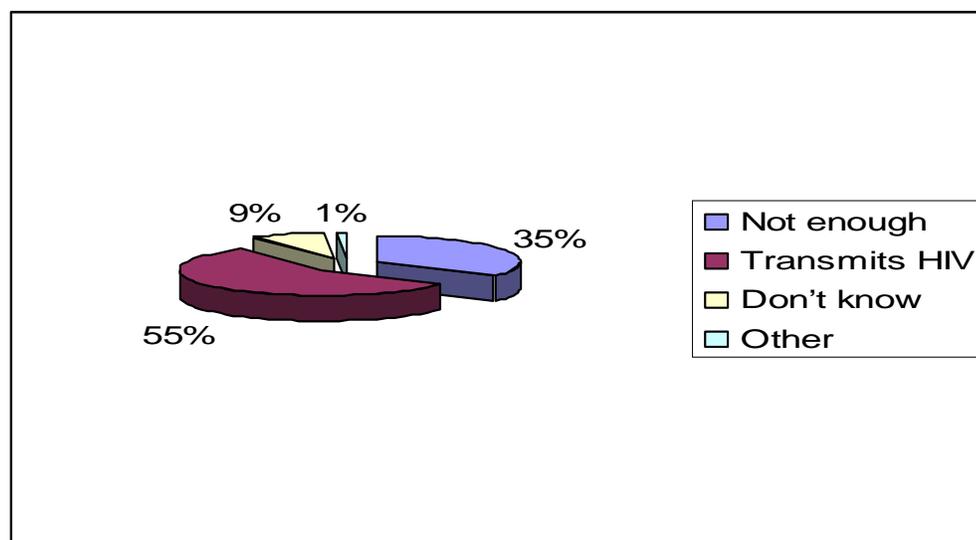


Fig.4.10.2 Disadvantages of breast milk (n=164)

Regarding the advantages of breast milk, ninety two (56.2%) said it is nutritious, thirty five (21.6%) said it is readily available and is a complete food for the baby and 12(7.4%) were not aware of the advantages of breast milk. Regarding disadvantages,

ninety (55.6%) indicated that it transmit HIV infection, fifty six (34.6%) said it is not enough for the baby, while 14 (8.6%) said they were not aware of the disadvantages of breast milk as shown in figures 4.10.1 and 4.10.2 above respectively.

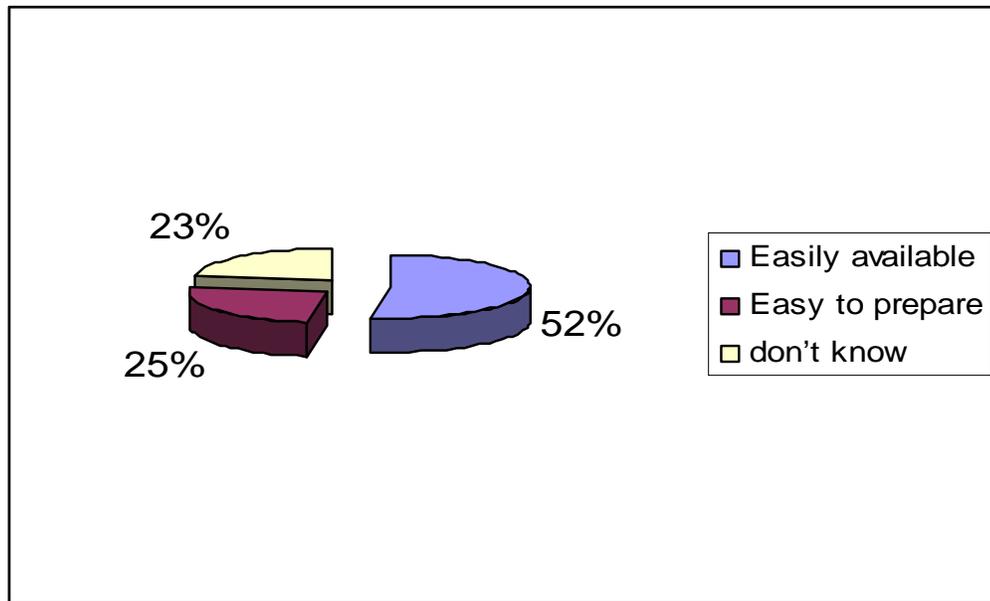


Fig 4.10.3 Advantages of animal milk (n=164)

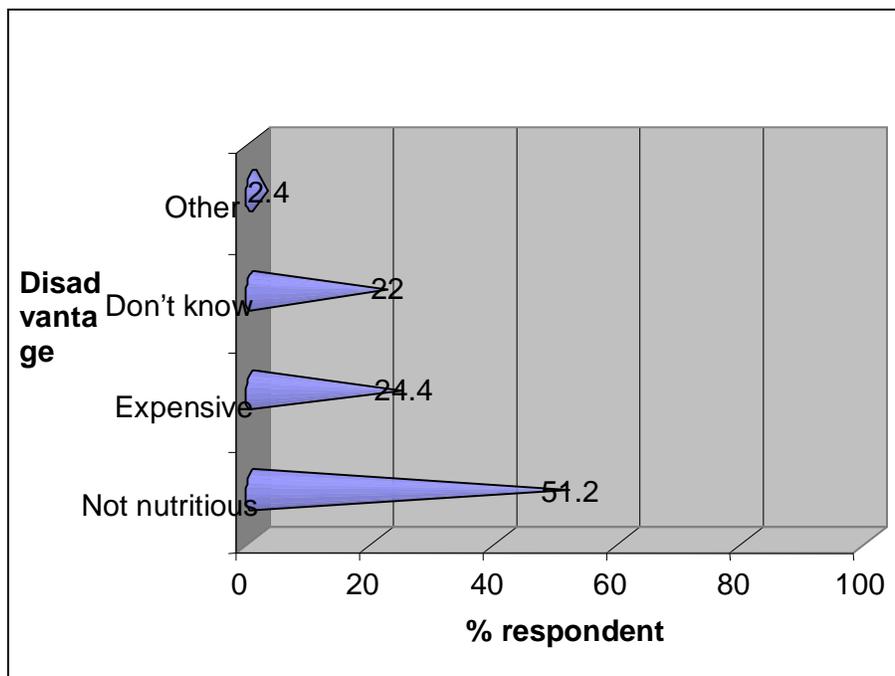


Fig.4.10.4 Disadvantages of animal milk (n=164)

The following advantages were indicated for animal milk: Eighty six, (52%) mentioned that it is easily available, forty one, (25%) said it is easy to prepare and thirty eight (23%) did not know. On the disadvantages, eighty four, (51.2%) said it is not nutritious, forty, (24.4%) mentioned it is expensive and not easily available, and thirty six (22%) indicated they did not know as indicated in figure 4.10.3 above and fig 4.10.4 above respectively.

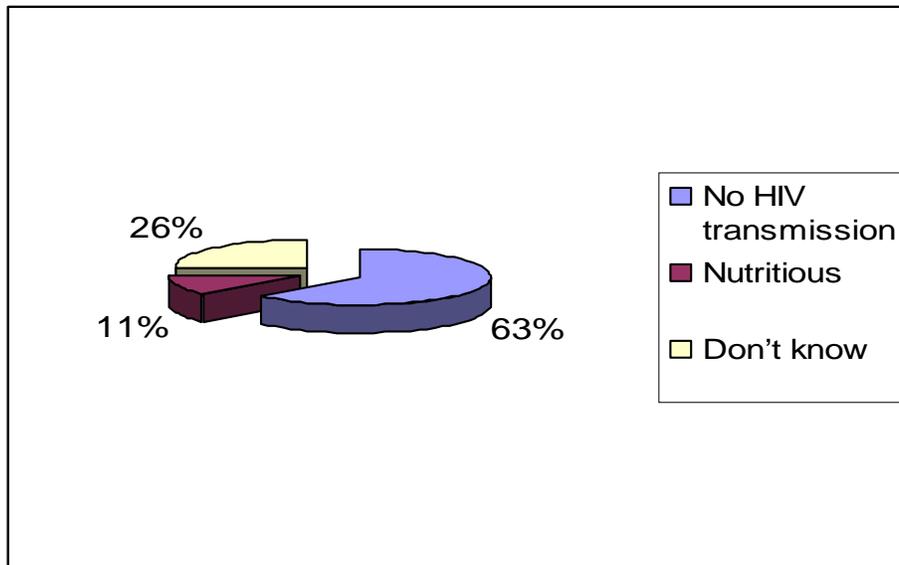


Fig 4.10.5 Advantages of formula milk (n=164)

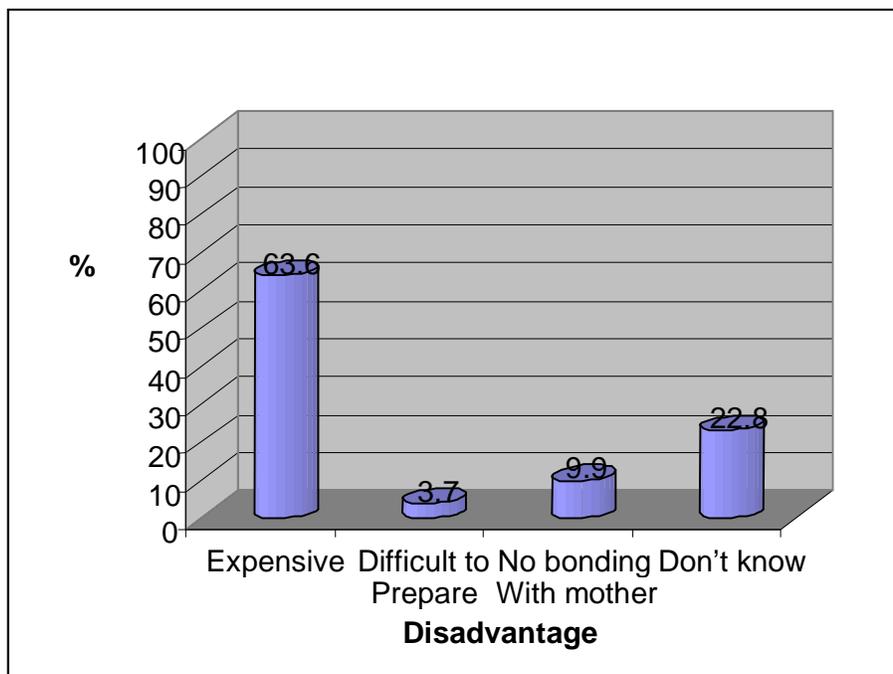


Fig 4.10.6 Disadvantages of formula milk (n=164)

Advantages of formula milk: One hundred and four (63.4%) mentioned that it does not transmit HIV infection to the baby, eighteen (11%) reported that it is nutritious, while forty two (25.6%) said they did not know. Regarding disadvantages, one

hundred and three, (63.2%) indicated that formula milk is expensive, and thirty seven (22.8%) said they did not know, sixteen (9.9%) reported that when one uses formula for her baby there is lack of bonding with the mother and others still six (3.7%) reported that formula feeding is difficult to prepare as indicated in figures 4.10.5 and 4.10.6 above respectively.

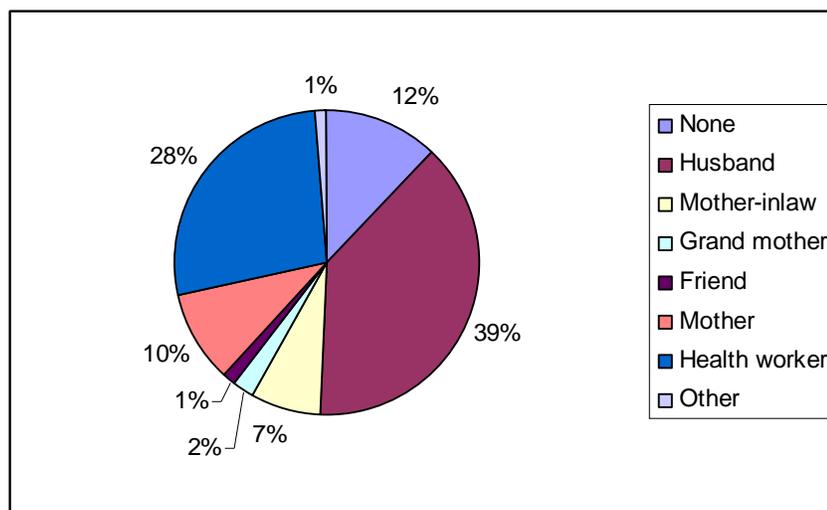


Fig 4.11 People involved in the decision making process (n=164)

Besides the respondents making their decisions alone, other people were involved in making the choice regarding which infant feeding method for their baby. Sixty three, (38.4%), mentioned the involvement of their husbands, forty five (27.4%) mentioned health care providers, sixteen (9.8%) mentioned that their mothers were involved, twelve (7.2%) mentioned the involvement of their mother in-law, four (2.4%) grandmothers, two (1.2%) mentioned friends and twenty (12.2%) said no one was involved in choosing the feeding option for their baby as shown in figure 4.11 above.

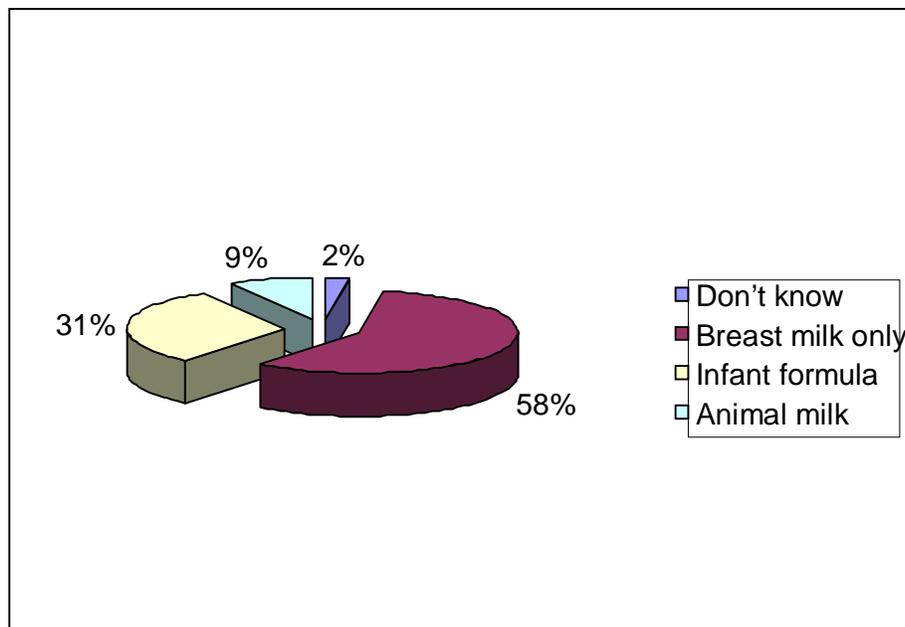


Fig.4.12 Feeding option advocated by others as the best in HIV context (n=164)

Figure 4.12 above indicate that, ninety six, (58.5%) of the respondents mentioned that the people involved in their decision-making process advocated for breast milk only as the best option, while fifty (30.5%) advocated for infant formula and fifteen (9%) advocated for animal milk.

CHAPTER FIVE: DISCUSSION

5.1. Preferred infant feeding option

In this study we have found that, more than half of the respondents, (63.4%), chose breastfeeding as a preferred method of infant feeding when HIV infected, whereas, (18.3%) chose formula feeding. This finding agrees with studies where breastfeeding is regarded as beneficial, as it protects the child against childhood diseases, malnutrition and waterborne diseases (Weinberg et al., 2000, Coutsoydis et al., 2001). It also agrees with the current WHO recommendations (WHO 2009:2) which states that:

HIV infected mothers should exclusively breastfeed their infants for the first six months of life, introducing complementary foods thereafter and continue breastfeeding for the first 12 months of life.

However, according to a large randomized control trial done in Africa, breastfeeding resulted in a 16.2% higher postnatal transmission of HIV than formula feeding (Nduati, 2000:154; Nduati, 2001:1652). Recent studies done in South Africa also indicated that breastfeeding with combined anti retroviral therapy can prevent MTCT. In the KwaZulu-Natal study, infants who were exclusively breastfed were significantly less likely to die by the sixth month than those that received replacement feeding (6.1% versus 15.1%) (Coovadia et. al., 2007: 2).

Formula feeding compared to breastfeeding combined with antiretrovirals for infants, showed that formula feeding was more effective at reducing HIV infection (Mbori-ngacha et al., 2000). However, formula feeding is not a realistic approach and may be harmful in resource poor settings where safe water and adequate formula may not be available (Doull, 2006:286; WHO, 2009:19).

5.2. Decisional conflict

Regarding the degree of difficulty in making the right choice on infant feeding mode, 21% of the respondents indicated that they were unsure of what decision to make, while 18% of the respondents indicated that they experienced pressure from health care workers when making decisions regarding infant feeding in HIV. This agrees with studies from South Africa where health care workers insisted that women should breastfeed their babies after delivery, regardless of personal choice, and they did not counsel women on the potential risks of breastfeeding if HIV positive (Seidel, 2000:25).

Research from Zambia and Kenya also found that counsellors provided appropriate information but failed to account for women's social and economic circumstances when making feeding recommendations (Coutsoudis, 2001:379). Furthermore, 18% of the study participants saw the expensiveness of infant formula as another difficulty in making a choice. Others (21%) included lack of enough food in the family and financial constraints.

Pressure from family members was also reported as one of the reasons for difficulty in making decisions regarding infant feeding in HIV (17%). Most of the participants

reported that they had a fear of disclosing their status to the family members and as such they would opt to breastfeed so that the family members would not suspect them of being HIV positive. This agrees with studies done in Tanzania whereby HIV infected mothers who were not breastfeeding faced social stigma and were abused, ridiculed and interpreted as selfish or promiscuous and thus they often felt that the society did not accept them (Basset et al., 2000; Seidel., 2000). 5% reported that they experienced pressure from work and thus they would not be able to exclusively breastfeed their babies hence creating a challenge on the practicability of exclusive breastfeeding for working mothers and probably those who have not disclosed their HIV status to anyone.

5.3. Stage in the decision-making

Most of the participants, (80.9%), had already decided on a method of feeding their baby, as opposed to the (13%) who were still undecided on which infant feeding method to choose. Regarding when is the best time to choose a method of feeding the baby, 47.6% of the respondents said early during pregnancy is the best time, compared to the 13.4% who did not know when it is the best time to choose a method for feeding the baby. This agrees with Enkin et al (2000: 440), who reported that most women who decided to breastfeed, made this decision either before pregnancy or early in pregnancy. He further illustrates that other factors such as the women's own previous experience, and the attitudes and experiences of their family members, friends, and caregivers, also had an important role in this decision.

5.4. Role in decision-making process

As regards role in decision making, majority of the respondents (42.1%), preferred to make decision with others, such as health care workers, husbands or mothers, mothers-in-law, while a slightly lesser percentage (36%), preferred to make the decision alone. This agrees with Doull (2006:287), who regarded pregnant women as 'Expert Patients' - those who are actively involved in their medical decision making. At the same time, patients should be supported to participate in weighing potential outcomes as this may be beneficial to improve self care practices and appropriate utilization of resources (Dawn, 2008: Doull, 2006).

5.5. Factors influencing choice of feeding option

Concerning the reason for choosing the best feeding option for the baby, majority of them (59.8%) chose a specific feeding option in order to reduce HIV transmission to the baby, while (8.5%) gave the reason as to avoid conflict in the family and others (7%) indicated that they chose a certain feeding method with the intention of protecting their own health. However, a systematic review done by WHO on the effect of prolonged breastfeeding on the health of mothers who are known to be HIV-infected indicated that there was no clear evidence of harm to the mother if she continued to breastfeed for long (WHO 2009:16).

5.6. Factors hindering choice of infant feeding option

Concerning problems hindering choice of the best option, (29.3%) mentioned cost of formula, while (28%) mentioned that HIV infection has put them in a situation whereby they cannot choose the best feeding option for their infants. Another,

(15.9%) reported that they experienced low breast milk output and this hinders them from breastfeeding exclusively.

The issue of low breast milk output has been mentioned elsewhere in studies where women perceived their milk as not being enough and hence they would supplement breast milk with other food leading to mixed feeding (Bakaki, 2002; Bequet et al., 2005). However this perception can be countered by providing HIV infected mothers with counselling and support on how to maintain lactation so as to ensure optimal breastfeeding practices among the general population (WHO 2009:11).

5.7. Process of decision-making

Decisional conflict is a problem that causes individuals to change their mind, regret the decision made, be dissatisfied and blame others for poor outcomes (Sun 2004; Gattellari & Ward 2005). Participants in this study were not different (79.9%) reported that they were clear about the best infant feeding option to use after delivery, as opposed to (20.1%) who reported that they were not certain of the best infant feeding choice for their babies.

About being informed on the advantages and disadvantages of infant feeding options, 56.5% of the respondents reported that they were aware of the infant feeding options that one can use when infected with HIV, while 45.1% reported that they were not informed. This indicates a gap in the pregnant women's knowledge regarding infant feeding when infected with HIV. The respondents also reported unclear values on infant feeding regarding the advantages and disadvantages of the various infant feeding options as depicted by the results 41.5% and 54.3% respectively.

5.8. Available support systems

Majority of the participants in this study, (74.7 %) identified their preferred method of obtaining support for decision making through discussion with health care providers. Although patients identified with health professionals as important sources of support for decision making, previous researches indicate that doctors, nurses and counsellors primarily intervene by providing information without necessarily addressing patients' other decisional needs(Gravel et al., 2006; Loh et al., 2006).

Most of the respondents reported they received support, (65.9%) from their husbands, healthcare workers, mothers, friends etc, in choosing the best infant feeding method for their babies, compared to 34.1% who did not receive any support at all. Close to half of the respondents (37.8%) reported to have experienced pressure from others including husbands, mothers, mothers-in-law, friends, healthcare providers etc while choosing the best feeding options for their babies.

5.9. Level of knowledge on infant feeding options

When asked as to whether they had enough information needed for them to make the right choice on which infant feeding option to use after delivery, 61.6% of the respondents reported that they had enough information, while 38.4% reported that they lacked information on the best infant feeding option one can use after delivery when infected with HIV.

The above findings; therefore, indicate clearly that interventions are required in the AMPATH PMTCT programme in order to support pregnant women, who are infected by HIV by providing them with adequate information regarding infant feeding options

in order for close the gap and to enable them to be actively involved in decision making so as to achieve the desired level of involvement and to address factors contributing to their decisional conflict. Patient decision aids and decision coaching by trained health professionals are effective interventions to increase patient participation in decision making to and ensure decisions are of higher quality (O'Connor et al., 2007; Stacey et al., 2007).

5.10. The Ottawa Decisional Support Framework

The Ottawa Personal Decision Guide is a protocol that can be used to facilitate decision coaching for various health and social decisions. Studies have shown that nurses are well positioned on the health care team to be decision coaches. Nurses who are trained in decision -coaching were more likely to discuss patients' values and address support issues without increasing the length of time with the patient (Stacey et al., 2006).

Summary

From the above discussion it is clear that there is need for decision support on infant feeding education for HIV infected mothers at the AMPATH PMTCT clinic. There is therefore need to adopt the Ottawa decisional Support Framework by the Health Workers in order to bridge the gap on education and to improve the decision-making capacity for HIV infected mothers.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

In this study we have found that:

1. There is evidence of knowledge gaps about the advantages and the disadvantages of the various infant feeding options in HIV among HIV infected women attending PMTCT clinic at AMPATH centre, Eldoret.
2. Decision making capacity among HIV infected women regarding infant feeding in the context of HIV is generally low.
3. Counselling strategies on infant feeding in the context of HIV are inadequate and shallow.
4. The Ottawa Personal Decision Support Framework is useful in this situation as it can address the above issues and can be used effectively in a setting like the AMPATH centre PMTCT clinic.

6.2 Recommendations

6.2.1. Recommendations for the program

1. There is need to incorporate a multi-disciplinary decision-support framework, the Ottawa Decisional Support Framework (ODSF), into the AMPATH PMTCT program as it may be useful in empowering pregnant women to become effective health decision-makers in infant feeding.

2. In order to improve on the uptake and implementation of PMTCT services at the AMPATH program, Counselling strategies need to incorporate broader issues that go beyond making decisions about infant feeding in the context of HIV to include empowerment, ongoing psychosocial and emotional support.

3. One of the evidence-based interventions that can be helpful in decision and emotional support is peer to peer group discussion on feeding options at the AMPATH PMTCT program lead by a trained PMTCT health worker.

6.2.2. Recommendations for research

Further research is needed on the impact of providing decision -support to HIV infected mothers in reducing Maternal to Child Transmission (MTCT) of HIV in the AMPATH PMTCT programme.

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APPENDICES

APPENDIX 1: Informed consent Form

Title: The decision- support needs of HIV-positive mothers regarding infant feeding at a PMTCT clinic in Eldoret, Kenya

Investigator:

Priscah Bundotich-Mosol: MScN student, Moi University

Introduction: I, Priscah Bundotich Mosol, am currently undertaking my master's degree in Maternal and Neonatal health at Moi University. I am conducting a research study on decision-support needs regarding infant feeding in HIV positive pregnant women and have permission from the institution to carry out the research. I am going to give you information and then invite you to be part of the research. Before you decide, you can talk to anyone you feel comfortable with about the research. There may be words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain.

Purpose and Background:

The purpose of this study is to explore the decision-support needs of HIV-positive pregnant women regarding infant feeding at the Prevention of Mother to Child Transmission (PMTCT) clinic at the Academic Model Providing access to Health care (AMPATH), of Moi Teaching and Referral Hospital (MTRH). It is hoped that the findings from this study will be beneficial to the PMTCT program in AMPATH, as it will inform the program on how to develop a shared decision-support intervention which will work towards reduction of MTCT during infant feeding.

Participant selection: Since it is not possible to include all HIV positive pregnant women in the research, a representative sample of the total population will be selected. Therefore you have been randomly selected as a participant in this research.

Procedure

Upon consenting for participating in the research, I will lead you to one of the rooms in the clinic. I will ask you questions from the questionnaire and I will tick your answers on the form. The questionnaire will take approximately 30 minutes of your time.

Benefits and Risks

There may not be any direct benefits for you from the study, but your participation is likely to help in developing appropriate care modalities to ensure that HIV infected pregnant women are supported in making decisions towards safe feeding options for their babies. There are no known anticipated risks for participating in the research since the research does not involve administration of medicines or undertaking any experiment on you. However, psychological harm may result from asking you personal socio-cultural-economic questions, but this will be explained to you prior to the interview process to reduce harm.

Confidentiality

The information that I will collect from this research project will be kept confidential. All your records will have a number on it instead of your name or your AMPATH registration number. These records will only be accessible by me and will be kept under lock and key.

Voluntary Participation

Your participation in this research is entirely voluntary and you have the option to participate or not. Your choice on participation or not, does not in any way affect the services you receive at this clinic. You may also stop participating in the research at any time you choose. It is your choice and your rights will still be respected. Should you have any further questions about any part of the research study do not hesitate to ask me.

Contact

If you have any questions you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact me at the following address and phone numbers:

Priscah Bundotich Mosol, P.O. Box 3, Eldoret.

Tel: 0721558607 or 0723576313

Consent

I have read the above information and I have been explained to in details about the study. I have asked the questions and received the answers and I agree to participate in the study.

Participant Signature _____

Date_____

Witness Signature_____

Date_____

For participants who cannot write

Thumb print _____

Date: _____

Witness Signature_____

Date: _____

Interviewer Signature_____

Date_____

- Occupation: None
 Formal employment
 Business
 Farmer
- Religion: Muslim
 Christian
 Hindu
 Other

Assessment of Decisional-support needs

1. What choices are you facing right now as concerns infant feeding in HIV?

- [1] To breastfeed the baby
- [2] To feed the baby with Formula
- [3] Animal milk
- [4]Other (specify below)
.....
.....

2. What difficulties are you having in making a choice on how to feed the baby?

- [1] Unsure what is the best to do
- [2] Pressure from family members
- [3] Pressure from health care providers
- [4] Cost of formula
- [5] Others-----

(b) Give reasons for the response above

3. How far are you in choosing a method of feeding your baby? -----

4. When do you think is the best time to choose a method of feeding the baby?

[1] Early during pregnancy

[2] During Mid-Pregnancy

[3] During late pregnancy

[4] After delivery

[5] Other (specify) below

5. The following table below shows some of the factors that lead to one making the correct choice of infant feeding method. Put Yes or No or undecided to the spaces provided below.

Decisional Conflict Scale (DCS)			
		Base (Y N U)	POST (YNU)
Certainty	k) Are you clear about the best infant feeding choice for your baby after delivery?	No	
	l) Are you sure of which option to feed your baby after delivery?	No	
Informed	m) Are you aware of the baby feeding option that one can use when infected with HIV?	Yes	
	n) Do you know the advantages of the baby feeding options?	No	
	o) Do you know the disadvantages of the baby feeding options?	No	
Values	p) Are you clear about which advantages of infant feeding options are most important to you?	Yes	
	q) Are you clear about which disadvantages of infant feeding options are most important to you?	No	
Supported	r) Is there someone who is helping you in choosing the best method to feed your baby?	Yes	
	s) When choosing the best infant feeding method for your baby, are you having any pressure from others?	No	
	t) Do you have enough information to make the right choice on which infant feeding option to use after delivery?	No	

6. A) Which of the infant feeding option do you perceive as the best for you?

[1] Breast milk only

[2] Formula

[3]Animal milk

[4] Other's Specify-----

7). Among the feeding options, which advantages and disadvantages are most important to you.

A) What are the advantages of breast milk of feeding the baby with Breast milk only?

[1] It is cheap

[2] Readily available

[3] Nutritious to the baby

[4] Don't know

[5] Other specify_____

B) What are the advantages of formula milk?

[1] Does not transmit HIV infection to the baby

[2] Nutritious

[3] Don't know

[4] Other specify_____

C) What are the advantages of animal milk?

[1] Easily available

[2] Easy to prepare

[3] Don't know

[4] Other specify_____

8. A) what are the disadvantages of feeding your baby with breast milk only?

[1] The milk is not enough for the baby

[2] It transmits HIV infection

[3] Don't know

[4] Other specify_____

B) What are the disadvantages of feeding your baby with formula?

[1] It is expensive

[2] It is difficult to prepare

[3] Does not encourage bonding with the mother

[4] Don't know

[5] Other specify_____

C) What are the disadvantages of feeding your baby with animal milk?

[1] It is not nutritious

[2] It is expensive and not readily available

[3] Don't know

[4] Other specify_____

9. A). Who besides you is involved in making the choice regarding which infant feeding method for your baby?

[1] None

[2] Husband

[3] Mother-in-law

[4] Grand Mother

[5] Friend

[6] Mother

[7] Other (specify) _____

B). Which infant feeding option do they advocate for as the best feeding option for your baby?

[1] Breast milk only

[2] Infant formula

[3] Animal milk

[4] Other (specify) _____

C) Do you encounter any pressure when making a choice towards which feeding option for your baby?

[1] Yes

[2] No

[3] Undecided

C) Are you getting any support when making a decision on which feeding option to feed your baby?

[1] Yes

[2] No

[3] Undecided

10. What role do you play in choosing the best method for feeding your baby?

[1] Make decision alone

[2] Make the decision with others

[3] Support the decision

[4] Don't know

[5] Other (specify) -----

11. Where else have you been looking for help in choosing the best feeding method for your baby after you deliver? From:

- [1] Health care provider
- [2] Traditional birth attendant
- [3] Friend
- [4] Mother
- [5] Grand mother
- [6] Other (specify) -----

12. As you make the choice on the best feeding option for your baby what do you want to achieve?

- [1] Reduce risk of HIV transmission to the baby
- [2] Avoid conflict in family
- [3] Protect the health of the baby
- [4] Protect my own health
- [5] Other-(specify) -----

11. What are some of the problems that may prevent you from choosing the best feeding option for your baby?

- [1] HIV infection
- [2] Doctors advice
- [3] Cannot afford to buy
- [4] No breast milk output
- [5] Pressure from Others
- [6] Don't know
- [7] Other (specify) -----

Thank you very much for you assistance and co-operation.

APPENDIX III