UNIVERSITY OF INDONESIA

INFANT FEEDING PRACTICE OF HIV-HIGH-RISK MOTHERS IN BANDUNG, WEST JAVA

THESIS

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PREFACE

The transmission of HIV through breastfeeding has created a dilemma for public health programs and for mothers and families affected by the disease. On the other hand, the increased risks of infant morbidity and mortality associated with artificial feeding in poor settings are also well known. International messages about infant feeding in HIV context changes from time to time. How these messages applied by local implementers are questioned.

This descriptive observational study was performed to explore infant feeding practice of HIV high risk mothers in Bandung, West Java. This study concluded that infant feeding practice in Bandung was affected by several aspects relating to resources for care, health resources as well as the community; the fulfillment of AFASS to those practicing replacement feeding is to be questioned; and weakness in essential components of the health system in charge of infant feeding program caused the program outcomes far from expectation.

This report consist of six parts; introduction (part 1), literature review of infant feeding practice in HIV context and associated factors (part 2), methods used in this study (part 3), description of results (part 4), discussion (part 5), conclusion and recommendations (part 6). Also attached is manuscript to be submitted to Social Science and Medicine Journal.

We hope this study will stimulate further study, help stakeholders in planning more appropriate feeding programs and improve infant feeding practices of HIV high risk mothers in Indonesia.

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Jakarta, June 2010

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Dian Nurtjahjati Basuki

PUBLICATION APPROVAL FOR ACADEMIC PURPOSES

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ABSTRAK

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Judul : Praktik pemberian makanan bayi pada ibu resiko tinggi HIV di Bandung, Jawa Barat

Risiko penularan HIV bila menyusui mengakibatkan dilema pemberian makanan bayi akibat ancaman kurang gizi atau terinfeksi HIV pada praktik yang tidak tepat. Studi observasi deskriptif ini bertujuan mengeksplorasi praktik pemberian makanan bayi pada ibu resiko tinggi HIV di Bandung. Pesan yang disampaikan para pemangku kepentingan, keberadaan konselor makanan bayi, periode terungkapnya status HIV, kepatuhan ibu serta kebiasaan masyarakat setempat adalah aspek-aspek yang mempengaruhi praktik makanan bayi setempat. Pemberian makanan bayi pengganti ASI tidak memenuhi criteria AFASS. Lemahnya komponen utama dalam sistem kesehatan yang mengelola program makanan bayi dari ibu resiko tinggi HIV menghalangi tercapainya tujuan yang diharapkan.

Kata kunci:
HIV, AFASS, makanan bayi, kualitatif, PMTCT

ABSTRACT

Name : dr. Dian Nurtjahjati Basuki, IBCLC

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Title : Infant Feeding Practice of HIV-High-Risk Mothers in Bandung, West Java

HIV transmission through breastfeeding caused dilemma in infant feeding practice due to likelihood of nutritional inadequacy or HIV transmission risk. A descriptive observational study was performed to explore infant feeding practice from HIV high risk mothers in Bandung. Aspects affecting the feeding practice were message of infant feeding endorsed by stakeholders, availability of trained counselors, the timing of HIV status revealed, mother's willingness to comply and the feeding norm. Replacement feeding practice was far from the expected AFASS criteria. Health system in charge of the infant feeding program lack main components to run properly and to reach the expected outcome.

Key words:
HIV, AFASS,infant feeding, qualitative, PMTCT

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LIST OF ABBREVIATIONS

AFASS	:	Acceptable, Feasible, Affordable, Sustainable, Safe
AIDS	:	Acquired immunodeficiency syndrome
ARV	:	Antiretroviral drugs
CD4	:	cluster of differentiation 4
CSW	:	Commercial sex worker
FAO	:	Food and Agriculture Organization
FGD	:	Focus Group Discussion
HIV	:	Human immunodeficiency virus
IDU	:	Injecting Drug User
MTCT	:	Mother-to-child transmission
NGO	:	Non-Governmental Organization
PITC	:	Provider Initiated Testing and Counseling
PLHIV	:	People living with HIV
PMTCT	:	Prevention of mother-to-child transmission
SC	:	Sectio Caesarea/Caesarian section
UN	:	United Nations
UNICEF	:	United Nations Children's Fund
UNFPA	:	United Nations Population Fund
UNAIDS	:	United Nations Joint Programme on HIV and AIDS
VCT	:	Voluntery Counseling and Testing
WHO	:	World Health Organization

OPERATIONAL DEFINITION

HIV : Human immunodeficiency virus is the virus that causes AIDS (Acquired immunodeficiency syndrome), active pathological condition that follows the earlier, non-symptomatic state of being HIV-positive

Mother-to-child transmission: transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery or breastfeeding.

Infant : Children less than 12 months.

Infant formula feeding :A breastmilk substitute formulated industrially in accordance with Codex Alimentarius Standards (FAO/WHO) to satisfy the normal nutritional requirements of infants up to six months of age.

Exclusive breastfeeding : giving a baby only breast milk, and no other liquids or solids, not even water. Drops or syrups consisting of vitamins, mineral supplements or medicines are permitted.

Replacement feeding: feeding infants who are receiving no breast milk with a diet that provides the nutrients infants need until the age at which they can be fully fed on family foods. During the first six months of life replacement feeding should be with a suitable breast-milk substitute. After six months the suitable breast-milk substitute should be complemented with other foods.

Mixed feeding : giving both breastmilk and other foods or liquids.

Breast-milk substitute: any food being marketed or otherwise represented as a partial or total replacement for breast milk, whether or not suitable for that purpose.

'Spillover': a term used to designate the feeding behaviour of new mothers who either know that they are HIV-negative or are unaware of their HIV status – they do not breastfeed, or they

breastfeed for a short time only, or they mix-feed, because of unfounded fears about HIV or of misinformation or of the ready availability of breast-milk substitutes.

Antiretroviral drugs (ARV)s: are used to reduce the amount of HIV in the body, example AZT (*azidothymidine*) and ZDV (*zidovudine*), refers to the same drug, and *nevirapine*

CD4 (cluster of differentiation 4): is lymphocyte T cell surface where HIV are attached.

Acceptable, feasible, affordable, sustainable and safe (AFASS): These terms refer to the conditions that should be in place for replacement feeding.

Acceptable: The mother perceives no barrier to replacement feeding. Barriers may have cultural or social reasons, or be due to fear of stigma or discrimination.
Feasible: The mother (or family) has adequate time, knowledge, skills and other resources to prepare the replacement food and feed the infant up to 12 times in 24 hours.
Affordable: The mother and family, with community or health-system support if necessary, can pay the cost of purchasing/producing, preparing and using replacement feeding, including all ingredients, fuel, clean water, soap and equipment, without compromising the health and nutrition of the family.
Sustainable: Availability of a continuous and uninterrupted supply and dependable system of distribution for all ingredients and products needed for safe replacement feeding, for as long as the infant needs it, up to one year of age or longer.
Safe: Replacement foods are correctly and hygienically prepared and stored, and fed in nutritionally adequate quantities, with clean hands and using clean utensils, preferably by cup.

CHAPTER 1
INTRODUCTION

1.1 Background

HIV and AIDS has been a global problem for two decades, and has profound impact in health, human, social, political, environmental and economic. Around 33.2 million people living with HIV and AIDS (WHO, UNICEF, UNAIDS, & UNFPA, 2006).

First HIV and AIDS case in Indonesia was reported in 1985. In 2000, HIV/AIDS cases in Indonesia was announced Concentrated Epidemy. Between 1999-2008, cumulative AIDS cases multiplied rapidly from less than 1000 cases, to almost 17.000 cases. Trend of changes in HIV transmission in Indonesia is seen where currently heterosexuals and IDUs have the highest percentage of risk (48% and 42% respectively), with almost 80% cases are in the productive ages (20-39 years), making higher exposure of HIV transmission to children.

Young children are dying from the infection. Most of these children become infected through their mothers. In Africa, 30 to 50% of all untreated HIV-positive children die before their first birthday and fewer than 30% survive beyond 5 years of age (Dray-Spira, Lepage, & Dabis, 2000).

Mother-to-child transmission (MTCT) of HIV accounts for the vast majority of children who are infected with HIV. In the last two decades, before the large roll out of prevention of mother to child transmission (PMTCT) programs, approximately 30%-40% of HIV infected women transmitted the virus to their newborn babies. These children have contracted the virus through vertical transmission, either in the womb during pregnancy, during the period of delivery or from being exposed to the virus over the period of breastfeeding (WHO, et al., 2006).

However, studies revealed child morbidity associated with mode of infant feeding in mothers with HIV. Results from a secondary analysis of data collected in the randomized trial of breastfeeding compared with formula feeding, in Nairobi, Kenya, suggested a threefold higher mortality rate in HIV-infected women in the breastfeeding group than in those in the formula feeding group (R.

Nduati, Richardson, & John, 2001). A study in Durban, South Africa, revealed infants who received both breast milk and other feeds were significantly more likely to be infected by 15 months of age (36%) than those who had been exclusively breastfed (25%) or formula fed (19%). Exclusive breastfeeding carried a significantly lower risk of HIV infection than mixed feeding (Hazard ratio 0.56, 95% CI 0.32–0.98) and was similar in this respect to never breastfeeding (Hazard ratio 1.19, 95% CI 0.63–2.22) (Coutsoudis, et al., 2001).

These facts lead to replacement feeding practices which unquestionably prevents all postnatal transmission but has been associated with increased risk of death from other causes. Non-breastfeeding was reported to be associated with higher rates of diarrhoeal and acute lower respiratory disease among infants, than breastfeeding (Heinig & Dewey, 1996). PMTCT has dilemma to balance the risk of infants acquiring HIV through breast milk with the higher risk of death from causes other than HIV, in particular malnutrition and serious illnesses such as diarrhoea among non-breastfed infants (WHO, 2009a).

The dilemma caused revisions in messages about infant feeding in HIV context, in order to accommodate emerging evidences. In 1997, the joint policy statement on HIV and Infant Feeding highlighted the need to provide alternatives to breastfeeding. In 2001, AFASS was introduced for the first time as conditions required for replacement feeding to become preferable feeding option. In 2006, the statement was revised by endorsing exclusive breastfeeding as the first option while still emphasizing AFASS be fulfilled for replacement feeding (WHO, et al., 2006). In November 30th 2009, a new recommendation was launched, underlining ARV's role in safer breastfeeding practice (WHO, 2009a).

Questions emerge concerning how national or local program likely determine which feeding practice to endorse, or how to determine acceptability, feasibility, affordability, sustainability and safety (AFASS) if replacement feeding is decided as the most suitable in different contexts, especially when cultural issue is in place. There were also questions concerning programs endorsed by international aids, such as replacement feeding subsidy. By providing subsidized replacement feeding, it was assumed that the transmission pathway through breastfeeding can be eliminated. However, replacement feeding itself poses

potential danger toward child's survival which caused WHO to recommend conditions required for ideal replacement feeding, known as AFASS. It is unknown whether health providers who influenced infant feeding decision in HIV affected family aware of such conditions.

A large prospective cohort study in South Africa (Doherty, et al., 2007) found the WHO/UNICEF guidelines were not being implemented effectively, leading to inappropriate infant-feeding choices and consequent lower infant HIV-free survival. The study then recommended counseling of mothers should include an assessment of individual and environmental criteria to support appropriate infant feeding choices.

In a country where majority of its population is under poverty, a national recommendation on feeding practice should consider all aspects required to implement the message correctly. Failure to investigate applicability of the recommendation might increase poverty, morbidity and mortality, especially to infants who is most vulnerable.

1.2 Rationale of the study

Messages concerning infant feeding practices in HIV context have consistently have evolved over the time with the improved scientific findings, the changes in lifestyle and socio-cultural aspects, as well as the severity of the disease. From provision of breastfeeding alternative (WHO, UNAIDS, & UNICEF, 1997), the introduction of AFASS as condition required for replacement feeding to be considered as safer feeding option than exclusive breastfeeding (WHO, 2001), then turned over by recommending exclusive breastfeeding if AFASS cannot be fulfilled (WHO, et al., 2006), and finally encourage choosing either breastfeeding with ARV or avoiding breastfeeding altogether (WHO, 2009a).

The constant changes will require constant socialization to health workers in order to comply with the most updated recommendation. Infant feeding message not only concerns what options are available, but each feeding option also requires specific conditions for ideal practice, such as exclusive breastfeeding or AFASS for replacement feeding. These messages should reach every HIV high

risk mothers, so they can then decide upon the most applicable option. Failure to communicate the complete messages will create gap between recommendation and practice, causing improper feeding practice which will only increased malnourished children or children with HIV.

Therefore, an exploration study of infant feeding practice in Bandung is needed, since the city is known for its high HIV cases due to high number of drug users and commercial sex workers. Donor agencies targeted the city for many HIV combating projects, among which are donations of replacement feedings for HIV affected children.

It is unknown whether feeding options are available or are services in place for providing infant feeding supports. The major influential factors, key actors in shaping the local infant feeding practice are not yet known. These questions can only be revealed by an exploration study of infant feeding practice on HIV high risk mothers in Bandung. The exploration is critical to provide information on the existing practice compared to the national and international recommendation.

1.3 Research question

How is the infant feeding practices of HIV high risk mothers in Bandung, West Java?

1.4 Objective of the study

1.4.1 General Objective

To explore infant feeding practice of HIV high risk mothers in Bandung, West Java.

1.4.2 Specific Objectives

1. To investigate aspects affecting current infant feeding practices of HIV high risk mothers.
2. To investigate AFASS fulfillment among HIV high risk mothers practicing replacement feeding.

1.5 Conceptual framework

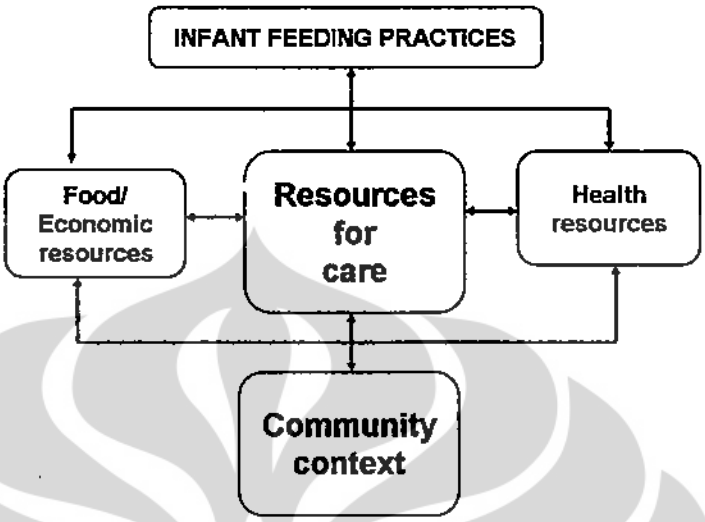

Figure 1.1 Conceptual framework of the study

Adopted from: (Piwoz, 2004)

1. 6 Facts and Hypothesis matrix

Table 1.1 Facts and Hypothesis matrix of the study

No	Variables 1	Variables 2	References
1-2.1	Infant feeding practice	Resources for care	(Piwoz, 2004) (WHO., 2005)
1-2.2	Infant feeding practice	Food/economic resources	(WHO., UNICEF., UNAIDS., & UNFPA., 2004b) (Hartmann, Berlin, & Howett, 2006)
1-2.3	Infant feeding practice	Health resources	(WHO., et al., 2004b) (LINKAGES, 2005) (Hartmann, et al., 2006)
2.1-2.2	Resources for care	Food/economic resources	(Gillespie & Kadiyala, 2005)
2.1-2.3	Resources for care	Health resources	(WHO., et al., 2004b) (LINKAGES, 2005)
2.1-3	Resources for care	Community context	(WHO., et al., 2004b)
2.2-3	Food/economic resources	Community context	(WHO., et al., 2004b)
2.3-3	Health resources	Community context	(WHO., et al., 2004b) (Piwoz, 2004)

CHAPTER 2
LITERATURE REVIEW

2.1 Overview of HIV, AIDS and Mother-to-Child Transmission (MTCT) of HIV

Human immunodeficiency virus is the virus that causes AIDS (Acquired immunodeficiency syndrome), active pathological condition that follows the earlier, non-symptomatic state of being with HIV.

HIV is passed from an infected man or woman to another person through exchange of HIV-infected body fluids such as semen, vaginal fluid or blood; during unprotected sexual intercourse; HIV-infected blood transfusions or contaminated needles; HIV can also pass from an infected woman to her child during pregnancy, at the time of birth or through breastfeeding (Figure 2.1). This is called **mother-to-child transmission** or MTCT (WHO, et al, 2004b).

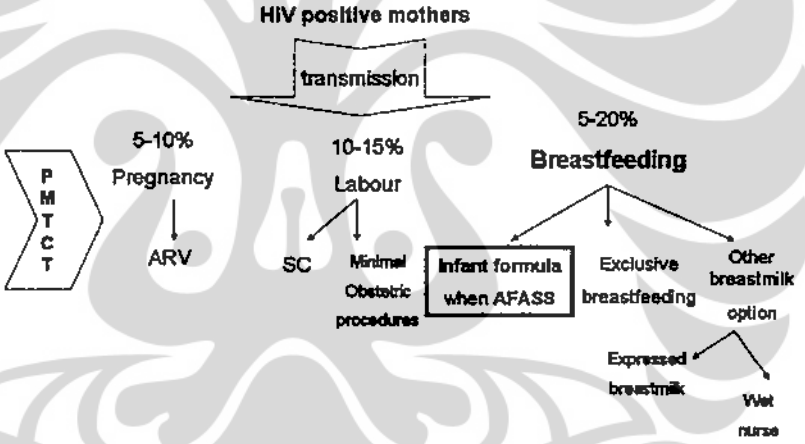

Figure 2.1 Estimated risk and timing of mother-to-child transmission/MTCT of HIV in the absence of interventions & type of infant feeding

Source: (WHO, UNAIDS, & UNICEF, 2000)

In 2000, WHO introduced several methods of PMTCT intervention to each method of transmission. Prophylactic ARV during pregnancy can reduce up to 10% risk of transmission, Caesarian delivery or minimal obstetric procedures can reduce up to 15% risk from delivery, and recommended infant feeding method can reduce up to 20% risk of infection from breastfeeding.

Although its main concern is to prevent new HIV infections, PMTCT programs also focuses on prevention with care and treatment for both mother and child, to reduce both mother and child mortality(WHO, 2009b). The UN strategic approach to prevent HIV transmission from mothers to their children, (PMTCT), consists of: 1) prevention of HIV infection in general, especially in young women, and pregnant women; 2) prevention of unintended pregnancies among HIV-infected women; 3) prevention of HIV transmission from HIV-infected women to their infants; and 4) provision of care, treatment and support to HIV-infected women, their infants and families. Parts 3 and 4 concern the prevention of transmission through breastfeeding (WHO, UNICEF, UNAIDS, & UNFPA, 2004a).

Several factors affects mother-to-child transmission of HIV, such as recent infection with HIV, severity of disease, sexually transmitted infections or obstetric procedures during pregnancy and labor, and several factors through breastfeeding. Duration of breastfeeding, exclusive breastfeeding or mixed feeding, breast condition, condition of the baby's mouth and ARV treatment are the factors which affect transmission of HIV through breastfeeding. *Mixed feeding* (feeding the infant both breastmilk and other foods or liquids) is thought to irritate the infant's gut and allow easier access of the virus. There is evidence that the risk of transmission is greater if an infant is given any other foods or drinks at the same time as breastfeeding. The risk is less if breastfeeding is exclusive. Other food or drinks may cause diarrhea and damage the gut, which might make it easier for the virus to enter the baby's body (WHO, et al., 2006).

2.2 Infant feeding practice in the context of HIV

To reduce HIV transmission to infants while at the same time not increasing their risk of morbidity and mortality from other causes, UN agencies have announced their recommendations for safer infant feeding practices.

In 1997, the Joint United Nations Program on HIV/AIDS, WHO and UNICEF, alert the world by issuing a joint policy statement on HIV and Infant Feeding, stating that *"HIV infection can be transmitted through breastfeeding, and that appropriate alternatives to breastfeeding should be available and*

affordable in adequate amounts for women whom testing has shown to be HIV-positive"(WHO, et al., 1997).

In 2001, clinical factors were recognized as influencing factors in HIV transmission by breastfeeding. On the other hand, replacement feeding increased risk of morbidity and mortality associated with malnutrition and infectious disease other than HIV. WHO/UNICEF/UNFPA/UNAIDS, then launched a joint recommendation stating that *"When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life"(WHO, 2001).*

Since then, new evidences revealed decreased transmission in those practicing exclusive breastfeeding and more data regarding clinical conditions which improve breastfeeding outcome, while new findings also revealed increased morbidity in the non breastfeeding group. These facts lead to updated statement in 2006 where "*Exclusive breastfeeding is recommended for HIV-infected mothers for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants before that time.*" (WHO, et al., 2006).

Since 2006, new evidence shows that giving ARVs to either the HIV-infected mother or HIV-exposed infant can significantly reduce the risk of transmitting HIV through breastfeeding. This research has major implications for how women living with HIV should feed their infants, and how health workers should support them. Based on this fact, in November 30th 2009, a new recommendation for infant feeding in the context of HIV was launched "*For individual mothers or infants who receive ARVs, breastfeeding is made dramatically safer and the balance of risks between different infant feeding options, i.e. between breastfeeding and replacement feeding (infant formula), is fundamentally changed. For national health authorities, the recommendations advocate that a single infant feeding practice should be principally promoted and supported across communities. Mothers should still receive information about other feeding practices.*" To support the recommendation, WHO also revised key messages on infant feeding to: *"Mothers known to be HIV-infected (and whose*

infants are HIV uninfected or of unknown HIV status) should exclusively breastfeed their infants for the first six months of life, introducing appropriate complementary foods thereafter, and continue breastfeeding for the first 12 months of life. Breastfeeding should then only stop once a nutritionally adequate and safe diet without breast-milk can be provided. National health authorities should decide whether health services will principally counsel and support mothers known to be HIV-infected to either breastfeed and receive ARV interventions, OR avoid all breastfeeding, as the strategy that will most likely give infants the greatest chance of remaining HIV uninfected and alive"(WHO, 2009a)

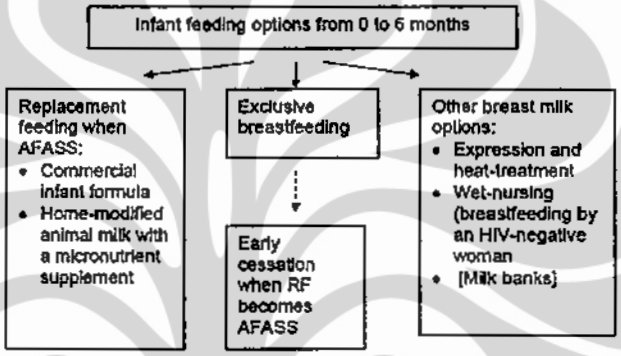

Figure 2.2 Infant feeding options from 0-6 months for mothers with HIV

Source: (WHO, et al., 2000)

A mother with HIV may have chosen a type of feeding option, but circumstances may change and a mother who starts off using one method may switch to another. For example, she may choose to breastfeed exclusively and then transition to one of the other breastmilk options or transition to replacement feeding when the AFASS criteria are met. Shortening the duration of exclusive breastfeeding will reduce the infant's risk of HIV infection (by reducing exposure to HIV in breastmilk). Mixed feeding should be avoided although this may be difficult during the transition to replacement feeding. At all other times, there should be no mixed feeding; the infant should be fed only breastmilk or only breastmilk substitutes (WHO & UNICEF., 2006).

The challenge of providing an adequate diet to non-breastfed infants does not stop at six months. Where resources exist, the infants of HIV-infected mothers

who have exclusively breastfed for up to six months should be eligible for receiving some kind of replacement milk from the time they stop breastfeeding. Infants and young children who are *malnourished* are most often found in environments where improving the quality and quantity of food intake is particularly problematic. To prevent a recurrence and to overcome the effects of chronic malnutrition, these children need extra attention both during the early rehabilitation phase and over the longer term. Nutritionally adequate and safe complementary foods may be particularly difficult to obtain and dietary supplements may be required for these children.

According to WHO, feeding non-breastfed children age 6-24 months should follow specific guidance on amount of food needed, food consistency, meal frequency and energy density, nutrient content of foods, use of vitamin-mineral supplements or fortified products, fluid needs, safe preparation and storage of foods, responsive feeding and feeding during and after illness (WHO, 2005).

2.3 Informed feeding choice

The WHO/UNAIDS/UNICEF guidelines on HIV and infant feeding (WHO, et al., 1997) recommend that HIV-positive mothers should be counseled on the advantages and disadvantages of infant feeding options and should be assisted to select the best option given her specific circumstances. It is the mother who makes the final choice on how to feed her child and she should be supported in whatever method she chooses. One of the arguments against free formula provision is that women may be induced into choosing formula as the feeding option even where this option is inappropriate to her living circumstances (Coutsoudis, et al., 2001). To prevent this, adequate counseling is necessary on the advantages and disadvantages of several infant feeding options, including discussion of whether she can prepare formula safely, and whether she will be pressured to breastfeed by members of her family or community (deWagt & Clarck, 2004).

Counselling an HIV-positive woman on infant feeding may need to take into account her disease progression. Recent evidence suggests a very high rate of

postnatal transmission in women with advanced disease (Leroy, et al., 2003). Whatever the feeding decision, health services should follow-up all HIV-exposed infants, and continue to offer infant feeding counseling and support, particularly at key points when feeding decisions may be reconsidered, such as the time of early infant diagnosis and at six months of age (LINKAGES, 2005).

2.4 Type of feeding according to recommendation

With respect to other option in the 2001 and 2006 recommendation as shown in figure 2.2, this section will only discuss two main feeding option: 1) breastfeeding, and 2) replacement feeding when AFASS.

2.4.1 Breastfeeding

Breastfeeding by women with HIV is a major means of HIV transmission, but not breastfeeding carries significant health risks to infants and young children. Breastfeeding is vital to the health of children, reducing the impact of many infectious diseases, and preventing some chronic diseases. Health services should protect, promote and support breastfeeding as the best infant-feeding choice for all women in general, while giving special advice and support to women with HIV and their families so that they can make decisions about how best to feed infants in relation to HIV(WHO, et al., 2004b).

Lack of breastfeeding compared with any breastfeeding has been shown to expose children to increased risk of malnutrition and life-threatening infectious diseases other than HIV, especially in the first year of life. This is especially the case in developing countries, where over one-half of all under-five deaths are associated with malnutrition. Not breastfeeding during the first two months of life is also associated, in poor countries, with a sixfold increase in mortality from infectious diseases (LINKAGES, 2005).

Controversies on HIV related to breastfeeding evolve through decades, summarized in the following chronology (Preble & Piwoz, 1998):

- **1985–1989:** Evidence emerges that HIV is present in breastmilk. Documented cases of HIV transmission during breastfeeding by mothers who were infected

postpartum are published, but risk of HIV infection during breastfeeding is believed to be small.

- **1990–1994:** Newer studies indicate clear evidence of HIV transmission through breastfeeding among women infected prior to delivery. However, the relative risk of postpartum transmission to infants (compared with in-utero or intrapartum transmission) cannot be determined.
- **1995–1998:** Larger studies using new HIV detection technologies and sophisticated analytic methods focus more intensively on the role of breastfeeding in mother-to-child transmission. Studies estimate the effects of breastfeeding on the risk of late postnatal HIV transmission.
- **1999–2006:** Studies found low maternal CD4+ count, high viral load in breast milk and plasma, maternal sero-conversion during breastfeeding and breastfeeding duration were confirmed as important risk factors for postnatal HIV transmission and child mortality, and follow-up trial data on the safety and efficacy of maternal HAART and on infant prophylaxis trials are awaited (WHO, 2006).
- **2006–2009:** Studies have confirmed the effectiveness of ARVs to reduce HIV transmission is transformational and in conjunction with the known benefits of breastfeeding to reduce mortality from other causes, justifies an approach that strongly recommends a single option as the standard of care in which information about options should be made available but services would principally support one approach (WHO, 2009).

Conditions known to increase the risk of HIV transmission during breastfeeding, include the mother's immune status (John, et al., 2001; Leroy, et al., 2003) mother's blood viral load (Richardson, et al., 2003; Semba, et al., 1999); the duration of breastfeeding (Read, Newell, Dabis, & Leroy, 2002); the presence of bleeding nipples (Embree, et al., 2000; John, et al., 2001), breast inflammation, mastitis, abscesses (Ekpini, et al., 1997; Embree, et al., 2000; John, et al., 2001; Semba, et al., 1999) or oral thrush in infants (Embree, et al., 2000). Mixed feeding may also increase the risk of HIV transmission (Coutsoudis, 2000; Coutsoudis, et al., 2001). Women who become infected with HIV while they are breastfeeding are also more likely to infect their infants during breastfeeding

because of the higher viral load that occurs at this time (Dunn, Newell, Ades, & Peckham, 1992).

Clinical or subclinical mastitis has been associated with transmission risk (John, et al., 2001; Semba, et al., 1999). Cohort study in Nairobi showed transmission by breastfeeding was independently associated with nipple lesions, maternal CD4+ cell count lower than 400 /mm3, infant oral thrush under the age of six months, and prolonged duration of breastfeeding (Embree, et al., 2000). When the 2006 recommendation was announced, the provision of antiretroviral drugs as a prophylaxis to breastfed infants or as a continued viral-load suppressant to breastfeeding women was still evaluated. Trials planned or under way of three regimens to reduce transmission to breastfed infants were the administration for up to six months of nevirapine alone, of nevirapine plus zidovudine, or of lamivudine (WHO, 2006).

The 2009 recommendations were based from results of the previous evaluations, which provided two alternative options for women who are not on ART and breastfeed in resource-limited settings:

1) If a woman received AZT during pregnancy, daily nevirapine is recommended for her child from birth until the end of the breastfeeding period, or
2) If a woman received a three-drug regimen during pregnancy, a continued regimen of triple therapy is recommended through the end of the breastfeeding period (WHO, 2009a).

2.4.2 Replacement feeding

UN agencies recommended that HIV-infected women avoid breastfeeding when replacement feeding is acceptable, feasible, affordable, sustainable, and safe (WHO, et al., 2006). Type of replacement feeding recommended by WHO when acceptable, feasible, affordable, sustainable and safe (AFASS), may be commercial infant formula or home-modified animal milk with a micronutrient supplement. If the AFASS criteria are not met, replacement feeding may present a greater risk to the infant's health than breastfeeding because breastmilk provides

protection against infections other than HIV, while factors relating to replacement feeding maybe susceptible to many potential harm (LINKAGES, 2005).

Many studies revealed consequences of improper replacement feeding practices. A study in urban setting, Kenya, where all the mothers were provided with free formula, had access to clean running water in their homes, and their infants were closely monitored for intercurrent illness found an increased incidence of diarrhea and dehydration in the formula fed infants during the first 3 months of life (Nduati, John, & Mbori-Ngacha, 2000). The MASHI Trial in Botswana showed although infants who were formula fed were less likely to acquire HIV infection, early mortality (at 7 months of age) was significantly higher in the formula fed group: 9.5% compared to 4.9% in the breastfed infants. The main causes of morbidity and mortality were malnutrition, diarrheal diseases and pneumonia (Thior, Lockman, & Smeaton, 2006). Another study in Botswana after an outbreak of diarrheal illness, discovered 90% of the women fed their infants formula; half showed evidence of poor growth prior to the illness, and half of the children who died did not receive adequate supply of infant formula. Mortality was significantly higher in the infants who developed Kwashiorkor. Not breastfeeding was associated with increased risk of hospitalization and subsequent death during the outbreak (Creek, Arvelo, & Kim, 2007).

The 2009 recommendation revised AFASS to conditions needed to safely formula feed (WHO, 2009a) with clearer indicators:

1) safe water and sanitation are assured at the household level and in the community, and,

2) the mother, or other caregiver can reliably provide sufficient infant formula milk to support normal growth and development of the infant, and,

3) the mother or caregiver can prepare it cleanly and frequently enough so that it is safe and carries a low risk of diarrhoea and malnutrition, and,

4) the mother or caregiver can, in the first six months, exclusively give infant formula milk,

5) the family is supportive of this practice, and,

6) the mother or caregiver can access health care that offers comprehensive child health services.

Since the first decade of HIV/AIDS, many studies have been performed to unravell mother-to-child transmission and find the best solution to prevent infants being transmitted with HIV. Most study performed in Africa, and lately in Asia, but very few explored the AFASS recommendation and it's applicability as a whole (table 2.1). Although evidence still very limited, many countries including Indonesia adopt the recommendation.

Table 2.1 Studies on HIV and infant feeding

SETTING	AUTHOR	TOPIC	AFASS Exploration
Botswana	(Shapiro, et al., 2003)	Adherence to recommendation	Acceptability, Sustainability
	(Willumsen & Rollins, 2001)	Comparing feeding practice PMTCT-non PMTCT	Acceptability, Sustainability, Safety
Kenya	(Oguta, 2001)	Feeding practice, maternal knowledge & BM alternative	Acceptability, Feasibility, Sustainability
South Africa	(Coutsoudis, 2000; Coutsoudis, et al., 2001)	Infant feeding pattern on MTCT	Sustainability
	(Chopra, et al., 2000)	Formative research	AFASS
	(Doherty, et al., 2007)	WHO guideliness efectiveness study	AFASS
	(Bland, Rollins, Coovadia, Coutsoudis, & Newell, 2007)	Counseling & choices	Acceptability to breastfeed
Nigeria	(Abiona, et al., 2006)	Exploration study	AFA
Tanzania	(DePaoli, Manongi, & Klepp, 2000)	Counselor's dilema	Acceptability
Uganda	(Matovu, Bukenya, Musoke, Kikonyogo, & Guay, 2003)	Free infant formula	AFASS counseling
Ivory Coast	(Dunne, et al., 2001)	Drinking water & infant formula	Safety
Zambia	(Bond, Ndubani, & Nyblade, 1999)	Formative research	AFASS
	(Omari, Luo, Kankasa, Bhat, & Bunn, 2003)	Feeding practice	Feasibility, Safety (nutrition adequacy)
Zimbabwe	(Israel-Ballard, et al., 2006)	Heat treated EBM	Feasibility, Acceptability
	(Tavengwa, et al., 2002)	Breastfeeding & replacement feeding availability	Acceptability, Safety (nutrition adequacy)
Asia	(Preble & Piwoz, 2002)	PMTCT Guidance	AFASS
Thailand	(Talawat, Dore, Le Coeur, & Lallemant, 2002)	Practice & attitude	Feasibility, Affordability, Safety
Myanmar	(Williams, 2001)	Adaptation of guideline	Replacement vs Bf

Source: http://www.qaproject.org/strat/sourcedoc.htm (QAP, 2009)

2.4.2.1 Acceptability

The mother perceives no barrier to replacement feeding. Barriers may have cultural or social reasons, or be due to fear of stigma or discrimination.

According to this concept the mother is under no social or cultural pressure not to use replacement feeding; and she is supported by family and community in opting for replacement feeding, or she will be able to cope with pressure from family and friends to breastfeed, and she can deal with possible stigma attached to being seen with replacement food.(LINKAGES, 2005).

2.4.2.2 Feasibility

The mother (or family) has adequate time, knowledge, skills and other resources to prepare the replacement food and feed the infant up to 12 times in 24 hours.

According to this concept the mother can understand and follow the instructions for preparing infant formula or other food, and with support from the family can prepare enough replacement feeds correctly every day, and at night, despite disruptions to preparation of family food or other work (LINKAGES, 2005).

2.4.2.3 Affordability

The mother and family, with community or health-system support if necessary, can pay the cost of purchasing/producing, preparing and using replacement feeding, including all ingredients, fuel, clean water, soap and equipment, without compromising the health and nutrition of the family.

This concept also includes access to medical care if necessary for diarrhoea and the cost of such care.It is important for Health Care Workers to help patients understand AFASS criteria by helping to calculate the expenses associated with formula as a feeding option (LINKAGES, 2005).

2.4.2.4 Sustainability

Availability of a continuous and uninterrupted supply and dependable system of distribution for all ingredients and products needed for safe replacement feeding, for as long as the infant needs it, up to one year of age or longer.

According to this concept there is little risk that formula will ever be unavailable or inaccessible, and another person is available to feed the child in the

mother's absence, and can prepare and give replacement feeds (LINKAGES, 2005).

2.4.2.5 Safety

Replacement foods are correctly and hygienically prepared and stored, and fed in nutritionally adequate quantities, with clean hands and using clean utensils, preferably by cup. This concept means that the mother or caregiver has access to a reliable supply of safe water (from a piped or protected-well source), able to prepare replacement feeds that are nutritionally sound and free of pathogens, able to wash hands and utensils thoroughly with soap, and to regularly boil the utensils to sterilize them, can boil water for preparing each of the baby's feeds and can store unprepared feeds in clean, covered containers and protect them from rodents, insects and other animals (LINKAGES, 2005).

2.5 Resources for maternal and child care

2.5.1 Knowledge on appropriate feeding

Current levels of knowledge, understanding and practice of HIV transmission and infant feeding and the feasibility of the various options for women with HIV among different groups of mothers and community members contributes to sustainability of caring practices. Long cultural beliefs about giving water to infants in the first six months of life, as well as honey or other solid foods should be taken into consideration upon feeding option decision.

Those who chose infant formula as feeding option, should have the ability to follow instructions on the tin for mixing the formula to ensure that it is not too concentrated or too diluted. Time to prepare feeds eight times a day, if refrigeration is not available should also is accounted for. Mother or caregiver prepares fresh commercial formula before each feed if refrigeration is not available (LINKAGES, 2005).

For women not with HIV or of unknown HIV status, there is a single infant feeding recommendation—exclusive breastfeeding for the first six months. Those who do not know their HIV status should know that exclusive breastfeeding may protect their infant from becoming infected with HIV (LINKAGES, 2005).

How mothers and caregivers understand and comply with the recommendation will affect the infant's outcome on PMTCT. The appropriate feeding choice can help achieve PMTCT's main goal to reduce HIV transmission to infant and at the same time will not increase risk of morbidity and mortality from risk of other infection or malnutrition (WHO & UNICEF, 2006).

2.5.2 Effect of maternal health toward caring ability

People living with HIV are usually aware of their outcome. Even before AIDS occur, health barrier may already be present to an HIV mother of infant.

If clinically indicated (WHO, et al., 2004b) and available, highly active antiretroviral (ARV) therapy should be used to treat the mother. By keeping mothers alive and healthy, antiretroviral treatment contributes to the health of the infant and delays or prevents children from becoming orphans. Where appropriate, the woman with HIV should receive nutrition counseling and support in addition to antiretroviral drugs. Nutritional care and support may be the only treatment to which she has access. Reduced appetite, poor nutrient absorption, and physiological changes can lead to weight loss and malnutrition in HIV-infected people. Nutritional requirements are known to increase as a result of HIV infection and should be met by increased intakes of nutritious foods. HIV infection increases energy needs by an estimated 10 percent (LINKAGES, 2005).

Post partum maternal condition also greatly affects mother's ability to feed and care for the newborn in the first days. Pains and discomforts will likely limit mother's activity, and increase dependency to other caregiver.

2.5.3 Presence of other caregiver

Not breastfeeding, as result of HIV, can have a harmful effect on mother-infant bonding, resulting in lack of, or reduced, care and stimulation for the infant. Being infected with HIV, a virus known to cause fatal outcome, may already contributes to maternal stress (WHO, et al., 2000).

Amount of burden a mother or caregiver has besides caring for the infant, such as other household duties, older children, and income generating activities, should also be considered. Women with HIV who choose replacement feed may

be stigmatized if these practices are not common locally especially in communities where breastfeeding is the norm. She needs domestic support to carry on the infant feeding option she chooses, as well as support to care for the child and support for herself to sustain her health (LINKAGES, 2005).

2.5.4 Household structure influence toward feeding practice

In environments where environmental sanitation is very poor, waiting until even later than 6 months to introduce complementary foods might reduce exposure to food-borne pathogens. However, because infants are beginning to actively explore their environment at this age, they will be exposed to microbial contaminants through soil, etc. even if they are not given complementary foods. Thus, the consensus is that six months is the appropriate age at which to introduce complementary foods.

It has been hypothesized that a more active style of feeding may improve dietary intake. Preparing and feeding five meals per day requires a considerable amount of time and effort by caregivers, which may prompt them to hold prepared food over from one meal to the next, thereby potentially increasing the risk of microbial contamination.

Maternal/caregiver decisions of optimal breastfeeding by mothers and of optimal complementary feeding practices by mothers/caregiver ultimately determine how an infant and young child is fed, although these decisions do not occur in isolation but rather reflect the immediate and overall environment in which they are made and carried out.

2.6 Food/economic resources of the family

2.6.1 Steady income

The effect of HIV/AIDS on income and assets is a measure of vulnerability. These effects will determine the strategic responses that households adopt to deal with this threat. Such responses in turn will have outcomes—nutrition and food security among them—that will themselves condition future susceptibility and vulnerability (Gillespie & Kadiyala, 2005).

In a cross-sectional comparison of households with and without an HIV individual in Free State, South Africa, per caput income in AIDS-afflicted

households was 50 to 60 percent that of unafflicted households (Booysen & Bachmann, 2002).

2.6.2 Household size and composition

Households experiencing adult mortality tend to become permanently smaller than other households. Changes in household size and composition following a death are sensitive to the age, gender, and position of the deceased adult. The impact of mortality on household demographics may be much more severe when the adult death is due to HIV/AIDS than with other causes of death. Two person-years of labor may be lost because of the weakening of the person and the amount of time spent caring for him or her before death. Adverse dependency ratios were observed in households with the death of an adult with HIV but not with the death of an adult without HIV, and there was a significant association between child-headed households and adult death from AIDS. (Gillespie & Kadiyala, 2005).

2.7 Health resources

2.7.1 Presence of formula donation program

Under International Code of Marketing of Breast-milk Substitutes and its subsequent resolutions milk donations cannot be given through the health care system. The health system if it wishes can provide free or subsidized formula to mothers with HIV, but the health service has to buy the formula to give to mothers, in the same way that it does for most drugs and food for patients and other supplies. In addition the health service should ensure that the mother will have a supply of formula for as long as her infant needs it – that is at least 6 months – and milk in some form after that. If hospitals and health centers have to buy formula, as they usually buy drugs and food, it is more likely that they will ensure that it is given out in a carefully controlled way, and not wasted or misused. Formula is more likely to be given only to mothers with HIV, who have been counseled and who have chosen to use formula (WHO & UNICEF., 2006).

Information on how to feed young children comes from family beliefs, community practices and information from health workers. Inadequate knowledge

about how to breastfeed, the appropriate complementary foods to give, and good feeding practices are often a greater determinant of malnutrition than the availability of food. Hence, health workers involved with infant feeding should be trained with the skills needed to support and protect breastfeeding and good complementary feeding practices (WHO, 2006).

2.7.2 Technical support and monitoring on infant feeding practice

Many governments promote formula feeding as an option but are unable to ensure availability. Policy makers do not understand the complications involved around infant feeding when creating policies that support the practice without designing and implementing sustainable supports for the practice. (WHO, et al., 2004a).

Programs where formula feeding is offered as an option must ensure Health Care Workers competencies around AFASS and provide adequate referal system. Programs that offer to supply formula to those choosing that option, must develop systems to monitor the availability of supply and only offer formula for the number of infants that it can guarantee availability, as well as planning proper way to distribute the supplies, accessible to the mother with HIV (WHO, et al., 2004b).

2.7.3 Recommendation for sustainable infant feeding practice

The Global Strategy for Infant and Young Child Feeding stated children have the right to adequate nutrition and access to safe and nutritious food, and both are essential for fulfilling their right to the highest attainable standard of health. Women, in turn, have the right to proper nutrition, to decide how to feed their children, and to full information and appropriate conditions that will enable them to carry out their decisions. The authorities have the duty to create an environment that will enable mothers, families and other caregivers in all circumstances to make – and implement – informed choices about optimal feeding practices for infants and young children. The primary obligation of governments is to formulate, implement, monitor and evaluate a comprehensive policy on infant and young child feeding (PAHO & WHO, 2003).

2.8 Community context

2.8.1 Feeding practices/norm

Breastfeeding and complementary feeding patterns, commonly available foods, prices, and seasonal influences as well as beliefs and cultural practices affects infant feeding related attitudes.

Local understanding of "acceptable, feasible, affordable, sustainable and safe", and how it might be expressed in practical terms, taken under consideration about cultural beliefs and taboos about infant feeding and the different feeding options – e.g., on expressing and heat-treating breast-milk.

The availability of general resources required for alternative feeding options, including fuel source, storage of supplies, water safety, and replacement milk (formula or other animal milk) even when free or subsidized milk is supplied by a program. *Low-cost complementary foods*, prepared with locally available ingredients using suitable small-scale production technologies in community settings, can help to meet the nutritional needs of older infants and young children. Sound and culture-specific nutrition and the widest possible use of indigenous foodstuffs will help ensure that *local foods* are prepared and fed safely in the home by ensuring that suitable foods for use in complementary feeding are produced, readily available and affordable.

2.8.2 Knowledge of HIV transmission

Mother-to-child transmission of HIV can occur before, during or after delivery, but only rarely in early pregnancy. Risk of transmission between populations is largely attributable to the characteristics of each population, how they relate to HIV infection and to the prevalence of factors influencing the likelihood of transmission (WHO, et al., 2004a).

Women with HIV and those who do not know their HIV status may decide not to breastfeed because of misinformation or fears about HIV, termed as 'spillover'. Exposure to unnecessary infant formula may lead infants to a greater risk of contracting other life-threatening illness such as infections and malnutrition as well as deprive their infants of the benefits of breastfeeding (LINKAGES, 2005).

2.8.3 Awareness of danger caused by improper feeding practice

The immediate consequences of poor nutrition during infancy and childhood include significant morbidity and mortality and delayed mental and motor development. In the long-term, early nutritional deficits are linked to impairments in intellectual performance; work capacity, reproductive outcomes and overall health during adolescence and adulthood (PAHO & WHO, 2003).

The cycle of malnutrition continues, as the malnourished girl child faces greater odds of giving birth to a malnourished, low birth weight infant when she grows up. Poor breastfeeding and complementary feeding practices, coupled with high rates of infectious diseases, are the principal proximate causes of malnutrition during the first two years of life.

Promotion of exclusive breastfeeding was estimated to prevent 13% of current child deaths, whereas the use of nevirapine and replacement feeding would only prevent 2% of current global child deaths (deWagt & Clarck, 2004). On the other hand, an explosive outbreak of diarrhoea occurred in Botswana where it's PMTCT programme provided free formula to all HIV-infected mothers. At the time of the outbreak about a third of all infants under 6 months were not breastfeeding: the practice of formula feeding had "spilled-over" to the uninfected population. Of the patients hospitalized, 97% had piped water. The largest risk factor was "not breastfeeding" (odds ratio 50.0; 95% confidence interval: 4.5–100). The dangers of formula feeding were evident in infants born to HIVinfected as well as to HIV-uninfected women, and were demonstrable despite provision of free formula and the availability of resources beyond what may be affordable for many countries (Coutsoudis, Coovadia, & Wilfert, 2008).

Preparing safe formula feeds requires a substantial amount of work and time on the part of the mother, particularly in resource poor settings. If mothers who chose formula feeding were not supported in preparing and feeding the formula in a safe manner, will caused higher infant morbidity. A PMTCT clinic in Durban, South Africa provided free formula to seventy percent of the mothers coming to the clinic. Sixty-four percent of the milk samples collected from the mothers contained E.coli and 26% Enterococci. A study on water safety in Abidjan, Cote d'Ivoire showed that even though municipal water is widely

available and of good drinking quality, it is often stored improperly at household level, resulting in many of the water samples containing E.coli (deWagt & Clarck, 2004). Mothers need to be informed of such potential danger in order for them to comply the proper replacement feeding practice.

CHAPTER 3

METHODOLOGY

3.1 VIM Matrix

Table 3.1 Variable, Indicator, Method matrix

No	Variables	Indicator	Method	References
1	Infant feeding practice	- Type of infant feeding -AFASS fulfillment - Informed feeding choice	Observation Interview	WHO, 2004, WHO2005, WHO, 2006 Piwoz, 2004 Linkages, 2005 Dewey, 2005 Hartmann et al, 2006
2.1	Resources for care	-Knowledge of appropriate feeding - Effect of maternal health toward caring ability -Presence of other caregiver - House hold structure influence toward feeding practice	-FGD -Interview -Observation	Piwoz, 2004 Dewey, 2005
2.2	Food/economic resources	- Steady income - Household size and composition	-Interview -Observation	Gillespie & Kadiyala, 2005 WHO, 2004 Piwoz, 2004
2.3	Health resources	-Presence of formula donation program -Technical support & monitoring on infant feeding practice -Recommendation for sustainable infant feeding practice	-Interview -Secondary data	WHO, 2004 Piwoz, 2004 Linkages, 2005
3	Community Context	-Feeding practices norm - Knowledge of HIV transmission risk - Awareness of danger caused by improper infant feeding practice	-FGD -Interview	Piwoz, 2004

3.2 Study Design

A descriptive observational study was performed from January to March 2010 to explore factors influencing infant feeding practices of HIV high risk mothers in Bandung.

3.3 Study Area

West Java was purposively selected due to its high rate of HIV cases, even one of the provinces with the highest rate in the nation.

Bandung was purposively selected, due to its highest cases of HIV in West Java, and was on top three highest in the nation. Bandung became target of many HIV combating projects supported by foreign donor agencies. This condition

triggered growth of local NGOs, thus provided Bandung's PLHIV with more support compared with other cities or districts in the province. Hasan Sadikin Hospital, Bandung's General Hospital, served a West Java referral facility for HIV/AIDS patients, supported by the government and based of several NGO projects. Almost all HIV patients had obtained or still routinely seek treatment from the facility. The hospital also host majority of outreach persons' and case managers' from NGOs dealing with HIV. Few other health facilities also located in Bandung provided HIV/AIDS caring services (counseling, testing and ARV), subsidized or supported by donor agencies. Four Puskesmas (Kopo, Ibrahim Adji, Salam and Pasundan) were specifically targeted to provide HIV care, due to their location in areas recognized as "red district", where prostitutes and drug users mostly found. These four Puskesmas were sent request letters for study objects, and continued with followed up visits to head of Puskesmas or officers in charge, to discuss technical issues of the study. Three Puskesmas responded the request letter positively during the three month data collection period, but despite the persistent follow up, no confirmation was received from one Puskesmas until the end of data collection period.

HIV services were also provided by several doctors in private practices. In relation to PMTCT, physicians treating people with HIV were obstetricians and pediatricians. Explorations of physicians in private practices preferred by PLHIV were also performed.

3.4 Source of informants

Locating people living with HIV was a very big challenge, due to stigmatism and discrimination that prevent this condition known to others. Several factors affected knowledge of HIV status include the timing that HIV status was revealed, the marital status in correlation with child, age of child's HIV status can be revealed, underlying factors of HIV transmission in the household as well as disclosures to other family members issue.

Only limited health facilities provided HIV services for patients in Bandung, which covered any HIV patient from different background, socio-economic status, or how they became infected. With information provided by

members of Impact Project Bandung sources of informants for the study were enrolled from Hasan Sadikin Hospital, Puskesmas, private practice patient's data bases, and NGOs dealing with PLHIV. These locations were decided after several preliminary visits and interview to the stakeholders three months prior the beginning of data collection.

As main informant, HIV high risk mothers of infant or those experienced caring an infant under HIV transmission risk were enrolled from information obtained from case managers, outreach persons, PMTCT projects field workers, and HIV specialist physicians.

Figure 3.1 revealed how HIV high risk mothers enrolled in the study were identified, and the channels that connected investigators to these informants.

Criteria for eligibility for main informants were HIV high risk mothers (either infected or partner of a man with HIV) confirmed by Hasan Sadikin Hospital, Puskesmas, clinics or NGOs data base of patients with HIV, currently have an infant (age less than 12 months) or experienced caring an infant during period of HIV transmission risk, lived in Bandung city or cared by NGOs based in Bandung. The number of main informants recruited were based on saturation of information obtained and variations were captured under this circumstances.

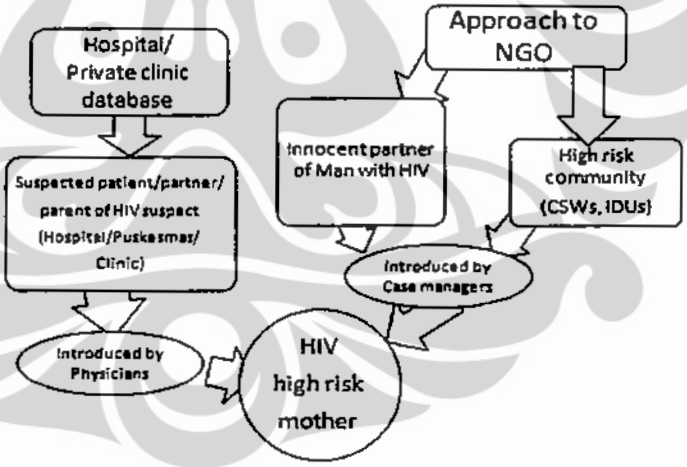

Figure 3.1 Source of main informants

Additional informants for in-depth interviews were those involved with HIV program, each one were recruited as informants based on new findings as the data collection proceed. FGD participants were selected from communities with

high HIV rate, with intention to obtain information from communities already aware of HIV transmission risk.

3.4.1 In-depth interviews

Twelve HIV high risk mothers were identified and contacted for main informants. These informants were purposively selected with consideration that their condition can provide rich information for the study. Eleven signed the informed consent, but only nine in-depth interviews were performed. Two informants recruited from private clinics agreed to be interviewed by phone, but later refuse to be interviewed at all, although their physician have suggested to participate. One other informant, although willing to participate, were unable to be followed up, due to loss of contact with the informant's case manager who can provide the only access to the informant's home. All nine informants were ask to sign their permission form, and interviewed using structured questionnaire while being recorded on tape. The questionnaire developed prior data collections were revised after interviews, and the final version was obtained after the third informant. Informants with child age less than one year were asked of current infant feeding practice, while those with child age more than one year were asked to recall past infant feeding practice.

Five health related providers were asked for inform consent and interviewed as additional informants and the interviews were recorded on tape. The first interviewed, an HIV specialist anthropologist, was recruited to provide background of HIV transmission and anthropological information in seeking informant's characteristic. Informants from Bandung National AIDS Commission representative, an NGO PMTCT program officer and a District Health Office nutrition officer were interviewed to obtained information on the milk donation programs while also triangulating the information from each stakeholder. The last additional informant, a midwife dealing with PMTCT was interviewed as triangulation of information regarding health services and infant feeding practices of the HIV high risk mothers. Interviews also used structured questionnaire, but each time added with several new questions relevant to the informant's role in PMTCT program and infant feeding practices on HIV context.

3.4.2 Focus group discussions

A total of 29 FGD participants were purposively selected from communities with high HIV rate, to obtain information from communities familiar of HIV transmission risk. With the purposive selection, richer information was expected to come up in the discussions.

Information obtained from HIV projects and confirmed by District Health Offices revealed four Puskesmas as HIV base project, Kopo, Ibrahim Adji, Salam and Pasundan. These four Puskesmas were then requested for source of FGD participants. Only three responded within data collection period, while one Puskesmas was not able to provide confirmation of official response during the period requested. Followed up discussion with head of Puskesmas and related officer (HIV counselor and nutritionist) resulted agreement of FGD location, timing of FGD and source of participants. In two areas, a mixture of Posyandu cadre and mother of infants were proposed, with maximum 10 participants each. In one Puskesmas, the AIDS Aware Community was invited instead, although pregnant mothers and mother of infants were also requested to join but none attended.

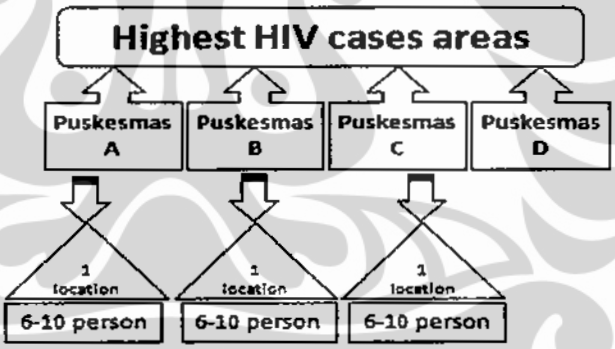

Figure 3.2 Source of FGD participants

The discussions were performed using structured questionnaires. At the end of every discussions, the participants were asked to work on picture exercise, identifying the common an uncommon feeding practice in their community. Signed informed consent were obtained from every participants, and the discussions were all recorded on tape.

3.4.3 Observation

Structured observations of feeding practices (to informants with children aged less than 12 months), home hygiene and sanitation were performed to households of the informants. Store surveys of retail outlets mentioned by informants were performed to provide additional information on infant formula price, expiry date and packaging condition as well as distance from informant's homes.

3.5 Triangulation

Findings obtained from different informants, or obtained from similar informants using different research methods (e.g., group discussions versus direct observation, interview versus observation and anthropometric measurements) were triangulated to obtain saturation of information for a more complete understanding of infant feeding practice. Secondary data were also gathered to triangulate information from health providers.

From the main informants, triangulation with other family members were not able performed, due to disclosure issues of HIV status to other family or household members.

3.6 Data collection procedure

People living with HIV (PLHIV) are constantly stigmatized. Disclosure is highly important for a person to be willing as an informant in this study. Special measures were taken in order to identify and locate those fits with the inclusion criteria. Key persons in HIV network who can provide information and open access to potential informants were approached.

Among the potential key persons included case managers, physicians, counselors, project officers of HIV programs. Their direct contact with the high risk communities (commercial sex workers, drug users), partners of men with HIV, patients and patient's family suspected with HIV proven help the respondent's acceptance to be recruited in the study. Establishing good contact with these key persons had begun before data collection period.

3.7 Data analysis

Data analysis began as soon as the first data collected and lead to revisions in the study tools. All in-depth interviews and focus group discussions were transcribed verbatim from audiotapes. Two field assistants also acted as transcribers. Transcripts reviewed for completeness and accuracy by reviewing audiotapes. Results from transcripts then coded and compiled to matrices according to main themes emerge from the data. Data coding were performed manually, using already developed code set. The reference codes were then added as new ideas or phenomena discovered in the transcripts.

Debriefed notes and observation notes were developed using taped interview and field notes made by team members. The developed debrief notes were used as reference for the next data collection, such as deciding where to look for the next informant.

Research question was use as guidance to group the data and point out similarities and differences. Matrices were developed to help group each emerging theme, and reveal repetitive phenomena, prompting saturation of information.

3.8 Ethical Consideration

Ethical clearance was obtained from Medical Faculty University of Indonesia. Permission from West Java authorities, Bandung authorities, Bandung District Health Office authorities, Hasan Sadikin Hospital authorities, several Puskesmas and several HIV non government organizations who provided data for the study were also be obtained. Before conducting the interviews, respondents were informed about the purpose and procedure of the study and benefit to subject and ensured that all data collection performed by qualified, trained personnel. Respondents were given the rights to refuse at anytime, and emphasized that their participation was on voluntary basis.

CHAPTER 4
RESULTS

Data collection was performed during January-March 2010. Several efforts were conducted to identify, track and approach the potential informants. With assistance from Provincial Health Office and members of Impact Project Bandung, we were able to identify and gained access to the required NGOs, case managers and Puskesmas.

Twelve mothers from NGOs were approached and asked their willingness to be recruited in the study as main informants. Two mothers initially agreed to sign the inform consent, later refused to be interviewed. One other person willing to participate as informant but were unable to be followed up, due to loss of contact with the informant's case manager who can provide the only access to the informant's home. Five key person from stakeholders were also interviewed as additional informants. Four Puskesmas (Kopo, Ibrahim Adji, Pasundan, Taman Sari) currently bases of HIV projects were selected as source of FGD participants, but one Puskesmas (Pasundan) was excluded because the authorities were not able to provide confirmation of official response during the period requested.

4.1 General Characteristics

Main informants were selected from NGOs, Puskesmas and information obtained from Hasan Sadikin General Hospital. Seven among the nine mothers recruited as informants were with HIV. Majority of these seven women were clients of Hasan Sadikin Hospital. The potential informants with HIV who were clients of private practices refused to be enrolled.

Table 4.1 General characteristic of children under study

Characteristics		n
Ages of child in months (n=9)	0-6	5
	7-12	2
	>13	2
Sex of child (n=9)	Female	5
	Male	4

Majority of the children aged bellow six months, and their sex were almost equal (Table 4.1).

Majority of informants aged bellow 30 years old, currently married, and lived with extended family, thus provided with multiple source of income to spend expenditures. One informant (divorced and jobless) relied on parent's income only; two other (house servant and commercial sex worker) relied on self income only. Two spouses were jobless and three had regular monthly income. Detail characteristic of main informants is described in Table 4.2.

Table 4.2 General characteristic of main informant

Characteristics		n
Ages of mother (n=9)	19	1
	20-25	1
	26-29	6
	30	1
Mother's education level (n=9)	Diploma	1
	High school	6
	Elementary	2
Occupation of mother (n=9)	Marketing staff	1
	Multilevel marketer	1
	House servant	1
	Housewife	3
	Commercial sex worker	1
	Case manager	1
	Jobless	1
Number of children (n=9)	1	4
	2-3	4
	>3	1
Marital status (n=9)	Married	6
	Divorced	2
	Widowed	1
Source of household income (n=9)	Self income only	2
	Parents only	1
	Multiple sources	6

The informants living with extended family were divided equally among those living with the spouse's family and with own parents or siblings. This situation caused complexity in the way informant's disclose their HIV status. Those living with one's parents and siblings mostly confirmed their family's knowledge of their or their partner's HIV status. While those living with the in-

laws declared that their HIV statuses have not been disclosed or only limited family member aware.

Box 4.1 revealed the complexity how a person became infected with HIV. A typical housewife may never realize her husband transmitted HIV until their child was proven with HIV, simply because her husband's history of drug use was never revealed. On the other hand, a mother with HIV maybe abandoned by her HIV negative husband and in-laws because they felt betrayed by her "good girl" image. Informant #2 requested her case manager to inform the investigators prior to interview not to ask questions related to HIV when family members other than her husband were present, while informant #5, a sexual worker, found out her HIV status in routine visit to a clinic for a syphilis injection.

Box 4.1 How the mothers became infected

"I had no idea my husband had HIV before we were married. He spent his teenage in Pesantren. I didn't know he was admitted there because he was a drug addict."
(Informant #7, status revealed from PITC in Hasan Sadikin Hospital when the child was hospitalized.)

"My ex-husband is negative. I'm solo carrier here."
(Informant #4, recently divorced, mother of 1 month old infant).

Table 4.3 revealed that from the nine main informants interviewed, two were HIV negative but spouse of men with HIV, and experienced pregnancy under condition of high risk HIV transmission. On the other hand, several husbands of the informants with HIV remained HIV negative, as reveled in Box 4.1, showing different ways how the informants became infected. Table 4.3 also displayed similarities of practices by informants 1, 2 and 3, as they were cared by the same NGO. In the later part of this chapter, these mothers' past infant feeding experiences with their older children were also described. These three mothers experienced the same situation where an older child had been confirmed with HIV (Table 4.9).

Table 4.3 HIV related characteristic of main informants

Characteristic	Informant #1	Informant #2	Informant #3	Informant #4	Informant #5	Informant #6	Informant #7	Informant #8	Informant #9
HIV status	Positive	Positive	Positive	Positive	Positive	Positive	Positive	Negative	Negative
Current partner HIV status	Negative	Negative	Positive	Negative	Unknown	Positive	Positive	Positive	Positive
HIV status of child under study	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Positive	Negative	Unknown
Age of child under study	4 months	6 months	1 months	1 months	8 months	4 months	3 years	6 years	12 months
Delivery method	C section	C section	C section	C section	Normal	C section	Normal	Normal	Normal
Place of birth	Hasan Sadikin General hospital	Hasan Sadikin General hospital	Hasan Sadikin General hospital	Hasan Sadikin General hospital	Midwife	Kebumen General hospital	Midwife	Private hospital	Midwife
Infant feeding type	Formula feeding	Formula feeding	Formula feeding	Formula feeding	Formula feeding	Formula feeding	Mix feeding	Exclusive breastfeeding	Mix feeding
Breast related problem	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	None	None	None

4.2 Aspects affecting infant feeding practices of HIV high risk mothers in Bandung.

According to the study's conceptual framework, infant feeding practice is affected by three direct factors (resources for care, food/economic resources, health resources) and one indirect factors (community context). The following results are divided in four aspects, representing four factors mentioned above.

4.2.1 Aspect related to food or economic resources

In the general characteristic data (Table 4.2) majority of the informants relied on multiple sources of income, either combination of self and spouse's income, or received from parents and other family members as additional income. From the six informants who had self income, only two had steady monthly income (case manager and house servant).

Table 4.2 also revealed that five informants had children more than two. These informants lived in extended family (with parents or in laws) who helped them in providing food and sharing household expenditures. However, ability of other family member to purchase nutritious food also varied. Often rice had to be sacrificed in order to keep food available for the infant (Box 4.2). This box also revealed how economic status of relatives can or cannot help provide food to households.

Box 4.2 Ability to purchase food

"I reduce buying rice so that I can buy the infant's formula"
(Informant #9)

"Their relatives can't help them either (with food) because they're also poor themselves"
(AIDS Aware Cadre)

4.2.2 Aspect related to resources for care

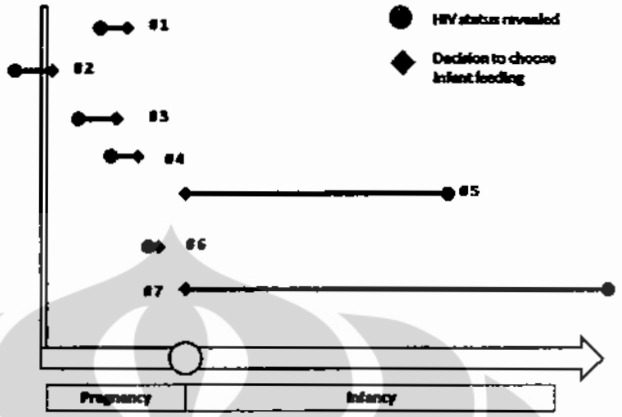

Figure 4.1 Preparedness of mothers on infant feeding decision

From seven informants with HIV, not all aware of their status prior the infant's delivery as shown in Figure 4.1. Six out of seven give replacement feed to her infant (Table 4.3), although one mother made the feeding decision before she was aware of her status. Timing of HIV status revealed reflects planning of PMTCT program, including ARV consumption. Those whose HIV status were revealed during pregnancy, were informed by their health providers during the third trimester to perform replacement feeding. One informant, who was aware of her HIV status before conceiving, was prepared for replacement feeding at time of her pregnancy confirmed.

Two informants whose HIV status were revealed during their children infancy, one decided to replacement feed to prepare the infant for adoption and the other decided to breastfeed around time of delivery. These informants conceived, delivered and made decision on child feeding and caring without the knowledge of being infected with HIV and realizing the risk of transmitting to their children.

Box 4.3 revealed informants who were HIV negative and breastfeed. One was aware of being HIV negative before the child was delivered, and decided to breastfeed after being assured that breastfeeding was safe for her infant. The other found out her husband was HIV and later confirmed herself HIV negative after the child was born. She decided to breastfeed although had history of being IDU.

Box 4.3 Awareness of HIV transmission risk

"My husband and I were IDUs, but we stopped before I was pregnant. We found out he had HIV when our daughter was one year old, and still breastfed. We never use condoms before."
(Informant #8, HIV negative)

"Before my baby was born, they tested me negative. So I decided to breastfeed"
(Informant #9, HIV negative)

Box 4.4 revealed how available feeding option was never discussed by health providers, case managers or those with direct contact to the mothers. Mothers with HIV were conditioned to give replacement feeding to their infants and were prepared to do so before delivery. However, unwritten agreement in the national level supported formula subsidy after the infant age six months, therefore in the national level there is an understanding that parents should have the freedom to decide infant feeding method in the 0-6 months period.

Box 4.4 Initiation of replacement feeding

"My newborn was directly separated, I don't get to see him until it's almost time to go home. The case managers already told us to prepare 6 bottles for feeding in the hospital, so they already given the formula and they gave me drugs for my breast."
(Informant #1, recipient of PMTCT subsidy from an NGO)

"Before they deliver their babies we make sure they (HIV mothers) don't breastfeed, even if the breast felt full."
(PMTCT field coordinator and midwife for local NGO)

"AFASS should be fulfilled as a whole. Any donation before six months is least likely sustainable. Therefore, it is an agreement that formula subsidy begin after infant six months where we have more chance that formula feeding will be more sustainable. Why mothers were conditioned for Caesarian Section and formula feeding are due to practicians still refer to old paradigm in eradicating HIV and

Table 4.4 only displayed the mothers practicing replacement feeding. Five mothers mentioned that the health providers cared for them never discussed the possibility of feeding option other than replacement feeding. Although three of them were aware of other feeding option, the information did not come from health providers.

Table 4.4 Information related to mothers with HIV who practiced replacement feeding

Characteristic	#1	#2	#3	#4	#6
Infant feeding suggested by health provider	Formula feeding	Formula feeding	Formula feeding	Formula feeding	Formula feeding
Aware of breastfeeding possibility as other option	Yes	Yes	Yes	No	No
Source of information on breastfeeding option	TV	A friend	A friend	N/A	N/A
Infant feeding practiced by mothers	Formula feeding	Formula feeding	Formula feeding	Formula feeding	Formula feeding

Replacement feeding also affects mother's condition. Mothers who had Caesarian section and whose infant were formula feed experienced mastitis in the first month (Table 4.3). Caesarian section caused post operative pain which limit the mother's ability to be mobile. Mastitis caused fever, thus limiting the mother's activity during feverish episodes. These conditions caused the mothers to be dependent of other people to care after their infants in the first months. On the other hand, Table 4.2 revealed that few of the informants were divorced and widowed. These informants had to rely on family members other than their spouses to look after their infants during the period they suffered from pain and fever.

Breastfeeding were practiced by HIV high risk mothers who had no knowledge of her HIV status, are aware that her current status is negative although risk of becoming infected from her partner who is with HIV is high, or are aware of transmission risk but continued to breastfeed since the child already depended on breastfeeding (Table 4.5). They all breastfed because breastfeeding was considered the norm.

Table 4.5 Information related to informants who practiced breastfeeding

Characteristic	Informant 7	Informant 8	Informant 9
HIV status	Positive	Negative	Negative
Current partner HIV status	Positive	Positive	Positive
HIV status of child under study	Positive	Negative	Unknown
Age of child under study	3 years	6 years	12 months
Age of child when mother performed HIV test	2 years	1 year	Before birth
Infant feeding type	Mix feeding	Exclusive breastfeeding	Mix feeding
Duration of breastfeeding	> 1 month	2 years	Still breastfeed
Timing of introducing replacement food	2 months	Never	Since birth

Box 4.5 revealed the information regarding breastfeeding option received by the mothers with HIV. The health providers around these mothers did not provide encouragement for these mothers to explore more on the breastfeeding possibility. All three mothers although considered breastfeeding as an option, feared to breastfeed because they have experienced breastfeeding with their older children who were later confirmed with HIV (Table 4.9).

Box 4.5 Knowledge of breastfeeding option

"I saw on TV about breastmilk donor for mothers with HIV, and I talked to my case manager about it. She asked me if I still produce milk and I said 'No'. She asked me also if I know anyone who are willing to donate her breastmilk and I said 'No'. So she suggested I stay with formula"
(Informant #1, mother with HIV of infant)

"The doctor said if I to consider breastfeeding, my CD4 should be above 600. My husband supported me to breastfeed. I just don't want to take any risk."
(Informant #2, mother with HIV of infant)

"A friend of mine told me that her NGO informed about a study in Africa which proved HIV mothers can breastfeed safely if exclusively. My husband actually supported if I want to breastfeed. But I'm afraid to do it."
(Informant #3, mother with HIV of infant)

4.2.3 Aspect related to health resources

Interviews with additional informants (stakeholders of PMTCT programs) revealed how the pregnant mothers with HIV were cared in the health facilities in relation to the infant feeding practices (Figure 4.2.).

Women from the high risk groups maybe confirmed with HIV by two different pathways, 1) by VCTs encouraged by NGOs or, 2) after PITCs in health facilities, especially hospitals. Caesarian Section will be performed to those with HIV who were discovered pregnant, and the infant separated from the mother to be given infant formula in perinatology ward.

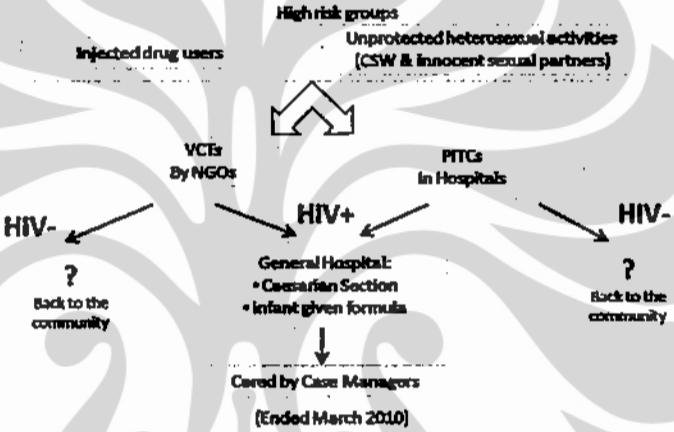

Figure 4.2 How informant's HIV status revealed and cared.

The 2008 national PMTCT training guide provide several methods of infant feeding for mothers with HIV. However as shown in Table 4.3. six out of seven informants formula feed their infants. We explored infant feeding message from the policy makers' level to the direct implementers' level and discovered transformations in the message route as shown in Figure 4.3. Infant feeding message recommended in the National level have evolved and decreased in the lower level. Only a single feeding message reached the PLHIV, which is formula feeding.

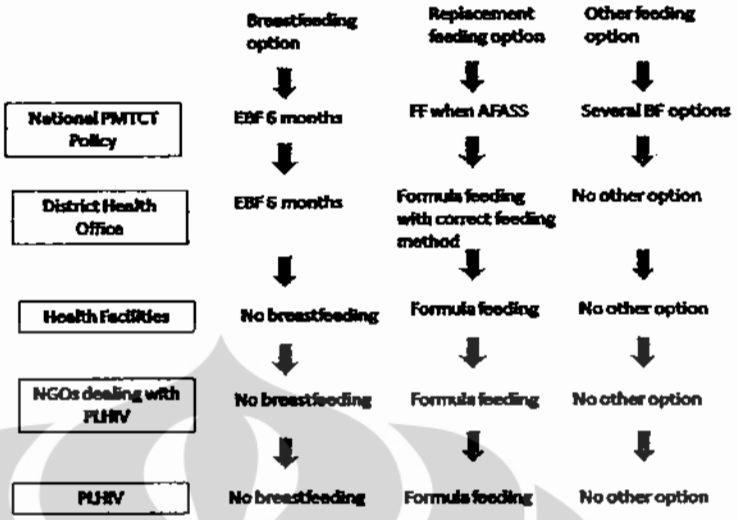

Figure 4.3. Deviation of infant feeding message from stakeholders

These procedures were explained to the mothers with HIV by their case managers before date of delivery, to enable the mothers prepare with infant feeding equipments (bottles and teats) as displayed in Box 4.2, although the mother may only recently aware of her HIV status (Box 4.4).

From six informants with HIV who had Caesarian Section (Table 4.3), five received subsidy for the hospital expenses from PMTCT program they were enrolled to prior delivery. One other informant, although conditioned for Caesarian Section, did not receive any subsidy, therefore hospital expenses was covered by Jamkesmas.

Box 4.6 Mother's acceptance of PMTCT program

"We've informed the mother (with HIV) about PMTCT, so she can be prepared for C section and formula feeding costs. But then she disappeared and I accidentally met her in the Puskesmas delivery room, just had a normal labor and was breastfeeding."
(AIDS aware cadre)

"I was nine months pregnant when they found out my (late) husband's (HIV) positive. He passed away few days afterward, and the hospital prepared me for Caesarian Section right after they tested me for HIV."
(Informant #6, HIV status revealed when her late husband was severely ill).

Health providers in hospitals and NGOs applied type of caring as shown in Figure 4.3, however health workers were not prepared to face mothers with HIV who refused to follow the PMTCT procedures endorsed, as revealed in Box 4.6. The cadres advised a pregnant mother with HIV to be prepared for Caesarian Section and replacement feed her infant. The mother was later discovered not following their recommendation. After their accidental encounter, the mother then moved to other place, so was not able to be followed up.

4.2.4 Aspect related to community context

To have description of infant feeding norm in the community, focus group discussions were performed in three locations, referred by three Puskesmas which currently are bases of HIV projects. Two FGDs were performed in Posyandu, and one was held in the Puskesmas. Participants were selected by Head of Puskesmas, HIV Counselor and Nutrition Officers. In two locations (Kopo and Taman Sari), all the participants were female, while in Ibrahim Adji one male participant attended. Majority of the participants in Kopo, Ibrahim Adji and Taman Sari have Senior High School background, with mixture of different education level in each location (Junior High School in Kopo, and minority had University background in Ibrahim Adji and in Taman Sari).

Table 4.6 General Characteristic of FGD Participants

Characteristic	KOPO	Ibrahim Adji	TAMAN SARI
FGD participants	7 Cadres 3 mothers of infants	7 active AIDS aware cadres 2 health workers	10 mothers of under five years olds
Age [1]	27-61	28-66	26-47

[1] range (min-max)

In two FGD located in Kopo and Taman Sari the discussion were held in the integrated health post, and participants were selected from cadres and mothers of underfive children living close to the post (Table 4.6). The FGD in Ibrahim Adji was held in the Puskesmas. The participants were selected from active cadres who had trainings on HIV and PMTCT for community and the Puskesmas HIV counselors. Several mother of infants and pregnant mother were invited to join the FGD but did not attend.

Table. 4.7 Identifying type of community

Characteristic	KOPO	IBRAHIM ADJI	TAMAN SARI
Type of areas	High number of IDUs in the near hamlets	Close to red district High number of IDUs	Community close to red district
Infant feeding norm	Dominantly breastfeeding	Breastfeeding Formula feeding Mix feeding	Dominantly breastfeeding
Dominant family type	Solid nuclear family or Extended family	Single parents	Solid nuclear family
Uncommon feeding practice	Wet nursing	Wet nursing	Wet nursing

Exercises using pictures of different types of families and different types of infant feeding practices were preformed to identify type of families dominant in each community and feeding practices commonly found in the community as shown in Table 4.7. From the three group discussions, Ibrahim Adji was the only place where formula feeding was mentioned as dominant feeding type along with breastfeeding. In this area single parenting was considered common, where the other two groups considered nuclear family most common family type.

Table. 4.8 Community Infant Feeding Perception

	Kopo	Ibrahim Adji	Taman Sari
Feeding problem identified	Not self identified. Problems only occur in "other" hamlets	Feeding practice is influenced by household economic ability	Not self identified. Problems only occur to other neighborhood
Awareness toward HIV transmission via BF	Not aware breastfeeding can transmit HIV	The high risks have been informed, but may not directly alter choice of feeding practice	Not aware breastfeeding can transmit HIV
Knowledge of proper replacement feeding method	Something mothers can self learn & deal (but rarely happens since mostly breastfeed)	Something which mothers can self learn. Cost affect length & way to feed (since mostly from low economic status)	Something mothers can self learn by herself

Result shown in Table 4.8 showed the lack of awareness of HIV transmission through breastfeeding in two FGD sites. Knowledge of proper replacement feeding was obtained through discussions on issues relating to replacement feed preparation.

The highest concern in replacement feeding was the affordability aspect which may lead to unsafe practices (Box 4.7), while other aspects such as

feasibility of preparing formula feeds was considered as something mothers can deal with.

Box 4.7 Danger of improper feeding practice

> *"We'll dilute the infant formula or start the solids (food) early"*
> (A mother of under five children in Tanjan Sari)
>
> *"People likely to ignore any recommendation (about reducing HIV transmission) and will just practice what they want, which will be normal delivery and breastfeeding "*
> (AIDS aware community cadres)

Past feeding experience of the mothers with HIV toward their older children was described in Table 4.9. All breastfed their infants because it was the common infant feeding method practiced by other mothers, although the length of period they breastfed varied. Three out of six were proven HIV positive, and the mothers recalled them as easily ill during their early childhood. Other two children were deceased due to illness at very young age. All six mothers then formula feed their current child (Table 4.3).

Table 4.9 Past infant feeding experience of mothers with HIV's older child

Characteristic	#1	#2	#3	#4	#5	#6
HIV status	Positive	Positive	Positive	Positive	Positive	Positive
HIV status of older child	Positive	Positive	Positive	Unknown	Unknown	Unknown
Current age of older child	5 years	Unknown	4 years	N/A	3 years	N/A
Type of infant feeding practiced	Breastfeeding > 2 years	Breastfeeding Briefly	Breastfeeding > 1 year	Breastfeeding 11 months	Breastfeeding 9 months	Breastfeeding 1 month + formula feeding
Condition of the child currently	Often had diarrhea & ARI	Cared by other family	Often ill	Deceased at 11 months	Adopted since 9 months	Deceased at 3 months
Age of child when mother's HIV status revealed	4 years	Unknown	3 years	Already deceased	3 years	Already deceased

4.3 AFASS fulfillment among HIV high risk mothers practicing replacement feeding.

Information concern AFASS practices were collected from informants with HIV. Interview about current feeding practices of the child under study aged less than one year and recalling in the past practice to those with children age more than one year, while direct observations only performed to those with child currently less than one year.

Table 4.10 compared the informants practices to the expected WHO standard. The data were collected through interviews of infant feeding practices, as well as observations. Practices considered supportive in fulfilling the required WHO standard were labeled under "favorable practices" and practices considered hindered the WHO standard achievement were labeled "unfavorable practices". Compared to the ideal WHO standard, more unfavorable practices were found practiced by the informants than the favorable.

Within the resources of care, the unfavorable practices were related to knowledge of infant feeding practice (incorrect scooping, milk dilution, lack of hygiene practice), stigma and discrimination (deny with HIV, neglected by family) and availability of other caregiver.

Several unfavorable practices identified were related to health resources, such as the deprived feed option, discriminations in health facilities and constrains in donation programs. The lack of infant feeding knowledge by caregivers were also related to health resources, as the lack of knowledge had occurred since the infants were still cared in health facilities but mothers had to self learn or seek the information needed from her peers.

Unfavorable practices related to food and economic resources were purchasing power of formula supply and expenditures related to replacement feeding as well as food for the family.

Table 4.10 Range of AFASS Practiced

AFASS	WHO standard component	Practice found	
		Favorable practices	Unfavorable practices
Acceptability	Pressure to use replacement feeding.		Forced to formula feed by separating infant, no other option ever given.
	Support for replacement feeding.	Husband & parents are supportive.	Neglected by spouse, rejected by in laws.
	Ability to cope with stigma of not breastfeeding.	Disclose HIV status as reason to not breastfeeding.	Deny HIV status, lie about reason to not breastfeeding.
Feasibility	-Knowledge on infant formula preparation.		Self learn from package instruction or taught by other mothers.
	Ability to prepare enough feeds in a day.	Able to prepare independently	Require assistance due to post operative discomfort and breast inflammation
	Support to prepare and feed.	Other family members assisted feeding.	No caregiver available to assist with feeding.
Affordability	Cost of all ingredients required to prepare replacement feeding.	Partial subsidy of formula supply, supplies delivered to home.	Amount formula purchased depended of daily income, self purchase other requirement including transportation.
	Expenditures on replacement feeding will not compromise the family's health and nutrition.	Expenditure for family food supported by extended household member.	Reduce rice expenditure, family member rely on festivities as source of animal protein.
	Access to medical care if diarrhea.		Self purchase over the counter drugs or goes to private clinics if illness persists to avoid discrimination in public health services.
Sustainability	Dependable distribution system of replacement food more than one year.		Unreliable donation schedule affects distribution schedule, donation term less than 1 year.
	Assurance of formula availability & accessibility.		Limited donation supply but targeted to age > 1 year, donation have reached end of program.
	Availability of other caregiver to prepare & feed the child in the mother's absence.	Extended family member available to assist feeding practice.	The only other family member available not able to prepare feeds.
Safety	Reliable safe water supply.	Cooked tap water, refillable drinking water.	
	Ability to prepare nutritionally sound replacement feeds.		Inaccurate scooping, dilute milk, give water only between feeds.
	Ability to prepare free of pathogens replacement feeds.	Dry & clean storage of supply. Proper utensil cleaning & boiling.	Lack of hand washing before preparing feeds, rare teat replacing, left over milk storing.

Information from additional informants (stakeholders of PMTCT programs) revealed two existing infant formula/milk donation for families affected HIV. One donation program was funded by international donor agency, utilizing local NGO to distribute milk to the HIV pregnant mothers and infant formula to infants of HIV positive mothers since delivery up to age six months. This program ended in March 2010.

Other milk donation was requested and distribution organized by Bandung National AIDS Commission, with source of donation from a milk company. To enable this activity, Bandung District Health Office issued a recommendation (Number 443.1/2955-Dinkes, dated 30 April 2009), stating:

1. Formula for infants 0-6 months and follow on milk up to two years should fulfill nutritional requirement to avoid nutritional problems.
2. Parents of recipients should receive proper information on correct feeding method.
3. Puskesmas and nutrition officers should monitor child's growth.

The program initially recruited 30 candidates for recipients, among which were two infants. As the program run, recipients declined to 22, all aged over one year old. This program has ended in February 2010. Stakeholders involved in milk distribution on both program is showed in Figure 4.4.

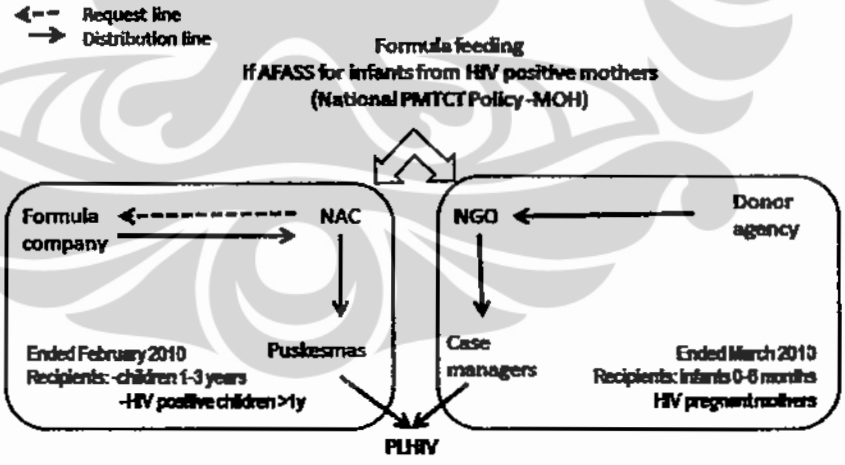

Figure 4.4 Request and distribution flow of milk donation

The milk donation from the formula company and given to NAC was a result of personal approach by the local PMTCT implementers with the milk company authorities. Agreement was made that the formula company will provide milk donation for several months, and evaluation report will be prepared at the end of the period for guidance on future donation plan. The evaluation was performed by a third party (Healthy West Java Coalition). The other milk donation funded by donor agency was part of international grant for national PMTCT projects. NGOs were appointed as executors in providing and distributing the milk supply.

Although Bandung DHO had issued a recommendation about usage of infant formula from 0-6 months infant of mothers with HIV, the milk donation provided by the formula company was distributed to children age 1-3 years. Information obtained from DHO officer and NAC officer revealed that the technical decision of the target age group was in the formula company authorities. The company feared of violating the health law on infant's right to be breastfeed and the 1981 WHA resolution of international code of marketing for breastmilk substitute which prohibits milk donation to infants.

Other barriers occurred to the milk donation programs from each stakeholder involved, such as the short donation period, distribution effectiveness and recipient's disclosure issues, as displayed in Box 4.8.

Box 4.8 Challenges in formula donation

"With such limited sample (of formula donation recipients) and such short period of donation, we cannot conclude any benefit or effect of formula consumption to the child's (consuming the donation milk) health"
(Nutrition officer, Bandung DHO)

"Utilizing 17 Puskesmas to distribute milk donation to 22 recipients is un-effective and costly. Ideally, that number (of Puskesmas involved) can cover 100 recipients."
(PMTCT program officer, NGO, Bandung)

"Some withdraw from the donation program because they're not willing to admit to the puskesmas that they have HIV"
(NAC program officer, Bandung)

"The child (receiving donation) was never taken here for growth monitoring. The parents afraid people might suspect something wrong with the child, why we're giving free milk to them only."
(Nutrition officer, Kopo Puskesmas Bandung)

CHAPTER 5
DISCUSSION

According to Ulin (2006) qualitative analysis can answer questions about how people make sense of the world. It also can address many objective dimensions of human action and interaction, relating these findings to the contexts in which they occur.

This study was able to reveal how each informant had unique individual and family characteristics. The ones living away from families lack support in child caring. This condition caused the mother to sacrifice her infant for adoption. Others living in extended families had not disclosed her HIV status, thus preventing her from gaining their support in child caring.

How a mother became infected with HIV also affects her social economic condition. An informant was abandoned by her spouse and in-laws and thus deprived from her only financial source because they perceived she had permissive pre marital sexual relation. Other informants struggled to earn money by becoming a house servant; one informant even had to earn money by becoming a sexual worker.

Another important finding was the role of non governmental institutions, including case managers, towards informants' similar infant feeding practices. Case managers were extensions of HIV programs, and had significant relationship with HIV high risk people. Their role could not be ignored in identifying the potential informants, and influenced informant's acceptability to be recruited in the study.

This study was also able to obtain information that a mother had walked away from PMTCT program. This finding provided us with information about the need to explore infant feeding practices from free living HIV high risk mothers, who might give other practice variation.

5.1 Aspects affecting infant feeding practices of HIV high risk mothers in Bandung

5.1.1 Messages about infant feeding

Several phenomena were uncovered by this study. In the resources for care aspects, method of infant feeding was influenced by the timing of mother's HIV status revealed. In this study mothers who were already aware of her HIV status before delivery all choose to replacement feed. These informants however, all had breastfeeding experiences as showed in Table 4.5 and Table 4.9. To mothers who were unaware of her HIV status or have tested negative, breastfeeding was the nature. A formative research study in Khayelistha, South Africa (Chopra, et al., 2000) found that caregivers suspected women did not breastfeed due to HIV. The same situation also applied in Bandung, where breastfeeding was considered norm. However, the community, as represented by FGD participants, considered replacement feeding as acceptable practice as well.

The study also found most mothers with HIV will not utilize information of other infant feeding option if not endorsed by the health provider. Study in Nairobi where 98% of the women breastfed, feeding alternatives (either expressed breastmilk, formula feeding or human milk donor) were influenced by knowledge of PMTCT (Oguta, 2001). In Botswana, most women with HIV in the PMTCT site choose to formula feed, while less than 20% chose exclusive breastfeeding for less than 6 months (Willumsen & Rollins, 2001).

In this study, data displayed from Figure 4.2 to Box 4.4 revealed replacement feeding as a single feeding method endorsed and practiced. Message about infant feeding options from the national level reached PLHIV through local stakeholders but the content was deviated. PLHIV received only one option, which was replacement feeding. Other feeding option, exclusive breastfeeding practice, was discouraged by health providers and mothers of older child with HIV were led to believe their past breastfeeding practice caused the child to become infected. Health providers assumed that safe breastfeeding practice is very unlikely found. This condition revealed the lack of skilled breastfeeding counselor's presence to support the mothers. The lack of information given to

mothers about proper replacement feeding revealed that health workers providing direct care to the HIV high risk mothers also lacked the required knowledge about proper infant feeding practices. The result was inadequate support on infant feeding provided to the HIV high risk mothers. This condition raised question whether health workers caring for HIV high risk mothers lack training to provide infant feeding counseling.

5.1.2 Concerns relating to breastfeeding practices

Health workers in Bandung only endorse replacement feeding, so they were not equipped with necessary information if dealing with mothers who are not willing to follow the endorsed replacement feeding. In KwaZulu, South Africa, trained counselors helped mothers explore their circumstances to find the most appropriate feeding method (Bland, et al., 2007). This effort resulted significantly more HIV-infected women intended to exclusively breastfeed, rather than replacement feed, while mothers who replacement feed were those who had the access and understood the importance of clean water supply and regular maternal income. In this study, the informants were willing to comply with the endorsed message to replacement feed. Although the availability of regular income and clean water were not discussed by the health providers, some of the informants were provided with milk donation. However, there was also information about a mother who walked away from PMTCT program. This condition showed the need for health providers to communicate their recommendation with the mothers, and explored her situation to find the best infant feeding solution.

Infant feeding practice recommendation of HIV affected families is aim to reduce HIV transmission to infant and at the same time the feeding practice must not increase risk of morbidity and mortality from other causes (LINKAGES, 2005). The endorsed replacement feeding method was intended to reduce HIV transmission, but failed to overlook higher morbidity and mortality risk caused by improper feeding practice. In this study, people in the community not only were unaware of HIV transmission via breastfeeding, they also denied conducting incorrect feeding practice and therefore lack awareness of the danger caused by such practice. If this condition persists, chronic infant morbidity and mortality

caused by improper infant feeding will occur. Local authorities need to take action to improve the feeding practice. Breastfeeding campaign should begin from the health facilities, and health workers should be trained with proper infant feeding skills to help new mothers practicing correct infant feeding practices before discharging to the community.

From all four aspects related to infant feeding practice, health resources had the strongest influence in shaping the local practice, because HIV belonged to health provider's area.

Over the years many efforts to combat HIV transmission had been carried out, especially through PMTCT programs. Despite all those efforts, gaps between the newest recommendations with implementation still existed in the fields.

Rationale behind the 2009 recommendation was that replacement feeding with infant formula unquestionably prevents all transmission of HIV through breastfeeding but in many settings can also increase the risk of death from other causes. Program and research groups have reported the difficulties of implementing earlier United Nations recommendations on HIV and infant feeding within health-care systems constrained by limited human resources. Since 2006, new evidence shows that giving ARVs to either the HIV-infected mother or HIV-exposed infant can significantly reduce the risk of transmitting HIV through breastfeeding. This evidence has major implications for how women living with HIV should feed their infants, and how health workers should support them (WHO, 2009a).

5.2 AFASS fulfillment among HIV high risk mothers practicing replacement feeding.

In Bandung, as displayed in Figure 4.2. message of infant feeding deviate from the national level to the implementers. Health providers in direct contact to PLHIV endorsed replacement feeding as a single message. However, these health providers were not aware of the condition required to implement this type of feeding, the AFASS. Therefore, the message of AFASS never reached the mothers.

If AFASS criteria are not met, replacement feeding may present greater risk to infant's health than breastfeeding, because breastmilk provides protection against infection other than HIV, while factors relating to replacement feeding maybe susceptible to many potential harm (LINKAGES, 2005). Breastfeeding of HIV-infected infants beyond 6 months was associated with improved survival compared to stopping breastfeeding, which was presented in the preliminary data from Botswana and Zambia (WHO, et al., 2006).

The actual fulfillment of AFASS criteria were found far from the standard. These condition although may succeed in preventing HIV transmission via breastfeeding, holds bigger potential to jeopardize infant's live due to other infection or malnutrition.

Health providers should ensure proper feeding practice in young child to prevent irreversible damage. Ironically, health providers only endorse formula feeding without AFASS, as a single choice for feeding an infant of mother with HIV. Whether the mother and family affected equipped with conditions required for AFASS, had never been explored, nor the outcome of the child as the result of such practice.

In 2008, Ministry of Health had established PMTCT Task Force, consisting stakeholders directly dealing with PLHIV. Part of the task force was an infant feeding unit, responsible for endorsing national recommendation for infant feeding practice and developed the infant feeding module in PMTCT training guide. The module referred to WHO's 2000th HIV and infant feeding: A Training course and 2006th Infant and Young Child Feeding Counseling: An Integrated Course. Infant feeding options were highly emphasized in the module.

Health authority also contributes to the AFASS dilemma. Two formula donation programs were implemented by two different stakeholders, among which Bandung District Health Office issued a recommendation. The targets of the donations include HIV positive children and HIV pregnant mothers. There was also an age gap between initiation of replacement feeding in the health setting with the recommendation for donation. This gap resulting many mothers who may benefit more in receiving the donation were left without aid. On the other hand the donation recipients were those no longer require formula donation due to age of

child already consumed solid food. PMTCT interventions providing free formula therefore mainly support better off women, often ignoring the needs of the poorer women who do not have any alternative to breastfeeding, at least for some months (deWagt & Clarck, 2004).

If these donation programs were to continue, some efforts need to be in place to improve the programs. One of AFASS component is sustainability. Unsustainable replacement feeding will jeopardize the infants nutritional status and health. Chopra (2000) reported that most of the mothers receiving PMTCT services in South Africa answered that the quantities of formula received were insufficient. Strategies used by mothers who run out of formula included: buying an alternative milk or formula, giving sugar and water or fruit drinks between formula feeds, giving fewer feeds per day and over-diluting the formula. National and local government should ensure sustainability of the programs to prevent this from happening.

Data presented from Table 4.10 to Box 4.7 revealed the essential health system components in the replacement feeding implementation. Health resources were related to several unfavorable AFASS practices, such as the lack of feeding option and constrains in donation programs. According to Kielmann (2005), a health system require three main components to form the service inputs, 1) the service programs, 2) the infrastructure to run the services and 3) how the services are set up in the service delivery structure. The service infrastructure consist of a) manpower, b) material, c) money (Kielmann, 2005). For the infant feeding program to succeed, the health service structure, the manpower and the financial support should be well prepared to implement the feeding program. The manpower required material to deliver the service, which includes proper trainings and adequate knowledge.

In this study, infant feeding recommendation had evolved from the national level to the direct implementers. Replacement feeding became the endorsed service program in the bottom level, especially with the existence of recommendation from the local District Health Office. The service infrastructure should include well trained service providers, sufficient financial resource to establish the replacement feeding which could fulfill AFASS and existence of the

milk supply as the materials. Another fundamental component is the service delivery structure and organization, in this case are interaction between replacement feeding recipients and the technical implementers.

Data in this study have revealed weaknesses in the system, such as unprepared implementers and insufficient donation supply. Health providers created demand for replacement feeding by endorsing the feeding method, without paying attention to the supply. Majority of the mothers were left to struggle with their difficulty in providing the milk supply, which caused threat to the infants' health. This situation caused the mothers to apply their own coping mechanism, including impaired infant feeding practices. These children were in threat of infection diseases or malnutrition problems in the long run.

5.3 Limitations of the study

Information on infant feeding practices in this study was only collected from those cared in the government health facilities. We have not succeeded in gathering information from mothers who came to private clinics. Our main access to HIV high risk mothers were from NGOs, especially case managers. This condition caused informants with similar practices, as result of similar care given by the NGOs. We have not been able to find solution to identify and recruit HIV high risk mothers who were not cared by NGOs..

This study was not aiming at generalizing the result to other community. Each informants provided unique information in shaping the complete picture. Time constrain also limit the opportunity to obtain more varied information.

CHAPTER 6
CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

- Aspects affecting infant feeding practice in HIV high risk mothers in Bandung were:
  - deviation of infant feeding message among stakeholders
  - infant feeding message endorsed in health facility to mothers with HIV
  - availability of trained infant feeding counselor
  - the timing of HIV status is revealed or awareness of HIV status
  - mother's willingness to comply with the recommendation
  - past feeding experience and feeding norm
- The WHO standard components required for AFASS to be fulfilled were not favorably in place. Therefore the fulfillment of AFASS in this study area is in question.
- Health system components in the infant feeding program of HIV high-risk-mothers lack especially in human resources and proper funding support in order to be able to run properly and reach the expected outcome.

6.2 Recommendations

- Government and stakeholders should consider adopting the 2009 WHO recommendation. The rationale behind the new recommendation recognize the same constraints found in this study, therefore the new recommendation addressed more applicable solution.
- Efforts are needed to eliminate the gap between recommendation and practice. Health workers dealing with HIV high risk mothers should be skilled or equipped with the required knowledge to provide the required aid in applying the correct feeding practice, either replacement feeding or breastfeeding. Adequate financial support should also be in place to strengthen the feeding program.

- If time and supports allow in the future, exploration infant feeding practice among the free living and those attending private practices will complement this study result in capturing the complex factors behind infant feeding practice in Bandung.

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Exploration of infant feeding practice of HIV-high-risk mothers in Bandung, West Java

ABSTRACT

HIV in young children not only concerns transmission risk, but also concerns nutritional aspects which threatens either the infant's nutritional status or morbidity from infection.

This descriptive observational study was performed to explore infant feeding practice from HIV high risk mothers in Bandung, West Java. Nine in-depth interviews and observations were performed to HIV high risk mothers. Additional information was obtained from five health providers in charge of PMTCT program and three focused group discussion in the community.

This study found that HIV high risk mothers were not given infant feeding option. Replacement feeding was given to all infants of mothers with HIV, and AFASS was never discussed by health providers. Breastfeeding was discouraged for mothers with HIV, although the mothers maybe aware of this practice as an option and may had previous experience in breastfeeding an older child.

Major aspects affected current practices in Bandung were the timing of HIV status was revealed or awareness of HIV status, message content endorsed in health facility to mothers with HIV, mother's willingness to comply with the recommendation and past feeding experience as result of feeding norm.

This study provide description of how infant feeding practice of HIV high risk mothers in Bandung, West Java, Indonesia, applied WHO's 2006 recommendation. This study result would help stakeholders in understanding current strength and limitation in adopting international recommendation to help formulate more applicable policies and programs.

KEYWORDS: HIV, infant feeding, qualitative, PMTCT, Indonesia, Bandung

INTRODUCTION

In the last two decades, approximately 30%-40% of HIV infected women transmitted the virus to their newborn babies (WHO, 2006). Studies revealed child morbidity associated with mode of infant feeding in mothers with HIV (John, et al., 2001). The risk of HIV transmission through breastfeeding has created a dilemma for public health programs and for mothers and families affected by the disease. Replacement feeding practice unquestionably prevents HIV postnatal transmission but has also been associated with increased risk of death from other causes especially in poor settings.

The dilemma caused revisions in messages about infant feeding in HIV context, in order to accommodate emerging evidences. In 1997, the joint policy statement on HIV and Infant Feeding highlighted the need to provide alternatives to breastfeeding (WHO, 1997). In 2001, AFASS was introduced for the first time as conditions required for replacement feeding as preferable feeding option (WHO, 2001). In 2006, the statement was revised by endorsing exclusive breastfeeding as the first option while still emphasizing AFASS to be fulfilled for replacement feeding (WHO., UNICEF., UNAIDS., UNFPA, 2007). On November 30th 2009, a new recommendation was launched, underlining ARV's role in safer breastfeeding practice (WHO, 2009).

Questions emerge concerning how national or local program likely determine which feeding practice to be endorsed as the most suitable in different contexts, especially when cultural issue is in place. These messages should reach every HIV high risk mother, so they can then decide upon the most applicable option. Failure to communicate the complete messages will create gap between

recommendation and practice, causing improper feeding practice which will only trigger increased of malnourished children or children with HIV.

An exploration study on infant feeding practice in Bandung is needed to reveal influential factors, key actors in shaping the local practice. These factors maybe complex since the city is known for its high HIV cases due to high number of drug users and commercial sex workers. These situation lead donor agencies target the city for many HIV combating projects, among which are donations of replacement feedings for HIV affected children.

It is unknown whether feeding options are available or are services in place for providing infant feeding supports. These questions can only be revealed by an exploration study, which is critical to provide information on the existing practice compared to the national and international recommendations.

To our knowledge, this is the first study in Indonesia aimed to explore infant feeding practice from HIV high risk mothers in Bandung, West Java.

METHODS

This was a descriptive observational study. Data collection was performed between January to March 2010. Locating people living with HIV was a very big challenge, due to stigmatism and discrimination that prevent this condition known to others.

Information provided by members of Impact Project Bandung enable us to locate sources of informants for the study from Hasan Sadikin General Hospital, Community Health Centers, private practice patient's data bases, and NGOs dealing with people living with HIV (Figure 1). These locations were decided

after several preliminary visits and interview to the stakeholders three months prior the beginning of data collection.

Using this method, nine HIV high risk mothers of infant or those experienced caring an infant under HIV transmission risk were recruited as main informants. These women who were either infected or partner of a man with HIV as confirmed by the health facilities, had an infant or experienced caring an infant during period of transmission risk, living in Bandung city or cared by NGOs based in Bandung were interviewed and observed. Additional information were also obtained from people living in communities with highest HIV rate in three focused group discussions. Five health providers dealing with PMTCT program were also interviewed.

Using research question as guide, matrices were developed from coded transcripts to help group emerging themes, and reveal repetitive phenomena, prompting saturation of information.

Instruments and Materials

Using WHO guideline for formative research (Piwoz, 2004), a structured open ended questionnaire was developed as in-depth interview guide to obtain information on infant feeding practice, AFASS fulfillment, challenges in child caring and support from family. Questionnaire was also developed to guide FGDs and in-depth interviews to the health providers. Pictures of infant feeding practice types were developed and used to help explore aspects of infant feeding during FGDs. All in-depth interviews and focus group discussions were recorded and transcribed verbatim.

Ethical approval was obtained from Medical Faculty University of Indonesia. Permission from local government, local health authorities, local department of education and local HIV/AIDS non government organizations providing data for the study were also solicited. Every informant signed written consent before interview performed.

RESULTS

Nine women (age range 19-30) were recruited as main informants, majority graduated from high school, married and supported with multiple source of income in the household, although their occupation varied uniquely, among which include house servant and commercial sex worker. Among the informants, two are HIV negative (Table 2).

Focus group discussions were performed in three locations, referred by three Community Health Centers which were bases of HIV projects. The participants were housewives, community health workers and nutrition officers (Table 1). All were female, except in one location (Ibrahim Adji) one male participant attended. Majority of the participants have Senior High School background. In all three locations the minimum age of participant was 26 and the maximum was 66.

Table 2. revealed that from the nine main informants interviewed, two were HIV negative but spouse of men with HIV, and experienced pregnancy under condition of high risk HIV transmission. On the other hand, several husbands of the HIV positive informants remained HIV negative (Box 1). Three informants (#1 ,#2, #3) had similar practices as they were cared by the same

NGO, and also experienced the same situation where an older child had been confirmed with HIV. Information of delivery method also revealed that mothers who experience Caesarian Section (#1,#2,#3,#4 and #6) suffered breast inflammation/mastitis in the first month. (Table 2).

Aspects affecting infant feeding practices of HIV high risk mothers in Bandung.

According to the study's conceptual framework (Figure 2), infant feeding practice is affected by three direct factors (resources for care, food/economic resources, health resources) and one indirect factor (community context).

Aspect related to food or economic resources

Five informants had children more than two. These informants lived in extended family (with parents or in laws) who helped them in providing food and sharing household expenditures. However, ability of other family member to purchase nutritious food also varied. Often rice had to be sacrificed in order to keep food available for the infant how economic status of relatives can or cannot help provide food to households (Box 2)

Aspect related to resources for care

Timing of HIV status revealed reflects planning of PMTCT program, including ARV consumption (Figure 3). Those whose HIV statuses were revealed during pregnancy, were informed by their health providers during the third trimester to perform replacement feeding. One informant, who was aware of her HIV status before conceiving, was prepared for replacement feeding at time of her pregnancy confirmed. Two informants whose HIV status were revealed during

their children infancy, one replacement feed and one breastfeed, decided their infant feeding method based on convenience in child caring at the time. The one breastfeed was because it was considered practical, and the one replacement feed was for the sake of preparing the infant for an adoption.

Box 3. revealed how available feeding option was never discussed by health providers, case managers or those with direct contact to the mothers. Mothers with HIV were conditioned to give replacement feeding to their infants and were prepared to do so before delivery. However, unwritten agreement in the national level supported formula subsidy after the infant age six months, therefore in the national level there is an understanding that parents should have the freedom to decide infant feeding method in the 0-6 months period.

From five mothers practicing replacement feeding (Table 3), all mentioned that the health providers cared for them never discussed the possibility of feeding option other than replacement feeding. Although three of them were aware of other feeding option, the information did not come from health providers. .

Breastfeeding were practiced by HIV high risk mothers who had no knowledge of her HIV status, are aware that her current status is negative although risk of becoming infected from her partner who is with HIV is high, or are aware of transmission risk but continued to breastfeed since the child already depended on breastfeeding (Table 4). They all breastfed because breastfeeding was considered the norm.

Box 4. revealed the information regarding breastfeeding option received by the mothers with HIV. The health providers around these mothers did not provide encouragement for these mothers to explore more on the breastfeeding

possibility. All three mothers although considered breastfeeding as an option, feared to breastfeed because they have experienced breastfeeding with their older children who are now confirmed with HIV (Table 2).

Aspect related to health resources

We explored infant feeding message from the policy makers' level to the direct implementers' level and discovered transformations in the message route as shown in Figure 4. Infant feeding message recommended in the National level have evolved and transformed in the lower level. Only a single feeding message reached the People Living with HIV (PLHIV), which is formula feeding.

Interviews with additional informants (stakeholders of PMTCT programs) revealed how the pregnant mothers with HIV were cared in the health facilities in relation to the infant feeding practices. Women from the high risk groups maybe confirmed with HIV by two different pathways, 1) by Voluntary Counseling and Testings/VCTs encouraged by NGOs or, 2) after Provider Initiated Testing and Counseling/PITCs in health facilities, especially hospitals. Caesarian Section will be performed to those with HIV who were discovered pregnant, and the infant separated from the mother to be given infant formula in perinatology ward. These procedures were explained to the mothers with HIV by their case managers before date of delivery, to enable the mothers prepare their infant feeding equipments (bottles and teats) as displayed in Box 3.

Aspect related to community

All nine informants have experienced breastfeeding, either experienced breastfeeding an older child in the past (Table 5), or currently breastfeeding her infant (Table 4). All breastfed because breastfeeding was considered the norm.

We triangulated this finding with perception in the community. Exercises using pictures of different types of families and different types of infant feeding practices were preformed to identify type of families dominant in each community and feeding practices commonly found in the community. From the three group discussions, only one place mentioned formula feeding as dominant feeding type along with breastfeeding (Table 6.). In this area single parenting was considered common. On the other hand the other two groups considered nuclear family most common family type and breastfeeding were dominantly practiced. In these areas people label themselves as those with the ideal feeding practice, and refers other neighborhoods as the ones having anomalies. Breastfeeding is labeled as their norm infant feeding practice, but any variation to the practice is considered acceptable including supplementing with formula (Box 5).

DISCUSSION

According to Ulin (2006) qualitative analysis can answer questions about how people make sense of the world, it also can address many objectives dimensions of human action and interaction, relating these findings to the contexts in which they occur.

This study was able to reveal how each informant had unique individual and family characteristics. The ones living away from families lack support in child caring caused her to sacrifice her infant for adoption. Others living in extended families had not disclosed her HIV status, thus preventing her from gaining their support in child caring.

How a mother became infected with HIV also affects her social economic condition. An informant was abandoned by her spouse and in-laws and thus deprived from her only financial source because they perceived she had permissive pre marital sexual relation. Other informants struggled to earn money by becoming a house servant; one informant even had to earn money by becoming a sexual worker.

Several phenomena were uncovered by this study. In the resources for care aspects, method of infant feeding was influenced by the timing of mother's HIV status revealed. mothers who were already aware of her HIV status before delivery all choose to replacement feed. These informants however, all had breastfeeding experiences as showed in Table 4. and Table 5. To mothers who were unaware of her HIV status or have tested negative, breastfeeding was the nature. A formative research study in Khayelistha, South Africa found that (Chopra et al, 2000) caregivers suspected women did not breastfeed due to HIV. The same situation also applied in Bandung, where breastfeeding was considered norm. However, the community, as represented by FGD participants, considered replacement feeding as acceptable practice as well.

The study also found most mothers with HIV would not utilize information of infant feeding option if not endorsed by the health provider. Study in Nairobi where 98% of the women breastfed, feeding alternatives (either expressed breastmilk, formula feeding or human milk donor) were influenced by knowledge of PMTCT (Oguta, 2001). In Botswana, most women with HIV in PMTCT project site choose to formula feed, while less than 20% chose exclusive breastfeeding for less than 6 months (Willumsen and Rollins, 2001).

In this study, replacement feeding was a single feeding method endorsed and practiced. Message about infant feeding options from the national level reached PLHIV through local stakeholders but the content was deviated. PLHIV received only one option, which was replacement feeding. Other feeding option, exclusive breastfeeding practice, was discourage by health providers and mothers of older child with HIV were led to believe their past feeding practice caused the child to become infected. Health providers assumed that safe breastfeeding practice is very unlikely found. This condition revealed the lack of skilled breastfeeding counselor's presence to support the mothers, as well as lack of required knowledge about proper infant feeding practices. The result was inadequate support on infant feeding provided to the HIV high risk mothers.

Because health workers in Bandung only endorse replacement feeding, they were not equipped with necessary information if dealing with mothers who are not willing to follow the endorsed replacement feeding. In KwaZulu, trained counselors help mothers explore their circumstances to find the most appropriate feeding method (Bland, Rollins, Coovadia, Coutsoudis and Newell, 2007). This effort resulted significantly more HIV-infected women intended to exclusively breastfeed, rather than replacement feed, while mothers who replacement feed were those with access to clean water supply and regular maternal income. In this study, the informants were willing to comply with the endorsed message to replacement feed. Although the availability of regular income and clean water were not discussed by the health providers, some of the informants were provided with milk donation. However, there was also information about a mother who walked away from PMTCT program. This condition showed the need for health

providers to communicate their recommendation with the mothers, and explored her situation to find the best infant feeding solution.

The 2006 recommendation was "*Exclusive breastfeeding is recommended for HIV-infected mothers for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants before that time*"(WHO, 2001). This study found that implementers were not prepared to support exclusive breastfeeding as well as understand the importance of AFASS before encouraging replacement feeding. The result was incorrect and unsafe feeding practices, which put the infant's health in jeopardy.

Experts launched the 2009 recommendation to emphasis that replacement feeding with infant formula unquestionably prevents all transmission of HIV through breastfeeding but in many settings can also increase the risk of death from other causes. Program and research groups have reported the difficulties of implementing earlier United Nations recommendations on HIV and infant feeding within health-care systems constrained by limited human resources. Since 2006, new evidence shows that giving ARVs to either the HIV-infected mother or HIV-exposed infant can significantly reduce the risk of transmitting HIV through breastfeeding. This evidence has major implications for how women living with HIV should feed their infants, and how health workers should support them (WHO, 2009).

Given the situation in Bandung, it is clear that the 2009 recommendation is more applicable and appropriate, and therefore should be implemented.

Information on infant feeding practices in this study was only collected from those cared in the government health facilities. We have not succeeded in

gathering information from mothers who came to private clinics. Access to HIV high risk mothers were from NGOs, especially case managers. This condition caused informants with similar practices, as result of similar care given by the NGOs. We have not been able to find solution to identify and recruit HIV high risk mothers who were not cared by NGOs.

CONCLUSION

This study revealed current infant feeding practices in Bandung have not been able to fulfill 2006th recommendation. The evolving messages of infant feeding of HIV high risk mothers have not reached the direct implementers, causing a gap between the expected practices as endorsed in the recommendation with the practice found in the study. Health workers were unaware of AFASS, and fear to support exclusive breastfeeding practice

Government and stakeholders should consider adopting the 2009 WHO recommendation. The rationale behind the new recommendation recognize the same constraints found in this study, therefore the new recommendation addressed more applicable solution.

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Table 1. General characteristic of main informant

Characteristics		
Ages of mother (n=9)	19	1
	20-25	1
	26-29	6
	30	1
Mother's education level (n=9)	Diploma	1
	High school	6
	Elementary	2
Occupation of mother (n=9)	Marketing staff	1
	Multilevel marketer	1
	House servant	1
	Housewife	3
	Commercial sex worker	1
	Case manager	1
	Jobless	1
Number of children (n=9)	1	4
	2-3	4
	>3	1
Marital status (n=9)	Married	6
	Divorced	2
	Widowed	1
Source of household income (n=9)	Self income only	2
	Parents only	1
	Multiple sources	6

Table 3. Information related to mothers with HIV who practiced replacement feeding

Characteristic	#1	#2	#3	#4	#6
HIV status	Positive	Positive	Positive	Positive	Positive
HIV status of child under study	Unknown	Unknown	Unknown	Unknown	Unknown
Age of child under study	4 months	6 months	1 months	1 months	4 months
Type of infant feeding	Formula	Formula	Formula	Formula	Formula
Feeding option discussed by health provider	No	No	No	No	No
Aware of breastfeeding possibility as other option	Yes	Yes	Yes	No	No
Source of information on breastfeeding option	TV	A friend	A friend	N/A	N/A

Table 2. HIV related characteristic of main informants

Characteristic	Informant #1	Informant #2	Informant #3	Informant #4	Informant #5	Informant #6	Informant #7	Informant #8	Informant #9
HIV status	Positive	Positive	Positive	Positive	Positive	Positive	Positive	Negative	Negative
Current partner HIV status	Negative	Negative	Positive	Negative	Unknown	Positive	Positive	Positive	Positive
HIV status of child under study	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Positive	Negative	Unknown
Age of child under study	4 months	6 months	1 months	1 months	8 months	4 months	3 years	6 years	12 months
Delivery method	C section	C section	C section	C section	Normal	C section	Normal	Normal	Normal
Place of birth	General hospital	General hospital	General hospital	General hospital	Midwife	General hospital	Midwife	Private hospital	Midwife
Breast problem	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	Mastitis during 1st month	None	None	None
Older child HIV status	Positive	Positive	Positive	Unknown (deceased)	Unknown	Unknown (deceased)	N/A	N/A	N/A

Table 5. Past infant feeding experience of mothers with HIV's older child

Characteristic	#1	#2	#3	#4	#5	#6
HIV status	Positive	Positive	Positive	Positive	Positive	Positive
HIV status of older child	Positive	Positive	Positive	Unknown	Unknown	Unknown
Current age of older child	5 years	Unknown	4 years	N/A	3 years	N/A
Type of infant feeding practiced	Breastfeeding > 2 years	Breastfeeding Briefly	Breastfeeding > 1 year	Breastfeeding 11 months	Breastfeeding 9 months	Breastfeeding 1 month + formula feeding
Condition of the child currently	Often had diarrhea & ARI	Cared by other family	Often ill	Deceased at 11 months	Adopted since 9 months	Deceased at 3 months
Age of child when mother's HIV status revealed	4 years	Unknown	3 years	Already deceased	3 years	Already deceased

Table 4. Information related to informants who practiced breastfeeding

Characteristic	Informant 7	Informant 8	Informant 9
HIV status	Positive	Negative	Negative
Current partner HIV status	Positive	Positive	Positive
HIV status of child under study	Positive	Negative	Unknown
Age of child under study	3 years	6 years	12 months
Age of child when mother performed HIV test	2 years	1 year	Before birth
Infant feeding type	Mix feeding	Exclusive breastfeeding	Mix feeding
Duration of breastfeeding	> 2 month	2 years	Still breastfeed
Timing of introducing replacement food	2 months	Never	Since birth

Table 6. Identifying type of community

Characteristic	KOPO	IBRAHIM ADJI	TAMAN SARI
Dominant infant feeding type	Breastfeeding	Breastfeeding and formula feeding	Breastfeeding
Dominant family type	Solid nuclear family or Extended family	Single parents	Solid nuclear family
Uncommon feeding practice	Wet nursing	Wet nursing, tandem breastfeeding,	Whole family eating together

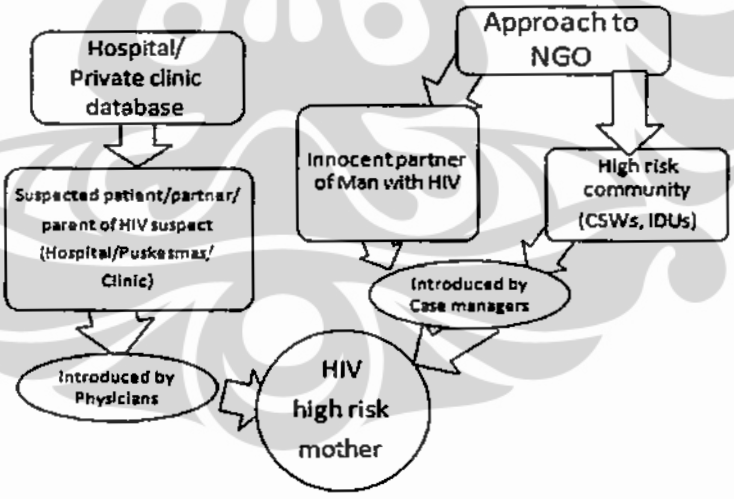

Figure 1. Source of main informants

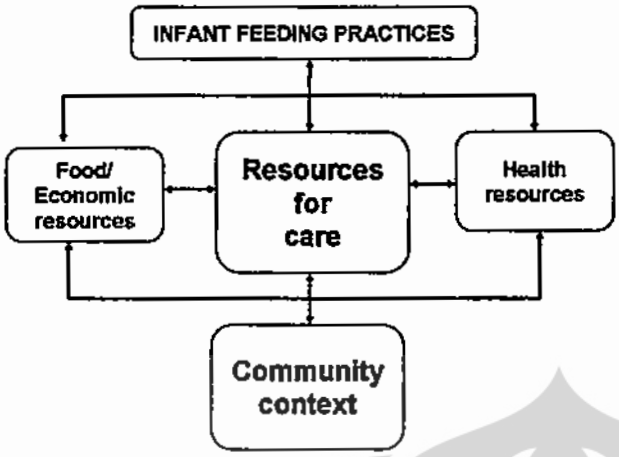

Figure 2. Conceptual framework of the study

Adopted from: Piwoz (2006)

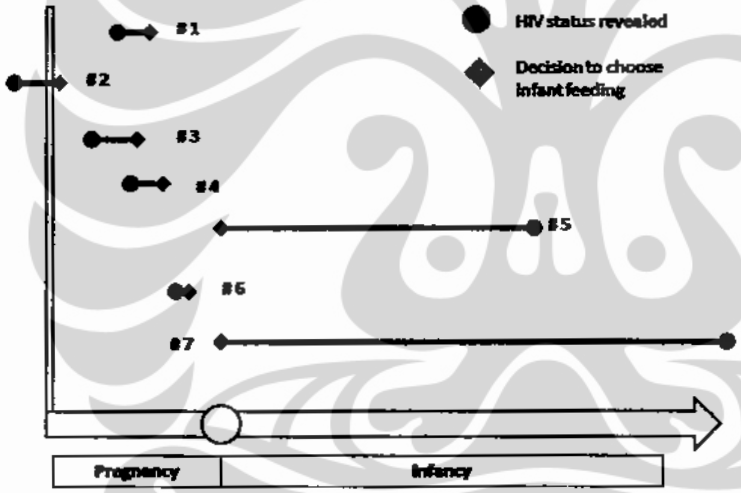

Figure 3. Timing of HIV status revealed and preparation of infant feeding method

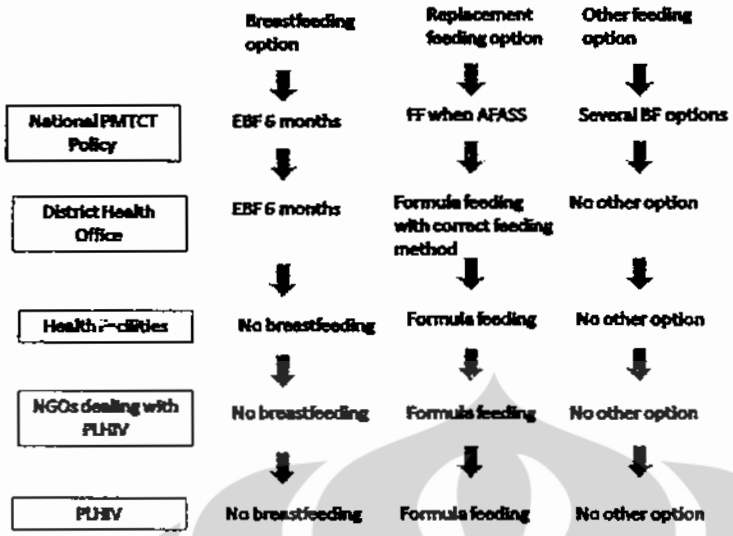

Figure 4. Alteration of infant feeding message from stakeholders

Box 1. How the mothers became infected

"I had no idea my husband was HIV positive before we were married. He spent his teenage in Pesantren. I didn't know he was admitted there because he was a drug addict."

(HIV positive mother, status revealed from PITC in Hasan Sadikin Hospital when the child was hospitalized.)

"My ex-husband is negative. I'm solo carrier here."

(Recently divorced mother with HIV of 1 month old infant).

Box 2. Ability to purchase food

"I reduce buying rice so that I can buy the infant's formula"

(Informant #9)

"Their relatives can't help them either (with food) because they're also poor themselves"

(AIDS Aware Cadre)

Box 3. Initiation of formula feeding

"My newborn was directly separated, I don't get to see him until it's almost time to go home. The case managers already told us to prepare 6 bottles for feeding in the hospital, so they already given the formula and they gave me drugs for my breast."

(A mother with HIV, recipient of PMTCT subsidy from an NGO)

"Before they deliver their babies we make sure they (HIV mothers) don't breastfeed, even if the breast felt full."

(PMTCT field coordinator & midwife for local NGO)

Box 4. Knowledge of breastfeeding option

"I saw on TV about breastmilk donor for mothers with HIV, and I talked to my case manager about it. She asked me if I still produce milk and I said 'No'. She asked me also if I know anyone who are willing to donate her breastmilk and I said 'No'. So she suggested I stay with formula"

(Informant #1, mother with HIV of infant)

"The doctor mentioned if I to consider breastfeeding, my CD4 should be above 600. My husband supported me (if I breastfeed). I just don't want to take any risk."

(Informant #2, mother with HIV of infant)

"A friend of mine told me that her NGO informed about a study in Africa which proved HIV mothers can breastfeed safely if exclusively. My husband actually supported if I want to breastfeed. But I'm afraid to do it."

(Informant #3, mother with HIV of infant)

Box 5. Perception of norm feeding practice

"None of the women here don't breastfed when they are ill, but we know some in the other hamlets."

(Cadre in Kopo)

"All of us breastfeeds. But we give formula as addition to the children"

(A mother of under five children in Taman Sari)

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Appendix table 1. Main informant's matrix-1

Informant	1	2	3	4
Date of interview	January 25th	January 29th	February 2nd	February18th
History of pregnancy & delivery	SC (PMTCT program subsidies from NGO), after HIV status revealed during pregnancy due to prolonged TBC	SC (PMTCT program subsidies from NGO) & supported by aunt who is an obstetrician. History of IDU	SC (PMTCT program subsidies from NGO) HIV status revealed during pregnancy after husband was found with HIV	SC funded by Jamkesmas. Pregnancy & HIV status revealed after 1st trimester due to prolonged diarrhea
Breastmilk production	Experienced breast inflammation for 1 month. Relieved breast engorgement by chest banding "*beubeut*", throw away expressed breastmilk & consume medication	Experienced breast inflammation & leaking breastmilk. Consume medication to stop lactation → frequently asked by family member why not breastfeeding	Milk leaking during interview, although consume medication to stop lactation → frequently asked by family member why not breastfeeding	Experienced breast inflammation at interview (5 days post SC). Consume medication to stop lactation
Family HIV status	Unknown at time of interview (4 months old). Older sibling with HIV	Unknown at time of interview (6 months old). 2 older sibling with HIV cared by other family	Unknown at time of interview (40 days old). Older sibling & father with HIV	Unknown at time of interview (5 days old). Older sibling died at 11 months. Father HIV negative.
Infant feeding practice	Formula feeding planned before delivery, receive formula subsidy self collected, supply not enough, need to buy additional. Milk preparation suggested to follow packaging instruction, only explained how to clean bottle. Never store left over milk, bring dry milk powder when travelling. Self isolate from neighbors. Infant was cared by mother in-law in 1st month due to family fear of possibility to be infected. Have considered of using milk donation, but fear of donor's health condition.	Formula feeding planned before delivery, receive formula subsidy, delivered to home at first months, now self collected, subsidy only enough for half month supply, need to buy additional Self learn how to prepare milk & how to feed child from health books & magazine. Introduced solid foods at 4 months. Understands conditions that enable mother with HIV to breastfeed safely (CD4 counts etc) but afraid to take risk.	Formula feeding planned before delivery, receive formula subsidy, delivered to home. Often dilute formula & alter giving formula & water. Rare washing hands before preparing milk even after changing diaper (as directly observed). Wash used bottle & teats once daily (reuse same bottle & teat for several feeds before changing with clean ones). Have heard of studies abroad that mothers with HIV can breastfeed safely if exclusive, husband was supportive if willing to try, but already formula feeding.	Self purchase formula supply. Buy smallest package when grandmother have enough money (both mother & father are jobless & later divorced, in law stopped financial support when discovered mother with HIV). Self learn how to prepare milk & how to feed child & taught by neighbor.
Previous infant feeding experience with older child	Breastfeed older child up to 2 years without formula supplement. Older child prone to respiratory infection & diarrhea, at 4 years revealed with HIV.	Older children from 1st husband are cared by child's father family. Current in-laws not aware that mother previously has children & not willing to discuss past child caring experience.	Older child breastfed up to 1 year, introduce solids at 6 months. Experienced caring the older child with other mothers in the neighborhood. The child has been confirmed with HIV.	Older child was breastfed until died at age 11 due to respiratory infection.
Health seeking behavior	Prefer to ask in-law who is a doctor	Prefer to midwife (who is not aware of HIV status)	Prefer going to private midwife after the hospital rejected to perform vaccination	Prefer to public health facility since cannot afford self payment (use Jamkesmas)

Appendix table 2. Main informant's matrix-2

Informant	5	6	7	8	9
Date of interview	February 17th	February 18th	February 18th	February 19th	March 18th
History of pregnancy & delivery	Unwanted pregnancy, delivered normal by midwife while not HIV status unrevealed yet. Currently a CSW. HIV status revealed when infant age 8 months.	Un-expected pregnancy 7 months after 1st child delivery. SC funded by Jamkesmas in the village. HIV status revealed 5 days prior SC after husband past away from AIDS. Consume prophylactics.	Normal delivery & exclusive breastfeeding after husband's HIV status revealed, during pregnancy never practice safe sex. Mother also former IDU.	Pregnant 40 days after miscarriage. Child born premature, normal, & had to spend 10 days in incubator. All mother-father-child triad with HIV.	Normal delivery in midwife.
Family HIV status	Unknown at time of interview (8 months old), the infant was adopted since birth. Father's identity unknown.	Unknown at time of interview (4 months old). Husband past away of AIDS only 1 week before delivery.	Mother & child confirmed HIV negative at 2 years (currently 6 years) . Husband's confirmed with HIV when child 1 year old..	Mother-father-child with HIV, revealed when child's hospitalized at age 2. Husband already with HIV before marriage but kept from wife.	Negative despite husband was confirmed with HIV.
Infant feeding practice	Intentionally not breastfed since birth to prevent bonding with child. Adoptive family covers all expenditures for formula feeding requirement.	Receive subsidy from General Hospital to purchase infant formula (fixed amount Rp200.000) although expenditure cost more, including transportation cost from village to hospital. Infant was recently left in the village & now cared by grandmother's sister.	Exclusively breastfeed for 4 months & continue to breastfeed up to 2 years with complementary feeding, although aware of HIV risk because status had not been confirmed. Reason to continue breastfeeding because both parents were jobless, knows the benefit of breastmilk and the child already dependent of breastfeeding.	Expressed breastmilk > 1 month due to premature supplemented with formula, then substituted with soy formula due to suspected of milk allergy. At age 2 the child experienced repeated diarrhea, ARI & other illnesses, refuses eating, was hospitalized for 1 month with severe malnutrition & massive melena. Currently recipient of milk donation	Mix feeding since birth (prescribed by the midwife). Introduce solid foods at 6 months as suggested by grandmother who is a hospital dietitian. Child currently still breastfeeds.
Previous infant feeding experience with older child	Other children were breastfeeds & had good bonding, although 3rd child was also adopted after breastfed for 6 months.	1st child breastfed 1month, but died at 3 months after suffered Candida infection & ARI since 2 months. After weaned was given diluted infant formula.	Not applicable (child under study is 1st child & planned not to have other child due to husband's HIV status).	Not applicable (only child).	Not applicable (only child)
Health seeking behavior	Go to private clinics	Cared & routinely monitored by local midwife	Go to private practices	Go to private practices	Prefer to midwife.

Appendix table 3. AFASS Fulfilled by each respondent

Respondent	Acceptability	Feasibility	Affordability	Sustainability	Safety
1	Formula feeding practiced by most family member	Other care giver present to assist	Formula donation reduced family expenditures	Free supply only available 6 months	Able to prepare nutritionally & hygienically safe feeds
2		Other care giver present to assist	Formula donation reduced family expenditures	Free supply only available 6 months	Able to prepare nutritionally & hygienically safe feeds
3		Other care giver present to assist	Formula donation reduced family expenditures	Free supply only available 6 months	
4		Other care giver present to assist			
5[1]	N/A	N/A	N/A	N/A	N/A
6		Other care giver present to assist	Formula donation reduced family expenditures	Free supply only available several months	
7[2]	N/A	N/A	N/A	N/A	N/A
8[3]	N/A	N/A	N/A	N/A	N/A
9[2]	N/A	N/A	N/A	N/A	N/A

[1]child adopted since birth, [2]mix feeding, [3]exclusive breastfeeding

Appendix table 4. FGD result matrix

Location	KOPO	IBRAHIM AJI	TAMAN SARI
Date of FGD	February 19th	February 24th	March 18th
Participants	7 cadres, 3 mothers of infants	7 members of AIDS aware cadres, 2 counselors	All mothers of infants
Local infant feeding practice	Mostly breastfeed up to 2 years & introduce solid foods at 6 months. Locally common first foods: Nestle porridge & blended fruits. Rice introduced at 1 year. Signs that baby is full: non verbal responses, enough sleep, gain weight, healthy	Cadres began promoting early breastfeeding initiations. The majority of HIV high risk groups from low socio-economic prefer normal delivery & breastfeeding despite being informed about transmission risk.	Mostly claims practice exclusive breastfeeding and continue breastfeeding up to 2 years. Common first food: Nestle porridge. Mothers mostly initiated weaning process. No breastfeeding difficulty identified because all infants know how to breastfeed on their own.
Problems in infant feeding practice	Infants separated from their mother at birth, delaying breastfeeding. Illness is not considered as obstacle to breastfeed because mothers can consume medication & continue to breastfeed. None aware about HIV transmission risk via breastfeeding.	Pediatricians endorse formula feeding is barrier to exclusive breastfeeding. The HIV high risk groups isolate themselves from the community; they prefer not knowing their HIV status so they can continue current practices.	Birth control medications affects breastmilk production. Working mothers also stop breastfeeding early. Children who started solid foods mostly do not prefer vegetables, so mothers will persuade by buying from street food vendors. A mother experienced not permitted to breastfeed by her physician because her breastmilk is considered "not good" to be given, although un-clear whether "not-good" means contains infectious disease.
Issue on orphan children, mother with infectious disease	Not experienced by the community. Their knowledge of mother's who had disease while breastfeeding or had passed away happened to other hamlets.	Families experienced fathers/mothers/both past away quite common. Widows tend to move out of town with her children, causing loss to follow up.	Community only experiences a mother with TBC who cannot breastfeed due to medication consumptions.
Knowledge about AFASS	Mothers can self learn from others how to prepare correct feeding, but rarely happens since mostly practiced breastfeeding.	Main concern is cost to buy infant formula, which will affect how long formula can be given, diluted or not, or introduce solid foods early.	Proper replacement feeding preparation can be self learn from milk package. Affordability is the most concerns, because can affect financial ability to buy rice. Another way to compromise is milk dilution.
Result of picture exercise	• COMMMON: breastfeeding (although predominant), children cared in nuclear or extended families, all family members support breastfeeding • UNCOMMON: homeless & single parents, wet nursing	• COMMMON: breastfeeding, formula feeding (in high risk groups who had delivery by SC), children cared in nuclear families, single parenting • UNCOMMON: homeless parents, wet nursing, tandem breastfeeding	• COMMMON: breastfeeding (predominant), children cared in nuclear families, • UNCOMMON: homeless parents, single parenting, whole family eating together

Appendix table 5. Additional informant matrix

Informant	A	B	C	D	E
Date of interview	25 January	25 January	26 January	9 February	16 February
Position	HIV anthropologist	NAC officer	PMTCT program officer	DHO nutrition officer	PMTCT midwife
Role in infant feeding practice of HIV high risk group	Provide recommendation from anthropological point of view to prevent unwanted impact in the community.	Technical implementer of milk donation distribution.	Provide recipients names for NAC milk donation (age >6 months). Manage funding & supervise technical distribution of infant formula & milk for pregnant mothers donation from donor agency.	Officer in charge of milk donation technical support. DHO had issued recommendation of milk donation to children of mother with HIV	Provide technical assistance in PMTCT program implementation (communicate with cadres, perform home visits to monitor health & nutrition status).
Knowledge on AFASS	None. Concerned that AFASS formed health programs to only focus on keeping a child HIV free for the first two years, then neglect social aspects of children affected with HIV beyond 2 years.	Aware about safety issues relating to milk consumption, therefore socialize to recipients about: how to prepare milk correctly, nutrition density in each milk served, child growth, discourage breastfeed.	-Concern about sustainability of milk donation, especially donations has reached end of term - Aware that milk alone is not enough to ensure nutrition requirement for child's growth - Commented that NAC milk donation cannot fulfill AFASS	Concern of puskesmas lack of supervision to children receiving donation, whether they truly consume or not, & how is the milk density served each time.	Know that a woman with HIV must not breastfeed. Know that children consuming infant formula has high risk of infection and malnutrition, therefore monitor hygiene and nutrition adequacy during home visits.
Barriers to implement AFASS	Concerns that any program driven practices is potential to cause unexpected impact in a community.	Milk donation had ended. No knowledge of any further donation program. Concerns about recipient's dependency caused by short term donation.	Milk donation had ended. No further donation program has been confirmed.	No conclusion can be drawn from the short period of donation. Concerns of possibility that donors will claim benefit of milk consumption in people with HIV.	Milk donation have reached end of program although recipient's age are varied. Inflexible list of donor recipients. Recipients only recruited in the beginning of the project, although new eligible candidates found who may benefit more from the donation.

Appendix table 6. Market observation

	Retail store A	Retail store I	Retail store S
Available package	900 gram[1] 600 gram[1] 150 gram[1]	600 gram 300 gram 150 gram	300 gram[3]
Price per package	Rp 56.000,-/900 gram[1] Rp 39.300,-/600 gram[1] Rp 10.575,-/150 gram[1]	Rp 39.350,-/600 gram[2] Rp 20.750,-/300 gram[2] Rp 10.950,-/150 gram[2] Rp 39.900,-/600 gram[3] Rp 20.850,-/300 gram[3]	Rp 21.230,-/300 gram
Package condition	Intact, smooth, clean	Intact, smooth, clean	Intact, smooth, clean
Expiry date	December 2011	December 2011[2], January 2012[3]	December 2011
Distance to nearest housing	± 300 m	± 300 m	± 500 m

[1] SGM 1 & 2, [2] SGM 2, [3] SGM 1,

Appendix table 7. List of codes

THEMES	CODES
PMTCT	Knowledge of HIV transmission PMTCT programs Prevent HIV transmission Method of delivery Separation from baby Subsidy for delivery
HIV status	Parent's HIV status Child's HIV status Time status revealed Denial Family acceptance Stigma in community
Health services	Health worker's attitude Discrimination in health facility ARV consumption Manager case's role Counseling Support from NGO
Child caring	Main caregiver Child growth Father's role Other caregiver
Infant feeding practice	Feeding norm Infant feeding option Informed feeding choice Problems in infant feeding Introducing solid foods
Breastmilk & breastfeeding	Breastfeeding initiation Breastmilk production HIV transmission from breastmilk Weaning
Formula feeding	Equipment for formula feeding Brand of infant formula Frequency purchasing formula Source of store
AFASS practice	Acceptable practice Knowledge of proper formula preparation Cost of infant formula Formula donation Length of donation Clean utensils Left over milk Milk density
Hygiene practice	Hand washing Soap use Diaper changing Clean water supply
Food consumption	Person in charge to provide meals Lack of food Animal protein consumption Food aids

Appendix table 8. Anthropometric indices for children

Indices	Categories
WAZ ≥ -2SD	well-nourished
WAZ -2 – (-3) SD	moderately underweight
WAZ < -3SD	severely underweight
HAZ ≥ -2SD	well-nourished
HAZ -2 – (-3) SD	moderately stunting
HAZ < -3SD	severely stunting
WHZ ≥-2SD	well-nourished
WHZ -2 – (-3) SD	moderately wasting
WHZ < -3SD	severely wasting

Source: WHO, 2007

Appendix table 9. Children Anthropometric result

	Sex	Age (months)	Weight (Kg)	Height (cm)	WHZ	HAZ	WAZ
1	f	44.52	13.4	90.2	0.6	-2.5	-1.07
2	f	12.09	8.15	72.6	-0.72	-0.59	-0.79
3	m	4.57	6.3	63.8	-1.26	-0.61	-1.31
4	f	6.51	6.6	67	-1.48	0.2	-1.03
5	m	1.02	3.8	53.1	-0.69	-0.87	-1.23
6	m	1.08	3.6	51	0.2	-2.09	-1.76

Appendix table 10. Children nutritional status result

Category		N=6
WAZ	≥ -2 SD (well nourished)	6
HAZ	≥ -2 SD (well nourished)	4
	-2-(-3) SD (moderately stunting)	2
WHZ	≥ -2 SD (well nourished)	6

DEPARTEMEN DALAM NEGERI
REPUBLIK INDONESIA
DIREKTORAT JENDERAL KESATUAN BANGSA DAN POLITIK

Jalan Medan Merdeka Utara No.7 Telp. 3450038 Jakarta 10110

SURAT PEMBERITAHUAN PENELITIAN
(S P P)

NOMOR : 440.02/2397.DI

MEMBACA : Surat dari Deputi Direktur Divisi Program SEAMEO-TROPMED RCCN Universitas Indonesia, Nomor 272/SEAMEO-PROG/XI/2009, Tanggal 23 November 2009, Perihal Permohonan Ijin Penelitian.

MENGINGAT :
1. Keputusan Menteri Dalam Negeri Nomor : 130 Tahun 2003 tentang Organisasi dan Tata Kerja Departemen Dalam Negeri.
2. Surat Keputusan Menteri Dalam Negeri Nomor : SD.6/2/12 Tanggal 5 Juli 1972 tentang Kegiatan Riset dan Survei diwajibkan melapor diri kepada Gubernur Kepala Daerah atau Pejabat yang ditunjuk.
3. Keputusan Direktur Jenderal Sosial Politik Nomor : 14 Tahun 1981 tentang Surat Pemberitahuan Penelitian (SPP).

MEMPERHATIKAN : Proposal Penelitian Ybs.

MEMBERITAHUKAN BAHWA :

NAMA : Dr. Dian Nurtjahjati Basuki, IBCLC

ALAMAT : Kampus UI Salemba, Jl. Salemba Raya 6, Jakarta 10430

P E K E R J A A N : Peneliti

KEBANGSAAN : Indonesia

JUDUL PENELITIAN : Penerimaan, Kelayakan, Keterjangkauan, Kesinambungan serta Keamanan Praktis Pemberian Makanan Bayi pada Ibu HIV Positif

BIDANG : Kesehatan

DAERAH : Provinsi Jawa Barat

LAMA PENELITIAN/ KEGIATAN : Desember 2009 s/d Maret 2010

PENGIKUT PESERTA : Terlampir

PENANGGUNG JAWAB : Dr. Drupadi HS Dillon, PhD

SPONSOR : -

MAKSUD DAN TUJUAN : Untuk melakukan eksplorasi terhadap kriteria dari WHO tentang penerimaan, kelayakan, keterjangkauan, kesinambungan serta keamanan praktik pemberian makanan bayi dari ibu HIV positif di Bandung, Jawa Barat.

AKAN MELAKUKAN PENELITIAN DENGAN KETENTUAN SEBAGAI BERIKUT :

1. Sebelum melakukan kegiatan Penelitian harus melaporkan kedatangannya kepada Gubernur Cq Kaban Kesatuan Bangsa dan Perlindungan Masyarakat/ Badan Informasi, Komunikasi dan Kesbang setempat dengan menunjukkan surat pemberitahuan ini.
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4. Apabila masa berlaku Surat Pemberitahuan ini sudah berakhir, sedangkan pelaksanaan penelitian belum selesai, perpanjangan penelitian harus diajukan kembali kepada instansi pemohon.
5. Hasil kajian agar diserahkan 1 (satu) eksemplar kepada Ditjen Kesbang dan Politik Up. Direktorat Pengembangan Nilai-Nilai Kebangsaan.
6. Surat Pemberitahuan ini akan dicabut kembali dan dinyatakan tidak berlaku, apabila ternyata pemegang Surat Pemberitahuan ini tidak mentaati/mengindahkan ketentuan-ketentuan seperti tersebut diatas.

Dikeluarkan di Jakarta

Pada tanggal, 17 Desember 2009

A.n. MENTERI DALAM NEGERI
DIREKTUR JENDERAL
KESATUAN BANGSA DAN POLITIK
Ub.
SEKRETARIS,

DEPARTEMEN DALAM NEGERI ★ REPUBLIK INDONESIA ★

WARNO PUTRA RAHARJO, M.Si
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Tembusan :

1. Yth. Gubernur Jawa Barat.
   Up. Kaban Kesbang dan Linmas Prov.
2. Yth. Deputi Direktur Divisi Program
   SEAMEO-TROPMED RCCN
   Universitas Indonesia di Jakarta.

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NOMOR : 449 /PT02.FK/ETIK/2009

KETERANGAN LOLOS KAJI ETIK

ETHICAL --- CLEARANCE

Panitia Tetap Penilai Etik Penelitian, Fakultas Kedokteran Universitas Indonesia dalam upaya melindungi hak asasi dan kesejahteraan subyek penelitian kedokteran, telah mengkaji dengan teliti protokol berjudul:
The Committee of The Medical research Ethics of the Faculty of Medicine, University of Indonesia, with regards of the Protection of human rights and welfare in medical research, has carefully reviewed the proposal entitled:

"Studi Penerimaan, Kelayakan, Keterjangkauan, Kesinambungan Serta Keamanan Praktik Pemberian Makanan Bayi Pada Ibu HIV Positif di Bandung, Jawa Barat (Acceptability, Feasibility, Affordability, Sustainability and Safety / AFASS in Infant Feeding Practice of HIV Positive Mothers in Bandung, West Java)".

***Peneliti** Utama* : **dr. Dian Nurtjahjati, IBCLC**
Name of the principal investigator

Nama Institusi : **Seamoe-Tropmed UI**

dan telah menyetujui protocol tersebut di atas.valuasi
and approved the above mentioned proposal.

Jakarta, 14 Desember 2009

Chairman
Ketua

Prof. Dr. dr. Agus Firmansyah, SpA(K)

-Peneliti wajib menjaga kerahasiaan identitas subyek penelitian.

PEMERINTAH PROPINSI JAWA BARAT
BADAN KESATUAN BANGSA, POLITIK
DAN PERLINDUNGAN MASYARAKAT DAERAH

Jalan Supratman No. 44 Telp. 720674 – 7106286
B A N D U N G
Kode Pos 40121

SURAT KETERANGAN

Nomor : 070/ 2267/HAL

1. Yang bertanda tangan di bawah ini :

   Kepala Badan Kesatuan Bangsa, Politik dan Perlindungan Masyarakat Daerah Provinsi Jawa Barat.

   Berdasarkan surat dari : Dirjen Kesbangpol Departemen Dalam Negeri Nomor : 440.02/2397.DI, tanggal 17 Desember 2009.

   Menerangkan bahwa :

a.	N a m a	:	**Dr. DIAN NURJAHJATI**
b.	Tempat/tgl lahir	:	Bandung, 14 Juni 1972
c.	Agama	:	Islam
d.	Pekerjaan	:	Dokter Umum
e.	Alamat	:	Jl. Cipinang Jaya KK No. 12 Jakarta Timur
f.	Peserta	:	6 (Enam) Orang
g.	Maksud	:	Penelitian
h.	Untuk Keperluan	:	Penulisan dengan Judul " Studi Penerimaan,Kelayakan, Keterjangkauan, Kesinambungan serta Keamanan Praktik Pemberian Makanan Bayi pada Ibu HIV Positif di Bandung, Jawa Barat '
i.	OPD yang dituju	:	Rumah Sakit Hasan Saidkin
j.	Lokasi	:	Kota Bandung

2. Sehubungan dengan maksud tersebut, diharapkan agar pihak yang terkait dapat memberikan bantuan/ fasilitas yang diperlukan.

3. Demikian Surat Keterangan ini dibuat untuk dipergunakan sebagaimana mestinya, dan berlaku sampai tanggal **30 Mei 2010.**

Bandung, 15 Januari 2010

A.n. KEPALA BADAN KESATUAN BANGSA, POLITIK
DAN PERLINDUNGAN MASYARAKAT DAERAH
PEMERINTAH PROVINSI JAWA BARAT
Kepala Bidang Hubungan Antar Lembaga,

PEMERINTAH PROVINSI JAWA BARAT
BADAN KESBANGPOLINMAS

EDWARD EDISON GULTOM, SH.
Pembina Tingkat I
NIP. 19580712 198503 1 006

PEMERINTAH KOTA BANDUNG
BADAN KESATUAN BANGSA, PERLINDUNGAN DAN PEMBERDAYAAN MASYARAKAT
Jl. Wastukencana No. 2 Telepon (022) 4230393 Bandung

Nomor : 070/62/BKPPM/2010
Lampiran : 1 Lembar
Perihal : ***Pemberitahuan Survey / Penelitian/Praktek Kerja***

Bandung, 18 Januari 2010
Kepada
Yth Bapak/Ibu/Sdr :
Terlampir

Kota Bandung
di-
B A N D U N G

Memperhatikan :
1. Surat Keputusan Gubernur Propinsi Jawa Barat Nomor : 124/A-I/2/SK/1974 tanggal 1 Januari 1974 tentang pedoman tata cara peredaran dan pelaksanaam Survey/Research/Praktek Kerja dan semacamnya.
2. Surat Edaran Walikotamadya Kepala Daerah Tingkat II Bandung Nomor 7 tanggal 11 Pebruari 1975.

Bersama ini disampaikan dengan hormat, bahwa :

Berdasarkan surat dari : BADAN KESBANG POL & LINMASDA PROP JABAR
No./tanggal : 070/2267/HAL

Sehubungan hal tersebut diatas, kami hadapkan :

N a m a : DR.DIAN NURTJAHJATI (Koordinator)
Tempat Tanggal Lahir : Bandung, 14 Juni 1972
A l a m a t : Jl.Cipinang Jaya KK No.12 Kel.Cip Besar Sel Kec.Jatinegara Kota Jakarta Timur
Pekerjaan, NRP/NPM : 0954045406720374
Yang bersangkutan telah menghadap kami tanggal : 18 Januari 2010

Dengan memperlihatkan identitas serta untuk kelancaran memperoleh bahan yang diperlukan, pada prinsipnya kami tidak keberatan ybs melaksanakan Survey/Penelitian/Praktek Kerja, sepanjang tidak menggangu tugas yang menyangkut rahasia jabatan masing-masing Instansi/SKPD.
Untuk melakukan : Penelitian

Dengan Judul " Studi Penerimaan,Kelayakan,Keterjangkauan,Kesinambungan serta Keamanan Praktek Pemberian Makanan Bayi pada Ibu HIV Positif di Kota Bandung, Jawa Barat ".

Dari tanggal : 18 Januari 2010 s.d 18 April 2010

Demikian, atas kerjasamanya kami ucapkan terima kasih.

An. KEPALA BADAN KESATUAN BANGSA,
PERLINDUNGAN DAN PEMBERDAYAAN MASYARAKAT
KOTA BANDUNG
Sekretaris

PEMERINTAH KOTA BANDUNG
BADAN KESBANG PERLINDUNGAN DAN PEMBERDAYAAN MASYARAKAT

H. SLAMAN RACHMAT W. Drs, M. Si
Pembina TK. I
NIP. 19540908 197707 1 001

Catatan :
1. Yang akan melakukan survey diwajibkan membawa kartu identitasnya masing-masing;
2. Pengumpulan bahan/data hanya dilakukan dalam bidang yang tercantum dalam surat pengantar ini;
3. Hasil-hasil penelitian tidak boleh dipergunakan untuk keperluan lain;
4. Selain ketentuan diatas, harus pula memperhatikan petunjuk para pejabat dimana para pelaksana mengadakan survey;
5. Pejabat terakhir yang didatangi pelaksana tersebut harus menyimpan ...
6. Melaporkan hasil Survey/Penelitian/Praktek Kerja pada Walikota Bandung c.q. Kepala Badan Kesatuan Bangsa Perlindungan dan Pemberdayaan Masyarakat selambat-lambatnya 1 (satu) minggu

Lampiran I : **Survey/Penelitian/Praktek Kerja**
Nomor : **070/62/BKPPM/2009**
Tanggal : **18 Januari 2010**

Daftar Lampiran :

1. Kepala Dinas Kesehatan
2. Kepala Rumah Sakit Hasan Sadikin
3. Kepala UPT Puskesmas Ibrahim Aji
4. Kepala UPT Puskesmas Kopo
5. Kepala UPT Puskesmas Pasundan
6. Kepala UPT Puskesmas Salam
   Kota Bandung

NAMA-NAMA ANGGOTA

1. DR.Ir.JUDHIASTUTY FEBRUHARTANTY MSc
2. DR.UTAMI ROESLI, SpA,IBCLC,FABM
3. ANDI MARIYASARI SEPTIARI, MSc
4. MEISA DIAN IRYANI, AMG
5. IKEU DIAH

PEMERINTAH KOTA BANDUNG
BADAN KESBANG PERLINDUNGAN DAN PEMBERDAYAAN MASYARAKAT

PEMERINTAH KOTA BANDUNG
DINAS KESEHATAN
Jalan. Supratman No. 73 Telp. 022 4203752
Bandung
Kode Pos 40114

SURAT KETERANGAN
Nomor : 070/ [illegible] Dinkes

1. Yang bertanda tangan di bawah ini :
   a. Nama : dr. Hj. AHYANI RAKSANAGARA, M.Kes
   b. Jabatan : Sekretaris Dinas Kesehatan Kota Bandung

   Dengan ini menerangkan bahwa :
   a. Nama : DR. Dian Nurtjahjati (sebagai Koordinator)
   b. Tempat/Tgl Lahir : Bandung, 14 Juni 1972
   c. Alamat : Jl. Cipinang Jaya KK No. 12 Kel. Cip Besar Sel Kec. Jatinegara Kota Jaktim
   d. NPM : 0954045406720374
   e. Maksud : **Pengambilan Data untuk Penelitian di UPT Puskesmas Ibrahim Aji, UPT Puskesmas Kopo, UPT Puskesmas Pasundan, UPT Puskesmas Salam Kota Bandung tentang Studi Penerimaan, Kelayakan, Keterjangkauan, Kesinambungan serta Keamanan Praktek Pemberian Makanan Bayi pada Ibu HIV Positif di Kota Bandung, Jawa Barat.**
   f. Waktu Pelaksanaan : Terhitung mulai tanggal 18 Januari s.d 18 April 2010
   g. Anggota Tim :

No.	NAMA ANGGOTA TIM PENELITIAN
1	DR. Ir. Judhiastuty Februhartanty, MSc
2	DR. Utami Roesli, Spa, IBCLC, FABM
3	Andi Mariyasari Septiari, MSc
4	Meisa Dian Iryani, AMG
5	Ikeu Diah

2. Surat keterangan ini dibuat atas dasar :
   a. Surat pengantar dari Badan Kesatuan Bangsa, Perlindungan dan Pemberdayaan Masyarakat Kota Bandung (BKPPM) Nomor : 070 / 62 / BKPPM / 2010, Tanggal 18 Januari 2010
   b. Surat Pengantar dari SEAMEO TROPMED Regional Center for Community Nutrition Universitas Indonesia Nomor : 289/SEAMEO-PROG/XII/2009
3. Berhubungan dengan maksud bersangkutan, diminta agar unit kerja yang terkait memberikan bantuan serta fasilitas seperlunya sepanjang tidak mengganggu kelancaran dan menyangkut rahasia jabatan.

Bandung, 22 Januari 2010
A.n KEPALA DINAS KESEHATAN
KOTA BANDUNG
Sekretaris

PEMERINTAH KOTA BANDUNG DINAS KESEHATAN

dr. Hj. AHYANI RAKSANAGARA, M. Kes
Pembina Tk. I
NIP. 19620713 198803 2 006

CATATAN
- Agar membuat laporan hasil kegiatan melalui Kepala Bidang Bina Program Kesehatan

Tembusan, disampaikan kepada Yth :
1. Kepala Bidang Bina Program Kesehatan Kota Bandung
2. Kepala UPT Puskesmas Ibrahim Aji
3. Kepala UPT Puskesmas Kopo
4. Kepala UPT Puskesmas Pasundan
5. Kepala UPT Puskesmas Salam

DEPARTEMEN KESEHATAN
DIREKTORAT JENDERAL BINA PELAYANAN MEDIK
RSUP Dr. HASAN SADIKIN BANDUNG
Jalan Pasteur No. 38 , Bandung 40161
Telepon : (022) 2034953 (hunting) Faksimile : (022) 2032216, 2032533
Surat Email : perjan_rshs@yahoo.com, humas@rshs.or.id
SMS hotline : 081220050547

Nomor : LB.02.01/00 22/2e/59 /II / 2010 — 22 Pebruari 2010
Hal : Ijin Penelitian

Yang terhormat,
SEAMEO Topical Medicine and
Public Health (Tropmed) Network
Regional Center For Community Nutrition (RCCN)
University Of Indonesia
Jl. Salemba Raya No. 6
Jakarta

Menindak lanjuti surat Saudara nomor : 026/SEAMEO_ PROG/ I/ 2010, tanggal 19 januari 2010, perihal tersebut di atas dengan ini disampaikan bahwa pada prinsipnya kami dapat memberikan ijin kepada mahasiswa Saudara tersebut di bawah ini :

No	Nama	Anggota Tim Peneliti
1.	Dr. Dian Nurjahyati Basuki	Penelili Utama
2.	Dr. Ir. Judhiastuti Februhartanty ,MSc	Anggota
3	Andi Mariyasari Septiari, M Sc	Anggota
4.	Dr. Ulami Roesli,SPA,IBCLC, FABM	Anggota
5.	3 orang tenaga pengumpul data	

untuk melaksanakan penelitian tentang "Studi penerimaan ,kelayakan ,keterjangkauan,kesinambungan serta keamanan praktik pemberian makanan bayi pada Ibu HIV positif di RSUP. Dr. Hasan sadikin Bandung."

Kegiatan tersebut dapat dilaksanakan dengan ketentuan sebagai berikut :
1. Tidak mengganggu pelayanan di RSUP Dr. Hasan Sadikin
2. Mematuhi prosedur / ketentuan yang telah ditentukan oleh RSUP Dr. Hasan Sadikin
3. Hasil dari kegiatan digunakan hanya untuk tujuan akademik (tidak dipublikasikan)
4. Menyerahkan laporan hasil kegiatan kepada RSUP Dr. Hasan Sadikin melalui Bagian Pendidikan & Penelitian yang disetujui oleh Komite Etik Penelitian Kesehatan, Tim Penanggulangan HIV/AIDS, Bidang Medik c.q. Seksi Rekam Medik, serta diketahui oleh Bagian Pendidikan & Penelitian RSUP Dr. Hasan Sadikin sejumlah 2 (dua) exemplar paling lambat satu bulan setelah selesai pelaksanaan.
5. Kegiatan dilaksanakan tanggal
6. Untuk pelaksanaannya dilaksanakan berdasarkan kesepakatan Saudara dengan unit terkait
7. Bersedia mempresentasikan hasil penelitian sesuai kebutuhan RSUP Dr. Hasan Sadikin dengan waktu ditentukan kemudian berdasarkan kesepakatan bersama
8. Perlu kami sampaikan proposal tentang judul diatas telah mendapat rekomendasi dari Komite Etik Penelitian Kesehatan FKUP / RSHS

Untuk memperoleh keterangan lebih lanjut sebelum melaksanakan kegiatan, kami harap peserta yang bersangkutan dapat menghubungi Ka. Bag. Pendidikan & Penelitian melalui Ka.Sub.Bag. Pendidikan & Penelitian Medik RSUP Dr. Hasan Sadikin Bandung guna penyelesaian administrasi.

Atas perhatian dan kerjasamanya kami ucapkan terima kasih.

DEPARTEMEN KESEHATAN REPUBLIK INDONESIA
RSUP Dr. HASAN SADIKIN BANDUNG

Direktur SDM & Pendidikan

Agus Nadjan Rahim, dr Sp. OT(K) , M Epid, M.H.Kes
NIP. 19600812 198812 1 001

Tembusan :
1. Direktur Utama RSHS (sebagai laporan)
2. Ketua Komite Etik Penelitian Kesehatan FKUP / RSHS
3. Ketua Tim Penanggulangan HIV / AIDS RSHS
4. Kepala Bidang Medik c.q. Seksi Rekam Medik RSHS
5. Kepala Bagian Perbendaharaan & Mobilisasi Dana RSHS
6. Yang Bersangkutan

Acceptability, Feasibility, Affordability, Sustainability and Safety in Infant Feeding Practices

Of HIV-high-risk mothers in Bandung, West Java 2009

South East Asian Ministers of Education Organization (SEAMEO)

Tropical Medicine and Public Health (TROPMED)

Regional Center for Community Nutrition (RCCN) - University of Indonesia (UI)

Jl. Salemba Raya 6 Jakarta Pusat

Phone : (021) 3913932 / 330205, Fax : (021) 3913933

IN-DEPTH INTERVIEW QUESTIONS WITH MOTHERS

Mother's name : **Age:**

Education : **Occupation:**

Infant's name : **Age:**

Address :

Currently living with: spouse/parents/inlaws

Date of interview :

1. HIV status and child caring

• Did you found out you have HIV before you expect this child? How did you feel carrying this child in that condition?

• Do your family know your condition? How do they feel about you having a baby in this condition?

• Who takes responsibility in caring the child? Who makes the decision in child caring?

• Were you provided with health care to prevent the child from being infected? What services/care was given? Do you consume ARV? Did the infant was given ARV?

• How often do you go to health facilities? Who accompanied you when you go? How were the health workers attitude?

2. Infant feeding practices

• How did you feed your baby when he/she was born (e.g., first day to first week of life)?

• At what age did you first introduce any liquids (such as water, sugar water, milk, infant formula)? Why?

• At what age did you introduce semi-solid foods to your baby (such as mashed fruit, porridge)? Why?

• Are you feeding this baby in the same way as you have fed your other children, or are you feeding him or her differently? Why?

• How do you feed your baby when he or she is sick? (Probe specifically about feeding practices when baby has diarrhea, a respiratory infection, and a loss of appetite).

• How do your spouse/partner feel about this feeding method? How do your family feel? Ho do people living around you react about this feeding method?

3. Attitudes about breastfeeding

• In this community, how do mothers feed their infant? *PROBE* replacement feeding alternatives, recipes for infant meal, foods and recipes, style of feeding (e.g., cup, bottle, plate, hand), who feeds them.

• Was breastfeeding common? How long do mothers usually breastfeed their babies?

• What are the reasons women stop breastfeeding before this age? *Is illness mentioned as a reason? (yes/no) Is HIV/AIDS mentioned? (yes/no)*

• Are there women in this community who do not breastfeed (at all, from birth)?

• Why do women not breastfeed? What are the reasons? *Is HIV/AIDS mentioned? (yes/no)*

• Is wet-nursing a common practice here? (yes/no)

• *If yes*, who wet-nurses the baby? How does she decides who should do it?

• Do babies who are not breastfed have special needs? (yes/no)

• *If yes*, what are these needs? *PROBE for psychological, caring needs in addition to feeding/nutritional needs.*

• What problems do babies who are *not* breastfed face? *PROBE about health, growth, development problems.*

• What problems do mothers who do *not* breastfeed face? *PROBE about family, health worker reactions, what people say, types of stigmatisation.*

• Are there many young children whose mothers have died in this community?

• What happens to young children when their mothers die? Who feeds and cares for them?

• What services/programs/informal arrangements are available in the community for feeding and caring for orphans?

• Have you heard the term "exclusive breastfeeding"?

• Describe what it means to you

• Do you think that breast milk alone is enough food for a baby during the first 6 months of life?

• What makes you feel that way?

• What problems do you think a mother might come across when trying to breastfeed exclusively? (*PROBE for problems with the baby and the mother's health. PROBE about her husband's, her mother-in-law's, and her neighbors' opinions about her practice of exclusive breastfeeding. PROBE to see if she thinks she has enough milk.*)

• How to overcome these problems? (*PROBE for each problem listed above.*)

• Who has given you information about breastfeeding in the past? (*PROBE about information from health care providers, mothers-in-law, husbands, neighbours, traditional birth attendants.*)

• What were you told?

• At what age do women typically introduce other liquids to their babies?

• What are these first liquids (e.g., water, tea, medicines)?

• Why do they give them?

• At what age do women introduce semi-solid food to babies?

• What are the first foods given? PROBE about food consistency; how fed (in cup, bottle, plate).

• How do you know a baby is ready for solid foods? PROBE for infant behaviour, development cues (e.g., cries, reaches for food, has teeth).

4. Infant feeding counseling on HIV mothers

(Discuss this situation with the mother) Several health facilities have trained infant feeding counselors. They will explain to a mother with HIV about risk of transmission during pregnancy, labor and breastfeeding. The counselor explained two method of infant feeding options, also each advantages and disadvantages.

The first option is to exclusively breastfeed for the first six months of life while mother and infant consume ARV, introduce solid food at six months but continue to breastfeed and ARV consumption until 12 months.

The second option is to avoid breastfeeding at all, and give infant formula under conditions needed to be fulfilled to ensure hygiene and nutrition adequacy.

• Do you think this information is useful?

• What do you think will influence a mother with HIV to decide her how to feed her infant?

• Will she talk to anyone to help her with a decision? Who?

• What are the advantages of a mother with HIV to breastfeed her baby?

• What about the disadvantages of breastfeeding?

• Will only giving breastmilk be enough for infant's food in the first six months? Why?

• What problem can occur to a mother trying to exclusively breastfeed? *(PROBE about infant problems, maternal health, spouse's, in-laws' or neighbour's opinion. PROBE does she think she can produce enough mik)*

• What are the advantages of infant formula for her baby?

• What are the disadvantages?

• Should a mother with HIV learn how to prepare formula save and correctly? Where can she obtain the correct information?

5. Use of commercial infant formula

ASK to mothers who already stated she formula feed

• How old was your baby when you gave him infant formula for the first time?

• What kind (brand names)?

• Have you ever been taught how to prepare it correctly?

• How do you feed this (cup, bottle, both, other)?

• How often do you prepare infant formula each day?

• How much does the baby takes?

• What happens with the leftover formula (*PROBE about storage, other uses*)

• Do you receive formula donation? *(If Yes, PROBE for other requirements such as bottle, teat, soap, fuel)*

Where the formula supplies delivered or should you collect them? Where? What is the distance to home? How much for travel cost?

•How much have you and will receive?

• Do you also need to purchase additional infant formula? How often?

• How much do you buy each time?

• What is the cost?

• Are there times when you do not have enough formula to feed the baby?

• What do you do when this happens?

6. Observation of infant formula preparation

• What is used to give the feeds to the baby? Is it clean?

• How much powder does she use? (Record amount.)

• What is used to measure the amount of powder?

• How much water?

• What is used to measure the amount of water?

• Was the water boiled (before or during preparation)?

• How long does it take to prepare (record minutes)?

7. Observations of home hygiene and sanitation

• What is the source of drinking water in the home?

• Is water stored in the home?

• Is water stored in a covered container?

• What type of latrine is present?

• Note condition of the home (tidy, swept, well organized; untidy but generally clean; untidy and unclean).

• Does the home have soap for washing hands or dishes today?

• Is the kitchen area clean/untidy?

• Are animals seen roaming in the food preparation and eating areas?

• How are infant's utensils cleaned?

• What type of cooking stove is in the home?

• Does the house have electricity?

• Does the house have a refrigerator?

8. Questions of food availability

Are any of the following consumed in the last months (yes/no)?

• Chicken, meat, egg or other animal protein source

• Rice, maize, potato, bread and other carbohydrate source

• Milk other than infant formula (specify brand)

• Commercial baby cereal (e.g., Cerelac), commercial baby food (e.g., Purity)

• Vegetables (specify)

• Beans and legumes

• Fruits (specify)

• Sugar

• Margarine and cooking oil

9. Questions about food security

• Who is responsible for providing food for you and your children?

• Were there days in the last **month** when you did not have food for yourself or your children? How many? What do you do for food then?

• Are there times of the year when you do not have enough food for yourself and your children? When? What do you do for food then? Who do you turn to for assistance?

• Do you think your household is currently facing a food shortage?

• Are you currently receiving any food assistance (from NGO, government programmes)?

11. Child anthropometric measurement

Body length/heigh (cm)		
Body weight (Kg)		
Appearance		
During interview were: **a. Diarrhea** **b. ARI**		

Study on Infant Feeding Practice
Bandung, Jawa Barat 2009
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Jl. Salemba Raya 6 Jakarta Pusat
Phone : (021) 3913932 / 330205, Fax : (021) 3913933

FOCUSED GROUP DISCUSSION

Date :
Name of sub-district :
Name of village :
Moderator :
Recorder :
Time started :
Time ended :

CHARACTERISTIC OF PARTICIPANTS

No	Name	Age	Sex	Age of children	Last education	Occupation
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

Format

Introduce the moderator and note-taker. Explain that we are here to learn more about HIV and infant feeding and that we want to learn from them in order to better design health programmes for women and families. Explain the ground rules for the meeting - that the discussion will last 1 to 1.5 hours; that everything they say will remain

confidential and their names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the discussion.

Materials

Discussion guides, notepads, pens, tape recorder, tapes, batteries, index cards.

Topic: Infant feeding

1. Breastfeeding practices

- How long do mothers usually breastfeed their babies?
- When do they stop? Why?
- Are there other reasons for weaning a baby (earlier than usual)? PROBE for illness in mother with HIV.
- Do you think that women with HIV should breastfeed their babies? Why? Why not?
- How would a woman make this decision? Who/what would influence her?

2. Alternatives to breastfeeding

- Are there women in this community who do not breastfeed? Why not? (*Is HIV/AIDS mentioned*)?
- How do these women feed their babies? (PROBE for wet-nursing practices, use of formula, or nonhuman milks)
- Are there babies in this community that were not ever breastfed? Why not? *PROBE to see if orphans are mentioned; mothers with HIV/AIDS.*
- What has happened to these non-breastfed babies? Are they healthy? Do they survive, grow and develop like other children? PROBE about psychological as well as health/nutritional needs of non-breastfed babies.

3. Attitudes about exclusive breastfeeding, not breastfeeding and early cessation

- What are the reasons a mother would not breastfeed her baby? PROBE about illness, separation,other reasons. What does the baby get fed to replace breastfeeding?

• Who feeds and cares for the baby?

• What services, if any, are available in the community to help families with this problem/
decision?

• What do people say or think about a woman who does not breastfeed (by choice or other necessity as mentioned above)?

• Explain the WHO recommendation for mothers with HIV about exclusive breastfeeding and early, rapid cessation.

• Have you ever heard this advice before?

• What do you think about it? (Note that more specific questions are asked next.)

• What do you think about giving breast milk only for the first months of life and nothing else to reduce the chance that the baby will become infected with HIV?

• How about the idea of early and rapid breastfeeding cessation?

• What do people in the community think about women who abruptly wean?

• Would abrupt weaning be something that is easy or difficult for the mother/ family/others?

• What effects would it have on the mother? On the baby? On others in the family?

• How would early/rapid weaning be done?

• How long would it take to stop breastfeeding like this?

• What problems would a mother have if she suddenly stopped breastfeeding?

• What can she do about these problems?

• What about fathers and other family members, can they help mothers with this practice?

• What should the baby who is no longer breastfeeding be fed during the day/ at night?

• How can a mother who is not breastfeeding comfort her baby when he/she cries?

• What about a mother who does not stop breastfeeding, how does she feed her baby when she begins to introduce new foods?

• Is there anything else you would like to say or to suggest about what we have discussed today?

• Are there any questions you would like me to answer about this issue?

4. AFASS application

• Is formula feeding common here?

• When do mothers first introduce formulas to her infant?

• Who is responsible to prepare each feeds? Who usually asked to help with the feeds?

• Any particular common brand popular in this community? What are the considerations in choosing milk? PROBE brand, price, composition, prize/bonuses

• What additional costs required to safely give formula feeds?

• Until what age do children given formulas? Why?

• What problem can occur from a baby who consume formula?

• How to ensure a formula feed infant to stay healthy?

5. Other feeding decisions

• At what age do mothers typically introduce other liquids to their babies?

• What liquids are given? How are they fed?

• Why are liquids introduced?

• At what age are solid foods first introduced to babies (use local names)?

• How do you know that a baby is ready for solid foods? PROBE for cues and milestones that are recognized (e.g., specific ages, teeth, sitting, crying, reaching for food, etc.)

• What are the first foods typically given to young babies? PROBE for name, ingredients, and consistency.

• How are these foods fed? PROBE for use of separate plate, cups, by hands, other utensils.

• During the day, how often do you prepare foods for your children (< 2 years old)?

6. Feeding style and responsive feeding

• How do mothers/care givers know how much food to give a baby (or how much a baby can eat at one sitting)? (PROBE for how a mother knows that the baby has eaten enough; are specific quantities recognized).

• How does a mother encourage her baby to eat more?

• What does it mean to you when a baby does not want to eat?

• What can be done in this circumstance? PROBE to see if they would go to the health clinic, participate in monitoring growth, consult others about the problem/who; suspect illness.

• What are the signs of a healthy baby? PROBE for descriptions related to growth, size, and demeanour.

• What can a woman do to ensure that she has a healthy baby (what are practices, things within her control)?

7. General MTCT

• Have you ever heard about transmission of HIV from mothers to babies?

• What have you heard?

• What about HIV transmission during breastfeeding?

• Do you think that all mothers with HIV who breastfeed will pass the virus/infect their babies?

• Is this a common problem in the community?

• How can it be prevented?

8. Picture exercise

• Group the pictures to "Common", "Rare", "Never". Please also explain why they belong to each group .

THANK YOU

1. PICTURES OF AFASS PRACTICES

2. PICTURES OF TYPE OF INFANT FEEDINGS

3. PICTURES OF TYPE OF FAMILIES

Acceptability, Feasibility, Affordability, Sustainability and Safety
in Infant Feeding Practices
Of HIV-high-risk mothers of infants in Bandung, West Java 2009

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IN-DEPTH INTERVIEW QUESTIONES WITH HEALTH SERVICE PROGRAM PROVIDERS

Respondent's name :.....
Institution :.....
Interview date : .....

1. HIV transmission

- What is the cause of such high HIV transmission in Bandung?
- What is the highest risk group?
- Are people aware of the risk HIV? What do they do to prevent transmission?
- What is the attitude to an HIV family member? Are they isolated/banned? Do they tend to deny?
- How do HIV women respond to her condition? Do they disclose? Do they seek help? Where to?
- What happened to children from HIV women? Who will be responsible for caring? How do the families responds?
- How do the HIV women's health seeking behavior? Is there discrimination?
- What are the health worker's attitudes in providing services to these women? Are they supportive? Do they fear the risk to be infected?

2. PMTCT Policy

- Do PMTCT program exist in Bandung?
- What guideline is use in PMTCT program? Does local policy exist?
- Are there anyone in charge of the four strategic PMTCT programs?
- Any specific area targeted for PMTCT? Any health facility specially supervised for PMTCT programs?
- Which institutions put interest in PMTCT in Bandung?

3. Local PMTCT program on infant feeding

- WHO recommendation for infant feeding of HIV mothers is formula feeding if AFASS applies. Any specific program to implement this recommendation in the field?
- How was this recommendation socialized to health facilities providing HIV services? How were the health workers educated? Any trainings performed?
- Any projects involving infant feeding of HIV mothers?

4. Infant feeding donation on PLHIV

- Is there policy for free infant formula for infants of HIV mothers?
- Any program for free formula supply? Who provide the funding/free supplies?
- How to organize the free formula distribution to infants of HIV mothers? Do donors distribute the supplies directly to the mothers or through health offices?
- What are the eligibility criteria to receive formula donation?
- Do milk distribution monitored? By whom?
- Do routine data collections of formula recipient eligible candidates exist in the health offices/PLWHA network?
- Do formula recipients given infant feeding counseling upon receiving the donations?
- Do infant's receiving formula donations routinely monitored for nutritional/health status?

Study on Infant Feeding Practice
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CHECK LIST FOR THE MARKET SURVEY

The purpose of the market survey is to record the availability and price of foods and ingredients that will be needed to safely implement the different feeding options.
The outlets observed are those mentioned by respondents when asked about where they purchase food items.

- Date of survey :
- Name of the shop or retail outlet, location :

Name of item & Brand	Item Size		Price	Expiration date	Packaging condition
	Weight(kg)	Volume (liter)			

- Other note about the product:
- Note on location:
  - Distance to residential area .....
  - Population .....
  - Other .....

SEAMEO TROPMED Regional Center for Community Nutrition
Universitas Indonesia
Jl. Salemba Raya No. 4 Jakarta 10430 Telp: 021 3914017, 31930205

SURAT PERSETUJUAN UNTUK BERPARTISIPASI DALAM PENELITIAN

"Studi penerimaan, kelayakan, keterjangkauan, kesinambungan serta keamanan praktik pemberian makanan bayi pada ibu dengan HIV di Bandung, Jawa Barat"

(Lembar untuk Ibu/Keluarga)

Setelah mendengar penjelasan mengenai tujuan penelitian, prosedur penelitian, resiko dan manfaat penelitian, dan semua pertanyaan-pertanyaan saya yang berkaitan dengan penelitian ini telah terjawab sepenuhnya,

Saya mengerti bahwa akan dilakukan terhadap anak saya dan diri saya:

1. Pengambilan data identitas yang tertera di catatan rekam medis saya.
2. Wawancara serta pengamatan tentang praktik pemberian makanan bagi bayi saya dalam rekaman suara.
3. Penimbangan dan pengukuran tinggi dan berat badan saya serta bayi saya.

Maka dengan ini saya yang bertanda tangan dibawah ini:

Nama : _____
Umur : _____ tahun
Jenis kelamin : _____
Alamat : _____
Telp/HP : _____

Menyatakan setuju bahwa saya akan berpartisipasi sebagai subyek penelitian ini secara sukarela dan bebas tanpa ada paksaan, dengan catatan apabila suatu ketika merasa dirugikan dalam bentuk apapun berhak membatalkan persetujuan ini.

Jakarta, tanggal ____/____/2010

Pembuat pernyataan,

(_____)

Mengetahui,
Penanggung jawab penelitian,

(dr. Dian Nurtjahjati, IBCLC)

SEAMEO TROPMED Regional Center for Community Nutrition
Universitas Indonesia
Jl. Salemba Raya No. 4 Jakarta 10430 Telp: 021 3914017, 31930205

SURAT PERSETUJUAN
UNTUK BERPARTISIPASI DALAM PENELITIAN

"Studi tentang praktik pemberian makanan bayi di Bandung, Jawa Barat"

(Lembar untuk Masyarakat)

Setelah mendengar penjelasan mengenai tujuan penelitian, prosedur penelitian, resiko dan manfaat penelitian, dan semua pertanyaan-pertanyaan saya yang berkaitan dengan penelitian ini telah terjawab sepenuhnya,

Saya mengerti bahwa akan dilakukan terhadap diri saya:

1. Pencatatan data identitas saya.
2. Wawancara tentang praktik pemberian makanan bagi bayi serta perekaman dalam rekaman suara.

Maka dengan ini saya yang bertanda tangan dibawah ini:

Nama : _____
Umur : _____ tahun
Jenis kelamin : _____
Alamat : _____
Telp/HP : _____

Menyatakan setuju bahwa saya akan berpartisipasi sebagai subyek penelitian ini secara sukarela dan bebas tanpa ada paksaan, dengan catatan apabila suatu ketika merasa dirugikan dalam bentuk apapun berhak membatalkan persetujuan ini.

Jakarta, tanggal ____/____/2009

Pembuat pernyataan,

(_____)

Mengetahui,
Penanggung jawab penelitian,

(dr. Dian Nurtjahjati, IBCLC)

SEAMEO TROPMED Regional Center for Community Nutrition
Universitas Indonesia
Jl. Salemba Raya No. 4 Jakarta 10430 Telp: 021 3914017, 31930205

SURAT PERSETUJUAN
UNTUK BERPARTISIPASI DALAM PENELITIAN

"Studi penerimaan, kelayakan, keterjangkauan, kesinambungan serta keamanan praktik pemberian makanan bayi pada ibu dengan HIV di Bandung, Jawa Barat"

(Lembar untuk Tenaga Kesehatan)

Setelah mendengar penjelasan mengenai tujuan penelitian, prosedur penelitian, resiko dan manfaat penelitian, dan semua pertanyaan-pertanyaan saya yang berkaitan dengan penelitian ini telah terjawab sepenuhnya,

Saya mengerti bahwa akan dilakukan terhadap diri saya:

1. Pencatatan data identitas saya.
2. Wawancara tentang praktik pemberian makanan bagi bayi serta perekaman dalam rekaman suara.

Maka dengan ini saya yang bertanda tangan dibawah ini:

Nama : _____
Umur : _____ tahun
Jenis kelamin : _____
Alamat : _____
Telp/HP : _____

Menyatakan setuju bahwa saya akan berpartisipasi sebagai subyek penelitian ini secara sukarela dan bebas tanpa ada paksaan, dengan catatan apabila suatu ketika merasa dirugikan dalam bentuk apapun berhak membatalkan persetujuan ini.

Jakarta, tanggal ____/____/2010

Pembuat pernyataan,

(_____)

Mengetahui,
Penanggung jawab penelitian,

(dr. Dian Nurtjahjati, IBCLC)

RINCIAN INFORMASI UNTUK SUBYEK IBU

TENTANG PENELITIAN

Judul penelitian:

Akan dilakukan penelitian berjudul:
" Studi penerimaan, kelayakan, keterjangkauan, kesinambungan praktik pemberian makanan bayi pada ibu dengan HIV di Bandung, Jawa Barat"

Pendahuluan:

Seorang ibu dengan HIV dapat menularkan HIV pada bayinya dengan menyusui. Karena itu, bila penerimaan, kelayakan, keterjangkauan, kesinambungan serta keamanan memungkinkan, seorang ibu dengan HIV disarankan tidak menyusui bayinya dan dianjurkan memberikan susu formula pada bayinya. Namun kenyataannya pemberian susu formula yang aman tidak mudah, sehingga mengakibatkan tingginya diare serta kurang gizi.

Tujuan dari penelitian:

Melakukan eksplorasi terhadap kriteria dari WHO tentang penerimaan, kelayakan, keterjangkauan, kesinambungan serta keamanan praktik pemberian makanan bayi dari ibu dengan HIV di Bandung, Jawa Barat.

Ibu dan bayi yang dapat berpartisipasi

- Ibu pernah menjalani pemeriksaan laboratorium dan terbukti HIV.
- Ibu memiliki bayi usia 12 (dua belas) bulan ke bawah.
- Ibu bersedia menandatangani surat persetujuan keikutsertaan (*informed consent*)

Kegiatan yang akan dilakukan

- Data anak ibu akan diambil dan dicatat
- Ibu akan diwawancara tentang praktik pemberian makanan bagi bayi ibu yang kami rekam.
- Ibu dan bayi ibu akan ditimbang dan diukur tinggi serta berat badannya.

Permasalahan

Penelitian ini tidak menimbulkan masalah dan risiko apapun pada ibu dan bayi ibu karena hanya melalui wawancara serta penimbangan tinggi dan berat badan.

Manfaat Penelitian

Penelitian ini akan memberi **manfaat** langsung kepada bayi anda (ibu) dan tak langsung bagi masyarakat:

- Informasi tentang benar/tidaknya praktik pemberian makanan bagi bayi (ibu). Bila pada akhir pengumpulan data ditemukan bahwa praktik pemberian

makanan bayi belum sesuai dengan rekomendasi, ibu akan mendapatkan informasi tentang praktik pemberian makanan bayi yang sesuai.

- Informasi tentang status gizi ibu dan bayi ibu melalui penimbangan dan pengukuran berat badan. Ibu dan bayi yang ternyata memiliki status gizi kurang akan diarahkan untuk mendapatkan layanan kesehatan yang diperlukan.

Kerahasiaan

Semua informasi yang diterima, informasi pribadi ibu dan bayi ibu, termasuk kondisi kesehatan ibu serta hasil pengukurannya akan diperlakukan secara rahasia; dan hanya ibu dan petugas berwenang saja dari penelitian ini yang dapat mengetahui/akses terhadap hasil wawancara serta pengukuran tinggi dan berat badan ibu dan bayi ibu.

Masalah Keuangan

Penelitian ini tidak menyediakan manfaat/keuntungan finansial bagi keluarga ibu apabila ibu dan bayi ibu berpartisipasi.

Hak Untuk Menolak atau Mengundurkan Diri Dari Penelitian

Setelah ibu mendapat informasi yang jelas dan memadai baik secara lisan maupun membaca informasi untuk responden tentang penelitian ini, beserta informasi rinci mengenai tujuan, menfaat dan resiko dari penelitian ini, ibu akan diminta untuk mengisi dengan menandatangani lembaran persetujuan.

Ibu berhak untuk menolak atau mengundurkan diri dari penelitian pada waktu kapanpun, tanpa ada sanksi apapun juga. Partisipasi ibu adalah **sukarela dan tanpa paksaan dalam bentuk apapun atau siapapun.**

Apabila diperlukan penjelasan lebih lanjut, dapat menghubungi:

dr. Dian Nurtjahjati, IBCLC

SEAMEO TROPMED RCCN - UI
Gedung SEAMEO TROPMED Kampus UI Salemba
Jl. Salemba Raya No. 6 Jakarta Pusat
Telepon: 31902739; 31930205 ext 203; 390-9205
Fax: 3913933 HP:08129135173

Dr. Ir. Judhiastuty Februhartanty, MSc

SEAMEO TROPMED RCCN - UI
Gedung SEAMEO TROPMED Kampus UI Salemba
Jl. Salemba Raya No. 6 Jakarta Pusat
Telepon: 31902739; 31930205 ext 203; 390-9205
Fax: 3913933 HP:08129135173

SENTRA LAKTASI INDONESIA/SELASI
Jl. Tebet Utara 1F No. 12 Jakarta Selatan
Telepon/Fax: 021-83795168

RINCIAN INFORMASI UNTUK SUBYEK MASYARAKAT

TENTANG PENELITIAN

Judul penelitian:

Akan dilakukan penelitian berjudul:
"Studi tentang praktik pemberian makanan bayi di Bandung, Jawa Barat"

Pendahuluan:

Departemen Kesehatan RI menganjurkan menyusui bayi segera setelah bayi lahir; memberikan ASI eksklusif yaitu hanya ASI saja tanpa makanan dan minuman lain sampai bayi berumur 6 bulan; memberikan Makanan Pendamping ASI (MP-ASI) yang tepat dan adekuat sejak usia 6 bulan; dan tetap meneruskan pemberian ASI sampai usia anak 24 bulan. Namun kenyataannya rendahnya pengetahuan ibu dan keluarga lainnya mengenai manfaat ASI dan cara menyusui yang benar, kurangnya pelayanan dan dukungan dari petugas kesehatan, faktor sosial budaya, kondisi yang kurang memadai bagi para ibu yang bekerja dan gencarnya pemasaran susu formula untuk bayi yang mempengaruhi para ibu dan petugas kesehatan, mengakibatkan tingginya diare serta kurang gizi.

Tujuan dari penelitian:

Melakukan eksplorasi terhadap praktik pemberian makanan bayi di Bandung, Jawa Barat.

Anggota masyarakat yang dapat berpartisipasi

- Memahami praktik pemberian makanan bagi bayi usia 12 (dua belas) bulan ke bawah.
- Bersedia menandatangani surat persetujuan keikutsertaan (*informed consent*)

Kegiatan yang akan dilakukan

- Data pribadi akan dicatat.
- Diskusi tentang praktik pemberian makanan bagi bayi yang berlangsung akan kami catat dan rekam menggunakan tape recorder.

Permasalahan

Penelitian ini tidak menimbulkan masalah dan risiko apapun pada ibu/bapak karena hanya melalui diskusi.

Manfaat Penelitian

Penelitian ini akan memberi **manfaat** tak langsung bagi masyarakat yaitu informasi tentang benar/tidaknya praktik pemberian makanan bagi bayi di lingkungan setempat. Bila pada akhir diskusi disimpulkan bahwa praktik pemberian makanan bayi di masyarakat setempat belum sesuai dengan rekomendasi, akan disampaikan pada instansi kesehatan terkait untuk mendapatkan informasi tentang praktik pemberian makanan bayi yang sesuai.

Kerahasiaan

Semua informasi yang diterima, akan diperlakukan secara rahasia.

Masalah Keuangan

Penelitian ini tidak menyediakan manfaat/keuntungan finansial bagi anggota masyarakat yang berpartisipasi.

Hak Untuk Menolak atau Mengundurkan Diri Dari Penelitian

Setelah mendapat informasi yang jelas dan memadai baik secara lisan maupun membaca informasi untuk responden tentang penelitian ini, beserta informasi rinci mengenai tujuan, menfaat dan resiko dari penelitian ini, ibu/bapak akan diminta untuk mengisi dengan menandatangani lembaran persetujuan.

Ibu/Bapak berhak untuk menolak atau mengundurkan diri dari penelitian pada waktu kapanpun, tanpa ada sanksi apapun juga. Partisipasi ibu/bapak adalah **sukarela dan tanpa paksaan dalam bentuk apapun atau siapapun.**

Apabila diperlukan penjelasan lebih lanjut, dapat menghubungi:

dr. Dian Nurtjahjati, IBCLC

SEAMEO TROPMED RCCN - UI
Gedung SEAMEO TROPMED Kampus UI Salemba
Jl. Salemba Raya No. 6 Jakarta Pusat
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Dr. Ir. Judhiastuty Februhartanty, MSc

SEAMEO TROPMED RCCN - UI
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Jl. Salemba Raya No. 6 Jakarta Pusat
Telepon: 31902739; 31930205 ext 203; 390-9205
Fax: 3913933 HP:08129135173

RINCIAN INFORMASI UNTUK SUBYEK TENAGA KESEHATAN

TENTANG PENELITIAN

Judul penelitian:

Akan dilakukan penelitian berjudul:
" Studi penerimaan, kelayakan, keterjangkauan, kesinambungan praktik pemberian makanan bayi pada ibu dengan HIV di Bandung, Jawa Barat"

Pendahuluan:

Seorang ibu yang HIV positif dapat menularkan HIV pada bayinya dengan menyusui. Karena itu, bila penerimaan, kelayakan, keterjangkauan, kesinambungan serta keamanan memungkinkan, seorang ibu dengan HIV disarankan tidak menyusui bayinya dan dianjurkan memberikan susu formula pada bayinya. Namun kenyataannya pemberian susu formula yang aman tidak mudah, sehingga mengakibatkan tingginya diare serta kurang gizi.

Tujuan dari penelitian:

Melakukan eksplorasi terhadap kriteria dari WHO tentang penerimaan, kelayakan, keterjangkauan, kesinambungan serta keamanan praktik pemberian makanan bayi dari ibu dengan HIV positif di Bandung, Jawa Barat.

Tenaga kesehatan yang dapat berpartisipasi

- Bekerja di fasilitas kesehatan yang memberi layanan pada pasien HIV/mengelola program mengenai HIV.
- Bersedia menandatangani surat persetujuan keikutsertaan (*informed consent*)

Kegiatan yang akan dilakukan

- Data pribadi akan dicatat.
- Wawancara tentang praktik pemberian makanan bagi bayi yang berlangsung akan kami rekam.

Permasalahan

Penelitian ini tidak menimbulkan masalah dan risiko apapun karena hanya melalui wawancara serta penimbangan tinggi dan berat badan.

Manfaat Penelitian

Penelitian ini akan memberi **manfaat** tak langsung bagi petugas kesehatan/pengelola program HIV. Instansi terkait akan mendapat masukan tentang benar/tidaknya praktik pemberian makanan bagi bayi dari ibu dengan HIV yang selama ini ditangani fasilitas kesehatan/program yang bersangkutan.

Kerahasiaan

Semua informasi yang diterima, akan diperlakukan secara rahasia.

Masalah Keuangan

Penelitian ini tidak menyediakan manfaat/keuntungan finansial bagi siapapun yang berpartisipasi.

Hak Untuk Menolak atau Mengundurkan Diri Dari Penelitian

Setelah mendapat informasi yang jelas dan memadai baik secara lisan maupun membaca informasi untuk responden tentang penelitian ini, beserta informasi rinci mengenai tujuan, menfaat dan resiko dari penelitian ini, ibu/bapak akan diminta untuk mengisi dengan menandatangani lembaran persetujuan.

Ibu/Bapak berhak untuk menolak atau mengundurkan diri dari penelitian pada waktu kapanpun, tanpa ada sanksi apapun juga. Partisipasi ibu/bapak adalah **sukarela dan tanpa paksaan dalam bentuk apapun atau siapapun.**

Apabila diperlukan penjelasan lebih lanjut, dapat menghubungi:

dr. Dian Nurtjahjati, IBCLC

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Appendix 5. Pictures from the field

Appendix 5. Pictures from the field

CURRICULUM VITAE

Name	: dr. Dian Nurtjahjati Basuki, IBCLC
Place & date of birth	: Bandung, June 14th 1972
Home	: Perumahan Cipinang Elok Blok U No. 1, Kelurahan Cipinang Muara, Kecamatan Jatinegara, Jakarta Timur 13420
Mobile phones	: 0811-152130, 021-33115480, 0812-9135173
Fax	: 021-8518800
email	: dian.basuki@gmail.com
Current position	: Research & Development Commitee Course Director, Lactation Consultant Indonesian Breastfeeding Center/Sentra Laktasi Indonesia.
Office	: JL Tebet Utara 1 F No. 12 Jakarta 12820 021-83795168 www.selasi.net, sentra.laktasi.indonesia@gmail.com

A. EDUCATION & CERTIFICATION

- Graduated from Faculty of Medicine, Christian University of Indonesia on 2001.
- Certified Lactation Counselor on Breastfeeding Counseling Training conducted by Indonesian Breastfeeding Center and St. Carolus Nursing Development Center on February 2004.
- Certified Trainer on HIV and Infant Feeding Counseling Course conducted by Indonesian Breastfeeding Center August 2004.
- Certified Infant Feeding in Emergency Counseling Course conducted by Indonesian Breastfeeding Center, The Ministry of Health and UNICEF January 2005.
- Inter-country Training for trainer on Nutritional Care and Support for People living with HIV/AIDS, held by WHO in Jakarta, 4-7 October 2005.
- Certified International Board Certified Lactation Consultant (IBCLC) on October 2007 by International Board of Lactation Consultant Examiner/IBLCE Washington DC, USA.
- Student for Master Degree in Community Nutrition in SEAMEO TROPMED RCCN UI, batch 2008.
- Academy of Breastfeeding Medicine member since December 31st 2008.
- Registered Doctor No. 31.2.1.100.1.06.019217.

B. EXPERIENCE

- ☐ Facilitated, Trained and Directed courses conducted by Indonesian Breastfeeding Center:
  - Breastfeeding Counseling Courses since August 2004, using WHO/UNICEF 40 hours module. Trainings conducted for UNICEF, World Vision Indonesia and Mercy Corps Indonesia.
  - HIV and Infant Feeding Counseling Course since 2004, using WHO/UNICEF/USAIDS module.
  - Infant Feeding in Emergencies training for health and nutrition workers in emergency situations, using ENN/IBFAN/UNICEF/WHO/CARE-USA/Linkages/Terre des homes/UNHCR/WFP module since 2005

- Nutrition, Care and Support for People Living With HIV/AIDS, adaptation training for PLWHA, conducted by Indonesian Epidemiology Network as part of the National Meeting for HIV/AIDS by National AIDS Commission, Surabaya, February 2007.

☐ Core Team member for Module translations/adaptation:
- WHO/UNICEF's Breastfeeding Counseling: A Training Course, for Indonesian Breastfeeding Center, UNICEF and the Ministry of Health in 2005-2006.
- WHO/UNICEF/UNAIDS' HIV & Infant feeding: A Training Course, for Indonesian Breastfeeding Center in 2004.
- Infant feeding in Emergencies: For health and nutrition workers in emergency situation (ENN, IBFAN, Terre des hommes, UNICEF, UNHCR, WHO, WFP) for Indonesian Breastfeeding Center, UNICEF and ENN Module 1 in 2005, Module 2 in 2008.
- Baby Friendly-Hospital Initiative: Revised, Updated & Expanded for Integrated Care (UNICEF/WHO), for Indonesian Breastfeeding Center, UNICEF and the Ministry of Health 2007.
- WHO/UNAIDS' Nutrition, Care and Support for People Living With HIV/AIDS for Indonesian Epidemiology Network and WHO, module adaptation 2006.
- National PMTCT Module for Ministry of Health Republic of Indonesia.

☐ Publication:
- Co-author of *"Indonesia Experience: Community Level Breastfeeding Support During The Emergency Situation"* Poster Abstract presented for 13th Annual International Meeting ABM, October 2008

☐ Lecturer/guest lecturer:
- Children Nutrition and Health subject for PGTK MENTARI INDONESIA (school for Kindergarten Teacher) 2007-2009.
- Lactation Science subject, for Master degree student majoring in Maternal Health, Nursing Faculty, University of Indonesia, batch 2008, 2009, 2010.

☐ Speaker for:
- PMTCT on National HIV and AIDS Research Symposium: Women, Children and Adolescent, December 13th 2007 in Jakarta, conducted by National AIDS Commission.
- Infant Feeding on ARV Prophylactics and Infant Feeding Practice for PMTCT Programs Symposium, Expert meeting, May 7th 2008, conducted by Directorate for Maternal Health, the Ministry of Health and UNICEF.

☐ Contributor for column about breastfeeding management & lactation science for MAJALAH TUMBUH KEMBANG, local health & nutrition magazine since January 2008.

☐ Secretary for IBCLC INDONESIA, association for Indonesia's International Board Certified Lactation Consultants since November 2007.

☐ PMTCT Task Force member for infant feeding unit, Ministry of Health of Indonesia (HK.00.SJ.B.0290) February 29th 2008.

☐ General practician for PT. Kereta Api Indonesia 2005-2008.