Attitudes and Perceptions of Health Providers and HIV Positive Mothers on Adopting Breastfeeding for HIV Exposed Children: A Qualitative Study in Rural Haiti.

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This thesis, Perceptions and experiences of HIV-Infected Mothers and Health care Providers on Adopting Breastfeeding for HIV-Exposed Infants: A Qualitative Study in Rural Haiti presented by Jean Christophe Dimitri Suffrin and Submitted to the Faculty of The Harvard Medical School in Partial Fulfillment of the Requirements for the Master of Medical Sciences in Global Health Delivery in the Department of Global Health and Social Medicine has been read and approved by:

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Perceptions and experiences of HIV-Infected Mothers and Health care Providers on Adopting Breastfeeding for HIV-Exposed Infants: A Qualitative Study in Rural Haiti.

Abstract

Transmission of HIV via breast milk is a pressing public health dilemma confronted by HIV/AIDS prevention programs around the world, especially in developing countries. HIV-infected mothers face a dilemma: they can provide their babies with the benefits of breastfeeding but risk exposing them to HIV infection, or they can avoid breastfeeding to minimize the risk of HIV transmission, but increase the risk of infant death from diarrhea and malnutrition.

Research now shows that providing women with Anti-retroviral therapy (ART) during exclusive breastfeeding can significantly reduce the risk of HIV transmission through breast milk. Since March 2010, the World Health Organization (WHO) has recommended exclusive breastfeeding for all HIV-exposed infants but indicated that some countries can still use formula feeding replacement when it is acceptable, feasible, affordable, sustainable and safe (AFASS).

In 2012, Partners in Health (PIH), a community-based NGO working in rural Haiti, shifted from a policy of formula feeding to one of breastfeeding for all HIV-exposed infants and ART for nursing mothers. This transition has been challenging for health care providers and patients in Haiti. Using interviews and participant-observation, this qualitative study investigated the perceptions and attitudes of HIV-infected mothers and health care providers about this policy change.
The study demonstrates that in adopting exclusive breastfeeding, HIV-infected mothers gained social and psychological advantages but lost some physical and economic benefits inherent to the formula policy. Breastfeeding reduced the social stigma created by formula feeding and allowed those mothers to reclaim a certain level of social and emotional normality. However, mothers experienced physical distress from breastfeeding and lost the liberating and the protective effect of the formula policy. Mothers felt powerless in the policy transition, which eroded the patient-provider relationship.

Study results indicated that the policy change emphasized the negative effects of poverty on women's agency. Therefore this study recommends more feeding-related assistance and support for HIV-infected mothers. Finally, this study set a stage for more studies about barriers to exclusive breastfeeding and impact of mixed infant feeding on HIV-exposed infant in resource-poor settings. We recommend that policy makers consider the needs of HIV-infected mothers in new PMTCT policies.
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1. Introduction

Postnatal transmission of HIV is a major concern in public health. Breast milk serves as a vector of transmission of HIV from mother to child. Before 2009, the most effective way to prevent this transmission from the HIV-infected mother to the infant was to avoid breastfeeding. When avoiding breastfeeding, the mother substitutes formula for breast milk. Infants receiving formula lose the advantage of bio-composition of breast milk but avoid the risk of HIV transmission. When implemented adequately with clean water, formula increases infant survival among HIV-exposed infants (Ivers et al., 2011). However, when formula is implemented without adequate means, even though the risk of HIV transmission is low, the infant survival is threatened by diarrhea and malnutrition. Since new evidence has shown that breastfeeding can be maintained as the main feeding option for infants even in the context of HIV, formula is no longer recommended for HIV-exposed infants. Therefore HIV-infected mothers in poor countries are instructed to breastfeed their infants exclusively until six months before introducing other foods and receive Anti-retroviral treatment (ART).

This study seeks to understand the perception and experiences of providers and HIV-infected women in rural Haiti, during the transition from artificial formula to exclusive breastfeeding for HIV-exposed infants. Knowledge generated from this inquiry can be used to inform further research and will afford insights to policy makers on the field of prevention of Mother-to-Child transmission of HIV (PMTCT).

This study employed a qualitative research methodology to illustrate the phenomenon under examination. Participants in this study are two purposefully selected groups: one of six providers and one of eighteen HIV-positive mothers. Both groups have implemented and
experienced the transition from artificial formula to exclusive breastfeeding for HIV-exposed infants.

This study sought to understand how HIV positive mothers perceive the shift in PMTCT policy from formula feeding to exclusive breastfeeding. By better understanding the experiences and point of view of HIV-positive mothers and their health care providers, we hope to better understand how this new policy shift shapes women’s experiences in feeding and caring for their infants. This newfound understanding can be used to inform the creation of PMTCT policies that most closely reflect the needs and priorities of HIV positive mothers in Haiti. The results of this study can also serve as a foundation for further research on the correlations between user’s perceptions and outcomes of programmatic change in context of HIV prevention and treatment among vulnerable populations.

2. Background

2.1 History of Haiti: Overview

The republic of Haiti is located in the West part of Hispaniola, the second largest Caribbean island after Cuba located in the Caribbean Sea in front of the Mexican Gulf. Haiti is mountainous, with a tropical climate, and its economy is agriculturally oriented. This part of the Island was a former colony of France populated by slaves brought from West African Coasts (Georges-Jacob, 1941). In 1804, the former slaves launched a revolution, freed themselves from France’s rule, and created the Republic of Haiti known as the first black republic in the world. Currently, Haiti is the 32nd most densely inhabited country in the world with 10.9 million inhabitants for an area of 27,000 square kilometers. The total fertility rate in Haiti is 3.5 children per woman, and women make up more than 50% of the Haiti’s population. Despite massive
migration to urban areas during the last decades, most of Haiti's population lives in rural areas (IHSI, 2009). Haiti has little ethnic diversity, 95% of black and 5% others mostly mulattoes (C.I.A, 2014).

Haiti’s distribution of wealth and services shows dire social disparities between urban and rural areas, and between ethnics group as well. The country is divided into 10 departments, each department is divided into "Arrondissements" and each "Arrondissement" is divided into communes. The department has a central city called "Chef-lieu." Despite all that subdivision, the country is highly centralized politically and administratively toward the capital city, Port-au-Prince. Haiti only has 4,266 kilometers of roadways with only 18% paved (C.I.A, 2014) and those roads are found mostly in the metropolitan areas (commune of Port-au-Prince, Petion-ville, Delmas, Cite-Soleil, Carrefour, Tabarre). Only 27% of the population has access to improved sanitation facilities, and 64% of those facilities are also found more in urban settings (MSPP, 2012).

Poverty and social inequalities shape the general context of Haiti. More than 58.5% of the population lives below the poverty line. Life expectancy is 62 years at birth. The adult literacy rate in Haiti is 61%. Females have lower literacy rate of 58.3% (MSPP, 2012). As in most poor countries, Human Development index (HDI) is low at 0.471 and the Gini coefficient is very high at 60.8 (C.I.A, 2014), underlining the poignant state of social inequalities in Haiti which link poverty to the poor health status of the population. Poverty and social inequalities are "co-factors" that limit access to basic health care and fuel the emergence of epidemic diseases in the population.
Recent DALY estimations shown that Haiti's burden of disease is largely attributable to communicable diseases such as tuberculosis, HIV, sexually transmitted diseases (STD) excluding HIV, diarrheal diseases, childhood-cluster diseases, malaria, and respiratory infections. Nevertheless, the great majority of the population lives in conditions with poor sanitation, little access to clean water, malnutrition and limited access to health services. Consequently, life expectancy in Haiti is 64.6 less than the global estimate. In 2010, a major earthquake laid waste to Port-au-Prince, killed 300,000 people and displaced millions. The subsequent Cholera epidemic have worsened Haitian's conditions and increased the burden of disease.

The study took place in two communes in Haiti, St-Marc and Mirebalais. The Commune of St-Marc is a coastal city located in the Artibonite department, one of the largest of the region. On the route between Port-au-Prince and Gonaive, St-Marc has a population of 160,000, and more than 60% of the population live in the mountains, far from access to adequate infrastructure, electricity, sewage systems, and potable water. A hospital with fewer than 100 beds and one health center (Dispensary of St-Marc) cover the health care needs of this population including the implementation of the PMTCT program.

The Mirebalais commune is a landlocked and mountainous area of the Central Plateau department, adjacent to Port-au-Prince, St.-Marc, and Hinche, the largest city of the Central department, and also to the Dominican border. 88,000 people populate Mirebalais and the 300 bed Mirebalais teaching hospital is the only health facility providing HIV care. These facilities are fully supported and managed by Partners In Health (PIH), a not-for-profit organization that has worked in rural Haiti for more than twenty years.
HIV in Haiti

In 2012, one fourth of deaths in the Caribbean due to HIV/AIDS occurred in Haiti. HIV/AIDS is the third cause of death in Haiti among the general population, and the leading cause of death for people aged 15-59 (WHO, 2012). More than 100,000 children (aged 0 to 17 years old) are orphaned due to HIV (WHO, 2014a) and related HIV-deaths represent 18% of all deaths among people aged 30-59 (WHO, 2014b). Although the prevalence of HIV infection dropped from 2.2 to 1.9 and the rate of new infections fell by 54% for the last decade (UNAIDS, 2013), gaps in HIV services persist, particularly in pediatric HIV services and PMTCT programs.

In Haiti the HIV/AIDS epidemic is widespread and disproportionately affects people that are economically and geographically isolated. Regional variation of HIV epidemic is still unchanged since the onset of the disease in the early 80's, despite the rapid urbanization of the population. According to the 2012 Haiti Mortality, Morbidity, and Service Utilization Survey (EMMUS V) the HIV infection rates vary according to geographical location, with higher infection rates in rural areas (2.3%), and lower rates in urban areas (1.7%) (MSPP, 2012). This is largely attributed to the relatively high concentrations of health services urban centers. The EMMUS-V of 2012 showed a difference in HIV prevalence between regions or department in Haiti. HIV prevalence is less than 2% in five departments (Grand Anse, Sud, Nord, Ouest and metropolitan areas, Centre) and 2% or higher in the five others (Nippes, Artibonite, Sud-Est, Nord-Est, Nord-Ouest) (MSPP, 2012).

Epidemiologically the HIV/AIDS infection in Haiti presents some epic characteristics in term of distribution in the population. According to the Monitoring and Evaluation Surveillance Intégrée (MESI) (2012) in Haiti, the HIV prevalence in men is 1.7% and in women is 2.7%.
MESI shows that women are more affected than men and represent 60% of people living with HIV (PLWHIV) population (MESI, 2012). In Haiti, HIV epidemic is predominant among risk groups such as men having sex with men (18%), sex workers (8.4%) (UNAIDS, 2012). HIV co-infection with tuberculosis is high. In 2014, 88% of TB infected patients also tested positive for HIV (WHO, 2012), which increases the weight of the burden of HIV disease.

**Infant feeding in rural Haiti**

Breastfeeding is the most common infant-feeding method in Haiti. The 2012 Haiti Mortality, Morbidity, and Service Utilization Survey (EMMUS V) reported that nearly 97% of mothers participating in this survey breastfed their infants. The UNICEF 2014 State of the World’s Children report indicated that 39.7% of infants below six months of age were breastfed, which is higher than the mean of the region including Latin America and the Caribbean. Mothers initiate breastfeeding for nearly half (47%) of infants in Haiti, and continue to breastfeed their infants for longer breastfed than the mean of the region. Among breastfed infants in Haiti, 30% are breastfed until their second year of age (UNICEF, 2014). However few infants are exclusively breastfed, and introduction of complementary foods is common before the age of 4 months (MSPP, 2012).

Local beliefs in Haiti play an important role in determining the pattern and duration of breastfeeding. Anthropological studies have long documented that Haitian mothers typically breastfeed their infants for a period of eighteen months after birth (Alvarez, 1990; Herskovits, 1937). Ethnographic work among mothers has emphasized a strong local belief in the insufficiency of breastmilk. Alvarez notes that women in Haiti often supplement breastmilk with other foods because they believe that breastmilk alone is not sufficient to meet the dietary needs
of infants (Alvarez, 1990). Farmer documents the widespread belief that the quality of
breastmilk is shaped by the state of a mother’s well-being. Specifically, it is believed that
breastmilk “spoils” when a woman undergoes a period of emotional distress. Farmer found that
people in Do Kay, Central Haiti, avoided breastfeeding during times of emotional distress in
order to protect the infant (Farmer, 1988). It is not rare for newborns to receive the traditional
"lock", a porridge, for her first infant meal. This first feeding of “lock” is a tradition that has
long been practiced in Haiti, and that was also practiced in pre-industrial Europe when the
common belief mistrusted the colostrum(Alvarez, 1990; Fildes, 1986).

In Haiti, breastfeeding practices are often bound with women’s capacity to pursue
economic opportunities outside of the house. Women are responsible for the domestic duties
within their own homes. In addition, woman who live in poverty are also responsible for seeking
work outside of the home in order to meet the economic needs of their families (Freeman, 2007).
Indeed, most families in Haiti are dependent upon women’s economic activities for survival
(Anglade, 1986). For women, especially those who have children, the purchase and preparation
of food is the most consuming issue in their lives and women generally reinvest all money
earned directly into the household (Maternowska, 2006, p. 61).

The majority of income-generative activities available to Haitian women require them to
work outside of their own homes. Historically, it has been unacceptable for Haitian women to
bring their children with them to work. This is true even for informal labor, such as selling
goods in the marketplace. The West African custom of working mothers carrying children tied
to their bodies was lost during the period of slavery in Haiti. Slave-owners in Haiti did not
authorize female slaves to bring their children with them to work the field plantation,
establishing a precedent for infant care to be exclusively carried out within the home (Herskovits, 1937; Morrison, 2012).

Today, mothers of young infants who must work outside of the home leave their children to be cared for by other members of the social network. Neptune Anglade notes that this network includes a variety of family members, notably mothers, aunts, and unemployed partners (Anglade, 1986). Without access to any institutionalized forms of day care, these social networks represent a vital form of social support for mothers who must work outside of the home. The economic pressures that impel women to pursue work outside of the home have created a legacy of separation between mothers and infants. This, in turn, has created a form of infant feeding that includes a mix of breastfeeding and supplemental food deemed appropriate for babies. Working mothers breastfeed their infants when they are home, and caregivers provide supplemental forms of feeding while mothers are away at work. Indeed, more than 60% of infants in Haiti are mixed-fed (UNICEF, 2014), which is more suited to working mothers in their struggle to meet the economic needs of their family.

**Historical aspects of breastfeeding**

Breastfeeding is commonly defined as the physiological process of feeding an infant with human breast milk, either directly with the breast or indirectly after expressing the milk from the breast. Within the realm of research and program design, there are many variations in how breastfeeding is defined. The WHO/UNICEF has provided definitions for four variations of breastfeeding: exclusive, complementary, predominant and breastfeeding (which includes anything other than human milk, bottle-feeding) (WHO, n.d; UNICEF, n.d; Coffin, Labbok, & Belsey, 1997). Variance between breastfeeding definitions may lead to misinterpretations;
therefore, there is room for development of more consistent definitions. Many scholars call for consistency in breastfeeding definitions and recommend that various types of breast milk feeding need to be distinguished from breastfeeding (Colin & Lee, 2013; Greiner, 2007; Labbok & Starling, 2012; Noel-Weiss, Boersma, & Kujawa-Myles, 2012). In her holistic concept analysis, Bomer defines breastfeeding as more than simply a feeding process; instead breastfeeding is a dynamic relationship between the lactating woman and a child. This relationship is initiated at a specific interval after birth and variations in breast milk composition in fact control the duration of that relationship (Bomer-Norton, 2014). In this approach, breastfeeding is understood to encompass the relationship of psychological interdependency between mother and child that has been inherited through millions of years of mammalian evolutionary history (Dettwyler & Stuart-Macadam, 1995).

Breastfeeding is a natural process that is practiced by all mammal species, including mankind. Different studies have shown biological and historical evidence that breastfeeding is the main nutrition for infant humans, and as mammals, our history of lactation is even more ancient (Fildes, 1986; Dettwyler & Stuart-Macadam, 1995). Archeological evidence has shown prehistoric evidence of breast milk use among humans (Eriksson & Lidén, 2013; Jenkins, Partridge, Thomas, Farley, & Robbins, 2001; Sillen & Smithh, 1984; Tsutaya & Minoru, 2003). Fildes' works on breastfeeding presents historical evidence back to 3,000 BC. First, she gathers artifacts and epigraphs belonging to that time illustrating breastfeeding and evidence about breastfeeding practice in the Sumerian and pre Sumerian peoples of Mesopotamia. Second, she presents scriptures that mention breastfeeding in the ancient Mesopotamian code of laws of Hammurabi, in the ancient Egyptian's scriptures, in the Old Testament, in the Talmud, in the Midrash and in the Koran (Fildes, 1986).
While throughout history breastfeeding has been framed as a "natural" part of human existence, human societies have developed alternate ways to feed children. Therefore, social processes have always shaped breastfeeding. In many societies, the biological mother did not always breastfeed her own child. In the historical evolution of infant feeding, a "wet nurse," a lactating woman other than the infant’s mother, was often used to provide human milk to the infant, particularly when the general belief argued against using the colostrum (Aristotle, 400BC). In Egyptian civilization, wet nurses were used for the nutrition of the highly-born and royalty (Fildes, 1986). In the Greek and Roman civilizations the practice of wet nursing was well established because of the preponderance of female slaves (Gellius, 1795). From the Middle Ages to the late eighteenth century, wet nurses were largely used and institutionalized in most European countries among wealthier people, whereas lower class women were more likely to breastfeed their own infants on both side of the Atlantic (Georges, 1982; Golden, 2001).

In colonial America, the practice of wet nursing was broadly used, institutionalized and regulated. Many conditions gave rationale to the use of wet nurse. Endemic malaria and delivery abnormalities caused high maternal mortality, which required an alternate way to feed the baby. Severe physical illnesses, nipple abnormalities, mastitis and mental disorders of the biological mothers might interfere with the "let-down reflex" and could prevent breastfeeding partially or completely (Golden, 2001, p. 19). Northern American private households did not accept cross-racial wet nursing. In the South, the norms of wet nursing overlapped closely with the system of social inequality and subjugation, in which black women were used as a "Nursing mammy" for white children at the expense of their black children's survival (Morrison, 2012; Youcha, 2009, p.60-66)
Though wet nursing that persisted in various forms in some parts of the world like in the Ivory Coast (Gottlieb, 2015), the practice of wet-nursing progressively vanished in postindustrial societies and was replaced by a more manageable and commercial artificial infant formula (Georges, 1982; Golden, 2001).

**The development and history of infant formula**

Infant formula is defined as a breast milk substitute and more specifically "a food which purports to be or is represented for special dietary use solely as a food for infants by reason of its simulation of a human milk or its suitability as a complete or partial substitute for human milk" (FDA, 2006). The use of animal's milk is the ancestor of the actual infant formula and was predominant until the industrial and modern times.

In the seventeenth century, within northern European countries common customs indicated the use of animal milk for infant feeding, and medical doctors of England highlighted the relative success in infant survival. However, in southern Europe animal milk was used less frequently for infant feeding, except within orphanages (Fildes, 1986). The animal milk was used in two different manners. The first use was the direct animal suckling. This practice did not spread too much toward southern Europe because of the belief that the animal's temperament could be transmitted to the suckling infant. The second one, named originally "hand feeding," involved the use of vessels to feed the infant with animal's milk or any mixed liquid for that purpose (Chamoux, 1973). During that time, the deaths related to the use of artificial feeding were attributed to lack of knowledge about suitable food preparation and sterilization, therefore hand feeding was recommended only by necessity (Fildes, 1986).
However, in the nineteenth and twentieth centuries the practice of artificial feeding gained momentum with the breakthrough of scientific and technological inquiries in the medical field that led to creation of artificial formula milk. A more adequate formula resulted from comprehensive research on topics such as human and animal milk composition, milk and hygiene based on the germ theory, calorimetry and human metabolism (William & Durham, 1953). Louis Pasteur invented pasteurization in 1864, which allowed for longer-term storage of cow’s milk. Pasteurization opened the way to three innovative breakthroughs for food preservation: in 1920, the Boston Floating Hospital's research team invented the process to dry milk; the Borden company presented to the public a successful frozen process; and a research team at Cornell University presented the canning milk process in which the milk could be preserved for two years (Golden, 2001). These advances from the early nineteenth to the twentieth century set a fertile ground for the widespread of animal's milk-based formula as an alternative to breastfeeding (Chamoux, 1973; William & Durham, 1953). The modern infant formula milk was created in the mid-nineteenth century with the work of Liebig, who developed the first formulation of artificial infant formula (Levenstein, 2003, pp. 122-123). With this invention, food processing firms (such as Nestle in Switzerland, Borden and Millin in England and in the United States) to begin to produce evaporated and condensed milk, which they sold extensively around the world. Therefore, at the end of twentieth century less than 35% of infants worldwide were breastfed exclusively during the first four months of life, and the global market for infant formula was estimated at more than 6 billion USD (White, 1999). Well-to-do people used formula because of the freedom formula permitted to women and as a form of social demarcation.
Extensive formula use in poor countries was an unintended consequence of public health action and marketing action that negatively impacted infant survival in poor countries. Baumslag & Michels (1995) offer an account of this issue. After World War II, UNICEF programs targeted the deficiency in protein in their fight against malnutrition, and UNICEF started a worldwide free powdered milk distribution to protect people against malnutrition. As a perverse effect, the free milk was used in some parts of the world for infants and newborns, decreasing the breastfeeding rates among those populations. By the end of the seventies, more than thirty formula companies dominated the infant feeding market worldwide. UNICEF’s free milk distribution opened the way to infant formula companies toward poor countries as potential market. Infant formula companies with their marketing touched mothers everywhere, but the poor women with meager education and resources were more affected. Images of wealthy people using formula, images of health professionals advising on formula, and free sample distribution in hospitals as sale inducements influenced those women not to breastfeed for their infants (Baumslag & Michels, 1995, pp.147-148). Consequently, the lack of money to buy an adequate quantity of formula milk and lack of access to clean water increased malnutrition and raised infant morbidity in developing countries.

This unethical advertising of formula and the negative effects on poor people motivated grassroots organizations, women's activists, and faith based-organizations to raise awareness of formula marketing practices. Outrage over these marking practices led to social movements against formula manufacturers including boycotts, particularly against Nestle and Bristol-Myers. In 1979, UNICEF and WHO launched the International Baby Food Action Network (IBFAN) to better address the issues of marketing practices for infant feeding products. By 1981, the World Health Assembly passed the International Code of Marketing on breast milk substitutes.
(Baumslag & Michels, 1995, p. 162). The Code emphasized the prohibition of free formula
distribution or free sample distribution. In addition, the Code prohibited contact between health
workers and infant formula manufacturers.

The adoption of the Code marked the beginning of the WHO's and UNICEF's global
crusade for breastfeeding. From this crusade some programs were successfully implemented
worldwide like the Baby Friendly Hospital initiative, which was a hospital-based initiative to
protect, promote and support breastfeeding (White, 1999). Moreover, as the driver of the
breastfeeding campaign, this initiative aimed to limit the use of artificial formula for the benefit
of the mother-infant dyad with an approach that included the mother, the provider and the health
facility.

In the early twentieth century, women moved toward more formula use, but by the late
twentieth century, the initiatives noted above again made breastfeeding the recommended
practice, with some exceptions. HIV infection was one exception worth particular examination
(White, 1999).

The role of infant feeding in PMTCT

Although policies like the Code prioritized breastfeeding over formula feeding,
HIV/AIDS represented an important exception. During the HIV/AIDS epidemic breast milk was
potentially fatal for the infant due to the potential for transmission of the virus from mother to
child. The transmission of HIV (Human Immunodeficiency Virus) from mother to child
(MTCT), also known as vertical transmission, is the spread of the infection from an HIV-infected
mother to her baby or babies during pregnancy, labor, or breastfeeding. Without specific
interventions, the HIV virus can be transmitted during pregnancy or delivery in about 15-25% of
cases (Bode et al., 2012; Dunn, Newell, Ades, & Peckham, 1992). Additionally, 5-20% of infants may become infected post-natally due to ingestion of infected breast milk. This transmission via breast milk is one of the most pressing public health dilemmas confronted by MTCT prevention programs around the world, especially in resource-poor countries (Gaillard et al., 2004). Avoiding breast milk was the most effective way to prevent breast milk transmission of HIV. Policy makers were forced to promote formula use in the context of HIV.

In 2006, the World Health Organization (WHO) published recommendations for infant feeding in context of HIV, in which HIV-infected mothers could choose to use formula as a replacement feeding method (WHO, 2006a). The recommendations indicated that when HIV-infected mothers decided to use replacement feeding, they should be provided with specific guidance and support to ensure adequate replacement feeding (WHO, 2006b). ART treatment was provided to HIV-infected mothers only during pregnancy to protect the baby. After childbirth, the mother’s health was clinically and biologically evaluated. If the mother was deemed healthy enough, she was taken off ART treatment, which marginalized the health of the mother because HIV is a chronic illness. ART treatment was continued if a woman's biological and clinical evaluation deemed it necessary for her health.

However, the ACGT 076 result study (O’Connor, 2009) followed by Malawi initiative (Kasenga, 2010) provided evidence to support the claim that exclusive breastfeeding and lifelong anti-retroviral therapy (ART) during breastfeeding significantly improved infant survival rates while protecting the baby from the risk of HIV transmission through breast milk (Kilewo et al., 2008; Thomas et al., 2011). In 2010, the WHO published an update of the PMTCT protocol, which recommended breastfeeding and six weeks of Zidovudine (AZT) treatment for all HIV-exposed infants and lifelong ART treatment for the HIV-infected mother.
That new protocol provided two innovative benefits. First the HIV-exposed infants could receive the advantages of breast milk while being protected against HIV transmission. Second, the HIV-infected mothers could continue to receive ART treatment for the benefits of their own health. This protocol protected the infant, and allowed the mother to receive the benefit of the long term ART for her own health. The new PMTCT intervention emphasized the need to keep those women alive and well.

**PMTCT and infant feeding in Haiti**

Before 1995 in Haiti, the HIV vertical transmission rate was estimated to be 27% (Jean et al., n.d.). External donors provided over 75% of the funding for Haiti’s HIV response. Since 2002 Haiti has received funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), and the US President’s Emergency Plan for AIDS Relief (PEPFAR) to scale-up antiretroviral therapy (ART) nationwide (Raymonville, Leandre, Saintard, & Colas, 2004). Local NGOs, international agencies and the public sector are working together for over two decades, with political commitment at the highest levels to provide high-quality HIV care in Haiti.

At the beginning of the HIV epidemic, the Ministry of Health in Haiti was assisted by two local NGOs to launch the first PMTCT program (Koenig et al., 2010): GHESKIO, the Haitian study Group for Kaposi sarcoma and Opportunistic Infections in Port-au-Prince, and Partners in Health (PIH), a community-based NGO working in rural central Plateau department. GHESKIO began a protocol with the Nevirapine-based therapy for HIV infected pregnant women until delivery. PIH, led by the great result of AZT 076 trial (Connor et al., 1994) and the aim to promote equity in health care, was the first NGO to providing the same AZT based-
regimen for PMTCT in resource-poor settings, as was currently available in the United States (Partners In Health, 2004).

PIH's care approach for HIV-infected pregnant women extended beyond the bounds of their pregnancies. This approach reached the woman's whole household and addressed health issues and social needs. PIH showed the success of the formula option as breast milk substitute when implemented with supports for HIV-infected mothers (Partners In Health, 2004; Farmer, Nizeye, Stulac, & Keshavjee, 2006; Raymonville et al., 2004). Every HIV-infected woman accessing the program received supplemental health care such as family planning and toxoid vaccines. Besides these supplemental health services, HIV-infected mothers received a package of clothes for their newborn, feeding bottles, free tools for clean water preparation (delivered monthly), detergent, and nutritional supports that were designed to complement the artificial formula milk. Because of the strong association between poverty and HIV infection, this package of supplemental supports was as important as the formula itself for the women. Women in the PMTCT program received group and individualized information sessions and social support from Community Health Workers called Accompagnateurs (Partners In Health, 2004, p. 6)

Formula supplementation did not negatively affect the tendency to breastfeed in the general population and was well accepted by HIV-infected women in rural Haiti (Ivers et al., 2011; Koenig et al., 2010). The use of formula in tandem with social supports reduced vertical transmission rate of HIV, which fell from 27% to less than 3% for HIV-infected women accessing health centers where the free formula protocol was implemented from 1995 to 2003 (Koenig et al., 2010) even though controversies arose about sustainability (Binagwaho et al., 2009; Coutsoudis, Coovadia, & Wilfert, 2008).
In March 2010, citing evolving scientific evidence about vertical transmission, the WHO recommended exclusive breastfeeding for all HIV-exposed infants (WHO, 2010). In 2012, PIH changed their infant feeding policy and adopted exclusive breastfeeding for all HIV-exposed infants and ART for the nursing mothers. Funds for fighting HIV come from international agencies which adopted cost-effective approaches for health intervention in resource-poor countries (Keshavjee, 2014; Raymonville et al., 2004). The breastfeeding policy was implemented only with few health care services and without all the complementary support for the HIV-infected women that had been previously provided under the formula policy. HIV-infected mothers had to breastfeed their infant exclusively until six months of age, after which other food could be introduced with breastfeeding. In this case, the infant could receive breastfeeding as long as the mother wanted to continue.

3. Methods

3.1 Rationale For Qualitative Design

The choice of study design was guided by a concern to identify the meaning that women and providers attach to their experiences during the shift from formula feeding to exclusive breastfeeding (Pope and Mays 2006). In an effort to capture this meaning, two types of data collection were used: semi-structured interviews and participant observation. Relying on multiple forms of data collection helped the researchers to capitalize on the strengths of each approach (Patton, 2002, p. 307). Interviews were an important vehicle for gathering information about past interventions and contemporary policies, and participant observation allowed the researcher to gather important contextual information about women’s experiences with current breastfeeding recommendations. Combining both approaches allowed the researcher to bring multiple perspectives to the same analytical space (Maxwell, 2013). Furthermore, while
interviews provided the researcher with the opportunity to elicit in-depth descriptions of participants’ experiences in their own words (Creswell, 1998; Patton, 2002), participant observation afforded the researcher the opportunity to better capture a holistic picture of the daily realities facing women undergoing this shift in breastfeeding policy.

The researcher is a physician who was previously engaged in the provision of PMTCT care in Haiti, a position that provided insight into the history and clinical processes of delivering PMTCT care in this context. As the researcher moved through various contexts, from the PMTCT clinics to women’s domestic spaces, the researcher’s positioning similarly shifted along a continuum of belonging – or “outsider” to “insider” status (Jorgensen, 1989).

This study was designed to examine a particular policy shift in PMTCT care. However, this shift is embedded within a longer historical narrative of various approaches to infant feeding. This study therefore relies on a processual approach to data analysis, which adopts a time-oriented perspective on the multiple continuities and changes that shape the shift from formula feeding to exclusive breastfeeding (Moore, 1987). This attention to “process” is embedded within a larger biosocial framework, which situates the policy shift in a particular set of economic, social and historical pressures (Farmer, Kleinman, Kim, and Basilico, 2013, pp. 17-20)

### 3.2 Data Collection

**Participants and sampling**

This study used a purposeful sampling process. In qualitative research purposeful sampling is the most consistent and common way to produce valuable data (Creswell, 1998; Patton, 2002). The two groups of participants (HIV positive mothers and providers) were
recruited according to the study's criteria and gave their informed consent before being interviewed by the researcher.

Thus, participants were asked to participate in the study according to following specific criteria. All providers were nurses or physicians at Zanmi Lasante (ZL/PIH). They had worked at least in the PMTCT program since 2009 and they had implemented both infant-feeding options that ZL/PIH had adopted. All HIV-positive mothers were 18 years of age or older and were enrolled in a PMTCT program where the study was conducted at St. Marc or Mirebalais hospitals. They had experience of both the formula feeding and breastfeeding options and were currently “in care,” meaning that the patient had least one visit in the PMTCT program during the last six months. This selection excluded any case of stillbirth and/or abortion; women with mental disorders; and women who were unable to provide informed consent.

**Recruitment**

Fifteen eligible providers were invited by email to join the study and the first six who responded were selected to participate in the study. When providers agreed to participate, the researcher conducted the informed consent process. Interviews were conducted at the provider’s convenience in Haitian Creole and lasted 50 minutes on average. Half of the interviews with providers were conducted at the providers' home and the other half took place at the PIH central office in Port-au-Prince. Interviews were audio recorded and the researcher took notes on age, gender of the participant, general atmosphere of the interview and non-verbal data. At the end of each interview, the audiotape was transcribed verbatim.

Initially, eligible HIV positive mothers were verbally invited to take part in the study by their regular provider during a regularly scheduled visit. After the participant agreed to take part
in the study, they were directed to the researcher desk in the facility for the consent process and interview. One interview was conducted at a patient’s home and the rest of the interviews took place at health facilities. The same researcher conducted all the interviews. Interviews lasted on average 45 minutes, were audio recorded, and the researcher took notes on the general interview atmosphere.

**Qualitative interviews**

The primary data for this study are results from 24 semi-structured interviews. The researcher conducted interviews with 18 HIV positive mothers using an interview guide of 21 open ended questions developed specifically to explore their experience with both formula feeding and breastfeeding (see appendices 1-2). The researcher also interviewed six health care providers using an interview guide of 14 open-ended questions to understand the providers’ perspective on working with their patients who were formula feeding or breastfeeding, and their overall view on the change in the policy. The use of qualitative interviews enabled those participants to tell their stories and their thoughts about what happened on their own terms (Patton, 2002).

**Participant observation**

At the conclusion of each interview with an HIV-positive mother, the researcher asked the participant whether they would like to be involved in participant observations. All HIV-positive mothers were invited, three declined, and 13 agreed to participate in the observations. The researcher selected three of them to complete the next phase based on the richness of their interviews. Before the observations started, the consent form and the study purpose were read to each participant in Haitian Creole, regardless of her level of literacy. Those three HIV-positive
women gave verbal consent to the researcher. The participant observations lasted three (3) days with each woman. The researcher observed each participant in three different situations: their journey to health facility, in their homes, and at a community activity. The community activities under observation were as follows: a funeral for the first woman, a day in the plantation field for second one, and at last a day in the local market for the third woman. Purposefully to avoid interruptions in the dialogue and participant to be inconvenienced, the researcher did not take notes during observation sessions. Field notes were written immediately after observation sessions.

3.3 Data Management and Analysis

At the end of each qualitative interview, the audiotape was transcribed verbatim in Haitian Creole and prepared for analysis. This work relied on an inductive, content-focused approach to data analysis. Two codebooks were developed through an iterative process of open coding the interview transcripts (Crabtree and Miller, 1999). This resulted in two codebooks, one for providers and one for HIV-infected mothers. The Researcher used atlas.ti software to code all resultant interview transcripts through a process of directed coding. Coded data was then examined inductively to build a set of final constituent categories that are reported in the first half of the results section below.

Fieldnotes from the participant observations were analyzed by creating analytical summaries that identified the key experiences and concepts of the key informants who were followed during this phase of the study. These summaries were then transformed into narrative case studies that are represented in the second half of the results section. Findings from the interviews and observations were integrated to produce the final argument.
Figure 1: Diagram of Study Design
4. Ethical Consideration

Ethical standards form the boundaries for any research in the modern time and prioritize highly the protection of study participants. This study received approval from Harvard IRB in Boston and locally from both research committee and ethical committee at Zanmi Lasante, PIH’s sister organization in Haiti. Informed consent remained a priority throughout the study. Voluntary consent was given to the researcher for both forms of data collection. Before each interview, the consent form and study purpose were read in Haitian Creole to participants regardless of their level of literacy. Health care providers gave written consent and patient participant gave their consent verbally. All interviews were de-identified and study-related records and data were stored securely to protect participant privacy.

5. Results

5.1 Findings from Interviews

The result section presents key findings obtained from 24 semi-structured interviews (18 with HIV-infected mothers and six Health Care Providers). Our qualitative analysis resulted in the identification of eight key thematic categories. The categories are as follows: (1) unrelenting management of formula implications, (2) formula as freedom, (3) physically demanding, (4) protective effect of formula package 5) reclaiming normality 6) feeling powerless 7) erosion of patient-Provider relationship 8) troublesome transition.

The section that follows presents a broad description of each finding bolstered by participant’s quotes, with a focus on hearing the participants’ experiences in their own words to allow the reader to a better understanding of participant experiences. Illustrative quotations are
presented for the purpose of depicting multiple participant perspectives and the complexity of the subject explored. Some results emerged as key themes from provider interviews or patient interviews. Other thematic categories were the result of reading across both datasets, comparing and contrasting provider and participant data.

**Study participants**

Participants for this study were health care providers and HIV-infected mothers. There were three male providers and three female providers, and all six have worked in the PMTCT program as a nurse or doctor for an average of 7.66 years (SD 1.03). For the 18 HIV-infected mothers participating in this study, three (n=3; 83%) of them had a partner, though not all women who had partners lived with their partners. Seven (n=7; 39%) had disclosed their HIV status to their partner. Only five (n=5; 28%) were literate, where literacy is defined as being able to, at minimum, read and write their name. Fifteen (n=15; 83%) were performing revenue-generating activities such as working on the field as a farmer, selling goods in the marketplace, or working as a housekeeper (see table below).

**Table 1: Participant Characteristics of HIV-positive mothers**

<table>
<thead>
<tr>
<th></th>
<th>Basic literacy</th>
<th>Revenue-generating activity</th>
<th>Have a partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>28%</td>
<td>83%</td>
<td>83%</td>
</tr>
<tr>
<td>No</td>
<td>72%</td>
<td>17%</td>
<td>17%</td>
</tr>
</tbody>
</table>
HIV-infected mothers participating in this study were 32 years of age in average and their average time in the PMTCT program was 8 years. Based on the inclusion criteria each of them had at least one infant born before 2012 and at least one infant born after 2012. Women participating in this study had an average of 4 infants, where one infant was born before the mothers knew their HIV-positive status and was enrolled in the PMTCT program (see table below).

**Table 2: Participant Characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Total number of children</th>
<th>Number of children born before the PMTCT program</th>
<th>Age (Mother)</th>
<th>Number years mother was in the PMTCT program</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>3.83</td>
<td>1.11</td>
<td>32.5</td>
<td>7.83</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>1.29</td>
<td>1.13</td>
<td>4.34</td>
<td>1.72</td>
</tr>
</tbody>
</table>

**1. Managing formula-related stigma**

Participants for this study expressed the feeling of being in a perpetual struggle to face and manage social context in which they were living. Contextually, in rural Haiti formula was not commonly used, unless in some cases of maternal diseases such as HIV/AIDS, as reported by patient participants of this study. Study participants were not able to breastfeed their newborns and they received free formula from the HIV Program, which marked them as HIV-positive, so these women experienced social stigmas such as humiliation and rejection from family and community members. The social stigma was depicted here as an unpleasant and oppressive atmosphere. Instead of being supported socially they experienced exclusion from community and
family. Patient participants reported that when either community or family members knew about their HIV status, they were more likely to be judgmental about that and using formula was seen as a visible proof of their sero-positivity. Participants reported being criticized or being "victim" of bad talk openly or behind their backs because of formula use, and felt they could request child support from others. HIV-infected woman understood that receiving formula prevented HIV-exposed infant from infection, but that the formula labeled them as HIV-positive, which made them lose some social support, as explained by this quote:

"My family gave lots and lots of problems; I was so humiliated that I went to my brother's house to seek refuge for a period. But his wife started to humiliate me too and one day in the middle of the night she locked me out!" Patient 6

"Even when I had to go out I could not leave my children with her for quick watch over, Then, whether I stay home, or I bring them with me [my children]. Patient 6

Another provider participant echoed this sentiment in the following quote:

"There was a stigma with the free formula. For instance, a mother who does not breastfeed in our community, especially in the rural area, is identified as being HIV positive, so those mothers got the free formula in secret." Provider 5

In their struggle, the mothers articulated two aspects that seemed to be paramount for them. First, HIV-infected mothers were constantly involved in the efforts of preventing unintended disclosure of their HIV status because of the formula usage. Second, eventually, when people in their family and/or in their community found out about their HIV status, patient participants had to manage people's judgment of their HIV status. Various maneuvers and efforts were deployed to manage these negative implications of formula use.
Patient participants explained that they had to "hide the very reason" for formula use which was an everyday challenge. When HIV status was not yet disclosed, patient participants spoke of "giving excuses for formula-feeding" and "lying" to family and community members anytime they were asked questions about "where" the formula came from and "why" they were using it instead of breast milk. In the context of rural Haiti, where family and community participation are highly valued, such a maneuver was not an easy task and placed the patient participant in constant emotional distresses, as these interview excerpts indicate:

"I use to tell them (family) that I am using formula because I have a problem with my breast I can't breastfeed, that's the reason I have bought formula milk." Patient 7

"All the time they used to ask where did I find the formula for the baby, I used to lie to them (neighbors) and said that the father of my baby bought them (formula)." Patient 6

One provider participant mentioned that the mothers would offer alternate reasons for formula use to avoid criticism from others in their community:

"Some patients used to lie, and they used to say to those who are asking questions about formula that they don't have enough milk to breastfeed the baby, or their breast milk is dry that was the reason for receiving milk from the hospital." Provider 4

Furthermore, to minimize stigma associated with formula use, patient participants did not discuss formula use with people in their social world. Diverting attention from their feeding methods was a daily struggle considering the culture of community participation in life events. Patient participants mentioned that they avoided sharing information about formula and being questioned at all about feeding choices. One participant explained that she viewed her feeding choices as a personal matter:
"People don't have to know about my personal life, whether I gave formula or not to my baby, people do not have to ask questions about what a give to my baby." Patient 9

Therefore, in the perspective of prioritizing what matters to them, patient participants managed these feedbacks by “ignoring” people's judgment of their HIV status. For them, the pursuit of a greater stake undermined judgmental feedbacks and allowed patient participants to keep heads out of the unpleasant social atmosphere mined by criticism and rejection. Patient participants placed their focus on what really mattered to them in the context of HIV and scarcity. For them it was unrelenting and exhausting management, as explained by these excerpts:

"For me, I felt great about it [formula] because I used to have eight cans of formula milk at my house to feed my baby without concerns. But those people who have criticized me, they were saying that I have AIDS, which did not surprise me, neither bothers me. People would trample on your feet to find a way to tell you that you have AIDS." Patient 9

"I used to say that I was receiving food to eat, and I am fat; they can talk as long as they want about me, that is their business." Patient 16

"... No, I did not have to [explain why I fed my child with formula] because I was managing my baby's future." Patient 6

2. Formula as freedom

Patient participants of this study emphasized the importance of income-generating activities in their life. Resuming activities after delivery was an important decision for mothers in rural contexts because many mothers supported the household partially or completely. When
women exclusively breastfeed their babies, they are bound to the house for the duration of the six months of breastfeeding. This responsibility cuts into their economic productivity, leaving them with no income. Patient participants explained because of that they have to either rely on close family or to borrow money in the neighborhood. The following quotes illustrate women's view on that matter:

"They recommend to you to breastfeed the baby ... while I am breastfeeding the baby I could not get to the market, my hands are empty, for myself I still have problem." Patient 3

"In the first child, I did not have any debt because I had found help for that baby. Now [with the change from formula to breastfeeding protocol] it is different until now I still have debts." Patient 1

Receiving free formula permitted women in this study to resume their activities in field plantations or in the local market, so very soon after delivery they felt able to get back to their income-generating activities. The HIV-infected mother who was using formula could regain her economic productivity and could contribute to or support the household. This mother’s quote illustrates:

"I was able to do some activities; I've never spent a night out, but I was able to spend the whole day (in the market)...." Patient 12

Provider participants explained that formula not only freed women but also "empowered" HIV-infected mothers because it allowed them to keep their financial autonomy in the community when they were able to resume their activities, as one participant provider explained in the following excerpt:
"In my opinion, the formula works best. The mom can leave the house and ask someone to feed the baby and spend the whole day in the garden. Versus if the mom had to breastfeed, she would not be able to leave the house." Provider 2

When the breastfeeding protocol was implemented, women were directed to breastfeed their baby for six months and they did not receive the artificial formula or the accompanying package of food and other tools useful for water purification. According to this new protocol, the baby did not have to receive either water or any food beside the breast milk. When patient participants were recommended to breastfeed their children, they lost the liberating advantage of the formula option. The six months of exclusive breastfeeding conflicted with their income-generating activities, which they underlined as paramount. In this context, women were not able to make use of their social support when breastfeeding their children; in contrast, patient participants explained that formula allowed them to draw on their social support. Furthermore, when their family accepted their HIV status, formula activated that social support and liberated them to get out into their income-generating activities. Patient participants reported that adopting breastfeeding disturbed and limited their economic capacity as elicited by these quotes:

"If it were formula, it would not interrupt my activities (in the market) ... because when I would have to go to my activities, my baby's father could stay and watch over." Patient 9

And also:

"Not having money was the most difficult for me. We used to be farmers, and it has not been raining for long. We did not have money to start activities in the marketplace. I could not go selling my crops in the marketplace because I had to stay home to breastfeed the baby. Considering that my partner was a farmer as well, He could not
Provider participants reported as well that women in rural Haiti always have revenue-generating activities, even though these activities might not generate enough to allow them a proper living. Therefore, the adoption of exclusive breastfeeding conflicted with their revenue-generating activities. One provider noted the importance of women's income-generation potential.

"These people do not get maternity leave, like people abroad, and they go right back to work after giving birth. Those moms, who have the opportunity to work, do not get to spend time with their newborns, they are always working, because in most cases they are the sole breadwinner in the household. The new protocol demands that moms stay in the house more to breastfeed." Provider 5

3. Physically demanding

Patient participants in this study reported that breastfeeding was not an effortless activity; instead it was physically demanding for women. For mothers living in resource-poor settings, where food insecurity and diseases often threaten woman health, breastfeeding requires effort and may have a certain physical cost subtracted from the woman. Breastfeeding was a pressing and exhausting activity for the physical body of the HIV-infected mother. During the breastfeeding period, patient participants had to face the increased need for food and rest time. Again, having more food required an increase in expenditures in a context of scarcity. Adopting breastfeeding for the woman enlarged some current basic needs that were already difficult to fulfill, as this excerpt illustrates:
"When it was the formula for the baby, no breastfeeding, you did not have to eat more than usual. But when the baby is sucking you repetitively you have to eat something. I could have ten plantains and two hours after I would be hungry and get to eat again during the day. But when the baby was taking formula you could have tea and wait for something later but when you are breastfeeding you cannot do that." Patient 12

Provider participants in this study mirrored this also, as seen in the following quotes:

"As health care workers, we know that when the mothers are breastfeeding, they have to eat well to produce adequate milk." Provider 6

"The patients were anxious to breastfeed. They said, 'they did not eat enough and were dizzy, how can they want them to breastfeed?' They thought the frequency in which they gave the milk corresponded to the mother's nutrition status." Provider 3

When breastfeeding, the women were also responsible for night feeding, which disturbed their rest time at night and affected their body. However, when using formula, their nutritional intake was not sucked out by breastfeeding the baby. In a particular situation like at night, any other member of the family could give the artificial formula, which gave the mother more time to rest.

"He sucked me for six months, he used to breastfeed a lot, and you know little male, they suckle all night. It was God who showed me how to take care of him because you have to eat very well to breastfeed a baby..." Patient 13

"...Only the thing was that my baby used to suckle me too much at night, that used to make me [sou] dizzy, I don't know about others but me I used to feel dizzy, I thought that
a need more sleep as the explanation to that [soulay] dizziness.” Patient 4

Under the breastfeeding protocol, these patient participants had to breastfeed their infants exclusively for six months which meant that they “gave” their nutritional intake to the baby, and this often drained from their last ounce of energy from them. A participant explained this using a symbolic idea of “not having anything left,” which created an “empty brain,” a “vacuum” in their head. This image of “empty brain” reflects the idea that all is taken from them. With the protocol change, the loss of formula left them with empty hands, and the breastfeeding requirement drained them of their strength leaving them with an tèt vid “empty brain.” These excerpts illustrate that:

"Every time I breastfeed him (the baby) I used to have "soulay" [dizziness], I used to feel dizzy, I cannot even lift the child, I usually feel that emptiness of my brains, a vacuum in my head, I was unable to stand up alone. So breastfeeding used to gave me a "fèbles" [physical weakness] and anemia." Patient 7

And then, one Provider participant reported parallel thoughts about mother's exhaustion when breastfeeding as well:

"The patients reported dizziness while breastfeeding. We could see them losing weight. If they were breastfeeding and did not receive a kit, given their precarious economic status." Provider 3

4. Protective effect of formula package

The participants described the formula package as beneficial, having a protective effect on the mother, the child and the whole family. The formula package included tools for clean water preparation, formula, and occasionally included other materials for household
management. Patient participants reported having received educational sessions for proper use of these tools.

When patient participants spoke about formula use, they invoked it as more suited to their situation as HIV-infected mothers living under constant threats of malnutrition and disease. They presented artificial formula as an important way for them to mitigate physical challenges that breastfeeding posed to them. With formula, there was no need to increase their food intake, as their physical strength was preserved and they had more time to rest.

"That was a good experience for me. They gave me supports that protected me because receiving free formula for baby's nutrition preserved my physical strength." Patient 1

This correlates with a provider's report, as poignantly noted in this quote:

"With the artificial formula, we did not have that problem [the effects of breastfeeding on the mother’s health]. The mother only worried about caring for the baby without affecting her health. The situation became delicate when breastfeeding depletes all the mother's energy." Provider 2

The use of formula promoted healthy babies. Patient participants reported that when their children received formula, because of continuity in supply and the observance of basic hygienic rules, their infants were in good shape and had grown better compared to other breastfed babies of their neighbors. Patient participants brought light on the relationship between the mother's nutrition and the physical development of the breastfed baby. Patient participants underlined that with formula use in the context of food insecurity, the baby's well-being was not dependent on the mother's nutrition. Moreover, formula-fed infants had particular attributes. According to participants’ description, the baby receiving formula was not only healthy but also was weighty
and “fat,” which was regarded as a rewarding outcome, a source of happiness and pride. This physical advantage was a solace for mothers in the sea of unpleasant difficulties as explained in these quotes:

"People used to say: How comes that? We are breastfeeding our babies, and our babies are not doing well, their hairs are red, and we have to get them to the hospital. Then I did not take care of what they were saying because only God and myself know what kind of attention my baby was receiving. At this moment even though I had a concern, I was happy because I realized that the formula was a protection for my child." Patient 1

"The fact that my baby gets fat I was happy. Because once your baby is healthy, beautiful for you, so you are proud about that." Patient 12

As an echo of patient participant's discourse, provider participants explained in a very similar way that formula-fed babies were more likely to be in good shape physically.

"We did observe that when we gave the [formula] milk, the babies were always healthy. They were not underweight because their nutrition was not dependent on the mother's milk." Provider 3

"Not only what they used to receive helped the mothers, but it also helped the children keep up with their nutritional needs and helped them grow healthy. The children that participated in the program were healthy; they were always chubby and beautiful."

Provider 1

In contrast, one provider remarked that when the formula program ended, they no longer saw these fat babies.
"Strangely I don't see chubby kids anymore." Provider 3

The formula package has affected positively the health of the whole family in two ways. The formula package directly provided clean water and food, and indirectly liberated funds so that women could reinvest their money for long-term benefits. When patient participants received free food from the program, the nutritional needs of the whole family could be covered. Likewise, when receiving tools like a stockpot boiler to prepare clean water for the baby, that pot could be used to prepare water for the entire family. Consequently, clean water became available in the household, then all children and adults could benefit from it, which impacted their health altogether. Patient participants spoke about it this way:

"They gave feeding bottle, a pot and mosquitoes' net. These things were very helpful because I used to boil water in the pot for preparing clean water, boil my glass feeding bottles. These tools helped the whole family as well. I saw that as a protection for my kids. I would have been incapable of buying them, and then I found them here (in the program). I used the pot as a place to stock feeding bottle, I used boiled my drinking water in the pot and so could keep the water protected." Patient 3

"The 'accompaganteur' [Community Health Worker] told me to boil the water and prepare the formula with it...then everyone in the house could have treated water to drink." Patient 8

Furthermore, rather than spending their money on food, or tools for clean water preparation, money was preserved because these elements were essential components of the monthly formula package. Therefore, the mother's money could be reinvested in long-term benefits that could cover other needs in the family.
"When I did that [formula package], I found the advantage of having little chicks to sell, or if you have a child who has a problem you can make some soup for that child or yourself. All of that is because the money you did not spend to buy these things (included in formula package) you just received (from the program), and you could use the money that way." Patient 7

5. Reclaiming Normality

All HIV-infected mothers participating in this study had the experience of using formula feeding earlier, and they reported that being recommended to breastfeed their next infants allowed them to reclaim some level of normality. For those patient participants, being able to breastfeed was the reinstatement of traditional infant feeding which reinsures positive emotions and social normality. They underlined that breastfeeding promoted mother-child bonding, and indicated that breastfed children were more emotionally bound to their mothers, as one participant explains here:

"The one who breastfeeds were more bound to me; others (Children) who received formula were less attached to me. I could go out and spend the whole day when he found milk that's ok, but with the one (baby) who received breast milk I could not do that."

Patient 5

Patient participants presented their perception about people attitude toward them with the idea of “feeling normal.” Women felt more normal by being able to breastfeed their baby, and they regained their capacity to be a 'normal' mother like any other woman in their social world. Breastfeeding removed the line that had separated them from being like others. As one patient participant explains here:
"I felt that was free from worries, being like all mothers who breastfeed their child."

Patient 6

The theme of “normality” emerged as well when providers spoke about what HIV-infected mothers regain with the adoption of breastfeeding for HIV-exposed infants. They echoed clearly the patient participants’ views in these terms:

"It [breastfeeding] diminished the discrimination the mothers experienced in the community. They were able to do for their babies what all the moms could. They also got more help from their families, the other members of the community, because they are more integrated. It was very positive for the mothers." Provider 2

Patient participants reported a regain of “normality” when explaining that people's attitudes had changed toward them because they were able to breastfeed. Being able to breastfeed made women less at risk to open criticism and rejection in the community. Just as formula was a visible proof of their disease, breastfeeding was a testimony of their “normality.” Participants reported their positive feeling about social “normality,” as we see from the following report:

"Then we were happy about that. That will always make you happy because you would receive fewer critics." Patient 1

6. Feeling Powerless

Patient participants reported at first that “not having money” shaped their acceptance of the breastfeeding protocol. They explained that formula had been accessible to them only because the program freely provided it. After the formula was no longer provided, patient participants had no other choice than to switch to breastfeeding. Furthermore, patient participants
explained their compliance with the breastfeeding option as what they had to do, considering their condition as patient. In other words “what patients do,” is to rely on providers and accept the agency of the more knowledgeable. Patients reported the feeling of being powerless, as noted here:

"Then I said if the doctor and the nurse say so, we would do it because we could not afford the formula milk. I said I will do it, I could not buy formula milk because my first partner died, the one I am with now, the father of my 4th child, and he doesn’t have much. I said then I will do it [breastfeed], and all mothers agreed to do it as well."

Patient 7

"They did not give me support at all for it [breastfeeding]. I was okay to breastfeed, but if they did not tell me to breastfeed I would have been happier. Given that they did not give formula anymore, I had to breastfeed because I did not have money to buy it [formula]."

Patient 14

The patients tried to adhere to the provider's recommendations. However, sometimes patients experienced confusion when the providers' recommendations were different than their own knowledge as mothers. For instance, the providers would tell the patients that the WHO recommends that exclusive breastfeeding should last six months before introducing any other food. The mothers were aware that in Haiti many mothers breastfeed for longer than six months.

Intuitively, the patients knew that they should breastfeed for longer than six months, but to comply with their providers' recommendation, they stopped breastfeeding at six months. The mothers felt lost in the process, which created a stressful and tense situation. The mothers faced this stressful choice and were concerned that they were putting their infant at risk by stopping
breastfeeding at six months. They felt that this would negatively influence their baby's
development but in the end, they followed the doctors' orders. The patients felt powerless to
suggest to the providers that they wanted to breastfeed for longer.

"I thought that when you weaned the baby that could regress the baby development.
Better to not give breast milk at all. Some people breastfeed for 18 months, 2 years and
16 months, and then you only can breastfeed the baby for six months, that is nothing for
the baby, better not give it [breastfeeding] at all.... That breastfeed baby was gaining
weight and well developed then when I weaned him [the baby] he did not take weight
anymore." Patient 16

Patient participants felt powerless over the protocol while also feeling “responsible for
the baby's safety.” Patients participating in this study shed light on how they felt about the safety
of their baby. They accepted the responsibility of their infant's “well-being” as well as for any
unfortunate outcome. Therefore, they were living with the burden of the responsibility to protect
their children from HIV. Any failure to have HIV-free infant could be seen as their fault.
Therefore, they were willing to do whatever was needed to succeed.

“The baby is already born, you carried him (the baby) for nine months, so you cannot let
the child get sick and suffer. It for that reason you have to protect yourself in a way to be
healthy, and to protect the baby. I would even beg on the street to manage and keep him
(the baby) healthy.” Patient 1

"I did not receive any support for this baby, and I breastfeed him (the baby). I would have
been happier if they had told me not to. I only breastfeed him (the baby) because I did not
have money to buy artificial milk.” Patient 14
7. Erosion of patient-provider relationship

Provider participants reported that transitioning from one protocol to another brought two significant changes in the program: the withdrawal of formula package and the new information about the safety of breastfeeding for HIV-exposed infants. Consequently, HIV-infected mothers perceived the removal of formula package from the PMTCT program as a “loss of benefits.” Providers explained that when patients received the formula package on a regular basis, they had an additional reason to respect their appointment and maintained stronger contact with the program. This close contact with the program allowed enhancement of patients' adherence to medication and recommendations. One provider explained that the transition had reduced patient adherence in general, as noted in these quotes:

"That has influenced patient adherence in the clinic because they had appointments to take formula, which created more contact with the clinic. The fact that they were more in touch with the clinic sensitized them more on their medication..." Provider 5

"I believe breastfeeding diminished patient adherence to get to the clinic regularly because the patient was only getting transportation fare reimbursement, they only came if they could, versus when they were getting a few cans of milk with each visit, they made more of an effort to come to the clinic regularly. Now things are different, and patients neglect to come to the clinic and in turn neglect to take their medications." Provider 2

Likewise, new information about the safety of breast milk created confusion and doubt for patients. Before the recommendation to breastfeed, tremendous programmatic efforts had been made to encourage HIV-infected mothers to use formula for their infants and to keep them aware of the threat of HIV transmission through breast milk. Women received education sessions
individually or collectively, during pregnancy and after delivery. Community health workers helped to assess and supervised women on daily basis. When the protocol change happened, patients reported their skepticism about the new recommendations to breastfeed all HIV-exposed infants. This state of fear and doubt expressed by patient participants are presented in these quotes:

"I was afraid to breastfeed the baby." Patient 1

"What if my baby gets the virus, what would I do. I was always thinking of that, I was saying, 'Oh Jesus! I don't want to infect my baby'." Patient 12

Provider participants echoed that when they explained at the roll out of this breastfeeding protocol many patients expressed a state of confusion, repeatedly asking the same questions at each clinical encounter.

The following quotes explain:

"Some of my patients were always questioning the fact that two to three years before, we were telling them not to breastfeed, but now we were telling them otherwise. They did not understand." Provider 4

"In the beginning, we told patients that their babies could get sick from breast milk, that's why we gave artificial milk. Then we told them to resume breastfeeding. They got confused and did not like that. Some of them were always worried." Provider 3

Furthermore, on the provider's side doubt arose around the strict observance of exclusive breastfeeding. Provider participants explained that the confusion and the context of poverty would make HIV-infected mothers reluctant to make the sudden change, which fueled the
mothers' doubt and damaged for patient-provider relationship. One provider participant explained:

"For those who have a husband that can support them that [breastfeeding protocol] could work, but most of them who did not have that chance, they were not breastfeeding rigorously, it was not exclusive breastfeeding." Provider 2

"As Provider, I had doubts for many reasons... I thought that those mothers might neglect, they would not breastfeed the baby enough as recommended." Provider 6

8. Troublesome transition

Provider participants described this transition to breastfeeding as a difficult experience that had short-term and long-term consequences for the PMTCT program. Provider participants spoke about trouble and concerns during the rollout and beyond. Because of the precipitousness of the transition, some providers reported that it created a transitional category of mothers who were receiving formula during breastfeeding protocol. An ethical problem arose about this “transitional cohort” of mothers when other mothers who now had to breastfeed asked questions about why some women received formula and others did not. One provider explained:

"When we first started with it [breastfeeding protocol], we have begun that transition a little bit hasty. We had a cohort of patients using formula. Unfortunately, they have not done with formula, and their babies had been for months under the formula protocol, and we had to announce briefly “no more formula” for infants. That was a handicap for us because we needed a transitional phase." Provider 1
Providers expressed the fear about stopping formula when already started, because feeding an infant with formula and breast milk at the same time exposed the infant to greater risk of HIV transmission even though the nursing mother were receiving ART.

“... But some of them (the mothers) approached us and said they still needed the milk. Not only that was unethical, and we could not stop giving them the milk because that would create conditions for transmission. What could we do? Tell them to breastfeed? That would create problems because it would not be exclusive breastfeeding.” Provider 5

"That would produce infections in the gastrointestinal tract exposing the child to HIV. We had to make sure to get sufficient money to have enough milk to give to the patients until they finish. That was a rapid decision we took to eliminate transmission.” Provider 4

Providers also offered their concerns about the recommendation to stop formula for this “transitional cohort.” Therefore, they underlined the temporality of the transition and spoke of it as inherent in the process of change, which increased their workload during the protocol change toward breastfeeding use, as demonstrated by these following excerpts:

"That (the new breastfeeding protocol) made more work for us, we spoke a lot with them (the mothers) about that, tell them what to do to succeed. So the staff made more efforts with breastfeeding than formula to sensitize them (the mothers), as you know, people will not breastfeed without mixing with foods.” Provider 1

Provider participants reported that patients perceived that policy change as a loss of “seen” and “unseen” advantages, which impacted women's lives and their families. Provider participants explained that, consequently, this loss created space for more financial requests from
HIV-infected mothers in the program. The new policy had an impact on their bodies and their income-generating activities:

"Then, when we recommended women to breastfeed their infants, we had more financial requests from them. Because those mothers who are breastfeeding a child had less time for income-generating activities." Provider 5

5.2 Case Studies

Freda, Elna, and Angel (all names were changed) were participants in the ethnographic component of the formula-breastfeeding transition study. The excerpts of these women’s life stories depict their social suffering, first as women living in poor conditions and second as HIV-infected mother struggling for their health and their infant’s safety. This context provides an understanding of the women's economic burden and the structural violence fostered by gender-based inequalities established by social and historical realities.

Case 1: Angel

In the a slum of La Source, Mirebalais, Angel, a shy thirty year-old patient of the PMTCT program, raised her four children, two boy and two girls. She was born in Dufailly, a rural village next to Mirebalais, and was the second child of a family of four children (See appendix 5). She was six when she went to school for the first time. A benevolent teacher started this school in their local evangelical church. Unfortunately, Angel’s schooling ended after three years when the teacher went back to Port-au-Prince. After the teacher left, Angel's parents did not send her to another school, because they needed her to watch over her younger siblings while the adults were at work in the plantation. Until she was eighteen, her main activity was
working in the field plantation and selling crops with her parent at local markets in Dufailly and Mirebalais.

At nineteen, Angel became pregnant with a man whom her family introduced to her. This partner worked in Port-au-Prince when he asked for her hand in marriage. Everyone in her family accepted him because he was able to take care of her. Angel stayed at her mother's home while her partner worked for months in Port-au-Prince. Angel did not know her partner very well. He was an old friend of her family and was older than Angel. Right after Angel's first son was born, her partner became sick and died.

Angel did not have money to deliver her baby in the hospital in Mirebalais or even in the local health care center in Tomonde. Therefore, she had her baby at home with a traditional birth attendant whom her mother paid with food and services.

Angel's first son received breast milk mixed with other food like porridge and animal's milk for almost a year. At around 12 months old, the baby got sick so Angel took him to the hospital in Tomonde where both Angel and her son were tested for HIV. Both mother and child started medication for HIV the same day with an "akonpagnate" (accompanateur) who came to Angel's house to give her medication every day.

Angel met her current partner during one of her visits in the HIV clinic at Tomonde Health Center. Angel's current partner was an important source of support to her both economically and in caring for her child. She also received support from the PMTCT program. At her partner's demand she decided to enter into “plasaj,” which is a form of marriage with the same reciprocal responsibility seen in church marriage. This union is socially approved but is not approved by the Catholic Church (Herskovits, 1937, p. 106; Romain, 1955). Because of her
partner, Angel moved into a one-room house in La Source, Mirebalais, where this observation took place.

Angel's house was close to the second biggest public market of Mirebalais, and her house could be reached on foot within ten to fifteen minutes from Mirebalais hospital. The path from Mirebalais hospital to her house crosses the main bridge of the town called "La Theme." This path passed through the public common square, named Place Geffrard, and then crossed a second bridge named "La Source" until it came to the public market, also named "La Source." Next to the public market, a tight alley between the general vicinity of a flat slum gave access to Angel’s house. Angel's house was almost at the end of the alley. Angel's house was part of a "lakou," which is in Haiti a group of three to five houses sharing the same yard and surrounded by a border. This "lakou" encompassed five houses but more than five families lived there. In this "lakou" houses were very close to each other and some even shared walls, which could be different from a lakou in rural areas where houses were very distant from each other. This "lakou" was bordered by "kandelam" which is the Euphobia Lactae, a type of cactus that people use to protect their houses. At the entrance of the "lakou" there was a well-designed number 42 on the gate. This number did not really mean anything. When using coordinates for home location, people are less likely to use a number for addresses in poor settings in Haiti because there is no standard system of numbering homes. The lack of work on the field of household localization and cadastre makes people reluctant to use numbers in addresses.

Angel's home was a one-room house, sharing walls with other houses on its north and south sides. The walls were made of concrete block. The roof was made of wavy metallic sheets and the floor was concrete. There were no windows and the front door was in the same wavy metallic material but painted in light blue. The interior of the house was crowded with one bed
behind a curtain, a little square table surrounded by four iron chairs. On the table there was a handcraft bouquet, made with recycled empty plastic beverage bottles. One bottle served as a vase, and other bottles had been cut and rolled to make green stems and red flowers out of the plastic. This bouquet demonstrated the creativity of Haitian people, and in a larger sense served as a way to personalize the space in which they were living.

The family had access to tap water from the public fountain and this water was stocked in gallons and buckets under the table for direct consumption and food preparation. The house was not far from the river La Source, a tributary of the Artibonite River, where Angel washed her laundry. There was no kitchen in the house. Meals were prepared outside close to the main entrance behind a leaf of wavy metal. There was no shower in this "lakou." People showered at night or early morning at the back of the "lakou." This shower was next to a pit latrine constructed for the all five houses and could be used only by adults.

Angel had five children and two adults living under her roof, and she provided for them all. Angel's first child was nine, and had received breast milk for more than a year. At the time of the observation this nine-year-old boy could not go to school because he was developing AIDS-related signs such as severe weight lost and a persistent fever. That young boy was skinny and pale with reddish hair. Having reached elementary school, this nine-year-old boy could name many letters, easily count beyond 200, and could execute many basic calculations. Angel spoke about that with pride:

"He is very intelligent, he knew how to count very early even before some older children in the 'lakou'. Sometime he is teaching them how to do addition and other stuff you learn in school. He knew money-related exercises very well. He is very good at school but now
he is getting sick every day. Last time I sent him to school he could not walk at the pace [with] the others, so I am keeping him at home. And pray to the Lord to say a word for my son. I did not know the father was infected. I saw him going to the hospital at Cange Hospital but he [father] told me to not worry. I was young. I did not know.”

Angel's other children were two girls of seven and six years old, and a three-year-old boy. Angel had those children with her current partner and they were born during Angel's follow up in the PMTCT program. Those children were HIV-free, were in good health, and they went to school regularly because of the school subsidy from the psychosocial services of the HIV program. Angel received help with her children's school fees because her activity in the market even combined with her partner's revenue from land labor could not keep them from extreme poverty. Angel's two daughters were formula-fed and had their follow up in Cange hospital until what Angel called their *exeat*, which was the final clinical verdict indicating the final status of an HIV-exposed infant in the PMTCT program. Patients saw the *exeat* as the final verdict after two years of clinical visits and laboratory testing for their infants. The *exeat* comes programmatically after the second or the third or PCR test (Polymerase Chain Reaction test) or a rapid HIV test at the second year of age of an infant born from a HIV-infected mother. When these tests are negative, that means the HIV-exposed infant born sero-positive for HIV had reverted into seronegativity for HIV. The *exeat* moment is also an important moment for the health care provider because the performance of the PMTCT program is most of the time gauged by the number of HIV-exposed infants that have become sero-negative for HIV.

Angel received free formula from the PMTCT program for six months, as well as a stockpot boiler, clothes for her baby, feeding bottles, free food and monthly subsidy for transportation, which helped her to alleviate the effect of her poverty. Angel and her partner
rented a one room house in Dufailly after the second infant was born, but they did not stay for longer than a year because Angel faced criticism from people in the Dufailly neighborhood. People asked questions about everything this family had, about frequent visits of the *accompagnateur* (community health worker) and about Angel's infant feeding practices, which people associated with her HIV sero-positivity. Haitian people value community participation in life (Herskovits, 1937; Romain, 1955). This means people will support members of their community, but with this support comes an almost intrusive involvement in others’ lives. In Dufailly, Angel and her family experienced stigmatization from people in her community. Angel and her partner decided that area was not safe for them and their children.

"People in Dufailly were acting weird with us. Some of them were provoking me and would end up saying to me that I am HIV positive. Some of them will name your disease. We could not live like that way so we left the neighborhood."

Angel’s younger son received breast milk exclusively for five months. At the time of this observation Angel's son was three, healthy and HIV free. Angel did not receive anything from the PMTCT program for that child. Angel was happy to breastfeed that child, but she started experiencing some symptoms like headache and dizziness after four to five months of breastfeeding. Doctors in the clinic linked these symptoms to anemia because of her poor nutrition and prescribed to her some red pill vitamins (*ti grenn rouj* in Haitian Creole) to take every day. The doctor recommended that Angel sleep more and eat more vegetables, fruits and meats. Angel's life condition did not permit that. She could not get more sleep because she breastfed at her baby's need, which was more likely during the night, and Angel did not have enough money to complete her diet with more energy-rich foods. Angel mix-fed her younger son beginning when he was five months old, because she needed to get back to revenue-generating
activities like doing laundry for people in Mirebalais town or selling goods in marketplaces or in the streets of Mirebalais.

In Mirebalais there were at the time of the observation two public markets, one at the La Source areas next to Angel house and one in Mirebalais town next to the public square at the confluence of the La Tombe and Artibonite rivers and close to the Catholic Church. In both cases the market overflowed the space allocated to it and sellers congregated all over the street. The older market was next to the Catholic place. This market extended to the street and even over into the public place. The first part of this public market was made of wood, uncovered, dirty with mud and water used to clean produce that remained on the ground due to the defective sewage system. At this market, merchants sold goods and livestock from remote areas. The extended part of this market occupied the paved street leading to the market. As the old part of the market, this street was crowded with people and products obstructing the street and recalling the colorful aspect of a Haitian naive painting. In this part of the market, people sold modern products like imported food, imported clothes, and many kind of used items from the states. This street was situated between two lines of old warehouses and shops constructed before the Duvalier era which contained imported items for Haitian consumption.

Angel had gone for many years, when possible, to these public markets as a retailer to sell any product she could find. She usually walked from place to place and sold her merchandise, as a *machann promenen* in Creole (ambulatory merchant). At the beginning of school period in October, she sold notebooks, pen, pencils, and school bags. In December she managed to find things like imported items for decorating Christmas trees. During the period of harvest she sold anything that people consumed in this period like squash, avocado, and mangos. She sometimes sold umbrellas in April and *fleur des mere* (mother's flowers) in May because
during that time people often wore a little flower to honor their mothers. According to the custom this traditional flower could be red when honoring a living mother and black or white when the mother had passed away. Angel preferred selling the flowers for two reasons: first, they were not heavy to carry over her head and second the profit was over hundred percent for the seller. When this was impossible, like after the birth of her last son, she could use the monthly transportation fee provided by the PMTCT program to purchase *sachet dlo* (water packs). These water packs contained the equivalent of one cup of water in a transparent plastic pack. She could buy two-dozen packs for 100 gourds or 2 USD and she would sell them per unit in the street to passing people for a profit of 20 gourds or 0.4 USD.

At the time of the observation, the Mirebalais valley was undergoing a period of drought and Angel's partner decided to buy some boxes of imported saltine crackers from the Dominican Republic for Angel to sell in the Market place or in the street. The choice of imported saltine crackers was strategic for Angel:

> “It is not a bad activity because these 'Bonbon sel' (saltine crackers) are largely used everywhere in Haiti. People use them for younger infants and prepare a porridge named *panada* when milk is scarce. Children could have them in their lunch box at lunchtime in school. Even adults took that cookie when waiting for regular meal.”

A typical sale day would start in the street on her way to the market place because she kept her merchandise in a paid storage place in the market. Angel left after preparing and sending her children to school. Angel's partner left earlier in the morning for plantation work or anything else that Angel said “is none of her [Angel's] business,” what she called *chemin gason* (man's way). In the street Angel voiced the names of her merchandise in other to advertise her
product. Once in the market place she took her place next to a *comere* (a friend) a comrade selling a different product, who had known her for long time. They did not have a table or shelf where they could arrange their products; instead they simply put their product container on the ground next to them. Sometime, they kept their containers on their head and called out their products’ names or offered them to passing folks in the market.

Angel participated with other retailers in cooperative called *sabotaj* in which every day each member of that consortium contributed the same amount of money to a pot so they could loan that money to one other. Angel’s consortium encompassed eight members or *Komè* that are in the same type of activity. Everyday they put fifty gourds or 1 USD to lend a total of four hundred or 8 USD to a member and same thing the day after. After eight days the *sabotaj* could restart again. There is a more institutionalized form of *sabotaj* in the banking system or at the pawnbroker Angel explained that she had two reasons for the arrangement with her *Komè* or peers. First, poor people in Haiti have lost faith in formal institutions as well as in *Gran neg* or economically and socially powerful people. People have proverbial sayings such as “*Ravet pa janm gen rezon devan poul*” (roaches are never right when facing chicken), which means that in Haitian custom, when there are situations of disagreement, decisions favor the more powerful person. Second, Angel does not have the fees necessary to take part in a formal institutionalized *sabotaj*.

This consortium helped Angel to renew her stock of products and protect her capital from being drained by economic needs from her household, As long as she could sell enough product, she could cover the *sabotaj* fee. After 1:00 pm Angel left the market place and made some rounds at the Mirebalais public square, then crossed the main bridge on La Theme River for the Mirebalais Hospital and headed back to her home. On this trajectory from the market place to the
Mirebalais hospital and back to her home, Angel continuously called her product's name with the bucket of crackers on her head. When Angel returned to her home she found her children waiting for her to cook the evening meal, which was the most consistent meal of the day.

"When you know you have left children at home, you will do your best to sell something. After paying your sabotaj you have to buy food for preparing the meal at home. This is you duty as mother, because hungry is not pleasant. Their father will bring something if he found but me, I have to. I sent them with only a piece of bread and some coffee in their stomach. Those who did not go to school stayed at home and at my neighbor, sometime they can receive something from them too. When I have more possibility I could leave some food for them at the fireplace to eat after class."

Case 2: Elna

Elna was thirty-three when the researcher met her at her home in Dubuisson, a town on the National Road 11, between Saut d'Eau and Mirebalais. She was living in poor conditions. Elna struggled every day for the most basic elements of survival for herself and her four children (See appendix 4). She grew up in Gascogne, a subsection of Mirebalais. She has been in school for only four years and also received a two-month training to be a florist who could work with artificial flowers. At the age of sixteen, she crossed the border to the Dominican Republic (DR) with one of her Aunts, who remained in the DR until she died. Elna spent three years in the DR and worked in a sugar cane plantation field.

When she returned to Haiti at the age of nineteen, she worked in her parent's field plantation and sold crops in the Mirebalais communal market. She later eloped with her first partner. Elna's first partner worked seasonally in the DR, crossing the border twice a year. They
lived in Gascogne and had two daughters who were at the time of this observation ten and eight years of age respectively. Elna's first partner contracted tuberculosis. After many months of hospitalization, he returned home, but his illness continued. He died at home during a course of treatment with an "Ougan" (traditional healer).

After her first partner died, Elna met her current partner, who helped her finish the house she stated building with her first partner. Elna had a son and another girl with this second partner. Elna's son is five years old and Elna's youngest daughter is thirteen months of age. These three children were born while Elna was in the PMTCT program and are HIV free. The family lives in a one-room house divided by a curtain into two spaces. The house walls are roughly constructed of stones covered with a cement-like mud and supported by eight wooden pillars included in the walls. The floor is earth and the roof is made of corrugated metal sheets supported by wooden sticks. There is a small window in one of the walls. The main entrance is a two part door in the front made of wood, in which was a hand drawing of a "JHS" symbol inside of a white chalky star. She probably paid for that drawing, as it is very common in Haiti for people who know masonic or kabalistic symbols to be paid to draw them on doors. People believe these drawings can protect against curses or bad spirits. Drawings on the ground or on walls are part of the voodoo tradition in Haiti to welcome or to invoke spirits. Elna explained the rationale for the drawing on the door:

"I have a friend of my father, a very good friend of my family, after my first partner died, they tried to take my two daughters too. You know when haters are after you they already put you on your knees. They will not stop until they're finish with you. They wanted my end because of that little piece of land my first partner and I bought. When my daughters
started being sick every day, I went to my father and he sent someone to block their attacks [with the drawing on the door]."

The house is right in the middle of a square yard bordered by little bushes, flowers and rampant plants. Elna's house has a latrine newly constructed by a community project behind the house. There is no access to electricity, no running water, and no bathroom. The family bathes outside of the house semi-nude. Most likely, the whole family goes to the river for bathing and laundry, or sometimes the children seek water in gallons or buckets at the Catholic Church at the opposite side of the National Road 11. Elna's house is located five hundred meters away from the National Road 11. There is no extra space for growing crops, only the house and a front yard, but many other garden surround her house. She did not have close contact with her neighbors, even though one of her neighbors was also in the PMTCT program at Mirebalais Hospital. For her, the only one in her community she could trust is her "akompagnate," a community worker, who at the time of the interview had brought Elna's medication every night for more than three years.

"I am living now. I am not open [about her HIV status] with others, because you never really know what people are capable of. If I have to go to 'Undobaye' for some work, I ask my little sister to come watch over my kids, while I am away."

Tap water is sold at a fountain in front the Catholic Church, on the National Road 11. In this fountain, each gallon cost about five cents, but during dry seasons there was no water in this fountain. Elna and her family needed to go farther to fetch water, or she took water from the river and treated (boiled) that water to drink. Elna received products for water treatment from the PMTCT program. The family used five to seven gallons a day for cooking and drinking.
Elna's family tree shows her family’s difficulties (See appendix 4). Elna's father died five years ago from prostate cancer in Mirebalais hospital. Elna's father was the last child in a family of four, and only one of his brothers was still alive at the time of this observation. Elna's father had twenty-three children total and lost six of them at different ages. Elna's father had ten children with Elna's mother, who was not his principal wife. Unfortunately, they lost two children out of those ten, where Elna was the fourth out of five girls. Elna father had ten more children with his principal wife: three boys and seven girls, but he lost two of them. Elna's father had three children with his third wife but they lost two of them.

At the time of observation, Elna had contact only with her mother, one little sister and one little brother. After her second child Elna was sick and was hospitalized in Mirebalais hospital, then sent to the Cange hospital for better care. Since then, Elna experienced rejection from some members of her big family, because they learned of her HIV status. Therefore, Elna's reaction to their attitude was to either ignore them or to avoid contact with them. Elna described feeling criticism from her family:

"Those who know (about her HIV status) rejected me and my children. For me I don't want to hear from them, I don't have time for their criticism. Even a piece of land left by my father, I did not have access to as heir. When I bought that piece of land, people in my family became harsher on me. They don't want me to survive."

Every morning Elna woke up before 6:00am. or earlier, what in Creole is called "douvan jou," or before the day, to prepare coffee for breakfast and lunch. She prepared the children for school, and went to her work in the plantation. In her way to the field she dropped her thirteen month-old daughter to her mom's house in Gascogne or to her little sister's house in Mirebalais
town, depending on where she was working. Elna and her partner were seasonal field workers, meaning most often they sold their labor to landowners. Sometimes when work was scarce, they could cross the border to work on Dominican plantations for up to three months. They had their own little plantation that she inherited from her mother. They sometime worked on their own plantation. Elna and her husband were part of a traditional form of agricultural mutual cooperative named "konbit," which is derived back from the free labor imposed on peasants by the first Haitian constitutional law in 1801 and reinstituted more recently as "la corvee" during the American military occupation. In this mutual agreement, everyone in the group works on each member's plantation on a designated day. Therefore, Elna and her partner did not have to pay for the labor.

At the time of this observation, Elna was harvesting "militon" (Chayote squash) on her mother's land. Elna had planned to receive a "konbit" that would help her to harvest in one day. She did not have to pay the workers because it was her turn to have help in the fields, unless she wanted extra help for which she would have to pay extra workers who were selling "jounen" (day labor). Typically, a work day in the plantation is divided into two halves: the first half occurs before the sun reaches the zenith, which corresponds to twelve noon, and the second half starts after two pm until sunset. The konbit started at sunlight, most of the work had to be done during the first half when the workers were fresh. The sun and the heat could reduce people's speed. During the work, people interacted with each other: they exchanged tools, shared water and shared hats. Jokes, commentaries, songs and stories filled the empty spaces between the activities workers completed. A konbit has a flat organizational structure where everyone is equal. Specifically, gender does not matter in militon harvest. The rampant stem of the militon plant either climbed around a stick or lay on the ground, and could be easily reached. The militon
leaf has a width of an adult hand and the fruit is about the size of a fist. During the breaks people drank, ate and talked together. Elna announced the time to resume the activity using the position of the projected shadow of a tree and asked for the exact time as to prove a point in a discussion. During the second half, most of the work was already done and they spent much of that period transporting the crop to the house of Elna's mother. The crops were carried by mules and humans from the plantation field to her mother's house. Elna knew all those people well, as they were living mostly at Gascogne and had come together to find a way to be productive in the context of scarcity. Their relationship to each other was based on confidence, integrity and camaraderie. However, if one person became sick and was unable to fulfill their share of the work in the konbit, they risked losing their membership in the group. Any situation that prevented participation of an individual would impact this community.

"When you take the 'jounen,' it is good for you because you needed it for work out the land and to produce something to sell in the market place. You have to get the money you invested to buy the seeds and fertilizer. Sometime it could be a loan from another in your community. You have to work you too; you cannot rely totally on the program. You have children, you have school and food to cover. Now imagine I have to work because I have already taken that 'jounen' I have to work nine days for those members in their plantation too."

Elna and her partner were not making very much money. Despite their work in the plantation field they were still under the two-dollars-a-day poverty threshold. According to her description about her expenses, more than 60% of her household annual revenue was spent on food and on children's school fees. Elna had some "Creole chicken" as livestock that she grew in her yard, and she underlined for me that these chicks were for her to sell on the market place.
Creole chicken is more valuable in the market place than imported chicken, therefore she sells them to have some cash that she use to buy more things for the household like clothes, cooking oil, kerosene for her lamp, even imported chicken legs. Elna hardly managed to put food on the table twice a day. Their breakfast was more likely bread and coffee before their second and only other meal of the day, which could happen between 3:00pm and 5:00m.

Elna's first child was born at home and was breastfed exclusively only for two months more or less when she was in the early "tinouris," post-delivery time. During that tinouris, she went a traditional process during which she had to stay in the house, avoiding contact with the wind, receiving the traditional hot intimate bath and having her belly tightly bound to put her internal organs back in place and to make her body strong again. After that time the baby was mixed-fed with cow's milk and porridge. She received help from her partner at that time and the baby developed well without any problems.

Elna became pregnant with her second child at the same period her partner became sick and then he was hospitalized for many months. She could not work at the time because she was taking care of her partner. Elna learned about her HIV status at this time and was enrolled in the PMTCT program. Her husband died before the baby was born. For that second child, Elna received free formula and tools for clean water preparation. The baby received exclusively formula for nine months, after which the child ate the same meals as the rest of the family. Elna received free food and financial support from the program at that time. That baby never got sick and developed well.

"They gave me formula for the baby every 15 days during nine months. I received a kit of stuffs like feeding bottles, bottle cleaner, detergent, stockpot, and clothes for the baby."

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Every month we had a meeting with the program staff for education and orientation. After each monthly meeting you received your monthly food support package and some money with which you can buy meat, and vegetable to eat. My whole family benefited from these things, the food, even the pot, the clean water served everyone. They usually gave these things to every woman in the program after giving birth to a child. I used to buy bleach, fuel for my lamp to light my home. It was truly important. That helped me, so I found means to buy soap. I washed not only baby's clothes but also everyone's clothes in the family."

Elna has two more children with her current partner, a little boy and a little girl. Elna's boy received formula exclusively for six months, and then many other foods were introduced in his diet. Elna preferred the use of formula, but her partner did not because Elna had not disclosed her status to her partner. She described how she explained her feeding choice to her partner:

"I told him that I had difficulties to wean my first baby when I want to resume to my work. When I weaned my first daughter, my baby's development regressed a lot. So since my second daughter doctors recommended me to not breastfeed at all. I told him to not worry about that my two first daughters were doing well. I told him our son will do great as well. He understands that I have to work."

For her youngest child, Elna did not receive formula. She only breastfed that baby for two months. She was afraid for this baby. She believed that the baby could be infected with HIV if she breastfed even though she was taking ART every day. Therefore she bought her own formula and some cow's milk for that baby. That decision was hard for her because at that time the PMTCT program did not provide women with nutrition assistance anymore. She managed
her feeding choice until the baby was five months old, and then she introduced other soft foods like *panada*. Elna's sister and her older daughter mostly raised this child, since Elna and her partner had to work more. Her partner preferred that Elna breastfeed the child, but his argument was easily overcome by the economic loss of Elna staying at home.

**Case 3: Freda**

Freda was born in L’Estere, a communal village built both sides of the Artibonite River, in the middle of the Artibonite department between Gonaive and St-Marc. She was the second child of five in her family (See appendix 6). Her parents died 10 years earlier than the time of observation, each from a similar disease. Freda went to school for fewer than six years so she can write her name but she can barely read. She spent all her life in L'Estere, working in the field plantations and selling in the local market with her mother. When the researcher met Freda, she was 28 years old and had three children: two girls aged nine and six, and a boy, three. The nine year old was deaf. Freda participated in the PMTCT program during her pregnancies, and her children were HIV free.

Her house has two rooms eight to ten square meters each, one containing a table and a bed raised on concrete blocks in other to have extra space under the bed for people to sleep at night. The other room served as living room but still had a bed behind a curtain. The walls were made of pieces of short rope tangled together and covered with a mixture of yellow clay and mud. The walls had holes in some parts, allowing an outsider to look into the home. The roof was made of dry leaves called "*paille*" in Creole. The ceiling was built to have an extra space to stock things like dry food and tools. There was no floor. The ground was earthly, and I imagined that it was difficult to clean it adequately, which might that explain the scars of cutaneous lesions.
visible on the skin of Freda and her family. The house was less than one mile from the National Road 1, but there was still no access to electricity or running water. The drinking water came from the public fountain located not farther than 100 meters from the house. The family gathered water in five gallon plastic buckets bought from the marketplace. These buckets were labeled indicating they had previously held detergent or paint. Almost everyone in this household bathed and washed their laundry in the L'Estere River, a branch of the longest river in Hispaniola, the Artibonite River.

The house stood almost in the middle of a muddy yard, as is the traditional fashion in rural Haiti. The latrine in the back yard accommodated only adults because it was an uncovered hole. The children's feces were brought to this latrine using shovels. The muddy front yard gives space to a fire corner in which stands three rocks, each approximately the size of a basketball, darkened by wood fire. The three rocks were spaced each from another by 30 to 50 centimeters, at angles of an imaginary equilateral triangle. Next to the fire corner stood a little wooden table and both were roofed by dry leaves and short ropes. This corner space was described as a kitchen.

The kitchen included a limited amount of utensils for cooking and some little plastic plates. The yard was surrounded by stick bushes that not only protect the inside yard from animal intrusion but also served as a place to dry clothes after laundry with sunlight. The presence of that bush border also defined a space of privacy and peacefulness. Freda said:

"When I am here behind the bush, I am in my yard, my own one, I am in peace with my family even without food, suckle grain of salt and we sleep. When I have money, we can
eat twice a day, but most of the time I have means to prepare something to eat only once."

As a child, Freda herself was breastfed for two years and then she shared the family's food and received cow's milk. The cow's milk was quite affordable in the Artibonite valley at that time. Even if a household did not have a cow, they could buy some cow's milk on the daily basis in the local market or from a neighbor. Freda received fruits and vegetables very early while she was breastfed.

Freda's method of feeding for her oldest girls differed from how she was fed. Freda's two girls received formula exclusively for nine months and then solid food was introduced in their diet. They never received breast milk at all. Only the older daughter had received the traditional "lock," an traditional porridge for her first infant meal. This tradition has been practiced in Haiti for a long time (and was also practiced in pre-industrial Europe when people did not feel the colostrum benefitted the child) (Fildes, 1986).

"When my daughters were born I received formula for them for 9 months. They gave me stockpot boiler, a big one. They taught me during each women's meeting in the health center. The nurse did many illustrations and role-plays. Every month after the women's meeting, I used to receive one hundred Haitian dollars [US $20 at that time] for detergent like soap and fuel or whatever I wanted to do. They gave a stockpot with feeding bottles and other things to clean them. I received some cloths too for my babies. After nine months, I received a monthly package of milk, food, oil, gas, [and many other items]. That was good. Sometime I could need help to get home with everything at once. I had that every month until the baby reached 2 years of age. It was because of that my
neighbors were saying that I was sick - you know what people are capable of. They sometimes said this was AIDS food in order to hit you. That did not bother me because things were working out pretty good for me. I had food regularly, my daughters were healthy, my partner was supporting me too, and was selling rice at the local market."

Before her son was born her situation was difficult because the two girls' father died five years ago. Freda had to manage everything by herself:

"He was not from the village, so when he died I had to manage everything for the funeral. His family came only to pay respect, only. After all these expenses, I had to take care of my children and myself. I was not doing anything big except buying fresh rice from little farmers, treat the rice myself and sell that refined rice on the marketplace. This is what my mother and I used to do together when she was alive. He was in the public transportation between L'Estere, Gonaive and Saint-Marc. He was helping me greatly to take care of the house. But when he died, he drained a part of me. Food every day, and clothes, hum! Everything is on me."

When her first partner died, Freda needed someone to take care of her and her children. She met a man who worked as a motorcycle-taxi driver. He moved in with her and together they had a son. Her partner also brought his young son from a previous relationship into the house. The situation did not get any better for her. When she got pregnant with her little boy, she went to the program where she learned she was pregnant, and the nurse announced to her that she would have to breastfeed this baby, though she had followed the formula feeding protocol for her two previous infants. After delivery at the hospital, Freda did not receive any assistance from the program beyond the transportation fee. Before heading back home she received an intensive
education session on breastfeeding. Freda breastfed her son exclusively for four months and then began mixed feedings for two months. After these six months, Freda went back to the program asking for formula. The nurse told her to stop breastfeeding because the baby now could take other food. Breastfeeding was hard for her physically and breastfeeding was an economic strain on her family because Freda was not able to work outside the home to contribute income.

"When I was breastfeeding that baby that made me feel physically weak, but I kept going. I could pass three days without eating anything and I breastfed no matter what! The baby never asks to be there, you have to feed him. It is my duty to protect the baby as my grandmother did for my mom, as my mother did for me. My grandmother used to say when she had my mother my grandfather had already died, she walk from site to site to find a way to feed my mother. She started helping and working for free so she could receive some food from people for her and the child survival. In the way I have to do whatever it takes to feed my baby. My partner did not have any work. I could not go out to sell rice. I could not because of the newborn. When I went to the program and the nurse told me to stop with breastfeeding, I felt it like a relief. When you are woman it is expected from you to bring the food on the table every day."

Freda was the second child in a family of five children. Her elder sister lived in Saint-Marc with a husband and three children. This sister was the only one in her family who was married. Freda's younger sister was living in the house with Freda too. This sister was 23, and at the time of this observation session she was eight months pregnant. Besides being pregnant she had a two year old boy who was paraplegic. The father of this paraplegic boy had abandoned Freda’s sister and she had not heard from him for a long time. Freda's sister found another man to take care of them both.
Freda told me that her nephew had never walked because of some mystical forces in her family, some "Loa," which for some Haitians are the spirits who protect the family. It is believed that sometime the "Loa" could ask to be honored in return for the protection they have provided to the family. This family might have believed that they did not properly honor these "Loa" at some point, and as a result the spirits took the child's ability to walk.

Freda's two little brothers were living in Gonaives with an aunt because Freda could not take care of them when her parents died ten years ago. One was 20 and he was not doing anything for a living other than to help in the field plantations of the aunt. That aunt was the only one of Freda’s mother's siblings who was still alive. Freda did not have a good relationship with that aunt. Freda's other brother was 13 and he was going to school when it was possible. The "when it was possible" made me think about political instability and natural disasters that could prevent children from going to school, but in this case her brother lacked the funding required to go to school full-time.

"My auntie doesn't have much but when she took the guys [Freda's brothers] in her house it was about time before they craved of hunger or move for errant life in Port-au-Prince."

Freda's parents were poor peasants without land who worked for a landowner most of the time. She did not know their ages or birthdays but she affirmed that they were born way before the Duvalier era. As with many peasants since the independence of the country, they were illiterate and spent all their life in the countryside without access to electricity, clean water, or basic sanitation.

Freda's grandmother was still alive, and was 90 years old. Freda and her grandmother had a close relationship. Freda listened to her and took care of her. I did not see her, because she was
immobile and sat on one side of the yard away from me and the other family members during my visit. Freda told me that her grandmother used to be a hard worker in the rice fields in L'Estere. Those women were essential in the rice fields. After male laborers tilled the land, those women were responsible first for the seedling preparation and then they would put the seed in the ground. They helped during harvest, and they dried and cleaned the crops on the concrete floor. Finally those women went to the market place to sell the product.

"I am the only one in the family who cares about ‘granmè’ (the grandmother). She had been a widow before Duvalier’s era. Her husband died during a land conflict [with other settlers], what we call in Creole 'Procès tè.'"

Freda’s grandmother had four children, two boys and two girls. Only the elder was still alive at the time of the observation. Freda's uncle and second aunt died before her mother and father. Her second aunt died during delivery eighteen years ago. That child was a girl and was Freda's mother responsibility. Then after Freda's parents’ death, that little cousin was Freda's responsibility. Freda's little cousin was 18 years old. She went to school for less than six years and was like a fourth child for Freda.

"I have to protect her from everything. She is weak."

They were bound together. They shared everything including clothes, shoes, hair weaves, and their beauty products. She helped Freda with children at home and with buying or selling rice in the local market. Freda's cousin did not know her father until she was 13 years of age. When Freda's parents died, the house was in poor condition. To relieve pressure on Freda, her cousin successfully launched a search for her father. Her cousin recounted this search:
"I found my father myself. I was 13 at this time I could go to school so I contacted him. He told me to come live his house with him, his wife, and his other children. I accepted, but they started to mistreat me. My father did not pay the school [fees] for me. Then, when I got pregnant he threw me out like garbage. He does not want to hear about me, neither do I [want to hear about him]."

Freda's cousin took care of her eight month old son without any support from the son's father. This little boy was severely malnourished and dehydrated. This little boy did not receive breast milk adequately because the mother thought her milk was insufficient. She gave to him some "panada" (a flour and oil mixture, much like porridge, often used to feed babies) and he started having diarrhea. They were thinking of giving the baby to an orphanage at L'Estere. Freda’s cousin explained to me her attempt to seek adequate care for her son.

"I went to the nutrition program my son once. They gave me peanut butter and generic formula milk for him. He started to improve, but when these supplements came to an end I did not have money to get back to the hospital. I did not have money to eat. Every day I am waiting for my cousin to share her food with me. I gave him some ‘panada,’ and he is having diarrhea since [then] every day. I already send a message to his father to come and take his son. He never responds. I will give the baby to the orphanage at L'Estere. I cannot take care of him. That should be better for him."

Freda's relationship with other people was difficult to describe. At her house she was in charge of everything. Her partner usually spent the day out. He only came home for sleeping. Freda took care of everything in the house and her partner did not know much about her. She did not disclose her HIV status to him. Freda thought that he should have some suspicions about her
status because people in the neighborhood always criticized her. At public events like funerals, Freda was silent and talked to very few people. She was afraid of having a “hysteria” crisis (similar to a seizure, this condition happens to people at funerals in Haiti) in public, which happened to her the last time she went to a funeral.

6. Discussion

This discussion section frames the above results within a processual approach that traces the experiences and implications of the PMTCT shift across time. One of the local health providers in this study explained that the shift in PMTCT feeding guidelines could be thought of as a set of “gains” and “losses.” This concept of “gain and loss” proved instrumental in framing our results across the PMTCT continuum. This discussion opens with an exploration of the concept of “gain and loss.” We then go on to examine how women’s experiences of “gains” and “losses” were variously shaped by the prevailing forces of paternalism, medicalization, and contemporary global health.

Gain and loss

During their time in the PMTCT program, HIV-infected mothers described the ways in which the program shift affected their health and the wellbeing of their infants and families. The concept of “gain and loss” illustrates the host of changes that women experienced in shifting from formula feeding to exclusive breastfeeding. By pairing the concept of “gains” with the concept of “losses,” we communicate the way in which the lived experience of the PMTCT shift created significant changes with real effects that were often simultaneously experienced by women as detrimental and beneficial. These “gains and losses” are manifest in terms of (1) women’s emotional experiences, (2) wellness of the self and others, (3) economic implications, and (4) fulfillment of social expectations.
1) Emotional experiences

Emotional experiences refer to the way each infant feeding policy affected the relationship within the mother-infant pair. Mother and child are emotionally and psychologically interconnected through a physiologic interdependency. Patient participants described the losses they experienced with formula feeding. First, when artificial formula policy was implemented, those women revealed that they lost an important connection with their child. Second, for those mothers, not been able to breastfeed represented an abnormality, a loss of their inner right as a woman. This finding is not specific to HIV-infected mothers in rural Haiti. Anthropological literature echoes the emotional implications for women who are not able to breastfeed with the same idea of lost normality. A study in Brazil reported the same concept of loss among HIV-infected women. Those women in Brazil expressed the idea that breastfeeding was an important responsibility of mothers and they "did not feel as women" when they were not able to breastfeed (MacCarthy, Rasanathan, Nunn, & Dourado, 2013).

In contrast, patient participants revealed that when the policy changed to require breastfeeding, the mothers gained stronger psychological connection with the breastfed child. Mothers in our study expressed that breastfeeding permitted them to reestablish the mother-child bond. Stuart-Macadam and Cesar reported on breastfeeding benefits for mothers and children, and found the same emotional implications: that the impact of breastfeeding extends beyond simply providing nutrition (Cesar et al., 2016; Dettwyler & Stuart-Macadam, 1995, pp. 8-9). The results of our study clearly demonstrate that adopting breastfeeding for HIV-exposed infants gave emotional benefits that also extended beyond simply providing breastmilk for the child.
Furthermore, breastfeeding offered to patient participants an opportunity to reclaim (to gain) a certain level of "normality" that had been lost when they were required to feed their babies only with formula.

2) Implications for the wellness of self and family

Analysis of the gain and loss in interviews and within the ethnographic observations of the women, highlights numerous implications for the wellness of the mother-infant pair and their family.

Another theme that emerges from the data is the mothers’ "physical distress." Overwhelmingly, patient participants referred to this theme when they talked about direct implications of both policies on their physical body. Physical distress was constantly present in their discussions about experiences with both breastfeeding and formula feeding.

HIV-infected mothers participating in this study reported experiencing physical difficulties during breastfeeding. They indicated that breastfeeding was physically demanding and caused additional stress for their frail bodies. They unveiled that breastfeeding could cause one participant described as a "vacuum in the woman's head" in the context of HIV and poverty. Patient participants expressed the idea of been constrained to perform an activity that drained them of their last ounces of physical energy. This represents the embodied experience of those women with the shift from formula feeding to breastfeeding. Women in this study reminded us that while breastfeeding might be natural, it was not effortless for them. The theme of physical difficulties resonates with findings in the anthropological literature. Jelliffe and Jelliffe's study about breast milk production and caloric need for nursing women described "maternal depletion syndrome," which is equivalent to physical distress presented in this study (1978). Scheper-
Hughes’ study reported that women in Alto, Brazil talked about breastfeeding as a cause of physical distress and even as a cause of disease like tuberculosis (Schepher-Hugues, 1993, p. 326).

In our study, women indicated that breastfeeding depleted their energy in the context of food insecurity. Under the formula policy, women did not have to experience the detrimental effect of breastfeeding on their body. Therefore women talked about how formula alleviated the physical distress that they associated with breastfeeding.

The ethnographic narratives also demonstrate the protective effect of the formula package on the health of these women’s families. Access to clean water provided protection to the whole family against water born diseases. At the time of the cholera outbreak, anyone who used water from near the Artibonite River or its related rivers risked exposure to cholera. Although Freda, Elna and Angel all lived close to the Artibonite River, their narratives did not include any mention of cholera in their families, and follow up questions confirmed that their families had not been affected by cholera. One explanation for the lack of cholera could be the free tools and education on how to prepare water for formula that all three of these women received. In essence, the formula package might have offered these families protection against the largest cholera outbreak of modern times (Farmer, 2011).

In context of poverty in Haiti, where women have a fixed role in the family structure (Maternowska, 2006), the narratives demonstrated that these women assumed the responsibility to keep their families healthy. Our study findings indicate that women bear responsibility for prevention of disease and home treatment of any disease in their family. Neptune-Anlage explored women’s roles in Haiti and also found that women assumed this role. Neptune-Anlage
also found that young girls received traditional knowledge about natural remedies in order to prepare for the time when they have families of their own (1986).

3) Economic implications

Patients and providers participating in this study revealed the idea of competing benefits and drawbacks of both policies in relation to the women’s economic activities outside the home. Participants distinctly stated that formula offered positive economic implications, whereas breastfeeding had negative economic implications. Again, HIV-infected mothers dealt with this “gain and loss” concept in their everyday life. Patient participants presented drawbacks such as the conflict of breastfeeding with income-generating activities and the need to increase their food intake when breastfeeding a child. Patient participants presented the benefits of formula as a liberating symbol (a “gain”) that allowed them to return to income-generating activities.

Patient participants indicated that breastfeeding kept them from being able to go out to the marketplace for income-generating activities. During the six months of exclusive breastfeeding, they felt tied to the house by their feeding tasks. Productive (income-generating) and reproductive (childcare, feeding) activities of those women conflicted during their six month period of breastfeeding. HIV-infected women perceived that breastfeeding prevented them from participating in the mainstream daily activities to generate income and be less dependent on men, and that this intensified the subordination of women to men. The life stories of those women show that women were expected to provide completely or partially for the family, and being tied to the house meant they relied more on men for income. Such implications are not only specific to women participating in this study. Even in wealthy countries like the United States, nursing mothers talk about how breastfeeding can worsen existing gender inequality. Specifically, in
Timori’s anthropological study on nighttime feeding with nursing women in the US, women talked about how nighttime feeding tasks interrupted their ability to be productive workers and therefore bolstered gender inequality within the capitalist system (Tomori, 2015, p. 38).

The women in this study experienced physical distress when breastfeeding, and they expressed the need to increase their food intake during the months that they breastfed their child. For the mothers, increasing their food intake meant they needed more money to buy that additional food, which depleted their financial assets. Some of the mothers revealed that during the time they breastfed their child, the need to eat more reduced their financial assets, which caused them to contract more debts or to beg within their social network. Patient participants felt trapped in a vicious cycle where they could not resume income-generating activities and at the same time they were forced to increase their food intake in the context of poverty, HIV/AIDS and food insecurity. Results of this study shed light on a phenomenon experienced by participants that reduced women to the status of invalid, consumer, and dependent. Maternowska presents data from Cite Soleil in Port-au-Prince Haiti that concurs with findings in this study that for many impoverished women, purchasing food is the most consuming issue in their life (Maternowska, 2006, p. 61).

On the other hand, results of this study demonstrate HIV-infected women's perception of formula as a gain in this context because they described formula use as a liberating factor. Formula allowed them to feed their children and also enabled them to resume productive activities. Resuming productive activities represented for them a way to access financial autonomy. Other studies have shown that low-income women demonstrate a preference for artificial formula. Scheper-Hughes presents a shift in feeding preference as corollary to social and economic hardship of the population of women in Alto Brazil (Scheper-Hughes, 1993, p.
Their findings indicate that poor women preferred to feed their babies with formula so they could return to income-generating activities more quickly (Scheper-Hughes, 1993, p.317). In line with our study results, Van Esterick explains that the liberal argument from the second wave of feminists in the sixties bolstered the use of formula feeding because breastfeeding, in the liberal perspective, presented more restrictions to the women who wanted to participate in the work force, whereas formula appeared to be the technological solution that could liberate those women (Van Esterick, 1989, p.95).

4) Social implications

The “gain and loss” concept also occurs in the form of social implications for the patient participants in this study. In Haiti, there is particular set of social expectations around breastfeeding. The social implications for breastfeeding women correspond to some expectations of their familial and social roles. The study results showed that women are expected to breastfeed their children in this particular setting. In the anthropological literature, some studies have showed that breastfeeding women experienced disadvantages in the work place. This has been demonstrated in Scheper-Hughes’ study in Brazil, where women experienced rejection in their workplace because of breastfeeding. In the same study, women reporting having experienced change in interpersonal relationships such as how they are treated by their husband or partner (Scheper-Hughes, 1993, p.325).

The “gain and loss” concept was at play when HIV-infected women were using formula feeding. Since the women were expected to to breastfeed their baby, formula feeding in rural Haiti was often associated with a health issue for the mother. Some participants explained that using formula was a visible proof of their HIV sero-positivity for people in their community.
Consequently, HIV-infected mothers and their children experienced social stigma such as being criticized and rejected by others because of formula use. This situation represented a loss within the broader “gain and loss” concept.

Freda experienced criticism from her neighbors and she evoked the idea of finding peace behind her the bushes that surrounded her property though her family faced dire economic need. Elna had been rejected by her whole family except her mother and one sister. Thought she had a large family, she could not count on them and could not benefit from her father’s legacy. Angel and her current partner had left their previous location because of people’s criticism which created a harmful environment for her children. The women’s suffering was related to the rejection and criticism they experienced because of their HIV status or the formula use itself. In the course of their stories these women indicated that their top priority was to keep their family safe. Elna, Angel and Freda fought every day in the street, in the market place, and the field plantation to make ends meet for their family. These women demonstrated their commitment to their family’s safety despite the dire poverty they faced.

II-"Gain and loss" and "Paternalism"

There is a poignant contrast between what these women expressed about the benefits of the breastfeeding policy and what is generally claimed about breastfeeding benefits for the mother in low-income countries. Beside biological and psychological benefits of breastfeeding, HIV-infected women in this study presented a range of negative implications of the breastfeeding policy on their life, considering their social conditions.

In 2006, prior to the adoption of breastfeeding, the WHO recommended to formula feed all HIV-exposed infants any time the breast-milk substitution was AFASS. When the
recommendation to breastfeed all HIV-exposed infants came out in 2010, investigation or inquiry into whether breastfeeding was even feasible for low-income mothers was neglected. Policy-makers presupposed that breastfeeding was always convenient for HIV-infected mothers because of its "naturalness" (Van Esterick, 1989, p.93). Presuming that breastfeeding is always convenient to HIV-infected mothers overlooks the fact that breastfeeding is a socio-biological variable. The recommendation to approach breastfeeding as a socio-biological variable had been made decades ago in the World Fertility Survey (Kent, 1981, p:5).

Breastfeeding is a socio-biological variable because breast milk production is governed by the complex interplay between biology and behavior which leads the lactation process (Elliott, 1976). Then, two things must be considered: first, the onset, the composition and the duration of lactation process are hormone-dependent. The breast milk composition and its volume are influenced by the mother's nutrition. Second, the socio-economic status of nursing mother influences breast milk's characteristics. Yang's measure of breast milk energy and macronutrient concentration of healthy urban Chinese mothers at different lactation stages showed the breast milk is influenced by long term nutrition status of nursing women (Yang et al., 2014). Kroening and Jackson have shown that the natural variations of human populations across countries and regions can affect breast milk composition (Elliot, 1976). The flow of breast milk is dependent on the "let down" reflex. Therefore, stressful situations and anxiety can block or diminish that flow (Chopra & Rollins, 2008). This phenomenon has been explored in rural Haiti in Farmer's studies on the concept of "bad blood and spoiled milk." In Farmer's study, lactating women reported having experienced a shortage of breast milk because of emotional distress (Farmer, 1988).
As demonstrated in the study results, the recommendation for women to breastfeed did not take into account their nutritional needs, their productivity and their role as provider or co-provider for their household. In their position of "subordinate" in the household, HIV-infected mothers expressed their anxiety about submitting their physical body to additional burden of breastfeeding in the context of HIV and scarcity. The patients report that breastfeeding increases their need for food, which adds additional psychological stress in their already stressful lives. Furthermore, participants presented that the formula program had a protective effect on their health because they could access clean water via the free tools they received for formula preparation. The results show that the protective effect extended to the whole family, which directly impacted their health. Unfortunately, this protective effect was lost in the process of transitioning to breastfeeding. This policy change did not consider all aspects of these women's lives.

On one hand, policy makers work to develop policies that are economically feasible, in line with global public health guidelines, and new scientific findings. On the other hand, the patient participants feel powerless and that they are at the mercy of policy makers who make choices that are supposed to be in the women's best interest. Contrasting patient participants’ and policy makers' views on breastfeeding that demonstrates a "paternalistic" attitude in the adoption of breastfeeding. The "paternalism" refers to the dominant attitude of one over another and the idea of superiority in term of one knows better than another (Schramme, 2015).

All together this reflects a broader history of paternalism that Haiti has been subject to for centuries. There is a historical legacy of public health interventions acting on the bodies of Haitian women without their say. Maternowska echoes this similar idea in her book on fertility and inequality in Haiti: that Haitian women have frequently been the object of public health
interventions but very rarely are they included in the decision-making processes (Maternowska, 2006, p. 121).

"Paternalism" was the predominant attitude of colonial medicine when colonial institutions were making decisions over the health status and health care for indigenous populations. Following Farmer and Kleinman's insights, this level of paternalism still exists in the contemporary model of public health interventions (Farmer, Kleinman, Kim, Basilico, 2013). This paternalism still occurs today, and Pogge argues a dose of paternalism is inevitable (Pogge, 2008, p. 42).

III. "Gain and Loss": The medicalization and “re-naturalizing” of breastfeeding

Since infant feeding has become a medicalized subject in context of HIV, infant-feeding policies have followed a pendulum path between breastfeeding and artificial formula feeding. In order to understand this association, it is useful to examine the multiple ways in which breastfeeding has been medicalized broadly, and the ways in which the medicalization and “re-naturalization” of breast milk has shifted over time in the context of HIV prevention. Therefore, returning to the “natural” practice of breastfeeding was not unproblematic and intersected with the women's responsibility for care.

Medicalization describes the appropriation of aspects of human life by medical authority through a power dynamic process that transforms these aspects of human existence into medical concerns for the purpose of health and social control (Zola, 1978, p.80). That process takes place within a social construct utterly accepted and underpinned by authoritative figures. Therefore, elements of human life are appropriated by medical authority, whereas before they were not considered under medical authority (Maturo, 2012; Farmer, Kleinman, Kim, Basilico 2013,
Farmer and Kleinman argue that global health interventions are not exempt from the intrusiveness of medicalization.

Beginning in the nineteenth century, many aspects in social life became "medicalized" and came to be managed by the medical corpus in the form of medical specialties (Lock & Nguyen, 2010, pp. 67-68). In particular, infant feeding has been fully integrated into the corpus of medical concerns for purposes of social control. Van Esterik recalls that the appropriation of infant feeding into the medical realm started at the beginning of the nineteenth century after the launch of commercial production of infant foods (Van Esterick, 1989, p.117). Furthermore, Eden advances that medicalization of infant feeding involves the nutrition of the infant regardless of whether human milk or a substitute is used, and encompasses the regulation of the milk substitution's frequency, duration and composition (Paige, Bernice, & Labbok, 2012, p.102).

The results of this study present a historical view of PMTCT programs in Haiti. Before 2012, HIV-infected women were provided with medical information that gave rationale to feeding with artificial formula to prevent transmitting HIV to their child. Therefore, formula became more of a remedy than a food. In this context, infant feeding became less about the natural duty of a mother and more about regulation of infection, falling clearly within the realm of medical management of disease.

Around 2009, medical understanding of HIV disease changed, giving way to a re-naturalizing process of breastfeeding in context of HIV. This scientific breakthrough provided evidence for adopting breastfeeding for biological and emotional benefits of mother-child, and imposed the recent shift to breast milk for HIV-exposed infant as "new paradigm." This re-naturalizing process unequivocally has restored mother-infant bonding and a certain degree of
normality for HIV-infected mothers, besides biological benefits for both mother and infants (Chimbwandira, Mhango, & Makombe, 2013; Elliot, 1976; Dettwyler & Stuart-Macadam, 1995).

The re-naturalizing of breastfeeding for HIV-infected mothers was guided by the presumption that breastfeeding is easier and unproblematic for women in resources-limited settings. But this shift was problematic. HIV-infected mothers in this study were keenly aware of the role breast milk can play in the transmission of HIV. After the policy change, they were told to breastfeed (a more "natural" form of infant feeding) based on new scientific evidence. Moreover, breastfeeding for HIV-infected mother living in context of poverty is not effortless task and even being very problematic because of the demand on their frail body.

Infant feeding in the context of HIV falls into the province of a medical condition associated with infant nutrition. Feeding options for HIV-exposed infants require specific knowledge, interventions, and scientific evidence. Improper treatment adherence or early mixed feeding could increase the risk of HIV transmission to the newborn. Yet, the threat of HIV transmission to infant is under control, but must not be trivialized. Even though HIV-infected mothers could breastfeed and recover a certain level of social normality, breastfeeding cannot be implemented the same way for HIV-infected mothers as it is for the non-HIV infected population.

The women’s narratives demonstrated how important and vital it was for them to protect their infants. HIV-infected mothers revealed that the health of their child was "on them." This is largely patterned by local social expectations, where women are responsible for the well-being of their children. This message has also been reinforced on a global level where the emphasis has been magnified the role of the mother in HIV transmission to infants. This has been
problematized by local activists who have drawn attention to the ways in which mother-to-child transmission discourse places the 'blame' of transmission squarely on mothers (Chase & Aggleton, 2001; Hollen, 2013). Despite their concerns about HIV transmission, women complied with their doctor's recommendations. In this study women expressed the feeling of being responsible for the wellbeing of their children, and they followed their inner tendency toward relationships and interdependence as they ordered human experiences in term of different priorities (Gilligan, 1993).

IV. “Gain and loss” within the context of global inequalities

The concept of gains and losses underscores the relationship between infant feeding and women’s capacity to manage the host of economic, social and health-related responsibilities placed on their shoulders. Angel's, Elna's and Freda's life conditions highlight the severe constraints that mothers living with HIV face in Haiti, as they seek to ensure the health of the families against the negative health effects posed by food insecurity, and poor sanitation. Women in our study repeatedly expressed the belief that the well-being of their infants and families was “on them.” This was no small feat, as demonstrated by the case of Freda who was responsible for the care of ten multi-generational dependents. Women are responsible for ensuring that the family as a whole gets by both socially and economically. In Haitian society, women represent a kind of “life jacket” for men: they fulfill the domestic duties of cooking, cleaning and caring for children and other dependents, and often engage in income generating activities that ‘prop up’ male heads of household (Anglade, 1986). Maternowska documents the high stakes of fulfilling this highly gendered responsibility.
A woman is often framed as an “investment” for a man, and failure to fulfill the gendered expectation of providing and caring for family and all aspects of domestic life can result in verbal and physical abuse (Maternowska, 2006).

Women in this study explained that their family depended on their income generating activities outside of the home, and under the old system of formula feeding they were able to resume such activities shortly after giving birth. For them, exclusive breastfeeding tied them to the house, and women were wary of the significant impact that this would have not only on their family finances, but on their capacity to fulfill the social expectations placed on them, namely the dual role of generating income and fulfilling domestic duties. Understanding the link between fulfillment of these social duties and exposure to potential violence underscores what is at stake in programmatic shifts that determine infant feeding practices.

In the context of global development, PMTCT programs are often enacted from the top-down. Recommendations are formulated by the WHO for best-practices in PMTCT care. Funding from various development organizations, ranging from PEPFAR to the Global Fund, is often contingent upon countries adopting these standard guidelines. Without financial support from these global funding streams, PMTCT programs in countries like Haiti would be completely undermined. This top-bottom approach constrains national leadership's capacity to adjust guidelines to local realities and priorities.

These constraints on the agency of policy-makers enacted at a national-global level are crystallized in the experiences of HIV-positive mothers who must navigate the daily effects of these programs. The feeding practices of HIV positive mothers in Haiti are, quite simply, dictated by the PMTCT program. In this era of the medicalization of infant feeding, the
displacement of feeding choices from mothers to physicians and health ministries passes as unremarkable. As Eden contends, the medical experts that develop these policies emerge as the locus of valued knowledge, and women are expected to adapt their practices and follow established guidelines (Paige et al., 2012, p. 101). Women in our study faced significant economic and social constraints, making it impossible for them follow infant feeding practices other than those dictated by the PMTCT program. While safety guidelines for infant feeding are well established in wealthier nations, individual women have more choices in infant feeding approaches because they have the financial means to do so. Women in wealthier nations can afford to formula feed if they choose, because they can either pay for formula out of pocket, or are able to access formula through established social welfare programs. The women in this study lack the financial means to enact their preferred means of infant feeding, and have no choice but to accept the feeding form dictated by the protocol shift.

The protocol shift from formula to exclusive breastfeeding can be understood as symptomatic of broader cost-saving measures underpinning global public health intervention broadly. PMTCT programs in resource-poor countries receive funding from a host of international and multi-lateral institutions. These institutions are shaped by neoliberalism and fiscal-driven logic in their way to approach public health issues in poor countries (Keshavjee, 2014). To be sure, PMTCT recommendations are deeply rooted in emerging biological knowledge about breast milk and its role in HIV transmission. However, breastfeeding recommendations are also differentially applied across the globe. The WHO acknowledges that artificial formula is the most effective way of preventing HIV transmission through breast milk. In the United States HIV-infected mothers on antiretroviral therapy are not advised to breastfeed their infant because the risk of transmission, while minimized, is still present (AAP, 2014;
Siberry, 2014). Recommendations for exclusive breastfeeding are limited to resource-poor settings such as Haiti. Such recommendations may be based in emerging knowledge about the biological safety of breast milk, but the selective application of these guidelines are legitimated by the prevailing neoliberal rationale of cost saving, completing the circle of complicity between neoliberalism, global public health interventions, and evidence-based medicine (Biehl & Petryna, 2013). This widespread inclination to rationalize health resources and adopt cost-effectiveness as a metric to guide health decisions amounts to a widespread neglect of the underlying structures that differentially shape the health of the poor. (Farmer, Kleinman, Kim, and Basilico, 2013, p. 224).

7. Limitations

The results of this study are intended to be broadly meaningful in other settings, but as qualitative results, they are not strictly generalizable. The observation component of the study captured the lived experience of these women, providing important contextualization for the interview data. However, the time allocated for these observations was limited; a more extended period of observation would have provided an even more in-depth portrayal of the conditions and experiences that framed women’s views on the shift from formula feeding to exclusive breastfeeding.

8. Conclusion

HIV-infected mothers face many challenges in their life. These challenges are established in their local world by many structural forces that are beyond their control. Especially in rural Haiti, women are expected to shoulder the burden of providing or co-providing food to their household. Women also bear responsibility for domestic work and infant care. Therefore women are trapped in the net of gender inequality and poverty where the male partner sees them as an
investment. Moreover, the moral responsibility puts mothers' needs after their partner's and children's needs in the social dynamic of the family. Those challenges are tangible effects of poverty and influence women's life at the individual, the community, and the society level.

The formula feeding policy as represented the medicalization of infant feeding acknowledged these structural challenges for the women since it was implemented with a supplemental package. Historically, at the implementation of the artificial formula there was consensus and dedication to protect a whole generation of infants against HIV. This campaign against transmission of HIV from mother to baby required effort and resources to make formula "work" in a context where the structural forces were against that policy. The implementation of formula with the supplemental package was key element for the success of the formula policy documented in local literatures in Haiti. Combining free formula with the supplemental package made formula feeding successful and also protected both the well-being of the mother-infant pair and well-being of the whole family. Artificial formula milk and its package created access to clean water and gave to women the possibility of returning to income-generating activities which allowed HIV-infected mothers to fulfill the important role of providing for their family. The package became the shield used in context of poverty to protect HIV-infected mothers against physical, social and health implications of caring for an infant, and for the entire family. Thus, the implementation of artificial formula combined with the package was the "fer-de-lance" (the main component of a strategy) of the fight to tackle the very reason of diseases in resources poor settings.

The new focus of the global medicalization of infant feeding is the process of re-naturalizing breastfeeding for HIV-infected women. The narratives in this study revealed that re-naturalizing breastfeeding is not unproblematic. First, the conceptual approach of breastfeeding
as “simple and natural” ignores women's challenges and erases the whole history that underpinned the implementation of formula feeding. Second, breastfeeding made these women vulnerable to threats of poverty by taxing their physical strength and increasing their need for food in quality and in quantity. Moreover, having to exclusively breastfeed an infant at home for six months has diminished women’s capacity to provide economically for their families, and made those women more affected by the gender supremacy. These HIV-positive women living in very poor conditions did not perceived the shift as simple return to the natural as it is label in policy makers discourses. Women's narratives in this study highlighted the ways in which breastfeeding have magnified the effect of poverty on their life.

This study is a call to refocus the attention on mothers' needs. The naturalness of breastfeeding does not empower poor women to overcome physical, social, and economical challenges, which had been achieved with the formula combined with the package. The package besides been designed for the formula-feeding option, helped HIV-infected mothers to mitigate socio-economic limitations when they were using formula milk as substitution for breast milk. Therefore, there is need to dissociate the support package to formula milk and re-localize this support package for mothers’ needs.

Therefore, a good breastfeeding policy needs to introduce an understanding of these structural challenges and to acknowledge necessity for the "support package" to cover the needs of HIV-infected mothers who are breastfeeding. Despite the fact that they are subject to massive social, economic and gender-based inequalities, the mothers in our study were so keenly attuned on keeping their child healthy and safe that it would be advantageous to support them in the mist of their social suffering.
Furthermore, we need to alter the package so that it meets the most pressing needs that women themselves expressed: 1) clean water for their families, and 2) nutritional or monetary support for lost income during the 6 months that they are doing exclusive breastfeeding.

This study has shown that there has been miscommunication between policy makers, providers and women, creating confusion about stopping after six-months of exclusive breastfeeding. There is need to clarify among participants along this chain of communication the requirement for longer breastfeeding so that women understand that they can continue breastfeeding after six months when desired.

Finally, more studies need to be done on mixed feeding and barriers to exclusive breastfeeding within HIV-infected population. These studies could provide new knowledge about factors that could explain sero-reversion among certain mixed-feeding infants in context of HIV.
9. References


Appendices

Appendix 1

INTERVIEW GUIDELINE

B-HIV positive Women.

Introduction:

Thank you for speaking with me today. I am talking to you to understand your perception of change we made in the program recently on the infant feeding option. You perhaps remember for your pregnancy (ies) before 2012 the program had provided you with milk formula for your baby (ies), and after 2012 the formula has been replaced by exclusive breastfeeding. We believe that this change might have impacted your life in some way, and we want to understand that. As someone who experienced this change, I want you to share your experience with me. Notice that there are no good or bad answers and feel free to tell whatever you want to share with me about your experience. Whatever you tell me will not be shared with no one else, out of the research team, neither your clinician nor your nurse. Please, feel free to stop me at any moment if you don’t want to continue with this interview.

1-You have been enrolled in the PMTCT program for several years and you have given births at least twice in the program.
   -Can you tell me how many children do you have?

   -Can you tell me their age or their date of birth?

I am going to ask you a few questions about the way you had fed the one born before 2012 from the program:

2-Can you tell me about your experience with your child who was born in the PMTCT program before 2012?
   -Can you tell me whatever you remember about this pregnancy?

   What did the staff told you to do to protect the Baby from having HIV?

3-Did you receive help from the Program for your Baby?
   -What kind and how?

   -What did you think about that?

   -Did that was useful?

   -Can you please walk me through?
4-We all know that the program provided you with artificial formula milk for free to feed the baby. How did you receive and use the formula? What did you think about that? What did that represent for you?

-Can you please walk me through?

5-How it was for you to use the formula for baby? What was that like? What did you think about that?

6-Tell me what other members of your family thought about what you received from the program? What did you think about their views?

-What did you do once your family members said that?

7-Tell me how the clinic staff provided you with formula? What did you think about that? Probe:

-Who gave it to you? How often?

-I would like to know more about what it was like for you to care for the baby. What did those first few days and weeks look like for you? Again, the recommendation at this time was formula feeding instead of breastfeeding. Can you tell me about this baby receiving formula instead of breast milk?

Breastfeeding:

Now I am going to ask some questions about your most recent experience in the PMTCT program. I mean your experience with your child born after 2012.

8-Can you tell me about your recent experience with the PMTCT program at this time (after 2012)?

-Please tell me whatever you remember about that?

What did the staff told you to do to protect that Baby from having HIV?

9-How would you describe the differences in the way the staff provided you with support this time?

10-I would like to know more about what it was like for you to care for the baby. Can you describe for me some of the biggest challenges that you faced after delivery of your baby? Can you describe for me what it was for you to breastfeed the baby?

-What did that mean for you?

Can you tell me all you can remember about this baby?

-For how long did you breastfeed the baby?

11-What support did you receive from the Program to help you with that child?
-How do you think those support affected your children born after 2012? -Do you notice any difference between those kids? Or any difference in your emotional relationship with those kids?
-Can you tell me what do other person in your environment told you about that? (The breastfeeding)

12-Did you have any concern about the change for breastfeeding instead of formula? What did you think about that?

Do you have any questions for me?

Thank you very much for your time.

Translation

KESYONE POU FANM VIH POZITIF YO.

Entwodiksyon:
Mèsi pou pale avè m 'jodi a. Mwen ap pale ak ou pou m ka konprann pèsepsyon ou ak lide’w sou chanjman nou te fè nan pwogram nan dényèman sou koman timoun ekspoze a VIH yo. Ou petèt sonje pou gwosè sou (yo) anvan 2012 pwogram lan te bay fòmil lèt pou tibebe w la (yo), epi apre 2012 fòmil let atifisyel la te ranplase pa “bay tete”. Nou kwè ke chanjman sa a te afekte lavi ou nan kèk fason, e nou vle konprann sa. Kòm yon moun ki gen eksperyans chanjman sa a, mwen ta renmen ou pataje eksperyans ou avè mwen. Konprann ke pa gen okenn bon oubyen move repons. Se pou ou santi ou lèb, pou’w di tou sa ou ta vle pataje mwen sou eksperyans ou. Kèlkeswa sa ou di, pa pral pataje ak oken yon lòt moun ki pa nan ekip rechèch la, ni Dokte, ni klinisyen enfimyè ou yo. Tanpri, santi ou lèb pou w sispann entevyou sa nan nenpòt ki moman si ou pa vle kontinye.

1. Ou te enskri nan pwogram PTME pou plizyè ane epi ou te bay nesans omwens de fwa nan pwogram nan.

-Eske Ou ka di m konbyen timoun ou genyen?

-Eske Ou ka di m 'laj yo oswa dat yo te fet?

Mwen pral mande w kèk kesyoun sou fom let timoun ki te fet anvan 2012 nan pwogram nan te resevwa:

2. Êske ou ka pataje eksperyans out e fe nan bay nesans a timoun kite fet nan program PMTCT avan 2012?
3. Èske ou ka di mwen 'tout sa ou sonje sou gwosè sa a?

4. Ki sa staf anplwaye program nan te kon di ou fè, pou pwoteje ti bebe a pou li pa gen VIH?

5. Eske ou te resevwa èd nan men Pwogram la pou ti bebe ou a?
   - Ki Kalite ak ki jan?
   - Ki Sa ou te panse osijè de sa?
   - Eske sa te itil ou ak tibebe a?
   - Rakonte mwen plis sou sa?

6. Nou tout konnen ke pwogram nan te bay ou lèt fòmil atifisyèl pou gratis pou tibebe a, kijan ou te resevwa ak itilize fòmil let sa?
   - Ki Sa ou te panse osijè de sa?
   - Kisa sa te reprezante pou ou?
   - Tanpri, explike mwen plis sous a?

7. Ki jan li te ye pou ou sèvi ak fòmil la pou ti bebe?
   - Kijan sa te ye pou ou?
   - Ki sa ou te panse osijè de sa?

8. Manyè di m 'sa ki lòt manm nan fanmi ou te panse sou sa ou te resevwa nan men pwogram lan?
   - Ki Sa ou te panse osijè de opinyon yo?
   - Ki Ou te fè yon fwa manm fanmi ou te di ke?

9. Manyè di mwen 'ki jan anplwaye nan klinik bay ou fòmil la?
   - Ki Sa ou te panse osijè de sa?
   - Kiyes ki te konn bawou li?
   - Kombyen de fwa konsa?

10. Mwen ta renmen konnen plis bagay sou koman sa te ye pou ou pou w pran swen ti bebe an.

11. Koman premye jou ak premye semèn yo te ye pou ou?

12. Yon fwa ankò, rekòmandasyon nan moman se te fòmil let atifisyel pou timoun ekspoze yo olye de tete. Kisa ou ka di mwen sou jan ti bebe te ye le lap resevwa fòmil atifisyel olye de let manman?
“Bay tete”:

Koulje a, mwen pral mande kòk kesyon sou eksperyans ki pi resan ou te fe nan pwogram PTME an. Mwen vle di eksperyans ou te fe ak pitit ou ki te fòt aprè 2012.

13. Èske ou ka pataje avek mwen eksperyans ou sot fe ak pwogram PMTCT an nan moman resan sa yo la (apre 2012)?

-Tanpri Di mwen tou sa ou sonje sou sa?

14. Ki sa estaf anplwayne yo te di ou pou w fè pou pwoteje bebe gen VIH?

15. Ki jan ou ta dekri diferans ki genyen nan jan estaf anplwayne yo te bay ou sipò tan sa a?

16. Mwen ta renmen konnen plis bagay sou koman sa te ye pou ou te pran swen ti bebe a. –Eske ou kapab dekri pou mwen kòk nan pi gwo defi ke ou te fè fas, apre ou fin ak ouche ti bebe ou a?

-Eske ou ka dekri pou mwen ki sa li te pou ou te pou w bayti bebe a tete?

-Kisa sa te vle di pou ou?

17. Èske ou ka di m tout sa ou kapab sonje sou koman ti bebe te ye?

-Pou Konbyen tan ou te tete ti bebe a?

18. Ki sipò ou te resevwa nan men Pwogram nan pou ede w ak tibebe sa?


20. Èske ou ka di m ’sa lòt moun nan anviwònman bo lakay ou te konn di sou sa? (Bay tete a)

21. – Eske ou te gen nenpòt enkyetid sou chanjman ki te fòt pou bay tete net olye de fòmil let atifisyel?

- Ki sa ou te panse osijè de sa?

Eske ou pa genyen nenpòt kesyon pou mwen?

Mèsi anpil pou tan ou.
Appendix 2

Interview Guideline: Providers

Introduction:
Thank you for speaking with me today. I am speaking with you today to gain a better understanding of your perception on the change that happened in the way to feed HIV exposed children in other to prevent transmission in 2012. All exposed children are now exclusively breastfeed. As someone who implemented this protocol change in your practice, I want you to share your experience with me. Please know that there are no right or wrong answers, I am interested in learning about your own experiences. So please feel free to tell whatever you want to share. Your responses will not be shared with anyone outside of the research team. Please, feel free to stop me at any moment if you don’t want to continue with this interview.

1-Can you tell me for how many years have you been working in the PMTCT program?

I would like to ask you a few questions about the infant feeding protocol (formula feeding) for exposed children before 2012.

2-Please describe the use of formula feeding in your program? Tell me how the clinic staff provided them with artificial milk?
-What did you think about that?

-When and How?

3-Did the staff use any practical strategy to provide HIV positive women with information during and after pregnancy about the formula use?
-Can you tell me what those look like? For instance posters, informative video or any extra-meeting with this intent?

4-What kind of support did the HIV positive women receive from the program to help with formula preparation? -Can you describe the purpose of each?
-What did you think about that?

-Did these types of support have any impact on the life of your patient and her child or children? Any examples or stories?

-What kind?

-Can you tell me what those looked like?

5-For example, can you please describe the relationship between formula utilization and your patient’s adherence?
The formula was used to eliminate the risk of transmission via breastfeeding. According to your own view, what was the impact of such practice, on:

a). The program?

b). The patients?

c). The baby (ies)?
D). Patient family or community?

6-How did other family member perceive those supports?
-Probe: Can you share any story about that?

7-I would like to ask you a few questions about your experience with the use of breastfeeding for exposed children after 2012.

8-Please describe the use of breastfeeding in your program? Can you tell me when and how you started with the breastfeeding in the program for exposed children?

9-Tell me how the clinic staff applies that new policy?
-What did you think about that?

-What did they think about that?

-When and How?

10-Did the staff use any practical strategy to provide HIV positive women with information during and after pregnancy about the use of breastfeeding for their baby?
-Can you tell me what those look like? For instance posters, informative video or any extra-meeting with this intent?

11-What kind of support did the HIV positive women receive from the program to help with breastfeeding? -Can you describe the purpose of each?
-What did you think about that?

-Did these types of support have any impact on the life of your patient and her child or children? Any examples or story?

-What kind?

-Can you tell me what those looked like/what is the purpose

For example, can you please describe the relationship between breastfeeding and your patient’s adherence?

12-The breast milk combines with Antiretroviral treatment to HIV infected mothers give is use to improve infant children surviving in context of HIV. According to your own view, what was the impact of such practice, on:

a). The program?

b). The patients?

c). The baby (ies)?

D). Patient family or community?

13-How did other family member perceive that new practice?
-Probe: Can you share any story about that?
14-What did the new protocol bring to your patients according to your own view?  
   -I mean by that, what kind of benefits does the fact for HIV infected mother to be able to breastfeed their baby bring to those women in your care?  
   -Can you tell me some stories about what that has looked like in your practice?  
   -Can you walk me through that?  

15-How do you think that the new change (use of breast milk) affected children?  
   -In what way?  
   -How do you explain that?  
   -Why?  
   -Did you have any concern about that?  

16-Do you notice any difference between infants who were fed with formula versus those fed with breast milk?  

17-Did you have any concern about the success of the breastfeeding as protocol?  

Do you have any questions for me?  

Thank you very much for your time.
Study Title: Exploring Attitudes and Perceptions of Health Providers and HIV Positive Mothers on Adopting Breastfeeding for HIV Exposed Children: A Qualitative Study in Rural Haiti.

Investigator: Dimitri Suffrin

(Creole Translation.)

-Kesyonè pou travayè :

Entrodiksyon


1-Èske ou ka di m ’pou konbyen ane ou ap travay nan pwogram nan PMTCT?

Mwen ta renmen mande w kèk kesyon sou pwotokòl manje tibebe (fòmil manje a) ekspoze anvan 2012.

1. Tanpri dekri itilizasyon fòmil manje nan pwogram ou an? Manyè di m ’ki jan anplwayne nan klinik bay lèt atifisyèl la?

-Ki Sa ou te panse osijè de sa?

-Kilè Ak Kouman?

2. Èske anplwayne yo sèvi ak estrateji pratik pou bay fam VIH pozitif enfòmasyon pandan ak apre gwosè sou jan pou sèvi ak fòmil la?

-Dim kisa yo te ye konsa? Pou egzanp postè, videyo enfòmatif oswa nenpòt siplemantè-reyinyon ?

3. Ki kalite sipò fam VIH pozitif yo te resevwa nan pwogram nan pou ede yo avèk preparasyon fòmil? –Èske ou kapab dekri bi yo chak?

-Ki Sa ou te panse osijè de sa?

-Eske kalite sipò sa yo te gen enpak sou lavi pasyan oswa piti li ? Nenpòt egzanp istwa?

4. Pou egzanp, ou ka tanpri dekri relasyon ki genyen ant itilizasyon fòmil ak aderans pasyan yo?

5. Itilize Fòmil la elimine risk pou transmisyon VIH atravè bay tete. Dapre ou menm, ki enpak
pratik sa yo te genyen sou:

a). Pwogram lan?
b). Pasyan yo?
c). Ti bebe a (yo)?

d). Fanmi Pasyan oswa kominote a?

6. Ki jan lòt manm nan fanmi an te wè sipò sa yo?
- Probe: Èske ou ka pataje nenpòt istwa sou sa?

Mwen ta renmen mande w kèk kesyon sou eksperyans ou ak itilizasyon bay tete pou ti bebe ekspoze a VIH apre 2012.

7. Tanpri dekri itilizasyon bay tete nan pwogram nan? Èske ou ka fè m 'konnen lè ak ki jan ou te kòmanse ak bay tete a nan pwogram nan pou tibebe ekspoze a VIH yo?

8. Manyè di m 'ki jan anplwaye nan klinik aplike nouvo politik sa?
- Ki Sa ou te panse osijè de sa?
- Kisa yo te panse osijè de sa?
- Lè Ak Kouman?

9. Èske anplwaye yo sèvi ak estrateji pou bay fanm VIH pozitif yo enfòmasyon pandan ak apre gwosès sou yan nou pou li bay tibebe yo bay tete?
- Dim kisa yo te ye konsa? Pa egzanp postè, videyo enfòmatif oswa nenpòt siplemantè-reyinyon?

10. Ki kalite sipò fanm VIH pozitif yo te resevwa nan pwogram nan pou ede yo avèk bay tete a?
- Eske ou ka dekri bi yo chak?
- Ki Sa ou te panse osijè de sa?
- Eske kalite sipò sa yo te gen enpak sou lavi pasyan oswa pitit li? Nenpòt egzanp istwa?

11. Pa egzanp, eske ou ka dekri relasyon ki genyen ant bay tete ak aderans pasyan yo?

12. Bay tete konbine ak tretman Antiretoviral pou manman ki enfekte ak VIH yo te itilize pou amelyore chans lavi tibebe nan kontèks nan VIH. Dapre ou menm ki enpak pratik sa yo te genyen, sou:

a). Pwogram lan?
b). Pasyan yo?
c). Ti bebe a (yo)?

D). Fanmi Pasyan oswa kominote a?
13. Ki jan lòt manm nan fanmi an te wè nouvo Pratik sa?

-Probe: Èske ou ka pataje nenpòt istwa sou sa?

14. Ki sa nouvo pwotokòl sa te pote pou pasyan yo dapre ou menm?

-Mwen Vle di pa sa, ki kalite benefis lefèt ke manman ki VIH positive yo te ka bay tete kounye a te pote pou fanm sa yo?

-Eke ou ka di m ‘kèk istwa sou sa ?

15. Ki jan ou panse ke chanjman nan nouvo la te (pou sèvi ak lèt tete) afekte timoun yo?

-Nan Ki sans?

-Kijan Ou eksplike sa?

: Poukisa?

-Dim nenpòt enkyetid ou te gen sou sa?

16. Eske w te remake diferans ant ti bebe ki te nouri ak fòmil e sila yo kit e nouri ak tete?

17. –Eske ou gen enkyetid sou siksè bay tete a kòm pwotokòl?

Eske w gen nenpòt kesyon pou mwen?

Mèsi anpil pou tan ou.

Appendix 3
“Angel”
“Elna”
Appendix 5

Freda’s kinship