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### **► To cite this version:**

Melissa C Morgan, Rose O Masaba, Mary Nyikuri, Timothy K Thomas. Factors affecting breastfeeding cessation after discontinuation of antiretroviral therapy to prevent mother-to-child transmission of HIV. *AIDS Care*, 2010, 22 (07), pp.866-873. <10.1080/09540120903483000>. <hal-00608803>

**HAL Id: hal-00608803**

**<https://hal.science/hal-00608803v1>**

Submitted on 15 Jul 2011

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HAL Authorization



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Journal:	<i>AIDS Care - Psychology, Health &amp; Medicine - Vulnerable Children and Youth Studies</i>
Manuscript ID:	AC-2009-03-0151.R1
Journal Selection:	AIDS Care
Keywords:	HIV, Mother-to-child transmission, Breastfeeding cessation, Prevention



**Factors affecting breastfeeding cessation after discontinuation of  
antiretroviral therapy to prevent mother-to-child transmission of HIV**

For Peer Review Only

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**Abstract**

In the Kisumu Breastfeeding Study, a prevention of mother-to-child HIV transmission study, highly active antiretroviral therapy (HAART) is provided from 34 weeks gestation, through delivery to six months postpartum. The study recommends that women practice exclusive breastfeeding for six months, then wean abruptly. We sought to explore factors such as, education, family support, cultural norms, and sources of information about perinatal HIV transmission, which may influence a mother's decision to comply or not comply with the study's recommendation to stop breastfeeding when HAART is discontinued. We used semi-structured interviews of a purposive sample of 18 mothers participating in the Kisumu Breastfeeding Study. By interviewing ten mothers who stopped breastfeeding and eight mothers who continued, it was possible to examine how different factors may have affected the groups of participants. All participants stated that it was not traditional to stop breastfeeding at six months. Participants who stopped breastfeeding reported more family support, were more educated, and were more likely to disclose their HIV status. Participants who continued breastfeeding more often expressed concern about stigma. Participants learned about mother-to-child transmission from clinics, churches, community groups, and other HIV-positive mothers. This substudy suggests that family support, education, and cultural norms are important factors that may influence a mother's decision regarding breastfeeding cessation. Thus, counseling and family support may play integral roles in the promotion of early breastfeeding cessation.

**Key Words:** HIV, mother-to-child transmission, breastfeeding cessation, prevention

## Introduction

Mother-to-child transmission (MTCT) of HIV is a devastating problem. Worldwide, approximately 420,000 new pediatric HIV infections occurred in 2007 (UNAIDS, 2007). Almost all of these infections were the result of MTCT and 90% occurred in sub-Saharan Africa. In resource-poor settings, MTCT rates are 25-48% in breastfeeding populations in the absence of interventions (De Cock et al., 2000). In Kenya, Nduati et al. (2000) found that 44% of all transmission was due to breastfeeding, and 75% of all breastmilk transmission occurred in the first six months. Additionally, they showed that HIV transmission in breastfed infants was 16% higher than in formula-fed infants, and that HIV-free survival at 24 months was significantly higher in the formula-fed group (Mbori-Ngacha et al., 2001, Nduati et al., 2000). However, Thior et al. (2006) found that HIV-free survival at 18 months was similar in formula-fed and breastfed infants receiving zidovudine in Botswana and that cumulative infant mortality at 7 months was significantly higher in the formula-fed group, mainly due to diarrheal and respiratory diseases. These results demonstrate the importance of preventing postnatal transmission, as well as the conflicting evidence regarding the role that replacement feeding should play in prevention.

In developing countries, breastfeeding is considered essential to child survival. A pooled analysis (WHO Collaborative Study Team, 2000) found that non-breastfed infants have a six-fold increased risk of mortality due to infections in the first two months of life compared to breastfed infants. Further, it found that breastfeeding increased protection against diarrheal deaths and acute respiratory infections six-fold and two-fold, respectively, in the first six months. Benefits of breastfeeding are greatest in the first six months (Fowler & Newell, 2002; WHO, 2000). Exclusive breastfeeding, defined as breastmilk only with no other liquids or solids (WHO, 1991), is associated with a significantly lower risk of HIV

transmission than mixed feeding (Coutsoudis, Pillay, Spooner, Kuhn, & Coovadia, 1999; Iliff et al., 2005). For these reasons, the World Health Organization (WHO) recommends replacement feeding only when it is culturally acceptable, affordable, feasible, sustainable, and safe. If it is not, exclusive breastfeeding is recommended for the first six months followed by breastfeeding with complementary foods until an adequate diet can be provided without breastmilk (WHO, 2006).

In resource-poor settings, several problems may exist with replacement feeding. Replacement feeding requires access to clean water, fuel, and feeding implements (UNAIDS, 1999). A South African study of 1253 HIV-infected women found that only 3% had access to clean water, fuel, refrigeration, and regular income (Bland, Rollins, Coovadia, Coutsoodis, & Newell, 2007). In Kenya, the median duration of breastfeeding is 20 months (Owuor & Mburu, 2004). Failure to breastfeed or early cessation may lead to unintentional disclosure of HIV status as it is contrary to common practice. In Zimbabwe, interviews revealed that women who do not breastfeed may face stigma because others believe they are promiscuous or HIV-positive (Piwoz et al., 2005). Studies in South Africa (Hilderbrand, Goemaere, & Coetzee, 2003), Brazil (Hebling & Hardy, 2007), and USA (Chezem, Montgomery, & Fortman, 1997) found that women experienced emotional pain, guilt, frustration, and sadness as a result of not breastfeeding or stopping earlier than intended.

Because replacement feeding is not feasible in most resource-poor settings, interventions that allow women to breastfeed without increasing their risk of MTCT are needed. In the Kisumu Breastfeeding Study (KiBS), all participants receive HAART from 34 weeks of pregnancy, during delivery, and for the first six months postpartum as a prevention of MTCT (PMTCT) intervention. HAART is discontinued after six months of exclusive breastfeeding for those women who do not meet WHO criteria for treatment. Participants are counseled on the risk of MTCT through breastfeeding after cessation of HAART and advised to wean over

two weeks prior to cessation. HAART is continued for women who meet WHO criteria (CD4 count  $<200/\text{mm}^3$  or clinical symptoms of AIDS and CD4  $<350/\text{mm}^3$ ) (CDC, KEMRI, & Kenyan Ministry of Health, 2005).

Despite the counseling they receive, some participants continue to breastfeed after stopping HAART. It is important to understand why this occurs. Although many studies have been conducted on factors affecting formula feeding (Abiona et al., 2006; Bland et al., 2007; Doherty et al., 2007; Doherty, Chopra, Nkonki, Jackson, & Persson, 2006; Hilderbrand et al., 2003; Kiarie, Richardson, Mbori-Ngacha, Nduati, & John-Stewart, 2004; Leroy et al., 2007; Thairu, Pelto, Rollins, Bland, & Ntshangase, 2005) and exclusive breastfeeding (Abiona et al., 2006; Becquet et al., 2005; Bland et al., 2007; Bland, Rollins, Coutoudis, & Coovadia, 2002; Doherty et al., 2006; Piwoz et al., 2005; Poggensee et al., 2004) among HIV-positive women, an extensive literature review indicates that few studies have examined factors affecting early breastfeeding cessation (Abiona et al., 2006; Becquet et al., 2005) and no studies have explored this topic among HIV-positive women receiving a prolonged course of HAART for PMTCT.

## Methods

This substudy was conducted among KiBS participants attending the Kenya Medical Research Institute (KEMRI)/U.S. Centers for Disease Control and Prevention (CDC) Clinical Research Center at the Nyanza Provincial General Hospital in Kisumu, Kenya. The HIV-1 prevalence among pregnant women in Kisumu is estimated to be 25-36%, with a 22% rate of MTCT at two years in the absence of HAART (unpublished) (CDC, KEMRI, & Kenyan Ministry of Health, 2005). Between July 2003 and November 2006, 522 women were

enrolled in KiBS; however, for this substudy we only enrolled from the 234 women who were at least six months postpartum when the substudy began in June 2006. Therefore, this substudy enrolled 8% of eligible women from KiBS. Purposive sampling was utilized. Eighteen participants, all aged 18 years or above, were selected based on their breastfeeding status. Ten participants stopped breastfeeding and eight continued breastfeeding beyond six months when HAART was discontinued. Participants in both groups were similar with regard to age and parity, and were evenly distributed in their duration in the study. No participants were receiving HAART at the time of this substudy. Women were recruited during routine KiBS clinic visits or were invited to come if they lived nearby. Women were compensated with a bar of soap and a fixed amount to cover transportation.

### ***Data collection***

The study utilized qualitative research methodology through semi-structured interviews with participants. All interviews were conducted in June and July 2006. The interview guide was developed in English and translated into Kiswahili and Dholuo. The interview guide employed open-ended questions about a broad range of potential factors while allowing the interviewers to ask additional questions on emerging themes. The mean interview length was 31 minutes. Three female interviewers conducted the interviews in a private setting in the language of the participant's choice. Data validity was supported by the fact that the interviewers were local women who spoke the predominant languages, Dholuo and Kiswahili. The interviewers were familiar with the techniques of field research and had previous interviewing experience. The protocol and interview guide were discussed in detail with the interviewers to ensure they understood the study objectives. Pilot interviews were



conducted to identify and revise unclear interview questions and provide additional training to interviewers on areas of weakness.

### ***Data analysis***

Interviews were audiotaped, transcribed, and translated into English. Transcription was performed by interviewers. Quality control was enhanced by comparing a random sample of early transcripts to taped interviews to detect transcription errors and correct them. Using the framework approach (Pope & Mays, 2000), data analysis consisted of five steps: (1) familiarization (listed recurrent themes by reading the translated transcripts); (2) identifying a thematic framework (identified major themes by which data could be examined); (3) indexing (applied thematic framework to all data); (4) charting (created charts containing summaries); (5) mapping and interpretation (used charts to find associations between themes). The statistical analysis was conducted using SPSS 13.0 (SPSS Inc., Chicago, IL). Interview transcripts were read multiple times by two authors to identify recurring themes. Analysis by two authors, one of whom was a member of the predominant local tribe, allowed minimization of subjective interpretations and ensured a high degree of inter-rater consensus. The thematic framework was reviewed several times to ensure that all data was included.

### ***Ethical approval***

Ethical approval was obtained from the Kenya Medical Research Institute and the U.S. Centers for Disease Control and Prevention. All women provided written informed consent.

## Results

### *Demographic and socioeconomic factors*

Demographic and socioeconomic characteristics of participants are shown in Table 1. Seventy percent of participants who stopped breastfeeding and 75% who continued felt that the cost of replacement food did not affect their feeding decisions. Among those who continued breastfeeding, two mothers said cost played a role in their decisions.

*“When the baby was able to take porridge, the follow-up staff told me to mix soya beans and finger millet for the baby’s porridge, but this was not available unless you buy them, and these things were affecting my decision to stop breastfeeding the baby.”* (Age 37; four children; small business operator; continued breastfeeding)

### *Psychosocial factors*

Psychosocial factors affecting compliance with breastfeeding recommendations are shown in table 2.

### *Partner and family support*

All mothers that stopped breastfeeding received support from their partner or other family members to stop breastfeeding.

*“My mom, when she got the news, she just told me to be free because it’s something that happened, something people have, so she just told me not to be stressed, not to be afraid. She’d be there in case of any problem.”* (Age 25; one child; unemployed housewife; stopped breastfeeding)

However, several faced questions from family members regarding their decision to stop breastfeeding. They responded with excuses for breastfeeding cessation, such as working or looking for a job.

*“It’s only my uncle who was against it because he felt I was to breastfeed the baby up to around three years. But I told him I could not breastfeed to that extent because I’m somebody who stays alone and must look for how the baby can eat. So I had to leave breastfeeding because I wanted to go and look for a job.”* (Age 25; one child; unemployed housewife; stopped breastfeeding)

Among mothers who continued breastfeeding, all lacked support from either the partner or other family members to stop breastfeeding. Most lacked support from both.

*“My husband saw that I have never stopped breastfeeding a baby with those months and he didn’t like the baby being stopped like that. So he was saying that the baby needs to be breastfed until he leaves (stops) on his own.”* (Age 25; three children; unemployed housewife; continued breastfeeding)

*“My husband refused that I should not stop breastfeeding the baby. Anytime I wanted to remove or stop the baby from breastfeeding, my husband could make a lot of noise... He didn’t allow me to stop breastfeeding, so I decided to continue breastfeeding to be at peace.”*

(Age 24; two children; small business operator; continued breastfeeding)

### *Emotional aspects of breastfeeding*

All mothers who continued breastfeeding and 80% of mothers who stopped felt that breastfeeding is important in developing an emotional bond with their baby.

*“When you breastfeed, it’s very important because the baby will be strong and that makes me feel that I’m a mother.”* (Age 23; one child; small business operator; continued breastfeeding)

### *Sadness and loneliness associated with breastfeeding cessation*

Seventy percent of mothers who stopped breastfeeding did not feel sad or lonely about breastfeeding cessation. One mother was happy to stop breastfeeding so she could look for work. Another was embarrassed about breastfeeding and felt relieved to stop.

*“You know many people don’t have jobs. We have to go and look for the job. Now when you leave somebody with your baby if he’s not breastfeeding, it’s much easier. You can leave the food behind and when the baby’s hungry, it can be given the food when you are away.”* (Age 25; one child; unemployed housewife; stopped breastfeeding)

In the group that continued breastfeeding, three mothers expressed sadness about breastfeeding cessation. Among those participants who expressed sadness, several said they felt better after successfully weaning their babies and two mentioned prayer as a way of coping with their sadness.

*“I was lonely, but for a short period, so what’s helped me a lot to overcome the loneliness is prayer. I was praying so that I do not feel sad about my baby not breastfeeding.”* (Age 23; one child; small business operator; continued breastfeeding)

#### *Benefits of breastfeeding and concerns about cessation*

All mothers who continued breastfeeding and 70% of those who stopped believed that breastfeeding is beneficial. Several said breastfeeding protects the baby from other diseases and one mentioned that breastfeeding prevents pregnancy. Among those expressing concern about cessation, some were worried about their baby’s health while others were apprehensive about the weaning process.

*“Some people say that if you don’t breastfeed, then the baby will be weak and other diseases will attack the baby, so breastfeeding protects these diseases that make the baby weak.”* (Age 21; two children; unemployed housewife; continued breastfeeding)

#### *Cultural factors*

Cultural factors affecting breastfeeding decisions are shown in table 3.

### *Cultural pressures associated with early breastfeeding cessation*

All mothers who continued breastfeeding and 80% of those who stopped felt that it is abnormal to stop breastfeeding at six months. One mother faced pressure from her community to continue breastfeeding.

*“In my community, it is not appropriate... and it doesn’t look good. They see if that you have underfed the baby with breastmilk and the baby cannot grow well.”* (Age 25; three children; unemployed housewife; continued breastfeeding)

Two mothers who stopped breastfeeding said it is acceptable to stop breastfeeding at six months only if the mother has insufficient milk or she is working. Six participants revealed reasons they used to explain their decision to stop breastfeeding; these included sickness of the baby or the mother, employment, and refusal of the baby to breastfeed.

*“They think that there’s something that I’m hiding, but I know that. I always tell them that the baby felt sick, that’s why he didn’t want to breastfeed more.”* (Age 23; two children; unemployed housewife; stopped breastfeeding)

### *Stigma associated with HIV*

Only one mother who stopped breastfeeding was worried that others would discover her HIV status as a consequence of not breastfeeding. Several participants said mothers may

choose or have other reasons for not breastfeeding, such as not having adequate breastmilk or having to work.

*“If you are HIV-positive, you have to accept your status, so even if one knows, I do not get worried.”* (Age 26; two children; small business operator; stopped breastfeeding)

Six mothers who continued breastfeeding felt that stopping breastfeeding might indicate one's HIV-positive status. One mother said stopping breastfeeding prematurely indicates pregnancy or promiscuity. Two participants overcame the stigma associated with not breastfeeding through counseling on positive living.

*“People who are HIV-positive are feared by many people.”* (Age 24; two children; small business operator; continued breastfeeding)

*“It's not normal. The community must ask. They might think that you're pregnant or you're moving a lot with other men.”* (Age 37; four children; small business operator; continued breastfeeding)

### ***Knowledge about MTCT and consequences of continued breastfeeding***

Participants received information about MTCT through KiBS, churches, clinics, traditional birth attendants, community members, and other HIV-positive mothers. Knowledge about MTCT and the consequences of breastfeeding are shown in table 4.

## Discussion

The results of this substudy demonstrate that many factors play a role in a mother's decision to stop or continue breastfeeding. Demographic and socioeconomic factors that appeared to increase compliance with recommendations included higher educational status, employment, and reliance on others for income. Education may increase awareness about MTCT and infant feeding options (Bland et al., 2002). In a related study in Côte d'Ivoire, Painter et al. (2005) found that women who participated in a MTCT intervention were more educated and less dependent on others for income than those who did not participate. In this substudy, most participants in both groups did not feel that the cost of replacement food influenced infant feeding decisions. This finding conflicts with those of a previous Kenyan study, which reported the importance of cost in such decisions (Kiarie et al., 2004). However, women in KiBS were encouraged to use locally available foods for replacement, which are considerably cheaper than formula.

Among the psychosocial factors, partner and family support were the most important in helping women stop breastfeeding. All mothers that stopped breastfeeding received support from their partner or other family members and all mothers who continued breastfeeding lacked partner or family support. In Côte d'Ivoire, Becquet et al. (2005) also found that women who failed to achieve early cessation were under pressure from the partner's family to continue breastfeeding. In Kenya, focus groups revealed that partner support is an important factor influencing infant feeding decisions (Kiarie et al., 2004). Disclosure of HIV status was more common among those who stopped breastfeeding. However, in Kenya, Gaillard et al. (2002) found that only one third of HIV-positive, pregnant women in a stable relationship disclosed their status to their partner. Two studies in South Africa revealed the perceived importance of breastfeeding in developing an emotional bond with the baby (Hilderbrand et



al., 2003; Seidel, Sewpaul, & Dano, 2000) and a Malawian study found that concerns regarding infant nutrition were a barrier to early cessation (Piwoz et al., 2006).

Cultural factors affecting compliance included the local custom of breastfeeding for approximately two years and fear of being stigmatized due to early cessation. These findings were similar to those found in a Zimbabwean study (Piwoz et al., 2005).

### ***Limitations***

This substudy has a few limitations. The small sample size and single site limits the generalizability of the results. Further, the study was conducted among clinical trial participants rather than the general population of HIV-positive breastfeeding women. Conducting the interviews at the trial clinic and using tape recorders may have made participants feel vulnerable. Given the repeated counseling on breastfeeding cessation at six months, participants may have biased their responses in order to please interviewers.

### ***Recommendations***

The WHO recommends replacement feeding when it is culturally acceptable, affordable, feasible, sustainable, and safe. In many resource-poor settings, these criteria are not met and exclusive breastfeeding is therefore recommended for the first six months followed by breastfeeding with complementary foods until provision of an adequate diet without breastmilk is possible (WHO, 2006). In the context of limited resources and risk of HIV infection, the challenge is to determine the right age to transition to replacement feeding with

the goal to wean infants from breastmilk as soon as they are strong enough to withstand the risks of replacement feeding. It is also important to explore interventions that allow women to breastfeed without increasing their risk of MTCT.

Despite the counseling participants receive throughout KiBS, some continue to breastfeed after discontinuation of HAART. Because support of the male partner appears important in determining whether a mother will stop breastfeeding, couples counseling and testing may be an effective way to involve the partner in MTCT interventions and allow him to understand the importance of compliance. This recommendation is in agreement with those made by previous authors (Eide et al., 2006; Farquhar et al., 2004; Gaillard et al., 2002). In Kisumu, men seldom accompany their partners to antenatal clinics. Involvement of the male partner in the antenatal process may also improve compliance. In order to promote safe disclosure of HIV status, counseling should address stigma and potential negative consequences of disclosure (Eide et al., 2006; Gaillard et al., 2002). Counseling should continue into the postpartum period.

Outreach to community leaders and other influential persons may increase social support for HIV-positive mothers and could modify cultural norms for breastfeeding cessation (T.M. Painter, personal communication, June 22, 2006). Support groups with other HIV-positive mothers would allow women to share experiences. The involvement of churches and community groups may also increase awareness about MTCT, thereby increasing uptake and compliance with interventions.

Additional studies should be conducted to confirm these results. Studies are also needed to determine the optimal age to transition to replacement feeding in resource-poor settings and to establish appropriate counseling to help women comply with infant feeding recommendations. While this study was done among participants who received HAART for six months postpartum, the findings highlight some issues that may be important in

determining if women meet WHO criteria for replacement feeding. If interventions such as those used in KiBS are implemented on a wider scale, then the findings are of additional significance for the future.

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## Acknowledgements

We would like to thank the mothers who were interviewed for this study. We wish to acknowledge Phoebe Okola, Jane Omanga, and Mary Othanya at the Kenya Medical Research Institute and Centers for Disease Control and Prevention in Kisumu for conducting the interviews and assisting with transcription and translation. We would also like to acknowledge the following staff at the Kenya Medical Research Institute and Centers for Disease Control and Prevention in Kisumu: John Okanda, Richard Ndivo, and Vitalis Sewe. We also thank Dr. Michael Thigpen and Dr. Thomas Painter at the Centers for Disease Control and Prevention in Atlanta for commenting on the study protocol. Finally, we thank Dr. Harold Jaffe and Dr. Premila Webster at the Department of Public Health, University of Oxford for commenting on the study protocol and manuscript. This study was supported by the Department of Public Health at the University of Oxford. This paper is published with approval of the Acting Director of the Kenya Medical Research Institute.

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Table 1. Demographic and socioeconomic factors

Factor	Discontinued breastfeeding (N=10)	Continued breastfeeding (N=8)
Age (median, range)	25.0 (22-30)	23.5 (20-37)
Member of Luo tribe	9 (90%)	7 (88%)
Member of other tribe	1 (10%)	1 (13%)
Married	8 (80%)	6 (75%)
Single	2 (20%)	1 (13%)
Widowed	0	1 (13%)
Parity (median, range)	2.0 (1-3)	2.0 (1-4)
Primary education	3 (30%)	6 (75%)
Secondary education	6 (60%)	2 (25%)
College education	1 (10%)	0
Currently working	5 (50%)	3 (38%)
Received income contributions from partner or family	8 (80%)	4 (50%)
Cost of replacement feeding affected decision	3 (30%)	2 (25%)

Table 2. Psychosocial factors

Factor	Discontinued breastfeeding (N=10)	Continued breastfeeding (N=8)
Disclosed HIV status to another person	9 (90%)	5 (63%)
Disclosed HIV status to partner	6 (60%)	4 (50%)
Received partner or family support	10 (100%)	2 (25%)
Felt breastfeeding important in developing emotional bond with infant	8 (80%)	8 (100%)
Felt sadness about discontinuing breastfeeding	3 (30%)	3/6 (50%)
Felt breastfeeding was beneficial	7 (70%)	8 (100%)

Table 3. Cultural factors

Factor	Discontinued breastfeeding (N=10)	Continued breastfeeding (N=8)
Perceived cultural norm for duration of breastfeeding (mean in years)	2	2
Felt it was abnormal to stop breastfeeding at six months	8 (80%)	8 (100%)
Worried HIV status would be discovered if breastfeeding was discontinued	1 (10%)	6 (75%)

Table 4. Knowledge about MTCT and consequences of continued breastfeeding

Factor	Discontinued breastfeeding (N=10)	Continued breastfeeding (N=8)
Knew infant could become HIV-infected if breastfeeding continued	9 (90%)	6 (75%)
Learned about MTCT from persons in the community	4 (40%)	3 (38%)
Shared knowledge gained from the study with others	9 (90%)	5 (63%)
Person with whom they shared knowledge was supportive	9/9 (100%)	1/5 (20%)