

## ORIGINAL RESEARCH ARTICLE

# “They call our children ‘Nevirapine Babies’”: A Qualitative Study about Exclusive Breastfeeding among HIV Positive Mothers in Malawi

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## Abstract

Infant feeding is estimated to be responsible for 5%-20% of the burden of HIV transmission from mother to child. HIV positive women who cannot afford safe formula feeding are advised to practise exclusive breastfeeding (EBF) followed by prompt weaning. We conducted a qualitative study using observations and in-depth individual interviews to explore patterns of EBF as well as which factors motivate or hinder women to practice EBF. HIV positive women who intended to practice EBF from urban Malawi were purposively selected and interviewed. All women were well informed and had high knowledge on HIV as well as on EBF but much less knowledge on basic facts about breastfeeding. Despite their intentions less than half of the interviewed women managed to practice EBF and the barriers were explained by perceived lack of milk, lack of control over the feeding situation, felt and enacted stigma as well as poor counselling. Women who succeeded were older, had the explicit support of their husband and lived without the presence of their mother-in-law. Weaning at the age of 6 months was reported to be as difficult for the women as EBF. Intention itself is not a sufficient determinant of successful EBF unless a number of enabling factors come together. Prolonged breastfeeding is the cultural norm in Malawi and programs must be sensitive to social expectations to mothers and involve mothers-in-law and fathers in counselling of mothers who intend to practice EBF (*Afr. J. Reprod. Health* 2010; 14[3]: 213-222).

## Résumé

**On appelle nos enfants les bébés « nevirapines » : Une étude qualitative sur l’Allaitement Maternel Exclusif chez les mères séropositives au Malawi.** On estime que l’allaitement est responsable de 5% à 20% de la charge de la transmission du VIH de la mère à l’enfant. Les femmes séropositives qui n’ont pas les moyens d’acheter l’aliment lacté artificiel pour nourrir leurs enfants sont conseillées de pratiquer l’allaitement maternel exclusif (AME) suivi du sevrage sans délai. Nous avons mené une étude qualitative à l’aide des observations et des interviews en profondeur individuels pour explorer les modèles de l’AME et les facteurs qui les encouragent ou qui les empêchent de le faire. Les femmes séropositives qui venaient du Malawi urbain et qui avaient l’intention de pratiquer l’AME ont été délibérément sélectionnées et interrogées. Toutes les femmes ont été bien informées et avaient une bonne connaissance du VIH aussi bien que de l’AME, mais elles possèdent beaucoup moins de connaissance quant aux données fondamentales concernant l’allaitement. Malgré leurs intentions, moins de la moitié des femmes interrogées ont réussi à pratiquer l’AME et elles ont expliqué que les obstacles comprenaient le manque perçu de lait, le manque de contrôle à l’égard de la condition de l’alimentation, la stigmatisation éprouvée et représentée aussi bien que le mauvais conseil. Les femmes qui ont réussi étaient les plus vieilles et celles qui avaient le soutien tacite de leurs maris et qui vivaient sans la présence de leurs belles-mères. On a déclaré que le sevrage à l’âge de six mois était aussi difficile que l’AME pour les femmes. L’intention elle-même n’est pas un déterminant suffisant d’un AME sauf si un nombre des facteurs son mis en place. L’allaitement prolongé est la norme au Malawi et il faut que les programmes soient sensibles aux attentes des mères et qu’ils associent les belles-mères et les pères au conseil des mères qui ont l’intention de pratiquer l’AME (*Afr. J. Reprod. Health* 2010; 14[3]: 213-222).

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Key words: Breastfeeding, exclusive breastfeeding, weaning, HIV/AIDS, Malawi.

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## Introduction

In recent years, the availability of antiretroviral (ARV) therapy has improved significantly, allowing more patients with AIDS to stay alive<sup>1</sup>. As a result, an in-

creasing number of HIV positive women are having children. If no preventive measures are taken, 30–45% of their children are at risk of contracting HIV during labour, delivery and the breastfeeding period<sup>2</sup>. Infant feeding in itself is estimated to be responsible

for 5%–20% of the burden of HIV transmission from mother to child<sup>2</sup>. Fortunately access to prevention-of-mother-to-child transmission of HIV (PMTCT) – consisting of a combination of short-term antiretroviral therapy during labour and delivery – has improved but remains insufficient to cover the existing need<sup>1</sup>. The effect of PMTCT programmes is only sustainable if the mother practises either exclusive breastfeeding (EBF) for six months followed by prompt weaning *or* chooses to feed the child with infant formula instead of breast milk<sup>3</sup>. The need to interrupt breastfeeding after six months is based on evidence showing that the risk of HIV transmission through breastfeeding increases gradually the longer the period of lactation becomes<sup>3</sup>. Thus, the question of whether or not to breastfeed has now become a critical component of an efficient HIV response in low-income countries.

The present study explores the challenges which HIV positive women in Malawi face when they have to decide how to feed their infants. They often find themselves in a conflicted position because the recommendations made by health experts are different from what is expected by kin. By using qualitative data we analyse patterns of breastfeeding and complementary feeding among a group of HIV positive mothers who all intended to practise EBF. We argue that even though mothers are the main caregivers for their children, they are not the only decision makers on feeding options. This is the case for women in Malawi regardless of serostatus but the situation of HIV positive mothers is further complicated because of conflicts between socially acceptable feeding patterns and public health based advice on how to prevent HIV infection. We also argue that to some extent, the women seem to be better informed on HIV than on basic breastfeeding techniques.

### *Breastfeeding and HIV Prevention*

Globally mother's milk is promoted by the health sector as the most appropriate infant feeding method with reference to its nutritionist value. Breastfeeding is also encouraged because of its potential for stimulating emotional connection between mother and child. However, in the light of research showing how HIV can be transmitted through lactation, HIV positive mothers-to-be who can afford acceptable, sustainable and safe replacement feeding are advised to avoid breast feeding and use formula instead<sup>3,4</sup>. If replacement feeding is not possible due to economic constraints, problems of correct storage or due to cultural practices, EBF for six months followed by prompt interruption is recommended by HIV experts<sup>3</sup>. This recommendation is based on the fact that the mortality and morbidity due to other infections such as diarrhoea outweigh the advantages of escaping the risks of HIV infection<sup>3,5</sup>.

The evidence for these recommendations is solid. Studies have suggested a strong statistically significant protective effect of EBF against postnatal HIV infection for the first six months of life as compared to mixed feeding<sup>6,7,8,9</sup>. It is documented that EBF can reduce the risks of MTCT during breastfeeding by 13%-15%.<sup>3</sup> Mixed feeding can be dangerous as replacement feeds and liquids might irritate the infant's stomach and thus make it easier for the virus to cause an infection<sup>11</sup>. It is a fine balance as showed by a randomized clinical trial in Kenya which found that *not* breastfeeding was associated with decreased HIV transmission by 40%, but also with increased risks of death from malnutrition and various diseases including diarrhoea and upper respiratory infections; hence not breastfeeding is associated with increased infant mortality<sup>10</sup>.

### *HIV and traditional unsafe practices*

The evidence that EBF leads to a lower rate of postnatal HIV transmission as compared to mixed feeding has motivated international donors and the national health sector to intensify the promotion of EBF in HIV prevalent areas<sup>8,9</sup>. However, a common lesson of these interventions aiming at translating global health concepts into communication seems to be that it is quite a challenge because they urge women to change behaviour in a social environment where mixed feeding – not EBF – is the cultural norm among lactating mothers<sup>12,13,14</sup>. The underlying message has been to change what is perceived as local, traditional and unsafe practices into something which seen from a health perspective is less likely to lead to HIV transmission to the infant<sup>14</sup>. This resonates with other behaviour change interventions that are given authoritative value by HIV prevention programmes which seek to motivate the individual to avoid so-called traditional practices which include unprotected sex or blood contact<sup>15</sup>. The approach is consistent with development discourses dating back to colonial times, which has often been translated into what can almost be described as 'social engineering' aiming at modifying individual behaviour<sup>15</sup>. The underlying assumption is that any responsible mother who receives appropriate knowledge will act on this information and change her behaviour accordingly. However, the lack of success from many HIV prevention programmes, suggest that transfer of information alone is not doing the job. In an anthropological study on how international NGOs address the role of traditional practices in HIV transmission in Malawi, Bruun<sup>15</sup> argues that understanding maternal decision making for infant care requires appreciation of these practices in their multi-layered local contexts, especially how they are challenged, negotiated and used differently by various groups of people. Breastfeeding does not take place in a social vacuum. There are intergenerational power relations and social conflicts involved<sup>13</sup>.

## *African experiences with promotion of EBF*

The large majority of infants who are infected with HIV live in sub-Saharan Africa. African health ministries have thus started to implement interventions to reduce MTCT, including efforts aiming at promoting EBF<sup>16</sup>. Studies show that in cases where high rates of EBF have been achieved, the key ingredients have been good quality follow up counselling provided by health care staff or peers to mothers<sup>17</sup>. Community-based interventions such as peer counseling, use of visual aids, home visits and postnatal support groups have shown to increase EBF rates in many parts of sub-Saharan Africa, including Malawi<sup>17,18,19</sup>. In a study from Rwanda conducted in 2005, 81% of HIV positive women practised breastfeeding and nearly 80% exclusively breastfed their babies up to six months. This was mainly achieved through continuous counselling of lactating mothers<sup>20</sup>. A study conducted in Zambia underlined the importance of considering the wider social context by specifically demonstrating an association between very high levels of exclusive breastfeeding in the first 4-6 months of life with effective counselling of lactating mothers as well as with family members on how to support the mother while practising EBF<sup>9</sup>. Disclosure as well as husband and family support have proved to be important in the promotion of EBF<sup>12</sup>. Studies conducted in Malawi indicated, as earlier mentioned, that paternal grandmothers are the key decision makers in deciding when to introduce foods to the infant and their involvement was seen to be useful to improve EBF<sup>13</sup>.

What seems to be common to successful interventions is that instead of transfer of information they promote *transformative learning*<sup>13</sup> where both mothers and other decision makers in relation to child nutrition are addressed jointly in order to empower the lactating mothers so they are able to modify feeding practices<sup>13</sup>.

### *Breastfeeding in the Malawian Context*

In Malawi, child malnutrition rates are high and have been so for nearly two decades<sup>21</sup>. As a response, breastfeeding has increasingly been promoted through the so called 'Baby Friendly Hospital Initiative' as a means to reduce the high prevalence of stunting among children and to improve child survival rates regardless of the serostatus of the mother. Exclusive breastfeeding is also specifically promoted with HIV positive women as the target group<sup>22</sup>.

However, EBF is not culturally acceptable in Malawi and most women start practising mixed feeding within the first 48 hours after birth of the child<sup>13</sup>. Often this practice originates on the advice of the paternal grandmothers who are perceived as sources of knowledge and authority in reproductive matters and good parenting.<sup>13</sup> Bezner-Kerr et al documented in a study from Malawi that women with

an unknown HIV status were likely to introduce foods or liquids (either porridge, water or herbal or root infusions) to newborns<sup>13</sup>. This study also showed that women are expected to partially breastfeed well beyond the age of six months and prolonged breastfeeding for up to two years is common. A mother who does not breastfeed is standing out of the group and can be subject to suspicion (e.g. being HIV positive).

With this study, we sought to understand factors that encourage or hinder HIV positive mothers in Malawi who wish to practice EBF from doing so. Most research has used a quantitative approach with a specific focus on the actual extent of EBF among HIV positive women; little is known about what motivates or limits the mothers of so-called 'Nevirapine babies' – the name that is widely used by members of the local community in Malawi to designate babies of whom the mothers are presumed to be on ARV therapy – to practice EBF.

### *Study location*

This study took place in Malawi, one of the poorest countries in the world, ranking 160 out of 179 countries at the Human Development Index<sup>23</sup>. Malawi has taken a high toll of HIV cases with an estimated prevalence in 2007 of 12.0%<sup>24</sup>. Approximately 80,000 children under the age of 15 years are currently living with HIV and an estimated additional 30,000 babies are born with HIV every year<sup>25</sup>. The data collection was conducted in Lilongwe, the capital of Malawi. The population of Lilongwe is estimated at 1,687,167 people<sup>26</sup> and the HIV prevalence among pregnant women is estimated at 12% in Lilongwe district<sup>24,27</sup>. The study participants were recruited from two sites: Bwaila Hospital and Kawale Health centre. These facilities are both part of the University of North Carolina PMTCT project which is currently the largest PMTCT project in Malawi as well as sub-Saharan Africa<sup>27</sup>. Both facilities are busy and physically located close to each other. Their clients include women from urban and semi urban areas of different economic status. Rapid testing and 'opt-out' approaches to testing are now standard in Malawi and the project reports that 98% of all pregnant women who attend their first antenatal visit accept HIV testing<sup>27</sup>. Even after decades of high HIV prevalence, stigma and discrimination are reported to be high in the general population<sup>16</sup>.

## **Methodology**

### *Data collection*

This study adopted a qualitative approach using individual in-depth interviews and observation as the main source of information. Data collection took place from December 2008 to January 2009 by the first author who has a public health background, as

well as training in qualitative methods and who is a Malawian citizen. Study participants were recruited from the two health facilities by purposive sampling techniques targeting HIV positive women at least 18 years of age with babies of 7–12 months who had intended to practice EBF for 6 months. A total number of 28 women who met these criteria were approached by the first author and 21 women were successfully interviewed. The reasons given by the seven women who declined returning for an interview were lack of time and Government holiday. The researchers stopped recruiting more participants when it was felt that saturation was reached and no new themes were emerging during the interviews.

### *Data analysis*

The first author developed the semi-structured interview guide which was then further developed and refined by the second author. The interviews were conducted by the primary investigator in Chichewa – one of the main languages in Malawi– audio-recorded and then transcribed into English. Data were analysed using the software programme NVivo 8.0.

Qualitative data analysis methods were used including reading and rereading field notes and interview transcripts<sup>28</sup>. All verbatim transcripts were analysed with a thematic approach where emergent codes were applied and linked to the raw data. The codes were identified based on topics which emerged through the analysis in relation to the core question. Comparisons were then made based on code frequencies and salience (i.e., the number of combinations in which a code co-occurs). Throughout the study, the WHO definition of EBF stating that “the infant receives only breast milk and no other liquids or solids, not even water, with the exception of drops or syrups consisting of vitamins, mineral supplements or medicines” has been used<sup>3</sup>.

### *Ethical considerations*

This study was conducted in compliance with international ethical guidelines and the research protocol was approved by the Malawi Health Science Research Ethics Committee and the University of Sheffield Research Ethics Committee. Permission to use the two clinics was obtained from the Lilongwe District Health Office and the management of the University of North Carolina Project. Each woman who participated was informed about the purpose, methods and procedures of the study and asked to give written consent or put a thumb print in the presence of a witness if illiterate to show her voluntary participation in the study. It was explained that they could stop the interview at any time and that the information they shared would remain confidential. It was emphasised that their participation would in no way affect their contact with the health system. All efforts were made to protect the confidentiality and

anonymity of the participants from the location of the interviews to using password protected transcripts of interviews. The informants received no direct benefit from their participation but were reimbursed for their transportation expenditures in line with the Malawi Ethical guidelines.

## **Results**

The mothers who participated in this study were aged between 18 and 40 and the majority were married (monogamously), six were separated and two were widowed but living with a new partner. The large majority had more than one child and mean parity was four live births with the highest being seven children. Almost all of the informants were literate. Despite their initial intention to practice EBF, less than half of the mothers (10 out of 21) included in this study reported breastfeeding exclusively for six months followed by prompt interruption. Those who did not practise mixed.

In the following, the findings are presented illustrating different issues that transpired during interviews using verbatim quotations followed by background information of the specific informant.

### *Living with HIV*

All of the women in this study either accepted an HIV test as a part of routine antenatal care or had a test at their own initiative because they suspected being infected with HIV. Fourteen of the women were already receiving ARV therapy. Some had become pregnant by choice whereas others, who already had several children, would have preferred to have terminated their pregnancy. As abortion is illegal in Malawi, a woman is required to see a private practitioner to terminate a pregnancy and many women do not succeed in ending an unwanted pregnancy. All the women who lived in a stable union shared the results of their HIV test with their partner after they had their positive diagnosis. Relationships ended in six couples immediately after disclosure of the woman's status and all couples who separated did so in cases where the woman had not told her partner that she would take a test. In the following quote a woman went alone for HIV testing without informing her husband and was then left by him. In the second case a couple went together and stayed when the results showed that she was positive but he was not:

*“...When I came to this antenatal clinic, I was tested for HIV and was found to be HIV positive. When I went home I disclosed my status to my husband and since he did not want me to have the test, immediately he started shouting at me as a prostitute who did not [respect him] ... then he left me.” (Mother of two, 20 years old, separated).*

The interviews indicated that the chances of the couples staying together after testing were highest if they had discussed the possibility of testing prior to their decision or even better if the couple went for testing together.

*"...We went together for the test and I was found to be HIV positive and my husband was found to be negative. After the results, he did not say anything and we are still staying together as a family without any problem" (mother of four, 28 years old, married).*

Women carefully select to whom they will disclose their status, including only people they trust, in particular their own mothers, their mothers-in-law or spiritual leaders. They wish to keep their status a secret because of fear of social disapproval as one woman explains:

*"If they know your HIV status they say a lot of things. Look at her. She got pregnant while knowing her status and now she wants to kill the child with her contaminated milk [Milk with HIV]. She is getting fat with ARVs". (Mother of six, 35 year, married).*

When the women accept an HIV test their decision seems to be rooted in the fact that they want to protect their unborn children from contracting HIV with biomedical technology that they can only access at the hospital. When they choose to share their HIV positive status with people in their close networks they explain it with a hope for support, financially as well as morally, for their children. Some also specifically mention the fact that they have shared their status with their mother so that she will understand when they try to practise EBF.

#### *Knowledge about breastfeeding and HIV*

All the respondents had been part of an EBF awareness raising project at either the Bwaila Hospital or Kawale Health centre. They had become quite 'HIV literate' and were able to explain how to prevent HIV infection and re-infection. They were able to paraphrase the definitions of EBF and to explain why they should avoid supplementary feeding. The women also stated that they initiated breastfeeding immediately after delivery as to give the baby colostrums which otherwise are considered as bad milk and avoided. However, when probed they indicated supplementing infant feeds and having an unclear perception of what the 'E' actually stands for in EBF:

*"I managed to practice exclusive breastfeeding for 6 months and only gave gripe water when my baby was crying a lot due to stomach pain. I also gave traditional drugs for fontanel closure nothing else but breast milk. I always give gripe water to all my children to reduce stomach pain that makes children to cry a lot" (mother of six, 35 years, married).*

It seems as though some of the traditional practices were so deeply rooted in the maternal catalogue of care that the women simply do not recognise them as being in opposition to the expert given definition of EBF which requires that breastfeeding is started immediately after delivery and that no other supplements are given to the child.

*"They said that if I breastfeed exclusively the child will be healthy and that will reduce the chances of transmitting the virus to my baby. Those who mixed feed within two or three month the chances are very high because the food can cause bruises on the intestines of the child and that makes it easier for HIV virus to pass to the baby. I only gave water to my baby". (mother of four, 25 years, married).*

The women explained that if they develop cracked nipples the chances of transmitting the virus are higher in which case they should contact the hospital.

The interviews also provide evidence that women who are part of this project struggle with the conflicting messages surrounding lactation and HIV. On one hand they are told that 'breast is the best' while on the other they understand that an HIV positive mother risks transmitting a deadly virus when she breastfeeds her newborn. The women interviewed are aware of the fact that the child could be given infant formula exclusively (instead of mother's milk), but the financial cost is high and they feel too poor to buy it. They fear that their breastmilk is toxic and they are afraid that the ARV medicines can harm the health of their child:

*"I was so concerned because at first I heard that if you are HIV positive you do not need to breastfeed your baby at all but when I came to the clinic I was surprised when they told me that I have to breast feed my child exclusively for 6 months. I felt as if I was giving poison to my child [milk with HIV] and so worried that my child will become infected with HIV." (Mother of five, 40 years, married).*

#### *Barriers to EBF and prompt weaning*

11 out of 21 of the women interviewed reported that they gave their infant supplementary feeding despite their wish to practice EBF. The barriers included perceived lack of milk, lack of control of feeding situation, felt and enacted stigma and poor counselling.

The most frequently mentioned reason for their failure to exclusively breastfeed was a perceived lack of milk. The respondents had all experienced episodes where their baby was crying loudly and they were unable to calm him or her quickly enough to prevent grandmothers from intervening. The women complained about insufficient amounts of human milk, but mentioned no way of stimulating milk

production, such as breastfeeding the infant more frequently. On the contrary, they prefer to let the infant sleep as long as possible and start introducing supplementary liquids. Additionally, the respondents explained the insufficient milk production with lack of nutritious food for themselves.

*“He was just crying a lot and by that time I was also staying with my parents and they said that may be the milk is not enough and I should try to give some porridge. I had to listen to what my parents said to me. When I gave some porridge to the child, he stopped crying and immediately he slept. I felt maybe it was really true”. (Mother of 4, 28 years, married).*

They loose weight and feel unenergetic which they associate with frequent breastfeeding. For an HIV positive mother who tries to breastfeed while keeping her status a secret, any visible sign that can be associated with AIDS is perceived as an added psychological burden:

*“The time I was breastfeeding I was losing a lot of weight and feeling dizzy as if I was sick and people started gossiping that I had AIDS. They said: “look at her she is now suffering from AIDS.” I became very slim unlike this time since I have stopped breastfeeding that was the other reason I decided to stop breastfeeding” (mother of three, 24 years, widow).*

One of the most frequently mentioned barriers during the interviews was lack of control over the feeding situation and it is striking that none of the mothers who did not realize EBF had disclosed their status to their mothers or mothers-in-law. The power of the paternal grandmother is important in Malawi, if decides that the infant should be given water, porridge or herbal infusion the mother cannot refuse unless she has the explicit and continuous support from her husband. This is in particular the case for a young mother who is perceived as inexperienced and less knowledgeable about child care. The paternal grandmother has influence over her son's choice of wife, whether the relationship shall continue and over who gets the child in case of divorce; furthermore, she often lives next door or in the same house. If the mother is separated, it is her own mother who steps in and exercises her power over child nutrition practices. Confronted with her own mother's interference, a young mother expressed her feeling of helplessness like this:

*“My mother just decided that the child should start eating porridge but for me I did not want to do that. I don't know why my mother did that because she just cooked the porridge and bring it to me and then started feeding my baby. I tried to reason with her not to do so but she could not listen to me” (mother of one, 18 years, separated).*

To adhere to the instructions given by the HIV counsellors, the women should also stop breastfeeding completely after six months and start feeding the infant weaning foods and liquids. All women interviewed reported that abrupt cessation of breastfeeding was just as difficult as EBF. As breast-feeding itself is a key element in their identity as mothers and women, it was perceived as socially stigmatising to abstain from this way of caring for your child, especially when the child is crying for the breast in front of other people. The reasons given for this are similar to those given above concerning EBF—social pressure, fear of being pointed out as HIV positive— but they specifically also mention poverty; how difficult it is for them to purchase nutritious replacement food for the infant:

*...It is also an issue if you don't breastfeed your child at such a small age. If you go for social gatherings and your baby start crying they start insulting you. “Why are you not breastfeeding the child? Is it yours or you have stolen from someone?” it is really very difficult to stop breastfeeding at this age” (mother of three, 24 years old, married)*

The respondents reported that the timing of the counselling was inappropriate as it took place right after they had received their HIV test result. They felt overwhelmed with confusion, fear and other emotions and thus unable to process information on how to breastfeed a yet unborn child. Furthermore, they expressed dissatisfaction with counselling in group sessions in which they were given ample information but in which they felt they lacked the opportunity to process this information. Instead they would have preferred counselling on an individual basis. Some ended up not revealing the fact that they failed to practise EBF to the HIV counsellors out of fear of antagonising the hospital staff. All of the respondents knew that the staff wanted them to practice EBF and even though the mothers agreed, they often did not realize their intentions. However, they only dared to admit that during interviews conducted for this study. It seems likely that failure to practise EBF is grossly underreported:

*“Usually they give us more information during the first visit. Sometimes it becomes difficult because this is the day you are told about your HIV status and at the same time they do give us a lot of information at once. Mostly women don't concentrate because they think of their status and how to break the news to the partner” (mother of one, 30 years, married).*

In addition to the above-mentioned barriers, these women are subject to negative labelling when they are called names such as 'HIV person' and their infants are referred to as 'Nevirapine babies'.

*"They say look at the 'Nevirapine baby' referring to your child because they know that HIV positive mothers are given Nevirapine during labour and the child is also given Nevirapine after delivery. They give us all sorts of names like 'HIV person' [Waka-chirombo]" surviving on top ups [ARVs]" (mother of three, 29 years, married).*

#### *When EBF is achieved*

There are many barriers to EBF and abrupt weaning in Malawi, yet almost half of the respondents reported that they succeeded. Those women who managed to breastfeed exclusively for six months had disclosed their status to their husbands as well as to their mothers-in-law and benefited from the explicit support in relation to child nutrition from their husband. Mothers who did not live in the same household with the grandmother were more likely to practice EBF for a sustained period of time. A contributing factor to success seems to be living in a stable relationship with a man rather than living alone. This might be explained by the fact that women living alone complained about shortages of quality food leading to inability to cater for their own nutritional needs. Women older than 25 who had already experienced child caring were also more likely to be able to practice EBF.

A key factor in successful EBF is a feeling of empowerment within the woman, which allows her to negotiate the conflicting expectations of her kin and to navigate society's expectations of how she should behave as a mother. On the one side there is hospital staff who instruct HIV positive mothers to abstain from supplementary feeding and on the other side there are the grandmothers who strongly believe that infants should be given traditional foods. Traditional advice from grandmothers who are present on a daily basis conflicts with instructions of the hospital counsellors who are distant and unable to provide support. Only women with determination and social power can overcome this conflict. One young mother explained how she had to stay physically close to her child at all times because she did not trust her own mother to respect her decisions. In her own words she needed to be 'so strong' when confronted with family members:

*"Sometimes my relatives and my mother were forcing me to start giving the child some food or water but I told them that I will follow what I have been told at the hospital. I was so strong and I managed to convince them on how I want to feed my baby. Being the first child they take you as if you don't have enough knowledge on how to feed your own child. They take you as if you don't know what to do. I always made sure that I move with my child everywhere to prevent them from giving food in my absence" (Mother of one, married, 30 years).*

## Discussion

### *Contextual Choices*

The long-term benefits of any PMTC programme in low income countries depend on its capability to support women in practicing EBF. The evidence is robust –international and national guidelines are based on research showing that EBF or exclusive feeding with infant formula can reduce the risk of vertical HIV transmission considerably<sup>3,4,29</sup>. In high income countries, HIV positive mothers are advised to replace human milk with infant formula, but in low income countries where access to safe water and replacement formula is difficult and where breastfeeding is the cultural norm, the recommendation to mothers is to opt for EBF followed by prompt weaning after six months<sup>3</sup>.

Massive funds have been invested by the international donor community in educating women in areas of high HIV prevalence on the various methods to protect themselves and their children against HIV infection or on how to live 'positively' with AIDS. These interventions have not been followed by the same public health driven efforts in empowering women on how to practice EBF. Instead, more than half of the women interviewed for this study do what is considered the most dangerous: they give mixed feeding and practice prolonged breastfeeding. The research results presented above suggest that in spite of globalized discourses, national implementation strategies at the ground and individual women's own intentions, mothers still find it difficult to practise EBF as well as abrupt weaning.

In this empirically based study we aimed at understanding the dilemmas between globalized public health concepts and locally lived lives seen from the perspective of a group of women in Malawi. Obviously, it would have added more strength to the study if time had allowed us also to interview grandmothers and fathers as they constantly are referred to by the respondents as influential decision makers.

HIV prevalent rates have been high in Malawi for such a long time that the society has been exposed to a number of different information campaigns about HIV and AIDS. The results indicate that to some extent the counsellors at the hospital had succeeded in teaching the women the technicalities of their HIV –they knew all the brand names of their medicines, they were aware of how HIV can be transmitted through mastitis, they remembered that it was advised to use condoms during sexual intercourse to avoid re-infection. What they seemed to be less knowledgeable about were the 'how to do' of breastfeeding –which apparently is being taken by the counsellors at the hospital as something that should come more or less 'naturally' to women. Breastfeeding seems to be perceived as a simple and practical task rather than the complex passage

to motherhood that it also constitutes. Women knew little about how to stimulate milk production such as feeding on demand, find the correct positioning and avoid pacifiers and bottles— and often found themselves frustrated with inadequate amounts of milk production.

The majority of the women complained about the quality of counselling in groups. The communication which takes place in such a group between one expert and a number of group members will tend to become passive learning (at best) where the participants are reluctant to voice their real concerns. Other studies have noted the tendencies by hospital staff to communicate in a rather repressive way pointing out the mothers' inability to perform correctly according to the guidelines<sup>13</sup>. Our study confirms that women would have preferred individual counselling. In spite of national communication campaigns followed by group counselling at 'baby friendly' hospitals, women found it difficult to practice EBF. We found that even though the hospitals might be awarded with the label of being 'baby friendly' the question of whether they are also truly 'mother friendly' remains open.

Overall, our results show that intention in itself to practice EBF is not a sufficient determinant of successful EBF followed by early cessation of breastfeeding unless a number of enabling factors come together. First of all, infant feeding is practised in a contextualised social and cultural room. There is no local credibility attached to exclusive breastfeeding. Many studies from the African continent have pointed to the fact that mixed feeding – not exclusive breastfeeding – is culturally mandatory<sup>30,31</sup> and that is also the case with prolonged breastfeeding – not early weaning. Our study confirms what is already shown in similar research that the narratives around breastfeeding are very strong and show that feeding responsibility is not confined to the mothers only. Grandmothers, especially paternal grandmothers, have a high stake in infant feeding and they act as catalysts for social pressure on young mothers to introduce complementary feeding shortly after birth—often for religious or traditional medical reasons. However, this study also shows that mothers do not necessarily want to obey traditions if they are presented with convincing arguments in favour of new alternatives. All of the respondents in this study agreed on the HIV information that they had received, but they felt that the group counselling did not give them the required social capital to actually practice EBF. The social capital can either be that they already had several children and therefore are a 'proven' mother or support from their husband. Independence and resources can be to live without the presence of a grandmother. The question is whether such social capital can be internalised by the women if the counselling they receive was problem oriented, individual and based on a dialogue.

The concept of 'transformative learning' as discussed by Bezner-Kerr et al seems to hold the potential for more active empowering of the young HIV positive women who are also mothers.

## Conclusion

Breastfeeding choices represent a genuine public health challenge in high prevalent HIV areas of the world. Whereas HIV-sero-discordant parents-to-be in rich countries have access to reproductive technology such as semen washing, donor insemination, caesarean section delivery and safe infant formula, women in poor countries who wish to have child have a much reduced pallet of choices. First of all, their access to primary prevention of HIV (male and females condoms) as well as to family planning and safe abortion is sub optimal. Secondly, access to PMTCT programmes is insufficient. Coupled with similar research, this study shows that one important way to eliminate HIV transmission from mother to child is to empower women who wish to practice EBF and to wean their children after six months. It also indicates that PMTCT programmes must be based on a better understanding of the fine balance between generations in the local community, so that the lactating mother can be prepared for communication with grandmothers and fathers on infant feeding. It is also a strong finding of this study that education on EBF and weaning should be given jointly to mothers, fathers and grandmothers for a more efficient response. To focus on the individual care giver is much too limited to grasp the complex reality that characterises infant feeding in Malawi.

On a larger policy level, it seems obvious that there is a need for sustained anti-stigma efforts so that the community comes to accept people living with HIV and their children. PMTCT programmes should focus on how to improve counselling to mothers –e.g. by more individual follow up, better communication skills and assertiveness among counsellors— on the need to practice EBF. PMTCT could also adopt a more holistic approach that integrates maternal and reproductive health. Families may benefit from breastfeeding techniques as a continued part of the dialogue between the HIV positive mothers and the health care system. It is important to understand that the women are not only HIV positive mothers, but also community members, wives, daughters and daughters-in-law. Placing relations and social competences at the centre of a dialogue on child feeding may increase understanding of the complex situation that these women find themselves in.

## Acknowledgements

The authors wish to convey their gratitude to all the women who shared their concerns and thoughts



with us. We would also like to thank Dr Paul Bissell and Michael James Calopietro for valuable comments. The field work was financed through the Erasmus Mundus programme of the European Union.

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