Breastfeeding and ART: new social and cultural issues WePeD6367

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Background

With the extension of PMTCT+ programs, an increasing number of women from low income countries may breastfeed their baby while getting ART. Moreover, trials have been set up to study the preventive efficacy of prophylactic ART on HIV transmission through breastfeeding. This situation raises new questions about perceptions and acceptability of breastfeeding and ART.

Mothers' perceptions about breastfeeding and ART may have three kinds of consequences:

- low observance of exclusive breastfeeding amongst mothers under ART, because they think that milk is fully protected from HIV by ART
- low adherence to ART amongst mothers that chose to breastfeed, because they think that ART might be toxic for the baby
- refusal of the option of exclusive breastfeeding by women under ART, to avoid perceived toxicity, which would hinder the future use of prophylactic ART.

Methods

Perceptions of women applying exclusive breastfeeding and early weaning while getting ART, and perceptions of HIV positive women about the effects of ART on breastfeeding and on mothers' and children's health are studied in a research project on "Social and cultural determinants of mother-to-child transmission of HIV through breastfeeding", held in 5 countries in Asia and Africa (Burkina Faso, Ivory Coast, Cambodia, Kenya, Cameroon), with an anthropological perspective. Preliminary data presented here come from Ivory Coast, Cameroon and Cambodia.

Results

The following perceptions have been identified.

ART is able to pass in breastmilk

Some women from Abidjan, Phnom Penh and Yaoundé, think that ART is present in breastmilk; some others don't.

Women explain presence of ART in breastmilk

- either by deductive reasoning, considering that the virus being in all parts of the body, treatment goes to the same places, for efficacy is the result of a kind of local fight; thus, treatment also goes to breast and passes into milk
- or according to local "popular" perceptions of physiology of lactation, which consider that milk is produced from all elements ingested by the mother.

> ***« Yes, yes, it passes. Since when you breastfeed, all things you eat, the baby gets them too » (Yaoundé, 20 years old woman, housewife, litterate, 1st child).***

Some women draw an analogy between food and medicines. They explain that if food may be useful for the baby, it also can cause him harm... thus, a treatment taken by the mother may also be either efficient or dangerous for the baby. These perceptions fit with the rich corpus of food prescriptions and proscriptions during breastfeeding, that have been described by ethnologists in various social and cultural settings[1].

ART is able to affect lactation

Some women think that ART may affect lactation, mostly by reducing the quantity of milk.

> ***« I say that because after taking this medication my milk doesn't come. ART reduces the volume of milk (with other medicines it is the same) » (Phnom Penh, 32 years old woman, illiterate, housewife, 1st child)***

This perception may be due to the fact that a relationship of causality between the set up of ART and the coming of the milk is established by women that live both events simultaneously. Another explanation may be that women get prolactin inhibitors, but don't make a difference with ART. More in-depth investigations on perceptions of the physiology of pharmaceuticals might show that, as in Dakar, ART are perceived as "strong medicines" that affect body fluids[2]. Further studies are needed on this subject.

ART is toxic for the baby

Most women trust health professionals and think that they wouldn't be given toxic medicines.

> ***« Since we take nevirapin and we are told we can breastfeed until four months, then it means it has no negative impact on breastmilk » (Yaoundé, 30 years old woman, housewife, 5th child)***

But this perception interfers with some different points of view, sometimes expressed with strength. They consider that ART is too strong for children, as it is so strong that it may be toxic for adults.

Moreover, toxicity of ART justifies formula for women who chose this feeding option. This may determine mothers' choice or be the result of a rationalization after choice; on that issue, women have different perceptions according to the feeding option:

> ***« I must take medicines that the baby must not ingest because medicines are strong, then if he takes them he may fall ill, then we prefer to give him formula » (Abidjan, 26 years old woman, housewife, 3d child)***

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[1] Desclaux A, Taverne B (eds). Allaitement et VIH en Afrique de l'ouest. De l'anthropologie à la santé publique. Paris, Karthala, 2000

[2] Desclaux A., Laniece I., Ndoye I., Taverne B. (Eds), The Senegalese Antiretroviral Drug Access Initiative. An Economic, Social, Behavioural and Biomedical Analysis, Paris: ANRS, UNAIDS, WHO; 2004, 230 p. (previously published in French) (existe en version française) available on www.anrs.fr

A woman from Phnom Penh expresses a different understanding of the impact of ART, rooted in local perceptions of health and disease as the result of hot-cold imbalance, a model that prevails in Asian area as well as in South American area and, to some extend, in European popular perceptions. For her, ART is not directly toxic for the baby through ingestion, but these medicines produce body heat for the mother, which can be transmitted to the baby by contact. Then, this lady wears long sleeves to carry her baby after taking ART. (Phnom Penh, 35 years woman, illiterate, factory worker, 1st child)

Pharmaceuticals are toxic and should be avoided during breastfeeding

Some women, litterate, assess that pharmaceuticals are toxic according to scientists and doctors.

> ***« I often read this in the medicines' notices, under contra-indications, it is written that you cannot take it when breastfeeding ». (Yaoundé, 28 years old woman, secretary, 1st child)***

But this concern seems to be limited, less important than in developed countries where promotion of breastfeeding includes warning about pharmaceuticals intake. This issue might have been neglected in breastfeeding promotion programs in developing countries. Specialists of breastfeeding consider that effects of pharmaceuticals on breastmilk are understated in developed countries, but the issue remains to be studied worldwide.

Traditional treatments may cure breast ailments and pass in breastmilk

> ***« There are many medicines that you, the mother, may take. And the baby takes them too » (Yaoundé, 20 years old woman, housewife, litterate, 1st child).***

Local understanding of physiology in Cameroon, as in other African countries, means that the mother and the baby being related through breastfeeding, a medicine taken by the mother will also treat the baby. Two situations may be seen: some traditional medicines are given to treat mother's ailments and, subsequently, her baby (for instance for malaria); in some cases, medicines are given when the mother is not ill: they are made to cure child's diseases that are due to breast ailments, conveyed by milk, or due to the composition or toxicity of breastmilk. These perceptions provide a model for understanding ART effects.

These perceptions about the relationship between ART and breastfeeding are also rooted in more general perceptions about ART effects on the mother and the baby.

Absence of knowledge about ART possible "side effects"

In Phnom Penh as in Yaoundé or in Abidjan, all women that had short treatment by nevirapin and some women who had one-month treatment did not report getting information about side effects of ART (given for PMTCT) from health professionals, during counselling nor during visits. But this doesn't mean that women do not feel side effects: some women who got one-month regimen reported body feelings such as vomiting or heat. Some complained about the difficulty of ingesting medicines - but it is not sure that these medicines are ART, since most mothers interviewed didn't recognize the kinds of medicines they were taking, mixing ART up with iron or vitamins.

Perception of ART side effects is an important and complex issue. It has already been shown in Senegal that people taking ART think that the efficacy of the treatment is related to its strength, which is modulated by individual compatibility of the patient's body with the medicine. Thus, they consider that adverse side effects are related to the confrontation of the patient's and the medicine's strengths. Such perceptions may jeopardize adherence to exclusive breastfeeding, that we'll explore in next interviews. In Dakar too, it was shown that health professionals did not explain much side effects to patients starting ART treatment (2).

Moreover, women didn't report getting information about the risk related to nevirapin of producing viral resistances that might hinder mother's treatment. However, most interviews were conducted before Feb. 2004, when the results revealing the importance of such resistances were published.

Absence of knowledge about ART limited preventive efficacy

Women think that their babies are fully protected by ART if they follow health professionals' indications. No woman reported that she was told that PMTCT results in risk reduction: all believe that PMTCT measures cancel risk.

> ***« A mother who does what she is told to do doesn't contaminate her baby »***
> ***(Abidjan, 24 years old woman, unemployed nursing auxiliary, 2nd child)***

Morever, some of them consider that preventive efficacy of PMTCT only depends on themselves.

> ***« If I take medicines properly, the baby cannot get [HIV/AIDS] »***
> ***(Abidjan, 24 years old woman, unemployed nursing auxiliary, 2nd child)***

This attitude, either due to health professionals discourses, or to mothers' interpretations, can be considered as making the victims feel guilty, and should not only be avoided but also challenged by counselling.

Conclusions: Propositions for counselling

Though preliminary, these data show the importance and insufficiencies of counselling. Women's attitudes and practices depend on the way levels of risk, efficiency of ART for risk reduction, and ART effects on breastmilk, have been explained to them. These issues are not considered in every program.

The content of counselling is of first importance. On such sensitive topics, it may easily convey either false feelings of security or exaggerated anxiety and requests for precautions. Moreover, when PMTCT turns to PMTCT+, counselling about infant feeding should be tightly related to counselling about ART. Support for infant feeding and for adherence to ART may be provided by the same services or community-based organizations. Integration of both aspects will raise new questions, while evaluation of adherence to exclusive breastfeeding has not yet been fully established, and when measures for adherence support have seldom been analyzed in programs providing ART in Africa.