DISCOURSE ON FORMULA FEEDING BY HIV POSITIVE MOTHERS IN CAMBODIA

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Background

Some policy-makers and NGOs fear that in societies adverse to milk substitutes, using the bottle could lead to stigma. Hence, concern for the individuals commands the promotion of exclusive breast-feeding in all situations, including when the mother is HIV positive. Conversely, in societies not opposed to the use of formula, emphasis is put on a global threat, the risk of "spill-over": HIV positive mothers could set a trend undermining "breast is best" policies. This research, conducted over 18 months (November 2003-May 2004), attempted to evaluate: 1. the risks of discrimination linked to artificial feeding and 2. the mothers' perceptions of breast and artificial milk nutritional values.

Methods

A total of eighty semi-structured in-depth interviews with 49 HIV positive mothers. A first interview when the child is between 1 and 6 months old (M1); a second interview at age 6-11 months (M2). Three mothers interviewed 3 times. Sessions were conducted in Khmer, by a mature female researcher selected on the basis of age and personal communication skills. All the interviews have been taped, translated word for word and analyzed through coded entry point.

Results

Profiles

Interviewee's mean age: 29, 2 years old. Mean number of children: 2, 4. Sixteen over 49 mothers (1/3) were illiterate, 29 had a mean of 5 years of primary education (data unknown for 5). Except for three mothers who could afford to pay for the formula by themselves, all the women interviewed were coming from the poor segments of society. Mean income was around one US dollar per day. Forty were directly referred by an NGO; 47 were relying on NGO's assistance for formula supply. Twenty six (more than half) were raising their children alone at the first interview. Six more were left alone at the second interview, as the husband was either dead, terminally sick or had abandoned them. One mother died after the first interview. Two babies died before the second interview.

Knowledge and perceptions of HIV transmission through breast-feeding

As in other studies in West Africa, results show that the mothers have to strike a balance between a social risk for themselves and eventually their older children (discrimination after their HIV status is revealed through use of formula milk) and a biological risk for the new born. This quandary is linked to their knowledge and representations of transmission through breast-feeding. This knowledge is shaped by access to one PMTCT program or another. None of the mothers received the full facts about rates of transmission and were "told what to choose" by the institutions. Four mothers received the advice to practice exclusive breast-feeding for 6 months; all the others were urged to adopt artificial milk. All of them finally decided not to breast-feed because the information about the safety of exclusive breast-feeding did not fit with what they had heard on TV, the radio or through neighbors and relatives. Folk representations of human milk link it to blood: "milk comes from blood" or "milk is made from blood". Since it is known that transmission occurs through blood, breast-feeding is perceived as extremely dangerous. One senior medical staff (Officier de Santé)

who had been told about the benefits of exclusive breast-feeding resorted to popular representations of milk ethno physiology

> « - You don't believe if the doctor tells you that you can breast-feed?
> - No, I am not sure because in the mothers' milk there is blood." (A12)

Coping with the biological risk

The risk of transmitting through breast-milk was not quantified properly. Most mothers thought that it was 100%. Percentages were difficult to handle for all of them, even for the mothers with a secondary education. But those who expressed beliefs in rates of 5 to 10% felt that even this was too much. All the mothers adamantly defended their choice of not breast-feeding, with explanations such as: "I pity my child" (A13, A39), "I am afraid to contaminate my child if I breast-feed" (A8, A9, A13, A14, A16, A20, A23, A39, A43), or "I have hope for him/her, because I did not give the breast" (A17, A29). One mother living in an institution for HIV positive women said:

> "Nobody there wants to give mothers' milk once they know that they are HIV positive. All those living there do not want to breast-feed, whatever the difficulties. They are afraid to contaminate the baby." (A9)

One mother who had previously lost a child from HIV after breast-feeding her said:

> "I have learnt my lesson" (A20)

Coping with the social risk

The problem of securing confidentiality and defusing suspicions arises in three different circumstances: at the maternity ward, at home and when going to the NGO's office to get the monthly supply. These settings imply different risks and different strategies. Several types of face-saving methods have been documented, fitting patterns observed in other countries.

1. It is in the hospital that most mothers feel embarrassed or afraid to be recognized as HIV positive by other patients. At the same time, since the encounter is brief and nobody knows them, it's easier to forge an excuse. Only two mothers said that when questioned about not breast-feeding they revealed their status. Questions had been asked by medical staff unaware of their condition and people sharing the same room. They reported getting sympathy after telling the truth. Sixteen other mothers found an excuse, the two most common being: insufficient breast milk and the need to go back to work. Some mothers said that they were sick, without elaborating.

   > "The other mothers in the room where surprised that I was not breast-feeding. I said that I had sore nipples and not enough breast-milk." (A47)

2. At home, mothers have to cope with their family and the neighbor's questions. A small minority (4 women) had not shared their status with their husband and 9 others had not told their immediate family (parents, siblings, children). In any case, economic and social difficulties implied already severed ties or institutionalization. It was easy then for these mothers to justify their feeding option as aid provided by one of the countless charities operating in Cambodia.

   > « When my husband came back he asked me why I was giving artificial milk. I had not told him that I have AIDS. I told him that when I was alone in the hospital

> I was given help because I was without any family support. He said that our child was lucky. Because for the other one I did not have enough breast milk." (A29)

A local feature is that in opposition to the cultural context in many African countries, formula feeding is a status symbol in Cambodia. Some mothers are using it by pretending to buy the milk:

> "When I am traveling people compliment me for being able to buy formula for my baby. And I tell them that bottle feeding is easier when I want to go somewhere. I can tell them anything, since they do not know my story. I am not afraid." (A24)

3. The mothers living outside institutional settings do not want the NGO's workers to do home visiting and choose to get their supplies in a different location. Meeting the NGO's workers at their office or in a third location implied encounter with other mothers, other staff and casual on-lookers. A socialization process occurred where mothers reported shame and timidity in the beginning before finally opening up to an opportunity to share their secret and practical know-how.

> "I am not ashamed anymore. The other people who go to get the milk, they know. We talk about it, we discuss. There is a woman from (X). She goes to get the milk. Her husband died on the 16th. We talked about it. We have the same story." (A15)

Together with these apparently clear-cut defense strategies it must be kept in mind that confidentiality and socialization of an HIV positive status is not a closed and well-rounded object. It evolves with the development of the disease, the support provided and the possibility to meet other patients. In that respect, the risk of discrimination linked to formula choice is worked up and controlled by their users who may shift allegiances and priorities.

Representations of milks values

Half a dozen mothers gave contradictory statements about their preferences or opinions, reflecting perhaps a mental struggle to cope with conflicting roles and messages. Six mothers said that there was no difference between the two. Thirteen mothers thought formula to be better, regardless of AIDS, mainly because it protected children from a maternal disease known in folk categories as ***toah*** (a post-partum condition well documented in other south-east-Asian countries). Eighteen mothers specifically judged maternal milk to be of better quality. Some based their opinion on evidence: they had seen other children thrive on breast-milk. Others mentioned representations mixing folk beliefs and medical ideas: the presence of vitamins or "good blood" in breast-milk was referred to by one over five mothers.

> "The mothers' milk is better. In the mothers' milk there is blood and it is more nutritious. The child that drinks artificial milk is weaker. I think that the mothers' milk is rich in vitamins. The child drinking breast-milk is strong and solid. He receives nutritious food through his mothers' blood." (A28)

Breast-milk was thought easier to use by 11 mothers, formula by ten mothers. The former allowed the mother to sleep at night while the latter gave her the possibility to go to work. Cleaning and preparation was felt as a burden by a fifth of the interviewees, many adding: "But never mind, I want to do it for my baby" (A47). More mothers (5) sensed that the quality of the relationship was

unaltered while three believed that it was less intimate. Only one mother expressed the regret that later, in case of emergency, her child would not be able to pray the goddess of maternal milk.

Ultimately, nineteen mothers reflected on their choice and stated that it was a good decision:

> "Yes, it was my choice. I do not regret it. If I were not HIV positive I would like to breast-feed. Which mother would not want to ? But I have this disease, I must accept the situation." (A28)

Conclusions:

In Cambodia, HIV positive mothers from poor backgrounds, make use of narrative, silence and denial to ward off suspicions about the reasons behind formula feeding. None of the social risks linked to providing HIV positive mothers with formula, (stigma or spill-over), could be foreseen.

Most of these mothers maintained that a mother's milk had a better nutritional value, confounding apprehensions that artificial feeding could prevail for complacent reasons. On the risk of a devaluation of breast-milk value, it can be said that mothers felt obliged to resort to formula because of their condition but regretted it.

In Cambodia, replacement feeding is socially acceptable. Conditions of feasibility, affordability, sustainability and safety, have to be assessed next in order to ensure the recommended avoidance of all breastfeeding by HIV-infected mothers (WHO, 2003).