Symposium on
Breastfeeding and HIV & AIDS

"Breastfeeding – Guarding Maternal & Child Health in an HIV & AIDS World"
Washington D.C. USA, 2 July 2005

Introduction

In the world of today where there is increasing awareness of the role breastfeeding plays in the establishment of optimal infant, young child and maternal health, breastfeeding faces increasing risk of losing its importance as the priority shifts more towards the prevention and control of HIV and AIDS. In recognition of this growing worldwide risk to breastfeeding, La Leche League International (LLLI) and the World Alliance for Breastfeeding Action (WABA) jointly sponsored this symposium themed "Breastfeeding – Guarding Maternal & Child Health in an HIV & AIDS World" in conjunction with the LLLI 19th International Conference. As stated in his introductory remarks, Prof. Michael Latham, International Advisory Committee (IAC) Co-Chair of WABA, identified the HIV/AIDS pandemic as the major challenge to breastfeeding in the 21st century.

Symposium Objectives

The major objectives of the Symposium were:

~ To bring together groups and individuals who believe in the importance of breastfeeding for optimal infant, young child and maternal health; to forge understanding; to discuss and to collaborate with the aim of protecting, promoting and supporting breastfeeding in the context of HIV and AIDS.
~ To brainstorm for progressive actions and common positions (e.g. framing of important messages that would be strategic for collaborations) that could be done through Advocacy, Research and/or Capacity building (ARC)*.

**Note: the concept of ARC was developed at the HIV and Infant Feeding Meeting in Lusaka, Zambia, February 2004.*

What is the problem?: Discussion points of the Symposium

The Symposium "Breastfeeding and HIV and AIDS" looked at the situation of breastfeeding in the context of the global HIV and AIDS agenda and current reality, and discussed possible collaborative efforts for advocacy, capacity building and research to protect, promote and support breastfeeding. Through online discussions and at the symposium, the following were identified as problem and priority areas.

Key Messages from the Symposium

1. **Health Outcomes**: Focus on survival and infants' health outcomes, not just the absence of HIV.
2. **Safe breastfeeding practices for all!**: Exclusive and continued breastfeeding is an essential global public health strategy, regardless of parents' HIV status.
3. **UN recommendation**: In the absence of acceptable, feasible, affordable, sustainable and safe (AFASS) replacement feeding, the UN recommendation is exclusive breastfeeding.
4. **AFASS**: If AFASS could not be fulfilled before baby is 6 months of age, it is not realistic to expect the mother/family to get animal-source and high energy density food after 6 months.
5. **Breastmilk Substitutes?**: Breastfeeding has to constantly prove its safety and efficacy, while the high-risk substitute is often considered acceptable until proven otherwise. (p/s: Powdered commercial milk formulas are not sterile and may be contaminated.)
6. **HIV+ Mother**: Keep the mother in the focus, for her own sake too. There is no additional mortality risk conveyed to the HIV-positive woman by breastfeeding.
7. **Mother-to-child-transmission (MTCT)**: MTCT puts the blame on the mother. We do not use the means of transmission to label other diseases.
8. **The myth of "Choice"**: There are cases wherein nurses are expected to recommend and mothers are expected to comply – both where AFASS is achievable and not. There should be a single globally applicable standard when it comes to informed choice.
9. **Food Security**: Breastfeeding ensures food security in HIV-prevalent and resource-poor areas and following natural and man-made disasters which prevent continuous supply of replacement feeding products to babies who are not breastfed.
10. **Threat of spillover**: Women whose HIV status is negative or unknown may decide not to breastfeed due to fear or misinformation about HIV transmission, and expose their infants to a greater risk of contracting other life-threatening illnesses.

A. Counselling and risk analysis

HIV-positive mothers are burdened with the dilemma of weighing the risks involved with different methods of feeding. From UN agencies to the lay person, making an informed choice has been viewed as the pivotal point thus further adding pressure on the mother to make the 'right' choice. However, the definition and implementation of making an informed choice is problematic, such as the possibility of continued breastfeeding with HAART treatment for the mother or the belief that babies who are breastfed by HIV positive mothers are more likely to get sick and die. Participants discussed the techniques / messages / guidance that are available to help explain practical dilemmas early so that an informed choice can be made.

The participants recommended that there be a clear decision tree or algorithm for an **individual risk analysis** for each baby in each one's specific circumstance, particularly if such algorithm needs to be developed.

A model of teaching counsellors on how to provide effective **counselling** regarding infant feeding decisions would be crucial.

The components of the **acceptable, feasible, affordable, sustainable and safe (AFASS)** assessments, i.e. when and how should the assessments be done, and what happens after assessments, are still unclear and are subject to health workers' interpretations. Health workers should know and experience the difficulties of assessing the feasibility of AFASS. Nonetheless, although AFASS has its loopholes it is still far better to have it implemented than not.

Clinical training or mentorship is another issue. Drugs and ART are not the only way to reduce post-natal transmission. It is imperative to increase the capacity of health workers' to help women breastfeed exclusively, and prevent and address breastfeeding problems such as sore nipples, that would help reduce risk of transmission.

Also lacking is the knowledge on the dilemmas and questions that mothers have and how health workers could best answer these questions.

B. Health Outcomes

Where is the empirical data for the health outcomes of infants, mothers and the population for different infant feeding methods? That was the question that participants had.

Observational data on feeding methods and **infant/ child and maternal health outcomes should be collected**. This would give more concrete evidence that could be shown to mothers in their decision making.

What is the evidence that, in terms of infant health outcomes, it is beneficial for HIV+ mothers to use **replacement feeding** under any conditions? Parents and health workers should bear in mind and be warned of the risks of bottle feeding regardless of HIV status. For example, formula powder by itself is not sterile. Health workers should experience the difficulties of using breastmilk substitutes before starting to counsel. Agencies or health workers that recommend replacement feeding in families should show evidence of positive impacts of replacement feeding in terms of mortality, morbidity, nutritional status etc, rather than just the possible negative impact of breastfeeding.

C. Cessation and complementary feeding

There are many possibilities on HIV and infant feeding beyond 6 months of age that have yet to be studied. Participants discussed the feasibility of a win-win situation by reducing risk of transmission while harnessing the benefits of breastmilk with the advantages of its nutritional value, cost (compared with formula or animal milk), and convenience in terms of lactational amenorrhea etc. For example, HIV+ mothers **expressing their breastmilk** to add to baby foods while cooking – to kill the HIV virus, at whatever age their babies cease breastfeeding.

When and how (e.g. rapid or gradual cessation) should an HIV+ mother stop breastfeeding, if at all? There are few best practices available until further evidence is known. The effect on morbidity and mortality of **early cessation** of breastfeeding is still unclear.

If AFASS could not be fulfilled before baby is 6 months of age, it is not realistic to expect the mother/family to get animal-source food and high energy density **food** if breastfeeding is stopped at that critical time in an infant's growth.

D. Policy: Global, national, community, organisational

The UN Framework for Priority Action states: When replacement feeding is acceptable, feasible, affordable, sustainable and safe (**AFASS**), avoidance of all breastfeeding by HIV-infected mothers is recommended; and otherwise, exclusive breastfeeding is recommended during the first months of life. UN agencies should be accountable to show that AFASS works, that this recommendation is feasible, and be explicit about its shortcomings or show that it does lead to improved outcomes.

Currently there is no systematic information on **national policies or practices**. We do not know which countries require/recommend to those who had tested positive not to breastfeed, what the results of these policies are, whether mothers were tested for HIV, whether

there were confirmatory tests available, or if diagnosis was made from symptoms. As a guide, countries could use existing documents and conduct rapid assessments on their country policies. National policy should not become a statement that protects the policy maker (like a **disclaimer**); instead it should protect the infant and mother.

The formulation of policy on HIV and AIDS should be based on collaboration among departments/agencies and be in line with other policies like 6-month exclusive breastfeeding. It is unclear how breastfeeding would continue to be promoted, supported and protected as a public health recommendation in the context of contradictory national policies. Governments should have more accountability in overseeing and ensuring this **collaboration and harmonisation** of policies.

Besides the dangers of using breastmilk substitutes, there is an inadequate appreciation for the **difficulties in sustaining on-going supplies** of formula for replacement feeding (for 3 months, 6 months, 1 year, 2 years?) in continents where there can be drought, flood, natural and man-made famine, political upheaval and withholding of food, civil war, displacement of people and other dire conditions. Even logistical problems such as foreign exchange shortages, supply, transportation and paperwork would pose extra challenges. In many low-income parts of the world, periodic stock-outs of products are common. Since this is considered a normal part of life, policy makers are unlikely to have realised that in the case of infants dependent on infant formula, such an otherwise undramatic event can be life-threatening. Thus in any such location the "sustainability" component of AFASS simply cannot be fulfilled except for mothers who can afford to travel to distant localities to buy formula when a local stockout occurs. This is an issue of food security for infants and families.

Moreover, the baby food industry could use the public fear of HIV and AIDS and the ambiguity of AFASS guideline as its **marketing strategy**. It could be a platform for them to have public-private partnerships with governments/agencies and an excuse for the re-entry of formula even in Baby Friendly Hospital Initiative (BFHI) facilities. The International Code of Marketing of Breastmilk Substitutes and subsequent World Health Assembly (WHA) resolutions should be applied; this is even more important in the context of HIV and AIDS.

There should be monitoring to evaluate policies and interventions. The tabulation of mortality outcomes in relationship to the policy implementation for example could help governments assess its effectiveness. To carry out such evaluation, there should be standardized **research protocol** that would primarily use standardized outcome research and definition of infant feeding.

E. Addressing fear and pessimism about breastfeeding

Recommendations and decisions on HIV and infant feeding are often fear-based rather than fact-based. There is ill-placed pessimism about the possibility of promoting exclusive breastfeeding.

The **HIV community's** apparent lack of knowledge of breastfeeding or lack of priority given to breastfeeding is reflected in their policies and materials. Do these groups have their plateful of HIV issues to tackle and not able to give time to breastfeeding, or are they really unaware of the consequences of ignoring breastfeeding?

There is an urgent need to break the prevailing cycle where breastfeeding has **to prove its safety** and efficacy, while the high-risk substitute is often considered acceptable until proven otherwise. Challenging this model of "proof" should also be a necessary component of our efforts to protect breastfeeding in the face of HIV.

The use of language and **terminology** could be a way to eliminate this pessimism. The distinction between "breastfeeding" and "infant feeding" should be made clear. Clearer terminology in educational course materials, policy and guideline documents, is needed to make the meaning and intention very clear to avoid ambiguities and euphemisms.

The term 'mother to child transmission (MTCT)' puts the blame on the mother when usually it is the case of 'father to mother to child transmission'. **MTCT** should be reworded in such a way as to not put the responsibility on the mother. Moreover, we do not use the means of transmission to label other diseases. In Latin America, breastfeeding groups have addressed this by using 'adult to child transmission' in Spanish.

Health workers and professionals may be pessimistic about whether women can breastfeed exclusively or would volunteer in participating in research. Breastfeeding groups should understand where health professionals, researchers and the HIV community are coming from in order to get the message of breastfeeding across more convincingly.

F. Choice

In the context of HIV, the concept of **infant feeding choice** as a human right may need to be re-examined. In resource-poor settings and where breastfeeding is the cultural norm, the possibility of alternatives to breastfeeding is unknown. Health-care is not seen as a matter of choice, since nurses expect to recommend and mothers expect to take advice. Presentation of replacement feeding as a choice may therefore be seen as a novel recommendation, creating a loophole for

the promotion of formula feeding by trusted and respected people in white uniforms. In addition, choice may mean different things in different contexts; while couples counselled about family planning choices are not barred from having children, mothers counselled about infant feeding choices could be given the impression that breastfeeding is dangerous. In these cases, choice is a "myth".

The difficulty of ensuring true informed-choice is universal, not only in resource-poor areas. The plight/situation of the **HIV positive mother in industrialised countries** may include laws, such as in Sweden, where breastfeeding by HIV+ mothers is prohibited. In countries where no such law is in place, like the United States, a mother still faces the risk of having her baby made a ward of the court and put in foster care if she decides to breastfeed.

The right of the mother to decide on her choice of infant feeding should not absolve the policy maker and counsellors from being responsible for the health consequences for infants and mothers. While the human rights framework should be used to empower mothers to make informed decisions, policy makers should be forthright about the **knowledge gaps** that exist in identifying the route of transmission of HIV (e.g. during pregnancy, birth or breastfeeding) and about the competing risks between breastfeeding and formula feeding for the HIV-exposed baby.

There are ways despite the obstacles to continue the culture of breastfeeding in an HIV and AIDS context, such as using milk banks as a **solution** for HIV+ mothers in Latin America.

G. Social concerns: Mother, family & society

In a breastfeeding culture, a mother who feeds her baby on substitutes may immediately and continually be identified as HIV-infected. Non-breastfeeding therefore becomes a known cause of stigma. Fear of stigmatisation could prevent people from going for testing. This results in mixed feeding, which is the worst combination for virus transmission than exclusive breastfeeding. Moreover, mothers who do not know their HIV status may choose to give replacement or mixed feeding due to the fear of transmission in case they are HIV+. The threat of a **spillover** effect of the Prevention of Mother to Child Transmission (PMTCT) programmes is real. We should consider and guard the needs of HIV-negative mothers as well.

Key Questions:

1. Any research should include at least 2 years of follow-up, so that HIV-survival can be ascertained.
2. Research is needed to show if HIV transmission an be reduced by carefully monitoring breast health and providing early treatment when problems occur; by encouraging and supporting exclusive breastfeeding; by including mother's CD4 count in AFASS assessments and through counselling.
3. Studies are needed to show that exclusive breastfeeding, followed by breastfeeding, may be safer in terms of HIV-free survival, in settings where child mortality rates are high from other infectious diseases.
4. Research is needed to determine whether women on HAART can safely breastfeed their children.

We should put women's needs in perspective and be more **gender** sensitive. Often, the mother is seen as responsible for transmitting HIV (e.g. MTCT), yet drugs and help that are given do not have her interest as a prime consideration. Women are blamed instead of being seen as the victims of a larger social problem. When drafting solutions to prevent transmission, we need to understand that she is first a woman: her reproductive cycle exists in relation to her health, choices and needs. Our advocacy strategy/messages should include prevention of HIV of the mother, instead of being concerned with just her pregnancy, safe motherhood and infant feeding.

Conclusion

The symposium ended on a high note with enthusiasm and optimism that participants could move forward with some of the activities proposed. All in all, the event was a stepping stone for breastfeeding and HIV and AIDS groups to begin collaboration and strategise in facing the challenges ahead. LLLI and WABA thank all participants who make this initiative possible and worthwhile.

***WE WELCOME** your participation in our HIV, infant feeding and breastfeeding discussions and activities. For information or a copy of the symposium report, email Liew Mun Tip at waba@streamyx.com. To join the WABA HIV & Infant Feeding e-group, please email Dr. Ted Greiner at tedgreiner@yahoo.com.*

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