A matter of life or death

The untold story of HIV, Breastfeeding and Child Survival

World Alliance for Breastfeeding Action (WABA)

WABA's advocacy role

WABA is an umbrella organization for the breastfeeding movement, linking core partners in over 120 countries. Breastfeeding and HIV is only one of WABA's eight programme areas, but the fear of HIV-transmission in breastmilk appears to be seriously undermining support for breastfeeding worldwide.

HIV transmission through breastfeeding

HIV prevalence is highest in resource-poor, developing countries, where the protective effects of breastfeeding combat simultaneously high rates of fertility and child mor-

tality. The highest risk factor for HIV-transmission

to the newborn baby is birth itself. While ~20% of newborns will be already infected, their HIV status cannot be known in the first days or weeks of life. HIV-infected mothers confront a dilemma of competing risks as they consider how to feed their infants: the possibility of transmission of HIV in their breastmilk vs the risk of death or disease due to the hazards of formula-feeding

if breastfeeding is withheld. Initial risk estimates due to breastfeeding for ~2 years were ~15%,¹² with 65% of all infants escaping infection by all routes.

Initiatives to reduce the number of babies infected through breastfeeding by recommending breastfeeding avoidance have had negative consequences for child survival in countries which can least afford the loss of breastfeeding, and in settings which cannot sustain safe formula-feeding. Support for breastfeeding has been withdrawn, and fear of HIV has effectively turned breastfeeding into an endangered practice.

Global HIV prevention efforts over the last decade, with the stated underlying rationale of saving lives, have exposed two main concerns:

- 1.) Has the risk of HIV transmitted through breastfeeding been <u>over</u>-estimated?
- 2.) Has the risk of NOT breastfeeding (formula-feeding) been under-estimated?

HIV and infant feeding policy in industrialized countries

Since 1985, HIV-infected mothers in industrialized countries have received clear advice not to breastfeed. While mothers' rights are suspended, this policy is consistent with public health principles based on an assessment of the competing risks to the HIV-exposed baby.³

For developing countries

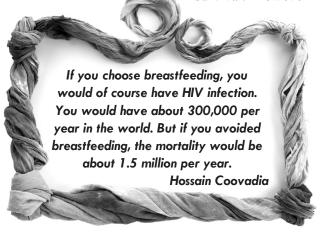
Initial HIV and Infant Feeding policy for developing countries supported breastfeeding because in countries of high HIV-prevalence, breastfeeding is a cornerstone of child survival. However in 1997, following a study in Thai-

land⁴ demonstrating that shortcourse antiretroviral therapy and no breastfeeding halved the risk of HIV-transmission to infants the recommendation to support breastfeeding was reversed.⁵ The situation was framed as an emergency which could not wait for evidencebased research, but required immediate action to save lives. On an assumption of the danger of breastfeeding and attain-

able conditions of safety for formula-feeding which could be superimposed locally, the new recommendations guided HIV-infected mothers towards choosing to feed their babies formula. Importantly, a new rationale of private rights rather than public health absolved healthworkers from accountability for the child health outcome since the decision to formula feed was the mother's.

Policy change poses difficulties

Such a radical change posed several problems for mothers and healthworkers alike. In developing countries prescriptive healthcare is expected. Mothers trust and respect health workers. Furthermore, in a traditionally breastfeeding culture, a choice to formula feed is uncultural, novel, alien, and startling enough to be perceived as a recommendation, effectively making it an intervention. To be ethical, an intervention should show a benefit, but there has never been any research demonstrating a child survival advantage to formula-feeding in developing countries - even in the context of HIV.



<u>Difficulties experienced by HIV and infant feeding counsellors</u>

Healthworkers find HIV and infant feeding counselling to be one of the most difficult aspects of their work. They report lack of training, conflicting information, a focus on formula-feeding, difficulty interpreting guidelines/protocols, and inadequate allocation of time for counselling due to understaffing. There is extreme concern about spillover of formula-feeding to uninfected mothers and withdrawal of previous initiatives to support breastfeeding, eg

- o staff training to support exclusive and continued breastfeeding,
- o support for the Baby-Friendly Hospital Initiative,
- o implementation of the International Code of Marketing of Breastmilk Substitutes,
- o activities to promote World Breastfeeding Week.

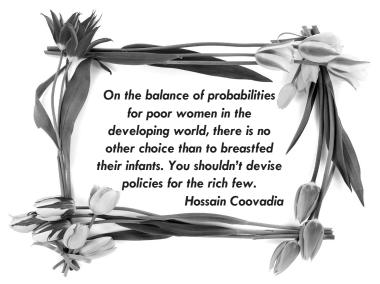
Participants at a La Leche League International/WABA Symposium on HIV and Breastfeeding held in July 2005 voted "counselling" as the major problem to be addressed.⁷ WABA receives many requests for clarification of ambiguous guidelines and recommendations from healthworkers and mothers.

New research on risk of HIV transmission due to breastfeeding

New research shows that the risk of HIV due to breastfeeding varies according to how breastfeeding is defined. Exclusive breastfeeding for the first 3 months of life poses a much lower risk than the original estimate for mixed feeding, being NIL in a 1999 South African study⁸ and 1.3% in a 2005 Zimbabwean study.⁹ The risk during continued partial breastfeeding for 15-18 months was 5.3% and 5.6% respectively, reducing the cumulative risk by 60%. Another recent large study from South Africa shows a 4% risk of transmission over 6 months of exclusive breastfeeding, achieved by 83% of the mothers recruited into the study.¹⁰ No research has yet shown the risk posed by continued breastfeeding after 6 full months' exclusive breastfeeding (as is recommended outside the context of HIV).¹¹

The importance of exclusive breastfeeding <u>0-6 months</u>

Exclusive breastfeeding for the first half-year of life provides dramatic protection against all causes of infant morbidity and mortality. Mixed breastfeeding and the premature addition of other foods and liquids exposes a baby to foreign pathogens and antigens and causes damage to the baby's gut. At the same time inadequate drainage of the breasts is more likely to occur with mixed feeding, causing milk stasis, breast permeability, and sub-clinical or actual mastitis, identifiable by elevated milk sodium levels and – for an HIV-infected mother – raising the viral load in her milk. In the presence of HIV-infection, this inter-play of maternal and infant factors makes contact of the virus with the infant's bloodstream more likely.



The risk of replacement feeding from birth

Research suggests that there is no significant difference in infant mortality at 18 months and 2 years between breast-fed and formula-fed African infants in Kenya and Botswana showing no child survival advantage to replacement feeding.^{12 13} In addition, a recent investigation into unacceptably high levels of infant malnutrition and mortality in Botswana revealed that 36% of all mothers, even those who were HIV-no longer initiated breastfeeding,¹⁴ up from 5% in 1999.¹⁵

Is there any advantage to early weaning?

Further recent research including results presented at the October 2006 WHO Technical Consultation on HIV and infant feeding, ¹⁶ and at the Conference on Retroviruses and Opportunistic Infections, Los Angeles in February 2007 ¹⁷ showed that premature weaning of HIV-exposed babies increased the risk of infant morbidity (especially diarrhoea) in Botswana, Malawi, Kenya, Uganda and Zambia. Continued breastfeeding vs early weaning increased the lifespan of babies who had already been infected at birth in Botswana and Zambia.

PMTCT Programme Sites

UNICEF began support for a pilot Prevention of Mother to Child Transmission (PMTCT) programme in 1998. Thirty thousand HIV-infected mothers at 18 pilot sites in 11 developing countries were to be provided with a package of services which included voluntary HIV counselling and testing, antiretroviral therapy to prevent transmission of HIV at birth, and free formula. The initial pilot projects have since been scaled up to thousands of sites around the world. Only a small proportion of HIV+ pregnant African mothers were provided with ART. The major focus has been to provide mothers with HIV and infant feeding counselling and formula, costing 25%-60% of programme budgets. Uptake of formula-feeding is high with a large proportion of HIV-infected mothers in several countries, indicating the programmes' apparent social marketing 'success':

- 80-100%, Thailand
- 40-100%, South Africa (depending on province)
- 89%, Botswana (36% of entire population)
- 87%, Rwanda
- 60%, Zambia
- 30-50%, Uganda

Programmatic evidence is missing

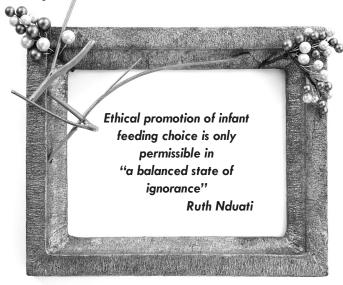
While negative reports about the sustainability and safety of (formula-feeding in the research setting have been presented at recent conferences, most results from the PMTCT sites are confined to internal memos and conference presentations which are not in the public domain.⁶ ¹⁸ There have been no published results of monitoring and evaluation from the clinical PMTCT sites to show

- o how many babies were prevented from acquiring HIV,
- o the overall rate of HIV-free survival (the number of babies surviving to be tested at 15-18 months).
- o the cause of death for babies who do not survive to this age
- o the number of babies who may have been lost to follow-up

This data is needed to inform future best infant feeding practice in individual settings, and especially to enable counsellors to advise mothers appropriately.

Ethical imperative to assess competing risks

Even in the absence of results from the PMTCT sites, ethical promotion of infant feeding choice is only permissible in "a balanced state of ignorance" (Ruth Nduati, 1998 19) This is not possible in the face of the known risks of morbidity/ mortality when breastfeeding is withheld. Even before the discovery of HIV-transmission through breastfeeding, not breastfeeding was known to be hazardous. A WHO study published in 2000 20 showed a 5.8-fold risk of death from formula-feeding compared to breastfeeding for babies aged 1-2 months which, though reducing with time, persisted to 9-11 months. From the perspective of an overall balance of risks, the total number of children >15 living with HIV at the end 2005 was 2.1 million.²¹ Every year, 300 000 children are infected with HIV through breastfeeding compared to 1.5 million children of HIV+ mothers who die because they are not breastfed.²² WHO have also identified that only 3% of global under-5 mortality is due to HIV, but that globally 53% is related to malnutrition, or over 5.5 million die from causes than could have been avoided by optimal breastfeeding 23 which has relevance for attainment of the Millenium Development Goals 1, 4 and 6.





All mothers have an entitlement to medical advice designed to maximize their baby's best chance of survival. Questions must be raised about:

- o the value of Western childcare practices exported into settings which cannot support them,
- o HIV and infant policy which has been developed for "the rich few", ²² and
- o the selective application of individual rights vs public health in different settings.

A rational policy for all

Policy for developed and developing countries needs to be aligned to reflect sound public health and accountability in all settings. Recent research clearly shows that overall child survival in countries of high HIV-prevalence is likely to be maximized by public health messages favouring exclusive breastfeeding to six months and continued partial breastfeeding for up to 2 years or beyond for all women, irrespective of their HIV status.

New modification to existing Policy

Recent research prompted experts meeting at a WHO Technical Consultation in Geneva in October 2006 to issue important clarifications of existing HIV and infant feeding policy ¹⁶ (see box). Unless interventions to protect babies from becoming infected with HIV are to cause more deaths than they prevent, these modifications need to be urgently disseminated and understood so that criteria for the rational use of formula can be appropriately applied.

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Evolving Policy on HIV and Infant Feeding Policy

Industrialised countries, 1985 to date

On the basis that the risk to the infant of acquiring HIV through breastfeeding is greater than the risk of mortality from formula feeding in the USA, the CDC and the American Academy of Pediatrics have continued to vigorously recommend that HIV-infected women in the United States not breastfeed or provide their milk for the nutrition of their own or other infants.³

Developing countries, 1992-1997

"Where infectious diseases and malnutrition are the main cause of infant deaths, breastfeeding should be the usual advice given to pregnant women, including those who are HIV infected because their baby's risk of HIV infection through breastmilk is likely to be lower than the risk of death from other causes if it is not breastfed." ²⁴ (WHO/ UNICEF May Consensus Statement 1992)

Developing countries, 1997-2006

"... it is mothers who are in the best position to decide whether to breastfeed particularly when they alone may know their HIV status and wish to exerice their right to keep that information confidential. It is therefore important that women be empowered to make fully informed decisions about infant feeding and that they be suitably supported in carrying them out.... When children born to HIV-infected women can be assured of uninterrupted access to nutritionally adequate breastmilk substitutes that are safely prepared and fed to them, they are at less risk of illness and death if they are not breastfed. However, when these conditions cannot be met – in particular in environments where infectious diseases and malnutrition are the primary causes of death during infancy – then artificial feeding substantially increases children's risk of illness and death. The policy objective must be to minimize all infant feeding risks and to urgently expand access to adequate alternatives so that HIV-infected women have a range of choices. The policy should also stipulate what measures are being taken to make breastmilk substitutes available and affordable; to teach the safest means of feeding them to infants; and to provide the conditions which will diminish the risks of using them." ²⁵

In 1998 a three-part Guideline and Review of HIV and infant feeding were published by UNAIDS/WHO/UNICEF, ^{26 27 28} which recommended:

- when replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended
- otherwise exclusive breastfeeding is recommended during the first months of life and should then be discontinued as soon as it is feasible.
- HIV-infected mothers should be supported in their choice, whether they choose breastfeeding or replacement feeding.
- when children born to women living with HIV can be ensured uninterrupted access to nutritionally adequate breast-milk substitutes that are safely prepared and fed to them, they are at less risk of illness and death if they are not breastfed.
- it is considered that milk in some form is essential, and replacement feeding options include commercial infant formula, and home prepared formula which can be made from animal milks, typically from cows, goats, buffaloes, sheep or camels.

Clarification of existing guidelines for developing countries 2006

"The most appropriate infant feeding option for an HIV-infected mother should continue to depend on her individual circumstances, including her health status and the local situation, but should take greater consideration of the health services available and the counselling and support she is likely to receive." Importantly, a new caution is expressed about formula feeding, "Exclusive breastfeeding is recommended for HIV-infected women for the first 6 months of life UNLESS replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants before that time." ¹⁶



The World Alliance for Breastfeeding Action (WABA) is a global network of individuals and organisations concerned with the protection, promotion and support of breastfeeding worldwide based on the Innocenti Declarations, the Ten Links for Nurturing the Future and the WHO/ UNICEF Global Strategy for Infant and Young Child Feeding. Its core partners are International Baby Action Food Network (IBFAN), La Leche League International (LLLI), International Lactation Consultant Association (ILCA), Wellstart International and Academy of Breastfeeding Medicine (ABM). WABA is in consultative status with UNICEF and an NGO in Special Consultative Status with the Economic and Social Council of the United Nations (ECOSOC). For more information, please contact: World Alliance for Breastfeeding Action (WABA) • P.O.Box 1200, 10850 Penang, Malaysia • Tel: 60-4-6584816 • Fax: 60-4-6572655 • Email: waba@streamyx.com • Website: www.waba.org.my

ABBREVIATIONS⁶

AFASS Affordable, feasible, acceptable, safe and sustainable

AZT Azidothymidine

BFHI Baby Friendly Hospital Initiative

CROI Conference on Retroviruses and Opportunistic Infections

EBF Exclusive breastfeeding EBM Expressed breast milk

ELISA Enzyme linked immunosorbent assay (HIV test for antibodies)

HIV Human immunodeficiency virus

HIV- HIV-negative HIV+ HIV-positive

ICYF Infant and Young Child Feeding

IF Infant feeding

MTCT Mother-to-child transmission

NVP Nevirapine

PCR Polymerase chain reaction (HIV test for viral particles)
PEPFAR President's Emergency Plan for AIDS Relief
PMTCT Prevention of mother-to-child transmission

PTCT Parent-to-child transmission RCT Randomised control trial RF Replacement feeding

UNAIDS Joint United Nations Program HIV/AIDS

UNICEF United Nations Children's Fund VCT Voluntary counseling and testing WABA World Alliance for Breastfeeding Action

WHO World Health Organization

who world hearth Organ

ZDV Zidovudine

EXPLANATION OF TERMS⁶

AFASS Conditions The following definitions for each of the AFASS terms were included in the revised WHO, UNICEF, UNFPA, and UNAIDS HIV and Infant Feeding: Guidelines for Decision- Makers. They were developed to provide guidance, with the understanding that they should be adapted locally based on formative research.

Acceptable: The mother perceives no barrier to replacement feeding. Barriers may include cultural or social reasons or be caused by fear of stigma or discrimination. According to this concept, the mother is under no social or cultural pressure not to use replacement feeding, and she is supported by family and community in opting for replacement feeding, or she will be able to cope with pressure from family and friends to breastfeed, and she can deal with any stigma attached to being seen with replacement food.

Feasible: The mother (or family) has adequate time, knowledge, skills, and other resources to prepare the replacement food and feed the infant up to 12 times in 24 hours. According to this concept, the mother can understand and follow the instructions for preparing replacement feeds and with support from the family can prepare enough replacement feeds correctly every day and at night, despite disruptions to preparation of family food or other work.

Affordable: The mother and family, with community or health system support if necessary, can pay for the cost of purchasing/producing, preparing, and using replacement feeding, including all ingredients, fuel, clean water, soap, and equipment, without compromising the health and nutrition of the family. This concept also includes access to medical care if necessary for diarrhoea and other illnesses and the cost of such care.

Sustainable: Availability of a continuous and uninterrupted supply and dependable system of distribution for all ingredients and products needed for safe replacement feeding for as long as the infant needs it, up to one year of age or longer. According to this concept, there is little risk that the replacement food will ever be unavailable or inaccessible. It also means that another person, who can prepare and give replacement feeds, will always be available to feed the child in the mother's absence.

Safe: Replacement foods are correctly and hygienically prepared and stored and fed in nutritionally adequate quantities with clean hands and clean utensils, preferably by cup. This concept means that the mother or caregiver:

- Has access to a reliable supply of safe water (from a piped or protected well source),
- Prepares replacement feeds that are nutritionally sound and free of pathogens,
- Is able to wash hands and utensils thoroughly with soap and to regularly boil the utensils to sterilise them,
- Can boil water for at least 10 minutes to prepare each of the baby's feeds, and
- Can store unprepared feeds in clean, covered containers and protect them from rodents, insects, and other animals.

Cessation of breastfeeding: completely stopping breastfeeding including suckling.

Infant formula: a breast-milk substitute formulated commercially in accordance with applicable Codex Alimentarius standards to satisfy the nutritional requirements of infants during the first months of life up to the introduction of complementary foods.

Early cessation of breastfeeding: stopping breastfeeding, including suckling prior to, at, or about six months of age, as soon as replacement feeding is acceptable, feasible, affordable, sustainable, and safe, with the idea of avoiding mixed feeding to the greatest extent possible.

Exclusive breastfeeding: giving an infant no food or drink, not even water, other than breast milk, except for drops or syrups of vitamins, mineral supplements, or medicines.

Human immunodeficiency virus (HIV): the virus that causes AIDS.

HIV-negative: refers to adults who have taken an HIV test and who know that they tested negative and to young children who have tested negative and whose parents or guardians know the results.

HIV-positive: refers to adults who have taken an HIV test and who know that they tested positive and to young children who have tested positive and whose parents or guardians know the results.

HIV status unknown: refers to people who either have not taken an HIV test or do not know the result of a test they have taken.

HIV-infected: refers to a people who are infected with HIV, whether or not they are aware of it.

HIV counselling: Counselling is a process, not a one-time event: For the HIVpositive client it should include life planning, and, if the client is pregnant or has recently given birth, it should include infant-feeding considerations.

Home-prepared formula: a breastmilk substitute prepared at home from fresh or processed animal milks, suitably diluted with water and with the addition of sugar and micronutrients.

Infant: a child from birth to 12 months of age.

Infant feeding counselling: counselling on breastfeeding, complementary feeding, and, for HIV-positive women, HIV and infant feeding. [PM comment: Commonly understood by HIV and infant feeding counsellors to mean counselling about NOT breastfeeding.]

Mixed feeding: feeding both breast milk and other foods or liquids.

Mother-to-child transmission (MTCT): transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery, or breastfeeding. The term is used in this document because the immediate source of the child's HIV infection is the mother. The term implies no blame, whether or not a woman is aware of her own infection status. A woman can acquire HIV from unprotected sex with an infected partner, contaminated blood, non-sterile instruments (as is the case of injecting drug users), or contaminated medical procedures.

Programme: an organised set of activities designed to prevent transmission of HIV from mothers to their infants.

Replacement feeding: feeding an infant who is receiving no breast milk a diet that provides all the nutrients the infant needs until the age when he/she can be fully fed on family foods. During the first six months, replacement feeding should be with a suitable breastmilk substitute. After six months, the substitute should be complemented with other foods.

Spillover: a term used to designate the infant-feeding behaviour of new mothers (who either know that they are HIV-negative or are unaware of their HIV status) who do not breastfeed, breastfeed for a short time only, or mix feed because of unfounded fears of HIV, misinformation, or the ready availability of breast-milk substitutes.

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