

# The difficulty in coping with policy change for HIV and infant feeding counselors

– by Ted Greiner, South Korea

Counselors who try to help HIV-infected mothers have been through a confusing roller coaster ride over the past 25 years since evidence began to accumulate that HIV could be transferred via breast milk. The first reaction on the part of the world's health authorities was unthinking panic. The head of WHO's AIDS unit opened the first WHO expert meeting on breastfeeding and HIV in June 1987 by asking the experts (all of whom were expert only in the second of the two issues under discussion) to give him a statement calling on HIV-infected mothers to avoid breastfeeding. Thanks to a couple breastfeeding advocates who were present (as observers, not experts), a few of the experts threatened to issue a minority statement unless the meeting agreed to the following wording: In countries where most infant deaths were due to malnutrition and infection, breastfeeding should be promoted to all mothers, irrespective of their HIV status.

Meanwhile, in relatively rich countries (which includes newly industrializing countries like Thailand and Brazil, which have portions of the country that are very poor), there was no question of "allowing" HIV-infected mothers to breastfeed. That would be considered child endangerment and policies ranging from a ministry of health directive in Sweden in 1987 to local interpretation of unwritten policies have ensured that whenever authorities knew of an HIV-infected woman who planned to breastfeed, they took steps to guarantee that this would not happen. If anyone knows of exceptions to this (ie, health authorities in rich countries who sanction HIV-infected women's right to choose to breastfeed), I would greatly appreciate knowing about it. (I am aware of efforts led by Pamela Morrison in the UK to at least avoid stopping breastfeeding in African women about to be extricated back to their home countries--an attempt to avoid an obvious case of iatrogenic harm if not death for the babies involved.)

The 1987 wording made it into the first WHO policy on HIV and infant feeding, which emerged in 1992. All was thus quiet on the HIV and infant feeding front in poor countries until 1997 when the involved

UN agencies (mainly UNAIDS, WHO and UNICEF) quietly launched a new policy. Again, despite their protestations later to the contrary, it was clear that no need was felt to consult the international community of breastfeeding experts. We were widely considered to be fanatics who believed in "breastfeeding at any cost." The HIV community, meanwhile, had the power and money and was blinded by its own mantra: "avoid HIV transmission at any cost." Indeed, even today, few if any PMTCT (prevention of mother to child transmission) programs gather data on any postpartum health outcomes of their program efforts besides HIV transmission rates. If that is the only statistic one looks at, then efforts that result in both decreases in transmission rates AND increases in infant death rates will look successful indeed.

The explanation given for the change in policy was not scientific (at that time there were virtually no relevant data to go on) but "human rights." Oddly, since mothers in rich countries had no choice as to how to feed their babies, it was somehow determined that poor mothers ought to have the right to an "informed choice." This was especially odd given that there was virtually no scientific information to offer them regarding likely risks of various infant feeding patterns for women in various socioeconomic circumstances. (There still is precious little of practical value in specific counseling circumstances.)

WHO and UNICEF staff who WERE breastfeeding experts were of course mortified and did all they could, but they were shouldered aside by the "real" experts, the virologists. Their impression was that the real reason that the policy had to change was "political." Some of this pressure, though no doubt coming from capitalistic governments, likely had its roots in the infant feeding industry, which was finally seeing an opening in poor countries where, ever since the International Code of Marketing had been passed, sales had lagged far behind soaring birth rates. Lancet quoted an example of a Nestle representative who, in a British classroom, shed a tear as he informed the students that Africans could no longer breastfeed because of AIDS. UNICEF was ferociously attacked on the first page of the Wall Street Journal for not

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accepting the purely “charitable” offers of free formula from the industry.

The new policy was followed up in 1998 by: (1) Already in March 1998, a press release from the three agencies stated that a “pilot trial” would start in 11 countries, providing free infant formula to >30,000 newborns whose mothers were presumably too poor to afford it. There was never any evidence provided that such mothers could safely use it; indeed, the pilot trial included no measure of infant health outcome. It was only looking at the logistical issues on the assumption that it was a good thing to do.

(2) An official literature review was commissioned by the first author of one of the only studies ever to find that artificial feeding from birth led to an increase in HIV-free survival. (3) A set of WHO guidelines was produced on how to implement the new policy. In the following years, these were supported by teaching materials and a detailed course curriculum. On the assumption that everyone using it would do so only after holding an existing five-day WHO breastfeeding counseling course, the new course focused largely on how to safely artificially feed in low-income settings.

By 2000, a minor revolution was occurring quietly behind the scenes. In particular, UNICEF country staff around the world were expressing their dismay over the harm they could see being done in the implementation of the new policy. WHO held a new expert meeting which modified the policy by, among other things, calling for the replacement of breast milk only in situations in which it was “acceptable, feasible, affordable, sustainable, and safe.” By 2003 the WHO Guidelines were changed accordingly.

But already by 2002, UNICEF was changing its tune. After ignoring earlier advocacy efforts by WABA, it started to say that it shared WABA’s views on the issue and agreed to a joint Colloquium on HIV and Infant Feeding, intended to bring the HIV and breastfeeding communities together in open dialog. This took place in Arusha in September 2002 (proceedings can be accessed at <http://www.waba.org.my/whatwedo/hiv/colloquium/programme.html>). By that time, UNICEF had also decided to stop supplying free infant formula to countries for HIV-infected mothers, issuing a statement to its partner agencies explaining this decision, quite controversial at the time.

Meanwhile, scientific studies began to make themselves heard. Beginning to appear as early as 1998, several studies showed that exclusive breastfeeding greatly reduced postnatal transmission compared to the more common feeding patterns in which

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infants are introduced to a wide range of unnecessary and unhealthy foods and fluids soon after birth. (A WHO “expert” had viciously attacked a UNICEF officer for agreeing with me a bit earlier that exclusive breastfeeding appeared to have this effect.)

Oddly, the main impact of this was a frenzy of negativity toward “mixed feeding” (confusingly, a term used earlier to refer to mixed breast and artificial feeding; now used for any pattern of predominant or partial breastfeeding despite the fact that they have quite different outcomes). Most

poor countries then implemented a policy (still commonly in effect) calling for low-income HIV-infected women to breastfeed exclusively for six months, followed by rapid cessation of breastfeeding in order to avoid the danger of “mixed feeding” although it also appears likely (though not proven) that HIV transmission rates among infants at 6 months fed complementary foods are lower than rates among younger infants who are partially breastfed.

Research in the past several years suggests that in many settings 6 months is too early to stop breastfeeding, and the resulting increased rates of severe morbidity, malnutrition and death negate and gains made in reducing HIV transmission. Based on this, WHO held another expert consultation in 2006 which resulted in another change in guidance (though the official WHO guidance has not officially been changed yet; nor have the teaching materials or courses). Even at 6 months, breastfeeding was to be continued unless cessation at that time was judged to be AFASS. There was little point in stopping before 6 months. And when infants were given early testing for HIV, a negative test had no implications for how the child should be fed. A positive test meant that there was no point in stopping breastfeeding at any particular time.

There is now little doubt that treating HIV-infected mothers with damaged immune systems (a low CD4 count) with antiretroviral (ARV) drugs, reduce overall postnatal HIV transmission rates by half or more. This in turn suggests that in settings where testing and treatment are easily available, breastfeeding should be practiced by all but extremely well-off mothers with access to high quality health care. However, this type of thinking is not reflected in any official guidelines that I am aware of.

Several studies suggest that providing ARVs to all breastfeeding mothers (or all breast-fed infants) provide such high levels of protection that rates of mother to child transmission begin to approach



those achieved with no breastfeeding at all. However, WHO does not consider the data to be adequate yet to recommend either approach. Look for an expert meeting examining these data in the next year or two.

Back to the poor infant feeding counselor's roller coaster ride: yes, no, maybe? And what exactly does AFASS mean in practical terms? While working at PATH, colleagues and I developed algorithms which take counselors through the various components of AFASS and, as far as possible, their real life meanings (for example, how much various

types of replacement foods cost locally). I presented them at the WHO Expert Consultation in 2006 but they were rejected as too complex (hmm, the reality counselors face is actually simple?) and looking too much like a "decision tree." (Counselors telling mothers what to do is common anyway, but the algorithms were clear that their purpose was to assist the counselor in helping the mother to make her own decision). They can be accessed on my website at <http://global-breastfeeding.org/2006/11/14/algorithms-to-assist-in-counseling-on-whether-it-is-afass-for-an-hiv-mother-to-stop-breastfeeding/>

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