Moderator: Deborah Cohan, MD MPH

March 6, 2012, a group of clinicians and researchers discussed the topic “Informed Choice Breastfeeding in the Resource-Rich Setting” at an informal session at CROI, 2012. The attached opinion piece “Informed choice in infant feeding decisions can be supported for HIV-infected women even in industrialized countries”\(^1\) provided a background. Deborah Cohan, MD MPH moderated the discussion utilizing the attached slides as a guide.

The discussion summary below is meant to be considered in conjunction with the attached slides.

Relevant Populations
Clinicians identified several specific populations of HIV-infected pregnant women in the US who either have asked about breastfeeding or have continued to breastfeed in spite of advice to the contrary.

- **African and Latina immigrant populations:** “I’ve learned to ask everyone if breastfeeding is an issue in your community.” For these women, the cultural norm is to breastfeed and bottle feeding could lead to stigma and possible disclosure of HIV status.

- **Natural breastfeeding-focused population.** “Some patients do not want any interventions or medications. We’ve had several perinatal transmissions with this group.” Some of these women are familiar with recent studies demonstrating low risk of lactational HIV transmission in the setting of maternal antiretroviral therapy in sub-Saharan Africa and are interested in extrapolating these data to their circumstances.

The National Perinatal HIV Hotline has received calls from clinicians for advice on counseling patients who want to breastfeed. Similar questions in Philadelphia caused the city health commission into look into the issue of HIV-positive women breastfeeding.

Possible Philosophical Approaches
The UK Department of Health *HIV and Infant feeding: Guidance from the UK Chief Medical Offices’ Expert Advisory Group on AIDS*, “Under exceptional circumstances, and after seeking expert professional advice on reducing the risk of transmission of HIV through breastfeeding, a highly informed and motivated mother might be assisted to breastfeed.”\(^2\)

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\(^1\) Morrison P, Israel-Ballard K, Greiner T. Informed choice in infant feeding decisions can be supported for HIV-infected women even in industrialized countries. AIDS. 2011, Vol 25 No 15, 1807-11.

In addition, the concept of “informed choice” has been used in counseling patients about contraception, abortion, and genetic testing. Further, harm reduction is a common approach to drug and/or tobacco use and has an accepted role in HIV prevention.

The WHO HIV guidelines\(^3\) offer countries (not the US) two prophylaxis regimen options for HIV-infected pregnant and/or breastfeeding women. Individual countries decide to utilize Option A or Option B for their population. Is there a role for adapting the WHO guidelines to HIV-positive US women who may, even with considerable counseling to the contrary, choose to breastfeed?

**Stigma, Disclosure, Adherence**

Bottle-feeding raises suspicions about HIV status within some communities. Disclosure to family and friends is paramount in breastfeeding discussions with immigrant and other women considering the guidance to bottle-feed.

Often, the group of women who struggle with disclosure also have difficulty remaining adherent to ARVs after delivery. This complicates supporting breastfeeding as a risk reduction measure.

When disclosure and stigma are effectively addressed along with discussions about potential transmission to their child, most women choose to formula feed (or use banked human milk) exclusively. Being open about this possibility and the known risks is time-intensive and requires the social worker and providers communicating regularly about the disclosure process.

Providing the woman with comprehensive education is a critical component of her deciding the best infant feeding option, and providing her with the arsenal of support needed to balance all the factors requires an integrated, family-centered program. This approach promotes patients to remain engaged in care. The approach works for many - but not all - women. Losing vulnerable women after delivery is a huge concern; pushing bottle-feeding is one of only many factors possibly triggering disengagement from care.

Finally, for women relying upon WIC and other public benefits, bottle-feeding with the pervasive “Breast is best” messaging causes repeated issues related to stigma and disclosure, as well as perceived decreased benefits of bottle-feeding in their particular circumstances.

**Ethical Issues**

Is there a role for hierarchal messaging (formula feed, but if not able to, then optimize ARV adherence if she is going to breastfeed? Or, by bringing up this issue are we enabling less than ‘safest’ behavior?)

Harm reduction is a valuable part of practice, but there are some areas of pediatrics in which we don’t employ a harm reduction approach, i.e. car seats, lead paint. Many pediatricians questioned the role of harm reduction in the setting of breastfeeding. “I care for several youth infected via-breastfeeding, and I can’t see endorsing this.”

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“To provide a truly informed-choice-option to patients, I need to more fully discuss the unknowns about lactational HIV transmission than I have.”

**Potential Benefits and Risks of Breastfeeding**

How can we balance the known potential risks and benefits reviewed in the slides?

The March 2012 *Pediatrics* Policy Statement *Breastfeeding and the Use of Human Milk*,

provides a new review of the risks of NOT breastfeeding, though this is not directed to an HIV-infected population.

**Novel Approaches to Providing Breast Milk**

The Human Milk Banking Association of North American has 14 sites, with two additional sites in development. Some insurance, including public sources, pay for human banked milk for HIV-exposed babies. Donated breast milk (one session participant had two HIV-positive new moms feed expressed milk donated from a colleague), a wet nurse, and flash pasteurization are additional options. PATH is exploring a low-tech model flash pasteurization method to be utilized in both low-resource settings and homes. PATH has successful larger-scale flash pasteurization models in Zimbabwe and South Africa. These novel approaches do not solve the disclosure issue – the largest dynamic in many breastfeeding conversations.

**Research and Other Needs**

- Pathophysiology of lactational transmission: Is it the cumulative RNA exposure is associated with lactational HIV transmission not the actual mixed feeding? What is the role of RNA vs. DNA? How clinically relevant is compartmentalization of HIV in breast milk?
- How long to ‘recommend’ breastfeeding for those women who choose this option despite recommendations to bottle-feed?
- Should providers prescribe infant ARV prophylaxis during breastfeeding?
- How often to monitor maternal viral load while breastfeeding?
- How best to monitor maternal (and/or infant) ARV adherence?
- How often to test the infant?
- Will infant ingestion of ARVs via breast milk affect sensitivity of DNA or RNA assays?

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• Which ARVs penetrate best into breast milk? Is it best to use a regimen that optimizes milk penetration to decrease transmission risk or will this increase the risk of toxicity?
• How to minimize the risk of resistance? Lactational transmission may induce drug resistance, even in the absence of maternal resistance.
• In the absence of complete data, how might a clinician counsel a woman interested in breastfeeding? Or a woman who will be lost to follow-up after delivery (even with intensive follow-up by case managers) and likely breastfeed?
• Are some breastfeeding women lost to follow up because they fear being reported to child protective services?

This material is intended for educational purposes for healthcare providers only. It is not intended as a substitute for professional medical care or advice, nor to replace a healthcare professionals' clinical judgment regarding their individual patient care.

Participants:
Lauren Poole
Betty Dong
Mary Margaret Andrews
Allan Taylor
William Short
Richa Tandon
Debra McLaud
Jenell Coleman
Melanie Murray
Monica Carten
Trudy Larsen
Laura Hoyt
Heather Watts
Jess Waldura
Alice Stek
Ron Goldschmidt
Kiersten Isreal-Ballard
Judy Levison
Madeline Sutton
Jill Foster
Roberta Lagurre
Amy Baranoski
Gregg Alleyne
Erika Aaron
Shannon Weber