Collaboration with State Primary Care Associations: Best Practices

Southeast AETC

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Disclosures

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AETC Program National Centers and HIV Curriculum

- **National Coordinating Resource Center –** serves as the central web –based repository for AETC Program training and capacity building resources; its website includes a free virtual library with training and technical assistance materials, a program directory, and a calendar of trainings and other events. Learn more: https://aidsetc.org/
- **National Clinician Consultation Center –** provides free, peer-to-peer, expert advice for health professionals on HIV prevention, care, and treatment and related topics. Learn more: https://nccc/ucsf.edu
- **National HIV Curriculum –** provides ongoing, up –to-date HIV training and information for health professionals through a free, web –based curriculum; also provides free CME credits, CNE contact hours, CE contact hours, and maintenance of certification credits. Learn more: www.hiv.uw.edu

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Breastfeeding/Chestfeeding among People with HIV

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- No disclosures

Objectives

- State what is known about the risk of HIV transmission via breastmilk with and without antiretrovirals
- Describe the motivations of those who want to breast/chestfeed
- Explain what has changed in the U.S. Perinatal HIV Guidelines as of 2023

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A note

- I may use breastfeeding/chestfeeding interchangeably. When I say breastfeeding, please also hear chestfeeding.
- Research done in the past on this topic has investigated cis-gender women; results are therefore reported on women.

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Some medical history…dating to the 1990s

Once upon a time…

- Prior to antiretroviral therapy (ART), the risk of perinatal transmission was ~25%. *Perinatal transmission refers to mother to child transmission during pregnancy, labor, and delivery (this does not include breastfeeding).*
- With zidovudine (AZT) during pregnancy and labor and for the infant after delivery for 6 weeks: 8%
- With ART: <1%
- With ART and undetectable VL at conception, throughout pregnancy, and at delivery (5482 mother-baby pairs reported):

Sibiude J,. Clin Infect Dis. 2022 Aug 29.

What is the risk of transmission via breastmilk in 2023?

- 16% transmission via breastfeeding without ART

- With ARVs: Original studies had suggested 1-5% but most did not include strict correlations with mother's viral load

Nduati et al. JAMA 2000; 283(9):1167-1174.

Bispo et al. J Int AIDS Soc. 2017; 20(1): 21251.

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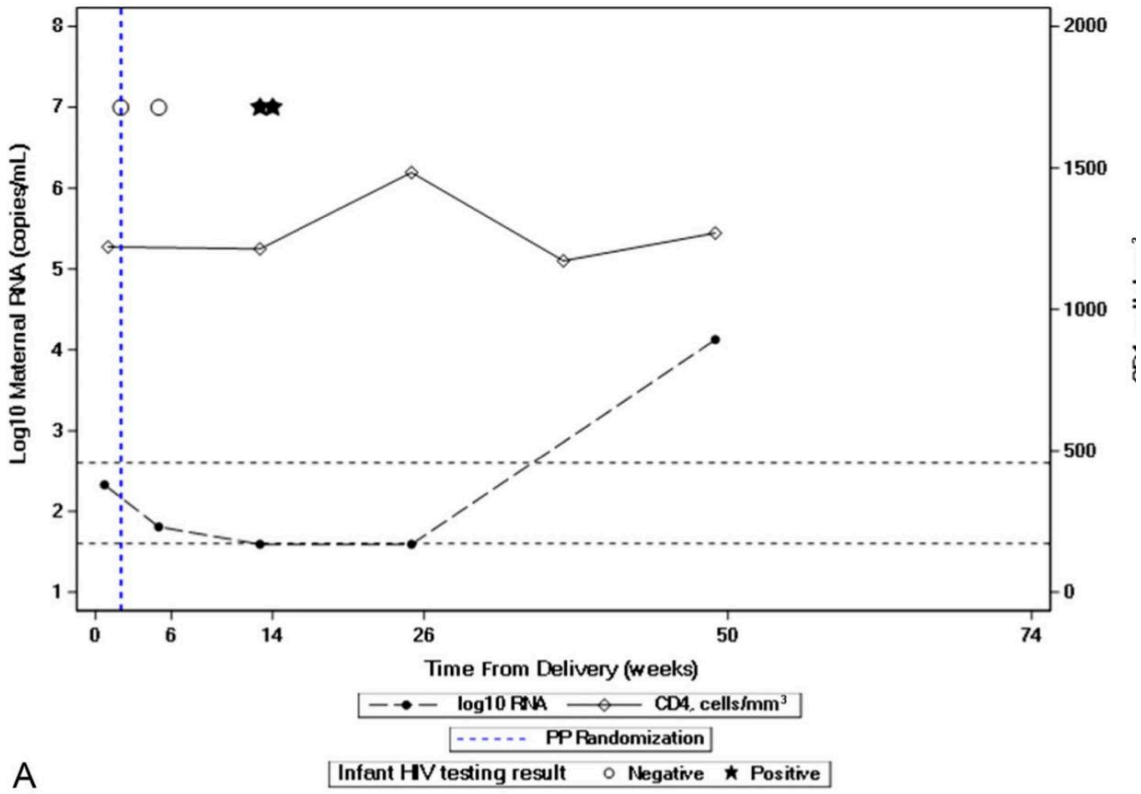
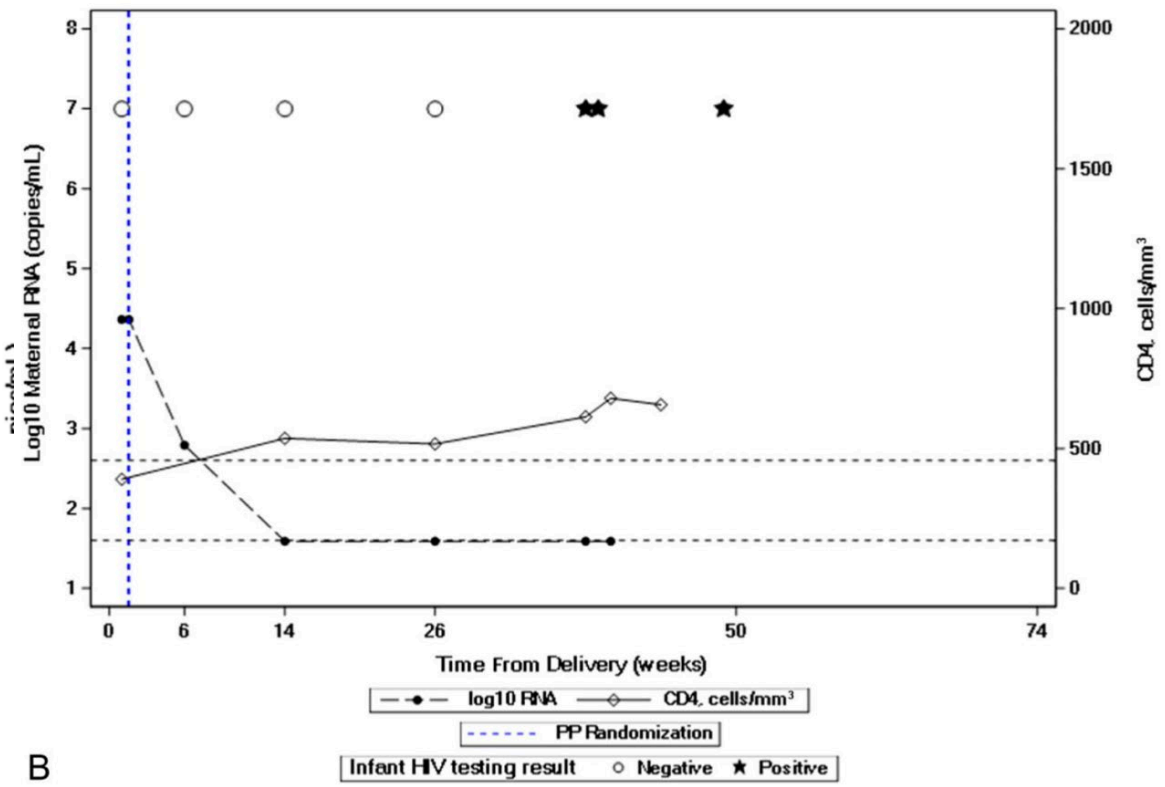
(PROMISE) study

- Randomized mother-baby pairs to either maternal ART or infant nevirapine while breastfeeding
- 0.3% and 0.6% transmission at 6 and 12 months postpartum = 3/1000 and 6/1000 at 6 and 12 months (n = 2431)

Flynn et al. JAIDS 2017; 77(4): 383-392
Flynn et al. JAIDS 2021; 88(2):206-213

Two cases of transmission diagnosed when mother had undetectable viral load





Flynn et al. JAIDS 2021; 88(2):206-213

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Does U = U Undetectable means Untransmittable ?

- **Preconception** U = U if partner living with HIV is taking ART daily and has an undetectable viral load
- **During pregnancy** U = U for her baby if a woman is on ART pre-pregnancy, during pregnancy, and has an undetectable VL at delivery
- **Postpartum**: a lot of variables:
  - postpartum cannot say U = U when it comes to breastfeeding but each individual must do their own risk:benefit assessment

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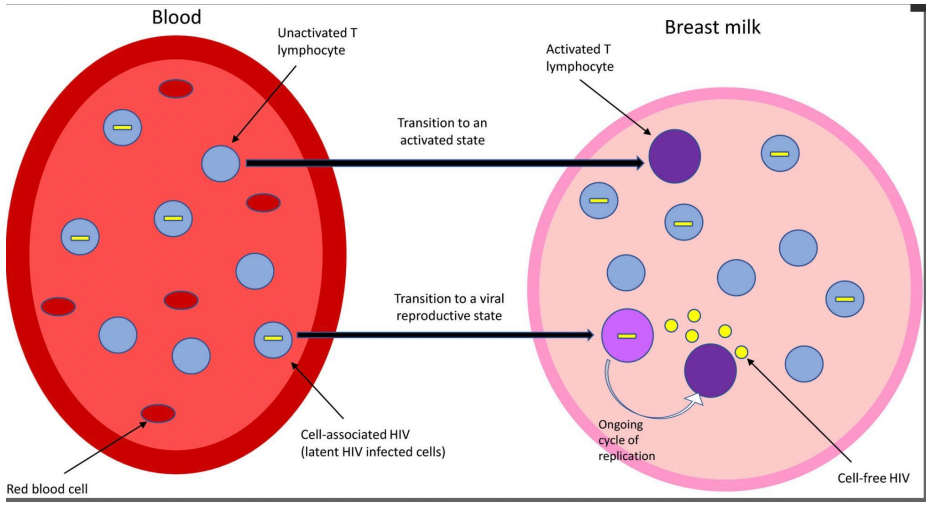
Cell-associated vs. cell-free HIV in breastmilk

- Cell-free HIV RNA appears to correlate with plasma viral load (VL)
- Even with undetectable plasma VL and undetectable cell-free RNA, there remains cell-associated HIV in breastmilk
- Whether the cell-associated HIV is infectious or as infectious as cell-free HIV is not known



Moseholm E and Weis N. Journal of Internal Medicine 2020; 287: 19-31

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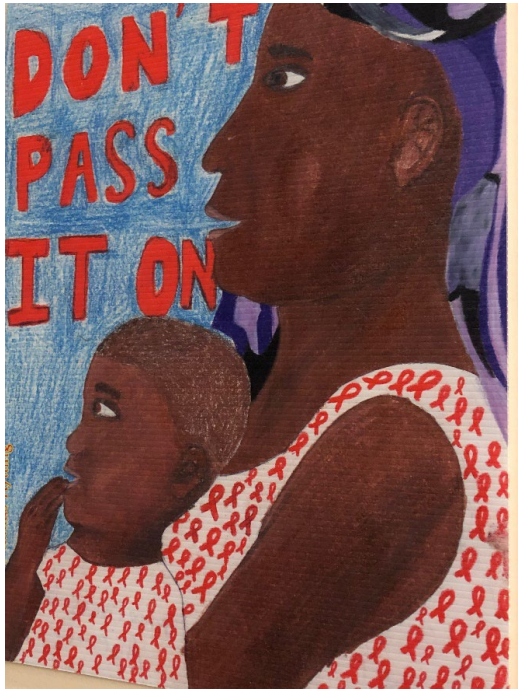
Why not give replacement feeding to all HIV-exposed infants globally?

- In low resource settings, higher mortality secondary to malnutrition and diarrheal disease than if breastfed
- Formula has been recommended where formula is acceptable, feasible, affordable, sustainable, and safe (AFASS)—which is not the case in most of the world
- As a result, exclusive breastfeeding had been recommended in resource-limited settings and replacement feeding in resource-rich areas (U.S., Canada, Europe)
- However, recent unsafe water in the U.S. (Flint MI, Jackson MS, and Houston TX) as well as formula shortages have raised questions about safety, feasibility, and affordability in the U.S.
- What about the health benefits of breastfeeding for infant and parent?

Coutsoudis A et al. (2003). Acta Pediatr 92: 890-895
Kagaayi J et al. (2008). PLOS ONE 3(12): e3877
Kuhn L et al. (2009). Current Opinion in Pediatrics 21: 83-93
Creek T et al. JAIDS (2009) 15(1): 14-19

Who wants to breastfeed in the U.S.?

- Case: A 32-year-old woman, originally from Nigeria, was diagnosed with HIV during her current pregnancy. During prenatal care, she communicated to her obstetrician her desire to breastfeed.
- She feared that not breastfeeding would raise suspicion in her community about her HIV status.
- She had also heard and read so much about breastfeeding being better for her baby (boosted immunity, fewer allergies, less obesity, fewer infections) as well as for her health (less diabetes, lower rates of breast and ovarian cancer).



Case (continued)

- The patient was referred to the local pediatric HIV specialist, who reviewed the risks of HIV transmission via breastfeeding. The patient expressed relief to discuss her concerns with a provider. Knowing she had options provided a space for her to contemplate the best decision for her situation.
- She opted to breastfeed for 3 months, both to "prove" to her community that she did not have HIV and in response to public messages that "breast is best." She remained virally suppressed on ARVs while she breastfed. Her baby was given daily nevirapine prophylaxis while breastfeeding. Her baby remained HIV-negative.

This was just one common example, but there are women of many other racial and ethnic groups who are expressing a desire to breast/chestfeed

Data are beginning to accumulate on breastfeeding in high resource countries

- Canadian series of 3 infants 
- Baltimore series of 10 and Washington DC series of 8 
- Italian series of 13 
- German series of 42 and 30 
- Swiss series of 41 
- North American series of 72 (includes 3 of Canadian and the Baltimore/Washington cases= 52 new cases) 

Nashid et al J Pediatric Infect Dis Soc. 2020
Yusuf et al J Pediatric Infect Dis Soc. 2022
Koay and Rakhmanina J Pediatric Infect Dis Soc. 2022
Prestileo et al Infectious Dis Reports 2022
Haberl L et al AIDS Patient Care and STDs 2021
Weiss et al Clinical Infectious Diseases 2022
Crisinel PA et al Eur J Obstet Gynecol Reprod Biol. 2023
Levison J, McKinney J et al. Clinical Infectious Diseases 2023 (online May 2023)

What has been the guidance around feeding choice for infants of people living with HIV?

1985:"HTLV-III/LAV-infected women should be advised against breastfeeding to avoid postnatal transmission to a child who may not yet be infected." (*CDC and Public Health Service*)

2015:"In discussing the avoidance of breastfeeding as the strong, standard recommendation for HIV-infected women in the United States, the Panel notes that women may face social, familial, and personal pressures to breastfeed despite this recommendation and that it is important to begin addressing possible barriers to formula feeding during the antenatal period." (*HHS Panel*)

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Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission. Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1- Infected Women for Maternal Health *and* Interventions to Reduce Perinatal HIV Transmission in the United States. https://clinicalinfo.hiv.gov/en/guidelines/archived-guidelines/perinatal-guidelines

What has been the guidance around feeding choice for infants of people living with HIV?

2018: New section:

Guidance for Counseling and Managing Women Living with HIV in the United States Who Desire to Breastfeed (Last updated March 27, 2018; last reviewed March 27, 2018)

Panel's Recommendations
• Breastfeeding **is not recommended** for women living with HIV in the United States **(AII)**.
• Women who have questions about breastfeeding or who desire to breastfeed should receive patient-centered, evidence-based counseling on infant feeding options **(AIII)**.
• When women with HIV choose to breastfeed despite intensive counseling, they should be counseled to use harm-reduction measures to minimize the risk of HIV transmission to their infants **(BIII)**.
Rating of Recommendations: A = Strong; B = Moderate; C = Optional
Rating of Evidence: I = One or more randomized trials with clinical outcomes and/or validated laboratory endpoints; II = One or more well-designed, nonrandomized trials or observational cohort studies with long-term clinical outcomes; III = Expert opinion

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Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission. Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1- Infected Women for Maternal Health *and* Interventions to Reduce Perinatal HIV Transmission in the United States. https://clinicalinfo.hiv.gov/en/guidelines/archived-guidelines/perinatal-guidelines

2023

Recommendations for the Use of Antiretroviral Drugs During Pregnancy and Interventions to Reduce Perinatal HIV Transmission in the United States

What's New in the Guidelines ?

The former section, *Counseling and Managing Individuals With HIV in the United States Who Desire to Breastfeed*, was revised and retitled to provide more comprehensive guidance on feeding infants born to individuals with HIV.

Content about breastfeeding in other sections was revised to align with and refer to updated recommendations in this section.

Infant Feeding for Individuals With HIV in the United States

Updated: January 31, 2023
Reviewed: January 31, 2023

Panel's Recommendations
• People with HIV should receive evidence-based, patient-centered counseling to support shared decision-making about infant feeding. Counseling about infant feeding should begin prior to conception or as early as possible in pregnancy; information about and plans for infant feeding should be reviewed throughout pregnancy and again after delivery **(AIII)**. During counseling, people should be informed that— ○ Replacement feeding with properly prepared formula or pasteurized donor human milk from a milk bank eliminates the risk of postnatal HIV transmission to the infant **(AI)**. ○ Achieving and maintaining viral suppression through antiretroviral therapy (ART) during pregnancy and postpartum decreases breastfeeding transmission risk to less than 1%, but not zero **(AI)**.
• Replacement feeding with formula or banked pasteurized donor human milk is recommended to eliminate the risk of HIV transmission through breastfeeding when people with HIV are not on ART and/or do not have a suppressed viral load during pregnancy (at a minimum throughout the third trimester), as well as at delivery **(AI)**.
• Individuals with HIV who are on ART with a sustained undetectable viral load and who choose to breastfeed should be supported in this decision **(AIII)**.
• Individuals with HIV who choose to formula feed should be supported in this decision. Providers should ask about potential barriers to formula feeding and explore ways to address them **(AIII)**.
• Engaging Child Protective Services or similar agencies is not an appropriate response to the infant feeding choices of an individual with HIV **(AIII)**.
• Clinicians are encouraged to consult the national Perinatal HIV/AIDS hotline (1-888-448-8765) with questions about infant feeding by individuals with HIV **(AIII)**.
Rating of Recommendations: *A = Strong; B = Moderate; C = Optional* ***Rating of Evidence:*** *I = One or more randomized trials with clinical outcomes and/or validated laboratory endpoints; II = One or more well-designed, nonrandomized trials or observational cohort studies with long-term clinical outcomes; III = Expert opinion*

https://clinicalinfo.hiv.gov/en/guidelines/perinatal

Recommendations for the Use of Antiretroviral Drugs During Pregnancy and Interventions to Reduce Perinatal HIV Transmission in the United States

Infant Feeding for Individuals With HIV in the United States

Updated: January 31, 2023
Reviewed: January 31, 2023

What's

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What is the major change?

The primary recommendation is now to support parental choice through shared decision making, *not a specific infant feeding mode*

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Rating of Evidence: *I = One or more randomized trials with clinical outcomes and/or validated laboratory endpoints; II = One or more well-designed, nonrandomized trials or observational cohort studies with long-term clinical outcomes; III = Expert opinion*

https://clinicalinfo.hiv.gov/en/guidelines/perinatal

Infant feeding considerations

Health benefits from breastfeeding	• *Infant: lower risk of infants developing asthma, obesity, type 1 diabetes, severe lower respiratory disease, otitis media, sudden infant death syndrome, gastrointestinal infections, and necrotizing enterocolitis.* • *Breastfeeding parent: decreased risk of hypertension; type 2 diabetes; and breast and ovarian cancers.*
Equity Considerations	• *Black women are disproportionately affected by HIV* • *People of color experience a greater burden of many health conditions that may be alleviated by breastfeeding*
Cultural Considerations	• *Environmental, social, familial, and personal pressures to consider breastfeeding* • *Fear that not breastfeeding would lead to disclosure of their HIV status*

https://clinicalinfo.hiv.gov/en/guidelines/perinatal

What is the risk of HIV transmission via breastfeeding?

Without maternal antiretroviral therapy (ART) or infant antiretroviral prophylaxis, the risk of an infant acquiring HIV through breastfeeding is **15% to 20% over 2 years**

Achieving and maintaining viral suppression through ART during pregnancy and postpartum decreases breastfeeding transmission risk to **less than 1%, but not zero**

https://clinicalinfo.hiv.gov/en/guidelines/perinatal/infant-feeding-individuals-hiv-united-states. Nduati R, et al. *JAMA*. 2000;283(9):1167-1174. (https://www.ncbi.nlm.nih.gov/pubmed/10703779) World Health Organization. HIV Transmission through breastfeeding: a review of available evidence; 2007 update. 2008. (http://apps.who.int/iris/bitstream/10665/43879/1/9789241596596_eng.pdf); Bispo S, et al. J Int AIDS Soc. 2017 Feb 22;20(1):21251; Flynn P, et al. *J Acquired Immune Defic Syndr* .1999 77.4 (2018): 383; Flynn P, et al. *J Acquir Immune Defic Syndr*. 2021 Oct 1;88(2):206-213

Overview of counseling and management

For people with HIV who are **not on ART and/or do not have a suppressed viral load at delivery**, replacement feeding with formula or banked pasteurized donor human milk is recommended to eliminate the risk of HIV transmission.

Individuals with HIV **on ART with a consistently suppressed viral load during pregnancy (at a minimum during the third trimester)** and at the time of delivery should be counseled on the options of formula feeding, banked donor milk, or breastfeeding

- The infant feeding options that eliminate the risk of HIV transmission are formula and pasteurized donor human milk
- Fully suppressive ART during pregnancy and breastfeeding decreases breastfeeding transmission risk to less than 1%, but not zero.

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https://clinicalinfo.hiv.gov/en/guidelines/perinatal/infant-feeding-individuals-hiv-united-states

How the new guidelines have dealt with intermittent use of formula

If breastfeeding is chosen, exclusive breastfeeding up to 6 months of age is recommended over mixed feeding (i.e., breast milk and formula), acknowledging that there may be intermittent need to give formula (e.g., infant weight loss, milk supply not yet established, mother not having enough stored milk). Solids should be introduced as recommended at 6 months of age, but not before.

Situations to consider stopping or modifying breastfeeding

In the case of a detectable viral load, … breastfeeding [should] be temporarily stopped. *Options include giving previously stored breastmilk, pumping/flash heating, providing replacement feeding, or cessation of breastfeeding; repeating viral load; and reassessing continuation or cessation of breastfeeding.*

If the repeat viral load is detectable … the Panels advise immediate cessation of breastfeeding; this guidance is more directive than counseling for individuals on suppressive ART.

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There is no consensus on ARV prophylaxis for infants of individuals with sustained viral suppression who are breastfed

Most Panel members agree on only 2 weeks of infant zidovudine (ZDV). However, several Panel members prefer to extend the duration of ZDV prophylaxis to 4 to 6 weeks.

Alternatively, some Panel members recommend 6 weeks of nevirapine (NVP), as currently recommended by WHO for breastfeeding infants at low risk of HIV transmission in resource limited countries.

Some others opt to continue NVP dosing throughout breastfeeding.

https://clinicalinfo.hiv.gov/en/guidelines/perinatal/infant-feeding-individuals-hiv-united-states

Engaging Child Protective Services or similar agencies is not an appropriate response to the infant feeding choices of an individual with HIV

Numerous pregnant people with HIV have reported that after expressing their interest/intention to breastfeed, their providers threatened to report them to Child Protective Services or actually did so.

Such engagements can be extremely harmful to families; can exacerbate the stigma and discrimination experienced among people with HIV; and are disproportionately applied to minoritized individuals, including Black, Indigenous, and other people of color.

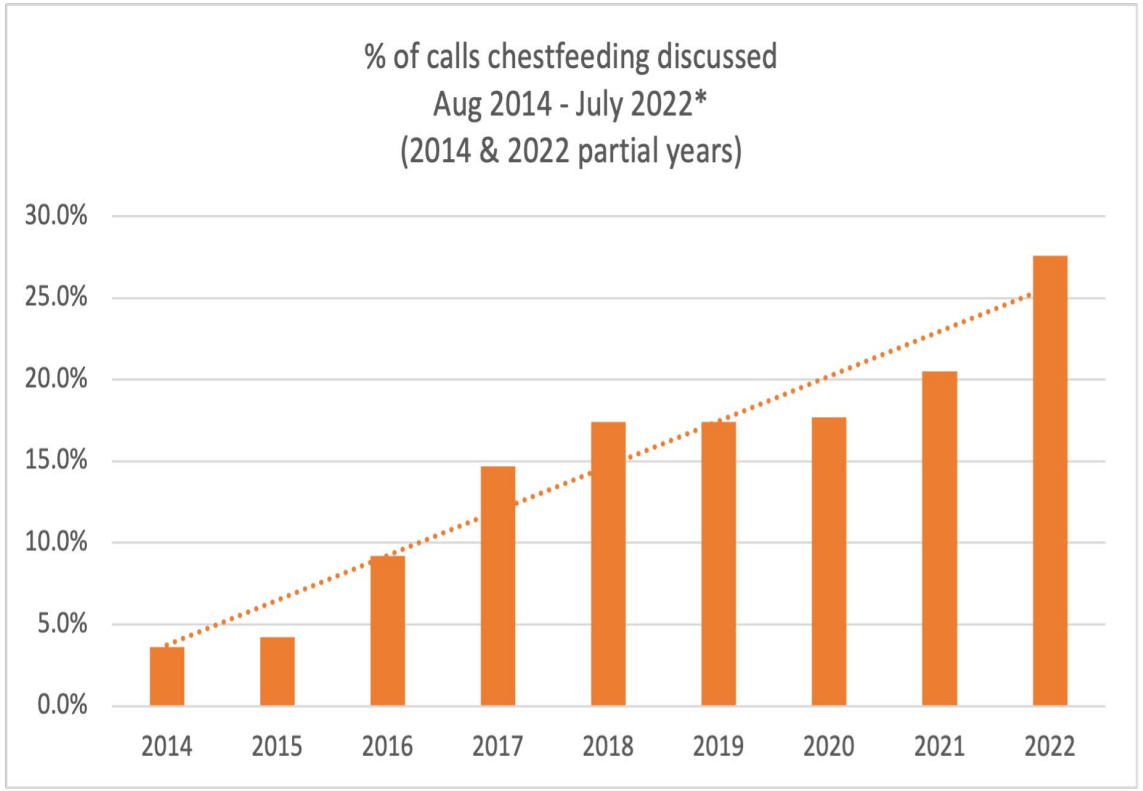
Putnam-Hornstein E, et al. *Am J Public Health*. 2021;111(6):1157-1163. Available at: https://www.ncbi.nlm.nih.gov/pubmed/33856822;
Roberts D. THE COLOR OF CHILD WELFARE. Vol. ed.: 2002.
Wall-Wieler E, et al. M.. *AmJ of Epi*. 2018;187(6):1182-1188. Available at: https://www.ncbi.nlm.nih.gov/pubmed/29617918
https://clinicalinfo.hiv.gov/en/guidelines/perinatal/infant-feeding-individuals-hiv-united-states

What was new in process of developing the 2023 guidelines?

- Integration of community input from members of The Well Project, International Community of Women Living with HIV - North America, and others
- Obtaining input from lactation specialists at CDC
- New level of collaboration between the Perinatal and Pediatric Panels
- CDC chose to refer any queries about infant feeding in the U.S. to the Perinatal Guidelines (rather than having their own recommendations)

https://clinicalinfo.hiv.gov/en/guidelines/perinatal/infant-feeding-individuals-hiv-united-states

The change in guidelines comes at a time of increasing interest among providers across the country



Rising number of calls on breast/chest-feeding on the Perinatal Hotline

https://nccc.ucsf.edu/

NATIONAL CLINICIAN CONSULTATION CENTER
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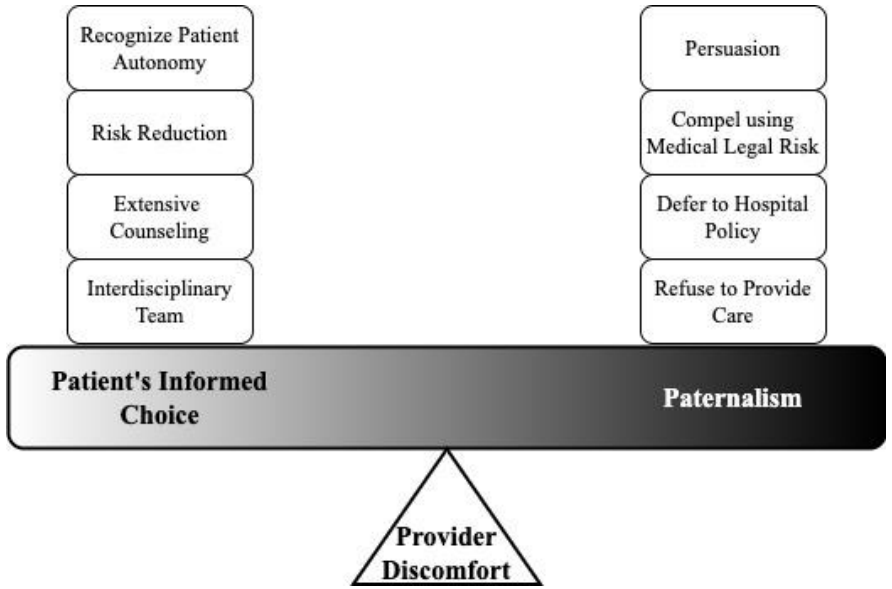
Providers in the USA have struggled to navigate support in the absence of more guidance

Survey in June/July 2021.
99 physicians, advanced practice providers, nurses, and lactation consultants

- 42% had cared for someone with HIV who sought to breast/chest feed
- 10% had an institutional protocol



Personal ethics: "I feel the need to protect the infant and think it isn't ethical to put the infant at increased risk, therefore we have to this point only allowed women with stable suppressed viral loads to [breastfeed] their infants."

Provider disagreement: "Some of the providers in our small group believe that our guidelines should be liberalized…Other providers feel that we should not allow BFing among WLHIV under any circumstance. It has been difficult to get consensus."

Lack of guidelines or data: "I would not feel comfortable because there aren't specific guidelines or literature to support the care, however I'm very interested in learning more for those who are interested in breastfeeding to be able to support that decision."

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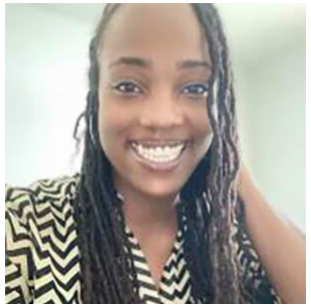
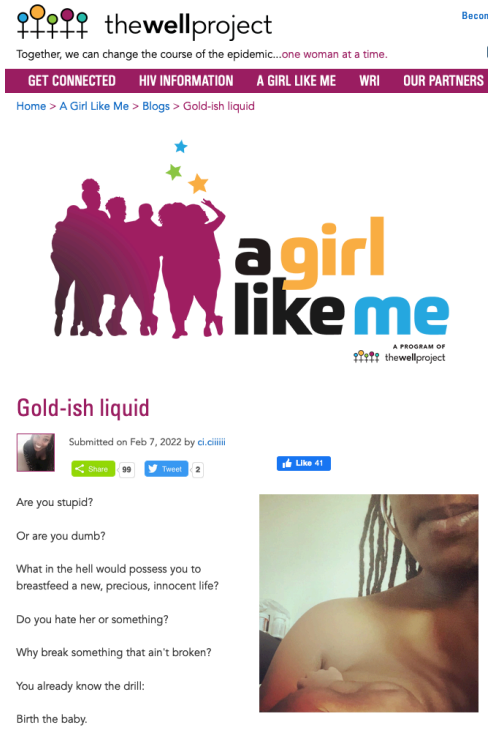
Lai A, et al. AIDS Patient Care and STDs. 2023;37(2):84-94.

Patients in the USA have struggled to navigate infant feeding in the absence of more guidance



"It is very important that we are given a choice … like I just need you to support what my decision is. It's not my provider's place to tell me what to do with my life or my babies. I just need you to leave the space open for discussion and choice."
- Ciarra (Ci Ci) Covin

2022 Annual National Perinatal HIV Hotline Roundtable: Breast/Chestfeeding https://www.youtube.com/watch?v=erWXE5pI5Xo



https://www.thewellproject.org/a-girl-like-me/aglm-blogs/gold-ish-liquid

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Resources as you navigate this new road …

CLINICAL INFO HIV.gov

www.hivinfo.nih.gov

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1-888-448-8765

https://nccc.ucsf.edu/

Conclusions

- We have come a long way
- We have listened to the people we hope we are serving/working with
- We still have a lot to learn

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Acknowledgements

- Our patients
- The Perinatal HIV Panel
- The Pediatric HIV Panel
- The Centers for Disease Control (CDC)
- Office of AIDS Research Advisory Council
- The Well Project

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- Ted Ruel, MD
- Elaine Abrams, MD

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